A PORTFOLIO OF STUDY, PRACTICE AND RESEARCH

VOLUME ONE

SUBMITTED FOR THE DOCTORATE OF PSYCHOLOGY (PSYCH.D) IN CLINICAL PSYCHOLOGY

UNIVERSITY OF SURREY

THE PERSONAL EXPERIENCES OF PARTNERS LIVING WITH SOMEONE SUFFERING WITH CHRONIC LOWER BACK PAIN: AN INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS.

CLAIRE ELPHICK

2002
ACKNOWLEDGEMENTS

I would like to give my sincere thanks to Dr. James Murray, Dr. Victoria Senior and Dr. Hilary Rankin for their constructive comments and suggestions throughout the study. I would again like to thank Dr. Hilary Rankin and also Dr. Yvonne Scarlet for supporting the research and their help in the recruitment of participants. This is also extended to Barbara O'Keefe and Penny Mortimer for their assistance in recruiting participants. Finally, I would like to thank the eleven individuals who gave up their time and talked openly about their personal experiences.
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Why is psychodynamic psychotherapy for older people lacking in clinical practice?
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Introduction to the Clinical Dossier

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Children, adolescents and families placement summary
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INTRODUCTION TO THE PORTFOLIO – VOLUME 1

This portfolio contains work completed as part of the PsychD in Clinical Psychology. Volume 1 comprises three dossiers of academic, clinical and research work. The academic dossier contains five essays covering the four core topics and one specialist topic. The clinical dossier consists of summaries of all placements undertaken throughout the training programme and summaries of the five clinical case reports completed. Finally, the research dossier includes the service related research project, the literature review and the major research project.

Volume 2 comprises the full clinical dossier, containing the five clinical case reports and all relevant formal placement documentation, including placement contracts, logbooks of clinical experience and placement evaluation forms. Due to the confidential nature of the material contained in this volume, it is kept within the Psychology Department of the University of Surrey.

The work presented throughout the portfolio reflects a range of client groups, referral problems and psychological approaches. The work is presented in chronological order to demonstrate the development of understanding and clinical skills over the three-year training period.
ACADEMIC DOSSIER
INTRODUCTION TO THE ACADEMIC DOSSIER

The academic dossier contains four essays from the four core client groups studied and one essay on a specialist topic. The essays critically examine a range of psychological theory and practice applied to various issues experienced across the life span, in a variety of contexts.
Compare and contrast the effectiveness of cognitive behaviour therapy and systemic therapy in the treatment of eating disorders.

Adult Mental Health Essay
Year 1
Psych.D Clinical Psychology

December 1999
Introduction

Clinical Effectiveness
With the introduction of the Governments 1998 White Paper (*A first class service: Quality in the NHS, 1998*), Clinical Governance has put evidence-based practice firmly in the centre of the health care service. Service providers must now ensure services are both cost and clinically effective. The aim within good clinical practice is to implement the most appropriate treatments and interventions for presenting problems, based on the research available. As the incidence of adult mental health problems are on the increase, the need for psychological therapies and treatments, which are cost and clinically effective, is increasingly important within the health care service.

The focus here is to consider the effectiveness of two psychological therapies in the treatment of eating disorders. The knowledge of effective treatments for eating disordered patients has become more pertinent due to the increasing number of patients diagnosed with an eating disorder in the age group of 15 to 24 years (Le Grange, 1999) and the severity and possible life threatening nature of these conditions.

Types of Eating Disorders
A number of eating disorders can be diagnosed based on DSM-IV (American Psychiatric Association, 1994) diagnostic criteria. These include anorexia nervosa, bulimia nervosa, binge eating disorder and eating disorder not otherwise specified. The more familiar eating disorders of anorexia and bulimia nervosa will be the focus here. To clarify the eating disorders of anorexia nervosa and bulimia nervosa, the diagnostic criteria set by DSM-IV are presented below.

