A PORTFOLIO OF ACADEMIC, CLINICAL AND RESEARCH WORK

EXPRESSED EMOTION, BURDEN AND COPING IN SPOUSAL CAREGIVERS CARING FOR A PARTNER WITH DEMENTIA

The work contained in this Portfolio by Louise Helen Adams has been submitted in fulfilment of the Academic, Clinical and Research components of the Doctorate in Clinical Psychology - University of Surrey.

August, 1997

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What is the evidence that psychosocial interventions have a positive effect on the course of psychotic disorders?
Schizophrenia is characterised by pervasive impairment in social, cognitive, affective and daily functioning. A review of the literature reveals three ways in which the descriptive psychopathology of schizophrenia has been traditionally described:

1. **Purely positive symptoms** - (i.e. hallucinations and other abnormal experiences, delusions and catatonia.)

2. **Traditional psychopathological groups containing positive and negative symptoms** - (i.e. thought disorder and disturbances of emotion) and

3. **Purely negative symptoms** - (i.e. impaired attention, intelligence, memory perception and will.)

Neither the description of positive symptoms nor negative symptoms exhaust the entire gamut of an individual with schizophrenia's subjective experience or entirely accounts for all possible behavioural sequelae and deficits associated with this deleterious disorder (Cutting, 1995). Historically, treatment intervention for this disorder has traditionally been through anti-psychotic medication and/or long term hospitalisation. However, despite the 'effectiveness' of antipsychotic drugs in acute schizophrenia and in preventing relapse, many patients continue to have persistent positive and negative symptoms (Kane & Marder, 1993).

As cited by Haddock & Lewis, (1996), Curson et al, (1988) found that just under half of the patients surveyed in a London psychiatric hospital continued to experience hallucinations and delusions despite the prescription of medication. In addition a review of the literature emphasises that factors associated with side-effects, and consequently, poor-compliance, occurs in up to 75% of individuals with first episode schizophrenia (Kissling, 1992). Further, up to 50% of patients discharged from hospital fail to take even 75% of their prescribed medication (Buchanan, 1992). These factors may partially explain the findings that 30% to 40% of schizophrenic patients relapsed on medication (Leff & Wing, 1971; Kavanagh, 1992; Greene, 1993). Further the policy of deinstitutionalisation and resultant community resettlement has led to the need to investigate other forms of treatment intervention.

Until the 1980's there was little evidence that psychosocial treatments could improve the course of schizophrenia. During the last two decades, considerable research interest in the role of social and situational factors in the development and mediation of relapse has resulted in the witnessing of a proliferation of studies of psychosocial interventions for individuals with a psychotic disorder such as schizophrenia, and for their families (Bebbington et al, 1993; Kuipers et al, 1988; Lam, 1991).
This paper aims to undertake a selective critical review of the literature on the amelioration of psychotic symptoms associated with schizophrenia by summarising the research on four major psychosocial approaches: social skills training; family therapy; cognitive rehabilitation; and cognitive behavioural therapy for the residual psychotic symptoms in an attempt to elucidate the effectiveness of psychosocial interventions for psychotic disorders.

**SOCIAL SKILLS TRAINING:**

Over the past decade, social skills training has become one of the most intensively researched and widely implemented psychosocial modality in the treatment and rehabilitation of severe and persistent psychiatric disorders. Social skills training has been defined as 'a generic set of learning activities such as modelling, reinforcement, role playing and in vivo exercises that help patients acquire a variety of skills in verbal and non-verbal behavioural domains' and these factors address the interpersonal, self-care and coping needs that patients encounter as they negotiate the demands of community living (Libermann et al, 1986).

Table 1 summarises the findings of five key studies which reflect an overview of research findings within the vast literature relating to schizophrenia and social skills training.

**Table 1:** Selective Summary of Studies of Social Skills Training for Patients with Schizophrenia.

<table>
<thead>
<tr>
<th>Study</th>
<th>Treatment Conditions</th>
<th>N</th>
<th>Frequency of Treatment</th>
<th>Symptom Outcome</th>
<th>Relapse</th>
<th>Social Adjustment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bellack et al, (1984)</td>
<td>Social Skills Training Control Group</td>
<td>29</td>
<td>3hr/wk for 3mths.</td>
<td>6 mths: Social Skills Group improved</td>
<td>1yr: No difference between groups.</td>
<td>-</td>
</tr>
<tr>
<td>Libermann et al, (1986)</td>
<td>Social Skills Training Holistic Health Group</td>
<td>14</td>
<td>10hr/wk for 9 weeks.</td>
<td>2 yrs: Social Skills Group improved</td>
<td>2 yrs: No difference between groups.</td>
<td>Social Skills Group better than control group.</td>
</tr>
<tr>
<td>Hogerty et al, (1986) (1991)</td>
<td>Social Skills Training Family psycho-education Group Combined Treatment Control Group</td>
<td>23</td>
<td>Social Skills Training 1 yr weekly then bi-weekly for 1 yr.</td>
<td>2 yrs: No difference between groups.</td>
<td>2 yrs: family psychoeducation better that social skills and control no difference between control and social skills groups.</td>
<td>2 yrs: Combination better than family education: Family education better than social skills.</td>
</tr>
<tr>
<td>Dobson et al, (1995)</td>
<td>Social Skills Training Social Milieu</td>
<td>15</td>
<td>4 sessions/wk for 9 wks.</td>
<td>9 wks: positive symptoms no difference negative symptoms better in social skills group 6 mths: no difference</td>
<td>12 months No difference between groups.</td>
<td>-</td>
</tr>
<tr>
<td>Hayes et al, (1995)</td>
<td>Social Skills Training Discussion Group</td>
<td>63</td>
<td>36 x 75-mins session over 18 wks</td>
<td>6-mths: No difference between groups.</td>
<td>6 mths: No difference between groups.</td>
<td>Social Skills Group better community functioning.</td>
</tr>
</tbody>
</table>
Two recent studies have shown that social skills training was minimally superior to social milieu or discussion groups among outpatients with schizophrenia (Dobson et al, 1995; Hayes et al, 1995). More specifically, although social skills training was superior to a control intervention (i.e. discussion groups) in improving social skill, the social skills training did not significantly (relative to control interventions) lower relapse rate, reduce symptoms, or improve cognitive functioning. These findings are conflictual to earlier studies which had shown that patients who had completed social skills training programmes experienced significant diminished psychiatric symptomology and decreased relapses or rehospitalisations (Bellack et al 1984; Hogerty et al, 1991). The methodological limitations relating to many of these studies have however, created difficulties in undertaking comparability of studies and therefore may propound an explanation as to the conflictual efficacy findings. For example, many of these studies are limited to the fact that intervention treatment periods were relatively brief, (i.e. between 9-18 weeks), and offered a wide variation of interventions. Replication of any one specific intervention programme has yet to be undertaken. Despite these factors, the studies have demonstrated that individuals with schizophrenia are able to be taught a wide range of social skills ranging from simple behaviours such as improved eye contact, to more complex behaviours such as assertiveness and conversational skills, which to a limited extent, appears to have some impact upon community functioning. However in relation to reduction in symptomology and relapse, the results appear to be less pronounced.

FAMILY INTERVENTIONS:
Evidence pointing to the negative affect in the family on the course of schizophrenia as well as the distress experienced by relatives coping with the illness has led to the development and evaluation of several different models of family intervention over the past two decades. The concept of ‘Expressed Emotion’ (EE) evolved in an effort to understand the impact of family and social environment on the vulnerability to relapse of schizophrenic patients. ‘EE’ is currently among the most thoroughly investigated psychosocial research constructs. Developed some three decades ago by Brown et al, (1972), the term ‘EE’ refers to ‘a global index of particular emotions, attitudes and behaviours expressed by relatives about a family member with schizophrenia’. As cited by Brown, (1985) a series of now classic studies by Brown, (1972) and Vaughn & Leff, (1976) demonstrated that high levels of criticism, hostility or emotional overinvolvement in relatives of schizophrenic patients predicted psychotic relapse during the first nine months following symptom exacerbation. Other findings found that relatives’ high expressed emotion status was the single most important factor in predicting clinical deterioration or relapse in schizophrenia (Brown et al, 1972;
Vaughn & Leff, 1976). The literature has been replete with provocative and stimulating studies about the theory and application of the concept of EE (Scheiber et al, 1995; Kazarian, 1992). A full critical review of this literature is beyond the scope of this paper, (see Kuipers et al, 1992 for an in-depth review). The general assumptions taken from an extensive and varied body of cross-national and culturally diverse empirical research has shown that schizophrenic patients returning to live with family members who exhibit high levels of expressed emotion (EE) are more likely to relapse than are patients returning to low-EE homes (Leeb et al, 1991; Kavanagh, 1992; Jenkins & Karno, 1992). Further, the EE construct has generated considerable debate among both family members and professionals (Meuser et al, 1993). Even within schizophrenia, not all of the studies have supported the EE hypothesis, and the notion that EE might be a primary determinant of relapse has attracted considerable scientific controversy (Hogerty et al, 1991; Kavanagh, 1992). Most of resentment to the concepts of EE has been due to the 'linkage of blame' to family members for causation of schizophrenia. Therefore a major limitation of most theories about EE has been the tendency to focus on a unidirectional model of the influence of negative family affect on patient symptoms. Issues as to its measurement (i.e. the methodological problems associated with the Camberwell Family Interview) have also caused the construct to be difficult to assess within the clinical setting. For example, the rating requires specialist training and can take between 1-2 hours to score. Recent developments of alternative measures, (i.e. such as the Five Minute Speech Sample - FMSS) has facilitated the recognition of the significance of the complex affective communicative styles within families upon the course of schizophrenia and other psychiatric illnesses (Malla et al, 1991). Consequently the elucidation of this research construct and its measurement has lagged behind 'clinical interest' in expressed emotion. As Koenigsberg and Handley (1986) stated that the elusive theoretical and empirical bases of the construct have gone unexamined. Precisely what is inside the 'black box' called expressed emotion has somehow remained mysterious, as has widely been acknowledged within the literature (Kuipers & Bebbington, 1988; Vaughn & Leff, 1976; Jenkins & Karno, 1992). Despite the fact that 'substantial questions remain about the nature and meaning of the global expressed index' (Vaughn & Leff, 1976) there has been voluminous investigation and application of family intervention studies. The acknowledgement that the family 'atmosphere' partakes a role in relapse in schizophrenia has led several authors to conduct intervention studies (Falloon et al, 1985; Leff et al, 1990; Hogerty et al, 1986; Tarrier et al, 1993) and furthermore has been shown to be one of the most promising psychosocial interventions. Interventions with families can be broadly divided into short-term (i.e. less than 3 months), or long-term interventions. Empirical trials of short-term family interventions appear to
contain the main focus on providing education to relatives (Birchwood & Shepherd, 1992; Vaughn et al, 1992). Some interventions have included the patient in the family sessions and have broadened the scope of therapy objectives to include both education and improved family functioning. A review of the short term studies of family interventions (which included psychoeducation related to the course of the disorder) have generally shown that family interventions produce rates of relapse over 1-2 years that are lower than those for standard treatment. On closer inspection however, individual study results appear to be significantly related to the duration of intervention. Studies in which intervention was less than three months appear to show equivocal results (Vaughn et al, 1992). More positive outcome results in relation to relapse rates on 1-2 year follow-ups have been found following longer family intervention trials (e.g. Leff et al, 1990; Tarrier et al, 1993; Randolph et al, 1994). In addition, several different long term family therapy models have been developed and empirically tested and found to produce beneficial clinical effects at 2-year follow-up. Within the literature there has been increasing demands for more empirically efficacious investigations. A number of control studies have been conducted comparing customary treatment with long term family therapy using a variety of models (e.g. Falloon et al, 1985; Leff et al, 1990; Hogerty, 1991). A summary of such studies has been reviewed in Table 2. These studies indicate that family therapy has a significant effect on reducing relapse rates to an average of about 50% of standard treatment which included no family therapy. Furthermore, some studies have reported positive effects of treatment on patients' social adjustment and a reduction in family burden (e.g. Falloon et al, 1985) and from a service cost effectiveness has been shown to reduce the number of days spent in a hospital in-patient setting (Tarrier et al, 1993). From a clinical perspective Lam, (1991) review of psychosocial interventions identified seven common components for effective family interventions for schizophrenia.

These can be summarised as follows:

1. **A positive approach and genuine working relationship between therapist and family.**
2. **The provisions of family therapy in a stable structured format with additional contacts with therapists if necessary.**
3. **A focus on improving stress and coping in the 'here and now' rather than dwelling on the past.**
4. **Encouragement of respect for interpersonal boundaries within the family.**
5. **The provision of information about the biological nature of schizophrenia, so as to reduce blaming the patient and family guilt.**
6. **The use of behavioural techniques, such as breaking down goals into manageable steps.**
7. **Improving communication between family members.**
Some research has also been undertaken with regards to the efficacy of individual family or multiple group family interventions (Leff et al 1990; McFarlane et al, 1993). Two notable trends can be seen from both studies. Firstly, that relapse was relatively low over two years for both individual and multiple family groups compared to control groups. Secondly, the differences between relapse amongst multiple and individual group formats were relatively small which is suggestive that they may both be of comparable efficacy. This has significant potential implication for interventions.

Table 2: Two Year Relapse Rates for Schizophrenia patients receiving long-term family therapy:

<table>
<thead>
<tr>
<th>REFERENCE</th>
<th>THEORETICAL ORIENTATION</th>
<th>SAMPLE SIZE</th>
<th>SINGLE FAMILY THERAPY</th>
<th>MULTIPLE FAMILY THERAPY</th>
<th>ROUTINE TREATMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falloon et al, (1985)</td>
<td>Behavioural</td>
<td>32</td>
<td>17</td>
<td>-</td>
<td>83</td>
</tr>
<tr>
<td>Leff et al, (1985)</td>
<td>Supportive</td>
<td>24</td>
<td>14</td>
<td>-</td>
<td>78</td>
</tr>
<tr>
<td>Leff et al, (1990)</td>
<td>Supportive</td>
<td>23</td>
<td>33</td>
<td>36</td>
<td>-</td>
</tr>
<tr>
<td>McFarlane et al, (1993)</td>
<td>Supportive</td>
<td>172</td>
<td>42</td>
<td>28</td>
<td>-</td>
</tr>
</tbody>
</table>

From the brief review of the literature it can be seen that the family intervention studies are of profound significance, since they appear to demonstrate that schizophrenia which has so often been regarded as ‘pervasive’, can be controlled (in the short term at least) through environmental intervention (Kuipers et al, 1992).

**Cognitive Interventions:**

Abnormalities are found in schizophrenia at all levels of the cognitive system, and in all phases of the course of the disorder (Libermann et al, 1986). Cognitive impairments are thought to play a number of roles in schizophrenia’s aetiology and expression. Therefore one hypotheses is that remediation of such impairments might lead to improvements in personal and social functioning (i.e a process intervention approach). The goal of process interventions is remediation of basic information-processing skills such as memory, vigilance, and conceptual abilities. The rationale underlying such ‘cognitive rehabilitation’ is that relapses may be prevented by addressing the cognitive deficits that serve as vulnerability markers for future psychotic episodes. Early efforts to treat schizophrenic cognition directly using self-instructional training approaches has since become ubiquitous to cognitive behavioural therapy. The approach involves rehearsal or self instruction designed to establish and
maintain continuous attention to tasks, inhibit impulsive responses and prompt-self reinforcement. Although the early studies showed beneficial treatment effects for this approach (as measured by improvements in interview performance, ambient social behaviour and neuropsychological tests), replicate studies have proven ambivalence in their findings.

Two recent well controlled studies have investigated the effects of cognitive rehabilitation on tasks involving vigilance and attention. Benedict et al, (1994) randomly assigned 38 outpatients with chronic schizophrenia either to an attentional training or to a no-treatment control group. Attentional training comprised 25-hours of repeated practice on computer administered vigilance tasks of graduated difficulty. However on assessment there were no improvements in relation to vigilance improvement. Many of the criticisms levied at such interventions are focused around the narrow scope many interventions implement, in that they are unable to address all the combinations cognitive deficits which are characteristic of schizophrenia.

More recently the focus of cognitive behavioural interventions have been used to directly reduce the symptoms and behavioural deviances associated with schizophrenia, (i.e. a content approach). Content approaches focus on changing the nature of, or one’s response to, the content of dysfunctional thoughts and thus can be seen to focus upon stress management than on enduring vulnerability markers (e.g. Eckmann et al, 1992).

Many recent studies have reported success in managing persistent positive symptoms of schizophrenia (such as modifying thought or beliefs associated with delusions; coping with auditory hallucinations) using such cognitive techniques (Tarrier et al, 1993). For example Kingdon et al, (1994) demonstrated benefit to 64 patients with schizophrenia treated with cognitive therapy in addition to routine clinical management. Cognitive interventions have been shown to reduce conviction in beliefs about hallucinations and even reduction in voice activity. Similarly Chadwick & Lowe, (1994) have reported a reduction in conviction about delusions and in preoccupation with them, following cognitive intervention. Garety et al, (1994) have reported a pilot study of 12 patients with medication-resistant persistent positive psychotic symptoms compared with a waiting list control group receiving only routine clinical treatment. The intervention group showed reductions in their symptoms, and in their conviction about their symptoms and affective disturbance. The control group did not show any changes.
**FUTURE CONSIDERATIONS:**

It can be seen that psychosocial interventions *(in particular, family interventions)* have shown a significant amount of consistency between researchers and clinicians, both cross-culturally and across continents. A review of the literature has shown that psychosocial interventions do work. However it is important to recognise that such interventions *do not* prevent relapse, but they do appear to delay it. Consequently in light of the focus of community care and the reciprocal shortage of inpatient hospital services there are beneficial both in cost-effectiveness and the social effects of hospital admissions. There however still appears to be a significant discrepancy about what has been developed through research and case/group studies about the effectiveness of psychosocial interventions and rehabilitation techniques, and its widespread application in clinical practice.

In relation to Social Skills Training, although the findings offer some efficacy to this intervention, there is still a need for replicated studies for particular interventions and a focus on the cognitive and symptom factors that mediate acquisition and maintenance and generalisability of social skills (Meuser et al, 1993).

The encouraging results of research on family therapy for schizophrenia also raises many questions about how these interventions can be optimally applied. As emphasised by Lam (1991) "the specificity and quality of family interventions" can only increase if theoretical links are considered. For example, Emotional Expression (EE) has never neatly fitted into available theories of family functioning. Little is known as to how it varies naturally over time, and how this might interact with coping skills, burden or distress and changes in patients symptoms.

The studies involving cognitive behavioural techniques have shown great promise for reducing residual psychotic symptoms, especially delusional beliefs. These techniques may augment patients' ability to cope with persistent symptoms, and thus reduce the likelihood of relapse. However the need for additional replicated studies as well as a further emphasise upon the factors that limit coping and skill acquisition will further facilitate the improvement of intervention strategies.

Other unresolved issues for all of the above mentioned psychosocial techniques are related to the durability of such interventions. For example, the family intervention study of Tarrier et al, (1993) lasted for nine moths and assessments at two years indicated some maintenance of effects. Many researchers and clinicians (e.g. McFarlane et al, 1993) have argued against all
time-limited intervention strategies, since the expectation that time-limited psychosocial interventions will have long-lasting effects on schizophrenia appears to be contra-indicative and inconsistent with the chronic nature of the illness. Leading on from this, a final set of remaining questions about psychosocial interventions pertains to the timing of such applications. It has been suggested that families are the more amenable to intervention when the patient is in the acute stage of illness and most current studies have initiated family interventions at this time (Bebbington et al, 1993). The need to construct case management around an empirically sound base of interventative strategies is therefore fundamental to improved efficacy of outcome. Therefore it can be seen that 'psychosocial interventions' for schizophrenia cannot operate in a vacuum but rather requires continuity and integration with other treatment services. Research on pharmacological treatment of schizophrenia has continued to make advances and there is a need to understand how to integrate medication with psychotherapy. Much work remains to be done in understanding how to better deliver existing psychotherapies, identifying which patients will benefit from each intervention, as well as further developing effective interventions. A focus of future work is needed in developing and evaluating psychotherapeutic interventions and the interactive effects between strategies. Also there needs to be more empirically evaluated studies on other psychosocial interventions such as vocational rehabilitation and case management. For example studies have shown that supported employment, which emphasises rapid job placement competitive work in integrated settings and long term supports have found to produce better vocational outcomes for schizophrenic patients (Becker & Drake, 1994).

Related to this area is the increased focus on 'personal therapy' and a recent interim report from Hogerty et al, (1991) on their ongoing trials of 'personal therapy' which has shown promising results. Stressing the need for schizophrenia research that includes more women, ethnic minorities and isolated patients (a major criticism of most previous psychosocial intervention research) they describe the rationale for their 'exercise in managing personal vulnerability through the process of individualised guided recovery'.

CONCLUSIONS:
As evidence supporting the benefits of psychosocial treatment for schizophrenia has accumulated, so too, has the realisation that the benefits may be temporary and that many patients require ongoing intervention to maintain their treatment gains (Bellack & Meuller, 1993). There tends to be only modest results in the absolute clinical gains resulting from family and individual psychosocial treatment when it occurs in isolation. Despite this, these
incorporation of these techniques together with other interventions (such as psychopharmacology and case management) may further improve the long term relapse prevention of many schizophrenic patients.

The evidence produced in this review appears to support the potential effectiveness of a variety of psychosocial interventions. Therefore the future questions related to this topic which may be more helpful to propose, are not whether psychosocial interventions have a role in the treatment of schizophrenia but which intervention approaches (or combination of approaches) are the most efficacious. In answering this research question there needs to be the incorporation of outcome measures relating to the feasibility for delivery within particular clinical settings. This question exemplifies the clinical need to develop guidelines, based on empirical research for the selection integration and sequencing of the multiple treatment options now available, and not solely on the availability of current resources or old practices in order to provide the most efficacious interventions for this challenging client group.

REFERENCES:


DOES COGNITIVE-BEHAVIOUR THERAPY WORK FOR CHILDREN AND ADOLESCENTS?
Cognitive-Behavioural Therapy (CBT) is 'an active, directive, time-limited structured approach... based on an underlying theoretical rationale that an individual's affect and behaviour are largely determined by the way in which he structures the world.'

(Beck et al, 1991)

The above quotation highlights the main tenets to the theoretical underpinnings of cognitive-behavioural interventions. Cognitive-behaviour therapy (CBT) is currently in the mainstream of contemporary psychotherapeutic approaches. Since the initial formulations of the theories and techniques associated with Cognitive-behaviour therapy, researchers and clinicians have continued to provide impressive empirical evidence regarding the efficacy of this type of psychological intervention for a multitude of behavioural and emotional disorders within the adult population (Beck, 1991, 1993; Haaga & Beck, 1992).

Nevertheless despite this trend, the 'cognitive' orientation has been until recently, slow to penetrate to interventions with children and adolescents, resulting in the continued dominance of behavioural (i.e. operant and classical conditioning), psychodynamic, and family systems paradigms in the treatment of child psychopathology (Graham, 1991). In general these theories view children as passive recipients of external influences. Although it is true that children are dependant on adults for many of their physical needs, cognitive theory challenges this notion that children have no influence over their own emotional reactions and that their emotional disturbance is only the result of systemic variables or reward contingencies. The continued success and familiarity with cognitive-behavioural therapy in the last five years within the adult population, has increasingly prompted the application of this therapeutic technique to a variety of emotional and behavioural problems associated with childhood and adolescence.

The aim of this paper is to undertake an examination and discussion of the conceptual underpinnings of the 'cognitive-behavioural model' and the main assumptions associated with 'cognitive-behavioural therapy' in order to review its theoretical and practical limitations, thereby being able to review its efficacy as a psychotherapeutic intervention with children and adolescents. This will be discussed by drawing upon a selective review of the empirical literature investigating the use of cognitive-behavioural therapy on a variety of problems associated with childhood and adolescence.
Inherent in the cognitive approach is the notion that individuals are not passive recipients of stimuli but active interpreters of their world, according to their own sets of values, beliefs expectations and attitudes. Further inherent in this approach is the inference that ‘...it is not things themselves which disturb us but the view we take of them’ (Ellis & Sparios, 1994).

Cognitive behavioural approaches can therefore be defined as a rational amalgam: a purposeful attempt to preserve the demonstrated positive effects of behavioural therapy within a less doctrinaire context and to incorporate the cognitive activities of the client into efforts to produce therapeutic change. Accordingly, cognitive-behavioural strategies with children and adolescents incorporate enactive, performance based procedures as well as cognitive interventions to produce changes in thinking, feeling and behaviour (Kendall, 1991a). To briefly summarise the cognitive aspect of cognitive-behaviour therapy, ‘cognitive’ therapy can be categorised according to the type of cognitive event that is the focus of intervention. The most frequently used distinction is between those interventions that teach cognitive skills and those that rectify faulty processes (Kendall, 1991b). The former approach (i.e. teaching cognitive skills) is based on the assumption that inappropriate behaviour and affect reflects a lack of some cognitive process. By implication, therefore intervention aims to teach the required skill. Included in these techniques are problem solving training, self-instructional training and self control techniques (i.e. self-monitoring, self-evaluation and self-reinforcement). The ‘rectifying cognitive processes technique’ proposes that negative affect and inappropriate behaviour reflect ‘errors’ or ‘distortions’ in cognitive processing. Interventions are therefore designed to teach the individual to be more accurate in their processing of information and includes methods such as ‘cognitive restructuring’ and ‘rational emotive therapy’ (Spence, 1994).

A review of the literature however reveals that despite its potential as a technique, there has been widespread apprehension as to the applicability of ‘cognitive’-behavioural therapy as a suitable psychotherapeutic intervention for children. Although there has been a historical acknowledgement of the involvement of numerous cognitive processes such as attention memory, perception and self regulation in the control of overt behaviour [for example Bandura's social learning theory model accepted the role played by cognitive events in the explanation of human learning], (Bandura, 1977), several major tenets of the cognitive behavioural approach have been cited in the literature as contra-indications for applying ‘cognitive’ treatment to children.

From a theoretical perspective, the integration of developmental theory with the practice of Cognitive-behaviour therapy with children has been heavily Piagetian in focus and has to
significant extent, limited the applicability of cognitive interventions with younger individuals. A cornerstone of Piaget’s theory is that the growth of knowledge involves a process of adaptation to the environment (Piaget, 1955). As cited by Kaplan et al, (1995) the human organism, whilst interacting with the environment from birth, constructs a set of evolving cognitive structures, whose growing organisation and complexity provide increasingly greater adaptation of the individual to his or her physical surroundings. A cognitive structure provides a generic form or way of knowing, and a general set of rules for processing information. These structural forms of knowing are to be found universally among people of all cultures, and they always develop in the same invariant stage sequence. Cognitive development involves an ongoing process of structural differentiation and integration with each successive stage constituting a more hierarchical conceptual reorganisation of what preceded. The reasoning strategies of each succeeding stage becomes more efficient and more effective. Increasingly the growing child develops greater comprehension of the world and enhanced problem-solving abilities. The child’s expanding understanding of the world however is not merely a matter of additive pieces of information as in Lockean epistemology, but instead is characterised by a qualitatively different way of knowing in the world at each new stage. The heart of Piaget’s epistemology resides in its ‘constructionist’ orientation. These structures are not innate categories of mind, since in Piagetian theory the new-born infant possesses only primitive schemas such as the ‘experience of grasping, and sucking. Upon interacting with the environment, however newly encountered demands and challenges lead to the refinement and co-ordination of these schemas into more complex organisations and to the invention of new structures. From the work of Piaget, children between the ages of 7 and 11 years, structure their world in an empirical and inductive manner. As a consequence, basic insights, concepts and beliefs are taught to children through intensive analyses of specific situations and the use of concrete examples and teaching illustrations. Children without logical thought structures (i.e. pre-operational egocentric children) have been argued as not being candidates since these children lack the logical thought structures necessary to effectively dispute irrational and dysfunctional cognitions. Furthermore, pre-operational and concrete operational counterparts are lacking in the development of the hypothetical-propositional thought structures, thereby restricting even further the employment of an abstract disputational therapeutic strategy (Kendall, 1993).

These developmental issues in relation to the use of Cognitive-behaviour therapy are of particular clinical importance in that the use of typical strategies such as logical analysis
disputation, generating options and alternatives, systematically searching for evidence and developing and testing hypotheses are thus clearly out of the range of most children but have been postulated as essential requisites for the effective use of Cognitive-behaviour therapy with children (DiGuiseppe, 1989). Further, many other aspects of cognitive development (e.g. meta-cognitive awareness, memory attention etc.) are also postulated as likely to influence the relative success of Cognitive-behaviour therapy intervention with children.

A review of research undertaken by Ager & Cole, (1991) has further indicated that pre-operational children are usually unable to spontaneously generate cognitive self-guiding strategies. Further, Piaget states that it is only when children are in the formal operational period, (approximately 12 years and older) that they are generally capable of the type of 'hypothetico-deductive' reasoning which is a necessary prerequisite for the disputational examination of irrational beliefs. Therefore from this perspective, the 'suitability' of a cognitive behavioural approach appears to be related to the level of operationalised thought processing of the child and adolescent and thus, precludes a child who has not yet reached that stage. However this statement has been increasingly seen as a contentious issue by many researchers and clinicians. A review of the literature in relation to adults with moderate learning disabilities who have been shown as not having attained Piaget's formal operational stage, has shown the successful implementation of cognitive behavioural therapy to a limited range of difficulties displayed by people in this client group (Benson, 1982; Lindsay & Mitchie, 1988). Therefore other sources of influence in relation to 'cognitive development' appear to be influential and thus may make 'cognitive-behavioural' interventions applicable to younger children. One important source of influence over the increasing applicability of cognitive based therapies with children has been the development of self-instructional techniques. Meichenbaum, (1979) attributed the origin of self instructional training to Luria's theoretical work (Luria, 1961), which stated that much of an individual's behaviour is under the control of their thoughts or internal speech. It has been shown that when children begin to learn control over their behaviour, it commences usually by external influences such as parents who reward or punish behaviour and provide instructions as to the behaviours which should or should not occur. As children mature it is proposed that they begin to control their behaviour through their own verbal instruction, thus they can be seen to talk out loud as they guide their behaviour. Gradually this control shifts to silent, inner speech (i.e. thoughts) and it is now well accepted that 'one is continually talking to oneself covertly and controlling one's behaviour in this way, until a level is reached when the response becomes automatic' Braswell, (1991). This idea was first suggested by Luria, (1961) who postulated that between the ages of five and seven, children normally have developed the ability to use language to
guide their behaviour. Unlike Piaget, who doubted the capacity of children to understand concepts prior to the operational stage, Donaldson, (1984) contended that the problem lies not in the ‘...child’s capacity’ but rather in the ‘...clinician’s inability to understand and translate the child’s concepts and interpretations’. Donaldson, (1984) further suggested that even young children as they acquire language at the same time gain the skills necessary to comprehend the meaning of objects and events, to make interpretations and to reach conclusions from situations. It has been clearly demonstrated, cognitive development is not as age related as previously thought, thus the ability to think operationally is not confined to adolescence, many younger children have developed the ability to think in an operational way about particular aspects, and are therefore well able to benefit from a cognitive behavioural approach. It however has been shown that abstract concepts used in Cognitive-behaviour therapy such as ‘fairness’, ‘friendship’ or ‘trust’ may still be difficult for the pre-operationalised child to understand. Therapeutic strategies therefore, which probe into the child’s ability to generate hypotheses, alternatives and solutions in an effort to dispute dichotomous and inflexible cognitions, are not likely to succeed with young children if kept at a highly abstract or hypothetical level. Consequently it appears to be particularly important for the therapist to adjust their communication style and expectations to the cognitive developmental level of each individual child. For example when working with very young children (under the age of 7 years) who may be able to understand some of the cognitive aspects of the intervention, one must be especially cognisant of their difficulty in taking the perspective of others (egocentrism) and considering more than one relevant dimension at a time. Further as children during this period rely heavily on perceptual analysis rather than on conceptual inference, it is best to de-emphasise extensive discussion and analyses of irrational concepts and instead rely on the child’s more advanced capacity for dealing with iconic representations and employ many concrete and simple materials (pictures, diagrams, stories, that young children can readily learn from. [Also, as an aside often resource materials, such as diary sheets, child handouts etc. that would assist in the practicalities of undertaking such therapy are frequently elusive in the literature and yet prove invaluable in clinical work. Only recently is the formal sharing of such resources being recognised by clinicians rather than on an ad hoc basis (Young & Brown, 1996)]. As Donaldson, (1984) has argued young children can think this way when the information makes “human sense” to the child, but have difficulties with problems of a more abstract and formal nature.

Cognitive behaviour therapists are now increasingly taking into account the child’s cognitive developmental status in selecting appropriate cognitive assessments procedures, rather than relying upon chronological age as a indicator of whether a cognitive intervention is
appropriate. Since basic learning processes and abilities (e.g. attention, memory and verbal mediation) appear to develop progressively over the childhood period, one needs to question the role of different developmental characteristics in determining the efficacy of cognitive-behavioural intervention. The main work in this area has been in determining whether children's level of cognitive development influences their capacity to profit from self-instructional training (Meichenbaum, 1979) which can be introduced at different levels of complexity employing different teaching formats. Kinney, (1991) further reconsiders the role of developmental theory in the use of cognitive-behaviour therapy (CBT) with children. It is argued that the assessment of both logical/analytical thought structures and social perspective-taking abilities may be useful in planning a course of Cognitive-behaviour therapy with children since many childhood problems tend to be social in nature (e.g. conduct disorder). Thus it is likely that in the course of Cognitive-behaviour therapy a child will be asked to examine the effect of their behaviour has on others. In other words, a child may be asked to focus on shifting their social perspectives. In these instances logical analytical thinking abilities may be necessary but not entirely sufficient in permitting the child to deal with the perspectives of the other individual in their social world. Thus Cognitive-behaviour therapy with children in many instances may require the child to be capable of not only logical and propositional analysis but also to be able to assume another person's point of view. Therefore children’s ability to have role taking abilities and the ability to shift and assume multiple perspectives (i.e. social-perspective-taking skills) have also been postulated as a major necessity for success with using Cognitive-behaviour therapy.

To summarise the above section, from a theoretical perspective, it appears that cognitive-behavioural therapy has been shown to be appropriate psychotherapeutic intervention for adolescents and with some methodological adaptations from the clinician a potential intervention for younger children (Friedberg, 1994). Nevertheless, before a final conclusion can be drawn it is necessary to review the empirical literature in relation to specific difficulties. Cognitive-behavioural approaches to interventions for children have been applied to a wide variety of difficulties including attention-deficit hyperactivity disorder (ADHD), (Braswell, 1993), anxiety disorders (Barios & Hartman, 1988; Kendall & Panchelli-Mindel, 1995), depression (Hollon et al, 1993; Wilkes et al, 1994), and impulsivity (Kendall & Braswell, 1985). Cognitive-behavioural approaches have also been used with children with chronic illness (Ellis & Sparios, 1994; Ehlers et al, 1995; Jay et al, 1995), enuresis (Ronen et al, 1992), and obsessive compulsive disorder (March et al, 1994; March, 1995). A selective
review will be undertaken to investigate the effectiveness of a cognitive behavioural intervention for these specific difficulties.

**Aggression:** Although aggression in mild forms is common during early childhood, aggression becomes clinically significant when it occurs with high frequency or intensity or across multiple settings (e.g. home and school). Kazdin, (1995) has reported that between five and ten percent of children frequently display clinically significant aggressive behaviour, with boys outnumbering girls by about three to one. Clinical concern has been focused on aggressive children because of the substantial stability of aggressive behaviour over time and because childhood aggression has emerged as a significant risk marker for subsequent substance abuse, delinquency and school failure (Ager & Cole, 1991). From a cognitive perspective aggressive children have been conceptualised as experiencing problems from both distortions and deficiencies in their cognitive processing. Cognitive distortions involve dysfunctional thinking processes, whereas cognitive deficiencies involve an insufficient amount of cognitive activity in situations which give greater forethought prior to action is needed. In addition reviews of the social cognitive models of children's aggressive behaviour and the cognitive behavioural interventions based on these models, have found that aggressive children often had distortions and deficiencies in their social information processing. Anger coping programs consistent with the social cognitive model have been presented, and the outcome effects for these intervention were shown to be positive (Ronen, 1995). Research has therefore shown that Cognitive-behaviour therapy is a promising form of treatment for aggression and secondary prevention of conduct and oppositional disorders. For example, Akande & Akande (1994), used a 20 session problem-solving skills training program with aggressive inpatient children, and have shown that problem-solving skills training produced significant reductions in parents and teachers ratings of aggressive behaviour at post-test and at a 1 year follow-up. As cited by Kazdin (1995), these results replicated similar studies which combined problem-solving skills training and parent behavioural management training with inpatient children and in a study with with aggressive and antisocial children treated in outpatient and inpatient settings. Some treatment effects for cognitive behavioural therapy have also been found with conduct-disordered children (Lochman & Lenhart, 1993). Ronen's (1995) research suggested that most children with aggressive or conduct related difficulties can benefit from cognitive therapy in general and from self-control training in particular.
Depression:- In relation to depression, Vostanis & Harrington, (1994) describe a successful cognitive-behavioural program for the treatment of depressive disorders in child and adolescent psychiatric patients. The treatment was based on research findings from studies on cognitive abnormalities in adult depression and on similar abnormalities which have been described in child populations. The aims of this treatment package are the recognition and labelling of emotions, the change of negative cognitive attributions, and the enhancement of social skills, (as indicated by Fennell, 1992).

In relation to suicide, Reinecke et al, (1996) describes a brief, highly structured 6-session outpatient treatment program for adolescent suicide attempters and their families based on cognitive-behavioural principles. The philosophy of this treatment approach suggests that changing and encouraging positive interactions, reframing the family's understanding of their problems, and altering the family's style of conflict resolution can reduce the risk of future adolescent suicide attempts.


Attention Deficit Hyperactivity Disorder (ADHD):- In relation to ADHD, Gomez & Cole's (1991) paper reviews recent research on the treatment of this disorder, including stimulant medication treatment, behavioural treatment, and cognitive therapy. Approximately 70-80% of children with ADHD respond favourably to stimulant medication, although there are concerns about side effects. Behaviour therapy alone has been found to be inadequate in the treatment of ADHD, but behaviour therapy combined with stimulant medication has proven effective. Results of many studies assessing the efficacy of cognitive-behavioural therapy have been disappointing in relation to ADHD.

Meta-analyses Across Disorders:- As cited by Baer & Nietzel, (1991), the literature reveals few meta-analyses of cognitive behavioural therapy for children and adolescents. One such study by Powell & Oei, (1991) examines empirically the process underlying the success of cognitive behaviour therapy in the treatment of childhood disorders. Sixty-three studies from 1974-1989 are reviewed to see whether there is support for the underlying changes in
cognitive processes that are assumed to mediate the therapy. Only nine of these studies attempt to document changes in children's cognitions. While Cognitive-behaviour therapy is relatively effective in treating some childhood disorders, there is little empirical evidence to support the underlying cognitive models of childhood disorders. Better methods of assessing children's cognitions need to be developed, along with more complex experimental methodologies that control for influential variables. In another meta-analysis of cognitive behavioural interventions for maladaptive children, Durlak et al., (1991) showed that children can benefit from a cognitive-behavioural approach. Cognitive interventions were described as best suited for pre-adolescents (aged 11 to 13 years), but younger children (aged 5 to 11) were also considered to benefit. Durlak et al., (1991) suggested that younger children's natural verbal abilities might interrelate positively with cognitive interventions focusing on strategies that emphasise language.

It therefore can be seen that it is very difficult to conclude an unanimous and unambiguous answer as to the relative efficacy of Cognitive-behavioural interventions for children and adolescents. Methodological weaknesses of the empirical outcome studies make it difficult to ascertain a clear conclusion as to the relative efficacy of such interventions, which is unlike the adult literature where many empirically sound comparison studies exist (Hollon et al, 1993; Karusu, 1990). There are few studies which effectively compare Cognitive-behaviour therapy with other interventions, such as parent training, family therapy and behaviour modification, in addition to other psychodynamic interventions or medicational treatments. Multi-method assessments are needed for all studies along with tests of clinical significance and statistical significance and consideration of cost-effectiveness (i.e. professional cost as well as child and family commitment). Further Clarkson, (1996) states that multi-modal interventions are necessary in the empirical literature since this reflects a more realistic evaluation of clinical intervention. Also, since Cognitive-behavioural therapies are based on the assumption that through practise and reward, changes in key areas of children's cognitive processing will result in behavioural changes, the current research does not ascertain that when these behavioural changes are found, whether these changes are in fact due to actual 'changes' in cognition (Kendall & Panichelli-Mindel, 1995). Most research of Cognitive-behavioural therapy interventions acknowledge that changes in behaviour are as a direct result of changes in cognitive processing, but little, if any outcome research investigates whether there is a causal relationship between behaviour and cognition.

In addition, as with most psychotherapeutic outcome research, little time is addressed to other factors associated with the clinical intervention, such as motivation for change, therapeutic relationships between therapist and child and indirectly to the parents. Leading on from this...
are other non-specific factors that affect treatment outcome such as the reactions and consequences provided after contact with the therapist by significant others in the child's life such as peers, teachers and family members. One such study by Kazdin, (1995) which examined pre-treatment factors that predicted favourable CBT treatment outcomes amongst conduct problem children, found three domains (i.e. severity and breadth of child impairment, parent stress and/or psychopathology and finally, family dysfunction) predicted some treatment outcome. Less dysfunction in each of the domains predicted who responded favourably to treatment on parent ratings of deviance and prosocial functioning but not on teacher ratings of these outcomes. These findings have implications for identifying youths who respond to available treatments. They also underscore fundamental questions about the assessment of treatment effects and the criteria for evaluating outcome. Nevertheless, additional studies of active and non active components of the treatment modality are needed. Further, although significant pre-post changes have often been found after cognitive-behavioural interventions, the lack of generalisation of treatment effects for this mode of treatment is a relative weakness. As noted in the outcome summaries, generalisations of behaviour change across settings, maintenance and across other domains of functioning (i.e. behaviour, self esteem and cognition) are increasingly being documented with some Cognitive-behaviour therapies, although mixed findings across research studies still exist (Kaplan et al, 1995).

This review of the empirical literature highlights that problems in study design and methodology hampers and restricts data interpretation across studies. However, despite these methodological weaknesses in many of these studies, most have consistently identified a improvement in outcome in many studies when looking at changes in behaviour, and therefore appears to support the efficacy for cognitive behavioural therapy for some child and adolescent psychopathology.

In relation to a 'clinical application' perspective, cognitive behavioural therapy can be seen as a positive intervention in many aspects. Concerns as to the impact associated with prolonged psychotherapeutic interventions, (in that it may lead to regressive behaviour and emotion and encourage dependency and decrease autonomy), facilitates the increased use of interventions which are brief and time-limited in focus. In addition, it is a decided strength of the cognitive behavioural strategy is the collaborative basis of the therapeutic relationship between the therapist and client which correspondingly fosters independent development as well as prosocial behaviour (McAdam, 1986). In addition, the literature on treatment of adult
disorders suggests that cognitive-behavioural therapy may be of possible value in reducing relapse and recurring disorders and although relatively unstudied in young people, relapse prevention may be a significant treatment outcome (Kendall, 1993). Likewise, as Lambert, (1992) emphasises, although there are treatment strategies that appear in therapies for various disorders, there are no rules carved in stone and the emphasis on cognitive information processing within a context that uses social reward and behavioural procedures to modify maladaptive methods of adjusting is intentionally flexible. Finally, at a time of economic rationing of therapy within the NHS and the resultant need for clear time limited models of intervention, and measurable outcomes Cognitive-behavioural therapy can potentially accommodate both, unlike many other psychotherapeutic interventions.

Future Considerations:
In clinical application, contemporary Cognitive-behavioural therapy for children and adolescents has clearly moved beyond the sole focus on the child-client and has incorporated strategies that involve parents, peers and schools, reflecting both interpersonal and social contexts. Despite this, the relative efficacy of these interventions within the research literature is still relatively sparse (Braswell, 1991; Sapp, 1994; Vostanis & Harrington, 1994; March et al, 1994; Belsher & Wilkes, 1993).

From my clinical experience and having undertaken this review I find it interesting that even though Cognitive-behavioural therapy has been used for a variety of presenting difficulties, there appears not to been a ‘component analysis’ of which aspects it will work on as in therapy one is usually working on a number of difficulties. From this review of the literature, it can be seen that the basic applications of Cognitive-behaviour therapy requires still further research, primarily in terms of the relative efficacy of the treatment as compared with alternative forms of psychological and pharmacological intervention. Despite this, it can be seen that in principle cognitive behavioural therapy is a workable model as a basis of intervention for children and adolescents with psycho-social difficulties. Nevertheless it’s effectiveness appears to be inextricably linked to a significant effect within a developmental framework and it has been shown to be most effective when they mesh effectively with the normal developmental trajectory with the clinician working and adapting their intervention to the child’s level of understanding.
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Discuss the use of Gentle Teaching approach with people with learning disabilities who show challenging behaviours. Are any of the techniques used in Gentle Teaching common to those used in applied behavioural analysis?
'Gentle Teaching is based on a posture that centres itself on mutual liberation and humanisation of all persons, a posture that strives for human solidarity and one that leads care givers to teach bonding to those who attempt to distance themselves from meaningful interactions.'

McGee, (1990)

In recent years a great deal of attention has been directed towards the provision of services and therapeutic interventions for people with learning disabilities who have additional challenging behaviour problems. Before embarking on the paper’s question it is useful to reflect on what is meant by the nature of ‘challenging behaviour’ in this client group. ‘Challenging behaviour’ has been defined as ‘behaviour of such intensity and duration, that the physical safety of the person or that of others, is likely to be placed in serious jeopardy.....’, or also as ‘...behaviour which is likely to limit or delay access to the use of ordinary community facilities’ (Emerson et al, 1987). These particular ‘difficulties’ experienced by a minority of the client group can be emphasised by the fact that despite recent advances in social policy (e.g. closure of hospitals, social role valorisation), a significant proportion of people with a learning disability who display challenging behaviour have largely been unsuccessfully placed in the community (Brandon, 1990).

The proposed aim of this paper is to undertake a discussion of the main assumptions acclaimed by Gentle Teaching, followed by a critique in regards to the methodological similarities to Behaviour Therapy which have been ascribed as ‘Gentle Teaching’, and finally, to discuss whether Gentle Teaching can be differentiated from Behaviour Therapy.

Developed in the United States (originating from research undertaken in Nebraska), Gentle Teaching ‘...is a philosophical approach to the care of persons with learning disabilities who exhibit severe behaviour problems such as self injury and aggression,’ (McGee et al, 1987; McGee, 1990; Crowhurst & Horsfall, 1993). The ethos of Gentle Teaching is described by its founder McGee et al, (1987) as being an ‘alternative’ to aversive, punishment-based practices - (i.e. practices which he believed to be representative of ‘the founding principles of ‘Behavioural Modification’). As such, Gentle Teaching can be seen to have been developed and founded on the reputed weaknesses of ‘behavioural techniques’. Gentle Teaching has three underlying assumptions: firstly, the concept of ‘Bonding’; secondly, that the
communicative nature is apparent in all challenging behaviour', and finally, the concept of 'unconditional value'. Each of these will be discussed in more detail:-

**Bonding**:- 'Bonding' is historically based upon the mother-infant relationship as postulated by Bowlby (1980). However, McGee used this term (i.e. bonding) to describe 'relationships in general' that are meaningful and important to both clients and carers which are based on affection, trust, and respect (McGee & Gonzalez, 1990). It is assumed that for people with challenging behaviour, 'bonding' has either never existed or has been diminished for any number of psychosocial reasons. A central issue in the interaction between caregiver and learner is that 'bonding' is said to occur while the task is being taught - (i.e. 'the task is regarded primarily as a 'vehicle' or a 'bridge across which interactions gain their meaning') (McGee, 1990). Therefore one primary objective in Gentle Teaching is reward teaching, (i.e. systematically and consciously teaching the goodness and reinforcing power inherent in verbal and tactile praise).

**Communicative Aspects of Challenging Behaviour**:- Gentle Teaching also implies that most, if not all 'challenging behaviours' are due to an individual's attempt to communicate. Challenging Behaviours are viewed as communicative messages through which one can indicate distress, discomfort or anger. The development of challenging behaviour in people with learning disabilities is assumed due to the fact that normal effective communication has often been encumbered by a combination of psychological, sensory, neurological, physical disability as well as societal prejudice and diminished social support (Jones & McCaughey, 1992).

**Value**:- The concept of 'value' is based on a philosophical belief that all human life has an inherent importance. This principle belief is based on the idea that human value is not contingent on deeds done or on the presence of appropriate social behaviour. As stated by McGee et al, (1987) 'every person's value is intrinsic, simply because they are a unique human being. This 'value' does not depend on any other qualities, characteristics or measurements. Therefore it can be seen that the development of solidarity between the caregiver and he learner as being of prime importance in maintaining dignity and respect for an individual is a unique human being'. Gentle Teaching assumes that frequent and unconditional value-giving is central to interactional change. Unlike contingent value-giving in behavioural techniques (i.e. where the person has to earn the reward), unconditional value-giving is when carers use '....words, touch and gestures unconditionally to praise and uplift
the person with severe behavioural problems' (McGee, 1990). These signals are given unconditionally and are not related to any current behaviours, whether adaptive or maladaptive. McGee et al’s (1987) paper was the first to suggest the emphasis on the posture or attitude of the caregiver and on the importance of ‘human engagement’ as being central to the effective reduction of challenging behaviour. From these assumptions, Gentle Teaching can be defined as ‘a non-aversive method of reducing challenging behaviours that aims to teach bonding and interdependence through gentleness, respect and solidarity’ (Jones et al, 1990). Gentle Teaching has been recommended to be relevant in a number of clinical situations. In the ‘formal-informal dimension’ an individual client either receives Gentle Teaching on a sessional basis when it is targeted at a particular behaviour, or when being helped by carers to change a number of behaviours less intensely throughout the day. In the ‘specific-ethos dimension’ either the behaviour(s) of one client is targeted, or the Gentle Teaching method is adopted as a learning approach within the home or day service setting. Finally in the ‘direct-indirect dimension’ behaviours may occur in everybody’s presence (and so are accessible to a skilled worker) or only under specific circumstances and may not even be observable by an outsider. Gentle Teaching not only focuses on lessening maladaptive behaviours, but also on other interactional variables.

In recent years there has been a growing controversy surrounding Gentle Teaching. The issues have engendered some of the most contentious debates of any aspect of service provision for people with a learning disability (Bailey, 1992; Barrera & Teodoro, 1990; Conboy-Hill, 1993). A review of the literature highlights that this debate has been marked by an intensity of emotion and the ‘polarisation’ of the discussion. For example, Behavioural Modification has been described as ‘sinful’ and as representing a ‘culture of death’. Gentle Teaching has been personified as being ‘biased, unscientific and naive’. This polarisation has been represented in Table 1. below which highlights the contrasting representations of Behavioural Modification and Gentle Teaching as represented in the literature.

Table 1: Contrasting Representation of Behavioural Modification and Gentle Teaching
(adapted from Crowhurst & Horsfall, 1993)

<table>
<thead>
<tr>
<th>BEHAVIOURAL MODIFICATION</th>
<th>GOAL</th>
<th>GENTLE TEACHING</th>
</tr>
</thead>
<tbody>
<tr>
<td>To change behaviour</td>
<td>Goal</td>
<td>To teach bonding</td>
</tr>
<tr>
<td>The identification and elimination of undesirable behaviour</td>
<td>Focus</td>
<td>Our solidarity and interaction with the person</td>
</tr>
<tr>
<td>Contingent reward</td>
<td>Strategy</td>
<td>Uncontingent valuing</td>
</tr>
<tr>
<td>Aversive/non-aversive practice</td>
<td></td>
<td>Non-aversive practices</td>
</tr>
<tr>
<td>Change in behaviour</td>
<td>Outcome</td>
<td>Using tasks as the vehicle to establish bonding</td>
</tr>
<tr>
<td>Compliance</td>
<td></td>
<td>People learning the value of human relationships</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Mutual liberation</td>
</tr>
</tbody>
</table>
From this table it appears that Behavioural Analysis and Gentle Teaching are two polarised approaches based on fundamentally different approaches. On closer examination however, there is a considerable overlap between the two. For example, as part of its methodology, Gentle Teaching encompasses specific supportive intervention techniques which will be discussed in order to gain an indication of its procedural perspective. These procedures can be summarised as task analysis; management of environment; errorless teaching strategies; prompting; modelling & shaping; the use of tasks as vehicles; participation with the person in order to show the meaning of participation; the identification of precursors to target behaviour; the reduction of verbal instructions or verbal and physical demands; choice-making; fading assistance and the integration of other caregivers and peers into the relationship; the use of dialogue as an expression of unconditional valuing (McGee et al, 1987).

Interestingly, it appears that seven techniques are clearly encompassed within 'behavioural methodology.' For example, in Gentle Teaching, staff are taught how to ignore regular bouts of aggressive or self injurious behaviours and are encouraged to engage the client in more constructive tasks which are subsequently rewarded. This is remarkably similar to the behaviour management procedure 'ignore-redirect-reward' (Turnbull, 1990). Also in the Gentle Teaching literature a response recommended in cases of difficult behaviours such as pica (i.e. the eating non-food substance), is to 'shadow the person's hand movements' and to then 'gradually make the environment more complex.' This appears to be similar to the basic definition of the behavioural technique 'shaping'.

From reviewing these procedures, Gentle Teaching does appear to be little more than a skewed collection of procedures taken from the 'differential reinforcement' techniques as employed by behavioural therapy, yet are posited as evolutionary techniques of Gentle Teaching. Explicitly and succinctly highlighted by Turnbull, (1990) he stated that the only difference between Behavioural Analysis and Gentle Teaching was that the terminology and language of Gentle Teaching was more in-keeping and constant with contemporary approaches and policies - (i.e. 'the terms such as 'extinction', 'reinforcement' and 'contingency' have been replaced by warmer words such as 'bonding', 'relationships' and 'gentle posture'.) Hence the main criticism of Gentle Teaching is primarily founded on its presentation as an alternative to more traditional methods of behaviour management when in fact, many of the techniques are identical to those implemented in Behaviour Analysis.
This belief is not however disputed by Gentle Teaching advocates who openly acknowledge that many of their techniques are encompassed within the behavioural approach framework but highlight that they differ from typical behavioural approaches. By this it is meant that although each discipline uses similar techniques, they are used to accomplish completely opposing goals. For example, behavioural approaches use techniques to achieve the primary goals of 'control and compliance,' whereas Gentle Teaching aims to establish a 'mutual relationship based on feelings of safety and security, participation and value'. (Brandon, 1990). In addition, McGee et al, (1987) implies that these behavioural techniques are meaningless without a 'humanising and liberating posture'. Further, these techniques can be applied without a systematic order (which is required in behavioural methodology) and can be implemented on a moment to moment order to encompass the changes in the learners' behaviour.

However, one can also argue that the three founding assumptions of Gentle Teaching (i.e. bonding, communication, value), can also be seen to be incorporated in Behavioural Methodology if viewed from a behavioural perspective. Firstly, by way of illustration, Behaviour Analysis recognises that the delivery of reinforcement by staff can cause the staff to become conditioned reinforcers (i.e. '....the individuals will frequently approach, caress or otherwise demonstrate that these staff members have become reinforcing to them'). Therefore the success of the caregiver could be attributed not to 'bonding' per se but to the influence of stimulus control, modelling, positive practice and a form of graduated exposure (Jones, 1990).

Secondly, Gentle Teaching appears to put forward the proposition that all or most challenging behaviours are the result of a deficit in communication on the part of the client (McGee et al, 1987). However as highlighted by Jones & McCaughey, (1992), this does not take into consideration the desire to escape from requests or training and physical problems (i.e. allergies or colds), which all can relate to causal behavioural problems independent of their ability to communicate. Therefore questionable ethical implications can be raised for the assumption that a case of 'head banging' as merely reflecting the sign that the client has not 'bonded' with another person, when in fact it could be an indication of a pathological nature such as 'seizure' (Shapiro, 1986).

Thirdly, 'mutual change', the second strength of Gentle Teaching implies that 'successful relationships require input and commitment from both parties, (i.e. the targeting of both
caregiver and individual with learning disabilities). Yet behavioural interventions also hold this tenet, as what would be the point to the endeavour. Also the philosophical belief attached to Gentle Teaching re: 'value' has questionable significance as an exclusive belief to Gentle Teaching since it is so widely accepted in most therapeutic interventions. Therefore this assumption does not differentiate Gentle Teaching or make it different from Behavioural Analysis.

Fourthly, Gentle Teaching is not alone in advocating alternatives to aversive, punishment procedures. A similar desire to develop alternatives to punishment has led to behavioural interventions that take a much broader, or 'ecological' view of the individual and their circumstances and consequently Behavioural Analysis has increasingly developed a more 'constructional' approach. In other words, the goal is to eliminate the person's behaviour not simply by showing the what not to do but what to do instead (Delprato, 1981; Goldiamond, 1974). Such techniques developed include 'differential reinforcement of alternative behaviour, differential reinforcement of other behaviour, differential reinforcement of low-rate behaviour, stimulus control.' In addition an often cited strength of Gentle Teaching is that unlike Behavioural Analysis, Gentle Teaching takes into account more than one behaviour at a time, and considers more than just proximal environmental variables when analysing behaviour problems and devising solutions (Jones & McCaughhey, 1992). However, as highlighted above, current behavioural methodologies acknowledge and embrace this orientation within the 'traditional' behavioural methodology (Lavigna & Donellan, 1986).

Finally, the last assumption is in relation to the 'posture or attitude' assumed by the caregiver while carrying out these specific techniques which is deemed fundamental to Gentle Teaching. This posture of solidarity, interdependence and respect is regarded as a central mediating variable in the successful reduction of inappropriate behaviour. However as defined by McGee, (1990) the attributes and qualities of staff (e.g. such as sense of humour, flexibility) closely resemble characteristics as needed in a 'behavioural technologist'. Therefore when viewed from a behavioural perspective three central concepts can be seen to underlying Gentle Teaching. These concern the importance of wider ecological variables in the analysis of inappropriate behaviour, the importance of the personal characteristics and behaviour of the caregiver and the contribution of non-contingent reinforcement to the elimination of challenging behaviour (Jones & McCaughhey, 1992).
Before further discussion can occur, it is necessary to consider the research literature on the effectiveness of the application of Gentle Teaching with people who display challenging behaviours. Early research papers, proposing the effectiveness of Gentle Teaching (McGee et al, 1987) have been highlighted to have many methodological flaws (i.e. no evidence of a control group or other research design is presented and there is no reliability data for any of these observations). Further discussions of these papers will therefore appear inappropriate as a method of analysing Gentle Teaching effectiveness. However later studies have attempted to address such weaknesses.

In the first evaluative study on the effects of Gentle Teaching, Jordon et al, (1989) compared the effectiveness of ‘Gentle Teaching’ and ‘visual screening’ (i.e. covering of the face) in reducing the stereotypy of three people with learning disabilities. The results showed that Gentle Teaching was not effective as visual screening and that ‘bonding’ (the goal of gentle teaching), occurred at the same low levels under both treatment conditions. Similar results were reported by Jones et al, (1991) and also in Paisley et al’s (1989) comparative study. This study discussed the effects of three non-aversive treatments of behaviour problems with two men with profound learning disabilities. In this study the effects of three non-aversive treatments were undertaken:- Gentle Teaching’, ‘differential reinforcement of incompatible behaviour plus brief interruption’ and ‘graduated guidance’. Results highlighted that the most effective procedure in reducing their self injurious behaviour was the ‘differential reinforcement of incompatible behaviour plus brief interruption’. Other studies have found that Gentle Teaching was non-effective in reducing self-injurious behaviour (Barrera & Teodoro, 1990). In summary, these studies illustrate that gentle teaching has not been shown to be more effective in decreasing ‘maladaptive’ behaviour.

As an aside, it should be highlighted that bonding (i.e. prosocial interaction) is not exclusively a collateral outcome of the application of Gentle Teaching. Positive accompanying behaviours are frequently associated with the use of aversive procedures. In addition the measurement of bonding has been traditionally based upon subjective experience and thus one can question its efficacy as its proposed as the central treatment variable in the Gentle Teaching paradigm. This is because since there is no objectively defined the term ‘bonding’, treatment failure can be attributed to the use of procedures not representing true Gentle Teaching rather than a failure to obtain bonding. Another interesting perspective is that although Gentle Teaching is regarded as the definitive non-aversive procedure for the reduction of challenging behaviour (Brandon, 1990) it has been suggested that in some contexts ‘Gentle Teaching’ may be regarded as aversive (Emerson et al, 1987). For example,
Gentle Teaching may be highly aversive to people whose self-injury is motivated by the desire to escape from contact with others. Ironically Mcgee's own writing seem to support the interpretation of Gentle Teaching as potentially aversive; '......at the beginning of the process of Gentle Teaching the person will display behaviours which obviously indicate that the person does not want anything to do with the caregiver, such as screaming, hitting and biting. The caregiver, however is advised to ignore these behaviours and continue with the process of Gentle Teaching ...'. The justification for this approach seems indistinguishable from the end-justifies the means rationale that has been claimed as being used by mainstream behaviourists to justify the use of aversive procedures.

Therefore it can be seen that there are clear similarities between Gentle Teaching and Behavioural Therapy. However are they different enough to be separated, or is Gentle Teaching simply a collection of 'behavioural procedures' or even 'behaviourism at its best'? Turnbull (1990).

A main criticism of Gentle Teaching is the absence of any clear precise operational definitions associated with the central concepts. This results in the fuzzy descriptions of quasi-behavioural terminology/techniques with no clear guidelines to put them into practice. This is significant as it highlights the ideology of Gentle teaching is not founded on a scientific model, unlike behavioural methodology. Therefore when a comparing the qualities of Behavioural Analysis and Gentle Teaching, a central issue is to where each can be placed along the philosophy-model-theory continuum. The above review of the literature recognises that Gentle Teaching only fits the requirements for a philosophical label. That is, Gentle Teaching is just an evolving philosophy and that the definitions proposed by Gentle Teaching (e.g. 'bonding & interdependence') do not define a procedure but an outcome and therefore fails to meet the requirements for a model or theory let alone a substantiated intervention procedure. However, Behavioural Analysis is founded on a empirically sound base, with terms which can be operationalised into definable, measurable procedures and hence are able to be scrutinised under scientific rigour.

Therefore although there are similarities in both Gentle Teaching and Behaviour Analysis, it would be misleading and damaging, (to Behavioural analysis) to class both together.

In summary, it can be seen that Gentle Teaching consists of primarily behavioural procedures, which are conceptually 'loose and ill defined', which after having undergone empirically defined research, have proven to be ineffective or inconclusive.
The application of such ill defined intervention methods as proposed by Gentle Teaching is felt generally to be a 'too high' a risk to undertake and therefore one has little choice but to ascribe and adopt scientific methodologically scrutinised procedures with such a vulnerable client group. The value of Gentle Teaching is that it has enabled a critical re-appraisal of behavioural analysis, which has consequently been shown to be continuing to aim at increasing the dignity of individuals with learning disability, through methods not associated with harm or punishment but associated with increasingly ecologically sound and scientifically based procedures.

REFERENCES:


WHAT FACTORS ARE INVOLVED IN SUICIDAL BEHAVIOUR IN OLDER ADULTS?
Friends, the hour has come
To put into practice
That virtue I have so often praised
A brief anguish is death
A wandering sigh leaves the breast
Where it had resided for so many years
Like in an inn, like a stranger,
And takes its flight to Olympus
The true abode of happiness

Seiden - Monteverdi's opera, "L'incoronazione di Popea"

'Suicide occurs when there appears to be no available path that will lead to a tolerable existence..... It is when the life interest is one despairing hopelessness that suicide occurs'  - Farber, (1968)

The above quotations highlights changing societal perceptions of 'suicide' and 'suicidal behaviour' through the ages. Suicide and suicidal behaviour is no doubt a contentious and emotional issue which crosses all societal, health and political boundaries. The aim of the paper is to critically review the literature on the social, physical, and psychological antecedents associated with suicidal behaviour, focusing specifically on older adults, and then discussing the role that clinical psychology may have at reducing the risks associated with suicidal behaviour and old age.

Initially it is important to clarify the extent of the problem. Official mortality statistics show a total of 3675 suicides in England and Wales, of which 19% were of people over the age of 65 years. A review of the literature highlights that (as in all age groups,) suicide rates are significantly higher for older men than for older woman. Furthermore, most countries (including Europe, USA and Great Britain) report escalating suicide rates with 'increasing' age, even in despite the recent increase of suicide rates in 15-24 year olds. (Carlson et al, 1991; Corin, 1995; Dennis & Lindesay, 1995; McCall & Land 1994; Vogel & Wolferdor 1989; Schmitz-Scherzer, 1995; Finkel & Rosman, 1995; Lapierre et al, 1992). Generally the male to female ratio of suicide in old age is reported as around 4-6 : 1 (McIntosh, 1992b). Analysis has further identified that the trend for the heightened proportion of males 'attempting' to commit suicide increases with age, particularly in those aged 75 years and over, making them the highest risk (Nowers, 1993; Lester, 1993). Research on suicidal behaviour in the elderly has indicated that there are many similarities in the profile of fatal and non-fatal suicide attempts (Lindesay, 1991; Nowers & Irish, 1993). Generally speaking, attempted suicides of the aged are more serious than those of the young in medical as well as psychological terms. While suicidal attempts are more common in the young the rate of
completed suicide is highest amongst the elderly. It has been estimated that the ratio of attempted suicide to successful suicide in the elderly is 4:1 as opposed to between 8:1 to 20:1 in the general population (McIntosh, 1992a). In addition, attempted suicide in the elderly carries a higher risk of subsequent completed suicide (Frierson, 1991; Nowers, 1993; Lyness et al, 1992; Merrill & Owens, 1990). Therefore ‘attempted’ suicides in the elderly should be considered ‘failed suicides’ (Tobias et al, 1992). The high rate of completed suicide among the elderly and the fact that elderly persons attempt suicide show more serious intent than others underscore the vulnerability of older adults to the consequences of suicidal behaviour (Conwell, 1995; Frierson, 1991). Further, there needs to be considered ‘rational suicide,’ (i.e. ‘a destructive behaviour which develops reflecting a type of ‘suicidal erosion’......’ (Carpenter, 1993). That is the intention, (which is often masked), to take one's own life by non-violent means through starvation or non-compliance with essential medical treatment and this has been an underreported but increasingly distinctive action in the ageing population (Moody, 1991; Battin, 1991). From the above discussion it can be seen that prevalence rates of suicide and suicidal behaviour are grossly unreliable since national figures only include suicide where ‘cause’ had been established ‘beyond reasonable doubt’ which therefore precludes deaths where ‘cause’ had not been recorded as suicide, although probable suicide had appeared to be evident, (such as in ‘rational’ suicide).

One recent development in suicide ‘statistical analysis’ studies has been the use of ‘age-period-cohort factors’ to analyses statistics which has resulted in a fuller appreciation of the various factors that operate to determine suicide risk. This has shown that the apparent association between age, sex and suicide is not as simple as it seems. The relationship between age and suicide appear to reflect cohort effects as well as those directly attributable to age itself. Period effects such as wars, changes in medication prescription procedures and the detoxification of domestic gas supply appear to further confound the issue. A review by Lindesay, (1991) of the secular trends in officially recorded suicides in the elderly in the UK indicated that there has been very little change in the overall rates of suicide of elderly men and woman over the past decade, compared to the dramatic fall in the 1960’s (due to the alteration of gas supply). In both sexes there has been a decline in suicides by self-poisoning due primarily to the substantial fall in barbiturate poisonings.

By contrast, rates of suicides due to overdose of analgesics and benzodiazepines in the elderly have been rising in recent years (Nowers & Irish, 1988). Another discernible trend in recent years has been the steady increase in suicide by car exhausts in elderly men (Lindesay, 1991). However despite the complexity of interactions between age, period, cohort and gender
effects, it is evident that there is a clear and significant relationship between suicidal behavior and increasing age. Yet despite these aforementioned trends in older age suicidal behavior, a review of the literature highlights that until the late 1980's apart from the work of Barraclough et al, (1974) suicidal behavior tended to focus on the young (McCall, 1991).

In addition to the age-cohort effects the association of age and suicide is also modified by a number of other risk factors, such as psychiatric illness and a variety of psychosocial variables (Blazer, 1991). These will be further discussed in greater detail. Most research in relation to suicide has focused upon the identification of potential psychiatric precursors or indicators associated with this behavior. Several studies have used the techniques of psychiatric ‘autopsy’ to make retrospective diagnoses on the basis of detailed interviews with nearest relatives supplemented by examination of primary care and hospital case notes in consecutive series of suicide victims. This approach (which requires clear evidence of a range of clinical features in order to permit psychiatric diagnosis), is important in avoiding the circular argument of regarding the suicide act itself as evident of psychiatric illness (Younger et al, 1990; Katona, 1994). Studies which specifically focused on old age samples or sub-samples both in the UK, USA and Europe have concluded that the overwhelming majority of suicides (over 90% in most studies) were associated with specific psychiatric illness (Cohen, 1990). Past and current psychiatric treatment appeared to be indicated in @ 30-54% of patients (Merrill & Owens, 1990). Within these, the most frequent diagnosis, occurring in approximately 70% of the total, was depression. Draper’s (1996) review of the five most recent studies reports depression occurring in 91% of cases, insomnia in 59%, psychosis in 12-40%, which mainly involved mood-congruent depressive delusions. This challenges earlier research which has indicated that the presence of psychosis in elderly depressives did not necessarily increase the risk of suicide attempt (Zweig & Hinrichsen 1993).

In relation to depression, research has shown that the risk of suicide is about four times greater than their younger counterparts (Duberstein et al, 1994; Wattis, 1990). A reason for why depression appears to be more strongly indicated with suicidal behaviour in the elderly has recently gained validation by studies which indicate specific biochemical changes in the brain which occurs in the ageing process. Primary depression results from various biological and chemical changes in the brain and nervous system or from changes in the endocrine systems. There’s increasing evidence that during ‘ageing’ there is a decrease in level and or activity of many neurotransmitters. The reduction in the levels of serotonin (5HT) and 5HIAA in the cerebrospinal fluid and a reduction the 5HT-2 binding sites in the frontal cortex have been found to be common features of ageing which may increase some elderly
individuals vulnerability to suicide (Lindesay, 1991; Rifia et al, 1992; Gross et al, 1990; Conwell & Caine, 1995). Therefore it is suggested that ‘biological ageing’ significantly contributes to suicide risk. In addition changes in the endocrine system especially thyroid, pituitary and hypothalamic function (often associated with illnesses which occur in old age) can produce changes in hormone levels which can contribute to late-life depression. Also virtually all recent studies have shown that many elderly suicides suffer from depressive symptoms reflecting an apparent increasing presence of depressive illness. Therefore there appears to be a clear relationship between suicide and psychiatric illness which indicates that elderly psychiatric patients (especially those with a diagnosis of depression, a history of previous suicide attempts and a family history of suicide) may be at particularly at high risk (Frierson, 1991; Shneidman, 1991; Zweig & Hinrichsen, 1993). However Vogel & Wolferdorff, (1989) study which investigated the relationship between suicide and mental illness in elderly persons by examining (1) whether the risk of suicide in elderly persons was confounded with increased psychiatric morbidity and (2) the extent to which suicides of older mentally ill persons were created by their mental illness demonstrated that although age was an autonomous risk factor, it was not always confounded with psychiatric morbidity. Therefore ‘psychiatric morbidity’ of older suicides appears not always sufficient to explain the suicidal act (Lester & Yang, 1992; Lester, 1994).

Leading on from this, in relation to personality variables a review of the literature has shown that there are very few studies of the relationship between affective disorders and personality disorders in the elderly. General ‘personality studies’ have suggested that depressed patients have high emotional instability, neuroticism, introversion and obsessionality, concluding that personality disorders predispose people to suicide and suicide attempts. A recent comparison study undertaken by Duberstein et al, (1994) described the personality characteristics of suicide completers and ‘aged gender’ matched non-suicidal attempters. Neuroticism traits appeared to characterise victims across all age groups, including older adults. Although there is limited evidence, studies of depression and attempted suicide in old age indicate that lifelong personality traits are important for example the incapacity for close relationships, (Murphy, & Brown, 1980) a tendency be helpless and hopeless and an inability to tolerate change, (Lindesay, 1991) have been indicated in suicidal behaviour. Furthermore it has been hypothesised that these traits may remain ‘invisible’ until ageing life-changes force the issue into the open (Clark, 1993; Kunik et al, 1993).
In terms of the clinical relationship between depression and 'organic' mental disorders, depression has been reported to occur with increased frequency with patients with organic mental disorders. However, as with the previous factors already mentioned this assumption is again fraught with circularity since conversely, cognitive dysfunction is part of the depressive syndrome (Alexopoulos, 1991). However research appears to have shown that suicide is more prevalent in patients with mild dementia than in the general population but that the suicide rate decreased in severely demented patients. From the above discussion it can be seen that 'psychiatric illness', especially depression appears to have a significant effect in the aetiology of suicide and attempted suicide in old age. However it is important to emphasise that the mere demonstration of psychiatric illness prior to suicide does not necessarily make psychiatric illness a sufficient explanation in itself (Vogal & Wolfersdof, 1989). Various psychosocial factors have been shown to contribute to the aetiology of depression and more significantly are factors associated with the experience of ageing (i.e. loss, stress, loneliness, low self-esteem, helplessness, anxiety, and loss of control). This makes the identification of the interrelationships of such factors and the establishment of 'causality' in relation to suicide extremely difficult. Other significant factors indicated in suicidal behaviour of older adults include, alcoholism, bereavement, physical illness, isolation, relocation and role adjustment factors.

Alcoholism has been found to be a major precipitating factor in late life suicide, its effect being labelled as 'chronic suicide', and 'playing dead' and as reflecting a 'substitute' for death (Osgood, 1987). It should be highlighted that many of the factors which contribute to depression also increase the risk of alcoholism (i.e. loss, stress, loneliness, low self-esteem, helplessness, anxiety, and loss of control). Medical illness is common in older adult suicide victims (Mellick et al, 1992). The extent to which physical health is a risk factor for attempted suicide is unclear. Impairment of health has been found to be more prominent in attempted suicide in old age compared to younger groups (Merrill & Owens, 1990; Osgood, 1992). Research has been varied, reflecting polar views. For example Frierson, (1994) found it to be a major influence while Zweig & Hinrichsen, (1993) reported that physical health did not distinguish suicide attempters from non-attempters. However many studies did not identify or quantify inclusion criteria re: illness or whether chronic or acute onset (Rifia et al, 1993), or contained control groups matched for other suicide risk factors. Cattell's (1988) study highlighted that in the majority of cases the medical illness and disability was not considered the principal reason for suicide but rather enhanced other co-existing factors. Research has increasingly postulated that it may not the degree of physical incapacity but
rather its 'impact on lifestyle', 'need for multiple medications', 'effect on morale', and 'the presence of pain' that is more important, especially when interacting with other psychosocial factors, such as institutionalisation (Draper, 1996).

Nowers, (1993) found that there were two distinct combinations of physical and mental illness in his sample of 88 elderly suicide attempters. One group consisting of the 'young old (65-74 years) males and 'old' old (75 years and over) females had high levels of multiple physical illness and low levels of mental illness, while the other group consisting of 'old' old males and young old females had low levels of physical illness and high levels of mental illness. These results suggest that there may be a complementary relationship with physical and mental illness that contributes to physical illness. There interestingly appeared to be a sex differential with males having reported higher and multiple rates of chronic illness. (Nowers, 1993; Draper, 1994). These two studies have also reported an inverse relationship between physical illness and severe depression (Nowers 1993; Draper, 1994). It therefore can be seen that the presence of physical factors and their relation to suicide is complex and it appears that much depends on the meaning of the disability to the individual, as well as the objective disability engendered.

In relation to marital status divorced men and woman have an increased risk of committing suicide, followed by the widowed and single. The divorced widowed and unmarried among the elderly, if considered as one group, are three times more likely to commit suicide than their married counterparts (Holding, 1984).

Another important predictor of suicide in older adults has been related to 'isolation'. Heikkinen & Lonnqvist, (1995) identified social isolation as a key variable in elderly suicides, with many other studies identifying that nearly half of all elderly suicides were permanently living alone. Isolation can become more apparent as one ages due to physical illness, frailty, reduction in social networks, and loss of potential roles in society. This reduction in social networks, and loss of potential roles in society can be precipitated by retirement and it has been shown that retirement can be frequently associated with risk of suicide, especially in the first few years after active employment (Weisman, 1991; Richman, 1991). Retirement has been explained as a high precursor to suicide in that work is the major, culturally dominant role for males in western society and the source of social status, self respect and identity. Retirement results in a major loss of self respect and social status and a crisis of identity. Further many people experience a relative decline in their social-economic
status following retirement and this has been implicated as a vulnerability factor for suicide in the elderly, since financial status has been shown to be a significant variable influencing life satisfaction in old age (Richman, 1991). However the relationship between suicide and socio-economic factors is not straightforward, since some of the most economically disadvantaged elderly have the lowest suicide rates (McIntosh, 1992a). It has been suggested that lifelong adversity may in fact be protective against suicide in old age since those who have experienced hardship will have a wider repertoire of support and help-seeking skills both internal and external. In addition when considering the association between suicide and old age, it must be emphasised that this is not a universal finding across all societies and cultures.

Issues around relocation have been shown to be important, with research showing that elderly people who committed suicide had moved significantly more often than those who didn’t commit suicide. The event of relocation has been associated with an increase in mood and behavioural psychopathology in elderly patients with psychiatric disorders (Anthony et al, 1987; Conwell, 1994). This has profound implications in relation to the impact of institutionalisation (such as placement in a nursing home) which commonly occurs with elderly people. Loebal et al’s (1991) study which showed that of the persons who gave specific reasons for their completed suicide, 44% left indications that this act was precipitated by anticipation of nursing home placement.

In relation to the ageing process another key factor which appear to be associated with this aspect of the life cycle is that of bereavement due to depression that it frequently elicits. However Weeks, (1994) indicate that bereavement infers potential direct and indirect consequences especially in elderly scenarios which in themselves contribute to risk of suicide. For example, i) ‘total isolation’ ii)loneliness iii) risk of institutionalisation of surviving partner as well as the iv) increased likelihood of depression. However research showed that there may be a key dependent variable (i.e. sex). An interaction effect appears to be evident between bereavement and sex, as the risk of suicide for widowed men is generally reported to be 3.3 times as high as for married men, but the risk of suicide for widowed women did not increase compared with that for married women (Li, 1995; Nieto et al, 1992; Gilewski et al, 1991).

From this discussion it has also highlighted the role that ‘social isolation’ may play in precipitating suicide. It has been well established and has received attention as an important social variable. Social support therefore can be seen as a major factor mediating negative
effects of stress and facilitating adjustment to status change and role transition. Social support is usually derived from family, other relatives, friends and neighbours. Findings from a variety of studies suggest that an intact social support system has a mediating or buffering effect on stress produced by life changes (such as bereavement, relocation, role transition and ill health (DeLeo & Dieskstra, 1990; Fawcett et al, 1987).

It can be seen that there appear to be number of factors and mediators that appear to be significant in relation to the risk of suicide amongst older people. Yet despite this only a limited number of models and frameworks (reflecting varying complexities) have been proposed to encapsulate the many factors associated with suicide and suicidal behaviour in older adults. Shneidman (1991) defines a psychological view of suicide (among the elderly and in general) as a reaction to idiosyncratically experienced, intolerable psychological pain that results from frustrated psychological needs. He states that suicide is not best understood as a psychosis, neurosis, or character disorder, but as a transient psychological constriction of affect and intellect.

Cohler & Jenuwine, (1995) explores how a life-course perspective and narrative methodology can be used to study risk factors for late-life suicide. A life-course approach to ageing and suicide requires consideration of age as both a social and personal construction. "On-" and "off-time" events and their impact on adjustment are used to illustrate social and personal constructions. Understanding the interplay of personality, social time, and life events is viewed as important in the effort to link changes presumed to take place across the course of life with the despair leading to suicide.

A life-story or narrative approach offers an alternative method for incorporating complicated factors in the study of late-life suicide. Perceptions of one's own future, a sense of a misfit between self and the world, and a sense of personal value are all discussed as potential areas for suicide relevance (Stillion et al, 1989; Corin, 1995). Leading on from this, is the adaptation of the concept of 'Openness to Experience' (OTE) which has been developed and incorporated into Duberstein's model of suicidal behaviour (Duberstein, 1995). He proposes that persons low in OTE are at risk for taking their own lives because their affective dampening, cognitive certainty, diminished behavioural repertoire, and rigidly defined self-concept have decreased their capacity to adapt to the changes in role, health, and function that accumulate with age.

An alternative explanation is posed by Fry (1986), who lists a number of persistent themes of fear and anxiety that may pose considerable emotional hardship to the elderly, (i.e. such as fear of sensory deprivation, fear of mental decline, fear of mental illness, fear of loneliness
and segregation, fear of crime and violence, fear of physical illness and fear of disability). By summing these themes of fear, Fry convincingly portrays the particular stresses of the elderly and the difficulties the elderly have in coping with increasing number of major events and fearful consequences with decreasing resilience. The role of such anxieties in the aetiology of suicidal behaviour has some empirical basis. There is some evidence that the sudden onset of a pervasive and anxious state could be a predictor of subsequent suicidal behaviour. Kerkof & DeLeo, (1991) hypothesise that the multitude of potentially fearful events triggered by multiple losses enhances a frequent reoccurrence of minor depressions or transient mood disorders. In this way suicidal behaviour in the elderly might be much more influenced by everyday fears that may develop into extreme intensity than by classical psychiatric syndromes. The numerous loss events inevitably accumulating in the later part of life provide a partial explanation (in psychosocial terms) of the greater prevalence of depression in this age group. Moreover, age-related biological changes may in some way predispose the individual to the onset of a depressive episode, and may perhaps also partially explain the tendency toward chronicity found in affective as well as organic disease in the elderly. In this way the role of depression in the genesis of suicidal behaviour in the elderly might be fundamentally different from that among younger adults, as those of personality traits and temperaments.

According to Carlson et al, (1991) 'whether an older person is able to resolve a suicidal crisis or succumbs to self inflicted death is very much a function of the ability to cope with stress; losses whether real threatened or imagined are stressors that require adaptation, flexibility and resiliency if persons are to cope successfully with ageing. Loneliness and severe depression are often caused by the many losses and stresses faced by older persons. Loss and stress contribute to feelings of helplessness and hopelessness, two major psychological factors in late life depression. Most individuals appear to be suffering from situational or reactive depressions, an emotional response to the losses and stresses of ageing. The loss of social roles, work role, family roles and community with concomitant losses of income, power, status and prestige. Physical loss such as declining health, painful chronic debilitating illness, losses of sensory acuity. The experience of personal loss such as death of spouse or close friend. Faced with such losses the older person lives in an ever contracting social world, increasingly cut-off from verbal and physical contact (Osgood, 1991; Cohen, 1990). Hopelessness previously linked with the prediction of future suicide was found to persist after remission of depression in elderly depressives who had previously attempted suicide and may represent a psychological trait (Rafia et al, 1994).
From a review of these models it appears that each play factor plays a valuable part in the understanding of suicidal behaviour. The aforementioned research has fuelled and developed most of the current concepts and models on suicidal behaviour. This has evolved around two interrelated themes of influence, 'Sociological' and 'Psychopathological'; in that suicide is viewed as either a response of an individual to certain social phenomena or in contrast, the impact of psychiatric factors (principally depression) as a mediating state of most factors leading to suicide (Murphy & Brown, 1980; Murphy et al, 1986). However the literature review has highlighted the need to expand on these frameworks since there appears to be many aspects associated with suicide that remain unanswered. The above discussion highlights that medical, psychiatric, personality and psychosocial variables all appear to have a role in suicide and suicidal behaviour, (see Table 1.). The process of ageing (and the factors associated with this) also impact on the potential for suicidal behaviour. It can be seen that these factors are not mutually exclusive is very difficult to disentangle the web of causality. Several authors emphasise not so much the impact of any one single factor, but consider the interaction between various factors as the crucial factor in the contemplation of suicidal behaviour The coping skills of the individual also impact upon the person’s adaptability to many of these factors and therefore indirectly upon the risk of suicide.

Table 1: Risk Factors for Suicide in Old Age:

<table>
<thead>
<tr>
<th>Demographic/General</th>
<th>Individual / Clinical</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>Expresses wish to harm self</td>
</tr>
<tr>
<td>Living Alone</td>
<td>Anhedonia</td>
</tr>
<tr>
<td>Past/Current psychiatric treatment</td>
<td>Prominent depressive cognition (guilt, helplessness, hopelessness)</td>
</tr>
<tr>
<td>Psychiatric/Affective disorder</td>
<td>Prior suicidal attempts</td>
</tr>
<tr>
<td>Alcohol abuse</td>
<td>Chronic physical illness</td>
</tr>
<tr>
<td>Socially Isolated</td>
<td>Personal affairs in order</td>
</tr>
<tr>
<td>Recent bereavement</td>
<td>Insomnia</td>
</tr>
<tr>
<td>Recent House move/relocation</td>
<td>Subjective/objective experience of loneliness</td>
</tr>
<tr>
<td>Financially slightly less secure</td>
<td>Reduced brain stem serotonergic activity</td>
</tr>
<tr>
<td>Un-married</td>
<td>Ease of access to method (i.e. car, firearm, medication)</td>
</tr>
<tr>
<td>Disrupted marital status (divorce; recent widowhood)</td>
<td>Recent severely stressful life event</td>
</tr>
<tr>
<td>Family psychiatric and suicide history</td>
<td>Situation perceived as 'unbearable'</td>
</tr>
<tr>
<td>Un-married</td>
<td>Family conflict</td>
</tr>
</tbody>
</table>

Most of the difficulties in the conceptualisation of a unified model of suicide in older adults is due to both conceptual and methodological limitations of the previous research. It is important to highlight that problems in study design and methodology hamper and restrict data interpretation across studies. Most existing studies have concentrated upon the
demography, methods, psychiatric diagnoses and physical health of elderly suicide attempts to provide a broad descriptive profile (Merrill & Owens, 1990). The design of studies appear to have been primarily descriptive (often single case studies, or small series) or Analytic (for example comparing groups of younger suicide population, accidental death, and age cohorts). Such retrospective studies of suicidal behaviour are limited by 'hindsight bias', lack of diagnostic specificity, lack of defined diagnostic criteria, sample biases, data that was not independently validated, the failure to state inclusion criteria and inadequate standardisation of measures (Fawcett et al, 1987; Lyness et al, 1992; Draper, 1996).

Furthermore, many of the studies only included cases in which official verdict of suicide had been reached (i.e. not probable suicide) and therefore may not be entirely representative of all people who attempt suicide. Also since few studies have assessed the above mentioned variables prospectively it is difficult to determine which factors preceded and ones which co-occur with suicidal behaviour (Heikkinen & Lonnqvist, 1995). In addition the 'data collection' methods of such studies can be seen to be fraught with confounding problems. For example 'psychological autopsy' results in much early life information being missed, especially if second generation informants are questioned; Coroner's reports are legally biased; Quality of detail in case notes extremely variable and Case registers rarely provide more than numerical data..

In addition many of the findings associated with suicide and old age, have been derived from both studies of suicide attempters and studies of persons who committed suicide, which may represent separate but overlapping groups (Cohler & Jenuwine, 1995). Further, cohort studies have also identified that certain sub groups exist and that research in relation to risk factors for psychiatric and non-psychiatric illness subgroups should be examined separately (Conwell et al, 1990; Conwell et al, 1991). Also the potentially profound effects of cohort, period, and historical events on risk for suicide creates significant difficulties in design methodology since these potentially confound many of the conclusions stated in recent studies. For example, a recent study (Blazer et al, 1986) has shown an association between depressive symptoms and increased age to be reversed when factors such as low income, physical disability, cognitive impairment and poor social support are simultaneously controlled.

Likewise virtually nothing is known about prevalence rates and symptomology of depression and suicidal behaviour in older people from the various ethnic minority populations in the UK. Research in younger generations have shown that there are significant factors associated with suicidal behaviour and more specifically associated with treatment outcome when cultural factors have been acknowledged and addressed in intervention design (Abas, 1995).
Despite methodological weaknesses in many of these studies, they have consistently identified a number of factors regarded as being associated with suicidal behaviour in old age. Recent research has attempted to overcome these methodological difficulties by focusing using a prospective design and standardised measures on carefully circumscribed groups of older adults (Zweig & Hinrichsen, 1991).

Past psychiatric treatment appears to occur in approximately 30-54% of patients (Merrill & Owens, 1991). This may however not be a reliable indicator of psychiatric illness since some studies have shown that many elderly people with severe psychiatric illnesses (who are at high risk of suicide) may be less likely than their younger counterparts to be referred to specialist psychiatric services. This is reflected in Conwell et al’s study (1990) who found that only 53 out of 246 completed studies in older adults had documented psychiatric illness though nearly half had affective disorders. Lyness et al, (1992) described the psychopathological characteristics of elderly suicide attempters admitted to an inpatient psychiatric unit by reviewing the records of patients (aged 60+ yrs). These results indicated that 80% of the attempters had a major depressive syndrome and may be a more accurate reflection of depressive symptomology present in elderly suicide attempters (Rifia et al 1992; 1993; 1994).

Finally some researchers have questioned the value of ‘generalised’ risk factors indicating that while risk factors may be useful in identifying high risk group of individuals, such criteria are far less useful when it comes to predicting ‘risk’ in the individual patient (Hawton, 1981). Clark, (1993) highlights the inherent danger in oversimplifying the factors associated with simplifying the causes of suicidal behaviour (for the sake he states for clear precise models) in that most have a significant potential for missing or mis-identifying the potential ‘elderly’ suicide victim. However, the crudity or lack of sophistication of the risk factors and the development of suicidal behaviour models appear to be more based on the aforementioned methodological difficulties in such research rather than on the paucity of usefulness of such data.

Despite some methodological weaknesses, current research has highlighted a number of potential risk factors for suicidal behaviour in old age. However even with this knowledge can anything be achieved in terms of intervention? The prevention of suicide is increasingly receiving greater attention at general public, health service and political levels. With this has come the recognition for the need of improved research methodology, and the identification of specific ‘at risk’ subgroups: - ‘There is a need for more research ...... to establish the most effective patterns of care for patients who deliberately harm themselves, while at the same
time making better use of scarce resources'. This has been further clarified in the 'The Health of the Nation' White Paper which specifically targets a reduction in the suicide rate. Although consequently, Health Services are now obliged to give 'active consideration' to possible preventative strategies, most research and public attention (as already mentioned), has mainly been centred on younger adults and adolescents (Cattell & Jolley, 1995). This is despite of predictions of markedly higher rates of suicidal behaviour for future older adults. For example, predictions of elderly suicide (although based on an assumption of stable rather than changing rates) produce estimates of more than twice the current number of suicides and a proportionate increase in the number of suicides from 1 in 5 for the 1980s to 1 in 3 by the year 2030 (McIntosh, 1992). However, despite this figure there has been little documented intervention work undertaken in this area with this client group. Regardless of etiological considerations, it is vital to modify the attitude of resignation so often characterising the clinical approach to psychiatric disturbances in the elderly. There are in fact no constitutional reasons why biological, psychological, or social therapeutic approaches in the elderly should necessarily be futile or ineffective. Once correctly identified, the clinical problems of depression are equally accessible to treatment in both young and old subjects (De Leo & Diekstra, 1990; Richman, 1993).

Therefore the first intervention required is in relation to 'therapeutic nihilism'. Most identified patients have treatable psychiatric illness and degrees of loss and social isolation which are amenable to environmental and psychotherapeutic intervention. Yet despite this, the losses and fears attached to ageing (such as loss of physical health, bereavements etc.) has created the aura of 'rationality' prevalent amongst professionals. It seems that many elderly people who commit suicide are not in close contact with primary care services as reflected in Cattell & Jolley's study of 100 suicide case where few cases were known to the services and more worryingly, where there was suggestion that some treatment was inappropriate, co-occurring with the very few referrals for specialist care. Rationality, I believe has been wrongfully attached to suicide in the elderly. It is in itself a misleading concept for a proper explanation of suicidal behaviour, and obscures the true reasons for elderly suicide. Such attitude state that old people 'rationally' choose to commit suicide and should not be prevented from doing so, because they have the right to commit suicide when confronted with the loss of a spouse, physical disability, isolation or other adversity. Despite evidence to the contrary, people in general tend to think that suicide among the elderly reflects a careful balance between the pros and cons and hence should be respected as a rational decision. However, the tendency to see many problematic situations as naturally tied
to the ageing process, precludes the fact that many elderly people experience similar losses and yet do not contemplate suicide. Some researchers and clinicians still maintain that there is a need and for the right to ethical and unobstructed suicide (Carpenter, 1993; Battin, 1991). Others have equally argued against this. Conwell & Caine (1991) conclude that ‘suicide in the absence of treatable affective illness in uncommon among the old.....to the extent that clinical depressive illness precludes rational decision making, the proportion of rational self-inflicted deaths does not increase with age.’

A variety of treatments have demonstrated effectiveness, including psychotherapy, interpersonal, and cognitive behavioural therapy (Salkoviskis et al, 1990). Structured therapeutic activities may promote self-esteem and self-worth, reducing the risk of suicide (Morgan, 1989; Liptzin, 1991; Osgood 1991; Richman, 1993).

Therefore there is a need to emphasise the recognition of suicidal factors and training a range of primary care, medical, surgical staff and the public in general both within this country and internationally (Glass & Reed, 1993; Moscicki, 1995). Further, accurate diagnosis and assessment of depression, alcoholism, vulnerability and potential suicide are required since these appear to be keys to suicide prevention among the elderly (Heinriksson et al, 1995). Primary prevention can identify and target high-risk groups (i.e. those with specific medical illnesses, disabling chronic diseases, those who are isolated, widows/widowers, and spousal caregivers) and to if necessary implement a psychosocial intervention (Osgood, 1992; Maltsberger, 1991; Weisman, 1991; Strasburger & Welpton, 1991). Secondary prevention in terms of physical health, improved management of pain and physical distress, better treatment of immobility and sensory disability appears to be required. The reduction of social isolation and interventions related to helping with role transitions are preventative measures which could be implemented to target against suicide. In addition special consideration should be given to those ‘at risk’ for example the isolated, depressed in the context of physical illness should be identified (Kastenbaum, 1992; Vassilas & Morgan, 1994).

**Future Considerations:**

In general the studies of the past decade have confirmed most of the major factors associated with attempted suicide. However there has been little refinement in the level of understanding of the processes by which these and other factors contribute to an older person’s suicide attempt (Leenaars et al, 1991). The findings of the literature review highlights that attempted suicide in the elderly closely resembles completed suicide and has a multi-factorial aetiology.
Psychiatric illness (prominently depression) and alcoholism appear to be prominent in many of the cases, but it is interacted with by many other psychosocial variables (including dysfunctional family history, relationship difficulties, previous history of suicide, family history of suicide) and those associated mainly with ageing, such as increasing physical illness, age and gender, loss, psychosocial stress bereavements (Canetto, 1992).

Despite all the research into suicidal behaviour in the elderly there is yet to be conceptualised a formalised psychobiosocial model of suicide among the elderly. It appears that this is due to the methodological difficulties associated with undertaking research into the aetiology of suicidal behaviour. Future studies should be prospective, longitudinal use standardised measures, matched control groups and include evaluations of past suicide attempt interventions, hopelessness and biological activity (Draper, 1996). Furthermore, the interaction of risk factors requires further assessment and exploration to see whether such interaction may differ according to gender, age, physical and mental health parameters to produce a number of suicide 'risk' profiles (Nowers, 1993; Draper, 1994). These need to investigated further in order to assist developing more appropriate suicide strategies. In addition more co-ordinated and comprehensive cross-cultural studies are needed of psychopathological correlates of suicide across the life course to reflect the multi-cultural society (Conwell & Brent, 1995).

**Summary:**
Several potential factors have been shown to lead to suicide in older adults. These include gender, age, psychiatric illness (principally depression) alcoholism, serious illness, bereavements, loneliness and isolation. An individual's perceived fear, ability to cope and adaptability to many changes associated with the ageing process can interplay on these factors which can arouse feelings of meaninglessness expressed by many suicidal persons leading to suicidal attempts.

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IS NEUROPSYCHOLOGICAL REHABILITATION EFFECTIVE?
The application of neuropsychological rehabilitation has been immense in recent years to include acute onset conditions (e.g. cerebral vascular accidents and traumatic brain injury) and progressive neurological illnesses (e.g. dementia and multiple sclerosis). The literature is too broad to discuss all these individual applications, therefore this paper will concentrate on its application to adult traumatic brain injury (TBI), since according to a recent survey by Putnam & Deluca, (1990) clinical neuropsychologists devote a greater proportion of their clinical time to patients who have suffered a TBI than to any other single group. For the purpose of this paper TBI will be used to broadly encompass ‘any injury to the head that engenders a change in consciousness’ (Williamson et al, 1996). This paper aims to undertake a critical review of the literature on the conceptual basis of neuropsychological principles to rehabilitation and then by selectively reviewing and summarising the research on interventions for traumatic brain injured adults will attempt to elucidate the effectiveness of neuropsychological rehabilitation.

Neuropsychology as a ‘science’ is the study of brain-behaviour relationships. Clinical neuropsychology as a ‘practice’ is the application of these brain-behaviour relationship principles to the individual patient for assessment, treatment and rehabilitative purposes. Traumatic brain injury has been estimated to effect nearly two million people each year. In the United Kingdom there are 80,000 people suffering from long term effects of serious head injury and that every year 2,000 people are added to this number (National Head Injury Association, 1992). The improved medical management at the acute stage of traumatic brain injury has increased and continues to augment the likelihood that patients will survive such injuries, creating a pressing need to provide effective rehabilitation for the traumatically brain injured person and their families. Consequently the treatment and rehabilitation of brain impairment following traumatic brain injury has proliferated in the past few years. Therefore people with a traumatic injury have received a great deal of empirical attention from neuropsychologists and affiliated professionals. A detailed discussion of the immense array of cognitive and behavioural sequelae after brain injury is beyond the scope of this paper (see McKinlay et al, 1981; Brooks, 1986; Prigatano & Fordyce, 1986; Kreutzer et al, 1994; Adams et al, 1996 for review).

The broad categories into which these deficits can be aggregated has been summarised by Lezak (1979) as:
1. disorders of arousal and attention.
2. disorders of learning and memory.
3. disorders of complex information processing incorporating speed and planning.
4. disorders of perception.
5. disorders of communication.

It therefore can be seen that cognitive deficits are often ubiquitous in head-injured patients.

In regards to general rehabilitation interventions as cited by Cope, (1995) there are still questions posed as to whether rehabilitation constitutes 'anything beyond and informed and well-intentioned 'handholding while natural recovery takes place'. This scepticism may be explained by the fact that as a discipline it lacks a unique boundried focus within the medical setting. By this it is meant that it incorporates many diffuse aspects of both physiological but often more social outcomes. Thus 'ownership' within a medical model thus proves more difficult. However, long-term follow-up studies of untreated brain injury patients have shown that with out any treatment interventions, many individual do not continue to make progress (Gianutsos, 1991). Further, the figures for late outcome following severe TBI emphasise that patients and families are often faced with problems of behaviour, social isolation, and unemployment. As described by Ben-Yishay & Diller (1983) since the cognitive deficits fundamentally affect the way a person experiences and responds to stimuli, they therefore 'unequivocally outstrip the physical deficits as the primary cause of difficulties in independent living, social re-adaptation, family life and vocational and educational pursuits'. For this reason many rehabilitation programmes for traumatic brain injured patients incorporate cognitive rehabilitation as a crucial element in the recovery process. Thus it is not surprising that cognitive remediation has become a major focus of attention when considering goals of rehabilitation.

A review of the literature highlights two major models which underlie most cognitive rehabilitation approaches: a restorative model (which has been facilitated by an explosion in the theoretical developments of cognitive psychology) which directs efforts at the restoration of lost or impaired functions via relearning and practice (i.e. use of visual imagery to aid word retrieval in a word-finding impairment) and a substitution model which directs efforts at replacing or altering the means of pathways that underlie a given behaviour in order to obtain a new approximation of that behaviour (e.g. use of a memory notebook). Cognitive remediation in traumatically brain injured patients is based upon the notion of behavioural substitution, that is the assumption that undamaged systems within the brain can be deployed toward different goals.
The restoration model is a provocative hypothesis since it challenges basic assumptions about nervous systems in that damaged tissue is able to be restored. However there appears to be increasing argument that damage accrued by 'shearing' and 'stretching' may at least be temporary and the functional effects of such damage may be restored once healing has taken place. The above discussion has emphasised the compelling need to provide cognitive rehabilitation to acutely brain-impaired individuals and the alternative models and techniques upon which TBI rehabilitation has been based. From this it can be seen that there is a need to evaluate empirically the efficacy of neuropsychological rehabilitation techniques in order to improve the quality of treatment, and from the purchaser's perspective in light of the cost of such programmes, its actual effectiveness in reducing the potential negative sequelae of TBI. Questions of effectiveness and efficiency in the context of neuropsychological rehabilitation can only be answered by careful evaluative trials of different techniques, which need explicit descriptions of the relevant procedures, such that they can be replicated in different centres, as well as sensitive and relevant measures of outcome. In essence such research would differentiate between genuine effects of treatment and improvements that could merely be attributed to spontaneous recovery or to familiarity with a particular testing procedure, although the latter may still from the basis of a useful training programme. However a review of literature by Chen et al, (1997) has shown the use of traditional research design in the area of cognitive rehabilitation to be severely limited. Research based on traditional groups designs is not well suited to this area because individual differences in the site and extent of brain lesions, as well as individual differences in neuro-behavioural sequelae, reduce the likelihood of obtaining treatment groups with heterogeneous deficits (Franzen & Harris, 1993). Single-subject design methodology has been postulated as being better suited to demonstrating the effect of a cognitive rehabilitation intervention but causes great difficulty in showing efficacy across groups of individuals and is dependant upon the outcome measures used (Franzen & Harris, 1993). Despite this a brief review of the literature in relation to cognitive rehabilitation will be undertaken to discuss the effectiveness of such interventions in relation to certain cognitive deficits.