Bulimia Nervosa
Bulimia nervosa is diagnosed in accordance to DSM-IV (1994) criteria if the following are present:

1. Recurrent episodes of binge eating (rapid consumption of a large amount of food in a discrete period of time.)
2. A feeling of lack of control over eating behaviour.
3. Recurrent inappropriate compensatory behaviour in order to prevent weight gain, such as: self-induced vomiting, use of laxatives of diuretics, fasting.
4. The binge eating and inappropriate compensatory behaviours both occur, on average at least twice per week for at least three months.
5. Self-evaluation is unduly influenced by body shape and weight.

**Anorexia Nervosa**

Following DSM-IV (1994) criteria anorexia nervosa is diagnosed if the following are present:

1. Refusal to maintain body weight at or above a minimally normal weight for age and height. E.g. weight loss leading to maintenance of body weight 15% below that expected.
2. Intense fear of gaining weight or becoming fat even though underweight.
3. Disturbance in the way in which one’s body weight, size or shape is experienced, undue influence of body shape and weight on self-evaluation, or denial of the seriousness of current low body weight.
4. The absence of at least three consecutive menstrual cycles.

**Treatment**

Many psychological therapies have been proposed for the treatment of anorexia and bulimia nervosa these include behavioural, psychodynamic, pharmacological, cognitive behavioural therapy (CBT) and family therapy (Garner & Garfinkel, 1997). The focus here is to consider the effectiveness of CBT and family therapy following a systemic approach in the treatment of anorexia and bulimia nervosa.

**Cognitive Behavioural Therapy**

Anorexia and bulimia nervosa although different in their symptomatology, have been described as sharing underlying features (Garner, Garner & Rosen, 1993: cited in Garner, Vitousek & Pike, 1997). Both eating disorders are comprised of distinct behavioural and cognitive aspects that are considered to perpetuate and maintain the disorder (Thackwray, Smith, Bodfish & Meyers, 1993; Garner, Vitousek & Pike, 1997).

Behaviourally bulimia nervosa is comprised of strict dieting behaviours and loss of control in eating which results in bingeing and purging. Purging behaviours include vomiting, excessive exercising, and excessive use of diet pills, laxatives and diuretics. Cognitively
sufferers of bulimia nervosa hold negative beliefs surrounding their weight and shape, have a distorted body image, pursue thinness, and believe they are out of control when they engage in bingeing behaviours (Cooper & Taylor, 1989: cited in Thackwray et al., 1993; Hus, 1990: cited in Thackwray et al., 1993; Thompson, 1990: cited in Thackwray et al., 1993).

Similarly anorexia nervosa has behavioural components that focus around the restriction of eating. Individuals diagnosed with anorexia nervosa of binge eating/purging subtype also engage in bingeing and purging behaviours. With regards to cognitions, sufferers of anorexia nervosa hold a belief of an ideal weight and shape, have strong beliefs in self control reflecting self esteem and a belief that self worth is based on body size (Mizes & Christiano, 1995).

Within a CBT model, it is the combination of both the behavioural and cognitive components, which are proposed to maintain the disorder in both anorexia and bulimia nervosa. It is paramount to address both these factors in treatment, if treatment is to be effective. Previous studies, which have for example, focused only on the behavioural component of bulimia nervosa, have been effective in cessation of bingeing and purging at the end of treatment. However only individuals who address their beliefs regarding their body image maintain these changes at follow-up (Freeman, Beach, Davis & Solyom, 1985: cited in Thackwray et al., 1993).

Due to the shared underlying principles of the development and maintenance of bulimia and anorexia nervosa, the treatment of these two eating disorders following a cognitive behavioural approach is observed to have some overlap. However due to the differences in patient motivation and the acceptance of weight gain some differences in the models of treatment exist (Garner, Vitousek & Pike, 1997).

**Bulimia Nervosa**

The cognitive behavioural model for the treatment of bulimia nervosa was first developed by Fairburn (1981). The model focuses upon the meaning the patient attaches to their
weight and shape and the perception they hold of an ideal weight and shape. The model proposes that in order to achieve their ideal weight and shape the patient restricts their intake, following rigorous and strict dieting rules. Due to the unrealistic restriction of food, the patient experiences psychological and physiological effects of starvation. They begin to crave foods high in carbohydrates as their body gives out signals that it requires foods to function. They become preoccupied with food as they try to uphold their strict rules surrounding foods they can and cannot eat.