Firstly it is important to reiterate the focus of cognitive rehabilitation. By this, cognitive rehabilitation assumes that the potential for recovery and retraining in TBI individual varies from one cognitive function to another. Secondly, that the same behavioural goal can be achieved by deploying different functional systems or by taking 'different routes' through the same system. Therefore the scope for rehabilitation depends upon the complexity of the task confronting the individual and upon their executive control of alternative strategies more than
upon any single overall measure of attainment. Two major categories of cognitive rehabilitation techniques, traditional and computer-assisted are widely used in contemporary treatment. Traditional techniques involve the use of cognitive strategies to retrain or alleviate deficits in attention and concentration, visual processing, language and memory, reasoning and problem-solving and executive functions (Sohlberg & Mateer, 1989).

In relation to memory rehabilitation a great deal of ‘optimistic effort’ has gone into the investigation of memory rehabilitation. For example the use of mnemonic strategies as a technique into improving memory has been advocated throughout the literature. Unfortunately the results by and large have not been promising (Wilson, 1992). Reflected in the memory rehabilitation literature there have been a number of reported obstacles that impede the progress of memory rehabilitation. For example often mnemonic strategies attempt to elaborate or strengthen the way in which to-be-remembered information is encoded. Although such strategies may partially address the decreased ability of TBI patients to spontaneously organise information they do little address an accelerated rate of forgetting. Also such strategies inevitably place a ‘weight’ on other functions that may also be impaired (e.g. concentration, semantic elaboration and planning). Also the spontaneous use and application of such strategies have been shown to be poorly generalised outside of the training session. Therefore the relative contributions of deficits in planning, problem solving initiative and motivation may all impact to decrease the likelihood that even if such strategies appear to be effective in the rehabilitation setting, they are of reduced value in relation to their generalisability in real life settings. Memory rehabilitation has recently drawn upon procedural memory and semantic priming abilities which have been shown to be relatively unimpaired in amnesic populations and thus have been incorporated into rehabilitation programmes together with the focus toward maximising the patient’s comprehension and ability to apply compensatory strategies such as the use of memory books (Bracy, 1985).

There has been a growing trend toward the use of computer-assisted interventions in relation to cognitive rehabilitation which typically have employed two different intervention approaches; the task-specific approach and the hierarchical approach. In the task-specific approach, individuals use computer programs that target specific cognitive deficits. For example if the individual has attentional problems, only programs that reportedly train attention form the basis of the rehabilitation programme. There have been a number of studies that have investigated the specific approaches in the areas of perception, attention, memory and problem-solving. For example in relation to perceptual deficits, Robertson et al.’s (1991) study using three participants in ‘single case with multiple baseline across-function’ design
found significant gains in reading and specific neuropsychological tests after completion of a perceptual rehabilitation. In relation to attentional deficits, Sohlberg & Mateer’s (1989) single subject multiple baseline across behaviour study reported on four TBI patients who obtained significant gains as measured by their scores on the PASAT test. Wood & Fussey’s (1987) controlled study found improvement in behavioural aspects of attention but no change in measures of psychomotor and vigilance measures. In relation to memory retraining, Kerner & Acker’s (1985) study comparing three groups (n=12 computer memory retraining; n=6 computer control; n=6 no exposure) pre-post found significant gains in memory test scores which generalised from training to testing materials. A recent paper by Chen et al, (1997) has reviewed a further thirteen studies that have investigated the computer assisted approach in the areas of perception memory and problem solving. Overall the studies which have used computer programmes resulted in significant gains in selected neuropsychological test scores. Nine studies found that TBI participants who received computer rehabilitation had significant gains in neuropsychological test scores, observed behaviour and learned skills. However four studies showed no significant improvement.

In the hierarchical approach, TBI individuals are trained on a sequence of computer programmes that are arranged hierarchically from training in fundamental to more complex cognitive functions. For example the individual starts with a computer program targeting attention, then moves up to visual spatial and perception, followed by memory retraining and lastly more complex problem-solving programs. Using this approach Bracy’s (1985) case study involving a TBI individual has shown a 20 point gain in IQ after approximately twelve month of therapy.

However in both specific and hierarchical training it can be seen that many variables which have implications for cognitive performance and spontaneous recovery (such as severity of injury, chronicity, length of therapy, outcome interval, handedness, and years of education) typically were not generally controlled for in these studies. The assertion by Sohlberg and Matter in 1989 that “… the efficacy studies in the areas of cognitive rehabilitation are still in its embryonic stage” can still be applied ten years later. Such factors including differences in brain organisation location of lesion, extent or magnitude of neurological damage rate of performance are all easily confounded with treatment effects thus making it difficult to evaluate treatment outcomes.
Further the measurement of improvement has been fraught with conceptual difficulties. Prigtano & Fordyce (1986) evaluated the benefits of neuropsychological rehabilitation programmes that included intensive cognitive retraining of selected residual deficits and psychotherapeutic intervention in addition to traditional rehabilitation techniques and found that after intervention a significant statistical difference between Performance IQ. However the magnitude of this difference was only four points. This minimal improvement in neuropsychological test scores has been found in other studies and the conclusions that "neuropsychological test improvement was not impressive and did not always accompany functional improvement" has led to the increased questioning of the assumed direct relationship between cognitive deficit and late outcome (Brooks et al, 1991b).

It is increasingly recognised that the most serious long term morbidity after head injury is psychological involving cognitive behavioural and social and family disturbance. It is the interaction of these factors which impact upon the individual and the system rather than the individual cognitive deficits (Brooks et al, 1991a). Therefore in addition to researchers and clinicians addressing the central questions such as the generalisability and persistence of treatment effects as measured on test scores or cognitive based measures of outcome, there has been an increasing concern to demonstrate change/improvement in terms of 'real life' outcome such as productivity, whether vocational or social. Consequently there has been the call for rehabilitation which is focused explicitly at cognitive deficits to have outcome measures aimed explicitly at a functional level rather than at cognitive deficit level. From the above discussion one can conclude that the effectiveness of neuropsychosocial rehabilitation is dependant on the particular adoption of 'outcome' criteria. In relation to cognitive deficits there has been shown to be some efficacy in relation to improvement of specific neuropsychological tests or within the clinic situation, However in relation to psychosocial outcome measures the picture has been shown to be less promising.

The growing recognition of the fact that the TBI individual and their family play a fundamental part in the rehabilitation process (in which the patient is expected to play an active role) which directly impacts on outcome has led to the re-focusing of the aims of 'neuropsychological' rehabilitation (Pössl & Von Cramon, 1996).

In order to give a meaningful account of these aims it is necessary to draw upon a scheme of conceptualising the consequences of disease which has been developed in association with the World Health Organisation. Under this scheme pathology is identified with abnormal physical structure or function (such as cerebrovascular accident), impairment is the organ or the body system dysfunction that result (i.e. hemiparesis), disability is the consequent
inability to perform significant tasks (i.e. unable to walk) and *handicap* is the inability to assume a significant or valued role (i.e. unable to play basketball) (McGrath & Davis, 1992). This model provides a conceptual scheme in clarifying the role of neuropsychological rehabilitation. Neuropsychological rehabilitation has been shown to have a long tradition in the study of brain-behaviour relationships and with clinical assessment and cognitive rehabilitation. Historically it can be seen that neuropsychological rehabilitation (and the role of a neuropsychologist) has been grounded at the pathology and impairment stage (i.e. site of lesion and memory impairment). However the role of a neuropsychology in rehabilitation has evolved across all the WHO classifications in which clinical neuropsychologist may play several different roles in working with the head injured patient their family, and the multi-disciplinary team and therefore can be seen to form the a more fundamental basis of a theoretically grounded 'rehabilitation model'. For example, the neuropsychologist may provide a careful and comprehensive assessment of the patient's strengths and deficits at the time of initial injury and during the course of recovery. In this role the neuropsychologist may recommends various types of rehabilitative approaches to the patient. As an educator the neuropsychologist may provide information to the rehabilitation team, the patient and to the patient's family. Personality and emotional functioning have increasingly been shown to be important variable in outcome both in terms of the individual and with their families Neuropsychological information is fundamental in knowing how to best work with such families. Although literature is sparse the literature has began to amass dealing with psychotherapeutic issues associated with long term outcome of TBI individuals and their families. For example eighteen patients with closed head injury were treated in an intensive six month rehabilitation programme which included group individual and family interventions and were compared with seventeen control patients on a variety of cognitive and emotional/personality measures. Modest effects were found on neuropsychological functioning but significantly greater effects on emotional distress and interpersonal skills were noted. It was further demonstrated that more patients with traumatic injury who participated in milieu programme including both individual and group therapy were productive (employed or students) 40 months after injury than those who did not receive such treatment (Stratton & Gregory, 1994).

According to Prigitano & Fordyce (1984), the psychosocial adjustment problems of patients with brain injuries can frequently be substantially reduced and psychotherapy aimed at helping clients recognise accept and compensate for there deficits is a vital components of any form of neuropsychologically orientated rehabilitation. Despite this need emotional
treatment for survivors often have been limited. According to Adams et al, (1996) people with brain injuries are often considered inappropriate candidates for psychotherapy except for behaviour modification. TBI patients have generally been excluded from traditional insight orientated or relationship psychotherapies and more structured cognitive behavioural treatment. It is suggested that this is because it is assumed that they could not benefit because of permanent cognitive linguistic and affective disturbance. It however can be seen that neuropsychologists may aid in the process of individual psychotherapy by sharing the neuropsychological evaluation and thus adapting if necessary, the therapeutic structure to best assist the TBI patient. Some examples of the potential difficulties which may arise have been summarised by Leber & Jenkins, (1997). For example to accommodate memory deficits the increased frequency of sessions, consistent appointment times, periodic telephone reminders, and memory compensation strategies (i.e. memory logs, calendars, lengthened sessions, frequent breaks) can all be easily accommodated into the session and may be a way forward to assist in better long term outcome measures and assist in generalisability out of the session. Also, by working closely with the rehabilitation therapists to provide information about intervention strategies or responses to treatment to create a co-ordinated rehabilitation program. For example, an individual who may be experiencing visual spatial difficulties may find it more difficult in physiotherapy settings to undertake a walking programme. Therefore this information is vital for the development of appropriate rehabilitation programmes (Jackson & Davies, 1995).

In summary it can be seen that neuropsychological rehabilitation has evolved into increasingly more complex and multifaceted model. Clinicians are now able to draw on an increasingly broad and sophisticated body of research to help conceptualise the nature and remediability of neurobehavioural deficits incurred as a result of a traumatic brain injury. As it stands now the relatively common occurrence attentional difficulties memory impairment personality changes and awareness deficits after TBI has been well established. Work remains to be done on defining the exact parameters of these deficits as well as the most effective means of remediating them. Likewise research is still required to explore the parameters of the organisational deficits which cut across memory language and executive functioning in the form of poorly organised discourse patterns inefficient mnemonic strategies and impaired ability to plan a sequence of actions. Greater attention has been placed on the social and vocational impact of TBI on both patients and their families. Undoubtedly there is an imperative need for researchers to pay careful attention into the experiential world of outside of the rehabilitation setting in order to maximise patients return
to physical psychological social and vocational well-being. Neuropsychological rehabilitation has developed at a tremendous pace during the last decade, facilitated by increasing knowledge of cognitive psychology, and as importantly by psychological and emotional consequences upon the individual and their family. By aiming rehabilitation at the level of handicap the neuropsychologist can creatively adapt existing knowledge about cognitive deficits and adaptation to injury and thus improve the effectiveness and efficacy in order to continue the facilitation of a more positive long term outcome with this challenging group of individuals.

REFERENCES:


CLINICAL SECTION
CLINICAL PLACEMENT DETAILS

PLACEMENT: ADULT MENTAL HEALTH

TYPE: CORE

CLINICAL SUPERVISOR: MR. PETER GARRATT

LOCATION: SOUTH Downs NHS TRUST
          HAYWARDS HEATH WEST SUSSEX

PLACEMENT BASE: LARCHWOOD LODGE
                PRINCESS ROYAL HOSPITAL
                CLINICAL PSYCHOLOGY DEPARTMENT
                HAYWARDS HEATH
                WEST SUSSEX

PLACEMENT DATES: OCTOBER 1994 - APRIL 1995

DAYS ON PLACEMENT: 76
ADULT MENTAL HEALTH PLACEMENT TRAINING CONTRACT:

Clinical Psychologist in Training: Louise Helen ADAMS

Clinical Supervisor: Mr. Peter Garratt.

Placement Base: Larchwood Lodge:
Princess Royal Hospital
Haywards Heath
West Sussex

Placement Dates: 14.10.94 - 05.05.95

AIMS OF PLACEMENT:

The aims of the placement are to:-

1. Provide wide experience to the adult mental health practice of the Trust.
2. Develop understanding of the roles of clinical psychologists in the Trust.
3. Develop an adequate competency in formal psychological assessment in adult mental health.
4. Develop an adequate competency in the provision of psychological therapy in adult mental health.
5. Develop skills in effective interaction with other members of the trust. This requires comprehension of the Trust’s structure and function.

EXPERIENTIAL COMPONENTS:

- Direct observation of supervisor

- Individual person centred, cognitive or behavioural therapy for a selection of suitable clients referred to the Clinical Psychology Department. This is to include assessment and therapeutic intervention experience with the following disorders: an anxiety problem, a depression problem, an eating disorder, an obsessive-compulsive disorder, a survivor of childhood sexual abuse, a functional somatic disorder, a marital/family problem, difficulty with emotional adjustment, substance misuse (tranquilliser withdrawal) and a problem for a person of non-Caucasian race.

- Experience and if possible co-facilitator of at least one short term intervention group based at The Villa, Psychiatric Day Hospital, Princess Royal Hospital (West Wing).

- Psychological Assessment for psychoneurological referrals.

- If possible, in-patient work referred from the in-patient ward as the need arises.
EXPOSURE COMPONENTS:
Spend specified time with:-

- At least one day with Psychologist specialising in abuse offenders, Psychologist specialising in Pain Management, Rehabilitation Psychologist (when in post).

- In Relation to the Rehabilitation/Continuing Care the trainee will observe psychological work in this speciality and if possible carry out a limited assessment and/or intervention with this client group.

- At least half a day with Psychiatrist, Social Worker, Occupational Therapist based in the In-patient ward. In addition wider experience will include attending ward rounds, spending time on an in-patient ward.

- The trainee will gain observation and practical experience in the following settings: CMHT's, resource centres, ‘The Villa Day Hospital’, ‘The Villa Inpatient Wards’, ‘out-patients at Larchwood Lodge Clinical Psychology Department’

Attend at least one meeting of:-

- The Trust Adult Mental Health Psychologist’s Meeting and any appropriate professional development meetings.

- Case Conferences as part of shadowing other staff

- In-patient ward rounds based within the in-patient psychiatric hospital

SUPERVISION:
Supervision with Mr. Peter Garratt for @ two hours per week, with further supervision through informal meetings and discussions.
The formal supervision sessions will be arranged at least two weeks in advance of each meeting.

INDIVIDUAL STUDY:
A session equivalent to one clinical day per fortnight will be available for the trainee to take as independent study. This remains flexible to accommodate both departmental and the trainees individual needs.

Signed:

------------------------------------------- (Supervisor)

------------------------------------------- (Trainee)
PLACEMENT: LEARNING DISABILITIES

TYPE: CORE

CLINICAL SUPERVISOR: MS. JO JOHNSON

LOCATION: WORTHING PRIORITY COMMUNITY CARE NHS TRUST
          WORTHING WEST SUSSEX

PLACEMENT BASE: COMMUNITY TEAM FOR PEOPLE WITH LEARNING
                DISABILITIES
                CLINICAL PSYCHOLOGY DEPARTMENT
                1 ST. GEORGE'S ROAD
                WORTHING
                WEST SUSSEX

PLACEMENT DATES: MAY 1995 - OCTOBER 1995

DAYS ON PLACEMENT: 78
LEARNING DISABILITIES PLACEMENT CONTRACT

Trainee: Louise Adams

Placement Dates: 18th May - 13th November, 1995

Summary of aims of placement

1. To gain knowledge of local service provisions for people with learning disabilities, and of Agencies differing responsibilities.

2. To work effectively within a multi-disciplinary team.

3. To undertake a variety of clinical assessments and intervention work with a range of clients in different settings.

4. To consider the similarities and differences in working as a clinical psychologist with people with learning disabilities, compared with working with adults with mental health problems.

Specific Areas

5. To focus primarily on individual work, and to have experience of working with 10 clients. This will include assessment as well as intervention, direct and indirect, and the clients should cover a range of ages from adolescence through young adulthood and middle age to older adults, a range of abilities from mild through to profound disability, present a balance of sexes and include work with a client from an ethnic minority.

6. To explore a range of clinical approaches in working with clients.

7. To have opportunities to observe colleagues Hilary Smith, Jo Johnson, (both Clinical Psychologists) and Kamel Waez (Clinical Nurse Specialist - Behaviour Therapy) in clinically related activities ranging from individual assessment or intervention through to meetings about clients.

8. To be observed doing clinical work at a variety of stages of that work.

9. To undertake group and teaching work, if appropriate opportunities arise.

10. Opportunities to observe or discuss issues relating to service provision, development and policy making.
11. To contribute to any appropriate ongoing service development/evaluation work in the Specialty.

12. If possible to have an opportunity to work with a client suffering from an anxiety related disorder.

13. If possible to have an opportunity to consolidate existing skills in working with an obsessional client.

Jo Johnson  
Chartered Clinical Psychologist

Louise Adams  
Psychologist in Clinical Training

22/06/95
CLINICAL PLACEMENT DETAILS

PLACEMENT: CHILD & ADOLESCENCE

TYPE: CORE

CLINICAL SUPERVISOR: DR. OLWEN WILSON

LOCATION: NORTH DOWNS COMMUNITY HEALTH NHS TRUST
GUILDFORD SURREY

PLACEMENT BASES: 1. CHILD & FAMILY CONSULTATION SERVICE
PSYCHOLOGY DEPARTMENT
GUILDFORD
SURREY

2. CHILDREN'S UNIT
ROYAL SURREY COUNTY HOSPITAL
GUILDFORD
SURREY

PLACEMENT DATES: NOVEMBER 1995 - APRIL 1996

DAYS ON PLACEMENT: 65
North Down's Community Health Trust


Name: Louise Adams
Type of Placement: Second year D. Psych child and adolescent core placement.
Training Course Base: Psychology Department University of Surrey
Clinical Tutor: Dr A.M. Johns
Clinical Placement Supervisor: Dr Owen H.M. Wilson
Placement Base: Buryfields Clinic/ Royal Surrey County Hospital

1. **AIMS**

To gain clinical experience of children with organic, cognitive, educational, emotional and behavioural problems in the pre-school and middle school age range. Some adolescence and family therapy experience will also be available.

2. **OBJECTIVES**

a) To observe and work with a wide range of children with developmental, behavioural and/or emotional problems.

b) To become familiar with a range of assessment tools and techniques.

c) To experience working within a team of other professionals and liaison with the wider network of professionals working with children.

3. **CLINICAL WORK**

a) To develop interviewing skills with young children and their parents.

b) To practise assessment and therapy with a range of pre-school and school age children individually, in groups and through parental management advice.

c) To liaise with other professionals working with the children including paediatrics, child psychiatry, speech therapy, physiotherapy, occupational therapy, nursery school teachers, special school teachers, educational psychologists, health visitors, ward staff, community nurses and general practitioners.
d) To research one particular topic from the clinical work and read material relevant to the clinical work.

e) To take opportunities to teach colleagues in allied professions (such as ward nurses).

f) To run a small project such as a social skills group.

4. INDIRECT OR OBSERVATIONAL WORK

a) Observation of supervisor and other professionals working with children in the Children's Unit, The Opportunity Playgroup, The Child and Family Consultation Centre, and Child Mental Health Outpatients.

b) Visits to other centres including special schools, respite care, nursery schools, special units in normal schools, and normal schools.

c) Attend case conferences and network meetings where appropriate.

5. PROFESSIONAL

a) To attend weekly supervision.

b) To attend speciality and professional liaison meetings where possible.

c) To keep accurate and up-to-date records of clinical work.

Owen H.M. Wilson (Supervisor)

[Signature]
CLINICAL PLACEMENT DETAILS

PLACEMENT: OLDER ADULTS

TYPE: CORE

CLINICAL SUPERVISOR: MS. ANNE FAWCETT

LOCATION: NORTH EAST ESSEX MENTAL HEALTH NHS TRUST
           COLCHESTER ESSEX

PLACEMENT BASE: LARCH HOUSE
                DEPARTMENT OF CLINICAL PSYCHOLOGY
                SEVERALLS HOSPITAL
                COLCHESTER
                ESSEX

PLACEMENT DATES: APRIL 1996 - OCTOBER 1996

DAYS ON PLACEMENT: 78
Elderly Mental Health

Clinical Psychology Service Placement Contract

Name: Louise Adams
Type of Placement: Second Year Elderly Placement
Training Course Base: Psychology Department, University of Surrey
Clinical Tutor: Dr A M Johns
Clinical Placement Supervisor: Anne Fawcett
Placement Base: Severalls Hospital

1. AIMS

To gain clinical experience of older people with mental health problems, the services available to them, and the system which delivers these services.

2. OBJECTIVES

a. To observe and work with a wide range of older people with mental health problems both functional and organic.

b. To become familiar with a range of assessment tools and techniques.

c. To experience working with the wider network of professionals working with this population.

d. To develop an understanding of the roles of others working with this population

3. CLINICAL WORK

a. To develop interviewing skills with older people and their carers.

b. To assess and provide appropriate intervention with older people with mental health problems and their carers.

c. To liaise with other professionals working with the older people with mental health problems and their carers.

4. RESEARCH/EVALUATION AND TEACHING

a. To research or evaluate one particular topic or area.

b. To teach colleagues in allied professions.
5. INDIRECT OR OBSERVATIONAL WORK

a. Observation of supervisor and other professionals working with Elderly Mental Illness Service.

b. Visits to other centres including EPH, Day Hospitals, Day Care Centres.

c. Attend case conferences, ward rounds, and network meetings where appropriate.

6. PROFESSIONAL

a. To attend weekly supervision.

b. To keep accurate and up to date records of clinical work.

Anne Fawcett
Consultant Clinical Psychologist

Louise Adams
Psychologist in training
CLINICAL PLACEMENT DETAILS

PLACEMENT:  FAMILY THERAPY

TYPE:  SPECIALIST

CLINICAL SUPERVISOR:  MRS. EVRIL SILVER

LOCATION:  LOCAL COMMUNITY NHS TRUST
            IPSWICH SUFFOLK

PLACEMENT BASE:  IVRY HOUSE
                 CHILD ADOLESCENT AND FAMILY CONSULTATION SERVICE
                 CLINICAL PSYCHOLOGY DEPARTMENT
                 IPSWICH
                 SUFFOLK

PLACEMENT DATES:  OCTOBER 1996 - APRIL 1997

DAYS ON PLACEMENT:  69
LOCAL HEALTH SERVICES TRUST

CLINICAL CHILD PSYCHOLOGY SERVICE SPECIALIST PLACEMENT

CONTRACT

October 1996 - April 1997

NAME: Louise Adams

TYPE OF PLACEMENT: Third Year Psych.D Specialist Placement

TRAINING COURSE BASE: University of Surrey, Psych. D Clinical Psychology

CLINICAL TUTOR: Dr A M Johns

CLINICAL PLACEMENT SUPERVISOR: Mrs Evril Silver

PLACEMENT BASE: Ivry House, Child, Adolescent and Family Consultation Service, Ipswich, Suffolk

AIMS:

• To gain an understanding and specialist clinical experience of the concepts that underlie the collective title of "systemic theory".

• To work with a range of children, adolescents and their families with organic, cognitive, educational, emotional and behavioural problems using systemic models.

• To develop an understanding of these problems within the context of both the intimate relationship of the family system and of the wider social network of which the 'family' is a part.

OBJECTIVES/CLINICAL EXPERIENCE/WORK:

• To gain clinical experience of working within a solution focused and systemic framework.

• To experience working within a family therapy team.

• To undertake referrals from both the Psychology Department and the Clinical Multi Disciplinary Team.
• To experience working within a team of other professionals and liaison with the wider network of professionals working with children and adolescents.

• To demonstrate the ability to select the most appropriate and relevant method of psychological intervention.

• To undertake a research literature review of one particular topic from the clinical work.

• To undertake a presentation of this review.

INDIRECT/OBSERVATIONAL WORK:

• Observation of supervisor and other professionals working with children/adolescents referred to the Child and Family Consultation Service and/or Child Health Assessment and Monitoring Project (CHAMP).

• Attend case conferences and network meetings where appropriate.

PROFESSIONAL:

• To attend weekly supervision.

• To attend speciality and professional liaison meetings.

• To keep accurate and up to date records of clinical work.

• To continue to develop understanding of the specific legal and statutory frameworks applicable to children and adolescents.

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

EVRIL SILVER
Clinical Psychologist

LOUISE ADAMS
Psychologist in
Clinical Training
CLINICAL PLACEMENT DETAILS

PLACEMENT: PAEDIATRIC NEUROPSYCHOLOGY

TYPE: SPECIALIST

CLINICAL SUPERVISOR: DR. CHRIS LAWES

LOCATION: NORTH EAST ESSEX RIVERS NHS TRUST COLCHESTER ESSEX

PLACEMENT BASE: CLINICAL PSYCHOLOGY DEPARTMENT ESSEX COUNTY HOSPITAL COLCHESTER ESSEX WEST SUSSEX

PLACEMENT DATES: MAY 1997 - SEPTEMBER 1997

DAYS ON PLACEMENT:
SPECIALIST PAEDIATRIC PSYCHOLOGY PLACEMENT

Trainee: Louise Adams  Start Date: 6th May 1997
End Date: 30th September 1997

Supervisor: Dr. Chris Lawes  Mid-Placement Review:
8th of July 1997

Agreed days:
During Term time: Wednesdays, Fridays
Alternative Tuesdays
From September - 5 days per week

Agreed hours: 9.00 a.m - 5.00 p.m
1. **Orientation/Induction: Child Neuro Psychology.**

**Prior experience:** Two previous child placements. The first, a core placement, the second a systemic based placement.

**Need:** To be aware of facilities and personnel within Neuropsychology in North Essex.

**Specific goals:**
1. Visit Neurocare, Head Injury Rehab Team, Children's Centre;
2. Visit EEG, Children's Ward, CAT Scanner;
3. Visit Headway;
4. Paediatric Therapists including Occupational Therapy, Speech & Language Therapy, etc.

2. **Observed experience, or joint work with supervisor.**

This may include:

- **a)** *observation with other professions;*
- **b)** *observation of ward rounds, case conferences, case discussions where appropriate;*
- **c)** *observation of supervisor.*

Planned observational experience:

- **a)** *observation of supervisor in assessment and intervention.*

3. **Consultation and Service Planning.**

Discussion of the role of child neuropsychology within Child Clinical Psychology.

4. **Direct Case Experience.**

Casework, undertaken independently or with the supervisor should include exposure to work:

- with adolescents and consideration of:
- with children - a range of assessment methods
- with families - a range of treatment approaches
- with parents - a range of presenting problems
- with the wider system - a range of age (0-5/5-11/adolescents)
It is hoped to cover the following areas:

<table>
<thead>
<tr>
<th>Type of Case</th>
<th>Approach</th>
<th>Age</th>
<th>Setting</th>
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</thead>
<tbody>
<tr>
<td>Congenital problems, e.g. Cerebral Palsy</td>
<td>Neuropsychological</td>
<td>0-5</td>
<td>-outpatient</td>
</tr>
<tr>
<td>Acquired Brain Injury e.g. Head Injury</td>
<td>Interventions</td>
<td>5-11</td>
<td>-ward</td>
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<tr>
<td>Pervasive Developmental Delay</td>
<td>Behavioural</td>
<td>11+</td>
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<tr>
<td>Problems in children with e.g.:</td>
<td>Cognitive</td>
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<td>Memory</td>
<td>Systemic</td>
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<td>Language</td>
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<td>Reading</td>
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In addition it is planned to address these issues:

- Behaviour Problems;
- Disinhibited Behaviour;
- Anxiety/Depression;
- Treatment - Breaking the News

5. **Regular Meetings.**

<table>
<thead>
<tr>
<th>1 District Child Psychologists - North Essex</th>
<th>Once a month on a Tuesday.</th>
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</thead>
<tbody>
<tr>
<td>2. Joint Clinic with Paediatrician, Speech &amp; Language Therapist</td>
<td>Once a month on a Tuesday.</td>
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<tr>
<td>3. Regional Neuropsychology Special Interest Group</td>
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</table>
6. **Other Experience.**

Please specify any additional aims you have for the placement:

- **Neuro-Interest Group** - Participation (Wednesday).
- **Court Work** - Looking at Court Reports

7. **Expected trainee caseload:**

At least:

- Several cases seen independently;
- Up to 4-6 cases on caseload at any one time.

8. **Expectation regarding written reports and correspondence:**

Written reports and correspondence to be completed appropriately and in line with 8.0 in BPS Guidelines on Training.

9. **Specific Placement Goals.**

See Appendix A (attached)

Signed...............................................Trainee........................................... Supervisor..............................................
APPENDIX A.

PLACEMENT GOALS.

1. Experience of appropriate neuropsychological tests.

2. To be proficient in the administration and interpretation to a level commensurate with her level of training.

3. To gain experience of using the tests with children who have an acquired injury.

4. To gain experience of both subtle and gross cognitive deficits. Across age and gender.

5. To be able to develop hypothesis and generate appropriate formulations that will influence treatment/rehabilitation.

6. To gain further understanding of neuroanatomy and how this relates to the behavioural correlates of the tests.

7. To gain familiarity with the current research literature and to be aware of the limitations of psychometrics within this context.

8. To keep a log book up to date.

9. To attend Supervision and develop a constructive open working relationship with the Supervisor.
CLINICAL CASE REPORTS

The following section contains a brief outline of each of the clinical case reports submitted as part fulfilment of the Clinical Components of the Doctorate in Clinical Psychology.
CASE REPORT I:

REFERRAL OF THE PROBLEM:

P.B, an eight year old boy with epilepsy was referred to the Clinical Psychology Department by an ‘Associate Specialist in Paediatrics’ based within the General Hospital’s Paediatrics Department due to concerns raised by his mother about his current educational and emotional difficulties.

CASE PRESENTATION:

P.B was an eldest child and currently lived at home with his mother, step-father and younger sister. His mother reported that P.B had been experiencing episodes of teasing and bullying in relation to his learning difficulties from his peers. Also he was becoming more anxious about his school performance and was beginning to show signs of refusal. In addition she reported that P.B was becoming more withdrawn at home and that it was difficult to encourage him to go to school. P.B presented as a shy quiet boy, who appeared to be visibly distressed as his mother explained the extent of his difficulties. He stated that he was ‘very upset’ as he was not ‘as able’ as other children in relation to school work and that he was ‘worried’ about many things.

MANAGEMENT:

To determine the nature of P.B’s academic problems a psychometric assessment was undertaken. This information was additionally supported by the completion of a behavioural rating scale by both the school and his parents. Individual Therapy was undertaken with P.B to further explore the nature of his fears. Information regarding the nature of P.B’s specific learning difficulties was discussed with both and his parents and with his class teacher.

OUTCOME:

After a period of intensive therapy sessions, in which issues relating to his fears surrounding epilepsy, members of his family and bullying by his peers were investigated P.B’s mother reported a significant reduction in P.B’s overall anxiety both at home and at school.
CASE REPORT II:

REFERRAL OF THE PROBLEM:
R.P, a six years 10 month old Afro-Caribbean girl was referred to the Clinical Psychology Department by a Paediatrician for help with behavioural and emotional difficulties following the death of her elder step-brother who had died unexpectedly four months previously from a cerebral tumour.

CASE PRESENTATION:
R.P lived at home with her mother, father and younger sister. Before her brother’s death, R.P had had an ambivalent relationship with her brother. Described as a ‘vivacious little girl’ who ‘enjoyed going to school’, R.P was reported to have had many friends and to be progressing highly academically. Since her brothers death, R.P had begun to experience significant problems with her peer group and a marked deterioration with her academic work. In addition, she had been sent home from school on three separate occasions, due to her complaining about non-specific abdominal and chest pain, which on physical examination by her General Practitioner had proven unremarkable. At home she was increasingly becoming withdrawn and isolated from the rest of her family members.

MANAGEMENT:
Four individual sessions were devoted to the exploration of the grief process using the medium of drawing, in order to help R.P improve her understanding of her feelings. One joint session was held with R.P’s mother to explore the issues highlighted in the individual sessions and to give her further advice as to ways of supporting her daughter and family. Advice was also given to R.P’s primary school teacher in relation to the management of R.P’s behaviour difficulties and to providing support to R.P whilst at school.

OUTCOME:
The sessions facilitated R.P in sharing her ‘secret’ beliefs and concerns about her responsibility regarding her brother’s death which enabled her to receive reassurance that R.P feelings had not contributed to his death. The sessions also facilitated the fostering of a more adaptive grief process within the family, by enhancing family communication and mutual support, and thereby facilitating a more appropriate expression of R.P’s and her families grief.
CASE REPORT III:

REFERRAL OF THE PROBLEM:
G.K, a thirty one year old single male with cerebral palsy was referred to the Community Team for People with Learning Disabilities by the Manager of the Day Centre which G.K was attending. Concerns regarding G.K's vulnerability in the community had been highlighted after he had been seen to accept a lift in a car from a male stranger after having been approached by the men in the car.

CASE PRESENTATION:
G.K lived in a small residential home, and attended a local day centre. Since his father's death, he had been spending a considerable amount of his free-time walking around the local community, which was his favourite activity. Increasing concerns were being raised by his keyworkers in relation to his increased drinking in the local pubs, his decreased motivation and concentration in activities at home and at the day centre and by him still 'talking' to his deceased father. G.K presented as an attractive young man, who initially appeared to be able to function independently in most aspects of his life. However, it became clear that G.K did have some difficulties understanding complex language and subtle social contexts.

MANAGEMENT:
A psychometric and a skills assessment were undertaken to assess the nature and extent of G.K learning difficulties. A detailed assessment was also undertaken in relation to ascertaining G.K's awareness of his safety and vulnerability in the community. In relation to his mood, an assessment was undertaken which incorporated discussing his recent bereavement and his current emotional reactions.

OUTCOME:
The assessments revealed that G.K's level of cognitive abilities were at a much lower level than from his initial presentation. This impacted upon the assessment of his vulnerability which found that he was unable to assess potential situations which could put him 'at risk'. The implications of these findings were discussed with G.K, his residential and day centre keyworkers and a plan of action to facilitate his independence, whilst ensuring his safety, was devised. In addition, guidance was given in helping staff support G.K through his bereavement.
CASE REPORT IV:

REFERRAL OF THE PROBLEM:

M.P an was referred to the Clinical Psychology Department by the Deputy Manager of the Day Centre for help with his current behavioural difficulties which were being displayed in the Day Centre. Exclusion from the day centre was currently being considered due to the increasing physical difficulties that staff experienced whilst supporting him at the centre.

CASE PRESENTATION:

M.P lived at his parental home with his parents and two twin siblings. M.P has athetoid cerebral palsy, and epilepsy and a severe learning disability, together with a long-standing history of challenging behaviours since childhood. However, since having transferred to the adult services there had been an exacerbation in his challenging behaviours which were particular frequent when attending the day centre.

MANAGEMENT:

A functional analysis of M.P’s behaviour was sampled using continuous and time-sampling methods within the day centre setting. Further a skills analysis was undertaken to ascertain M.P’s other communicative strengths undertaken. Behavioural Management guidelines was devised in conjunction with day centre staff and a gradual plan of re-integration of M.P was initiated.

OUTCOME:

Analysis of the pre-and post time sampling of M.P’s behaviours found significant decrease in the challenging behaviours and a co-commitment increase in more positive communicative behaviours. As a result his permanent provision at the day centre was agreed by day service managers.
CASE REPORT V:

REFERRAL OF THE PROBLEM:
G.W, a thirteen year old girl was referred to the Clinical Psychology Department for a neuropsychological evaluation after having sustained a severe traumatic brain injury following G.W's involvement eighteen months previously in a road traffic accident in which she was a pedestrian.

CASE PRESENTATION:
G.W lived at home with her mother, father and younger brother. Despite the nature of her injuries G.W had apparently recovered quickly from her accident and had returned into mainstream education. However she was reported to been experiencing both academic and behavioural difficulties with significant problems in her peer relationships. G.W's mother was also increasingly concerned as to her daughters mood swings and emotional lability.

MANAGEMENT:
A preliminary neuropsychological assessment was undertaken to determine the nature of G.W's academic problems. This aimed to define her cognitive strengths and weaknesses, to determine what classroom modifications may assist her in working to her academic potential and if other supportive interventions were required.

OUTCOME:
On testing, G.W achieved a verbal and performance IQ scores which were consistent within the average range of intellectual functioning when compared to her peer group. However she appeared to experience some significant difficulties in the speed of information processing, dual attention tasks, as well as an apparent exacerbation of her pre-morbid specific learning difficulties with spelling and to a lesser extent with arithmetic. In addition there was evidence of very poor self esteem and depressional ideation (with biological symptoms) which impacted upon certain aspects of G.W's test performance.
RESEARCH SECTION
THE EFFECTS OF ADULT TRAUMATIC BRAIN INJURY UPON FAMILY FUNCTIONING
INTRODUCTION:
The objective of this review is to examine the literature on the effects of Adult Traumatic Brain Injury (TBI) upon the functioning of the family. This synopsis aims to address the following areas:

- The clarification of the clinical characteristics of traumatic brain injury which impinge most upon families,
- The potential effects of traumatic brain injury upon family members, and
- Recent developments in rehabilitative interventions for families with a traumatically brain injured member, looking at both the short and long-term effectiveness of clinical interventions.

The report is divided into four key sections: Firstly, a general summary of the clinical characteristics of Traumatic Brain Injury. Secondly, a description of the particular difficulties that individual family members experience as a result of an adult family member acquiring a brain injury. This will focus particularly on ‘primary carers’, ‘children of brain injured parents’, ‘marital relationships’ and upon the family unit as a whole. Thirdly, a selective critical review of the main current clinical rehabilitative interventions will be briefly summarised in order to assess the relative efficacy of interventions designed to support such families. Finally, an overall summary of these papers findings are then presented together with an indication of possible future research considerations.

DEFINITION OF TRAUMATIC BRAIN INJURY (TBI):
Traumatic Brain Injury (TBI) is an insult to the brain, not of a degenerative or congenital nature but caused by an external force that produces diminished consciousness or coma. It is most commonly defined as ‘neural damage resulting from closed or open-head injuries following an insult to the head’. Closed head injury is the traditional term for a non-penetrating injury that results in brain dysfunction (Alexander, 1982). Where the skull is penetrated, as from a gunshot wound, the damage to the brain is referred to as an open head injury (Lishman, 1987; Stratton & Gregory, 1994).

In this review Traumatic Brain Injury (TBI) will refer to ‘closed head injuries’ since these are far more common than ‘open-head injuries’, constituting the vast majority of cases of TBI (Jennett, 1990). In the case of closed head injuries the predominant damaging force is that of
impact of a mechanical force to the skull, such as resulting from vehicular accidents (Alexander, 1982).

**DEMOGRAPHIC DETAILS:**
In the United Kingdom there are 80,000 people suffering from long term effects of serious head injury and that every year 2,000 people are added to this number (National Head Injury Association, 1992). Of those adults admitted to hospitals with a brain injury approximately 5% are suffering from *severe* head injury (i.e. in coma), scoring eight or less on the Glasgow Coma Scale. A further 5-10% are suffering from *moderate* traumatic brain injury scoring between nine and twelve on the Glasgow Coma Scale, while the majority (85-95%) are regarded as having suffered *minor* traumatic brain injury in terms of their level of consciousness (Miller, 1993). There appears to be a selective incidence of TBI, with the highest prevalence occurring among males between the ages of fifteen and thirty-five years. Therefore many are on the threshold of adult life, and about half are married or in the early stages of establishing their families. Other demographic factors also appear to co-occur, with head-injured persons tending to come from a lower social/economic background and have a history of social maladjustment (Fahy et al, 1967; Bond, 1983). As it appears that head injured persons may not represent a random sample of the population, pre-existing psychiatric difficulties, such as violence, substance abuse, and marital instability may further confound family adjustment after the injury (London, 1967; Panting & Merry, 1972; Brooks, 1984; Livingston et al, 1985a, 1985b; Urbach et al, 1994).

**CLINICAL CHARACTERISTICS OF TRAUMATIC BRAIN INJURY:**
The literature is replete with descriptions of the common sequelae associated with a TBI. However it is fundamentally recognised that no two head injuries are neuropathologically alike (Jennett & McMillan, 1981). Despite this heterogeneity, neuro-behavioural assessments of individuals with severe TBI usually indicate insult to the anterior frontal lobe, anterior temporal lobe and brain stem and therefore feature many similar behavioural symptoms (Brooks, 1984). The precise determinants of the sequelae are numerous and include sites of lesion, extent of lesion, pathophysiology, neuroendocrine and systemic involvement, age and sex of the traumatically brain injured, pre-morbid level of intellectual and emotional functioning, pre-morbid personality and mental health, educational level, pre-morbid health of the brain, pre-morbid socio-economic and vocational status.
The impairments resulting from TBI can be severe and range from disturbances in cognitive abilities (i.e. such as perception, information processing, language and memory), effective disorders, personality alterations, sensory motor deficits and post-traumatic epilepsy. These sequelae have been extensively researched and documented in the literature (Lezak, 1978; Brooks & McKinlay, 1983; Rosenthal & Muir, 1983; Prigatano et al, 1986; Prigatano & Fordyce, 1986; Elsass & Kinsella, 1987; Villki et al, 1994).

A review of the literature reveals that early research investigations were more concerned with focusing on the biological neurological aspects (i.e. the description of the recovery process and cognitive, intellectual changes, pre-morbid psychological functioning of the individual and the determining of specific psychosocial outcomes), ‘rather than examining how traumatic brain injury uniquely alters the family system and interaction within it’. (Brooks, 1991b). However an increasing proportion of research studies have begun to address variables related to family structure and interactions and their impact on the adjustment of the CHI patient (Brooks & McKinlay, 1981; Bicknell, 1982; McLaughlin & Schaffer 1985).

**IMPACT OF TRAUMATIC BRAIN INJURY UPON FAMILY MEMBERS:**

**IMPACT UPON FAMILIES**

It has been quoted in the literature that the family members of TBI patients ‘face a bitter irony’ (Jacobs, 1989). Improved medical management has increased the likelihood that patients will survive such injuries as described previously, yet the effects of the injury has been shown to create immense demands upon the family Rosenbaum & Najenson, 1976; Rosenthal & Muir, 1983; Zarski et al, 1987). The magnitude of the problems which permanently disabled survivors can impose upon close relatives have been summed by London, (1967) in his statement; “one of the most distressing effects of severe cerebral injury is that associated with the patient’s personality and this lays a much heavier burden on the family than on the community”. Blazyck, (1983) has documented the disruptive effect of Traumatic Brain Injury (TBI) on family functioning as representative of a ‘crisis’, rather than just a ‘problem’. A review of the literature further highlights that families react in different ways to the devastating reality of TBI (Rosenthal & Muir, 1983; Wood & Eames, 1981; Zarski et al, 1987). Often, when confronted with the contrast of an individual following their sudden injury, numerous emotions are generated amongst family members, including, denial, incomprehension, anger, guilt and grief. The process of adjustment by families to the brain injury of a family member has been likened in the literature to following a similar course of
adjustment after bereavement. Grief models have been adapted from the classic grief model as proposed by Kubler-Ross, (1969) (in which the progression through stages of denial, euphoric hope, despair, resignation, and then acceptance and adjustment to the experience) as a representation of how family members come to terms with a TBI family member (Rosenthal & Geckler, 1986). However, the experiences are actually fundamentally different as brain injury is not like death, in which one can complete the ‘grief cycle’. A traumatic brain injury puts relatives of the traumatically brain injured person into an undefined and therefore uneasy, state of limbo. Since there is the continued presence of the TBI person, these losses are never ‘final’. The grief experienced by families of survivors of TBI is intense and disorganised, since families are uncertain about the permanence of the losses in physical and mental function resulting from the TBI, which consequently produces long-term disorganisation of the mourning and hence difficulties in completing the adjustment process. Also, it is important to recognise that the deficits in mental and behavioural functions of the TBI individual also have a deleterious effects on the adjustment processes able to be undertaken by the family (Brooks & McKinlay, 1983).

One of the earliest papers describing family response and reaction to Traumatic Brain Injury was the article by Romano, (1974) which described social work observations of the families of thirteen patients who had experienced TBI during the period of 1968-1972. The most striking observation noted was the protracted persistence of denial of disability among the patient families. Although denial may be seen as a 'coping mechanism' and therefore an adaptive mechanism during the early stages of recovery if it continues it becomes a preventative measure to adaptation and acceptance of the residual disability. Perceived loses which the families acknowledged included the loss of companionship, emotional support, a sexual partner, previously personality, income, previously held roles, hopes and dreams and normal social contact. Coping styles have been conceptualised along two broad dimensions: a) functional/expected, versus b) dysfunctional. In the former, despite the natural shock sadness and bitterness the family eventually adapts to the existence of brain injured relative. Power, (1985) has described functional versus dysfunctional coping patterns in families with severely neurologically impaired members. Although the study was based on forty-nine families with a member with multiple sclerosis he described the positive coping strategies as including the ability to orient their lives to encompass new illness related events with limited disruption of family functioning. Dysfunctional families on the other hand were described as neglecting customary family duties and responsibilities, There were tense communication patterns between family
members frequent misunderstandings of important facts associated with the illness and feelings of being overwhelmed and trapped associated with caring for the patient. On-going denial was paramount to the extent that treatment issues were often ignored. Denial has been described as a defence mechanism employed to reduce psychic stress and threat of reality and has been considered both functional and dysfunctional. Beisser (1979) stated that denial is functional if it promotes affirmative attitudes towards health. Often it is the means by which families maintain hope. In addition denial can be constructive if that is the only way an individual can cope with distressing news.

The importance of family adjustment has been emphasised by the fact that it has been suggested that good family relationships tend to facilitate successful rehabilitation and that patients with strong family support progressed further than those without family involvement (Fahy et al, 1967; Oddy & Humphrey, 1980; Mauss-Clum & Ryan, 1981). Also clinical observations have shown that if successful adaptation to brain injury by the entire family is not achieved, serious family dysfunction and/or disintegration can occur (Rosenthal & Young, 1988).

**BURDEN OF CARE:**

There is now a general acknowledgement of the current trend toward community-based care with heavy family involvement and the resultant impact of this 'burden' upon family relationships (Cooper, 1976; Klonoff & Prigitano, 1987; Brooks 1992; Acorn, 1993). Families generally serve as the major source of support, socialisation and assistance for the person with TBI (Jacobs, 1989). Upon discharge over 80% of individuals with TBI return to their homes (Kreutzer et al, 1994b). The effects on family have often been categorised in terms of 'burden', particularly the sense of stress and distress felt by family members who have responsibility for caring for the head injured person (Brooks, 1991a). The concept of 'burden' shares characteristics associated with social performance, since one person's social performance is another person's burden. Both concepts are relative to social expectation, which are likely to be very variable (Platt, 1985). The existence of burden indicates a breakdown of the reciprocal arrangements that people maintain in their relationships, such that one person is 'doing more than their fair share'. This may merely result in them taking on greater proportion or number of shared tasks, but it may also restrict activities outside of that relationship (Fadden et al, 1987). The dissection of the 'concept of burden' through the investigation of the effects on the changes of roles carried out by relatives has primarily been undertaken in psychiatric populations (Cooper, 1976). With regards to traumatic brain injury,
the term 'family burden' has been used to more precisely characterise the stresses and coping patterns of family members (Brooks et al, 1986). Panting and Merry's (1972) study reported that 61% of families interviewed after head injury indicated that they were experiencing a considerable amount of stress as a direct result of the injury and its consequences.

Systematic research has attempted to examine the primary characteristics of psychosocial burden as perceived by a relative after the TBI (McKinlay et al, 1981; Brooks & McKinlay, 1983). Most research has utilised Hoenig & Hamilton's conceptualisation of family burden which consists of 'subjective' and 'objective' burden (Hoenig & Hamilton, 1969). Objective Burden can be defined as stressors resultant from changes in family routine, family health, housing conditions, financial status, social/leisure activities, post-traumatic symptoms and changes to the patient’s behaviour and personality. Subjective Burden can be defined as the degree of stress felt by the person caring resulting from the presence of Objective Burden (Brooks, 1984). The former (i.e. subjective burden) has been studied by means of a variety of self report methods, and the latter (i.e. objective burden) has also tended to be measured in terms of changes which are reported by relatives in comparison with the patient’s premorbid behaviour (Brooks et al, 1986; McKinley et al, 1981).

One such study by Oddy et al, (1978a) gave a checklist concerning personality changes and somatic, sensory, cognitive and psychiatric symptoms which was given to a close relative of forty-nine patients with a Traumatic Brain Injury. The symptoms that were mentioned most frequently by the relatives were 'trouble remembering things, becomes tired easily, often impatient, often loses temper and often irritable'. The relatives also received a detailed interview and depression questionnaire within one month of the accident and at roughly six and twelve months afterwards. The results indicated that there were overt disturbances in approximately 25% of the patients' families, whether measured by the depression scale or relatives report. The level of reported stress was highest during the first month following head injury and appeared to reach a plateau between six and twelve months. More than half of the physical illnesses that were reported could be regarded as stress related. (i.e. migraine, and asthma). Many relatives had received support and medication from their general practitioners, but none had received psychiatric treatment. Family relationships appeared to be significantly poorer in the case of patients who had suffered adverse personality changes (Oddy & Humphrey, 1980). The frequency of arguments and disagreements and problem in communication increased markedly between six and twelve months which replicated the findings of an earlier study by Thomsen, (1974). A similar investigation was carried out by
Brooks and Aughton, (1979) in the case of relatives of thirty-five patients with severe blunt head injuries. They received a subjective assessment in which they were asked to rate the extent of their experienced burden or stress along a seven point scale in addition to an objective questionnaire concerned with observable changes in family routine, health or housing resulting from the patient's head injury and with the patient's post-traumatic symptoms and changes in behaviour and personality. The most frequently reported items of objective burden when relatives were assessed six months after the initial head injury proved again to be related to the patient's mental impairment, and more specifically to changes in the level of irritability, slowness, tiredness and tension/anxiety; conversely the least frequently cited items of objective burden were concerned with physical and sensory changes. The items of objective burden that best predicted the relatives perceived subjective burden were patient's childish behaviour, loss of interest, change in sex life, depression and tension and anxiety.

From these studies it can be seen that while cognitive deficits are likely to acquire adjustment from family members, characterological alterations in the form of behaviour and personality changes, are experienced as more difficult to deal with than physical or cognitive changes (Brooks & McKinlay, 1983; Jacobs, 1989; Lezak, 1978; Mauss-Clum & Ryan, 1981; Thomsen, 1974). Therefore as highlighted by Brooks & Aughton, (1979) "...families are apparently able to deal with physical impairment, but find emotional and personality change in the patient a source of great burden."

McKinlay et al, (1981) summarised ten frequently reported emotional problems at three, six and twelve months post injury according to fifty-five relatives of TBI patients, which caused high levels of burden. A number of emotional difficulties were highly endorsed, including irritability, impatience, tension, anxiety, bad temper, depression and personality change. There was also a trend towards higher endorsement over time of irritability impatience and bad temper. A later study by Brooks and McKinley, (1983) further documented such personality changes at three, six and twelve months post injury. A clear trend toward an increasingly wide variety of personality problems over a twelve month period was reported. These results indicate not only that personality changes are significant stresses to the family, but that these problems may be exacerbated with time as patients are unable to understand and cope with residual cerebral deficits. Oddy et al, (1978) studied fifty-four head injured patients and their families also found that the level of stress did not diminish over time. Thus
as suggested by Bond & Brooks, (1976) stresses caused by TBI may vary in intensity and duration but certainly create a heavy burden on all members of the family system.

The long term nature of these personality problems is exemplified by the finding of Thomsen, (1984) who reported in her study of forty severely head injured patients that changes in behaviour continued to be the most serious burden to relatives, ten to fifteen years post injury. These results not only suggest that personality changes are highly enduring and disruptive but that they can worsen with time. There have been attempts to identify which personality changes result in the greatest stressor subjective burden in relatives. Klonoff et al, (1986) had relatives and close friends rate the behavioural and social role functioning of closed head injured patients two to four years post injury. Ratings on the Katz Adjustment Scale - relatives form (KAS-R) for sixty-three closed head injured subjects compared with age-appropriate normal control subjects and psychiatric patients indicated significant elevations in the R1 subscales of belligerence, verbal expansiveness, negativism, suspiciousness, withdrawal and retardation, general psychopathology and confusion in the head injured sample of relatives. Similar findings have been reported by Prigitano et al, (1986). Lezak, (1978) highlights the basic changes of personality and behaviour reported as most likely to cause problems to the families of head injured persons. Lezak (1978) cites that these can be conceptualised in five broad, overlapping categories of change: i) Capacity for social perceptiveness; ii) Capacity of self control; iii) Learned social behaviour; iv) Ability to learn; v) Emotional alteration. It therefore can be seen that a major cause of stress on family functioning following TBI is personality and behavioural change in patient (Bond, 1983; Oddy et al, 1978b). Using the ‘burden of care’ model, it has been shown that there are certainly increasing levels of subjective/objective burden as perceived by the relatives up to five years after injury and that these sometimes persist in duration.

However research into the relationship between relatives perceived burden and formal psychiatric symptomology has given contradictory evidence. This is an important issue as it has been argued that the burden is little more than ‘minor’ levels of dysphoria. Oddy et al, (1985) study which followed-up TBI individuals and their families from a study by Weddell et al, (1980) found that 17% of relatives obtained significant levels of anxiety. This result was not significant in terms of incidence of anxiety within the general population. However more recent studies using measures of affective symptomology, most particularly anxiety and depression, have shown that around one in four family members within seven years of injury have levels of affective disturbance that would normally be thought to warrant clinical
intervention (Livingston et al, 1985a; 1985b; Livingston, 1987; Kreutzer et al, 1994; Linn et al, 1994). In trying to identify which families' members have very high levels of burden and affective symptomology, a number of variables have been investigated including severity of patient injury, severity of the consequent disabilities in the patient, and the nature of the family member's own coping resources. Research has resulted in a mixed result but it is generally validated that all three have an effect (Brooks, 1991a; Mauss-Clum & Ryan, 1981; Oddy et al, 1985; Livingston, 1987).

Within the literature there are major difficulties ascertaining comparisons across studies. The relative heterogeneity of family members contained within the research samples has been shown to mask the subtle effects associated with relational associations (i.e. the differences between spouse and mother). A number of later studies have distinguished carefully between marital, and other family relationships, and have studied burden separately within these role situations. These studies will be discussed in more detail in the following sections. Other studies, while implicitly commenting upon differences between specific family relationships did not examine their results specifically in these terms (e.g. Fahy et al, 1967; Panting & Merry, 1972; Thomsen, 1974) and thus have not been included further in the review.

**EFFECTS ON THE PRIMARY CARETAKER:**

There is a growing, but limited literature on the role of specific family members and their reaction to severe traumatic head injury (Jacobs, 1989). Livingston et al, (1985a) point out that studies of family burden tend to focus on the caregiving relative of the family unit. The primary caregiver is typically defined as the family member who provides primary care to the patient. This is usually the spouse or mother (Resnick, 1993). However, a review of the early literature on primary caretakers rarely examines or makes the distinction between parents, spouses and other relatives (Romano, 1974; London, 1967). Also research articles do not document whether the relative interviewed undertook a direct care role with the TBI family member. Many studies which have examined the long term effects of head injury have drawn their samples from consecutive discharges from rehabilitation programmes. Since males typically outnumber females two to one or three to one and the highest risk age group is sixteen to twenty-four years hence most of the research has been conducted on young males living with their families of origin so family research has generally focused on the stress and adaptation of parents. The effects of the relationship of carer to the TBI patient in relation to the amount of 'perceived' burden reported has received contradictory evidence. Most later research studies indicate that parent-child relationships are considered to be more resilient than spousal relationships (Mauss-Clum & Ryan, 1981; Thomsen, 1984; Hall et al, 1994).
However Livingston et al’s, (1985b) study did not support the findings that spouses underwent a greater degree of dysfunction than mothers of head injured patients.

This was also reiterated in Brooks & McKinlay’s study (1983) of fifty-seven consecutive male TBI patients who were assessed at home together with a female relative at three, six and twelve month periods after injury. Results highlighted that relatives had significant and persistent psychiatric and social dysfunction and relatives considered themselves to have a high burden in caring for the relative. However, no particular relationships were found to be more vulnerable. The most frequent predictor of the relatives psychiatric and social status was the level of symptomatic complaints voiced by the patients. Further, Kreutzer et al’s (1994) study attempted to obtain empirically defined measurements in the prevalence of psychological distress and unhealthy family functioning among primary caregivers of sixty-two adult outpatients with TBI using the Brief Symptom Inventory (BSI) and the Family Assessment Device (FAD). Approximately half the care givers reported elevated distress as indicated by scores on the BSI General stress index. Anxiety and depression were commonly reported and there was evidence of elevated scores of psychoticism and paranoid ideation subscales that suggested that feelings of burden and alienation were commonly reported. There was also a trend for spouses to report greater unhealthy family functioning than parents.

Hall et al, (1994) longitudinally studied the relationship of family stress to a number of factors. Primary caregivers of fifty-one TBI inpatients were interviewed upon rehabilitation admission, then at six, twelve and twenty-four months post-injury. Primary caregivers reiterated common complaints which have been cited in earlier studies that psychological/cognitive deficits were more of a problem at the two year assessment. Stress was significantly higher in caregivers of those at risk (i.e. psychosocial history) and those without sufficient funds for services. Reviews of studies have also revealed that primary carers consistently reported higher levels and severity of personality and behavioural difficulties in the TBI patient than other family members (Brown & McCormick, 1988; Florian et al, 1989; Graffi & Minnes, 1989; Guth, 1989; Lezak, 1988; Livingston, 1987; Brooks, 1988). These emotional responses include depression denial, anger and grief psychosomatic manifestations.

Rosenbaum and Najenson, (1976) compared the reports of open and closed head injured patients to wives of paraplegics and normal controls, one year post injury. Head injured patients were described by their wives as being more self-orientated, childish, demanding
and dependant. The wives also reported increased depression, significant loss in their social lives, and a reduction in sexual relationships. Other studies have produced similar findings (Lezak, 1978; Mauss Clum et al, 1981).

The differences between parents’ and spouses reaction to the person with TBI have been attributed to the spouses difficulty in accepting the regressive behaviour of the injured person, which is often childish and inappropriate. Parents may find it easier to accept these changes because dependency is a natural part of the relationship between parents and their offspring, even though over time this dependency diminishes. However childish dependency is not generally an accepted aspect of a marital relationship and therefore may damage these relationships (Kreutzer et al, 1992; Florian & Katz, 1991).

**EFFECTS ON MARITAL STABILITY:**
As indicated earlier, research conducted has inconsistently shown that there appears to be a significant deterioration in spousal relationships more than any other relationship (Panting & Merry, 1972; Thomson, 1974; Kreutzer, 1994; O'Hare, 1994). Several authors have stressed the impact of personality changes on spouses, highlighting that spouses often feel that their partner who they had married was now a ‘stranger’. Such feelings preclude the maintenance of a normal marital relationship (Kreutzer et al, 1994).

A reason which may account for inconsistent findings on the specific difficulties with spousal relationships is that some feelings and reactions of spouses may be elusive to empirical research because of their very personal nature. For example, Walker (1972) reported that wives would report personality changes in TBI husbands, but were hesitant to report changes in sexual functioning. Lezak (1978) discussed the special problems faced by the spouse of the head injured patient. The same general problems were seen in a more pronounced form in a two year follow-up study carried out by Weddell et al, (1980). This involved forty-four severely head injured patients from a regional rehabilitation centre. Once again, increased irritability among the patients was a common problem leading to higher levels of friction within their families. Changes in personality /behavioural characteristics in these TBI patients found that difficulties in communication, increase in arguments appeared to be more apparent between the married patients and their partners than between single patients and their parents.
It is generally reported that there is a deterioration in social and marital adjustment during the first year (Bond 1983; Livingston, 1987; Peters et al, 1990). Wives of severely injured TBI patients report decreased marital disagreements. Factors such as the wife’s personality and chronicity (up to eight years post injury) are not factors in the diminished post trauma marital adjustment (Peters et al, 1990). It should be noted that much of the research cited in these papers (e.g. Peters et al, 1990; Florian, 1989) focuses on the effects of TBI member on females (i.e. males are presented as victims of TBI). This skewed sampling reflects that the fathers, husbands or sons of the TBI victims were not often used as relatives in the samples.

Liss & Willer’s review study (1990), highlights that in about 40% of cases where there is no couple or family intervention (and fairly often even when there is) when a member of a couple under the age of fifty suffers a TBI, they eventually separate or divorce. Bond, (1984) observed that wives of older men with TBI are more likely to stay with their husbands. Younger, more recently married couples may be less able to cope with the increasing pressures. Thomsen’s study (1989) fifteen year follow-up data indicated that there may be a higher level of marital separation when compared to the general population. Of the forty subjects in Thomsen’s study, nine were married at the time of the injury. At the fifteen year follow-up period only two of these couples had remained together. Panting & Merry, (1972) found that ten patients that were married pre-injury, three separated and three divorced, within seven years post-injury. These findings have been replicated in further studies (Jacobs, 1989). As indicated earlier these studies have small samples, but the evidence suggests that TBI poses considerable threat to the longevity of a marriage. The behavioural effects of head injury often include personality changes for the individual. Spouses frequently observe that the individual is no longer ‘the person I married’ (Mauss Clum & Ryan, 1981; Wood & Eames, 1981). The behavioural and physical ramifications of TBI may effect the sexual relationship. McKinlay et al, (1981) found that at one year post injury, wives reported feeling resistant to having sexual relations with their husbands because they felt that their husbands were now different people. Rosenbaum and Najenson, (1976) study of wives of head injured serviceman found a significant difference in perception of burden compared to a control sample of wives with paraplegic husbands.

A review of the literature indicates that a significant proportion of wives of men who experienced personality alterations as a result of TBI, frequently reported feelings of loneliness and isolation, the need to assume total responsibility of the family, and the
impaired or low quality of intimate, marital relationships (Guth, 1989; Lezak, 1988; Rosenbaum & Najenson, 1976).

EFFECTS UPON CHILDREN:
Studies of how a child relates to a parent who becomes disabled are especially lacking (Buck & Hohmann, 1981). Studies of disability however demonstrated that a parent's chronic illness can increase the risk of child psychopathology (Friedemann & Tubergen, 1987; Frank, 1994). Although considerable data have been reported about the stresses imposed by head-injured patients on primary caretakers within the family, relatively little is known about how children are affected when a parent sustains such injuries (Urbach, 1989; Urbach & Culbert, 1991). As indicated earlier, due to the demographic factors related to the prevalence of TBI within most western populations there is indicated that significant proportion of TBI patients will be likely to be parents (Bond, 1983; Fahy et al, 1972). In addition, as it is recognised that TBI may not represent a random sample of the population (i.e. the pre-existence of parental psychosocial difficulties), children may have faced a disruptive environment before the trauma and may also bear heritable risk for the parent's prior psychiatric problems (Bond, 1983).

However, it is generally concluded in the literature that most effects on these children appear to follow the parental injury itself (Anthony & Cohler, 1987; Urbach et al, 1994). Psychological and social disruptions within the family can influence children's psychological and social well-being, and this possibility is often a stated major concern by injured individuals and their spouses to rehabilitation staff (Willer et al, 1991). Lezak, (1988) reported through clinical observations that younger children often bear the brunt of the injured parent's competition for the 'well' parent's attention, and that older children may respond to family stress by acting out behaviour such as school truancy and running away. However this area has received little empirical research attention. Rosenbaum & Najenson (1976) reported that fathers with TBI reduced their role in parenting and had less to do with their children than they did before the injury. Also if as a consequence of the injury, the TBI parent displays aberrant behaviour, children may experience feelings of shame, guilt and anger at not being able to bring friends home (Lezak, 1988). As a result of the impaired parent's behaviour and physical limitations previous family activities may have to be curtailed causing additional resentment and anger. Often as the children develop their abilities and overtake those of impaired parent, that parent may begin to resent the children. In some cases the healthy parent may rely on children for assistance, which may also cause the
impaired parent to resent them. With time, the children may become part-time or full-time caretakers of their disabled parent (Florian et al 1989; Guth 1989; Rutter, 1987).

An interesting paper by Pessar et al, (1993) reports a study which examines the effects of parental brain injury on children’s behaviour as reported by the uninjured parent. Its purpose was to investigate the frequency of psychological and behavioural problems in these children, the nature of such problems and the factors in both parents which are associated with children’s problems. The findings found that the effect of the presence of a TBI parent on a child varies with the age of the child, the mental health of the child, the member of the family who has suffered a TBI (i.e. mother, father), the nature, duration and severity of the injury and the adjustment the family has made. It was found that children were assigned or they assumed responsibilities that were not age-appropriate, and that children felt that they are not allowed to express emotions, especially anger, frustration towards the injured family member. This resulted in frequent behavioural/academic or social problems being displayed by children (Bond, 1983). Urbach et al’s (1994) fundamental paper describes the impact of parental brain injury, possible responses of children to parental brain injury within a developmental framework and clarifies the issues for the clinician in assessing the effects on children. This is substantiated by two case reports to validate these issues.

**Effects upon the Family Unit:**

It can be seen that even though more recent investigations have examined family involvement in traumatic brain injury recovery, these studies have focused on individuals (i.e. primary carers, parents and mothers, husbands and children) but not on the family unit per se (Brooks & McKinlay, 1983; Weddell et al, 1980; McKinlay et al, 1981). This is in despite of the fact that recent family therapy models have increasingly highlighted that attempts to establish causality for family’s difficulties by focusing on the head injured member is limited and potentially harmful to the recovery process. Also it has been documented that the primary caregiver may not be the most ‘burdened’ family member. A member of a family system who is not involved to any great extent with the care of the TBI patient (i.e. children) may experience anxiety and in some cases exert a dysfunctional influence on the family (Livingston & Brooks, 1988). Until recently very few investigations have addressed the manner in which the family system could be used as an effective resource in helping to remediate the multifaceted deficits of their relatives and to enable effective adjustment by the whole family. Recent interest in how families adjust to traumatic events has encouraged more research with varying results. Various models have been proposed to view the process of
adjustment. One such model has been to view the process of adjustment from a systems perspective. Leaf's (1993) article explores the basic systems tenets and provides data on varying adjustment issues for families.

This systems theory has four key points: i) All individual are connected; ii) the system develops over a life-span and is constantly evolving; iii) A change in the system, even in only one aspect changes it for all and iv) each system is unique. In another article, Moore et al, (1993) uses a family life cycle model which categorises stresses on family systems in terms of their source and their effects on family members. ‘Centripetal’ forces bring family members together whilst ‘centrifugal’ forces lead to loosened intrafamilial ties. This study examined the association of normative, developmental and centripetal forces acting on sixty-five families of married male TBI patients were used as independent variables in stepwise multiple regressions with criterion measures of quality of life outcome used as dependant measures. Results suggest that families normatively dealing with the developmental stage of the family with young children may face a unique challenge when a husband sustains a TBI. Also stages in family development involving conflict between centripetal and centrifugal forces may be the most problematic for the families to resolve and potentially the most effective periods for intervention.

Florian et al’s (1989) paper reviewed the dynamics and functioning of families with a severely head-injured member. In order to stress the unique problems faced by persons with brain damage and their families, a comparison with spinal cord-injured individuals is used. The study highlights that the problems that are unique to TBI disability and therefore necessitates the delivery of special support services focused on the family, rather than on the head-injured person. A review of the research on families of the TBI is important in the light of the assumption that these families are faced with adjustment problems that are different from those encountered with other disability types. Despite the similarities between brain injury and spinal cord injury there is a fundamental difference between these two disabilities. The theoretical models that deal with loss and adjustment to a disability stress the importance of the continuity between the past and the present in the life of the person and his/her family. Clinical experience has shown that in the case of persons with TBI, owing to the nature of this condition, the continuity has been disrupted. This disruption has a profound impact on the adjustment of the individual and especially the family.

Moore et al, (1989, 1991, 1993) published a series of articles examining the relationship between individual and system coping in individuals and families with TBI. Most recently,
they demonstrated the likelihood that family coping and marital resources are overwhelmed by TBI that coping may only have a minor role in eventual outcome. External circumstances such as improved child care, patient respite services and increased social support may be overriding factors in predicting outcome.

The above section summarises reactions of family members to brain injured relatives and the primary effects on relatives during the more chronic stages of recovery. The effects of TBI on family functioning in terms of the assessment of the family as a unique entity highlights that the nature and extent of effects of TBI upon the family depend on several factors. These include the composition of the family group, its place within the fabric of society, the role formally played by the injured person, and the ability of members of the family to cope with the stress that develops. Interpersonal relations are also affected by changes in family income, work patterns, and social activities (Bond, 1984; Brooks 1985; Lezak, 1978; Lezak, 1987; Livingston, 1990; Krefting, 1990; DePompei & Zarski, 1991).

CLINICAL INTERVENTIONS FOR FAMILIES WITH A TBI MEMBER:

APPROACHES OF INTERVENTIONS:
The role of the family in rehabilitation process is crucial, both in terms of outcome measures of the TBI patient and adjustment of individual members of the family unit. Jennett, (1975) considered that prophylactic and on-going psychosocial counselling of the patient and the family might influence the outcome of closed head injury more significantly than physical rehabilitation. Even the most organised family often is unable to adapt to meet the demands placed on it by the sudden event of a member experiencing a TBI (Versluys, 1980). In addition, family stressors resulting from traumatic brain injury of a family member results in problems such as depression, anxiety, isolation, and feelings of guilt in other family members. One of the earliest studies that attempted to identify the special needs of families with a member who has a TBI was carried out by the Family Survival Project (Friss et al, 1990). They found that these families expressed an average of three unmet needs when they sought assistance. Among the foremost needs expressed were emotional support, general information about brain damage, legal services rehabilitation, respite care, financial assistance, behaviour management and help with placement. The acknowledgement for a systematic form of family intervention for families of TBI patients have been well documented in the literature (Bond, 1983; Mauss-Clum & Ryan, 1981; Rosenthal & Muir, 1983; Zarski et al, 1988; Jackson & Haverkamp, 1991). However, the most appropriate form of intervention is open to debate and
there has been little empirical research on the efficacy of various approaches (Jackson & Haverkamp, 1991). Although an increasing number of studies on families of persons with TBI have begun to use quantified assessment of family functioning, many professionals continue to rely on clinical judgement, intuition and simple applications of a particular family therapy school (Bishop & Miller 1988; Johnson & Higgins, 1987). Rosenthal & Muir, (1983) state that the early identification for intervention and type of intervention required is essential. The assessment process may be conceptualised as consisting of at least three major components: i) careful analysing the premorbid history of the patient and family ii) establishing accurate estimates of severity and duration of the physical and mental sequelae and iii) attending to the ‘signals’ from the family that might reflect a need for intervention. It is extremely important to highlight that not all families experience problems after head injury that require intervention. Research has highlighted that there are several categories of high risk families that would be most likely to experience the greatest degree of dysfunction. These include:- (i) pre-morbid history of maladaptive behaviour patterns (i.e. marital discord, alcohol problems) (ii) Prolonged use of denial by either patient or family, (iii) severe chronic physical and/or mental deficits persists (Rosenthal & Muir, 1983).

A variety of interventions have been proposed which can be placed into three main categories, family counselling (which includes patient-family education), family support groups and family therapy (Nilson-Diehl, 1983; Goldenberg & Goldenberg, 1985; Soderstrom et al, 1988; Solomon & Scherzer, 1991; Stratton & Gregory, 1994).

FAMILY COUNSELLING:

Family counselling is often directed toward the family of the head injured patient. A major goal of family counselling is to assist the family in the mourning process that accompanies adaptation to the brain injury. Another goal of family counselling is to assist the family in understanding and accepting the disability and the potential consequences. Family counselling may include providing information on the recovery process, expectations for recovery of specific cognitive functions, establishment of realistic goals and other kinds of information required by the family (Brown & McCormick, 1988; Couper & Sheenan, 1987; Rosenthal & Young, 1988).

Oddy et al, (1985) reported that families are often dissatisfied with the amount and type of information received regarding nature and extent of the injury and prediction of outcome. Within the past few years patient-family education programmes have become popular technique in rehabilitation centres throughout the United States. Emotional counselling can
help the family deal with feelings of loss and helplessness that often accompany TBI and can help the family cope with the implications of TBI during the stages of rehabilitative process (Rosenthal & Young, 1988). The literature that deals with the impact of TBI on sexual functioning suggests that sexual dysfunction after TBI rarely has physical basis (Berrol, 1981). Therefore supportive counselling for both partners may enable partners to understand the impact of TBI on emotional and sexual behaviour. There has been recent attempts to objectively determine the effectiveness of family education component of Family Counselling by comparing knowledge base of families who participate in such programs and those who do not receive formal education. The initial findings indicate that patient education can be of great benefit to families who experience head injury (Leaf, 1993; Godfrey et al, 1991).

**Support Groups:**
Campbell, (1988) assessed the needs of relatives living with a head injured survivor and the usefulness of support groups in meeting these needs. Support groups were reported to be useful in meeting educational needs, psychological needs and to discuss personal issues. These findings have been found by other studies (Mauss-Clum & Ryan, 1981; Acorn, 1993). Acorn’s (1993) study aimed at determining the needs of the family (caregiver) while caring for a head-injured person at home, to assess the availability, use and helpfulness of support group groups in meeting the identified needs. The stressful areas reiterated issues highlighted by previous studies such as cognitive impairments, mood swings. In relation to the usefulness of the support group, results indicated that the groups facilitated in supporting high educational needs, psychological needs (such as knowing what the future holds). Most rehabilitation programmes in the USA acknowledge the effectiveness of support groups as effective in providing emotional support and information, reducing social isolation, decreasing the burden of caregiving and assisting with the adjustment from hospital to home (Campbell, 1988). However the establishment of such groups in the UK are limited. (Hall et al, 1994) This is despite that other research indicates that social support provided to families in crisis may protect the health of family members (Kaplan et al, 1977; Mor-Barak, 1988).

**Family Therapy:**
One of the most promising developments in the field of family psychology has been the emergence of integrative models of family adjustment (e.g. Frye, 1982). The Family and Disability Assessment System appears to be particularly sensitive to the alteration in roles, beliefs and social interaction patterns that persons with disabilities and their families typically confront. Whitman (1991), highlights that there is the need for a systems perspective in
facilitating an interdisciplinary, rehabilitation process, and that the early identification of the need for intervention and the type of intervention required is essential in order to prevent secondary disability produced by maladaptive interactions between the patient and family. She further states that 'ideally the family should be integrated into the treatment team during the acute phase, that is during the first twelve months following TBI, since most of the sequelae of the accident are acted out within the family context and it is in the family that many sequelae can be exacerbated or attenuated. The sequelae can become a source of intolerable stress leading to a breakdown of the family. However the sequelae can be attenuated if the family can learn new ways to communicate, if they can learn to adapt to the neurogenic and reactive changes in behaviour of the TBI and hence re-establish family dynamics based on redefinition of responsibilities and roles.'

Integrating the family into the rehabilitative process from the beginning places the focus of the family therapy on 1) educating the family about the sequelae 2) on what to expect as the TBI member improves, 3) on helping the family to cope, to work throughout the stress of trauma, 4) on adapting to changes in the responsibilities of the family members 5) on how to keep lines of communication open between all members including the TBI individual 6) on altering maladaptive patterns of interaction and communication and on working through the mourning process (Bond, 1983; Rosenthal & Muir, 1983; Lezak, 1986; Hall et al, 1994; Kreutzer et al, 1994). Rosenthal & Muir, (1983) state that family intervention in all stages of the recovery process is essential.

Until recently the literature offers little in the way of theoretical models or specific treatment procedures which may be used to implement family therapy with TBI patients. Zarski et al, (1987) cites the structural family systems model as proposed by Minuchin et al, (1978) as being helpful in understanding families with a TBI member. Zarski et al, (1994) highlights the five characteristics of family interaction that appear to be relevant to TBI patient’s family are enmeshment, over-protectiveness, rigidity, lack of conflict resolution, and involvement of the TBI patient in parental conflict. However it should be noted that this system is based on an open systems model of psychosomatic disease and that the TBI patient is a sibling within a two parent family system. Therefore it is not a sound model to be applied to a family system where an adult (hence parent) has a had a traumatic head injury. Initially research has focused on systems variables such as family communication patterns, family cohesion, family adaptability, family satisfaction, and family capabilities and their relationship to family functioning and adjustment process following head injury (Brooks, 1984; Bicknell, 1982).
Zarski et al, (1988) study explored postmorbid family functioning in order to arrive at a more systematic understanding of family differences in reaction to a head-injured member. The primary objective of this study was to explore the differences between various family types on clinically relevant dimensions of family functioning based on Olson’s Circumplex model. (Olsen et al, 1979; Olsen, 1986) There have only been limited detailed studies on empirically investigating systematic interventions with families. Most of this work has been undertaken with children of head injured parents. Three case reports of children with head injured parents are presented in Urbach & Culbert’s (1991) paper, followed by a discussion of treatment considerations for this emerging at risk population. In each of these cases, significant improvement in the child’s functioning and resolution of emotional difficulties occurred during the course of treatment. Therapeutic modalities included ‘supportive’ individual psychotherapy for the child and each parent, some ‘couple sessions to address marital issues, family therapy interventions, cognitive behavioural techniques such as self monitoring, cognitive restructuring and relaxation training and psycho-education’ to help family members understand the nature of head trauma, neuropsychiatric consequences and constructive ways of responding to them. Group therapy has also been tried as an effective treatment tool for children in these circumstances. In summary, interventions for families of TBI individuals require a great deal of therapeutic flexibility which at times necessitates shifts in treatment modality and in who is treated. The paper concludes that the potential for constructive therapeutic intervention with these children and other members of the family mandates their early identification, referral and treatment.

Despite the above mentioned studies there have been no empirically detailed studies undertaken that show conclusively that intervention therapies have differentially affected ‘outcome’ in terms of adjustment for the family and outcome measures for the TBI patient.
CRITICAL APPRAISAL OF RESEARCH PAPERS:
It is acknowledged that gaining insight into family functioning can be elusive to empirical research because of the difficulties in quantifying such subjective information (Klonoff & Prigatano, 1987). Arriving at a satisfactory and generally accepted way of defining adjustment has proven to be difficult, as within the literature there are a multiple definitions possible, all of which vary according to ones theoretical perspective. Many of the early studies were unsatisfactory in terms of methodological flaws and weaknesses. It is difficult to draw clear conclusions owing to inadequate specification of selection criteria for patients, and inadequate description of study populations, especially with regard to severity (e.g. Mauss-Clum & Ryan, 1981; Brooks et al, 1979, Brooks et al, 1991a). This can been seen by reviewing the tabulation of research papers in the Appendices. Later studies have tried to redress these issues (e.g. Kreutzer et al, 1994; Hall et al, 1994).

Most researchers have typically have taken indices of self report measures by individual family members. As previous studies have highlighted family functioning may differ according to who reports. The responses are not always made apparent yet the statistical data draws upon this sample as a similar group of people. There are also a number of limitations in using survey and interview research techniques. Difficulties associated with a low return rate, the inability for elaboration of responses, missing/incomprehensible data, as well as the bias of population more likely to be included in such research. In addition, the retrospective nature of many of the studies may increase the likelihood of imprecise respondent perceptions and recollections. Also there must be some recognition of the drop out rate in many of the longitudinal research that families who are coping poorly may be underrepresented, since these families may not have the time to participate in such research. Most studies did not consider head injured patients at much later phases of the recovery process, or individual differences related to personality or stressors. Later assessments may give a more realistic description as to how families are coping and adjusting since often medical involvement often finishes at around two years. Although some variables relative to family functioning were controlled namely age, and length of head injury, future studies will need to consider other important demographic variables (i.e. areas of brain damage, pre-family difficulties, family construction). Clearly larger samples of families would lead to greater confidence in the findings. Also a larger sample of mothers with brain injury is especially important for understanding possible gender differences in family stress. Also the uninjured relative was often used as the principal source of information in relation to gaining information of family difficulties. This may have led to confounding the information obtained, since earlier research
has highlighted that the principal caretaker often experiences depression, which may effect their accounts of family functioning.

A major difficulty in relation to much of the literature discussed in this review relates to the fact that a vast majority has been carried out in United States. Its transferability to U.K is limited due to the differing, cultural, family dynamic, roles, and rehabilitation medical services experienced. In addition the more empirically validated measures of family functioning have not been normalised on UK samples.

On a more theoretical grounding, there are currently no substantiated models of adjustment which have been empirically shown to validate the experiences of TBI families. In addition methods of intervention are largely ad-hoc and based on clinicians gut reactions rather than following a defined model of intervention. Therefore when reviewing the results of these studies there are a number of methodological weaknesses which dictate caution when interpreting the results.

**SUMMARY:**
The consequences upon many families of adult traumatic brain injury, no matter how they are defined, are major, serious and of long term duration. Researchers typically have taken indices such as self reports by individual family members, and these show that those relatives to the patient report increasing levels of burden as the years go by, with an increasing sense of isolation, frustration and bitterness (Jacobs 1989; Frank et al, 1990).

Consequently, rehabilitation programmes are placing increasing emphasis on involvement of the family in rehabilitation process following traumatic brain injury. This involvement typically consists of education, training supportive counselling and family therapy all of which are intended to assist the family in learning how to adapt and manage the disability within the family system. One approach to assessing the family system as it relates to the disability is through the use of interviewing techniques and standardised psychological instruments. In addition to gathering information by interviewing the family data are occasionally gathered through the use of standardised instruments such as the Katz Adjustment Scale (KAS) and the McMaster Family Assessment Device (FAD). The use of standardised procedures such as these can assist in identifying how the individual family members are coping with the disruption in their lives and what particular coping strategies are being utilised to maintain personal integrity (Rosenthal & Young, 1988).
These studies have clearly established the burden created by TBI. Later studies have examined the functioning of families in measuring their adjustment to these burdens. The measurement systems have drawn upon quantified family relations using family measurement scales. These have utilised different to models of family functioning and have resulted in apparently disparate reports. To date, some research undertaken has documented the need for family intervention, but none has demonstrated that successful family intervention differentially affects outcome. Despite the lack of scientific evidence clinicians are reporting that the inclusion of family intervention into the broad spectrum of rehabilitative treatment for TBI is essential (Lezak, 1986; Testani et al, 1992; Whitman, 1991).

However in practical terms, despite universal health care, co-ordinated services for the brain injured are virtually non-existent in the United Kingdom. Currently millions of pounds are being spent on acute, trauma care, with poor provision of rehabilitative and re-integrative services. This has been highlighted most recently in an intensive study of twenty families conducted by the Joseph Rowntree’s Foundation (Hubert, 1995) of service provision for families (especially those in need of most urgent intervention), with a head injured member. This has shown that responses from support services are often inadequate and short-lived and do not sufficiently recognise the long-term effects on family life and relationships. Support for relatives is clearly important. It is generally agreed that this should go well beyond general advice and include more constructive and dynamic forms of treatment such as family therapy, group therapy and psychotherapy. Yet it can be seen from the review that there is currently insufficient empirically derived information on the family’s response to obtain a solid foundation on which to base such interventions. Therefore at this present time, in the absence of adequate rehabilitation facilities, many families of brain injured patients must rely on volunteer self help and support groups such as those organised in the UK by Headway, the National Head Injuries Association, and in the US by the National Head Injury Foundation.

**FUTURE RESEARCH CONSIDERATION:**
As evident by clinical observation and empirical investigations, the occurrence of TBI in an individual will have major implications for the quality of life for the entire family. Research has highlighted that maximisation of recovery of the head injured person is tightly interwoven with optimal family functioning. From this literature review, it hopefully can be seen that rehabilitation and re-integration programmes cannot isolate the individual from their family, and more importantly families cannot be expected to deal with this burden alone. The move towards incorporating the family within rehabilitation programmes and developing
rehabilitation programmes within a systems perspective is facilitating ideas for clinical interventions for this group. Additional research on family systems is needed to clarify the most relevant theoretical model of adjustment and appropriate intervention strategies for rehabilitation settings once the TBI patient returns home. Future research investigating coping strategies and psychological adjustment in families with head injury should obtain information from all members of the family, as well as utilising an appropriate control group of families without a member who has sustained a TBI. The tasks that are yet to be accomplished involve more controlled research into the effects of head injury on the family system and determining the most effective and reliable methods of interventions to maximise patient and family adaptation.
REFERENCES:


3-29


Panting, A. & Merry, P. (1972). The long-term rehabilitation of severe head injuries with particular reference for the need for social and medical support for the patient's family. *Brain Injury Rehabilitation, 38*: 33-37


APPENDIX

TABULATION OF SELECTIVE RESEARCH PAPERS 1967-1994
<table>
<thead>
<tr>
<th>STUDY</th>
<th>ORIGIN</th>
<th>SUBJECTS</th>
<th>ASSESSMENT</th>
<th>FINDINGS</th>
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</thead>
<tbody>
<tr>
<td>Fahy (1967)</td>
<td>USA</td>
<td>five - six year follow-up</td>
<td>Measures of return to employment</td>
<td>• All gainfully employed pre-injury&lt;br&gt;• Post-injury 7 reduced earning capacity, 4 unable to work&lt;br&gt;• All subjects experienced sequelae associated with TBI.&lt;br&gt;• Psychiatric dysfunction less easily tolerated by relatives than compared to motoric dysfunction.&lt;br&gt;• Relatives most concerned about outburst of rage&lt;br&gt;• Reasons for reduced earning capacity related to behavioural problems.</td>
</tr>
<tr>
<td>Panting, A. &amp; Merry, P</td>
<td>USA</td>
<td>seven years post injury 30 severe TBI</td>
<td>Assessment interviews with relatives</td>
<td>• Need for professional support of the family&lt;br&gt;• Persistence of emotional sequelae following injury&lt;br&gt;• Personality, emotional, behavioural problems more difficult for relatives than physical deficits.&lt;br&gt;• Most concerned about 'pathological laughter'&lt;br&gt;• Many relatives on supportive treatments post injury (i.e. tranquillisers)</td>
</tr>
<tr>
<td>Romano, M.D.</td>
<td>USA</td>
<td>13 TBI patients and their families 7 M . 6 F</td>
<td>Observation</td>
<td>• Denial exhibited by relatives</td>
</tr>
<tr>
<td>Thomsen, I.V.</td>
<td>Denmark</td>
<td>50 Severe TBI patients</td>
<td>Interview average 30 months after TBI relatives self questionnaire re: physical, mental and mental state</td>
<td>• Relatives complained of changes in personality (temper, irritability, lack of spontaneity, restlessness, emotional regression, emotional liability)</td>
</tr>
<tr>
<td>Bond (1975)</td>
<td>U.K</td>
<td>56 severe TBI</td>
<td>Assessment using devised mental/social scales</td>
<td>• Interviews conducted in patients' homes to make a direct assessment of home situation</td>
</tr>
<tr>
<td>Rosenbaum M &amp; Njensn T</td>
<td>Israel</td>
<td>10 severe TBI male patients (military personnel)</td>
<td>One year after TBI</td>
<td>• Significant levels of friction in spouses of TBI than compared to wives with physical injuries&lt;br&gt;• Wives of TBI patients reported drastic life changes, felt lonely, isolated&lt;br&gt;• Interpersonal relationships tense in TBI families with many wives assuming husband's previous roles.</td>
</tr>
<tr>
<td>Oddy, M Humphrey, M,</td>
<td>U.K</td>
<td>54 severe TBI patients 16-39 close relatives</td>
<td>Relative interviewed first four weeks to obtain pre-morbid personality and social adjustment and repeated 6 &amp; 12 months later Katz Adjustment Scales, Symptoms checklist, Wakefield Depression Inventory</td>
<td>• One month 39% family members having high probability of disturbance requiring psychiatric treatment&lt;br&gt;• Relatives reported high incidence of depression at six months&lt;br&gt;• Relatives reported high degree of depression at on year</td>
</tr>
<tr>
<td>Oddy, M. &amp; Humphrey, M.</td>
<td>U.K</td>
<td>54 Severe TBI patients PTA &gt; 24 hours aged 16-39 interviewed close relatives</td>
<td>Relatives interviewed within first four weeks</td>
<td>• Only six patients were still not back to work but more had not resumed all leisure activities. Family difficulties generally resolved although social contact less frequent</td>
</tr>
<tr>
<td>STUDY</td>
<td>ORIGIN</td>
<td>SUBJECTS</td>
<td>ASSESSMENT</td>
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<tr>
<td>Weddell, Oddy &amp; Jenkins, 1980</td>
<td>U.K.</td>
<td>44 TBI patients 31 male, 13 female age range (16-39)</td>
<td>Interview 12 months</td>
<td>• Marked changes in occupational status, leisure, social contacts &amp; changes in family life.</td>
</tr>
<tr>
<td>McKinlay, Brooks, Bond, Martinage &amp; Marshall (1981)</td>
<td>U.K.</td>
<td>55 TBI Patients 46 male 9 Female 16 -60yrs mean 35:7yrs 19 single, 33 married, 1 separated, 1 divorced 1 widowed close relative wives/ mothers</td>
<td>Interviewed 3,6,12 months</td>
<td>• Levels of stress experienced by relatives appeared to remain similar to that experienced three months. Levels of stress related degree of behavioural/personality difficulties</td>
</tr>
</tbody>
</table>
| Mauss-Clum, N. & Ryan, M. (1981) | USA | 30 male TBI patients relatives 19 wives, 11 mothers | Retrospective questionnaire investigating changes in patient, Family reactions | • 27 relatives reported personality change in TBI patient with degree of change reported varied depending on severity and location Of injury, patient's pre-morbid personality and family structure  
• Difficulties included personality changes, memory, dependency, impatience, depression, lowered initiation, temper outbursts, lack of insight  
• One half of wives/mothers experienced frustration, irritability and annoyance of depression and anger, almost half of wives identified with the statement, "I'm married, but I don't really have a husband" |
| Zarski, DePompei & Zook 1983 | USA | 45 TBI and significant carer TBI 33 males, 12 females Carer 7 Male (1 spouse, 6 fathers) 38 female (5 spouse, 33 mothers) Family Assessment Device - (FAD) Family Adaptability & Cohesion Scales - (FACES III) Family Vulnerability Test - (FIT) | Family Assessment Device - (FAD) Family Adaptability & Cohesion Scales - (FACES III) Family Vulnerability Test - (FIT) | • Relatives found to have significant and persistent psychiatric/social dysfunction and experienced high burden of care. |
| Thomsen (1984) (follow-up from Thomsen 1974) | USA | 10-15 years after injury 40/50 TBI of original group 28 males (15-44 years) mean 21.5 years 12 females (15-44 years) mean 27.3 years PTA > 1 month | Relatives self questionnaire re: physical, mental and mental state | • Changes in behaviour continued to be the most serious burden and though evidence of fluctuation in symptoms the frequency did not change  
• Isolation of family relationships strained intrafamilial/extramfamilial relationships  
• Burden intensity more significant in spousal relationships |
| Livingston, Brooks & Bond (1985a) | U.K. | 42 male TBI patients assessed 3 months after injury PTA > 48 hours Female relatives | GHQ-60, Leeds General Scales for Anxiety & Depression | • 45 % relatives above anxiety threshold  
• 57% of relatives significant scores on GHQ-60 wives more psychosocially handicapped but no significant levels of depression |
| Livingston Brooks & Bond (1985b) | U.K. | 57 TBI patients and a defined female relative 42 TBI patients & relatives seen 1 month 47 TBI patients & relatives seen 6 months 50 TBI patients & Relatives seen 12 months | GHQ-60, Leeds General Scales for Anxiety & Depression | • Relatives found to have significant and persistent psychiatric/social dysfunction and experienced high burden of care. |
| Brooks et al, (1986) (follow-up study Livingston 1985a 1985b) | U.K. | 42 from initial 57 TBI patients & close relatives interviewed 5 years after TBI | GHQ-60, Leeds General Scales for Anxiety & Depression | • Very similar results obtained as in 1985b study. Indicates significant persistence and worsening of burden of care  
• Strain of injury increased over five year period. Patient personality change and threats of violence were reported by relatives to have increased. 15% relatives reported threats of violence increased to 54% at the five year interval.  
• The greater the magnitude of behavioural and personality changes the greater the burden on relatives. |
<table>
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<tr>
<th>STUDY</th>
<th>ORIGIN</th>
<th>SUBJECTS</th>
<th>ASSESSMENT</th>
<th>FINDINGS</th>
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<tbody>
<tr>
<td>Livingston</td>
<td>U.K</td>
<td>41 minor TBI (male) &amp; female relatives 57</td>
<td>Relatives (minor TBI) assessed 3 months</td>
<td>Significant psychosocial difficulties which persisted throughout the year</td>
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<td>severe TBI (male) 7 female relatives</td>
<td>Relatives (severe TBI) assessed 3.6 &amp; 12 months</td>
<td>Relatives of severe TBI patients obtained significantly high scores in</td>
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<td>GHQ-60, Leeds General Scales for Anxiety &amp;</td>
<td>social dysfunction and anxiety insomnia</td>
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<td>Depression</td>
<td>At 3, 6 and 12 months one third of all relatives were experiencing</td>
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<td>significant anxiety levels (i.e. caseness)</td>
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<td>Relatives of severe TBI patients perceived burdened of care was greater</td>
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<td>than relatives of mild TBI patients.</td>
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<tr>
<td>Resnick, C.</td>
<td>USA</td>
<td>136 TBI patients (31.2% returned) Male 58.1%</td>
<td>Retrospective survey mailed to TBI families</td>
<td>Respondent statements suggest professional support, education and</td>
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<tr>
<td>(1993)</td>
<td></td>
<td>Female 39.7% Relatives 50% mothers, 15.9%</td>
<td>in New Jersey</td>
<td>interventions could assist families in coping with TBI and prevent</td>
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<td>fathers, 12.9% wives 5.3% husbands 3.8%</td>
<td></td>
<td>family deterioration</td>
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<td></td>
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<td>sisters 0.8% brothers 1.5% daughters 1.5%</td>
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<tr>
<td>Pessar, L. Coad,</td>
<td>USA</td>
<td>24 families 1 parent with severe TBI with</td>
<td>Both parents questionnaires Child Information</td>
<td>Indicated that 22/24 families reported children experienced some degree</td>
</tr>
<tr>
<td>M., Linn, R. &amp;</td>
<td></td>
<td>child who lived at home. Children age range 2-23</td>
<td>Form Behavioural Rating Scale SCL-90 Health</td>
<td>of negative behavioural change</td>
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<tr>
<td>Willer, B.</td>
<td></td>
<td>TBI parent father 16, mother 8 age range 25-53</td>
<td>and Activity Limitation Survey interview with</td>
<td>10 families experienced significant and problematic changes.</td>
</tr>
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<td>(1993)</td>
<td></td>
<td>mean 38.4 time since injury 16-84 months</td>
<td>uninjured parent</td>
<td>Poor relationships with injured parent, acting out behaviour and</td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td>emotional problems</td>
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<tr>
<td>Leach L.R.,</td>
<td>USA</td>
<td>119 TBI patients male TBI 70% ages 17-76</td>
<td>Family Needs Questionnaire administered to</td>
<td>Correlates of poor outcome for the children were injured parents</td>
</tr>
<tr>
<td>Frank, R.G.,</td>
<td></td>
<td>mean 32.5 sd 12.1 mean time since injury 15.9</td>
<td>family members</td>
<td>gender, compromised parenting performance of TBI parent, depression in</td>
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<tr>
<td>Bouman, D. E. &amp;</td>
<td></td>
<td>months relatives wives 28%, mothers 39% fathers 8%,</td>
<td></td>
<td>uninjured parent</td>
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<tr>
<td>Farmer, J.</td>
<td></td>
<td>husbands 7% siblings 8% others 12%</td>
<td></td>
<td></td>
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<td>(1994)</td>
<td></td>
<td></td>
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<tr>
<td>Hall, K.,</td>
<td>USA</td>
<td>71 TBI patients 71 caregivers (51 followed fо 2</td>
<td>Assessment families within 1 week of rehabilitation admission Families</td>
<td>Review of responses revealed that most needs were judged as important,</td>
</tr>
<tr>
<td>Karzmark, P.</td>
<td></td>
<td>years)</td>
<td>contacted by phone 6, 12,24 months post injury</td>
<td>especially pertaining to information and reassurance.</td>
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<td>Stevens, M.,</td>
<td></td>
<td></td>
<td>Subjective complaints checklist Family assessment</td>
<td>Pattern of frequently reported unmet needs suggested that many family</td>
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<td>Englander, J.</td>
<td></td>
<td></td>
<td>device Support for significant other scale</td>
<td>members felt misunderstood, isolated and unsupported.</td>
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<td>O'Hare, P. &amp;</td>
<td></td>
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<td>Perceived stress scale Social readjustment scale</td>
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<td>Wright, J.</td>
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<td>(1994)</td>
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<tr>
<td>Kreutzer, J.S.,</td>
<td>USA</td>
<td>62 TBI Patients (outpatients) and primary</td>
<td>Brief Symptom Inventory Family Assessment Device</td>
<td>Caregivers most common complaints about TBI relative lack of involvement</td>
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<td>Gervasio, A.H. &amp;</td>
<td></td>
<td>caregivers</td>
<td></td>
<td>in leisure activities, fatigue slowness forgetfulness temper outbursts,</td>
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<td>Campfair, P.S.</td>
<td></td>
<td></td>
<td></td>
<td>anxiety self-centredness increased over time, aggressiveness reported as</td>
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<td>(1994)</td>
<td></td>
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<td>moderate or severe 31% cases by 2 years post injury</td>
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<td>No trend toward greater self-reported stress over time by relatives of</td>
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<td>those with an at risk psychosocial history and those without sufficient</td>
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<td>funds for services reported significantly higher stress.</td>
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<td>Caregivers reported increases in medication use and substance use</td>
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<td>Spouses reported greater number of behavioural problems (mood</td>
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<td>disturbances)</td>
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EVALUATION OF AN EDUCATIONAL SUPPORT GROUP FOR CAREGIVERS OF RELATIVES WITH DEMENTIA IN THE COMMUNITY
ABSTRACT:
'Dementia' has been reported to induce 'psychological' morbidity not only in the patients but also in the families taking care of them. Many studies have described the impact of caregiving on the physical and psychological health of the caregiver. Recently, a proliferation of clinical, theoretical and descriptive reports have emphasised the role of informal and formal social support in reducing the burden and strain that accompanies caregiving responsibilities for dementia patients. Paradoxically, the need for well-grounded intervention strategies has never been greater in the United Kingdom, since family caregivers now have the statutory right to a separate assessment of their needs (Keady, 1996).

'Educational Support Groups' for families of relatives with a dementing illness have been increasingly utilised as a means to alleviate the burden of caregivers. Research studies employing clinical impressions, typically report 'successful' outcomes of such groups. However studies utilising more objective quantitative measures appear to be inconclusive (Broadaty et al, 1994).

An Educational Support Group had been funded, established and run by a local charitable organisation. This Educational Support Group was a short-term structured intervention programme for family caregivers comprising of ten two-hour weekly sessions. These sessions consisted of explaining about the nature of the disease, discussion of the emotional impact of caregiving, guidance relating to the behavioural management of challenging behaviours, and learning about the available resources within the community. A request was made to the Clinical Psychology Department to undertake an evaluation study as to the Group's efficacy as a "valid intervention" for families caring for a relative with dementia.

The objective of this evaluation study was to measure the efficacy of this Educational Support Group Programme for caregivers of relatives with dementia in the community as a way of improving caregivers' knowledge about the disease process and its implications to caregiving, together with improvements in caregivers' level of burden and psychological well-being. Using both quantitative and qualitative data from 'ten' participants of the Educational Support Group, information regarding the positive and negative assessment of the group are presented in the following report. The self-selected caregivers consisted of seven females and three males taken from two groups that were convened during June-July 1996 and August-November 1996. The Educational Support Group caregivers' mean age was 63.60 ($sd = 12.63$) and the median time spent as a caregiver was 20 months. A group of
‘four’ caregivers (who did not take part in the Educational Support Group) were used as a comparative Control Group. The Control Group Caregivers’ mean age was 51 years ($sd = 8.00$) and the median time spent as a caregiver was 49 months. Subjects from the Educational Support Groups were evaluated on entry and after the completion of the Group, (approximately 10-12 weeks later). The comparison Control Group were followed up over the same comparable time period.

The outcome variables used to assess the effectiveness of the Educational Support Group were the Revised 25-item Dementia Quiz [Gilliard & Groom, 1994]; the ‘Screen for Caregiver Burden: (SCB) [Vitalino et al, 1991]; the General Health Questionnaire: (GHQ) [Goldberg, 1978]; the Hospital Anxiety and Depression Scale: (HAD) [Zigmond & Snaith, 1983]. In addition a qualitative questionnaire was completed by the Educational Support Group Caregivers after the completion of the Group.