After a time the patient can no longer uphold their rules of dieting and give in, entering into a period of binge eating. Binge eating leads to feelings of guilt and overwhelming anxiety in relation to weight gain. To reduce this anxiety the patient uses purging behaviours. Purging can therefore act to maintain the cycle as the patient always has a method of reducing their anxiety of weight gain after bingeing.

Bingeing and purging may leave the patient with feelings of self-disgust and worthlessness, which in turn may lead to a sense of lowered self-esteem. To increase self-esteem the patient enters once again into dietary constraint, believing that if they reach their ideal weight they will be popular, well liked, get a boyfriend, etc. This dietary restriction will once again lead to loss of control and binge eating (Wilson, Fairburn & Agras, 1997).

The main focus of this model is upon what maintains the disorder and dictates that intervention must do more than reduce and eliminate the maladaptive behaviours of dieting, bingeing and purging. Treatment must address both the behavioural and cognitive components if outcome is to be successful. In doing so a three-stage treatment approach has been devised. The initial stage focuses on the behavioural change, aiming to reduce and eventually eliminate the behaviours of dieting, bingeing and purging. The aim is to replace these behaviours with ‘normal’ eating patterns. The second stage focuses upon the cognitive factors that maintain the disorder. Treatment identifies the patients’ dysfunctional thoughts with regard to body image, weight and shape and aims to help the patient find alternative ways of thinking about weight and food. The third stage considers relapse prevention and aims to maintain change over time (Wilson et al., 1997).
Effectiveness of CBT in the Treatment of Bulimia Nervosa

In the 1980's relatively little research existed considering the treatment of bulimia nervosa. Although psychological and pharmacological approaches had been proposed, there was a lack of systematic studies examining the effects of these interventions. As a result conclusions regarding effectiveness could not be reached. Over the last twenty years this has changed dramatically. Research trials have lead to CBT being regarded as the first line treatment of choice for bulimia nervosa in clinical practice (Wilson, 1999a).

Evidence for the effectiveness of CBT in the treatment of bulimia nervosa has been generated from randomised control studies implemented around the world by different clinicians (Wilson 1999a). Reviews of the conducted research have shown promising results for CBT as an intervention, illustrating a reduction in purging behaviours and significant remission rates. Reviews of '10 studies yielded a mean reduction in purging of 79% and a 57% remission figure' (Craighead and Agars, 1991: cited in Wilson & Fairburn 1998, p.509). Other reviews tallying 'nine controlled studies of CBT reported estimates of a mean reduction in purging of 83.5% and a 47.5% remission figure.' (Wilson & Fairburn, 1998, p.509).

Further randomised control trials have compared CBT with other alternative treatments for bulimia nervosa. In considering drug treatments, for example Fluoxetine, studies have concluded that CBT is superior to drug treatment alone (Agras, Rossiter, Arrow, Schneider, Telch, Raeburn, Bruce, Perl & Koran, 1992: cited in Wilson & Fairburn, 1998; Leitenberg, Rosen, Wolf, Vara, Detzer & Srebnik, 1994: cited in Wilson & Fairburn 1998). Research trials combining CBT and drug treatments conclude, the combination of treatments does not appear to be more superior to CBT alone (Goldbloom, Olmsted, Davis, Clewes, Heinmaa, Rockert & Shaw, in press: cited in Wilson & Fairburn 1998). In comparing CBT and behavioural therapy, studies have found CBT to be the more effective at post-treatment and at 6 month and 1 year follow ups, on measures of dietary restraint and attitudes to weight and shape (Fairburn, Jones, Peveler, Carr, Solomon, O'Connor, Burton & Hope, 1991; Fairburn, Norman, Welch, O'Connor, Doll & Peveler, 1995). When comparing CBT with supportive psychotherapy, CBT has been found to be a more

Evidence for the effectiveness of CBT is encouraging but it is a specialist form of treatment that is considered expensive to deliver to patients (Cooper, Coker & Fleming, 1996). Interest has arisen to produce a less costly form of CBT that can be delivered by non-specialists. This has taken the form of manual based treatment (Cooper, 1995; Schmidt & Treasure, 1997).