Statistical analyses found that there were no significant statistical differences between either groups of caregivers in the Educational Support Group or Control Group before or after completion of the Educational Support Group. However the caregivers who participated in the group indicated its usefulness and felt that it had positively affected their ability to manage their caregiving responsibilities. Additional Statistical analyses within the Educational Support Group yielded only a statistically significant increase in level of ‘knowledge about the disease’ amongst caregivers with no significant statistical difference on the other outcome variables after completion of the group. However when the caregivers in the Educational Support Group were compared to the control group the increase in level of dementia knowledge was not statistically significant.

It was concluded that this type of support group appeared to have only minimal impact on psychological and physical morbidity in relation to the quantitative measures used in the evaluation of efficacy of the Group. However, although not statistically significant the data did suggest that caregivers were able to benefit from the structured programme and improve their level of knowledge in relation to the disease process and ways of managing difficulties associated with caregiving. This present study draws attention to the issues surrounding family caregiving and the difficulties associated in the conceptualisation of caregiver distress and methodological design in conducting research in this area, especially in relation to the construction of a comparable control groups, issues as to the use of appropriately sensitive outcome measures, sample size, and the multi-dimensional factors which impact upon caregiver’s experience of caring for a relative with dementia.
INTRODUCTION:

CONSEQUENCES OF CARING FOR A RELATIVE WITH DEMENTIA.

In Great Britain, it has been estimated that there are about 600 000 dementia sufferers (Aronson, 1988; Oerton, 1990). A review of the literature highlights that eighty per cent of people with dementia are living at home with either their spouse or another family member (Braithwaite, 1990). It therefore can be seen that families play a pivotal role in the long term care of relatives with dementia (Biegal et al, 1991). Indeed, family support has been suggested as being the most crucial factor in determining continuing life in the community for sufferers of dementia (Brodaty & Hadzi-Pavlovic, 1990; Drapper et al, 1995; Fuller-Jonop & Haley, 1995; Schultz et al, 1992; Zarit, 1994; Stephens et al, 1990).

Family caregiving has been a topic of intensive research for over a decade, and can be conceptualised along two main themes: description of the caregiving experience and interventions to facilitate continued caregiving within the community. It is now acknowledged that caregiving can be a rewarding but demanding experience (Toseland & Smith, 1990). Increasing evidence demonstrates the 'stressfulness' of, as well as 'variability' in caregivers adaptation to caregiving, but that generally it is acknowledged that the many pressures and demands placed on a person caring for a dependant adult relative with dementia can often be quite over-whelming (Aneshenal et al, 1993; Chappell & Penning, 1996; Coope et al, 1995; Zarit & Zarit, 1982; Zarit et al, 1986).

Many studies have investigated the consequences (or outcome) of caring upon the caregiver and report high levels of 'stress', 'burden' and psychiatric morbidity, including depression, global psychological distress, increased use of medication, sleep loss and poorer physical health. Other frequently cited symptoms of emotional disturbance are anxiety, guilt, self-blame and psychosomatic disorders, and resultant conflict in marital relationships. Also caregivers' social lives are often curtailed and many caregivers have reported feeling isolated and alone in their caregiving responsibilities. These factors appear to support the consensus that caregivers' experience higher levels of distress (as measured by these factors) than in the normal population (Andrews & Robinson, 1991; Fisher & Lieberman, 1994; Gallagher-Thompson, 1994; Pinkston, 1994). Further, research has shown that the accumulated physical, social and psychological stressors (i.e. burden) can impair caregivers' ability to provide care and can jeopardise their relationship with the family member whom they care for, leading to earlier institutionalisation of the dementing relative (Chappell & Penning, 1996; Schulz et al, 1993).
Therefore the ability of family caregivers to cope successfully is essential not only for the preservation of their own health, but for the prevention of inappropriate or premature nursing-home or hospital placement, (Huckle, 1994; Jerrom et al, 1993; Mittleman et al, 1994) and thus reduce the demand for 'dwindling' inpatient resource provisions.

It is now recognised that caregiving is a complex issue and the attempts to conceptualise the process within a variety of models has been undertaken to more fully understand the factors and mediators that impact upon an individual's experience of caregiving (Pearlin et al, 1990; Barer & Johnson, 1990; Pearlin et al, 1994). The literature is now beginning to reflect researchers' recognition of the conceptual and methodological difficulties which have impeded earlier attempts to demarcate and understand all the issues associated with the phenomenon of caregiving. A fuller discussion of this literature has been undertaken in the succeeding research project (Adams, 1997).

Even though there is still limited agreement as to a model which fully conceptualises all aspects of caregiving, most health and social services have generally recognised that caregiving is often a 'burdensome' and 'stressful' experience which can have negative effects upon the psychological and physical well-being of the caregiver. Consequently, due to this recognition that caregiving can be 'stressful' for caregivers, the development of a variety of intervention strategies, to facilitate 'improved' caregiving experiences have been introduced and form the structure of Community Care Policy. However, there has been little agreement, nor conclusive results concerning the most effective intervention to maintain and improve the well-being of caregivers for people with dementia (Whitlach et al, 1991). The central issue both at a clinical and service level, (in light of the increased focus upon 'Community Care' provision, ) is whether there are effective ways of lowering the stress on family caregivers, both to reduce the health and emotional risks to these caregivers, and thereby enable them to provide care for an optimal period of time (Keady, 1996).

Formal support systems, such as community home help, day care, respite care and financial benefits can help to remove some of the burden and isolation that caregivers' experience. However it is now recognised that these interventions conceptualised the factors associated with the difficulties in caregiving in overly simplistic terms (Wells et al, 1990). For example, evaluations of such interventions (i.e. respite, day care etc.) upon caregiver well-being have not always resulted in a reduction of caregiver burden. In addition research has shown that
even with permanent institutionalisation many caregivers still experienced continued psychological distress.

There has been a growing amount of research interest in the attempt to identify mediating variables which might influence the caregivers emotional response (Morris et al, 1988; Schultz et al, 1990; Pinkston, 1994). Factors such as the meaning carers attribute to the situation, the quality of their relationship with the dementia suffer, carer’s coping strategies, and level of caregivers understanding of the disease process have all been shown to interplay with carer level of distress. This research has important implications since it suggests that attempts at reducing carers' distress may increase their willingness to continue providing care, even without any reduction in the objective problems (Gilleard & Groom, 1994). Research indicates that supportive intervention can effectively help family members cope with the stresses of caregiving (Toseland & Rossiter, 1989; Toseland et al, 1990). However despite nearly two decades of copious implementation of support services, little is known on the relative efficacy of these different intervention modalities (Gallagher et al 1989; Collins et al, 1994).

**Caregiver Support Groups:**

Recently there has been a proliferation of clinical, theoretical and descriptive reports which have emphasised the role of psychosocial interventions as a way of reducing the burden and strain that accompanies caregiving responsibilities for dementia relatives. Several studies have confirmed some benefits of social support groups whereby caregivers could “ventilate and validate” their emotional feelings in a supportive atmosphere (Aronson, 1984; Wright et al, 1987). During the last fifteen years, a significant part of the caregiver literature has focused on the descriptions and evaluations of groups as a means of relieving stress and burden of caregivers of relatives with a dementing illness (e.g. Barnes et al, 1981; Clark & Rakowsky, 1983; Glosser & Wexler, 1985; Chiverton & Caine, 1989; Brodaty & Gresham, 1989; Greene & Monahan, 1989a; 1989b; Haley, 1989; Toseland et al, 1989; Brodaty et al, 1994).

A review of the literature has shown that there are currently three main models which have been used by professional and caregivers themselves for Caregiver Support Groups. The first is an ‘educational’ based model such as described by Trepeka & Whittick, (1987) which is a brief time limited intervention designed to provide factual information about dementia, the availability of local resources and services, and practical advice about caring for a relative at
home. While the educational components are emphasised there is equal weighting placed upon the groups function as a means of ‘stress reduction’ amongst caregivers by providing supportive contact (Trepka & Whittick, 1987). An alternative model is the ‘peer support group’ where groups operate without professional guidance. Such groups are for mutual exchange and support (Mace & Rabins, 1985). They are based on a philosophy that caregivers benefit from sharing their experiences with other people and the ‘best’ people to understand are people who are in the same position as themselves, (i.e. other caregivers.) The third model can be described as a ‘therapy group model’, but also contains element of the other models previously described (Hettiaratchy & Manthorpe, 1992).

A review of the literature (as well as through professional contact with services) has revealed the prolific establishment of such groups within the Health and Social Services and especially the Voluntary Sectors to support caregivers of people with dementia. Also these groups appear to be increasingly based upon ‘time-limited’ and ‘educationally-focused’ interventions.

**Educational Support Groups:**

It has been suggested that Educational Support group interventions have “.....the potential to prevent stressors from overwhelming caregivers by providing a much needed respite from caregiving; reducing isolation and loneliness; providing an opportunity to share feelings and experiences in a supportive environment, with peers who share similar concerns and educating caregivers about the effects of chronic disabilities; and informing them about community resources” (Toseland & Rossiter, 1989).

Many clinicians and researchers have reported that caregiver stress and burden is caused due to the fact that caregivers are often unprepared for the role of ‘caregiver’ and they are frequently not well-informed concerning the physiological, psychological, behavioural and emotional changes and needs experienced by the person with dementia. Interventions designed to improve caregivers knowledge and skills may reduce their distress and indirectly help persons with dementia, perhaps decreasing their likelihood of institutionalised placement (Brodaty et al, 1994; Talkington-Boyer & Synder, 1994). Therefore such groups are based on the ‘rationale that both education and support are essential to function effectively in the caregiver role, and that these are best obtained through the leadership and mediation of expert professional staff.’
Educational Support Groups have usually been based on closed-time-limited programmes comprising a series of modules which focus on the medical, psychological, social, financial, legal aspects of dementia or have taught specific skills on how to cope with particular problems (Toseland & Rossiter, 1989; Brodaty, 1992; Brodaty et al, 1994). Most Educational Support Groups emphasise the importance of understanding as much as possible about the disease and its effects, comprising of a description of the physical causes of dementia and behavioural consequences, an awareness of available services and resources and guidance in the practical solutions to some of the problems confronting caregivers. By providing family caregivers with ‘normative’ data regarding not only the progression of their relative’s illness but also ‘caregivers’ responses to caregiving can provide perspective to caregivers which is both accepting and encouraging. By contrast inadequate information regarding either domain may lead family caregivers to adopt inappropriate expectancies for either their relative or themselves (Kahan et al, 1985a).

While appealing in theory, it is essential that, ‘from a public point of view’, there is a need to determine the relative effectiveness of such group interventions. Unfortunately a review of the literature reveals that there has been little systematic quantitative research on the effectiveness of such psychosocial interventions for caregivers in comparison to the number of groups in existence. From the limited existing data, the evidence for success from such programmes for training informal caregivers has not been compelling (Brodaty et al, 1994; Lovett & Gallagher, 1988; Montgomery & Borgatta, 1989; Whitlach et al, 1991; Zarit et al, 1987; Clark & Rakowski, 1983; Farran & Keene-Hagerty, 1994) The review of the literature revealed that impressionistic reports by caregivers and group leaders were almost always positive but that there was little evidence of change when more structured measures were employed. For example, Haley et al (1987) compared the efficacy of a skills group to an education/support group and a wait-list control group in reducing depression and increasing life satisfaction in caregivers of dementia patients. The support/education group met for 10 sessions and provided information about the nature of Alzheimer’s disease, common caregiving problems, the need to structure time away from caregiving responsibilities the common services available and an opportunity to discuss and resolve individual caregiving issues. The skills group covered the same material as the education/support group and received training in behavioural relaxation and the use of cognitive techniques to manage stress. Caregivers were randomly assigned to one of two groups or the wait-list condition. The results indicated that caregivers liked both groups but did not demonstrate reductions in depression or increase in life satisfaction relative to the caregivers in the wait-list condition.
The authors suggested that a time-limited group intervention may not be sufficiently potent to influence global measures of depression and life satisfaction because of the multiple needs of the caregiver. Also, Herbert et al’s (1994) study of 41 caregivers who were randomly assigned to either a structured Educational Support Group (n = 23) (which consisted of 8 weekly 2 hour education sessions about dementia,) or to a Control Group (n = 18) were assessed on entry, after completion of the Group, and eight months follow-up, found only slight changes on improved knowledge for the support group participants and no other differences on other outcome variables, such as depression and health changes.

Several other studies have also failed to demonstrate a consistent efficacy of educational programmes (Kahan et al, 1985b; Lipkin & Faude, 1987; Brodaty et al, 1994; Magni et al, 1995; Hebert et al, 1994).

However, other educational focused intervention programmes, such as a comprehensive and intensive highly structured 10-day programme of education and training, stress reduction, skill acquisition and family support has succeeded in reducing caregiver distress, delaying institutionalisation and reducing mortality whilst at the same time being cost-effective (Brodaty & Gresham, 1989; Brodaty & Peters, 1991; Brodaty et al, 1994).

An important paper by Knight et al, (1993) undertook a meta-analysis of psychosocial interventions and reported that uncontrolled and quasi-experimental designs showed that although participants were often very satisfied with many support programmes, generally psychoeducational group interventions were ineffective.

It can be seen that the current literature on this form of caregiver intervention is ambiguous and often contradictory. Many conceptual and methodological problems are noted within the literature. For example, attempts to document the effectiveness of intervention programs typically are accused of improper design, use of inappropriate outcome measures and the failure to take into account of the use of extraneous measures and predisposing characteristics of program participants (George & Gwyther, 1988; Knight et al, 1993). In addition most studies of interventions to improve caregiver well-being reported only subjective evidence of positive outcomes such as caregiver satisfaction, with no objective measures of well-being (Toseland et al, 1990). Of critical importance is that even fewer studies measured changes in the levels of knowledge, a factor which is seen as being the theoretical underpinning of such interventions!! (Brodaty et al, 1994). There also appear to be few studies that had simultaneously reported comprehensive analyses of the data by means of both quantitative and qualitative procedures. Abel (1990) argued the merit of employing qualitative and quantitative methodologies, stating that “........... the primary goal of researchers should be
the attempts to understand the experiences of caregivers and to help to articulate their concerns." Furthermore, Abel, (1990) pointed out that quantitative analyses tended to impose the construction of "simplistic measures of complex phenomena that cannot easily be scaled..." thus advocating the use of qualitative and quantitative analyses of such interventions.

AIMS:
In line with the current views on evaluative assessment as proposed by Abel (1990) and Schultz et al, (1993) the aim of this present study was to determine the effectiveness of a structured Educational Support Group for family caregivers which had been established as a method for positive change in relation to level of knowledge, caregiver’s psychological well-being, and level of burden, drawing on both quantitative and qualitative methods to analyse the data.

HYPOTHESES:
• Attendance at the Educational Support Group would improve caregivers’ knowledge, decrease their sense of burden and improve their personal sense of well-being.
• Caregivers who participated in the group would demonstrate a greater reduction of emotional distress and greater increase in knowledge than caregivers who did not attend the group.
• Caregivers would feel more able to undertake their caregiving role after attending the group.

METHOD:
SUBJECTS AND STUDY PROCEDURE:
The Educational Support Group had been funded, established and managed by a local charitable organisation. The evaluation was based upon two support groups that were convened between June - July 1996 and August - November 1996. Participants had been recruited through the local charity branch, local radio and newspaper advertisements, or referred by other professional agencies, (such as Social Services or Health Services.)
A Control Group of caregivers were randomly selected from 'known' community caregivers who had not undertaken the Educational Support Group. All caregivers completed a declaration of agreement to take part in the research, after having read an information sheet explaining the background to this study. (see Appendix B) They all had the opportunity to withdraw from the study at any time if they desired, without jeopardy to their current or future service requirements. Inclusion into the Educational Support Group was not precluded to caregivers who were unwilling to participate in the evaluation.

Prior to inclusion into the Educational Support Group the potential participants had been through an initial screening (undertaken by the group convenors) to assure that they were family caregivers of relatives with dementia. Caregivers could be either spouses or other relatives, but they had to be the patient's primary caregiver in that they undertook a substantial responsibility in the welfare and care of the relative with dementia. Participating caregivers completed several questionnaires a week prior to commencing the Educational Support Group or between the introductory session and first teaching session during a one and a half hour personal interview which was conducted in the caregiver's home.

The control group of caregivers also completed a one and a half hour personal interview at their home in which they completed similar questionnaires.

After the completion of the Educational Support Group (i.e. between 10-12 weeks later) the caregivers undertook a follow-up interview in which they were requested to complete the same questionnaires. As part of the follow-up interview the caregivers also completed an Evaluation Questionnaire. The control group were also followed-up after the same comparative time frame and completed the questionnaires. They however did not complete the evaluation questionnaire.

**SAMPLE:**

It is important to highlight that not all participants who attended the Educational Support Groups were included in this study. Of the original sample (n = 18), only 14 caregivers were included in this study, (N=10 Educational Support Group; N= 4 Control Group). This was due to difficulties in assessing caregivers in the Educational Support Group prior or post attending the course, or due to subject attrition (i.e. carer's relative's death before completion of the study). Also not all data for each measure was obtained for the Educational Support Group caregivers (due to the
difficulties of assessing people prior to the first group commencing). Difficulties in obtaining follow-up data from the caregivers in the control group also contributed to data attrition.

Since this was a pilot study only the principle characteristics of both caregivers and patients were considered. These details are summarised in Table 1 and Table 2. The caregivers in the Educational Support Group were predominantly female whilst gender was equally split amongst those in the Control Group. (i.e. 70% and 50% respectively). 70% of Caregivers in the Educational Support Group were taking care of an impaired spouse whilst 30% were adult children taking care of their parent. In the Control Group there was an equal distribution of spouse and adult children caregivers. The Educational Support Group caregivers’ mean age was 63.60 (sd = 12.63) and the median length of time spent as a caregiver was 20 months. The Control Group Caregivers’ mean age was 51 years (sd = 8.00) and the median length of time spent as a caregiver was 49 months.

Table 1 Demographic Variables for Caregivers in the Educational Support Group and Control Group.

<table>
<thead>
<tr>
<th></th>
<th>EDUCATIONAL SUPPORT GROUP</th>
<th>CONTROL GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=10</td>
<td></td>
<td>N=4</td>
</tr>
<tr>
<td>Mean (sd) Age caregiver (yr.)</td>
<td>63.60 (12.63)</td>
<td>51.00 (8.00)</td>
</tr>
<tr>
<td>Mean (sd) Number of sessions attended</td>
<td>8.10 (1.97)</td>
<td>N/A</td>
</tr>
</tbody>
</table>

Table 2 Descriptive Demographic Variables for Caregivers in the Educational Support Group and Control Group.

<table>
<thead>
<tr>
<th></th>
<th>EDUCATIONAL SUPPORT GROUP</th>
<th>CONTROL GROUP</th>
</tr>
</thead>
<tbody>
<tr>
<td>N=10</td>
<td></td>
<td>N=4</td>
</tr>
<tr>
<td>Caregiver Gender</td>
<td>3 M, 7 F</td>
<td>2 M, 2 F</td>
</tr>
<tr>
<td>Care-recipient Gender</td>
<td>4 M, 6 F</td>
<td>1 M, 3 F</td>
</tr>
<tr>
<td>Where care-recipient living</td>
<td>8 with caregiver; 2 sheltered accommodation</td>
<td>4 with caregiver</td>
</tr>
<tr>
<td>Caregiver Relationship to care-recipient</td>
<td>7 spouses; 3 adult children</td>
<td>2 spouses, 2 adult children</td>
</tr>
<tr>
<td>Length of time caring (Median)</td>
<td>20 months</td>
<td>49 months</td>
</tr>
</tbody>
</table>

All participants were asked about the use of resources beyond those offered by the Educational Support Group. ‘Control’ caregivers did not appear to differ from ‘Educational Support Group’ caregivers in that all caregivers usage of community resources seemed variable, which appeared
to reflect the progression of the care-recipients’ disease. There however appeared to be some differences in the type of behavioural difficulties reported to be displayed by the care-recipients of the two groups. (see Appendix C).

Caregivers who attended the Educational Support Group were considered to have completed the class if they attended at least seven out of the ten sessions. The mean number of sessions attended by caregivers at the Educational Support Group was 8.1 sessions.

**Educational Support Programme:**

The programme was a ten week Educational Support Course which aimed to provide psycho-social and emotional support for the individual caregiver.

The summary structure of the course consisted of:

- Introduction - What is dementia?
- Benefits/Finances
- Legal Advice
- Community Care
- Continence Management
- Coping Skills
- Orientation
- Stress Management
- Lifting Techniques
- Summary/Overview of Issues

All group sessions were co-led by two independent group facilitators, specifically employed by the charity to devise, organise and run the group. *They were not involved in the collection or analysis of the evaluation data contained in this report.* The format of each session was conceptualised with an educational focus in which basic information was provided through a series of invited professional speakers in relation to some of the aforementioned topics, which further facilitated informal discussion of the issues around the particular topic. All formal lecture/discussion sessions were supplemented with reading material for the caregiver’s to take away from the session.

Other parts of the programme were conducted by the facilitators and focused on the emotional adjustment associated with being a carer, such as stress management, coping skills, management of challenging behaviours as well as facilitating the expression of caregivers individual emotional reactions to the illness.
MEASURES:
A variety of self-report measures were used to measure the different dimensions of emotional distress, physical well-being as well as level of knowledge about dementia.

CARING INTERVIEW:
A schedule was designed especially for this study which covered demographic information on both the caregiver and their relative.

BEHAVIOURAL CHECKLIST:
A list of common behavioural difficulties associated with dementia was adapted from Brodaty & Hadzi-Pavlovic's (1990) list of behavioural disturbances for caregivers to indicate the current difficulties that their relative with dementia was experiencing.

DEMENTIA KNOWLEDGE:
The Revised 25-item Dementia Quiz (Gilleard & Groom, 1994) assessed caregivers' knowledge across a broad range of domains: (i.e. biomedical aspects of dementia, services needed by dementia sufferers and their families, and methods of coping with some of the problems presented by people with dementia.) Validity measures have been obtained and internal reliability for the three subscales and total score of the Dementia Quiz have been undertaken. Alpha coefficients of reliability ranged from .63 for the biomedical knowledge scale; .57 for the coping knowledge scale; .47 for the knowledge of services scale; and .88 for the dementia quiz total. In addition the Dementia quiz has been shown to correlate with a previously established Dementia Knowledge Quiz. (Gilleard & Groom, 1994)

MEASURES OF CAREGIVER’S PHYSICAL AND MENTAL HEALTH:
Measures of caregivers’ current physical and mental health were assessed using the Hospital Anxiety and Depression Scale (HAD) [Zigmond & Snaith, 1983] which assessed global ratings for depression and anxiety symptoms and the General Health Questionnaire (GHQ) [Goldberg, 1972] which is a screening test for detecting psychiatric disorders in community settings. Both these questionnaire have been shown to have good internal reliability (Zigmond & Snaith, 1983; Goldberg, 1978).

MEASURES OF CAREGIVER BURDEN:
Measures of ‘perceived burden’ was assessed using an adapted version of the Screen for Caregiver Burden: (SCB) [Vitalino et al, 1991] which is designed to assess objective and
subjective burden and is used to target potentially distressing experiences. Scoring of the SCB yields two scores: Objective Burden (OB) and Subjective Burden (SB). The former consists of a prevalence count of caregiving experiences whereas the latter reflects ratings (from 1 to 4) of distress in relation to each experiences. The psychometric properties of the SCB have been demonstrated in two independent samples (Vitaliano et al, 1991) Internal consistency coefficients were .85 and .88 for Objective Burden and Subjective Burden respectively. Construct validity has been supported by the relationship of care recipient behavioural and cognitive functioning with Objective Burden and caregiver distress and personality variables. Criterion validity (differences in burden between caregivers of dementia relatives versus controls) has been demonstrated using age- and sex-matched controls and it has been shown to be sensitive to change within the caregiving trajectory.

CAREGIVER APPRAISAL OF EDUCATIONAL SUPPORT GROUP.

A Satisfaction Evaluation Questionnaire was specifically devised for this study which was modelled after a questionnaire by Woods, (1984) as cited by Lovett & Gallagher (1988) to help assess caregivers' overall satisfaction with the group and to gain an indication of the helpful components of the group. The questionnaire listed the potentially beneficial aspects of the group and caregivers were asked to mark items which they felt were helpful to them. In addition they rated their overall satisfaction with the groups on a scale of 1 (“very dissatisfied”) to 5 (“very satisfied”) Caregivers were also asked to rate on a similar scale the impact of the group upon their beliefs about their future ability to care for their relative. (See Appendix D for copies of the Questionnaires)

ANALYSES:

Due to the limitations of the Group composition numbers (especially with the Control Group N=4) only limited data analysis between the two groups was undertaken. Pre-Group and Post-Group comparisons of the Educational Support group was undertaken together with between groups analysis using non-parametric and where appropriate, parametric statistical analyses for each each measure. Effectiveness of the Educational Support Group was measured by caregivers self perceived change in four areas: i) increase in level of knowledge; ii) reduction in emotional response to caregiving (i.e. Burden); iii) reduction in psychiatric and physical symptomology. The variation of the scores in the above described scales were considered as the main outcome measures. Caregivers who presented no variation or a worsening in one of these scales were considered not have benefited from the programme. An evaluation was also
undertaken of the qualitative information obtained from the participants who attended the Educational Support Group.

RESULTS:
Before discussing the results it should be highlighted that subject numbers were small and thus the results are preliminary in nature and must therefore be treated with caution.

DEMENTIA KNOWLEDGE:
Analysis of the scores for the Educational Group revealed that the mean score was 13.90 (sd 4.33) whilst the control group average score was 14.25 (sd 2.96). However statistical analysis of these pre-intervention dementia knowledge scores using the Mann-Whitney Test indicated that there was no significant difference (z = -.213, p > .05) between the two groups in their level of knowledge before intervention. (see Figure 1.)

Figure 1  Educational Support Group and Control Group Baseline Mean Total Scores on the Dementia Quiz.

At follow-up the results of the within group analyses (using the paired t-test) revealed that there was a significant statistical increase ($t = 2.47$, $p < .05$) in the overall level of knowledge amongst caregivers who attended the Educational Support Group. This showed that caregivers on average improved their knowledge about factors associated with dementia by 2.4 questions. However comparison with the Control Group found that this was a non-significant increase reflecting the slight increase in the Control Group's Knowledge score. (see Table 3.)
Table 3. Scores Obtained on the Dementia Knowledge Quiz by the Educational Support Group Caregivers and Control Group Caregivers Pre-Post Intervention.

<table>
<thead>
<tr>
<th></th>
<th>Overall Level of Knowledge mean (sd)</th>
<th>Bio-Medical Knowledge mean (sd)</th>
<th>Coping Knowledge mean (sd)</th>
<th>Service Knowledge mean (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pre Group</td>
<td>13.90 (4.33)</td>
<td>14.25 (2.96)</td>
<td>4.40 (1.96)</td>
<td>4.50 (1.73)</td>
</tr>
<tr>
<td>Post Group</td>
<td>16.30 (2.95)</td>
<td>15.25 (2.06)</td>
<td>4.70 (1.16)</td>
<td>5.00 (1.15)</td>
</tr>
</tbody>
</table>

CAREGIVER PHYSICAL AND MENTAL HEALTH:

Analysis of the scores for the Educational Group revealed that the mean score on the General Health Questionnaire was 16.25 (sd 6.13), whilst the Control Group average score was 15.00 (sd 4.97). The scores revealed that caregivers in both the Control Group and Educational Support Group were experiencing higher than the threshold score of psychiatric 'caseness', indicating notable caregiver distress (Goldberg, 1978). Analysis of these pre-intervention General Health Questionnaire scores using the Mann-Whitney Test indicated that there was no significant difference (z = -.5722, p > .05) between the two groups in their level of distress at pre-intervention assessment. (see Figure 2.)

Figure 2 Educational Support Group and Control Group Baseline Mean Total Scores on the General Health Questionnaire (GHQ).
At follow-up the results of the within group analyses (using the paired t-test) revealed that there was a non significant statistical decrease \( t = -.59, p > .05 \) in the overall level of caregiver distress amongst caregivers who attended the Educational Support Group. Analysis between the Control Group caregivers and those who attended the Group revealed also a nonsignificant difference between scores on follow-up. \( z = -.5709, p > .05 \) (see table 4).

Table 4: Scores Obtained on the General Health Questionnaire by the Educational Support Group Caregivers and Control Group Caregivers Pre-Post Intervention.

<table>
<thead>
<tr>
<th>General Health Questionnaire</th>
<th>Edu/Supp Group</th>
<th>Control Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>( N=7 )</td>
<td>( N=4 )</td>
<td></td>
</tr>
<tr>
<td>Pre Group</td>
<td>16.29 (6.13)</td>
<td>15.00 (4.97)</td>
</tr>
<tr>
<td>Post Group</td>
<td>15.00 (7.19)</td>
<td>15.50 (4.20)</td>
</tr>
</tbody>
</table>

Analysis of the scores for the Educational Group revealed that the mean depression score on Hospital Depression and Anxiety Scale was 6.17 \( (sd 4.42) \) whilst the control group average score was 9.00 \( (sd 4.97) \). The Control Group were shown to be experiencing clinically significant level of depression. Analysis of the scores for the Educational Group revealed that the mean anxiety score on Hospital Depression and Anxiety Scale was 8.14 \( (sd 4.30) \) whilst the control group average score was 7.75 \( (sd 4.92) \) which showed that caregivers in both groups were experiencing mild clinically significant levels of anxiety. However the statistical analysis of scores on Hospital Depression and Anxiety Scale for the two groups revealed no significant difference between the depression and anxiety scores at pre-intervention assessment. \( z = -.85, p > .05 \) and \( z = -.19, p > .05 \) (See Figure 3.)

Figure 3: Educational Support Group and Control Group Baseline Mean Scores on the Hospital Anxiety and Depression Scale (HAD):
Within group post test analyses showed a raising of anxiety (although not statistically significant) in the Educational Support Group Caregivers. There was also a slight raise in anxiety and depression scores obtained from the Control Group. There was no change in the level of depression score in the Educational Support Group. However it must be noted that the pre-assessment level did not indicate a clinically significant level of depression.

Analyses between the groups indicated a non significant statistical difference in level of depression and anxiety after intervention ($z = -1.13$, $p > .05$ and $z = -1.23$, $p > .05$).

Table 5: Scores Obtained on the Screen of Caregiver Burden (SCB) by the Educational Support Group Caregivers and Control Group Caregivers Pre-Post Intervention.

<table>
<thead>
<tr>
<th></th>
<th>HAD - Anxiety mean (sd)</th>
<th>HAD - Depression mean (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Edu/Supp Group N=7</td>
<td>Control Group N=4</td>
</tr>
<tr>
<td>Pre Group</td>
<td>8.14 (4.30)</td>
<td>7.75 (4.92)</td>
</tr>
<tr>
<td>Post Group</td>
<td>10.86 (3.89)</td>
<td>8.00 (4.55)</td>
</tr>
</tbody>
</table>

CAREGIVER BURDEN:
In relation to levels of Objective and Subjective Burden, it was shown that caregivers in both the Educational Support Group and Control Group were experiencing high levels of objective and subjective burden at the initial assessment. The mean Objective and Subjective Burden scores for the Educational Support Group were $15.14$ ($sd 4.56$) and $34.57$ ($sd 12.15$).

The mean Objective and Subjective Burden scores for the Control Group were $12.00$ ($sd 0$) and $34.00$ ($sd 6.33$). The analysis of scores on the Screen of Caregiver Burden for the two groups revealed no significant difference between the scores of objective and subjective burden at pre-intervention assessment ($z = -1.23$, $p > .05$ and $z = -.47$, $p = >.05$ respectively). (see Figure 4)
Within group post test analyses showed that although there was a reduction in scores in objective Burden and Subjective Burden after attending the group they were not statistically significant \( (t = -1.21, p > .05 \) and \( t = -0.35, p > .05 \) respectively).

Analyses between the groups indicated a continuing non significant difference in level of objective and subjective burden after intervention \( (z = -0.57, p > .05 \) and \( z = -0.37, p > .05 \) respectively). (see Table 6)

### Table 6: Scores Obtained on the Screen of Caregiver Burden (SCB) by the Educational Support Group Caregivers and Control Group Caregivers Pre-Post Intervention.

<table>
<thead>
<tr>
<th></th>
<th>OBJECTIVE BURDEN</th>
<th></th>
<th>SUBJECTIVE BURDEN</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean (sd)</td>
<td></td>
<td>Mean (sd)</td>
<td></td>
</tr>
<tr>
<td>Edu/Supp Group</td>
<td></td>
<td></td>
<td>Edu/Supp Group</td>
<td></td>
</tr>
<tr>
<td>Pre Group</td>
<td>15.14 (4.56)</td>
<td>12.00 (0)</td>
<td>34.57 (12.15)</td>
<td>34.00 (6.33)</td>
</tr>
<tr>
<td>Post Group</td>
<td>13.00 (4.00)</td>
<td>14.75 (3.59)</td>
<td>33.14 (13.43)</td>
<td>33.25 (6.29)</td>
</tr>
</tbody>
</table>

### 5.4 Correlational Analysis:

Table 7 and Table 8 show the results of the Pearson's Correlations of the 4 caregiver measures: Burden, (Subjective & Objective), Depression, Anxiety, and General Wellbeing (GHQ) and Dementia Knowledge at Pre-Intervention over the two time periods.
Table 7  Pearson Correlations of the measures of Caregiver Distress and Level of Knowledge - Pre Intervention

<table>
<thead>
<tr>
<th></th>
<th>HAD DEPRESSION</th>
<th>HAD ANXIETY</th>
<th>GHQ</th>
<th>DEMENTIA KNOWLEDGE</th>
<th>SCB SUBJECTIVE</th>
<th>SCB OBJECTIVE</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAD DEPRESSION</td>
<td></td>
<td>.6478*</td>
<td>.6185*</td>
<td>.1454</td>
<td>.1842</td>
<td>.0633</td>
</tr>
<tr>
<td>HAD ANXIETY</td>
<td>.6478*</td>
<td></td>
<td></td>
<td>-.4088</td>
<td>.3183</td>
<td>-.2408</td>
</tr>
<tr>
<td>GHQ</td>
<td>.6185*</td>
<td>.6219*</td>
<td>-.4088</td>
<td>-.1464</td>
<td>.4336</td>
<td>.0797</td>
</tr>
<tr>
<td>DEMENTIA KNOWLEDGE</td>
<td>.1454</td>
<td>-.4088</td>
<td>-.1464</td>
<td>-.3583</td>
<td>-.3583</td>
<td>.6312*</td>
</tr>
<tr>
<td>SUBJECTIVE BURDEN</td>
<td>.1842</td>
<td>.3183</td>
<td>.4336</td>
<td>-.3583</td>
<td>.6312*</td>
<td>-.0206</td>
</tr>
<tr>
<td>OBJECTIVE BURDEN</td>
<td>.0633</td>
<td>-.2408</td>
<td>.0797</td>
<td>.6312*</td>
<td>-.0206</td>
<td></td>
</tr>
</tbody>
</table>

* = SIGNIFICANT LEVEL AT .05
** = SIGNIFICANT LEVEL AT .01 (2-TAILED)

As would be expected the GHQ and the HAD correlate highly together over both assessments. Therefore both measures seem to be probably measuring the same sorts of emotional distress and may be reliably so.

The Screen For Caregiver Burden (Objective) appeared to correlate with knowledge at initial assessment. The Screen For Caregiver Burden (Subjective) appeared to negatively correlate with knowledge at follow-up and Objective Burden to positively correlated with depression. This negative correlation may be a chance result bearing in mind the large number of

Table 8  Pearson Correlations of the measures of Caregiver Distress and Level of Knowledge Post Intervention

<table>
<thead>
<tr>
<th></th>
<th>HAD DEPRESSION</th>
<th>HAD ANXIETY</th>
<th>GHQ</th>
<th>DEMENTIA KNOWLEDGE</th>
<th>SUBJECTIVE BURDEN</th>
<th>OBJECTIVE BURDEN</th>
</tr>
</thead>
<tbody>
<tr>
<td>HAD DEPRESSION</td>
<td>.4569</td>
<td>.8763**</td>
<td>-.5868</td>
<td>.5712</td>
<td>.7864**</td>
<td></td>
</tr>
<tr>
<td>HAD ANXIETY</td>
<td>.4569</td>
<td>.7098*</td>
<td>-.0095</td>
<td>.1164</td>
<td>.0081</td>
<td></td>
</tr>
<tr>
<td>GHQ</td>
<td>.8763**</td>
<td>.7098*</td>
<td>-.3537</td>
<td>.5301</td>
<td>.5742</td>
<td></td>
</tr>
<tr>
<td>DEMENTIA KNOWLEDGE</td>
<td>-.5868</td>
<td>-.0095</td>
<td>-.3537</td>
<td>-.7031*</td>
<td>-.3917</td>
<td></td>
</tr>
<tr>
<td>SUBJECTIVE BURDEN</td>
<td>-.5712</td>
<td>.1164</td>
<td>.5301</td>
<td>-.7031*</td>
<td>.5104</td>
<td></td>
</tr>
<tr>
<td>OBJECTIVE BURDEN</td>
<td>.7864**</td>
<td>.0081</td>
<td>.5742</td>
<td>-.3917</td>
<td>.5104</td>
<td></td>
</tr>
</tbody>
</table>

* = SIGNIFICANT LEVEL AT .05
** = SIGNIFICANT LEVEL AT .01 (2-TAILED)

3 - 62
correlations carried out, and since no other significant correlations occurred with this measure. If however this is a true correlation, this indicates that low factual knowledge of dementia is associated with high score on the Subjective Burden Scale; a person with little knowledge of the condition of dementia is more likely to regard caring for their relative as burdensome. Also, since the Dementia Knowledge Quiz is a questionnaire of factual knowledge of dementia, it is not surprising that this failed to correlated with self-report measures of emotional distress.

Spearman Rho Correlations were undertaken with the reported total frequency of difficult behaviours displayed by the care-recipient and the measures of caregiver distress. Positive correlations were found between level of depression and general health questionnaire and frequency of reported difficult behaviours displayed by the care-recipient. (i.e. r = .77 and r = .78 at the .01 level of significance). There was found to be no correlation between either Burden measures and frequency of reported behaviours. This may be explained by the fact that it is not the total number of difficult behaviours which cause perceived level of burden, but rather the specific nature of the behaviours which are seen to be more challenging.

CAREGIVERS’ APPRAISAL OF EDUCATIONAL SUPPORT GROUP.

The Post-Group qualitative evaluation showed that the caregivers rated their overall satisfaction of the group as 3.9 out of 5 (sd 1.60). In relation to whether the group facilitated caregivers in managing/coping as a caregiver to their relative, the caregivers rated the group as 4.3 out of 5 (sd 0.82) indicating that on average the group made caregivers slightly more able to cope and manage with caring for their relative. These details are summarised in Table 9.

Table 9: Caregivers’ Level of Satisfaction and Perceived Helpfulness of the Educational Support Group

<table>
<thead>
<tr>
<th>Satisfaction with Educational Support Group</th>
<th>Helpfulness in enabling carer to undertake Caregiving Task</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>3.9 (1.60)</td>
<td>4.3 (0.82)</td>
</tr>
</tbody>
</table>

Table 10. summarises the percentage of caregivers who found specific aspects of the Educational Support Group to be helpful or useful and that they were positively experienced by them. It can be seen that between 70 - 90 % of the caregivers found that ‘learning that their problems were not unique; learning about the availability of community resources;
finding out about the biological aspects of the disease and its subsequent affects upon their relative's behaviour; Seeing how others were handling situations similar to mine; Receiving advice or practical suggestions about how to deal with some of my problems; Feeling supported and approved of by the others in group; Finding that there were other people I could turn to for help; no longer feeling alone’ as being helpful and were scored as moderate to highly positive experiences of the caregivers’ after having been part of the Educational Support Group. In addition ‘Recognising that life was sometimes unjust and unfair'; and ‘finding someone to pattern themselves on;' were consistently rated by caregivers as not having been experienced whilst being part of the group.

Many of the other factors such as ‘Receiving encouragement to consider not only my relative's needs but also my own life and my own happiness; Expressing negative feelings, getting some things off my chest, being able to talk rather than hold it in’ were equally weighted in relation to the caregiver’s perceptions of whether or not they experienced them during the group. It should be noted that there were significant discrepancies in the frequencies of ratings of these dimensions amongst individual caregivers, reflecting a very significant individual difference amongst caregivers attending the same group.
Table 10: Qualitative Aspects of the Support Group that Caregivers Rated as Being Helpful.

| Learning that my problems were not unique; that others who face a similar situation also had experiences like mine. | 80% |
| Learning about available community resources and getting the resource guide from the individual speakers. | 70% |
| Finding out about the effects of dementia on the brain and how this affects my relative’s behaviour. | 70% |
| Getting encouragement to experiment with new ways of managing my problems. | 60% |
| Belonging; being an involved member of the group; feeling close to others. | 60% |
| Receiving encouragement to consider not only my relative’s needs but also my own life and my own happiness. | 50% |
| Seeing how others were coping and enduring was inspiring and uplifting to me. | 60% |
| Being able to express warm feelings to others in the group. | 60% |
| Seeing different ways of approaching the same problem. | 40% |
| Seeing how others were handling situations similar to mine. | 70% |
| Gaining insight into the causes and sources for the difficulties I have experienced. | 60% |
| Receiving advice or practical suggestions about how to deal with some of my problems. | 70% |
| Learning what medical science knows about senile dementia. | 60% |
| Expressing negative feelings, getting some things off my chest, being able to talk rather than hold it in. | 50% |
| Feeling supported and approved of by the others in group. | 70% |
| Learning about nursing management (such as hygiene, bowel and bladder) from the registered nurse. | 50% |
| Recognising that the tasks of caring for an impaired relative were extremely difficult for everyone. | 66.7% |
| Getting honest feedback from others about what I was doing. | 50% |
| Finding that there were other people I could turn to for help; no longer feeling alone. | 80% |
| Coming to accept the true condition of the person I am caring for and what I can and cannot do for him/her. | 60% |
| Receiving encouragement to get away from my caregiving responsibilities occasionally (take a break). | 50% |
| Revealing some of my fears and anxieties. | 60% |
| Understanding better the person I am caring for. | 50% |
| Helping others who were facing a similar situation, giving part of myself to others. | 40% |
| Receiving encouragement to get outside help in caring for my relative. | 80% |
| Specific planning or practice during the group about how to handle problems. | 70% |
| Having the chance to get out of the house to come to the group. | 70% |
| Learning new ways to think about my problems to help me control my emotions. | 40% |
| Learning that I could count on my own judgement. | 40% |
| Recognising that I must take responsibility for my own decisions and actions in this situation. | 50% |
| Understanding why I think and react the way I do. | 50% |
| Learning progressive muscle relaxation techniques. | 60% |
| Getting away from my problems for a while. | 50% |
| Seeing that I was just as well off as others. | 50% |
| Learning more about by own positive strengths. | 40% |
| Having the opportunity to receive a free home visit from the nurse for evaluation of my patient. | 30% |
| Getting a sense of hope. | 40% |
| Learning how I come across to others. | 40% |
| Recognising that life is sometimes unjust and unfair. | 20% |
| Finding someone I could pattern myself after. | 20% |
| Feeling more able to obtain help from services. | 60% |
| Feeling more able to communicate better with my relative | 30% |
| Feeling more able to manage practical issues such as lifting, bathing. | 40% |
| Feeling more able to handle financial matters and legal issues. | 70% |
DISCUSSION:
The findings from these analyses are preliminary since they reflect only the immediate follow-up results from a small sample of caregivers who have completed the Educational Support Group. The analysis of results indicated that the caregivers who participated in this evaluation study improved their 'level of knowledge about dementia' after having completed the Educational Support Group. However when compared to the Control Group this change was non significant. In relation to the other variables there were no significant changes of improvement in measures of Objective and Subjective Burden, Anxiety, Depression, or Psychological Well-being (as measured by the GHQ) after completing the Educational Support Group compared to the Control Group. Therefore one can conclude that the intervention in the form of Education Support appeared to be unsuccessful in reducing the level of emotional distress suffered by the caregiver.

Also of significance was the fact that the Caregivers who completed the Educational Support Group appeared to be experiencing a non significant increase in level of anxiety. However their level of depression remained stable. The Control Group Caregivers reported a non-significant increase in their level of depression. The increased level of anxiety in the caregivers may be explained by a number of reasons. Firstly, the information from the Educational Support Group may relieve some anxiety about the present state of the care-recipient but could also could generate stress, because caregivers become aware of what will happen to their relative and anticipate additional burdens upon themselves in the future. This probably counteracts the benefits of such groups. Secondly there has been evidence of response bias in self-report measures whereby caregivers often underreport their feelings of burden. It may well be that after caregivers were encouraged to express their feelings concerning caregiving during the Educational Support Group sessions they may have then been more likely to accurately report feelings concerning their caregiving experience after completing the group.

Although the quantitative data indicated that the group was unsuccessful in altering levels of strain, the evidence for positive efficacy of the group from the qualitative data was substantiated. This indicated that caregivers felt more able to continue in their caregiving role and that the group had facilitated this. For example, one caregiver stated that it was 'reassuring to learn that there was a physical basis to the disease and the behavioural and personality changes that they had been seeing in their spouse were not just a product of their
partner's 'wilfulness'! Further the facilitators encouraged members to maintain contact with one another outside of the group (which many continued after the group).

Another significant factor was that caregivers who had not had any prior contact with their local Alzheimer's Disease Society Branch made contact, and thus the group facilitated a continued source of further support for the caregiver to access if required in the future. This may explain the slight decrease in Objective Burden Score (i.e. increase information about practical supports such as home helps, bathing aids, home sitters etc.)

Therefore in summary it appears that albeit caregivers were subjectively satisfied with the group intervention and that they reported that it would help them better manage in their role as a caregiver, it did not lead to significant measurable changes on objective measures of caregiver functioning and well-being.

METHODOLOGICAL DIFFICULTIES:
There are potentially many reason why a treatment effect was not found. Firstly, sample size precluded detailed statistical analysis of all the variables between groups. The small number of participants, especially the control group also reduced the statistical power of detecting significant effects.

Also several methodological limitations of this study must be noted. Specific design problems included the limited applicability of random assignment, lack of credible placebo, sample size which indicates that one has to view the preliminary results with caution. These will be discussed in more detail.

This pilot study has highlighted many difficulties associated with the measurement of efficacy of treatment strategies (i.e. Educational Support Groups), particularly as a method of improving caregiver well-being. Part of the difficulty in measuring the efficacy of treatment strategies is related to the inadequate knowledge about the specific aspects of well-being that are particularly affected by the burden of caring for a person with dementia. Thus it has not been clarified as to what constitutes an appropriate set of outcome measures. Further the outcome measures chosen for this study are themselves problematic in that they may be a too 'gross measure' of psychological well-being to adequately assess the subtle impact of changes
in caregivers state after completion of Educational Support Groups. To illustrate this one can look at the GHQ which although it has high reported validity and reliability its high test retest reliability may be less sensitive to subtle changes. It may be that a time limited group intervention may not be suitable or sufficiently potent to influence global measures of psychological well-being and burden because of the multiple needs of the caregivers.

Also given that coping with caregiving is a long-term process and some of the benefits of attendance at the Group may be preventative (i.e. decreasing deterioration of the caregiver) and thus treatment effects upon these measures may only become evident later in the caregiving relationship. This study is severely limited in that data was only collated from one follow-up. However the ethical difficulties of precluding 'control' caregiver access to similar services limits the applicability of obtaining long-term follow-up data across both groups.

Nevertheless, it did appear that even after the completion of the group some change does occur. Therefore one may hypothesise that this pilot study has given further evidence to suggest the measuring of specific behavioural changes may be more productive than measuring global psychological changes or global changes in stress and burden. Also the group appeared to impact upon and influence other important dimensions of the caregiving experience such as coping skills and social support. It may therefore be more useful to measure these indices than the measures of psychological well-being or burden.

From discussing with the caregivers it also became clear that a major factor appeared to be in the reported changes in the dyadic relationship between the caregiver and care-recipient. It may be that alternative measures which measure the subtleties of such factors may help in adding efficacy to educational support group interventions. (i.e. the measurement of Expressed Emotion). However little work has been undertaken using this measure with this client group.

Also the caregivers in both the Educational Support Group and to some extent in the Control Group were quite 'heterogeneous' in their pre-treatment level of distress. This heterogeneity made it difficult for group means to show significant improvements. Individual caregivers' initial scores on the dependant measures were quite varied. As noted by many researchers some caregivers initially report few problems or symptoms on dependant measures. Consequently there is little opportunity to demonstrate improvement in a portion of the sample, leading to the possible underestimation of the positive impact of the interventions.
Also statistical probabilities increase the likelihood of regression to the mean and thus results in underestimating the impact of the intervention.

In this study measures of Subjective Burden and Depression were scores that showed great variance amongst caregivers. Although in the literature the rates of depression among caregivers are reported to be higher than in comparison samples of non-caregivers (Gallagher et al, 1989), the mean level of depression was not found to be significant amongst the caregivers of this study. This seems to be a factor in many similar studies which have shown that many people who volunteer for treatment programs initially report little or no depressive feelings (Zarit, 1990).

In addition the measure used to assess knowledge about dementia (i.e. The Revised 25-item Dementia Quiz [Gilleard & Groom, 1994]) is itself a relatively new measure and following this study has been shown to have significant limitations which may have contributed to the lack of a significant relationship between knowledge and distress. The indices of knowledge were biological knowledge, coping knowledge and service knowledge. There appeared to be problems in that there was a high range of variability amongst caregiver initial scores with some obtaining near ‘ceiling’ results. The ceiling effects make it impossible to draw definite conclusions about the relationships of knowledge and distress. Also there appeared to be some ambiguity in relation to some of the answers (i.e. multiple ‘right’ responses depending on how one reads the question) and the recent changes in the ‘benefits system’ creating ambiguity in the potential responses. Further one may also question the relative efficacy of knowledge about some questions in relation to changes in impact of burden. There is significant scope for the further development of a measure of knowledge that has more ecological validity in relation to caregiver’s difficulties with everyday caregiving.

In relation to the structure of the sample composition there are several methodological issues which need to be addressed in future studies. Firstly because participants had been self-selected into the educational groups it cannot be known how representative this group is in relation to the caregiver population at large. Research by Toseland and Rossiter, (1989) noted that participants in reported interventions are likely to be systematically different from the caregivers studied in community surveys, who are in turn systematically selected in unknown ways from the total population of caregivers. Caregivers who finished intervention studies are likely to be selected in other ways as well. People who volunteer for and stay with an intervention to the end are very likely to be those who enjoy the intervention or the leaders. This selection bias suggests that there is little point in only measuring or reporting
consumer satisfaction in intervention evaluations. However this has important implications in relation to recruitment of participants for future groups in that it does highlight that caregivers who self-select themselves for such interventions are more likely to ascertain benefit. As noted earlier attempts were made to overcome some of these difficulties by recruiting subjects through various sources. This included through the media (radio), distribution of brochures and direct contact with relevant health and aged care services. However this procedure raises the issue of self-selection bias because programme participation relies on the initiative of the caregiver to apply to the ‘intervention’.

Also the groups evaluated in this study were a heterogeneous group in that it contained different types of caregivers in terms of relationship to care-recipient and gender of caregiver. There is much evidence suggesting that the relationship to the care-receiver, and to a lesser extent gender, has an important impact on individual response to caregiving (Fitting & Rabbins 1985). According to Zarit & Toseland (1989), aggregating findings from a diverse participant pool may dilute treatment effected for specific subgroups. It may be that certain caregivers comprise a group of special needs who respond differently to psychoeducation than do other caregivers. Also there appeared to be a wide diversity in relation to the length of time caregivers had been caring for their relative. It has been shown that caregivers needs alter throughout the caregiving trajectory and thus by having a wide diversity increases the likelihood that not all caregivers needs will be adequately addressed.

A major problem which arose from this study was in relation to the construction and use of a Control Group. They are seen as essential for the determining the effects of interventions, but the rigid application of such experimental methods to treatment efficacy studies can result in questionable internal and external validity of their application.

For example, in this study, random assignment was not obtained for either group which again highlights the question of whether the Control Group was a representative sample. Also the long duration of the Educational Support Group interventions made it more likely that Control subjects obtained further assistance on their own. 

Also the effect of having to complete the questionnaires in the control group may have highlighted caregivers as to services which were available to them and enlightened them to obtain more information in their own right.

Indeed, this appeared to be the case for at least one ‘control’ caregiver who recognised that she needed more support and information regarding her husband’s illness and had contacted
the local Alzheimer Disease Society for further support and information. Therefore one can question the relative efficacy of the employment of control groups in this kind of intervention programme as these extraneous factors impinged on the reliability of their ‘Control’ status.

**Future Consideration:**

This pilot study has shown that the Educational Support Group interventions have the potential to prevent stressors from overwhelming caregivers by providing a much needed escape from the isolation of caregiving, providing the opportunity to share feelings and experiences in a supportive environment with people who share similar concerns, and most importantly by educating caregivers about the effects of chronic disabilities, informing them of community resources, encouraging a mutual sharing of information about effective coping strategies. These therapeutic benefits can make group intervention particularly appealing modality for assisting caregivers.

However the construction of such Groups as well as the methods used to assess for their efficacy continue to need careful consideration.

It is proposed that future studies should target specific subgroups of caregivers who share common issues and concerns such as ‘adult children’ or ‘spouses’. Group members often have very different reasons to attend such groups and therefore their stress levels may differ widely. However it is recognised that it is not often practical to create separate groups in intervention studies or to limit a sample to specific kinds of caregivers, but at the very least longitudinal data should be reported separately for different groups. In addition to documenting any qualitative changes in the lives of the care-recipient, data about changes in health service utilisation could be used as a basis for cost-benefit analyses of the effects of caregiver support groups.

Future research should also consider optimal intensity and duration of educational support group interventions. Research is needed to find the most effective time to undertake such educational support groups to obtain the most potency for caregivers. There is also the need for clearer specification of aims which are founded on an attainable basis. For example, a ten week educational support programme is not likely to address all aspects of strain or distress that a caregiver experiences, so it is necessary to specify which dimensions should be influenced by the intervention. Future work needs to identify the specific goals of the
intervention and the changes likely to occur rather than expecting global, non-differentiated processes of change. Some of the concrete effects of the group were that the caregivers appeared to learn more information about their relative’s illness and the care alternatives available to them and the feeling of being supported. The development of new measures or the adaptation of measures which have been used in other caregiver-care-recipient dyads may be a way of addressing these difficulties. Also longer term follow-up is also needed to explore the long term implications of attendance at such Groups.

Also, rather than allowing caregivers to self select into interventions, groups should target interventions to caregivers with specific needs. Also given the lengthy and progressive nature of dementia the services needed are likely to be different in the early, middle and late stages of a dementing illness.

However it is recognised that the practicalities of service requirements are torn between having relatively small homogeneous groups and having a large enough sample pool to justify the undertaking of an intervention.

**SUMMARY:**
Educational Support Groups may help some people in their role as caregivers for a relative with dementia. However the results of the pilot study have not supported the justification. Many conceptual and methodological problems clearly impacted upon this analysis in relation to whether Educational Group Interventions are beneficial to caregivers. However the lack of efficacy shown by this and other similar studies highlight that awareness needs to be shared with all agencies and should guide future intervention programme structures. Also the potential negative effects upon some participants (i.e. increased anxiety) should also be highlighted to emphasise and ensure that intervention programmes do not occur in isolation, but with a structured network of services which can continue to support the caregiver after completion of such Groups.

It is evident that whilst caregivers ‘needs’ are now more firmly on the agenda (reflected by the increased focus of resources towards caregivers and care-recipients) the establishment of appropriate interventions have generally been slow to develop. This appears to be largely due to the failure to specify appropriate caregiver specific outcomes (Nolan et al, 1994). Also it appears that whilst services are seeking to address caregivers needs there still is lacking the
use of an adequate theoretical framework and empirical evidence to guide and evaluate practice. This is in spite of the development of such models (i.e. Pearlin et al, 1990).

Also despite a decade of fertile research into caregiving (George 1990) it is evident that there remains a general failure of services and caregiving models to grasp the interactive and contextual nature of the caregiving relationship between caregiver and care-recipient and further investigation of this may facilitate the development of more empirically sound interventions for caregivers and care-recipients with dementia.
APPENDIX A:

SERVICE IMPLICATIONS:

Information from this research project has been collated and used as part of proposal for the further funding of a similar educational support groups for caregivers of relatives with dementia.
APPENDIX B: REFERENCES:


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APPENDIX C:

SAMPLES OF QUESTIONNAIRES AND EVALUATION SHEETS
Below are a number of statements which have been given by caregivers about their experiences of caregiving. Please could you indicate whether you have experienced such experiences, and if so, indicate the level of your distress to the incident.

<table>
<thead>
<tr>
<th>No occurrence of the experience</th>
<th>Occurrence but no distress</th>
<th>Occurrence with mild distress</th>
<th>Occurrence with moderate distress</th>
<th>Occurrence with severe distress</th>
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</thead>
<tbody>
<tr>
<td>1. My relative continues to drive when he/she shouldn’t</td>
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<td>2. I have little control over my relative’s illness</td>
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<tr>
<td>3. I have little control over my relative’s behaviour</td>
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<td>4. My relative is constantly asking the same questions over and over again</td>
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<td>5. I have to do too many jobs/chores (feeding, shopping, paying bills that my relative used to perform)</td>
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<td>6. I am upset that I cannot communicate with my relative</td>
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<td>7. I am totally responsible for keeping our household in order</td>
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<td>8. My relative doesn’t co-operate with the rest of our family</td>
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<td>9. I have had to seek use savings/allowances to use savings to pay for my Relative’s Medical care/treatment/care</td>
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<td>10. Seeking public assistance is demeaning and degrading</td>
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<td>11. My relative doesn’t recognise me all the time</td>
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<td>12. My relative has struck me on various occasions</td>
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<td>13. My relative has gotten lost in the supermarket</td>
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<td>14. My relative has been wetting the bed</td>
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<td>15. My relative throws fits and has threatened me</td>
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<td>16. I have to constantly clean up after my relative eats</td>
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<td>17. I have to cover up for my relative’s mistakes</td>
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<td>18. I am fearful when my relative gets angry</td>
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<td>19. It is exhausting having to groom and dress my relative every day</td>
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<td>20. I try so hard to help my relative but he/she is ungrateful</td>
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<td>21. It is frustrating trying to find things that my relative hides</td>
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<td>22. I worry that my relative will leave the house and get lost</td>
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<td>23. My relative has assaulted others in addition to me</td>
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<td>24. I feel so alone - as if I have the world on my shoulders</td>
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<tr>
<td>25. I am embarrassed to take my relative out for fear that he/she will do something bad</td>
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</table>
The Dementia Quiz

Please read each question carefully. For each, please circle the answer you think is correct. If you are not sure, circle 'don't know'.

Biomedical knowledge

1. Multi infarct dementia is caused by:
   (a) a series of little strokes that destroy small areas of brain cells,
   (b) several heart attacks,
   (c) increased levels of aluminium in drinking water,
   (d) excess drinking (alcoholism),
   (e) don't know.

2. How many people over 86 develop dementia:
   (a) five in a hundred,
   (b) 20 in a hundred,
   (c) 10 in a hundred,
   (d) 10 in a thousand,
   (e) don't know.

3. In its early stages dementia can be recognised by:
   (a) an inability to recognise familiar faces
   (b) inappropriate behaviour like going out in one's night-clothes,
   (c) headaches and nausea,
   (d) forgetfulness and confusion,
   (e) don't know.

4. Your chances of developing multi-infarct dementia are greater if:
   (a) you are of above-average intelligence,
   (b) you have blood circulation or blood pressure problems,
   (c) your parents or grandparents suffered from Parkinson's disease,
   (d) you are a woman,
   (e) don't know.

5. People who have never smoked or never drunk alcohol are
   (a) more likely to develop Alzheimer's disease,
   (b) less likely to develop Alzheimer's disease,
   (c) neither more nor less likely to develop Alzheimer's disease,
   (d) less likely to become senile,
   (e) don't know.

Coping knowledge

9. If your confused relative begins to wander it is best to:
   (a) not let them out of your sight so you always know where they are,
   (b) install unfamiliar locks on street doors so they won't be able to get out,
   (c) keep them in one room most of the time and only let them out with supervision,
   (d) ask the doctor to prescribe sedatives,
   (e) don't know.

10. If your elderly relative suffers from a poor memory you can help by:
    (a) constantly repeating things to them until they sink in,
    (b) provide them with memory aids such as diaries, notes and calendars,
    (c) ignore their constant questions and/or tell them it's important,
    (d) don't know.

11. If you disagree with your relative and you know you are right, you should:
    (a) argue with them till your point sinks in,
    (b) avoid confrontation by seeking something to distract them,
    (c) make your point and if (s)he doesn't agree go back to it later on,
    (d) point out that they do not understand because of their brain failure,
    (e) don't know.

12. If you find you are embarrassed by your confused relative when you go out in public you should:
    (a) simply leave your relative at home when you go out,
    (b) find excuses not to visit others and stay home,
    (c) explain to your friends and neighbours what is the matter and hope they will make allowances,
    (d) treat the matter as if nothing happened,
    (e) don't know.

13. If your confused relative follows you about all over the house it is best to:
    (a) encourage them to stay in just the one room,
    (b) always tell them where you are going and what you are going there for,
    (c) ignore them completely,
    (d) lock yourself in the toilet or bathroom to give yourself a break,
    (e) don't know.

14. If your confused relative becomes alert and agitated at night, the first thing to do is:
    (a) ask your GP to prescribe some sleeping tablets for them,
    (b) put a night light in the bedroom,
    (c) make sure (s)he has plenty of exercise during the day,
    (d) organise a break for yourself and get someone in to 'take over' once a week,
    (e) don't know.
15. If your confused relative refuses to take a bath you should:
(a) be firm and insist that they need to have a bath regularly,
(b) let the matter pass and try later on,
(c) tell them not to be silly and trust you as you know best,
(d) sponge them down in the bed the next morning,
(e) don't know.

16. If your confused relative starts to hallucinate (sees or hears things that are not there) the best thing to do is:
(a) tell them clearly there is nothing there,
(b) comfort their feelings without denying or acknowledging the hallucinations,
(c) pretend you too can see or hear them and tell them that there is nothing to worry about,
(d) ask your GP for some pills,
(e) don't know.

17. Once the elderly person receives a diagnosis of dementia you should:
(a) take over as many tasks as possible to alleviate any added mental stress,
(b) discuss with your doctor about placing the person in a home as soon as possible,
(c) encourage the person to be as independent as possible,
(d) carry on as usual and make sure the sufferer is unaware that anything has changed,
(e) don't know.

18. Details about benefits and allowances can best be obtained from:
(a) the local social security office,
(b) the tax office,
(c) the library,
(d) the surgery,
(e) don't know.

19. The district nursing service can provide help with:
(a) general household tasks and shopping,
(b) financial support and benefits,
(c) prescribing some medicines,
(d) bathing and helping a person get in or out of bed,
(e) don't know.

20. The best source to get information on legal issues affecting carers is:
(a) the library,
(b) GP surgery,
(c) Citizen’s Advice Bureau,
(d) district hospital,
(e) don't know.

21. You can obtain a list of registered nursing homes from:
(a) your local district health authority,
(b) the town hall,
(c) your GP,
(d) the post office,
(e) don't know.

22. If you need to install a downstairs toilet or replace a bath with a shower, you should contact:
(a) the GP,
(b) the council's housing department,
(c) the library,
(d) the social services department,
(e) don't know.

23. Respite care means:
(a) getting someone to come and help you at home,
(b) hospital care for those with terminal illnesses,
(c) a period of hospital or residential home admission to give carers a break,
(d) providing nursing care at the person’s home as an alternative hospital,
(e) don't know.

24. If someone arranges in advance for someone to look after their affairs should they become incapable is called:
(a) Court of Protection order,
(b) enduring power of attorney,
(c) guardianship order,
(d) an appointeeship,
(e) don't know.

25. To claim Invalid care Allowance you must:
(a) be caring for someone receiving Attendance Allowance,
(b) have savings of less than £6000,
(c) have part-time earnings of under £24 per week,
(d) be related by either blood or marriage to the invalid dependant,
(e) don't know.

Services knowledge

17.05.96 LHA DEMQUIZ
This questionnaire is designed to measure how you have been feeling recently. Read each item below and underline the reply which comes closest to how you have been feeling in the past week. Don’t take too long over your replies, your immediate reaction to each item will probably be more accurate than a long thought-out response.

1. I feel tense or ‘wound up’
   - most of the time
   - a lot of the time
   - from time to time, occasionally
   - not at all

2. I feel as if I am slowed down
   - nearly all the time
   - very often
   - sometimes
   - not at all

3. I still enjoy the things I used to enjoy
   - definitely as much
   - not quite so much
   - only a little
   - hardly at all

4. I get a sort of frightened feeling like ‘butterflies’ in the stomach
   - not at all
   - occasionally
   - quite often
   - very often

5. I get a sort of frightened feeling as if something awful is about to happen
   - very definitely and quite badly
   - yes, but not too badly
   - a little, but it doesn’t worry me
   - not at all

6. I have lost interest in my appearance
   - definitely
   - I don’t take as much care as I should
   - I may not take quite as much care
   - I take just as much care as ever

7. I can laugh and see the funny side of things
   - as much as I always could
   - not quite so much now
   - definitely not so much now
   - not at all

8. I feel restless as if I have to be on the move
   - very much indeed
   - quite a lot
   - not very much
   - not at all

9. Worrying thoughts go through my mind
   - a great deal of the time
   - a lot of the time
   - not too often
   - very little

10. I look forward with enjoyment to things
    - as much as I ever did
    - rather less than I used to
    - definitely less than I used to
    - hardly at all

11. I feel cheerful
    - never
    - not often
    - sometimes
    - most of the time

12. I get sudden feelings of panic
    - very often indeed
    - quite often
    - not very often
    - not at all

13. I can sit at ease and feel relaxed
    - definitely
    - usually
    - not often
    - not at all

14. I can enjoy a good book or radio or television programme
    - often
    - sometimes
    - not often
    - very seldom
This questionnaire is designed to assess how your health has been in general over the last few weeks. Please answer all the questions simply by underlining the answer which you think most applies to you.

HAVE YOU RECENTLY

1. been able to concentrate on whatever you're doing?
   better than usual
   same as usual
   less than usual
   much less than usual

2. lost much sleep over worry?
   not at all
   no more than usual
   rather more than usual
   much more than usual

3. felt that you are playing a useful part in things?
   more so than usual
   same as usual
   less useful than usual
   much less useful

4. felt capable of making decisions about things?
   more so than usual
   same as usual
   less so than usual
   much less capable

5. felt constantly under strain?
   not at all
   no more than usual
   rather more than usual
   much more than usual

6. felt you couldn't overcome your difficulties?
   not at all
   no more than usual
   rather more than usual
   much more than usual

7. been able to enjoy your normal day-to-day activities?
   more so than usual
   same as usual
   less so than usual
   much less than usual

8. been able to face up to your problems?
   more so than usual
   same as usual
   less able than usual
   much less able

9. been feeling unhappy and depressed?
   not at all
   no more than usual
   rather more than usual
   much more than usual

10. been feeling reasonably happy, all things considered?
    more so than usual
    about same as usual
    less so than usual
    much less than usual

11. been losing confidence in yourself?
    not at all
    no more than usual
    rather more than usual
    much more than usual

12. been thinking of yourself as a worthless person?
    not at all
    no more than usual
    rather more than usual
    much more than usual
## EVALUATION QUESTIONNAIRE:

Below are a number of statements which other carers have reported about their experience after having attended a support group.

<table>
<thead>
<tr>
<th>Statement</th>
<th>No I did not experience this</th>
<th>Yes slight experience of this</th>
<th>Yes moderate experience</th>
<th>Yes extremely positive experience</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Learning that my problems were not unique; that others who face a similar situation also had experiences like mine.</td>
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<td>2. Learning about available community resources and getting the resource guide from the individual speakers.</td>
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<tr>
<td>3. Finding out about the effects of dementia on the brain and how this affects my relative's behaviour.</td>
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<td>4. Getting encouragement to experiment with new ways of managing my problems.</td>
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<td>5. Belonging; being an involved member of the group; feeling close to others.</td>
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<tr>
<td>6. Receiving encouragement to consider not only my relative's needs but also my own life and my own happiness.</td>
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<td>7. Seeing how others were coping and enduring was inspiring and uplifting to me.</td>
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<td>8. Being able to express warm feelings to others in the group.</td>
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<td>9. Seeing different ways of approaching the same problem.</td>
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<tr>
<td>10. Seeing how others were handling situations similar to mine.</td>
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<tr>
<td>11. Gaining insight into the causes and sources for the difficulties I have experienced.</td>
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<tr>
<td>12. Receiving advice or practical suggestions about how to deal with some of my problems.</td>
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<td>13. Learning what medical science knows about senile dementia.</td>
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<tr>
<td>14. Expressing negative feelings, getting some things off my chest, being able to talk rather than hold it in.</td>
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<tr>
<td>15. Feeling supported and approved of by the others in group.</td>
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<td>16. Learning about nursing management (such as hygiene, bowel and bladder) from the registered nurse.</td>
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<tr>
<td>17. Recognising that the tasks of caring for an impaired relative were extremely difficult for everyone.</td>
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<tr>
<td>18. Getting honest feedback from others about what I was doing.</td>
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<tr>
<td>19. Finding that there were other people I could turn to for help; no longer feeling alone.</td>
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<tr>
<td>20. Coming to accept the true condition of the person I am caring for and what I can and cannot do for him/her.</td>
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<tr>
<td>21. Receiving encouragement to get away from my caregiving responsibilities occasionally (take a break).</td>
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<tr>
<td>22. Revealing some of my fears and anxieties.</td>
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<td>23. Understanding better the person I am caring for.</td>
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<tr>
<td>24. Helping others who were facing a similar situation, giving part of myself to others.</td>
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<td>25. Receiving encouragement to get outside help in caring for my relative.</td>
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<td>26. Specific planning or practice during the group about how to handle problems.</td>
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<td>27. Having the chance to get out of the house to come to the group.</td>
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<tr>
<td>28. Learning new ways to think about my problems to help me control my emotions.</td>
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<td>29. Learning that I could count on my own judgement.</td>
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<tr>
<td>30. Recognising that I must take responsibility for my own decisions and actions in this situation.</td>
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<td>31. Understanding why I think and react the way I do.</td>
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<td>32. Learning progressive muscle relaxation techniques.</td>
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<tr>
<td>33. Getting away from my problems for a while.</td>
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<tr>
<td>34. Seeing that I was just as well off as others.</td>
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<td>35. Learning more about my own positive strengths.</td>
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<tr>
<td>36. Having the opportunity to receive a free home visit from the nurse for evaluation of my patient.</td>
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<td>37. Getting a sense of hope.</td>
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<td>38. Learning how I come across to others.</td>
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<tr>
<td>39. Recognising that life is sometimes unjust and unfair.</td>
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<tr>
<td>40. Finding someone I could pattern myself after.</td>
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</table>
Overall satisfaction with the group

1  2  3  4  5
not at all satisfied extremely satisfied

Overall helpfulness of the group in relation to managing/coping in your role as a caregiver of your spouse

1  2  3  4  5
has made me significantly less able to cope and manage with caring for my spouse
has made me slightly less able to cope and manage with caring for my spouse
has made no difference in how I cope and manage with caring for my spouse
has made me slightly more able to cope and manage with caring for my spouse
extremely helpful to me and I feel much more able to cope and manage with caring for my spouse

Any other additional comments:
EXPRESSED EMOTION, BURDEN, AND COPING IN SPOUSAL CAREGIVERS
CARING FOR A PARTNER WITH DEMENTIA
ABSTRACT:
Expressed Emotion (EE) is a well-known concept that has been extensively used in the study of caregivers of people with Schizophrenia. It has been used with other populations and found to be a useful indicator of risk in relation to the adjustment of families to an ‘ill’ family member. This study of spousal caregivers caring for partners with a dementia aimed to examine the relationship of EE levels in caregivers to aspects of the circumstances of their relationship, measured by their level of burden, impact on their physical and mental health, caregivers’ perceptions of level of care-recipient cognitive, and behavioural functioning. This was further investigated in relation to whether this was mediated by specific coping strategies and their perception of their affective attitude towards their partner. Attempts were also made to discover whether spouse caregivers perceived in themselves EE attitudes similar to those assessed by external raters using a standardised measure of expressed emotion.

A randomised selection of caregivers were recruited from a variety of agencies within a local community. 32 spousal caregivers agreed to participate in the study. The average age of spousal caregiver was 70.9 years (sd 8.40) with the average age of care-recipient being 72.06 years. (sd 7.94). A structured Caregiver’s Interview Schedule which had been designed especially for this study collated caregivers’ and their care-recipients’ demographic and social information. Care-recipients’ physical, cognitive and behavioural impairment was assessed by caregivers using the Behaviour and Mood Disturbance Scale (BMD) (Greene et al, 1982) and the Bathel ADL Scales (Mohoney & Barthel, 1965). The 28-Item General Health Questionnaire (GHO) [Goldberg, 1978] was used to measure caregivers’ psychological morbidity. Caregiver burden was assessed using the Screen for Caregiver Burden: (SCB) [Vitalino et al, 1991]. The Five Minute Speech Sample (FMSS) [Magaña et al, 1986] was used to assess Expressed Emotion (EE). This data was categorised into high EE or low EE based on the categorisation of Magaña et al, (1990). The Adjective Checklist [Friedmann & Goldstein, 1994] was used to ascertain caregivers awareness of their emotional expression. The Coping Responses Inventory (CRI) [Moos, 1990] (Part II) was administered to ascertain the types of coping responses used by caregivers in managing their caregiving role.

A number of planned correlations were undertaken to investigate the relationship of expressed emotion and caregiver distress. Categorisation of caregivers by EE scores using the EE-hostility criteria were undertaken using the dichotomised cut-off scores of high-EE and low-EE as proposed by Magaña et al, (1986). 17 caregivers (53.1%) were rated as high-EE (critical) and 15 caregivers (46.9%) as low-EE. Analysis of the data revealed a non-significant difference
between the low and high EE groups for the rating of Objective Burden. However there was a significant difference between caregivers rating of subjective burden (U = 45.0 p < 0.002).

Analysis of individual coping strategies between high-EE and low-EE caregivers revealed a statistically significant difference between high-EE caregivers use of Emotional Discharge as a mechanism for coping when compared to low-EE caregivers.

Separating the caregiver spouse group into different grouping variables revealed that there were no significant differences between groups when analysed by younger or older onset dementia criteria, reflecting that differences between caregivers may be better assessed by caregiver stress measures, rather than by classification by caregiver age.

The relationship between self-ratings of affective response and EE was assessed by comparing the adjective ratings and the FMSS-EE ratings. A series of two-tailed Mann-Whitney U tests were conducted to address the question of whether relatives in the FMSS-EE groups differed with respect to their adjective ratings. Spouse caregivers in the high EE-critical and low-EE groups did not statistically differ in their adjective ratings when describing their negative behaviour toward their care-recipient partner (i.e. high-EE caregivers:- mean = 2.58 [sd 1.56]; low-EE caregivers:- mean = 2.57 [sd 1.65]; U = -.60, p > .05). Also, when describing their care-recipients' negative behaviour towards them, the caregivers' did not differ significantly in their ratings of negative behaviour by FMSS-EE groupings. (i.e. high-EE caregivers:- mean = 3.17 [sd 1.92]; Low-EE caregivers:- mean = 3.07 [sd 1.81], U = -.36, p > 0.05). Spouse caregivers in the high-EE (critical) and low-EE Groups did not differ in their ratings of positive adjectives when describing their own behaviour toward their care-recipient. (i.e. high-EE caregivers:- mean = 6.24 [sd 1.59]; low-EE caregivers:- mean = 5.93 [sd 1.75]; U = -1.53, p < 0.05). However, when describing the care-recipient's behaviour toward them there was a significant difference in the positive adjective ratings by FMSS-EE groups (i.e. high-EE caregivers: mean = 4.09 [sd 2.00]; low-EE caregivers: mean = 4.67 [sd 1.71]; U = -2.87, p > 0.01).

This present study draws attention to the issues surrounding spousal caregiving and the difficulties associated in methodological design in conducting field research in this area. The findings emphasised the need to investigate caregiver distress upon a number of contrasting variables. This study has reinforced the need to move beyond the behavioural and instrumental dimensions alone since the quality of the relationship between that care-recipient and their spouse appears to be a crucial determinant in predicting caregivers ability to continue to provide home care.
SECTION I: CAREGIVING AND ITS CONSEQUENCES UPON CAREGIVERS.

INTRODUCTION:
In Great Britain, it has been estimated that there are about 600,000 dementia sufferers (Morris et al., 1991). Dementia is not a disorder in its own right, rather a syndrome or a grouping of symptoms which can be manifested in variable combinations. It is often characterised by a progressive loss of mental abilities accompanied by changes in behaviour and a gradual loss of the skills needed to carry out ordinary daily activities (Weiner, 1991; Alzheimer's Disease Society, 1996). Dementia has been classified by the World Health Organisation as 'a progressive and irreversible global impairment of higher cortical functions, including memory, the capacity to solve the problems of day-to-day living, the performance of learned perceptuo-motor skills, the correct use of social skills and control of emotional reactions, in the absence of gross 'clouding of consciousness' (Alzheimer's Disease Society, 1993). In addition to the cognitive symptoms there are reported to be a number of non-cognitive features of dementia (NCF’s) which are a heterogeneous group of symptoms, comprising of psychotic symptoms (e.g. hallucinations & delusions), depressive features (e.g. sadness, and lack of interest) and behavioural disturbances (e.g. aggression & wandering) (Martinson et al., 1995). A key feature of caring for a person with dementia is the progressive decline in the relationship with that person, associated with the cognitive and behavioural deterioration of the dementia sufferer (Morris et al., 1988b; Burns et al., 1990).

IMPACT OF CAREGIVING:
As briefly reviewed in the earlier study (Adams, 1997) the literature highlights that eighty percent of people with dementia are living at home with either their spouse or another family member with families undertaking a pivotal role in the long term care of relatives with dementia. Indeed, family support has been suggested as being the most crucial factor in determining continuing life in the community for sufferers of dementia (Brodaty et al., 1990; Drapper et al., 1995; Fuller-Jonop & Haley, 1995; Schultz et al., 1990; Zarit, 1994). Numerous research articles have concluded that caregiving can be a rewarding but demanding experience (Toseland & Rasch 1980; Jones & Miesen, 1992). The psychological, emotional and physical impact upon relatives caring for dementia sufferers in the community has been extensively studied over the past 10 years and as George (1990) has verified, the research literature on family caregiving has grown both in 'volume and sophistication'. Yet despite this 'decade of fertile effort' there remains much to be learned about caregiving and dementia at both a
conceptual and empirical level (Kahana & Young, 1990; Keady & Nolan, 1994; Adams, 1996). While there is widespread agreement that caregiving is stressful, no consensus has emerged about the best way to demarcate the impact of stress upon family caregivers. The increasingly recognised methodological and conceptual difficulties of previous research has been exacerbated by a considerable degree of semantic confusion as to what is meant by ‘stress, strain and burden’ (which will be expanded upon in a later section) and has resulted in the ‘decrying’ of the continued explosion of research studies (i.e. Zarit, 1989b), especially of those that do not deepen theoretical understanding. Paradoxically however, the need for a well-grounded clinical strategy founded upon a robust empirical basis has never been greater in the United Kingdom, since family caregivers now have the statutory right to a separate assessment of their needs (Keady, 1996) which theoretically implies that there are interventions which are able to be offered to support those caregivers who are struggling in their caretaking role. Thus this has renewed attempts to understand the process of caregiving.

**MODELS OF CAREGIVING**

The development of a number of models to explain the ‘caregiving phenomenon’ have recently been presented to facilitate the identification and understanding of the interrelationship of the many factors that impact upon caregiving (Pearlin, et al, 1990; Kahana & Young, 1990). In recognition of this, the following research paper has selectively drawn upon a theoretically rigorous conceptualisation of caregiving based on a ‘transactional model of stress’ as proposed by Pearlin, (1994) which incorporates many of the key components involved in caregiving. Further this model has increasingly been postulated as the basis for future clinical research and intervention with caregivers and care-recipients (Woods et al, 1997; Moniz-Cook & Agar, 1997).

**A STRESS-PROCESS MODEL OF CAREGIVING.**

The theoretical model advanced by Pearlin et al, (1990) views stress as a “dynamic process unfolding over time encompassing four separate but dynamically related domains of caregiver stress framework each of which subsumes a number of components or dimensions”

These four dimensions are:

- the stressors,
- the manifestations of stress,
- the mediators of stress, and lastly
- the background and context of stress.

The conceptual detail of each of these domains will be described in more detail as they pertain to the present research questions. (see Figure 1)
Figure 1  THE STRESS-PROCESS MODEL OF CAREGIVING

[Adapted from Pearlin, 1994]

OUTCOME PATTERNS

PSYCHOLOGICAL
PHYSICAL
SOCIAL

MEDIATORS
(resources)

COPING

SOCIAL SUPPORT

PRIMARY STRESSORS

OBJECTIVE

SUBJECTIVE

SECONDARY STRESSORS

ROLE STRAINS

INTRAPSYCHIC STRAINS

BACKGROUND & CONTEXTUAL FACTORS

3 - 93
Stressors
Stressors originate from two general sources:- Primary Stressors and Secondary Stressors. PRIMARY STRESSORS are stressors emerging directly from the care-recipient’s care and can be divided into i. Objective Stressors which are anchored directly in caregiving activities (e.g. washing) or care-recipient characteristics (e.g. level of cognitive impairment or types of non cognitive features such as hallucinations or behavioural disturbance) and ii. Subjective Stressors which include overload, deprivation and loss (Boss et al, 1988; Wuest et al, 1994). Several research studies have examined the relationship between activities of daily living limitations (i.e. self-care problems) and caregiver burden. Most papers did not report a significant independent relationship between these variables (e.g. Yeatman et al, 1993) but Harper & Lund, (1990) found that ADL limitations predicted burden in female caregiver but not in males. In summary, the findings indicate that in heterogeneous samples of caregivers the severity of dementia (as identified in the amount of physical care required, or level of cognitive decline) has not been found to be simply related to levels of stress outcome shown in caregivers (Pearlin et al, 1990; Cantor, 1983; George & Gwyther, 1986; Baldwin, 1994; Grafstrom et al, 1994a).

In contrast, a review of research conducted by Donaldson et al, (1997) highlighted that most studies (with the exception of Zarit et al, 1985) which had investigated aspects of non-cognitive disturbances (NCF’s) found that these behaviours were related to caregiver stress (Lawlor, 1994). Several studies have been cited by Donaldson et al, (1997) that report NCF’s to be the strongest correlate to the measurement of caregiver burden (e.g. Gilleard et al, 1984; Greene et al, 1982; Harper & Lund, 1990; O’Conner et al, 1990; Drapper et al, 1995; Farran et al, 1993; Chappell & Penning, 1996). Some studies have measured subcategories of NCF’s separately and demonstrated differential relationships with burden. For example Green et al’s (1982) and LoGudice et al’s study (1995) suggest that deficits of behaviour (i.e. withdrawal, apathy) are more closely related to carer burden than excesses of behaviour (i.e. hoarding, sleep disturbance).

In relation to cognitive deficits in patients (i.e. memory loss, visuo-spatial disturbances) the research presents an equivocal picture. Some studies have shown a non-significant correlation between these variables (Zarit, 1986; Farran et al, 1994; Huckle, 1994), although other studies have shown some associations with caregiver burden (O’Conner et al, 1990).
In summary, the relationship between non-cognitive features and outcome appear to be significant together with a weak relationship with cognitive problems.

**SECONDARY STRESSORS** are stressors that are in the domains other than caregiving but arise from or are exacerbated by the caregiving demands. These can be divided into i. *Intra psychic strains* such as problems due to perception of and feelings about self, (e.g. self esteem, mastery), and ii. *Role Strains* which are caused by enduring problems experienced as an incumbent of a particular role or status (e.g. family conflict, job-caregiving conflict). This can also incorporate the feeling of role captivity which is a quality of being and acting in one role while wanting to be and act elsewhere, yet feeling there is no easy way to extricate oneself from that role (Skaff et al, 1996; Aneshenel et al, 1993). As Pearlin et al, (1989) observed persistent role strain can confront people with "...dogged evidence of their own failures, or lack of success and with inescapable evidence of their inability to alter the unwanted circumstances of their lives."

**Outcomes**

There is substantial literature documenting the stressfulness of caregiving for a family member with a dementing illness. Concepts used to identify the consequences of caregiving upon caregivers have focused on outcomes such as burden (e.g. Zarit et al, 1986), psychological well-being (e.g. George & Gwyther, 1986), distress (e.g. Vitalino et al, 1989) and impact (e.g. Orbell et al, 1993). Pearlin's model conceptualises caregiver outcomes within three key domains of 'caregiving consequences': *Psychological, Physical, and Sociological*. In an attempt to elucidate the specific physical, social and psychological effects of caregiving a brief review of this literature will be undertaken:

**Psychological**

*Burden*: - Caregiver burden has been defined as "the physical, psychological or emotional, social and financial problems that can be experienced by family members caring for an impaired relative" (George & Gwyther, 1986). The quotation emphasises that 'burden' can been examined and conceptualised in several different ways (Talkington-Boyer & Synder, 1994; Fadden et al, 1987; Kosberg et al, 1990). Consequently, this has resulted in 'burden' being used as an umbrella term that can apply to variety of factors which impact as a result of caregiving and therefore the absence of a uniform definition makes retrospective analyses of research studies difficult. Historically, Grad & Sainsbury, (1963) were the first to acknowledge the impact or 'burden' felt by caregivers of people with mental illness and the
suggested explication of objective and subjective burden. Objective burden is related to the impact of concrete events and activities resulting from caregiving whilst subjective burden refers to feelings, attitudes and emotional reactions to the caregiving experience (Montgomery et al, 1985). Thus the ‘burden’ experienced by family members appears to be mediated by whether the caregiver perceives the actual stressor as problematic. That is, the caregivers subjective experience is the major variable in determining the level of burden (Zarit et al, 1986; Mangone et al, 1994; Grafstrom et al, 1994b).

**Psychological Well-Being:** In Europe, (especially in Britain) and Australia most outcome studies have tended to examine ‘psychological well-being’ rather than ‘burden’ (Schulz et al, 1995). Most of these studies have used standardised self-report inventories to measure psychiatric symptomology such as depression together with more broadly-based self report instruments to assess psychiatric caseness, such as the General Health Questionnaire - GHQ (Goldberg, 1978). Incidence of depression in particular has been reported to be more likely amongst caregivers of dementia relatives when compared to population norms and other caregivers caring for relatives with physical illnesses (Zarit et al, 1987; George & Gwyther, 1986; Boss et al, 1990; Schultz & Schultz, 1990; Lawton et al, 1991; Schulz & Williamson, 1991; Baumgarten et al, 1992; Clipp & George, 1993; Coope et al, 1995). A review of the literature by Gallagher-Thompson et al, (1992) reported rates of depression among caregivers of care-recipients with dementia ranging from 14% to 47% in various samples. Further, spouse caregivers appear to be particularly susceptible to stress and depression (George & Gwyther, 1986). Using a cross-sectional design, a comparison of spousal caregivers and 86 non-caring spousal subjects (matched on age, sex, and education) found the stress of caregiving had given rise to a greater cumulative incidence of depressive symptomology during the caregiving period than during the same time period in controls. Gallagher-Thompson, et al’s (1992) study of 35 spousal caregivers of dementia patients in USA (mean age 62; 68.5% Female) investigated level of depression using the BDI and correlations of caregivers factors. The mean depression score was 7.17 with no correlations found between depression score and other factors. In addition caregivers have been reported to be suffering from chronic fatigue, anxiety and anger (Rabins, 1994). In the study by Kiecolt-Glaser et al, (1991) 69 spousal caregivers (mean age 67.5; 75% female) and 69 non-caregiving comparison subjects were assessed using a number of psychological measures over two time periods and showed that 25% and 32 % of caregivers met the criteria for a depressive disorder as measured by the Hamilton Depression Rating Scale (HDRS) [8.07 and 6.73] at the first and subsequent assessments respectively, compared to 0% and 6% of control subjects. In Britain,
Gilleard et al’s, (1984) study used the GHQ to assess for psychiatric symptomology in caregivers. He found that between 57% and 74% of participants in three different samples of caregivers scored above the scale’s cut-off for psychiatric caseness. This compares to prevalence rates in community samples of 16-22% (Goldberg, 1978). Also an additional 10% of caregivers were found to meet clinical criteria for anxiety. Other studies have reported the increased incidence of anxiety within dementia caregiver populations. For example Gallagher-Thompson et al’s, (1989 & 1992) studies also found that cognitive and behavioural problems in care-recipients were highly correlated with anxiety. However the reported incidence of anxiety in the literature is ambiguous. For example, Ungerson’s (1993) study assessed cognitive and daily living effects in care-recipients and found no significant associations between these symptoms and anxiety in caregivers.

Physiological

As cited by Donaldson, (1997) there has been a significant focus of the caregiving impact on the health functioning of caregivers. It has been hypothesised that the physiological status such as immuniolgical functioning may be altered by affective states (such as depression) created within the caregiver (Schulz & Williamson, 1994). Deimling & Bass, (1986) reported that ADL limitations had the strongest direct effect upon caregivers physical health. Immuniolgical functioning in relation to its suppression, may also be altered by these affective states, which may increase the susceptibility of the caregiver to physical illness (Lieberman & Fischer, 1991). Also, reflecting the large literature linking stress to physical illness (i.e. respiratory disease and hypertension), it has been shown that caregivers’ higher incidence of physical illness may be related to their chronic exposure to stress. Gafstrom et al, (1994) cites from Hayley et al’s (1987) study, which reported that from a sample of 44 primary caregivers of dementia care-recipients, 72% rated their health as poorer overall than a control group of non-caregivers. Further there was increased reporting of chronic illnesses, and increase use of psychotrophic medication (i.e. antidepressants). However this small-scale correlational study and a similar study by Brodaty & Hadzi-Pavolic, (1990) did not find significant relationships between specific care-recipient variables and caregiver health. Other studies have shown that caregivers of elderly people with dementia had poorer self-perceived health than controls, reported more somatic complaints more frequently suffered from chronic diseases and had poorer quality of sleep (Grafstrom et al, 1994; Pruchno & Potashnik, 1989; Hooker et al, 1992; Baumgarten et al, 1994).
Sociological
The multiple demands of caregiving have been conclusively reported to put caregivers at risk of social isolation (Gilhooley et al, 1994). Two key large scale studies by Deimling & Bass, (1986) and Pruchno & Potashnik, (1989) noted that ADL limitations and disruptive behaviours had adverse direct effects on caregivers social participation. From these findings it is evident that caring for a relative with dementia restricts the social and recreational activities of caregivers. This is because caregiving is associated increased labour intensive activities (i.e. ADL problems) and also due to the need to undertake supervisory requirements (i.e. to monitor wandering etc.). It can be easily seen that the resultant unmet personal and interpersonal needs (subjective burden) brought about by loss of social contact rather than physical or operant demands (objective burden) associated with caregiving is seen as the most devastating to a caregiver’s sense of well-being (Fisher & Lieberman, 1994).

Stress Mediator Factors:
It can be seen that caregivers who provide support and care to their spouse with dementia struggle with a multitude of stressful demands (Morgan & Laing, 1990; Pearlin et al, 1990; Zarit et al, 1985). However a review of the literature highlights that there is considerable variance in adaptation to the caregiving role amongst caregivers, with many adapting quite well to their role. This has led to the attempt to identify mediating variables which might influence the caregivers emotional response (Morris et al, 1988b; Morris et al, 1989b).

Within Pearlin’s model of caregiving there have been identified key mediators of stress which have the capacity to influence the direction of the stress process and to blunt its impact on the caregiver. These key constructs which have been postulated to explain why caregivers in similar circumstances show great variability in managing their stress have been identified as coping and social support. To date, a number of studies have examined the ways that caregivers of persons with dementia cope with these stressful demands and the impact of social support upon this outcome (Pearlin et al 1990; Williamson & Schulz, 1993).

Coping
A general theory of stress and coping as postulated by Lazarus & Folkman, (1984) known as the ‘process model of stress and coping’ has been extensively used in research into caring and has been incorporated into Pearlin’s Model. (see Figure 2) A fundamental theoretical assumption in stress and coping research is that under comparable stress, coping strategies
differentiate individuals who become psychologically distressed from those who do not (Folkman & Lazarus, 1984; Billings & Moos, 1982; Patterson et al, 1990). The model advocates the role of intra-personal and socio-ecological factors in mediating the effects of stress and conceives the individual as 'actively' and 'creatively' seeking to manage the stressors as they are encountered (Brody, 1990; Hooker et al, 1994).

Figure 2  THE PROCESS MODEL OF STRESS AND COPING:

(Adapted From Lazarus & Folkman, 1984)
The advantage of incorporating Lazarus & Folkman’s model within Pearlin’s model is that it is a general model of stress and coping and not specific to families caring and therefore has been able to draw upon a wealth of information from many sources as it is now acknowledged as the most comprehensive model of stress and coping and adjustment (Cohan et al, 1990; Coppell et al, 1985).

In relation to caregiving, this coping model views coping as a process that can mediate and moderate the effects and impact of the demands caregivers confront on their psychological and emotional well-being (Brashares & Catanzaro, 1994). Therefore determining the coping strategies that are associated with psychological adjustment to the multifaceted demands of dementia caregiving is important for both theoretical and practical reasons. Lazarus and Folkman, (1984) defined coping as “the process of managing demands (external or internal) that are appraised”. As cited by Pearlin et al, (1989) the definition encapsulates four key concepts. First, coping is a process or ongoing complex interaction between an individual and the environment. Second, coping is viewed in terms of management as opposed to mastery (i.e. a realistic view of stress is taken in that it recognises that not every problem can be mastered). Third, the definition includes the notion of appraisal. The development of this model encapsulates a cognitive perspective which emphasises subjective appraisal in that it focuses on how the individual “perceive, interpret and cognitive represent the phenomena”. Thus a situation is only stressful if perceived as such. The appraisal is mediated by situational and personal factors. Finally, coping is a mobilising of effort. It includes both “cognitive and behavioural efforts to manage (reduce, minimise, master or tolerate) the internal and external demands of the person-environment transaction that it appraised as taxing or exceeding the person’s resources” (Lazarus & Folkman, 1986). The general psychological literature has consistently shown that coping resources account for variance in psychosomatic complaints and psychological distress (e.g. Cobb, 1976; Vaughn & Leff, 1976) and the availability of resources affects the appraisal of the event or situation and determines which strategies individuals can use.

The cognitive style and coping mechanisms used by caregivers have been recent areas of research interest. A number of studies have looked at the relationship between caregivers attributions about their caregiving role and their stress levels, with studies showing that coping strategies thought to be ineffective or maladaptive (e.g. avoidance or passivity) are usually related to increased distress (Matson, 1995). For example, there is much evidence that high levels of stress coupled with inadequate coping serve as a mediating variable for various.
psychiatric symptoms the most frequently cited as being depression (Toseland & Rossiter, 1989; DeLongis & O'Brien, 1990). Conversely strategies thought to be effective or adaptive (e.g. problem solving, seeking social support) are not related to distress. Several researchers have examined the coping strategies employed by caregivers. Increasingly the focus has been examining the range and variety of coping strategies employed in relation to the experience of stress and burden. The findings reveal that various coping responses are associated with lower levels of caregiver depression and burden, and with higher levels of life satisfaction and self-reported health (Gilhooley, 1994; Garwick et al, 1994). In an effort to provide more effective coping skills for family caregivers, Levine et al, (1983) surveyed coping skills used by caretakers who differed in the amount of role strain. Although the findings were not desegregate by spouse and offspring caretakers or by gender, those best able to cope with caretaking demands attempted specific strategies for solving such caretaking problems as wandering or improving capacity for self care. This research has important implications since it suggests that attempts by reducing carers distress may increase their willingness to continue providing care even without any reduction in the objective problems (Gilleard, 1987).

Discussing the techniques used by caregivers for adapting to caregiving demands of dementia relatives, Johnson, (1983) reported a high frequency of either psychological distancing from the patient or the opposite pattern in which the patients relative become totally involved in the caretaking, withdrawing from other relationships and focusing all remaining energy on the patient. However this coping strategy may lead to withdrawal from the very community resources that might be particularly helpful for both the patient and caregiver in the relief of strain, ultimately increasing family stress (Levine et al, 1983). The possible range of coping responses in a given stressful encounter is very diverse, and only recently have efforts been directed at trying to categorise coping activities descriptively. In relation to the efficacy or 'adaptiveness of coping strategies there have been many types of studies. Although earlier accounts were extremely subjective most classification schemes include the distinction as proposed by Folkman & Lazarus between ‘approach-focused’ coping and ‘emotion-focused’ coping. This work will be reviewed in more detail.

Coping strategies are actions, behaviours and thoughts used to deal with a stressor (Levine & Folkman, 1984). They have two functions: emotion-focused (avoidance) coping and problem-focused (approach) coping.

Emotion-Focused Coping:- This avoidance coping serves to ease the painful or distressing emotions resulting from the stressor. These coping efforts are directed at the somatic level
and/or level of feelings. For example, the use of tranquillisers and relaxation techniques are examples of coping strategies directed at the somatic level of emotional distress. The function of these strategies are to reduce the physical sensations of being stressed. Emotion-focused coping aims to change the emotional state. Watching the television, reading a book having fun with friends are examples of such strategies.

**Approach Coping**:- This problem solving coping action can be directed internally and/or externally which is aimed to alter the 'troubled person-environment relation causing the distress (Lazarus & Folkman, 1984). Problem-focused coping directed at an external source of stress includes strategies such as using negotiation to resolve an inter-personal conflict, asking for practical help. Internally directed problem-focused coping includes cognitive restructuring (i.e. redefining the stressor and mentally challenging irrational beliefs).

The negative impact of caring in relation to specific caregivers coping strategies has increasingly been investigated within the literature. For example, in a study of spouse caregivers, Morrisey et al, (1990) investigated the extent to which patient disability level and caregivers external coping resources impacted upon the marriage work and recreational pursuits of spouses. The mean age of the caregivers was only 64.7 with over 50% employment at the time of the survey. The level of the care-recipient’s physical independence was the strongest predictor of the caregivers perceived negative impact of their spouses disease upon the marriage and caregivers recreational pursuits. Also the level of depression in non-employed caregivers correlated inversely with the size of their non-kin social network indicating that non-family contacts were used as a resource of coping support.

**Social Support**
As reflected in the aforementioned research study, another important factor within the ‘mediator’ component of Pearlin’s model comprises ‘Social Support’. It has been shown that the ‘type’ and the ‘amount’ of family and social support experienced by the caregiver has been shown to be a buffer from the burden of the caregiving role. Indeed it has been argued that health providers should be working to enhance existing social support networks in order to promote the well-being of the caregiver (Morris et al, 1989a; Zarit & Toseland, 1989). Social Support has been identified as an important source of feeling of control, both in terms of the reflected appraisals of one’s performance and the assistance provided that increases the ability to overcome difficulties (Krause, 1990; Krause & Keith, 1989). It has been described that as the demands of caregiving begin to infiltrate and expand in the caregivers life, (a process known as role engulfment), there may be an attenuation of contact with other people,
thus limiting the sources of support and positive feedback that might help nurture feelings of well-being. Shrinkage of support may begin with the deterioration of the care-recipient spouse who often has been an important source of social support before the onset of illness. However, a simple hierarchical relationship between higher level of formal and informal support has not been found. For example, Gilleard (1987) reported reduced stresses level among caregivers attending day hospital placement but Morris et al, (1986a) reported a positive relationship between strain in caregivers and levels of informal support from health and social services. Early work by Zarit et al, (1980), suggests that the social network may influence the caregivers level of burden. They further reported that frequency of contact with relatives were negatively related to uni-dimensional burden measures. Studies of the role of social support in ameliorating caregiver burden have led to inconclusive results (Gilleard et al, 1984). It is notable that in Gilhooly’s (1994) study, caregivers’ satisfaction of received help from other relatives was correlated with the caregivers own mental health, whilst the availability and use if support was not. These findings suggest that it is the quality of the social support as perceived by the caregiver that best predicts caregiver psychological adjustment. Therefore it can be seen that the role of social support in ameliorating caregiver burden has inconclusive findings (Gilleard et al, 1984; Zarit et al, 1980). Studies of the role of social support suggest a relatively weak association between psychological adjustment of the caregiver and caregiver support. This may be accounted for the use of a number of definitions used to differentiate and define the support systems and networks.

Background and Contextual Factors:
Within Pearlin’s model the whole stress process is set within individual background and contextual factors such as the social and economic characteristics of caregiver (e.g. relationship of caregiver to patient, gender, occupational status, economic class, ethnicity, age, and caregiving history). These are fundamentally important aspects to the entire stress process, since these kinds of attributes are markers of people’s locations in larger social systems and their links to social institutions. They are also indicative of access to power and resources. They act upon each and affect the stress process at each of its junctures; by differently exposing caregivers to different stressors, by shaping coping repertoires, social support systems and other mediating forces and by channelling people toward different stress outcomes (Pearlin et al, 1989; Pearlin, 1994). Two of these key factors which are important to the present study will be expanded upon in more detail:

Gender:— There has been some research to suggest that female caregivers generally report higher levels of strain and depressive symptoms than their male counterparts (Harris, 1993).
Researchers have reported differences in responses to adult day care, reactions to illness and health attitudes. Gender differences have also been documented in use of formal and informal supports, and in the coping behaviours of caregivers with women reported to use less adaptive coping mechanisms (i.e. avoidance coping). Women’s subjective reaction to caregiving tend to be more negative than those of men. Women report higher levels of burden and psychological distress associated with caregiving (Zarit & Zarit, 1982) and report more negative physical and mental health consequences associated with this role (Barusch & Spaid, 1989; Barber & Pasley, 1995).