Research trials have shown CBT administered as manual based treatment to be an effective intervention. Cooper et al., (1996) reported a reduction of 80% in bulimic episodes and a 79% reduction in self-induced vomiting, in patients following a programme of manual based CBT. Weight and shape concern also improved, by 38% and 28% respectively. Effects were maintained at one-year follow-up. Similar results were also reported by Treasure, Schmidt, Troop, Tiller, Todd, Keilen and Dodge, (1994). Manual based CBT was observed to significantly reduce the frequency of binge eating and weight control behaviours.

In comparing manual based CBT with full CBT, no significant differences are reported. Treasure et al., (1994) reported full remission in 22% of patients following manual based CBT compared to 24% of patients who followed full CBT. Such findings suggest manual based CBT is an attractive comprise to full CBT, when considering the increasing demands on therapist clinical time and the limited resources available.

Limitations of CBT
Although there is substantial evidence for the effectiveness of CBT in treating bulimia nervosa (Wilson, 1999a), its effectiveness does have limitations. Only 50% of patients
cease bingeing and purging. Some patients partially improve and some patients gain no benefits from this intervention (Wilson, 1996). Particular problems have arisen with manual based CBT, due to its limited form (Wilson, 1999a). It has been shown to be effective in eliminating dieting, bingeing and purging behaviours but to be less effective in altering patient beliefs surrounding their weight and shape (Walsh, Wilson, Loeb, Devlin, Pike, Roose, Fleiss & Watermaux, 1997).

To increase the effectiveness suggestions have been made to revise the manuals that are currently used in clinical practice. Amending the manuals to cover more varied modules that can be applied to patients who share the same disorder but who have differing treatment agendas (Wilson, 1999b). This would allow for more flexibility by therapists, who have been opposed to treatment manuals in the past, arguing such intervention undermines therapy (Davison & Lazarus, 1995: cited in Wilson, 1996) and under-utilises therapists (Arrow, 1999; Wilson, 1998). Further, manual based CBT has faced criticism as it fails to allow for case formulation (Malatesta, 1995: cited in Wilson 1996; Persons, 1991: cited in Wilson, 1996). The introduction of case formulation is likely to increase its effectiveness within clinical practice (Wilson, 1996) and is a fundamental requirement of the collaborative approach endorsed by CBT.

**Anorexia Nervosa**

Garner and Bemis (1982) first proposed a cognitive behavioural model for anorexia nervosa. This model was modified from the techniques used for the treatment of depression (Beck, Rush, Shaw and Emery, 1979: cited in Garner & Bemis 1985). The model identifies the importance of dysfunctional core beliefs as well as behaviours in perpetuating and maintaining anorexia nervosa.

Weight gain is an important treatment goal in anorexia nervosa. Unfortunately it is unusual for weight gained during an in-patient admission to be maintained once the patient has been discharged (Le Grange, 1999). Garner and Bemis (1982) emphasised the importance of cognitions in the development and maintenance of anorexia nervosa, highlighting that although many explanations have been put forward for the development of anorexia, a
common belief held by patients is ‘I must be thin’. In addressing the cognitive processes as well as the problem of weight loss the model suggests weight restoration would be maintained after in-patient treatment.

Treatment follows through progressive phases. Initially addressing the issue that most patients with anorexia due to their fear of fatness are unwilling and resistant to treatment. To overcome this resistance the focus of treatment is on building a collaborative relationship with the patient and developing a strong therapeutic alliance. Treatment moves onto an educational component emphasising the health risks of starvation and introduces the cognitive behavioural model. After weight stabilisation the aim is to change the patients' beliefs related to food and weight, using behavioural techniques and cognitive restructuring. Finally treatment aims to maintain changes over time and prevent relapse (Garner & Bemis, 1985).

**Effectiveness of CBT in the Treatment of Anorexia Nervosa**

There is a strong theoretical rationale for developing cognitive behavioural treatments for anorexia nervosa. Patient beliefs regarding their weight and shape are central to the development and maintenance of the disorder. Change in patient beliefs concerning their weight and shape is pertinent to their recovery (Cooper & Fairburn, 1984).