Relationship of caregiver and care-recipient: The nature of the relationship between the relative and care-recipient has been extensively studied. The general conclusions have shown that the closer the blood/role relationship, the more stressful caregiving becomes (George & Gwyther, 1986). Spouses of people with dementia reported greater burden, especially due to their limitations in their social functioning, higher levels of depressive symptomology and physical symptoms when compared to adult children. Moreover it has been well-established that spouses very often (particularly elderly spouses) do not construe what they do for their dependant spouses as ‘care’, since they understand the rules of marriage as in themselves implying that they are ‘carers’ throughout the period of marriage (Ungerson, 1993).

In summary Pearlin et al’s (1990) model attempts to unify previous research findings on the mediating variables and gives an overview systems scheme of the relationships between background factors, secondary and primary stressors, intrapsychic strains (attribution and outcome) and stress levels. Pearlin et al. (1990) states that caregiver stress is a ‘mix of circumstances, experiences, responses, and resources, that may vary considerably among caregivers and that consequently, vary in their impact on caregivers health and behaviour. This model has done much to help conceptualise the experience of caregiving from the ‘first generation’ studies, that is, studies which have tended to trawl every aspect of caregiving. It strength lies in the fact that it is based upon large heterogeneous groups of caregivers and has thereby enabled the identification of the key processes within caregiving relationships.
As highlighted by Kahana & Young (1990), a difficulty with the development of macro-model conceptualisations such as Pearlin's Stress-Process Model is that it is limited to the extent it is able to address the more subtle dyadic interactive features of caregiving relationships. Kahana & Young, (1990) theorise a different, but complementary model of the caregiving process, using an interactive approach, reflecting a detailed analysis of the fit between the demented person's behaviour and the caregivers response. It can be seen that both models provide a useful conceptual framework upon which to guide clinical practice and base future research questions about the nature of spousal caregiving. In light of the points highlighted by Kahana & Young, (1990) and from my own 'clinician's perspective' of working with individual couples referred to services due to major difficulties in caregiving, there is a need to incorporate both models and fine-tune the existing knowledge base in order to gain a more sophisticated understanding of the stress process. Related to this, has been the recent redefining of traditional caregiving research studies, away from trawling every aspect towards the focusing of research questions to one or two specific aspects of the caregiving process, especially to those related to the caregiver-care-recipient dyad affective relationship with specific cohorts of caregivers (Gatz et al, 1990; George, 1990; Pearlin et al, 1990; Russo et al, 1995).

Accordingly, the focus of this following research paper was aimed towards 'spousal caregiving' relationships. The focus upon this specific group is grounded upon the fact that research has conclusively shown that the closer the blood relationship the more stressful caregiving becomes (George & Gwyther, 1986; Kiecolt-Glaser et al, 1991; Jerrom et al, 1993; Russo & Vitalano, 1995). Also, knowledge from longitudinal outcome studies, (which highlight that the risk of institutionalisation is significantly reduced when the caregiver is the partner's spouse, together with recent epidemiological studies that have shown that spouse-caregivers provide the most extensive community care), indicates that there is potentially a growing number of spouse caregivers undertaking a 'caregiving role' in the community (Colerick & George, 1986; Cohen et al, 1990). Therefore the need to understand the unique aspects of spousal caregiving relationships becomes ever more clearer.

Within the spouse dyad there has been an increasing focus upon the pre- and current quality of the marital relationship upon the sense of burden perceived by caregivers. A number of
studies have reported that a positive previous relationship between caregiver and caregiver results in lower stress levels (Gilleard et al 1984; Morris et al, 1988a). Morris et al, (1988a) attributed from the findings '.....that spouses with good past relationships undertook caregiving for emotional reasons of affection, rather than as a result of social role expectation of obligation'. Despite this intriguing finding, until recently very few studies have focused on the marital relationship of such couples and the specific quality of their interactions (i.e. their affective dyad) has rarely been considered as a predictor of continued home care (Wright, 1994).

A review of a wider body of research has shown that the quality of the affective relationship impacts significantly upon outcome of the 'ill' family member. The perspective of dialectical human development argues that it is the nature of the reorganisations (i.e. how husband and wife interact with each other, and with their environment after illness) and not the illness alone that determines outcomes (Wright et al, 1994). Within the caregiving literature few researchers have investigated dyadic interactions as predictors of longitudinal outcomes, but those who have reported interesting findings. Pruncho & Potashnik, (1989) found that fewer positive interactions between caregivers and care-recipients were predictive of nursing home placement. His caregiver sample consisted exclusively of spouse caregivers (n = 220, 68% wives, 32% husbands caregivers). Zarit et al, (1986) found that the quality of the relationship prior to illness onset was found to be highest for those caregiver spouses who continued to provide in-home care after two years, lower for those who had placed their spouse into a nursing home and lowest for those whose afflicted spouse had died. Furthermore, prior low quality of the relationship correlated significantly with caregiver’s perceived burden. The afflicted spouses cognitive impairment and behaviour problems were not significant predictors of institutionalisation (Lieberman & Kramer, 1991). This caregiver sample consisted of 64 spouse caregivers (50% male, 50% female) whose partners were diagnosed with Alzheimer’s disease (67%) or multi-infarct dementia (33%). Horowitz & Shindelman, (1983) have suggested that caregiving does not emerge with a life of its own but takes place within a historical context they state that both the elderly person and the caregiver enter the caregiving relationship with a history of interactions that either facilitate or impede the caregiver in carrying out their activities. A close prior relationship means that caregiving can be performed with less resentment anger and ambivalence. These findings also appeared to be independent of gender related factors which as mentioned previously has also shown to have a confounding effect upon caregiving experiences.
It however is evident within the literature that few studies have focused exclusively on spousal caregivers and their impaired partners and even then, the quality of the interactions between afflicted caregiver dyads have rarely been investigated. This has primarily been due to the difficulties in ascertaining effective measurement criteria in relation to dyadic measurement which are robust and theoretically coherent. Thus there is a lack of a comprehensive understanding of the associations between burden, distress and coping and qualitative features of the relationship between caregiver and care-recipient (Bledin et al, 1990).

As advanced by Kahana & Young, (1990) although some work has been undertaken in relation to pre-morbid marital satisfaction, until recently little attention has investigated the impact of the current quality of the social interaction between caregiver and care-recipient upon caregiving outcome relating to dementia.

A review of a wider body of literature in relation to caregiver/care-recipient affective relationships and other disorders (most prominently schizophrenia) has shown a much wider appreciation of the effects of dyadical interchange upon illness outcome (Brown et al, 1972; Kuipers & Bebbington, 1988; Fischmann-Havstad & Marston, 1984; Florin et al, 1992; Asarnow et al, 1993; Asarnow et al, 1994). The measurement of the quality of the social interaction and relationships within families has been facilitated by the development and use of a measure of the affective quality known as ‘Expressed Emotion’ (EE) (Brown, 1985; Vaughn & Leff, 1976).

**EXPRESSED EMOTION:**

Expressed Emotion (EE) is a measure of attitudes toward the care-recipient, as indicated by the number of “critical comments” and the presence or absence of “hostility”, and the level of “overinvolvement” made by a caregiver when speaking about the care-recipient. Koenigsberg & Handley, (1986) describe EE as “a measure of the extent to which relatives express critical, hostile or over-involved attitudes about a patient when discussing the patient’s illness and family life with an interviewer”. This assumes that “a high degree of expressed emotion on one occasion is a measure of a relatives propensity to react in that way to that particular patient, even though other factors may be needed to precipitate this”.

Reviewing a wider body of research, the literature has shown that in relation to schizophrenia, relatives’ high expressed emotion (high-EE) status is the single most important factor in predicting clinical deterioration or relapse (Brown et al 1972; Vaughn & Leff, 1976; Fallon et
al, 1984; Hahleg et al, 1989; Jackson et al, 1990). More recently, Smith et al, (1993) has shown that high-EE relatives reported higher levels of disturbed behaviour in their schizophrenic relative, more subjective burden and perceived themselves to be coping less effectively than low-EE relatives.

EE AND THE COURSE OF OTHER DISORDERS:
As indicated by Kazarian (1992) and Kavanagh (1992), the scope of EE research has broadened considerably in recent years with the recognition that EE could be a more ‘generalised’ risk factor for relapse in psychiatry and health psychology (Koeningsberg & Handley, 1986; Neuchterlein & Gitlin, 1992). As a result, links between EE and outcome has been shown to be influential in a variety of psychiatric and physical conditions. These include depressive neurosis, (Florin et al 1992; Hooley & Teasdale, 1989; Goldstein, 1992), bipolar affective disorder, (Miklowitz et al, 1988; McCarrick-Wuerker, 1994; Miklowitz et al, 1984), diabetes, (Sensky et al, 1991), obesity, (Fischmann-Havstad & Marston, 1984; Maveras et al, 1992), eating disorders, (Asarnow et al 1994; Cook et al, 1991), acute & chronic illness, obsessive compulsive disorder, (Hibbs et al 1991), depression, conduct disorder and substance abuse in children (Schwartz et al, 1990; Asarnow et al 1993; Vostanis et al, 1994), and chronic illness in children, (Stubbe et al, 1993).

To summarise this literature, it is now recognised that the EE concept is relevant to many disorders as a “marker” variable or risk indicator and can be generalised to any close caring relationship (Vaughan, 1989; Kasermann & Altorfer, 1989; Rosenfarb et al, 1995; Scheiber et al, 1995).

COMPONENTS OF EXPRESSED EMOTION:
As mentioned earlier the components of EE are critical comments, hostility, emotional overinvolvement, warmth and positive remarks. The abbreviated version of the Camberwell Family Interview (CFI) which is a semi-structured interview has traditionally been used as the standard method of measuring the expressed emotion construct (Vaughn & Leff, 1976). The descriptions of these components are briefly summarised in Figure 3.

A more detailed account of the measurement and description of each component can be found in Leff & Vaughn, (1985).
**Figure 3  SCALES OF EXPRESSED EMOTION.**

(Leff & Vaughn, 1985)

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**CRITICAL COMMENTS:** Criticisms are rated on the basis of content and/or tone. Remarks are considered to be critical if there is a clear or unambiguous statement that the relative dislikes, disapproves of or resents a behaviour or characteristic. The dissatisfaction is expressed emphatically and intensely; the relative must use phrases such as “it annoys me” or “I don’t like it”. Vocal aspects of speech such as pitch, speed, inflection and loudness are used to identify critical tone.

**HOSTILITY:** Hostility is rated when the patient is attacked for what s/he is rather than for what s/he does. Negative feeling is generalised in such a way that it is expressed about the person her/himself rather than about particular behaviours.

**EMOTIONAL OVERINVOLVEMENT (EOI):** EOI is rated when there’s an exaggerated emotional response to the patients illness (i.e. statements of attitude, dramatisation, lack of objectivity, emotional display), marked concern reflected in unusually self-sacrificing and devoted behaviours, or extremely overprotective behaviours.

**WARMTH:** Ratings of warmth are based on the sympathy, concern and empathy relatives show when talking about the patient, the enthusiasm for and interest in the patients activities the number of spontaneous expressions of affection and the tone of voice used when talking about the patient.

**POSITIVE REMARKS:** Positive remarks are statements that express praise, approval or appreciation of the behaviour or personality of the patient.

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**EE AND DEMENTIA:**

In regards to the association between the affective relationship and sense of burden, a review of the schizophrenia caregiving literature can be seen to parallel the many issues seen within the dementia literature. Despite this fact, remarkably few studies have systematically investigated the relationship between EE and ‘burden’ in spouse caregivers who care for a relative with dementia. As cited by Vitalino et al, (1991) there are significant similarities about the ‘unrelenting chronic nature’ of the demands associated with caring for a spouse with dementia to that of a long term mental illness. Therefore ‘there is the potential for dysfunctional caregiver behaviour such as those categorised as High-EE responses at any time during the course of the care-recipients' disease for both types of caregivers’ (Vitalino et al, 1991).

A review of the dementia literature has only revealed five studies which have specifically investigated EE and aspects of caregiving. A study by Orford et al, (1987) examined EE (using the CFI) in 12 key relatives of demented patients as part of a broader study assessing EE in families with adult psychiatric patients. The results found that the proportions of high EE rated dementia care-recipient relatives (i.e. %high EE = 17%) were similar to those relatives caring for a relative with a chronic physical illness.
A study by Whittock (1987) of people with dementia used a ‘patient rejection scale’ as an approximation to the measurement of EE. The study found that high EE was correlated to lower morale and poorer ratings on mental health. However the measurement of EE by using this scale has not been reliably replicated. A later study by Gilhooly & Whittick (1989), examined the association between EE and several factors previously investigated in relation to caregivers of demented elderly persons. Their study found that no relationship existed between caregiver EE and the cognitive and functional abilities of the dementia care recipients. However the frequency of critical comments (ascertained in semi-constructed interviews) was significantly correlated with a number of relationship variables such as caregiver’s sex, caregivers psychological well-being, contact with friends and the quality of caregiver and care-recipient’s prior relationship.

Bledin et al’s (1990) study investigated EE levels in 25 daughters who were caring for a parent with dementia. Caregivers rated high on EE, were significantly more likely to report higher levels of strain and distress. Of greater significance was the finding that more effective coping strategies were shown by caregivers who made fewer critical comments and more positive remarks. At nine months follow-up however there was no definite link between high EE and poor outcome.

A fundamental study by Vitalino et al, (1989) further demonstrated that high EE spouses rated care recipient functioning as more impaired that either spouses low in EE or independent interviewers. In a later longitudinal study Vitalino et al, (1993) investigated whether caregiver affect could predict subsequent problems in care recipients (such as in relation to cognition, activities of daily living and negative behaviours). It was predicted that care-recipient behaviours may be more susceptible to be influenced by caregivers emotional affective style and behaviour. This process was also hypothesised to be reciprocally reinforcing. The findings from this research suggested that EE was predictive of increased negative behaviours over time.

In summary, it therefore appears that the limited research related to EE and burden appears equivocal at best. However much of the previous work has been thwart with methodological difficulties as to the measurement of EE. Despite these factors the most recent paper by Vitalino et al, (1991) has shown that the specific predictors of negative care-recipient cognitive/ADL decline may also be determined by environmental factors (such as the affective relationship with their caregiver) as well as to the organicity of the disease. It therefore can be seen that an exacerbation of behavioural problems can be created in a reinforcing cycle, thus creating additional stressors, and thereby increasing the sense of
caregiver stress. This has significant implications because as already mentioned, there is substantial evidence that caregivers become more distressed by negative care-recipient behaviours than by care-recipient cognitive or ADL decline.

Leading on from the above discussion, it can be seen that it is generally assumed that exposure to high-EE attitudes is a stressor for the patient and that over time, increases the likelihood in deterioration of functioning. However, it is important to note that the measurement of EE status has been based on an outside observer’s inferential assessment of the emotional attitudes that a caregiver may hold towards their care-recipient, since EE is assessed on a ‘directed response’ in order to tap emotional attitudes that would not be otherwise expressed in a straightforward manner. This has traditionally been the rating of key affective components which are derived from the Camberwell Family Interview. Hence relatives perceptions of their own feelings toward the care-recipient have rarely been measured. Such knowledge concerning relative’s awareness of their affective attitudes would be helpful in planning potential intervention strategies. There have been some attempts to ascertain the extent of relatives’ awareness of their affective attitudes, particularly in relatives of schizophrenics. For example, Friedmann & Goldstein, (1994) revealed that in general relatives of schizophrenic patients perceived in themselves attitudes that paralleled those assessed by an outside rater using standardised interviews.

Another fundamentally important question which has been almost exclusively ignored is related to the age of dementia onset (and thus age at which spouse caregivers undertake caretaking) upon the experience of spousal caregiving. Although dementia is most typically thought of as a disease of the ‘old’, there are variants of the disorder which present at a younger age (Delany & Rosenvinge, 1995). As cited in Alzheimer’s Disease Society, (1991) the World Health Organisation uses the age of 65 to distinguish between dementia with a ‘younger onset’ and dementia with a ‘later onset’. Whilst the incidence of dementia in the population over the age of 65 years is now well established there are, at present no nationally representative epidemiological studies indicating the prevalence, or incidence rate, of younger onset dementia (Keady & Nelson, 1994). However younger onset dementia has been reported to affect an estimated 17,000 people in the UK at any one time, (Williams et al, 1995) although this figure may be a significant underestimation. With regards to spouse caregiver age, there appears to be conflicting and ambiguous evidence in the literature regarding age related differences in the incidence of stressors. In regards to disease presentation, there are reported to be a significant differences. For example it has been reported that younger-onset
dementia is associated with more pronounced aphasia, and general overall decline (Filley et al, 1986; Rubin et al, 1995). The increased presentation of these 'stressors' could be postulated as requiring the caregiver to cope with more stressful situations. Indeed, within clinical dementia services there is increasing calls for the recognition that the experience of younger caregivers is different to older caregivers, reflected by the increase call for specialist services and resources for this client group. However as reflected in the previous literature review section much, if not all of the 'Stress Process Model of Caregiving' has been grounded in research of older caregivers, reflecting a significant lack of research on the specific issues associated with the younger onset dementia patient and their caregivers (Cox, 1991; Sperlinger & Furst, 1994). The available scant literature on this subgroup of caregivers also presents an ambiguous picture as to the nature of caregiver's experiences. For example, Cox, (1991) postulates that from a service planners perspective, younger onset dementia sufferers and the caregivers who have 'grown-up' families, appear to pose fewer demands upon Health and Social Services provision than an elderly person with dementia and failing physical health. This is also substantiated by drawing upon the wider source of literature, which assumes a special significance for older adults because of the frequency and intensity of stressful life events that they experience during a life state when their economic, physical social and psychological resources are diminishing. The relationship of social-psychological stress to illness has been extensively studied and reviewed extensively in the literature. It has been hypothesised that the elderly are more susceptible to the effects of stress because they experience many negative life events and experience many losses during a period of physical decline and when rigidity in coping responses are apparent. Thus they experience special demands for adaptation at a time when their adaptive capacities are diminishing (Russo & Vitalino, 1995).

However, in relation to the experiences of older- and younger- caregiver burden, the aforementioned hypotheses have been significantly and dramatically questioned at a clinical and service level, reflecting the establishment of specialist services for younger care-recipients and their caregivers and the establishment of a Working Party within the Alzheimer's Disease Society, to particularly focus upon the needs, resources and services required by younger care-recipients and their families (Alzheimer's Disease Society, 1993).

By using Pearlin’s model it is easier to hypothesise as to why it may be that younger caregivers experience more difficulties than older caregivers. Firstly the contextual differences in relation to social cohorts, whereby younger and older caregiver perceptions of
role and duty may be different. Also, different primary stressors in relation to the physical health of the caregiver and the care-recipient, different secondary stressors (i.e. multiple conflicting roles (mother/wife) and increased financial pressures. There is also evidence that coping mediators (i.e. availability of social support and services,) are often unavailable for caregivers of younger people with dementia thereby reducing the potential buffering effect that they provide against the stressors of caregiving.

Therefore it can be seen that Younger Onset Dementia caregivers may potentially appear to experience a greater range of losses including their job, money status, familial role in addition to cognitive faculties and hence the potential for higher burden, since the onset of dementia is early the impact coincides with a stage in the family life cycle where the number of dependant family members is likely to be greater including children and grandparents who are looking for emotional and financial support.

In summary it can be seen that there is the potential for additional caregiving stressors caused by age of onset. In many ways the aforementioned discussions reflect the differing stages in the life cycle model but it does not explain why some older and younger spouses caring for a partner with dementia families are able to manage whilst others are not.

This section has attempted to clarify some of the subtle factors (such as the affective attitudes within dyadic spousal relationships) which have been shown to impact upon the caregiving relationship between caregiver and care-recipient. In particular, it has focussed on the increasing evidence that critical comments and hostility (as a basis of high EE identification) correlate with caregiver’s increased sense of subjective burden and increase reporting of negative caregiver behaviour. It has also highlighted that there may be a relationship between high EE presentation and the types of coping mechanism that caregivers employ to manage their caretaking responsibilities. Also highlighted, is that even within the relative homogenous group of spousal caregivers there are in fact two separate groups of caregivers, which have traditionally been unrecognised in many of the spousal caregiving studies. Therefore, a greater and more detailed understanding is needed of the association between strain, distress and coping and qualitative dyadic features of the relationship between caregivers and the care-recipient which may facilitate a way of identifying caregivers who are at risk of experiencing difficulties in their caregiving roles.
SECTION III: METHODSological considerations addressed in this study

While there is increasing evidence concerning the impact of the affective aspects of the caregiver and care-recipient relationship upon the caregivers sense of burden, much of this research suffers from serious conceptual or methodological problems. These methodological issues may account for the reported equivocal findings on many aspects of caregiver outcome (Barer & Johnson 1990).

Sample Selection:
Most early caregiver research incorporated caregivers from heterogeneous groups thereby making it difficult to draw clear conclusions as to the interactional effects for specific carer relationships (Morrisey et al, 1990). Caregiving processes and consequences have been reported to differ substantially when gender and kinship relationships are considered. However analysis of caregiving experiences has usually failed to separate potentially distinct caregiving patterns and the counter effects such as gender, or the partner kinship characterising the care-recipient and caregiver dyad (Kahana & Young, 1990).

Further, most studies which have examined the psychological consequences associated with caregiving are convenient samples drawn from only one source, usually hospital services. Samples drawn from sources such as these, are potentially biased. Such selection effects operate to yield samples that are not representative of the caregiver population at large. Also, most research has been conducted with caregivers caring for a relative with older onset dementia, which questions whether the findings are relevant to carers for relatives with younger onset dementia. Further the period of time within the caregiver trajectory has been shown to be significant factor in relation to caregivers experience of burden. However many studies have not commented as to the caregiving duration.

Measures:
There has been little consistency in the research field in the conceptualisation and measurement of psychological burdens or impact. This has prevented comparison of findings across studies and made it difficult to determine whether inconsistent findings across studies are theoretically relevant or merely a function of the different conceptualisations and measures adopted.

Expressed Emotion:- As indicated in previous studies the measurement of Expressed Emotion has been fraught with both conceptual and methodological difficulties. Despite the impressive evidence available on the reliability and validity of the CFI, two major issues concerning the
measurement of EE have continued to prevail. The first relates to the use of non vocal aspects of speech as a criteria for the ratings of the critical comments component of EE (Kuipers & Bebbington, 1988). The second concerns the administrative aspect of the CFI. The interviews are time-consuming, with each interview taking between 60 and 90 minutes to administer and even longer to rate. Rating also requires specialist training before one can administer or rate the questionnaire. Due to these administrative shortcomings of the CFI its applicability to clinical settings is severely restricted thus there have been attempts to develop less arduous and time-consuming approaches to the measurement of expressed emotion. Attempts to use alternative measures of Expressed Emotion Construct have been evident in many recent research studies, but have been flawed due to non attainment of reliability and validity measures. However a brief alternative measure for assessing EE attitudes by Gottschalk & Gleser, (1969) and adapted by Magaña et al, (1986) from a five minute speech sample (FMSS) has been increasingly shown to be a valuable measure since the conceptual similarities and prognostic utility of less arduous measures have been replicated with this measure (Kazarian 1992).

Five Minute Speech Sample (FMSS):
In this procedure, a key relative is interviewed alone and is instructed to speak for five minutes about the patient. The task is aimed at identifying the respondents attitudes and feelings about the patient as well as perceptions of the quality of their relationship. As in the case of the CFI, the FMSS speeches are audiotaped and the expressed attitudes and feelings of the relatives are rated on dimensions analogous to those of the CFI. Further, in contrast to the CFI the examiners need not be trained in the coding system in order to administer the task. Relatives are classified as high EE-critical on the basis of a single negative initial statement, or an overall negative relationship indicator. Similarly, relatives are classified as high-EE-emotional overinvolvement on the basis of one of three indices of emotional overinvolvement: affective display during the interview, self-sacrificing/overprotectiveness behaviour, and two of three behaviours involving excessive detail about the past, emotional overinvolvement and exaggerated praise. Two separate studies have shown a reasonable degree of correspondence between EE ratings derived from the FMSS and the CFI (Malla et al, 1991; Magaña et al, 1986), although when compared to the CFI, the FMSS provides a lower base rate of high EE ratings (i.e. underestimates high levels of EE - see Figure 3). However further studies (e.g. Leeb et al, 1991) have demonstrated a high level of correspondence between FMSS-EE measures and the CFI measure with a variety of care-recipient conditions.
This study has attempted to overcome some of these conceptual and methodological limitations of previous caregiver research. The caregivers were randomly selected from a number of agencies. All caregivers were limited to spouses who were living with the care-recipient in the community. Also in relation to the caregiving histories, the length of time in the caregiving role was selected from a narrow time frame, at a time when it has been recognised that caring can be at its most stressful. Attempts have also been made to obtain spouse caregivers from two age ranges. Researchers have traditionally been torn between having a relatively large homogeneous group and having a large enough sample to test treatment effects. Despite the pull towards using 'broad inclusion criteria' and aggregating findings from a diverse participant pool, this research method has recently been cited as a methodology which limits the applicability of previous research findings (Caine, 1994). Consequently in the following study attempts were undertaken to use measures which have been substantiated with reliability and validity measures and to implement a strict inclusion criteria.
SECTION IV: AIMS AND HYPOTHESES OF THE STUDY:

As emphasised in the above review, there has been in recent years an increasing awareness of the extent of family care-giving and its importance in maintaining the growing number of people with dementia who reside in the community. A large body of research has identified both negative and positive effects of caregiving (Lawton et al, 1989; Vitalino et al, 1991 Zarit, 1980) As this research has progressed, the focus has become more sophisticated to include both longitudinal studies of caregiver distress (Haley et al 1987b; Vitalino et al, 1991) and the examination of dyadic interactions of caregivers and care-recipients. (Deimling & Bass, 1986; Haley et al, 1987a) and specific mediators which impact upon caregiving such as coping.

The purpose of the study was to explore the affective experiences of spouse caregivers living in the community with their partner in relation to coping mechanisms and other key factors as emphasised in Pearlin’s Model of Caregiving (Pearlin et al, 1990). This was felt to be particularly important since little investigation of Expressed Emotion has been undertaken with spousal caregivers of dementia care-recipients in Great Britain. This study of spousal caregivers of partners with a dementia specifically examined to what extent EE levels in relatives were related to aspects of the circumstances of the relationship, measured by relatives perceived level of burden, impact on caregivers physical and mental health, caregivers’ perceptions of level of care-recipient cognitive, and behavioural functioning. Further assessments were also undertaken in relation to whether this was mediated by specific caregivers’ coping strategies and their perception of their affective attitude towards their partner. Attempts were also made to discover whether spouse caregivers perceived in themselves EE attitudes similar to those assessed by external raters using a standardised measure of expressed emotion.

HYPOTHESES:

• HIGH EE CAREGIVERS WILL EXPERIENCE A GREATER REPORTED LEVEL OF BURDEN, PSYCHOLOGICAL AND PHYSICAL DISTURBANCE COMPARED WITH LOW EE CAREGIVERS.

• HIGH EE CAREGIVERS WILL REPORT GREATER LEVELS OF BEHAVIOURAL AND MOOD DISTURBANCE IN THEIR CARE-RECIPIENT COMPARED WITH LOW EE CAREGIVERS.
- Higher levels of strain as measured by burden and GHQ would be related to caregivers who had more ‘non-adaptive’ coping responses.

- Younger caregivers will report higher psychological distress and greater burden.

- Quality of the previous marital relationship will impact upon level of burden.

- Caregivers will be able to perceive in themselves EE attitudes similar to those assessed by a standardised measure of expressed emotion.
SECTION V:  

METHOD:

PARTICIPANTS:
32 spouses caring for their partner with dementia were recruited from known cases within the North East Essex Region via Mental Health, Medical or Social Services or recruited through cases known to volunteer services such as the Alzheimer Disease Society or National Carers Association.

Criteria for inclusion into the study were that:

1. All spouses were primary caregivers in that they resided with their partner with dementia (care-recipient) within the community.
2. There had been a formal diagnosis of a dementia process in the care-recipient as classified within the ICD-10 and/or a preliminary diagnosis of a dementing process which had been given by a General Practitioner. In cases where a diagnosis of dementia had been given by a General Practitioner, caregivers were also required to report a history of intellectual decline which had continued for at least six months prior to inclusion in the study.
3. Time since diagnosis was between three months to two years.
4. All spouses spoke English.

PROCEDURE:
Prior to the undertaking of this research study ethical approval was applied for and obtained through the Ethics Committee of the Mental Health Trust from which some of the participants were recruited (see Appendix B).

Caregivers were initially randomly contacted by telephone to see if they were willing to take part in the study. Those who expressed an interest were sent an introductory letter explaining the protocol and procedure of the study. A total of 46 introductory letters were sent out. Those who agreed to participate were re-contacted by telephone to arrange an interview date at a time convenient to them. Informed written and witnessed consent was obtained from the caregiver spouse prior to the interview occurring, once having read an information sheet explaining the background to this study (see Appendix C).

All participants had the opportunity to withdraw from the study at any time if they desired, without jeopardy to their current or future service requirements.
Participating caregivers were required to undertake a single personal semi-structured interview which lasted between one and one and a half hours and was conducted in the caregiver’s own home. Each caregiver completed several questionnaires and spoke about their current relationship with their partner which was audiotaped.

MEASURES:
A variety of self-report measures and a taped interview were used to exam the different dimensions associated with caregiving. The questionnaires and taped interview were scored using each established scoring criteria.

Background & Contextual Factors:
A structured Caregiver’s Interview Schedule was designed especially for this study to collate caregivers’ and their care-recipients’ demographic and social information.

Stressors:

i. Care-recipient’s Cognitive and Behavioural Impairment.
Care-recipients cognitive and behavioural impairment was assessed by caregivers using the Behaviour and Mood Disturbance Scale (BMD) (Greene et al, 1982). It is a 34-item questionnaire designed to measure caregiver’s perception of mental and behavioural disturbance in their relative. Caregivers were asked to rate the severity of each item on a five point likert scale - ‘never, rarely, sometimes, frequently, always’. An overall score of behavioural disturbance was obtained. Reliability coefficients have been obtained together with construct validity (Greene et al, 1982).

ii. Care-recipient Physical Impairment.
The Barthel ADL Scales (Mahoney & Barthel, 1965) was used to measure caregiver’s perception as to the level of their partner’s functional ability. A total score between 0 - 20 for Activities of Daily living (ADL) dependence was computed to reflect the number of tasks with which the care-recipient needed physical assistance or supervision.

Outcome:

i. Caregiver Physical and Mental Health.
The 28-Item General Health Questionnaire (GHQ) (Goldberg, 1978) version of this self-administered questionnaire was used to measure overall psychological morbidity. It has been
used as a screening test for detecting psychiatric disorders in community settings. The total score calculated was used in the present analyses. Test-retest reliability of the schedule is high, and split-half reliability is reported to be 0.95 (Golberg, 1978). Scores of 4/5 are indicative of significant psychological distress while scores over 6 suggest a level of psychological morbidity consistent with the presence of psychiatric disorder.

ii. Burden Associated with Caregiving.
Caregiver burden was assessed using the Screen for Caregiver Burden: (SCB) (Vitalino et al, 1991) which is a 25-item multi-dimensional measure designed to assess objective and subjective burden. Scoring of the SCB yields two scores: Objective Burden (OB) and Subjective Burden (SB). Objective burden is based on problem care-recipient behaviours that have potentially negative consequences for the caregiver. Subjective Burden appraises caregiver distress in relation to each problem behaviour. The psychometric properties of the SCB have been demonstrated in two independent samples (Vitalino et al, 1989, 1991). Internal consistency coefficients were 0.85 and 0.88 for Objective Burden and Subjective Burden, respectively. Construct validity (convergent/divergent) has been supported by the relationship of care recipient behavioural and cognitive functioning with Objective Burden and caregiver distress and personality variables. Criterion validity (i.e. differences in burden between ‘dementia’ caregivers versus controls) has been demonstrated by using age- and sex-matched controls.

iii. Caregiver Affective Relationship with Care-recipient:
The Five Minute Speech Sample (FMSS) (Magaña et al, 1986) was used to assess Expressed Emotion (EE). This measure evaluates comparable affective attitudes expressed by the caregiver during a five minute speech sample monologue using instructions suggested by Gift et al, (1985). Each caregiver was asked to speak without interruption for five minutes about “what kind of a person (the patient) is and how you two get along together”. The task was aimed at identifying each caregiver’s attitudes and feelings about their care-recipient as well as perceptions of the quality of their relationship. The responses were audiotaped and the speech samples subsequently coded according to a system developed by Magaña et al, (1986). The FMSS has been shown to correlate well with the more traditional method of rating EE with the CFI (Kazarian, 1992; Magaña et al, 1986), although it is reported to give conservative estimates of the high levels of EE. The validity and reliability of the criteria used in the coding system have been shown by Magaña et al, (1986).
iv. Caregiver Awareness of Expressed Emotion:
The Adjective Checklist (Friedmann & Goldstein, 1994) was used to ascertain caregivers awareness of their emotional expression. It consisted of 20 adjectives, 10 of which were positive and the other 10 negative. The caregiver rated each adjective in relation to its description of their behaviour towards their partner over the previous three months. The caregiver was also asked to rate the list of adjectives from their spouses perspective. (i.e. the care-recipient spouse’s behaviour towards the caregiver spouse.) This checklist assessed whether the caregiver was aware of their affective attitudes towards their partner and whether this matches outside rater assessment (as measured by the FMSS). It also attempted to access the interaction of the spouse with dementia with their caregiver and visa versa.

It has been shown to be a useful indicator of awareness of emotional expression with a sample of spouses who were caring for a partner with schizophrenia, although it has not been used with any other caregivers.

Mediators:

i. Coping

The Coping Responses Inventory (CRI) (Moos, 1990) (Part II) was administered to ascertain the types of coping responses used by caregivers in managing their caregiving role. This part of the inventory consisted of a 48-item questionnaire based on eight scales which are classed as shown in the table below.

<table>
<thead>
<tr>
<th>COGNITIVE COPING STRATEGIES</th>
<th>APPROACH COPING RESPONSE (POSITIVE COPING)</th>
<th>AVOIDANCE COPING RESPONSE (NEGATIVE COPING)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Logical Analysis, Positive Reappraisal</td>
<td>Cognitive Avoidance, Acceptance or resignation</td>
<td></td>
</tr>
<tr>
<td>BEHAVIOURAL COPING STRATEGIES</td>
<td>Seeking guidance &amp; support, Taking problem solving action</td>
<td>Seeking alternative rewards, Emotional Discharge</td>
</tr>
</tbody>
</table>

Each coping response item was rated on a four-point frequency scale, ranging from ‘never’ (0) to ‘fairly often’ (3). Raw scores were derived from each of the eight subscales and overall composite ‘Approach Response’ and ‘Avoidance subscales’. The score on the coping subscales were computed into standard scores to aid comparison across scales. From the
literature review it was assumed that the higher the scores on the avoidance subscale the less adaptive (i.e. negative) the coping.

The reliability of the Coping Response Inventory has previously been investigated by means of the internal consistence of the subscales and by the test-retest method over a one-year period on a variety of sample populations, which has indicated satisfactory reliability. The validity of the CRI has been shown to correlate highly with earlier coping questionnaires (i.e. coefficients of 0.56 to 0.83) (Billings & Moos, 1981).

(See Appendix D for Questionnaires)

**ANALYSES:**

The following analysis of data collated from the stated measures was carried out using the SPSS for Windows (Version 6.0).

To consider the general trends within the data and to investigate those that characterised spouse caregiver subgroups, the data was analysed for the sample as a whole, and for the subgroups derived by EE classification, gender and age of caregiver. A number of planned correlations between caregiver and care-recipient variables were undertaken to examine the strength of their relationship to level of caregiver burden, EE and coping strategies employed.

In addition caregiver's awareness of their affective relationship with their partner and external observer ratings of expressed emotion, were assessed using further non-parametric analyses.
SECTION V:  

RESULTS:

This section comprises of three main components:

PART A:- presents the demographic and profile information obtained for the whole sample of caregivers and the care-recipients.

Part B:- presents the analyses undertaken in relation to the subgroupings:- High-EE Caregivers and Low-EE Caregivers presenting further multi component analyses of the collated data.

Part C:- presents data ascertaining caregivers awareness of their emotional expression as compared to FMSS-EE measurement ascertained by external rating.

PART A:

SAMPLE:

Thirty-three spouse caregivers consented to participate in the study. However one caregiver when visited proved to be an unsuitable participant since he was too distressed to complete the interview. Consequently the final sample contained 32 subjects, only 69.56% of those originally contacted by letter. The principle characteristics of both caregivers and care-recipients were considered. Their details are summarised in Table 1 and Table 2.

Table 1  Demographic Characteristics of Caregivers

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>Mean (sd)</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age caregiver (yrs.)</td>
<td>70.9 (8.40)</td>
<td>71.5</td>
</tr>
<tr>
<td>Age caregiver (yrs.)</td>
<td>72.06 (7.94)</td>
<td>73.5</td>
</tr>
<tr>
<td>Length of time caregiving (mths)</td>
<td>24.38 (10.79)</td>
<td>22</td>
</tr>
<tr>
<td>Length of Marriage (yrs)</td>
<td>46.41 (14.41)</td>
<td>45.5</td>
</tr>
</tbody>
</table>

It can be seen that the caregivers average age was 70.9 years (sd 8.4) [median age 71.5 years] with the average age of the care-recipient being 72.06 years (sd 7.94) [median age 73.5 years] Caregivers and care-recipients had been married for an average of 46.41 years (sd 14.41) [median length of marriage 45.5 yrs] and had been in the caregiving role for an average of 24.38 months (sd 10.79) [median time in caregiving role 22 months].
Caregiver gender was represented by 14 males (43.8% of the sample) and 18 females (56.3% of the sample) with the inverse representation of care-recipients. 23 care-recipients were classified as diagnosed as having a later-onset dementia (i.e. onset after the age of 65 years) whilst 9 were classified as having younger-onset dementia (i.e. before the age of 65 years). All caregivers were retired and also no care-recipient was in either full or part-time employment.

Table 2  DESCRIPTIVE DEMOGRAPHIC DETAILS OF CAREGIVER AND CARE-RECIPIENT SAMPLE

<table>
<thead>
<tr>
<th>Demographic Characteristics</th>
<th>14 male, 18 female</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Gender.</td>
<td></td>
</tr>
<tr>
<td>Care-recipient Gender.</td>
<td>14 female, 18 male</td>
</tr>
<tr>
<td>Care-recipient age of dementia onset</td>
<td>23 Older Onset; 9 Younger Onset</td>
</tr>
<tr>
<td>Caregiver Employment:</td>
<td>All retired</td>
</tr>
<tr>
<td>Care-recipient Employment:</td>
<td>All retired</td>
</tr>
<tr>
<td>Quality of the marital relationship (pre-illness onset)</td>
<td>Good 28 (87%)  Indifferent 3 (9.4%)  Poor 1 (3.1%)</td>
</tr>
<tr>
<td>Quality of the marital relationship (current)</td>
<td>Good 12 (37.4%)  Indifferent 14 (43.8%)  Poor 6 (18.8%)</td>
</tr>
</tbody>
</table>

Table 2 also shows the percentage of caregivers ratings of the quality of their relationship with the care-recipient both prior to illness onset and current relationship. 87% of caregivers rated their relationship as being ‘Good’, 9.4% of caregivers rated their relationship as being ‘Indifferent’, whilst only 3.1% of caregivers stated that their relationship was ‘Poor’ prior to the dementia-illness onset. However there was a significant difference in their ratings of their current marital satisfaction with only 34% rating their relationship as ‘Good’, 43.8% rating their relationship as ‘Indifferent’ and 18.8% rating as ‘Poor’.

CARE-RECIPIENT BEHAVIOURAL AND PHYSICAL IMPAIRMENT:

Caregiver’s average rating of behavioural and mood disturbance was shown to be 45.22 (sd 21.44) [median score 48.50]. In relation to physical impairment, the caregivers’ average rating on the Barthel was 10.72 (sd 4.91) [median score 10.00] (see Table 3). These scores indicated that the care-recipients appeared to experience significantly higher cognitive and mood disturbance than physical impairment. These results reflected similar trends as shown in existing research with this client group.
Table 3  **MEAN CAREGIVER RATINGS OF CARE-RECIPIENT BEHAVIOURAL AND PHYSICAL IMPAIRMENT**

<table>
<thead>
<tr>
<th></th>
<th>MEAN (sd)</th>
<th>MEDIAN</th>
</tr>
</thead>
<tbody>
<tr>
<td>Behaviour Mood Disturbance Scale</td>
<td>45.22 (21.44)</td>
<td>48.50</td>
</tr>
<tr>
<td>Barthel ADL Scale</td>
<td>10.72 (4.91)</td>
<td>10.00</td>
</tr>
</tbody>
</table>

**CAREGIVERS' COPING SKILLS:**

Individual raw scores obtained from the Coping Response Inventory for each of the eight coping responses were initially converted into standard scores in order to compare caregivers' response across each coping rating. The mean standard score and standard deviations for each of the coping responses are contained in Table 4. In addition the coping strategies were also grouped into general categories of 'Positive Coping Strategies' and 'Negative Coping Strategies' and mean scores and standard deviations were calculated. This was undertaken to facilitate overall comparison of adaptive and non-adaptive coping strategies, and thus reduce the likelihood of creating statistically significant results by reducing the number of correlation analysis to be calculated in later analyses.

Table 4  **CAREGIVERS' MEAN STANDARD SCORE:- COPING STRATEGY.**

<table>
<thead>
<tr>
<th>COPING STRATEGY</th>
<th>MEAN STANDARD SCORE (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sum of All Positive Coping Strategies</td>
<td>48.15 (5.70)</td>
</tr>
<tr>
<td>1Logical Analysis</td>
<td>44.41 (9.90)</td>
</tr>
<tr>
<td>1Positive Appraisal</td>
<td>44.47 (8.87)</td>
</tr>
<tr>
<td>1Problem solving</td>
<td>50.31 (10.04)</td>
</tr>
<tr>
<td>1Seeking Support</td>
<td>50.44 (10.84)</td>
</tr>
<tr>
<td>Sum of All Negative Coping Strategies</td>
<td>55.29 (5.31)</td>
</tr>
<tr>
<td>2Alternative Rewards</td>
<td>52.09 (10.07)</td>
</tr>
<tr>
<td>2Acceptance</td>
<td>54.91 (8.50)</td>
</tr>
<tr>
<td>3Avoidance</td>
<td>55.81 (10.32)</td>
</tr>
<tr>
<td>3Emotional Discharge</td>
<td>58.31 (11.41)</td>
</tr>
</tbody>
</table>

1= positive coping strategy  
2= negative coping strategy

There was shown to be a higher score associated with the overall higher use of negative coping strategies amongst caregivers.
In an attempt to assess the interrelationship of the individual coping strategies Pearson correlations were undertaken for each of eight strategies. Intercorrelations of the coping items were at best, moderate in magnitude, ranging from $r = .01$ to $.49$. The statistically significant negative correlation of 'logical analysis' with 'cognitive avoidance' ($r = -.46$, $P < .05$) indicated that the use of 'logical analysis' as a strategy decreased the likelihood of using 'cognitive avoidance' strategies. Other statistically significant findings also indicated that using 'positive appraisal' strategies decreased the use of using 'cognitive avoidance' strategies. In addition the increased use of 'logical analysis' as a strategy was associated with a decrease use of 'alternative reward' strategies and also 'problem solving' strategies were associated with less use of 'emotional discharge' strategies ($r = -.38$, $p < .05$).

Interestingly the use of 'logical analysis' strategies were shown to be positively associated with the use of 'acceptance' strategies and thus may be an indicator of a more positive adjustment to coping in the role of caregiver.

**PSYCHOLOGICAL/PHYSICAL OUTCOME MEASURES:**

Caregivers’ mean results on the outcome measures relating to caregiving are summarised in Tables 6 and Table 7. It can be seen that the average score of caregiver objective burden was 15.78 (5.18) whilst caregiver subjective burden was 35.28 (14.52).

### Table 5  INTERCORRELATIONS BETWEEN THE INDIVIDUAL COPING STRATEGIES.

<table>
<thead>
<tr>
<th></th>
<th>Cognitive Avoidance</th>
<th>Acceptance</th>
<th>Alternative Rewards</th>
<th>Emotional Discharge</th>
<th>Logical Analysis</th>
<th>Positive Appraisal</th>
<th>Problem Solving</th>
<th>Seeking Support</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive Avoidance</strong></td>
<td>1.00</td>
<td>.29</td>
<td>-.25</td>
<td>.17</td>
<td>- .46**</td>
<td>- .64**</td>
<td>.07</td>
<td>.09</td>
</tr>
<tr>
<td><strong>Acceptance</strong></td>
<td>.29</td>
<td>1.00</td>
<td>-.09</td>
<td>-.07</td>
<td>.49**</td>
<td>.16</td>
<td>-.08</td>
<td>-.24</td>
</tr>
<tr>
<td><strong>Alternative Rewards</strong></td>
<td>-.25</td>
<td>-.09</td>
<td>1.00</td>
<td>.14</td>
<td>-.43**</td>
<td>-.10</td>
<td>-.25</td>
<td>.01</td>
</tr>
<tr>
<td><strong>Emotional Discharge</strong></td>
<td>.17</td>
<td>-.07</td>
<td>.14</td>
<td>1.00</td>
<td>.01</td>
<td>-.04</td>
<td>-.38**</td>
<td>.23</td>
</tr>
<tr>
<td><strong>Logical Analysis</strong></td>
<td>-.46**</td>
<td>.49**</td>
<td>-.43*</td>
<td>.01</td>
<td>1.00</td>
<td>.19</td>
<td>-.06</td>
<td>-.03</td>
</tr>
<tr>
<td><strong>Positive Appraisal</strong></td>
<td>-.64**</td>
<td>.16</td>
<td>-.10</td>
<td>-.04</td>
<td>.19</td>
<td>1.00</td>
<td>-.14</td>
<td>.21</td>
</tr>
<tr>
<td><strong>Problem Solving</strong></td>
<td>.07</td>
<td>-.08</td>
<td>.25</td>
<td>-.38**</td>
<td>-.06</td>
<td>.14</td>
<td>1.00</td>
<td>.22</td>
</tr>
<tr>
<td><strong>Seeking Support</strong></td>
<td>.09</td>
<td>-.24</td>
<td>.01</td>
<td>.23</td>
<td>-.03</td>
<td>.21</td>
<td>.22</td>
<td>1.00</td>
</tr>
</tbody>
</table>

* - Significant Level .05   ** - Significant Level .01  (2-tailed)

### Table 6  CAREGIVERS' MEAN SCORES OF THE PSYCHOLOGICAL OUTCOME MEASURES.

<table>
<thead>
<tr>
<th></th>
<th>Mean (SD)</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective Burden</td>
<td>15.78 (5.18)</td>
<td>14.50</td>
</tr>
<tr>
<td>Subjective Burden</td>
<td>35.28 (14.52)</td>
<td>33.00</td>
</tr>
<tr>
<td>General Health Questionnaire</td>
<td>24.88 (11.95)</td>
<td>23.00</td>
</tr>
</tbody>
</table>
Table 7  **FREQUENCY OF REPORTED IMPACT OF CARING UPON CAREGIVERS’ HEALTH**

<table>
<thead>
<tr>
<th>Caregiving Impact on health</th>
<th>Frequency of Reported Presentation</th>
</tr>
</thead>
<tbody>
<tr>
<td>No Impact 6 (18.8%)</td>
<td>Slight Impact 7 (21.9%)</td>
</tr>
<tr>
<td>Major Impact 19 (59.4%)</td>
<td>Good 21.5%</td>
</tr>
<tr>
<td>Poor - 15.6%</td>
<td>Variable 15.6%</td>
</tr>
</tbody>
</table>

In relation to caregivers’ health, 59.4% of caregivers reported that they felt that caring for their spouse had had a ‘significant impact’ upon their own health, with a further 21.9% reporting that caring had a ‘minor impact’ and with 18.8% reporting ‘no impact’. Further only 21.5% of caregivers reported to regularly having a ‘good’ night’s sleep during the last three months with 40.6% reporting poor sleep, although 15.6% was due to caregiver’s difficulties whilst 25% due to care-recipient difficulties (i.e. wandering etc.).

**RELATIONSHIPS BETWEEN CAREGIVERS’ COPING, BURDEN AND PSYCHOLOGICAL WELL-BEING AND CARE-RECIPIENT IMPAIRMENT VARIABLES:**

Pearson correlations showed that Objective burden and Subjective burden were highly correlated ($r = .588 p < .01$). These results indicated that objective and subjective burden scores were not independent measures of each factor. Also, the level of subjective burden experienced by spouse caregivers were also positively associated with the greater use of maladaptive coping strategies ($r = .387, p < 0.05$). However maladaptive coping and the GHQ scores were not significantly correlated. Further positive coping scores were not and any of the caregiver outcome variables (i.e. subjective, objective burden, GHQ) or with any of the care-recipient variables (see Table 8).

Table 8  **PEARSON CORRELATIONS OF CAREGIVER OUTCOME, CAREGIVER COPING, MECHANISMS AND CARE-RECIPIENT FACTORS:**

<table>
<thead>
<tr>
<th></th>
<th>NEGATIVE COPING</th>
<th>OBJECTIVE BURDEN</th>
<th>SUBJECTIVE BURDEN</th>
<th>GHQ</th>
<th>POSITIVE COPING</th>
<th>BARTHEL</th>
<th>BMD</th>
</tr>
</thead>
<tbody>
<tr>
<td>NEGATIVE COPING</td>
<td>1.0000</td>
<td>.1568</td>
<td>.3870*</td>
<td>.1735</td>
<td>.2134</td>
<td>-.1497</td>
<td>.2997</td>
</tr>
<tr>
<td>OBJECTIVE BURDEN</td>
<td>.1586</td>
<td>1.0000</td>
<td>.5888**</td>
<td>.0970</td>
<td>-.0756</td>
<td>-.0317</td>
<td>.1376</td>
</tr>
<tr>
<td>SUBJECTIVE BURDEN</td>
<td>.3870*</td>
<td>.5888**</td>
<td>1.0000</td>
<td>.1045</td>
<td>-.0966</td>
<td>.0574</td>
<td>.3197</td>
</tr>
<tr>
<td>GHQ</td>
<td>.1735</td>
<td>.0970</td>
<td>.1045</td>
<td>1.0000</td>
<td>-.01516</td>
<td>-.1257</td>
<td>.1148</td>
</tr>
<tr>
<td>POSITIVE COPING</td>
<td>.2134</td>
<td>-.0756</td>
<td>-.0966</td>
<td>-.1516</td>
<td>1.0000</td>
<td>-.0572</td>
<td>-.0670</td>
</tr>
<tr>
<td>BARTHEL</td>
<td>-.1497</td>
<td>-.0317</td>
<td>.0574</td>
<td>-.1257</td>
<td>.0572</td>
<td>1.0000</td>
<td>.0764</td>
</tr>
<tr>
<td>BMD</td>
<td>.2997</td>
<td>.1376</td>
<td>.3195</td>
<td>.1148</td>
<td>-.0670</td>
<td>.0764</td>
<td>1.0000</td>
</tr>
</tbody>
</table>

* - Significance Level .05  ** - Significance Level .01  (2-tailed)
RATINGS OF EE COMPONENTS:
Categorisation of caregivers by EE scores using the EE-critical comments criteria were undertaken using the dichotomised cut-off scores of High-EE and Low-EE as proposed by Magaña et al, (1986). The speeches that did not meet the requirements for high-EE (critical) were rated as Low-EE.
In relation to EE-critical, 17 caregivers (53.1%) were rated as high-EE (critical) and 15 caregivers (46.9%) as Low-EE. Attempts to assess caregivers using the EE-Emotional Overinvolvement (EOI) criteria created many difficulties, due to the ambiguity of rating criteria to the specific aspects of spousal relationships. For example following the initial analyses of 25 audiotapes only two caregivers could be placed in the high EOI category. Therefore EE ratings were only based on the rating of critical comments. No further analyses using the EOI-EE criteria were undertaken in this study.