In practice however, the use of CBT in treating anorexia nervosa has been insufficiently studied (Wilson, 1999a; Wilson & Fairburn, 1998). The few studies, which have been conducted have had a number of shortcomings including, small sample sizes, methodological flaws and have failed to be randomly controlled (Wilson, 1999a). This has made it difficult to generalise findings and to draw any firm conclusions of the effectiveness of CBT in treating anorexia nervosa (Fairburn, Shafran & Cooper, 1999).

Channon, De Silva, Hemskey and Perkins (1989) conducted one of the few existing controlled studies, examining the effectiveness of CBT compared to behavioural intervention alone in treating patients with anorexia nervosa. It was expected that CBT would be superior to behavioural treatment at the end of treatment and at 6 month and
final follow up. The results failed to support this hypothesis. A significant difference was however observed in the number of sessions, which were attended by patients in the two groups. Anorexic patients in the CBT group attended more sessions, suggesting that CBT is more acceptable to this patient group (Channon et al., 1989). This is an interesting and useful finding in a patient group that is difficult to engage in treatment (Garner & Bemis, 1982).

A further study by Cooper and Fairburn (1984) considered the effectiveness of CBT in treating five patients with anorexia nervosa. The treatment approach had been adapted from CBT used in treating people with bulimia. The findings were mixed. Two patients did well, one showed some improvement, and two gained no benefit at all (Cooper & Fairburn, 1984). Although this particular study shows some support for the use of CBT people who have anorexia, the findings cannot be generalised due to the very small sample size.

Although there has been little systematic research into the effectiveness of CBT in the treatment of anorexia nervosa, a new cognitive behavioural theory has been proposed by Fairburn et al., (1999). This model combines the first cognitive behavioural view developed by Garner and Bemis (1982) and a less well-known theory by Slade (1982) of 'functional analysis' (Slade, 1982: cited in Fairburn et al., 1999). The introduction of a new model to understand the development and maintenance of anorexia nervosa, may renew interest and promote clinicians to conduct much needed research into the effectiveness of treatment within this area.

**Systemic Therapy**

The treatment of anorexia and bulimia nervosa using a systemic approach has been developed within family therapy. Family therapy following a systemic approach was developed by Minuchin, Rosman and Baker (1978: cited in Dare & Eisler, 1997), and Selvini-Palazzoli, Boscolo, Cecchin and Prata (1978: cited in Dare & Eisler, 1997). Although family therapy is mainly applied to the treatment of anorexia nervosa, it has been
suggested that the influence of the family system in the development and maintenance of bulimia nervosa is just as important (Schwartz, Barrett & Saba, 1985).

**Anorexia Nervosa**

The goal of weight restoration in the treatment of anorexia nervosa within an in-patient setting is relatively uncomplicated (Le Grange, 1999). Unfortunately the majority of patients do not maintain their weight after discharge, resulting in relapse and re-admission (Le Grange, 1999). To overcome this cycle it has been suggested that other, more effective treatments need to be developed which address more than the behavioural aspect of the disorder. Family therapy is one alternative intervention to the constant and repeated re-feeding and reduces the need for re-admission.

Minuchin et al., (1978: cited in Dare & Eisler, 1997) and Selvini-Palazzoli et al., (1978: cited in Dare & Eisler, 1997) were the first to present family therapy as a useful means of treating anorexia nervosa. Their beliefs were based on observations of families with anorectic patients sharing certain characteristics. These families were observed to be excessively close, have blurred boundaries between family members, and have a tendency to avoid conflicts.

More recent models have been developed based on such earlier approaches to family therapy, for example the Maudsley Model (Dare & Eisler, 1997). This model operates within a specific cultural and family context. The family is observed to progress through a developmental life cycle, created by the social context in which the family live. The life cycle is an important factor as it organises the family. Thus the organisation of the family at any one time will depend on what life stage the family is at. The model places the illness of anorexia nervosa outside of the individual and their family members. This allows external sources and the context in which the family live, to be considered in the development of the illness. In doing so, blame is removed from the family itself for the development of the illness.
The model emphasises the impact the symptoms have on the family as well as the individual. Strong emphasis is placed on understanding that the dysfunctional family is not the antecedent of the eating disorder. Instead the dysfunction is perceived as a consequence due to the reaction of the illness. The effects of socio-cultural factors are also considered within the model as having an influence on the family.