INTER-RATER RELIABILITY OF MEASUREMENT OF EE:
In order to examine the reliability of classifications of EE-(Critical), the inter-rater reliability of the initial ratings of eleven randomly selected audiotapes was undertaken by experienced Clinical Psychologist (AF) who was blind to the personal details pertaining to these caregivers. One caregiver audiotape was unable to be rated due to its inaudible quality therefore analyses were based upon 10 audiotapes. Using the Kappa statistic (which measures the agreement between two raters) the calculated Kappa value for agreement on the EE category was .62 reflecting agreement on 90% of the ratings.
PART B

COMPARISON OF HIGH-EE AND LOW-EE CAREGIVERS IN RELATION TO DEMOGRAPHIC INFORMATION:

Because of the small sample size of 32, two-tailed non-parametric tests were initially chosen to explore the relationship between EE and the elements of burden experienced by spousal caregivers. As shown in Table 9 and Table 10 analyses of the demographic details were undertaken using a series of non-parametric Mann-Whitney U tests to determine whether the EE subgroups differed with regard to specific demographic factors.

Table 9 DEMOGRAPHIC CHARACTERISTICS OF CAREGIVERS AND CARE-RECIPIENTS ON BASIS OF EE-RATING.

<table>
<thead>
<tr>
<th></th>
<th>HIGH EXPRESSED EMOTION (HOSTILITY)</th>
<th>LOW EXPRESSED EMOTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 17</td>
<td>N = 15</td>
</tr>
<tr>
<td>Age of caregiver (yrs.)</td>
<td>70.18 (8.19)</td>
<td>71.8 (8.88)</td>
</tr>
<tr>
<td>Age of care-recipient (yrs.)</td>
<td>71.35 (7.88)</td>
<td>72.87 (8.20)</td>
</tr>
<tr>
<td>Length of time caregiving (mths)</td>
<td>24.06 (12.16)</td>
<td>24.37 (9.40)</td>
</tr>
<tr>
<td>Length of marriage (yrs.)</td>
<td>45.88 (10.63)</td>
<td>47.00 (18.73)</td>
</tr>
</tbody>
</table>

The analyses revealed that caregivers in the High-EE and Low-EE Groups did not differ in relation to caregiver and care-recipient age, length of time caregiving and length of marriage.

Table 10 DESCRIPTIVE DEMOGRAPHICS DETAILS OF CAREGIVERS AND CARE-RECIPIENTS ON BASIS OF EE-RATING.

<table>
<thead>
<tr>
<th></th>
<th>HIGH EXPRESSED EMOTION (HOSTILITY)</th>
<th>LOW EXPRESSED EMOTION</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N = 17</td>
<td>N = 15</td>
</tr>
<tr>
<td>Caregiver Gender.</td>
<td>7 Male</td>
<td>7 Male</td>
</tr>
<tr>
<td>Care-recipient Gender.</td>
<td>10 Female</td>
<td>8 Female</td>
</tr>
<tr>
<td>Quality of the marital relationship (pre-illness onset)</td>
<td>Good 14 (82.35%)</td>
<td>Good 14 (93.33%)</td>
</tr>
<tr>
<td></td>
<td>Indifferent 3 (17.65%)</td>
<td>Indifferent 0 (0%)</td>
</tr>
<tr>
<td></td>
<td>Poor 0 (0%)</td>
<td>Poor 1 (6.67%)</td>
</tr>
<tr>
<td>Quality of the marital relationship (current)</td>
<td>Good 5 (29.4%)</td>
<td>Good 7 (46.67%)</td>
</tr>
<tr>
<td></td>
<td>Indifferent 9 (52.94%)</td>
<td>Indifferent 5 (33.33%)</td>
</tr>
<tr>
<td></td>
<td>Poor 3 (17.64%)</td>
<td>Poor 3 (20.00%)</td>
</tr>
<tr>
<td>Caregiving Impact on Health</td>
<td>No Impact 3 (17.65)</td>
<td>No Impact 3 (20%)</td>
</tr>
<tr>
<td></td>
<td>Slight Impact 4 (23.53)</td>
<td>Slight Impact 3 (20%)</td>
</tr>
<tr>
<td></td>
<td>Major Impact 10 (58.82)</td>
<td>Major Impact 9 (60%)</td>
</tr>
<tr>
<td>Quality of sleep</td>
<td>Poor - 3 (17.65%)</td>
<td>Poor - 2 (13.33%)</td>
</tr>
<tr>
<td></td>
<td>Variable 1 (5.88%)</td>
<td>Variable 4 (26.67%)</td>
</tr>
<tr>
<td></td>
<td>Good 3 (17.65%)</td>
<td>Good 4 (126.67%)</td>
</tr>
<tr>
<td></td>
<td>Poor 5 (29.41%)</td>
<td>Poor 3 (20.00%)</td>
</tr>
<tr>
<td></td>
<td>Variable 5 (29.41%)</td>
<td>Variable 2 (13.33%)</td>
</tr>
</tbody>
</table>
In relation to the dichotomous variables a number of contingency tables were created and statistical analyses by means of chi-square or Fishers exact test revealed that caregivers in the High-EE and Low-EE sub-group showed no significant differences gender, in pre-marital or current marital satisfaction.

**RELATIONSHIP BETWEEN EE AND PSYCHOLOGICAL OUTCOME IN CAREGIVERS:**

Further non-parametric tests were chosen to explore the relationship between EE and the elements of burden experienced by the caregiver. Caregiver objective and subjective burden were examined separately in relation to caregiver EE, together with psychological well-being as measured by the General Health Questionnaire.

**Table 11 MEAN SCORES AND STANDARD DEVIATIONS OF OBJECTIVE AND SUBJECTIVE BURDEN AND GENERAL HEALTH QUESTIONNAIRE.**

<table>
<thead>
<tr>
<th></th>
<th>Mean Score (sd)</th>
<th>High Expressed Emotion (Hostility) N = 17</th>
<th>Low Expressed Emotion N = 15</th>
</tr>
</thead>
<tbody>
<tr>
<td>Objective Burden</td>
<td>16.47 (4.81)</td>
<td>15.00 (5.63)</td>
<td></td>
</tr>
<tr>
<td>Subjective Burden</td>
<td>42.71 (11.56)</td>
<td>26.87 (13.10)</td>
<td></td>
</tr>
<tr>
<td>General Health Questionnaire</td>
<td>27.59 (8.68)</td>
<td>21.80 (14.52)</td>
<td></td>
</tr>
</tbody>
</table>

There was a non-significant difference between the low and high EE groups for the rating of Objective Burden. However there was a significant difference between caregivers' rating of subjective burden (U = 45.0, p <0.002). In addition, although not statistically significant, there appeared to be a trend towards significance for the General Health Questionnaire ratings (i.e. U = 80.5, p = .0756). For both these responses a higher mean response was associated with the high-EE group. Therefore the hypothesis was partially supported in that high-EE caregivers reported to having experienced higher levels of subjective burden of care than low-EE caregivers.

**COPING STRATEGIES AND EE:**

In order to answer the hypotheses of whether spousal EE was related to the use of specific coping strategies a number of analyses were undertaken. Because of the relatively small sample size (and therefore lack of power analysis requirements needed for some statistical analyses), only two-tailed non-parametric tests were chosen to explore the relationship between EE and the individual elements of the coping strategies.
Table 12  **MEAN SCORES AND STANDARD DEVIATIONS OF COPING SCORES OBTAINED FROM HIGH EE CAREGIVERS AND LOW-EE CAREGIVERS.**

<table>
<thead>
<tr>
<th>COPING STRATEGY</th>
<th>MEAN STANDARD SCORE</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>HIGH EXPRESSED EMOTION (HOSTILITY)</td>
</tr>
<tr>
<td>Logical Analysis</td>
<td>44.82 (12.31)</td>
</tr>
<tr>
<td>Positive Appraisal</td>
<td>45.58 (8.29)</td>
</tr>
<tr>
<td>Problem solving</td>
<td>47.35 (10.86)</td>
</tr>
<tr>
<td>Seeking Support</td>
<td>50.29 (12.16)</td>
</tr>
<tr>
<td>Alternative Rewards</td>
<td>53.82 (10.08)</td>
</tr>
<tr>
<td>Acceptance</td>
<td>54.88 (7.98)</td>
</tr>
<tr>
<td>Cognitive Avoidance</td>
<td>57.24 (9.97)</td>
</tr>
<tr>
<td>Emotional Discharge</td>
<td>66.18 (8.45)</td>
</tr>
</tbody>
</table>

Analysis of individual coping strategies between high-EE and low-EE caregivers revealed a statistical significant difference between high-EE caregivers' use of 'emotional discharge' as a strategy for coping when compared to low-EE caregivers.

**YOUNGER ONSET AND LATER ONSET SPOUSAL CAREGIVERS**

Using the criteria of younger and older onset dementia as another exploration of the data, the sample revealed that 9 caregivers were caring for a spouse with younger onset dementia and 23 caregivers were caring for caregivers with later onset dementia. The means and standard deviations on the caregiver and care-recipient variables are presented in Table 13.

Table 13  **YOUNGER AND OLDER ONSET DEMENTIA CAREGIVERS**

<table>
<thead>
<tr>
<th></th>
<th>MEAN STANDARD SCORE (sd)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>YOUNGER ONSET</td>
</tr>
<tr>
<td>Objective Burden</td>
<td>18.44 (4.77)</td>
</tr>
<tr>
<td>Subjective Burden</td>
<td>39.22 (15.82)</td>
</tr>
<tr>
<td>General Health Questionnaire</td>
<td>25.47 (13.31)</td>
</tr>
<tr>
<td>Barthel</td>
<td>9.77 (5.80)</td>
</tr>
<tr>
<td>BMD</td>
<td>56.11 (18.38)</td>
</tr>
<tr>
<td>Adaptive Coping</td>
<td>48.38 (6.70)</td>
</tr>
<tr>
<td>Non Adaptive Coping</td>
<td>57.16 (6.12)</td>
</tr>
</tbody>
</table>
GENDER:

Using the criteria of caregiver gender as another exploration of the data the sample revealed that 14 caregivers were male and 18 caregivers were females. The means and standard deviations on the caregiver and care-recipient variables are presented in Table 14.

Table 14 ANALYSIS OF CAREGIVER DATA BY GENDER

<table>
<thead>
<tr>
<th></th>
<th>MALE CAREGIVER</th>
<th>FEMALE CAREGIVER</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Objective Burden</strong></td>
<td>12.93 (4.39)</td>
<td>18.00 (4.71)</td>
</tr>
<tr>
<td><strong>Subjective Burden</strong></td>
<td>26.86 (12.54)</td>
<td>41.83 (12.66)</td>
</tr>
<tr>
<td><strong>General Health Questionnaire</strong></td>
<td>25.64 (9.58)</td>
<td>24.28 (13.75)</td>
</tr>
<tr>
<td><strong>Barthel</strong></td>
<td>10.57 (5.22)</td>
<td>10.83 (4.78)</td>
</tr>
<tr>
<td><strong>BMD</strong></td>
<td>46.14 (17.90)</td>
<td>44.5 (24.32)</td>
</tr>
<tr>
<td><strong>Adaptive Coping</strong></td>
<td>49.14 (6.49)</td>
<td>47.37 (5.05)</td>
</tr>
<tr>
<td><strong>Non Adaptive Coping</strong></td>
<td>55.55 (5.59)</td>
<td>55.08 (5.22)</td>
</tr>
</tbody>
</table>
PART C:

CAREGIVERS’ AWARENESS OF THEIR OWN EXPRESSED EMOTION:

Caregiver’s awareness of their affective disposition toward their care-recipient was assessed by using a self-report adjective checklist and was then compared to their FMSS-EE (Critical) ratings of Expressed Emotion.

Reliability of the Adjective Scale

Initially the degree to which the group of 10 positive and 10 negative adjectives each measured the same domain was assessed by creating separate negative and positive adjective sub-scales and calculating the corresponding alpha reliability coefficients for the two times the spouses rated the adjectives (i.e. when describing their own behaviour and the behaviour of their partner).

Table 15  CAREGIVER SELF RATINGS AND CAREGIVER RATINGS OF CARE-RECIPIENT BEHAVIOUR OF POSITIVE AND NEGATIVE ADJECTIVES:

<table>
<thead>
<tr>
<th></th>
<th>Spouse Caregivers Self Rating</th>
<th>Spouses' Rating of Care-Recipient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive Adjectives</td>
<td>6.09 (1.67)</td>
<td>4.37 (1.89)</td>
</tr>
<tr>
<td>Negative Adjectives</td>
<td>2.65 (1.60)</td>
<td>3.12 (1.87)</td>
</tr>
</tbody>
</table>

The caregivers’ mean self-rating on the negative adjectives was 2.65 (sd 1.60) and their mean rating of their relatives’ on the negative adjectives scale was 3.12 (sd 1.87) Using the Spearman’s Rho correlation it was shown that there was a significant relationship between caregivers’ self-rating of their negative behaviour and their spouse care-recipient’s behaviour (i.e. r = .29; p < 0.01).

The caregivers’ mean self-rating on the positive adjectives scale was 6.09 (sd = 1.67) and was also shown to be significantly correlated to their mean ratings of their care-recipient’s positive behaviour (i.e. r = .09; p < .05).
It was also found that the spouses mean self ratings on the negative adjective scale was inversely related to their mean self-ratings on the positive adjectives scale (r = -.28, p < .01). Also caregivers’ the ratings of their care-recipient on the negative adjectives scale was inversely related to their ratings of their care-recipient on the positive adjectives scale (r = .09, p < .05).

The close association of self- and care-recipient ratings on both the positive and negative subscales along with the inverse relationship of negative and positive ratings by the caregivers and their ratings of their care-recipients suggest that the spouses were giving responses that reflected the accordant attitudes regarding the emotional quality of their relationship with their partner.

ASSOCIATION BETWEEN ADJECTIVE RATINGS AND FMSS-EE RATINGS:

Another central question addressed in this part of the study was whether the spouse caregivers of perceive in themselves EE attitudes similar to those assessed by raters outside the family. The relationship between self-ratings and EE was assessed by comparing the adjective ratings and the FMSS-EE ratings. As demonstrated in the previous section the spouse caregivers were able to be placed into one of two groups: high-EE critical and low-EE depending on their FMSS-EE Ratings. A series of two-tailed Mann-Whitney U tests were conducted to address the question of whether relatives in the FMSS-EE groups differed with respect to their adjective ratings.

Negative Adjectives:

Spouse caregivers in the High EE-critical and Low-EE Groups did not statistically differ in their adjective ratings when describing their negative behaviour toward their care-recipient partner (i.e. High-EE caregivers:- \( \bar{x} = 2.58 \ [sd 1.56] \); Low-EE caregivers:- \( \bar{x} = 2.57 \ [sd 1.65] \); \( U = -.60, p > .05 \)).

Also, when describing their care-recipients' negative behaviour towards them, the caregivers’ did not differ significantly in their ratings of negative behaviour by FMSS-EE groupings. (i.e. High-EE caregivers:- \( \bar{x} = 3.17 \ [sd 1.92] \); Low-EE caregivers:- \( \bar{x} = 3.07 \ [sd 1.81] \), \( U = -.36, p > 0.05 \). (See Figure 6)
From these results it appeared that the High-EE spouses did not rate themselves higher on the negative adjectives when describing their own behaviour toward their care-recipient or their care-recipients' behaviour towards them when compared to Low-EE spouses.

**Positive Adjectives:**

Spouse caregivers in the High-EE (critical) and Low-EE Groups did not differ in their ratings of positive adjectives when describing their own behaviour toward their care-recipient. (i.e. High-EE caregivers: mean = 6.24 [sd 1.59]; Low-EE caregivers: mean = 5.93 [sd 1.75]; U = -1.53, p < 0.05).

However, when describing the care-recipient's behaviour toward them there was a significant difference in the positive adjective ratings by FMSS-EE groups (i.e. High-EE caregivers: mean = 4.09 [sd 2.00]; Low-EE caregivers: mean = 4.67 [sd 1.71]; U = -2.87, p > 0.01). [see Figure 7]
From this analysis it appears that relatives were sensitive to their level of positive behaviour, such that their ratings on the positive behaviour differentiated the two groups. Nevertheless the caregivers appeared not to be sensitive to the level of their perceptions of their own and the care-recipient levels of negative behaviour.
DISCUSSION:

The discussion will focus on four key issues: The first section will link in the analysis findings from the study with the postulated research hypotheses, which will then be discussed in relation to the current literature. A critique of the current research will be undertaken in the second section, reflecting upon the methodological and conceptual difficulties associated with research investigating emotional expression and associated difficulties with undertaking research with this population. In the third section a discussion will be undertaken as to the clinical implications of these research findings, both in terms of the provision of services and in relation to specific caregiver-care-recipient interventions. Finally, future research questions are presented in light of the findings ascertained from this present study.

One needs to be cautious in interpreting the results, given the number of statistical comparisons conducted on the data and overall size of sample. Nevertheless the results of this study provide some support for the existence of the relationship of EE and the burden experienced by spouse caregivers caring for a partner with a dementing illness. From the analysis of the data spousal caregivers who were shown to be ‘at risk’ of higher levels of subjective burden’ were those who reported:- a poor marital satisfaction prior to illness onset; were female; reported care-recipient need for high levels of physical care; and displayed high expressed emotion (critical). These findings have then supported some of the hypotheses posed at the beginning of this research paper. It is now recognised throughout the caregiving literature than many caregivers experience a high degree of stress as reflected in their subjective burden and GHQ ratings and the chronic nature of this experience can create long term physical health problems for the caregiver. Evidence was also collated to highlight that the affective climate (reflected by the critical EE) appeared to be associated with greater caregiver distress. However there was no relationship between EE classification and caregivers reported behavioural, cognitive or ADL decline in the care-recipient. This particular finding has been replicated other studies in certain aspects in that cognitive and ADL decline was not related to EE (i.e. Vitaliano et al, 1990).

In relation to separating the caregiver spouse group into different grouping variables revealed that there were no significant differences between groups when analysed by younger or older onset dementia criteria, reflecting that differences between caregivers may be better assessed by caregiver stress measures, rather than by classification by caregiver age.
Analyses of coping strategies revealed that most caregivers reported the use of more emotional discharge coping. However overall it was evident that caregivers generally reported that they had a wide range of coping (both maladaptive and adaptive) strategies available to them.

The assessment of caregivers awareness of their own emotions indicated that they were unable to predict the negative emotions as they had been rated by the FMSS. This may therefore offer a way of intervening with caregivers via an educative cognitive behavioural framework, by which to facilitate caregivers awareness of their reactions and the reciprocal effects upon the care-receiver.

Looking at the distribution of caregivers allocated into groups by EE, emotional discharge was shown to be significantly related to caregivers in high EE group. Since the classification is based on the expression of hostility these findings may report the presence of a more generalised expression of emotional discharge within the spousal relationship (i.e. lability, frustration). Some of the difficulty with current research on EE has stemmed from the discussion of the nature of ‘expressed emotion’. This research fails to identify whether the pattern is a long-standing family interactions or merely a response to a stressful situation. It still can be argued that its full clinical meaning needs to be elucidated. In addition this study has only investigated one perspective of the interactive model (i.e. the caregivers). However this study has to a limited extent supported the proposal of a specific dyadic model of interaction between spousal caregivers and care-recipients to help explain the process of caregiving. This model may be more helpful in understanding the interrelationship between the factors highlighted by Pearlin et al, (1990). In this proposed interactive model, it can be seen that care-recipient symptoms and other problem behaviour elicit frustration, distress and concern from the spousal caregiver, and prompts attempts to cope (see Figure 8). Unfortunately these attempts at coping sometimes involve critical or intrusive interactions. The resultant negative emotions exacerbate their partner’s symptoms and make it more difficult for them to function effectively. The interactive approach sees the behaviour of both caregiver and care-recipient as reactions to stress, and as attempts to cope with it. In doing so it implicitly recognises the role of the two moderator variables; the interpretation that each individual makes of the other’s behaviour and the coping skills that each can bring to bear. Interpretations of behaviour that attribute a benign intent (e.g. an attempt to help me) reduce the chance of a negative interaction developing. Similarly better coping skills (or a less confrontational style of coping) will increase the chance of a more positive outcome of the
interaction. This model is embedded within the context of external stressors that are simultaneously operating on the individuals. This description links the EE concept both within a cognitive-behavioural approach to aggression (e.g. Patterson, 1982) and within the literature on stress and social support. To adapt these approaches explicitly to dementia, the biological component of dementia needs to be included. It is this factor that induces the cognitive and activities of daily living (ADL) decline and the potential development of psychotic symptoms.

In relation to spousal caregivers, their response to their care-recipient partner has been shown to be a 'stress reaction'. When their partner engages in behaviour that has potentially negative effects, it triggers attempts by them to control the behaviour or minimise its negative effects. When considerable effort is required to monitor their partner's behaviour and reduce its negative impact, the attempt can disrupt other activities and been seen as extremely burdensome (Fadden et al 1987). Individual instances of problem behaviour can also elicit expressions of anger and frustration. Within the model, all of these reactions are moderated by the interpretation of the behaviour and by the coping resources the person has available. Sometimes attempts to deal with the situation are based on misunderstandings about the reasons for the patient's behaviour, or by the inability of carers to moderate their own stress reactions, for example displaying their anger over incessant questions. When attempts to cope with patients behaviour involve interactions that are perceived as critical or intrusive, a potentially destructive feedback loop is established. For example, a relative may try to encourage their partner to have a bath by shouting to him/her. If a relative (due to cognitive difficulties) views this as unwarranted intrusion he/she may respond angrily. Frequently both parties then become upset and the relative refuses to have a bath for even longer. This study has shown that there is evidence that hostile interchanges do occur in high EE environments (Stachan et al, 1989). When negative interchanges occur frequently coping strategies become automised, fixated and non-flexible. This further perpetuates the cycle and thus exacerbates the difficulties associated with caregiving.
Figure 8: Hypothetical Dyadic Interactional Model of Caregiving Between Spousal Caregiver and Care-Recipient.

- **Inputs**: Internal + External Stressors
  - e.g., Primary Stressors (e.g., Cognitive, behavioral, physical decline of care-recipient)

- **Outputs**: Adaptive or maladaptive (e.g., high EE)

- **Perceived Burden**

- **Psychological**
  - Emotional
  - Physical

- **Mediator**: Coping

- **Negative Impact**
**Methodological Limitations:**

It is important to highlight a number of methodological problems associated with the preceding study, which need to be taken into account when reviewing its findings. Firstly, the sample was comprised of a relatively small sample size. Since power analysis was not attained, one must view the statistical analyses with reasonable caution when interpreting the non-significant findings. However, despite the smallness in sample size, the homogeneity of spouse caregivers in relation to certain characteristics, (i.e. recruitment of caregivers from a specified length of time within the caregiving trajectory and spousal caregivers), has provided detailed information about the experiences of spousal caregivers. In relation to the measurement of variables, it should be noted that there were significant difficulties in finding reliable and valid measures which adequately measured the subjective factors and experience of caregiving (e.g. burden and EE- emotional overinvolvement). In the case of the latter measure, the FMSS-EE is a categorical, dichotomous non-parametric measure that primarily uses content analyses of speech as its raw data and as such uses a dichotomous key of high and low EE as it classification of expressed emotion. It therefore has the potential to lose useful information since it ignores the ‘continuum’ as well as limiting the application of more sophisticated statistical analyses. In addition the EOI diagnostic category appeared to be unhelpful in this study. However, the comparative difficulties in the measurement of over-involvement with spousal caregivers appeared to be in-keeping with other studies. This was not to say that caregivers did not express some concern. It was felt however that this is not necessarily rated as high EE according to the original criteria of unusual self-sacrificing or overprotective behaviours. Therefore it may be helpful for future research to modify these diagnostic categories.

In addition, there has been recent concern as to whether EE measures reflect the ‘usual’ and consistent patterns of family interaction. Although research has demonstrated a strong relationship between high levels of EE and the course of serious psychopathology, the exact mechanisms by which these affective attitudes have an effect remain to be fully delineated (Friedmann & Goldstein, 1993). Also, behavioural interventions using EE measurement as an outcome measure has increasingly been questioned and has been recently cited as being ‘too gross’ to measure the subtleties of change in caregiver dyad relationships, especially those relating to spousal dyads (Mathews, 1995). Indeed the concept of Expressed Emotion and its dichotomous classification appears to generate simplistic and unwarranted theoretical assumptions about the mechanisms of action.
For example the assumption that:

1. EE measures unidirectional transactional process within a family,
2. the affective attitudes towards the care-recipient arises independently of the stress placed upon the family by the relatives psychiatric disorder, both on its past and present manifestations, and
3. relatives are exclusively responsible for the affective climate of a family containing the ‘ill’ individual.

As indicated earlier, this study also found that objective burden (i.e. the practical activities associated with caregiving) was the key factor related to caregivers reporting of subjective burden. This result may be an artefact of the rating scale design, since both scales are constructed from the same data.

The term however has never been located within a matrix of theory but has instead, been defined mostly by criteria developed from empirical findings. Its strength lies in the careful operationalised criteria for measuring expressed emotion the consequent aggregation of results that justify its significance as predictor of recurrence of a disorder and the linkage between risk factors identified and the subsequent family interventions that were developed and tested in controlled trials.

The strength of this study is that it attempted to use standardised measurements of coping, psychological well-being, and Expressed Emotion amongst a homogenous group of spouse caregivers who were coping with similar kinds of stressors. It can be seen that research has focused upon a number of themes associated to the stress felt and experienced by many caregivers, (for example the severity of dementia and level of problem behaviour shown by the care-recipient, the type of relationship between caregiver and care-recipient and the quality of the past relationship, the cognitive and coping styles used by caregivers and their mediation upon stress outcomes.) Although it is evident that caregiving has enormous psychological impact, it is still un-certain which combination of these elements in the caregiving experience contribute to or mitigate this distress. Such information could greatly enhance treatment strategies and assist policy makers.
**Clinical Implications:**

A number of clinical applications seemed evident as a result of curtailing the length of the EE assessment. The FMSS procedure could be used to assess dimensions of family emotional atmosphere in a way that would aid in the selection of appropriate treatment. Therefore determining the quality and the nature of the relationship in spouse appears to be the foundation upon which to base proactive caregiver interventions for these caregivers who are at risk of difficulties in the future. With the emphasis upon community care in current health care policy, the opportunity to provide psychotherapeutic interventions, addressing coping techniques, and/or affective styles within dyadic relationships appears to offer a way of active support and intervention. Indeed, this intervention has been shown to have a great impact with other chronic conditions such as schizophrenia. Further, in light of caregivers legal right for their own assessment of need, it offers an opportunity to offer an intervention which does not necessarily require an increase in limited care-recipient resources (i.e. day-care or respite care).

**Future Research:**

The main criticism of this research is that caring for a relative with a dementing illness has been traditionally conceptualised as a unitary stressor. Consequently it does not provide information about how relatives' cope with specific stressors imbedded within the general stressful experience of caring for a spouse with dementia. Yet, it seems likely that quite different strategies are adaptive in coping with challenges that range from providing physical care to watching someone's gradual decline. Psychosocial intervention aimed at reducing EE in families may then be more appropriate in improving coping and or reducing strain and distress and possibly in promoting continuing community care.

The temporal stability of the EE measure needs to be investigated properly together with the co-variation of the relative level of burden and coping skills and patients level of symptomology and social functioning. In addition there is a growing recognition of the relationship between appraisal of the stressful situation and the use of specific coping strategies reflecting a more complex process associated with coping. This study has only focused on examining caregivers' coping strategies and thus did not collate information relating to caregiver appraisal to their situation. Future research needs to implement additional multi-variate analyses and longitudinal designs with frequent reassessment and follow-through studies.
It is also clear that the concept of EE is not a unitary one, and probably represents an amalgam of general and stable interpersonal attitudes and responses to the patient, together with more specific responses to the impact of having a partner with dementia. Therefore, in future research it may be helpful to re-fashion or at least subdivide EE into more meaningful components in order for it to relate to the concepts of illness and burden-related variables. Also little work has been undertaken on the reciprocity of emotional attitudes (as with more traditional family therapy) between caregiver and care-recipient and it can be seen to be a fundamental necessity for future research.

**SUMMARY:**
The findings emphasise the need to investigate caregiver distress upon a number of contrasting variables. This study has reinforced the need to move beyond the behavioural and instrumental dimensions alone. The quality of the relationship between that care-recipient and their spouse appears to be a crucial determinant in predicting caregivers ability to continue to provide home care. Determining the quality and nature of this relationship in spouses appears to be a necessary clinical requirement upon which to base more efficacious caregiver and care-recipient interventions.
REFERENCES:


Billings, A. & Moos, R.H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioural Medicine, 4:* 139-57


Moos, R.H. (1990). Coping Responses Inventory Manual. Social Ecology Laboratory, Dep’t Psychiatry and Behavioural Sciences, Stanford University and Veterans’ Administration Medical Centres, Palo Alto, CA


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Wright, L.K. (1994). Alzheimer’s disease afflicted spouses who remain at home: Can human Dialectics explain the findings? *Social Science & Medicine, 38*(8) 1037-1046


Ms Louise H Adams
Clinical Psychology Department
Severalls Hospital
Boxted Road
COLCHESTER

Dear Ms Adams

EMOTIONAL EXPRESSION, LEVEL OF BURDEN & COPING AMONGST SPOUSAL CAREGIVERS OF PARTNERS WITH YOUNGER ONSET AND OLDER ONSET DEMENTIA

Thank you for attending the meeting of the Research Ethics Committee on 4th March 1997. Approval to proceed has been granted on condition a final report is received by the Ethics Committee.

Yours sincerely

Dr P E Dixon
Chairman
Research Ethics Committee
APPENDIX C:

CAREGIVER RESEARCH INFORMATION SHEET AND CONSENT FORM:
Dear

Following our telephone conversation asking if you would be willing to participate in a study about the ‘experiences of carers’, I have enclosed an information sheet which explains in more detail about the research project.

As you will read in the sheet you will be asked to complete some questionnaires and to talk about your experiences of caring for your partner.

I would like to emphasise that your participation is voluntary and you do not have to participate. This will not effect any services that you or your partner currently receive or any future services.

As agreed during our telephone conversation I will visit your home on . If for any reason this is not convenient, please do not hesitate to contact me or Georgina Charlesworth (Clinical Psychologist) on the above telephone number.

Thank you for your help.

Yours sincerely,

Louise Adams
(Clinical Psychologist in Training)
Introduction:
It has been estimated that there are about 600,000 dementia sufferers in Great Britain. Eight out of ten people with dementia live at home supported by their spouse or another family member. Family support is thought to be the most important thing in helping a person with dementia to stay in their own homes. However, the many pressures and demands placed on carers can prove over-whelming.

Dementia is not a disorder that just affects older people (i.e. people over the age of 65 years), it can affect people as young as 20 years of age.

This study aims to gather information about the experiences of carers who are caring for a partner with a dementia type illness and would be grateful if you would consider taking part. This information sheet aims to answer some of your questions, as you are deciding whether or not you wish to participate.

What is this study for?
The aim of the study is to learn about the experience of being a carer for someone with a dementia type illness. It will be trying to find out from your point of view, how you see your caregiving role and how this affects other areas of your life such as your mental and physical health, your personal relationships with your partner and other family members. It will also be seeing if there are common themes amongst carers about how they cope and manage and to see if there are ways of identifying carers who may require more support.

Why have you been approached?
The aim of this study is to learn from those who know most about what it is like to care for someone with a dementing illness.

What will you have to do?
I will arrange to meet up with you, preferably when you have some time to yourself. This can be at your home, or if necessary at another convenient location. I will show you the types of questionnaires that you will be asked to fill in during the interview.
If you wish to take part, the interview will probably last between one and two hours. With your permission, part of the interview will be recorded as most people find this far less distracting than someone taking extensive notes.

**What will You be asked about?**
You will be asked a range of questions about your experiences of caring for your partner. This will also include questions about your health, how you cope, and caring situations that you find stressful.

**Do You have to take part?**
No, participation is not compulsory and you can take part but opt not to answer all questions. All the information you give will be treated in confidence, and neither your name, nor the name of the person you care for, will appear in any report written about the study.

Taking part will not effect the current or future support you receive from either Health or Social Services, and you may withdraw from the study at any point without having to give a reason, without prejudice to the person you care for, your care or the care of your family.

**What will happen to the information?**
Once the information on the audio tapes has been analysed by myself and Ann Fawcett (Clinical Psychologist) the tape will be destroyed. The questionnaires will be stored in a secure file at the Clinical Psychology Office, King's Wood Centre, Colchester. Essex.

If you have any more questions, please do not hesitate to contact:

Louise Adams, Clinical Psychologist in training,  
or Dr. Georgina Charlesworth (Clinical Psychologist)

Clinical Psychology Department, King's Wood Centre, Turner Road, Colchester, Essex. CO4 5JY Tel: 01206 228970
I have read the 'Information Sheet for Carers: Study of Carer's level of expressed emotion, levels of burden and coping abilities upon caring for a spouse with a dementia-type illness' and agree to participate in this study.

Name of Carer: .....................................
Signature: ........................................  Date: ......................

Witnessed: ........................................
Signature: ........................................  Date: ......................
APPENDIX D:

QUESTIONNAIRES & SCHEDULED ADMINISTERED TO CAREGIVERS

- Carer’s Interview Schedule:
- Emotional Adjective Checklist:
- Behaviour & Mood Disturbance Scale:
- Barthel ADL Index:
- GHQ-28:
- Screen of Caregiver Burden:
- Coping Responses Inventory:
- Five Minute Speech Sample:
<table>
<thead>
<tr>
<th><strong>NAME OF CARER</strong></th>
<th><strong>D.O.B</strong></th>
<th><strong>M/F</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>NAME OF CARED FOR PARTNER</strong></td>
<td><strong>D.O.B</strong></td>
<td><strong>M/F</strong></td>
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<tr>
<td><strong>RELATIONSHIP</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>DIAGNOSIS</strong></td>
<td><strong>DATE OF FORMAL DIAGNOSIS</strong></td>
<td></td>
</tr>
<tr>
<td><strong>DURATION OF DEMENTIA FROM THE FIRST EVIDENCE OF DISEASE</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>CARER MARITAL STATUS</strong></td>
<td><strong>DATE OF MARRIAGE</strong></td>
<td></td>
</tr>
<tr>
<td><strong>WHERE PARTNER CURRENTLY LIVES</strong></td>
<td>(IF APPLICABLE)</td>
<td></td>
</tr>
<tr>
<td><strong>CARER/PARTNER EMPLOYMENT</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>NUMBER OF CHILDREN (THOSE AT HOME)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>OCCUPATIONAL HISTORY OF CARER/PARTNER</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>INCOME</strong></td>
<td></td>
<td></td>
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<tr>
<td><strong>LENGTH OF TIME CARING FOR PARTNER</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>EXTENT OF CARER’S FORMAL SUPPORT</strong></td>
<td></td>
<td></td>
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<tr>
<td><em>No of agencies:</em></td>
<td><em>Satisfaction with Support (1-5):</em></td>
<td></td>
</tr>
<tr>
<td><strong>EXTENT OF CARER’S INFORMAL SUPPORT</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
CAREGIVER HEALTH:

MEDICAL/PSYCHIATRIC HISTORY

DESCRIPTION OF CURRENT HEALTH

CURRENT MEDICAL PROBLEMS

UNDER MEDICAL SUPERVISION

REGULAR MEDICATION USAGE

SLEEP

IMPACT ON HEALTH DUE TO CARING FOR RELATIVE

PARTNER'S MEDICAL/PSYCHIATRIC HISTORY

MEDICAL/PSYCHIATRIC HISTORY

DESCRIPTION OF CURRENT HEALTH

CURRENT MEDICAL PROBLEMS

UNDER MEDICAL SUPERVISION

REGULAR MEDICATION USAGE

SLEEP

CARERS PERCEPTION OF MARITAL SATISFACTION BEFORE PARTNER'S ILLNESS:
(GOOD/INDIFFERENT/POOR)

CARERS PERCEPTION OF CURRENT MARITAL SATISFACTION:
(GOOD/INDIFFERENT/POOR)

ANY OTHER INFORMATION
### ADJECTIVE CHECKLIST

Below is a list of adjectives describing types of interaction which can occur between people. Please rate using the scale below *your* behaviour towards your *partner* during the last three months.

<table>
<thead>
<tr>
<th>Adjective</th>
<th>Scale</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting</td>
<td>1-8</td>
</tr>
<tr>
<td>Active</td>
<td>1-8</td>
</tr>
<tr>
<td>Angry</td>
<td>1-8</td>
</tr>
<tr>
<td>Bored</td>
<td>1-8</td>
</tr>
<tr>
<td>Clear</td>
<td>1-8</td>
</tr>
<tr>
<td>Co-operative</td>
<td>1-8</td>
</tr>
<tr>
<td>Considerate</td>
<td>1-8</td>
</tr>
<tr>
<td>Contrary</td>
<td>1-8</td>
</tr>
<tr>
<td>Deceitful</td>
<td>1-8</td>
</tr>
<tr>
<td>Devoted</td>
<td>1-8</td>
</tr>
<tr>
<td>Easy to get along with</td>
<td>1-8</td>
</tr>
<tr>
<td>Friendly</td>
<td>1-8</td>
</tr>
<tr>
<td>Good-Natured</td>
<td>1-8</td>
</tr>
<tr>
<td>Hostile</td>
<td>1-8</td>
</tr>
<tr>
<td>Irresponsible</td>
<td>1-8</td>
</tr>
<tr>
<td>Irritable</td>
<td>1-8</td>
</tr>
<tr>
<td>Lazy</td>
<td>1-8</td>
</tr>
<tr>
<td>Loving</td>
<td>1-8</td>
</tr>
<tr>
<td>Mean</td>
<td>1-8</td>
</tr>
<tr>
<td>Rude</td>
<td>1-8</td>
</tr>
</tbody>
</table>
ADJECTIVE CHECKLIST

Below is a list of adjectives describing types of interaction which can occur between people. Please rate using the scale below your partner's behaviour towards yourself during the last three months.

<table>
<thead>
<tr>
<th>Adjective</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
</tr>
</thead>
<tbody>
<tr>
<td>Accepting</td>
<td>Never</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<tr>
<td>Active</td>
<td>Never</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<tr>
<td>Angry</td>
<td>Never</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Bored</td>
<td>Never</td>
<td>1</td>
<td>2</td>
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<td>5</td>
<td>6</td>
<td>7</td>
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<tr>
<td>Clear</td>
<td>Never</td>
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<td>3</td>
<td>4</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Co-operative</td>
<td>Never</td>
<td>1</td>
<td>2</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Considerate</td>
<td>Never</td>
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<td>2</td>
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<tr>
<td>Contrary</td>
<td>Never</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Deceitful</td>
<td>Never</td>
<td>1</td>
<td>2</td>
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<td>7</td>
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<tr>
<td>Devoted</td>
<td>Never</td>
<td>1</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Easy to get along with</td>
<td>Never</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
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<tr>
<td>Friendly</td>
<td>Never</td>
<td>1</td>
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<tr>
<td>Good-Natured</td>
<td>Never</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Hostile</td>
<td>Never</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Irresponsible</td>
<td>Never</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td>6</td>
<td>7</td>
</tr>
<tr>
<td>Irritable</td>
<td>Never</td>
<td>1</td>
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<td>3</td>
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<td>7</td>
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<tr>
<td>Lazy</td>
<td>Never</td>
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<td>6</td>
<td>7</td>
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<tr>
<td>Loving</td>
<td>Never</td>
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<td>7</td>
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<tr>
<td>Mean</td>
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<td>7</td>
</tr>
<tr>
<td>Rude</td>
<td>Never</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
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<td>6</td>
<td>7</td>
</tr>
</tbody>
</table>

(Friedmann & Goldstein, 1994)
BEHAVIOUR & MOOD DISTURBANCE SCALE:
(Greene et al, 1982)

ID No: ............. Date: .................

Please indicate the degree to which the following behavioural and mood difficulties are currently being displayed by your spouse.

<table>
<thead>
<tr>
<th></th>
<th>NEVER</th>
<th>RARELY</th>
<th>SOMETIMES</th>
<th>FREQUENTLY</th>
<th>ALWAYS</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>Does not take part in family conversations:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>Does not read newspapers, magazines, etc.:</td>
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<td></td>
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<tr>
<td>3.</td>
<td>Sits around doing nothing</td>
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<tr>
<td>4.</td>
<td>Does not show an interest in news about friends and relatives:</td>
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<tr>
<td>5.</td>
<td>Does not start and maintain a sensible conversation</td>
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<td></td>
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<tr>
<td>6.</td>
<td>Does not respond sensibly when spoken to:</td>
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<td></td>
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<tr>
<td>7.</td>
<td>Does not understand what is said to him/her:</td>
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<tr>
<td>8.</td>
<td>Does not watch and follow television:</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>9.</td>
<td>Does not keep him/herself bust doing useful things:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>Fails to recognise familiar people:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>Gets mixed up about where he/she is:</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>12.</td>
<td>Gets mixed up about the day, year etc.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>Has to be prevented from wandering outside the house:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>Hoards useless things:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>Talks nonsense:</td>
<td></td>
<td></td>
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<tr>
<td>16.</td>
<td>Appears restless and agitated:</td>
<td></td>
<td></td>
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<tr>
<td>17.</td>
<td>Gets lost in the house:</td>
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<td></td>
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</tr>
<tr>
<td>18.</td>
<td>Wanders outside the house at night:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>Wanders outside the house and gets lost:</td>
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<td>20.</td>
<td>Endangers him/herself:</td>
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<td>21.</td>
<td>Paces up and down wringing his/her hands:</td>
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<td>22.</td>
<td>Wanders off the subject:</td>
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<td>23.</td>
<td>Talks aloud to him/herself:</td>
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<td>24.</td>
<td>Seems lost in a world of his/her own:</td>
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<td>25.</td>
<td>Mood changes for no apparent reason:</td>
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<td>26.</td>
<td>Becomes irritable and easily upset:</td>
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<td>27.</td>
<td>Goes on and on about certain things:</td>
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<td>28.</td>
<td>Accuses people of things:</td>
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<td>29.</td>
<td>Becomes angry and threatening:</td>
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<td>30.</td>
<td>Appears unhappy and depressed:</td>
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<td>31.</td>
<td>Talks all the time:</td>
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<td>32.</td>
<td>Cries for no obvious reason:</td>
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<td>33.</td>
<td>Looks frightened and anxious:</td>
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<td>34.</td>
<td>Gets up unusually early in the morning:</td>
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<td>ADL</td>
<td>Description</td>
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<td>BOWELS</td>
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<td>BLADDER</td>
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<td>GROOMING</td>
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<td>2 = walks with help of one</td>
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<td>BATHING</td>
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<td>1 = independent</td>
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FIVE MINUTE SPEECH SAMPLE (FMSS)

PROTOCOL:

The specific instructions given to the caregiver were

[ "... I'd like to hear your thoughts about (Patient's name) in your own words and without my interrupting you with any question or comments. When I ask you to begin, I'd like you to speak for five minutes telling me what kind of person (patient's name) is and how the two of you are getting along together...."

"After you have begun to speak I prefer not to answer any questions. Are there any questions you would like to ask me before we begin?"

This information will be recorded on audio tape. This data will be analysed and rated according to the criteria proposed by Magana et al (1986).
Below are a number of statements which have been given by caregivers about their experiences of caregiving. Please could you indicate whether you have experienced such experiences, and if so, indicate the level of your distress to the incident.

1. My spouse continued to drive when he/she shouldn’t
2. I have little control over my spouse’s illness
3. I have little control over my spouse’s behaviour
4. My spouse is constantly asking the same questions over and over again
5. I have to do too many jobs/chores (feeding, shopping, paying bills) that my spouse used to perform.
6. I am upset that I cannot communicate with my spouse
7. I am totally responsible for keeping our household in order
8. My spouse doesn’t co-operate with the rest of our family
9. I have had to seek public assistance or use savings to pay for my spouse’s medical treatment/care.
10. Seeking public assistance is demeaning and degrading
11. My spouse doesn’t recognise me all the time
12. My spouse has struck me on various occasions
13. My spouse has gotten lost in the supermarket
14. My spouse has been wetting the bed
15. My spouse throws fits and has threatened me
16. I have to constantly clean up after my spouse eats
17. I have to cover up for my spouse’s mistakes
18. I am fearful when my spouse gets angry
19. It is exhausting having to groom and dress my spouse every day
20. I try so hard to help my spouse but he/she is ungrateful
21. It is frustrating trying to find things that my spouse hides
22. I worry that my spouse will leave the house and get lost
23. My spouse has assaulted others in addition to me
24. I feel so alone - as if I have the world on my shoulders
25. I am embarrassed to take my spouse out for fear that he/she will do something bad
Coping Responses Inventory

This is your copy of the Coping Responses Inventory. It contains questions about how you manage important problems that come up in your life.

Please answer each question as accurately as you can. All your answers are strictly confidential. If you do not wish to answer a question, please circle the number of that question so that we know you have intentionally skipped it. If a question does not apply to you, please write ‘N/A’ (Not Applicable) in the margin next to the question.

We appreciate your cooperation.

What is your name? .................................................. 
What is today's date? ..............................................
COPING RESPONSES INVENTORY

Dealing with a problem or situation

Please think about the most important problem or stressful situation you have experienced DURING THE LAST 12 MONTHS (for example, having troubles with a relative or friend, experiencing the illness or death of a relative or friend, having an accident or illness, having financial or work problems). Describe the problem in the space provided below. If you have not experienced a major problem, then list a minor problem that you have had to deal with.

Describe the problem or situation


Part I

Please answer the following questions about the problem you have listed. Place an 'X' in the appropriate box.

<table>
<thead>
<tr>
<th>Question</th>
<th>Definitely No</th>
<th>Mainly No</th>
<th>Mainly Yes</th>
<th>Definitely Yes</th>
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</thead>
<tbody>
<tr>
<td>1. Have you ever faced a problem like this before?</td>
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<td>2. Did you know this problem was going to occur?</td>
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<td>3. Did you have enough time to get ready to handle this problem?</td>
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<td>4. When this problem occurred, did you think of it as a threat?</td>
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<td>5. When this problem occurred, did you think of it as a challenge?</td>
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<td>6. Was this problem caused by something you did?</td>
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<td>7. Was this problem caused by something someone else did?</td>
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<td>8. Did any thing good come out of dealing with this problem?</td>
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COPING RESPONSES INVENTORY

Part II
Please think again about the problem you described at the beginning of this Inventory; indicate which of the following you did in connection with that situation.

<table>
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<tr>
<th>Did you:</th>
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<th>17</th>
<th>18</th>
<th>19</th>
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<tbody>
<tr>
<td>1. Think of different ways to deal with the problem?</td>
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<td>2. Tell yourself things to make yourself feel better?</td>
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<td>3. Talk with your partner or other relative about the problem?</td>
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<td>4. Make a plan of action and follow it?</td>
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<td>5. Try to forget the whole thing?</td>
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<td>6. Feel that time would make a difference – the only thing to do was wait?</td>
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<td>7. Try to help others deal with a similar problem?</td>
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<td>8. Take it out on other people when you felt angry or depressed?</td>
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<td>9. Try to step back from the situation and be more objective?</td>
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<td>10. Remind yourself how much worse things could be?</td>
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<td>11. Talk with a friend about the problem?</td>
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<td>12. Know what had to be done and try hard to make things work?</td>
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<td>13. Try not to think about the problem?</td>
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<td>14. Realize that you had no control over the problem?</td>
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<td>15. Get involved in new activities?</td>
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<td>16. Take a chance and do something risky?</td>
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<td>17. Go over in your mind what you would say or do?</td>
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<td>18. Try to see the good side of the situation?</td>
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<td>19. Talk with a professional person (e.g. doctor, lawyer, clergy)?</td>
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<td>20. Decide what you wanted and try hard to get it?</td>
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COPING RESPONSES INVENTORY

Questions about how you handled the problem you described at the beginning of this Inventory (continued)

<table>
<thead>
<tr>
<th>Did you:</th>
<th>NO</th>
<th>YES, once or twice</th>
<th>YES, sometimes</th>
<th>YES, fairly often</th>
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<tbody>
<tr>
<td>21. Daydream or imagine a better time or place than the one you were in?</td>
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<td>22. Think that the outcome would be decided by fate?</td>
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<td>23. Try to make new friends?</td>
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<td>24. Keep away from people in general?</td>
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<td>25. Try to anticipate how things would turn out?</td>
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<td>26. Think about how you were much better off than other people with similar problems?</td>
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<td>27. Seek help from persons or groups with the same type of problem?</td>
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<td>28. Try at least two different ways to solve the problem?</td>
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<td>29. Try to put off thinking about the situation, even though you knew you would have to at some point?</td>
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<td>30. Accept it; nothing could be done?</td>
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<td>31. Read more often as a source of enjoyment?</td>
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<td>32. Yell or shout to let off steam?</td>
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<td>33. Try to find some personal meaning in the situation?</td>
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<td>34. Try to tell yourself that things would get better?</td>
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<td>35. Try to find out more about the situation?</td>
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<td>36. Try to learn to do more things on your own?</td>
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<td>37. Wish the problem would go away or somehow be over with?</td>
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<td>38. Expect the worst possible outcome?</td>
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<td>39. Spend more time in recreational activities?</td>
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<td>40. Cry to let your feelings out?</td>
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<td>41. Try to anticipate the new demands that would be placed on you?</td>
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</table>
FIVE MINUTE SPEECH SAMPLE (FMSS)

PROTOCOL:

The specific instructions given to the caregiver are

[ "... I'd like to hear your thoughts about (Patient's name) in your own words and without my interrupting you with any question or comments. When I ask you to begin, I'd like you to speak for five minutes telling me what kind of person (patient's name) is and how the two of you are getting along together.... " ]

"After you have begun to speak I prefer not to answer any questions. Are there any questions you would like to ask me before we begin?"

This information will be recorded on audio tape. This data will be analysed and rated according to the criteria proposed by Magana et al (1986).