The aims of family therapy based on this model are firstly to explain the dysfunctional behavioural patterns occurring in the family system, aiming to reduce the effect of the illness on the patient’s life cycle and to reduce the effect the illness has on the relationship between the patient and their family. Secondly, it aims to change the family style to be more direct and open in their interactions. These aims can be achieved in a number of ways and treatment can be directed towards the individual or the family as a whole.

**Effectiveness of Family Therapy in the Treatment of Anorexia Nervosa**

Although the effectiveness of family therapy in the treatment of anorexia nervosa has been reported and inferred for many years, few controlled trials and follows ups have actually been conducted to demonstrate its efficacy.

The first evaluation study of the effectiveness of family therapy in anorexia nervosa was conducted by Russell, Szmukler, Dare and Eisler (1987). The study comprised a controlled trial comparing family therapy with individual therapy. Patients were randomly allocated to one of the two treatment trials and placed into sub groups based upon age of onset, duration of disorder and disorder type.

The findings suggest family therapy is effective in the treatment of patients who are below the age of 19 when onset occurs and have a duration of illness of three years or less. In contrast findings tentatively suggest individual psychotherapy to be more effective in patients where onset is above age 19 years and symptoms are more chronic.

At 5-year follow-up, the efficacy of family therapy and individual therapy was assessed (Eisler, Dare, Russell, Szmukler, Le Grange & Dodge, 1997). The benefits gained from
the previous treatment were still evident. These findings support the earlier conclusion that family therapy is a more favourable treatment for patients below the age of 19 years, where illness has a duration of three years or less.

Minuchin et al., (1978: cited in Dare, Eisler, Russell & Szmukler, 1990) made inferences regarding the effectiveness of family therapy in the treatment of anorexia nervosa based on clinical observation. An examination of their patient population reveals that 51 of the 53 cases they report were under the age of 19 years and were less chronic in symptomatology. This lends further support to the suggestion that family therapy is effective in the treatment of younger patients whose symptoms are less chronic.

The results of Russell et al., (1987) suggest, had the majority of patients in Minuchin et al., (1978) population have been older and their symptoms more chronic their conclusions of the effectiveness of family therapy would have been very different (Dare, et al., 1990). This highlights the importance of the systematic evaluation of treatments rather than inferences based on clinical observation.

The findings of Russell et al., (1987) have been supported by Robin, Siegel, Koepke, Moye and Tice (1994) who compared behavioural family systems therapy with ego-orientated individual therapy in a controlled study. Patients were randomly allocated to one of the two conditions. The results of the study suggest family therapy to be more effective in the treatment of adolescents with anorexia nervosa. However caution is raised in the interpretation of these findings, due to a small sample size and lack of control group (Robin et al., 1994).

In comparison other controlled studies have failed to show family therapy to be a more effective intervention in treating anorectic patients. Crisp, Norton, Gowers, Halek, Bowyer, Yeldham, Levett and Bhat (1991) evaluated the effectiveness of three types of treatment for anorexia nervosa. Behavioural, individual and family psychotherapy were compared. Results showed all three interventions to be highly significantly effective in
terms of weight gain, social and sexual adjustment and menstruation at one-year follow-up.

In comparison significant changes were not observed in the control group. However this study also suffered methodological flaws, having difficulties engaging patients and suffering a high drop out rate. This implies results should be interpreted with caution.

**Bulimia Nervosa**

The advances which have apparently been made in treating patients with anorexia since studying the family system, would lead one to assume that the families of people with bulimia have also been studied in detail and treatment models developed (Schwartz et al., 1985). Interestingly this does not appear to be the case.

*Effectiveness of Family Therapy in the Treatment of Bulimia Nervosa*

Clinical observations and case studies have shown support and a clear theoretical rationale for the use of family therapy to treat patients with bulimia nervosa (Keeney & Ross, 1985: cited in Dare et al., 1990; Wynne, 1980: cited in Dare et al., 1990). Although case studies and clinical observations are useful, they do not allow firm conclusions to be drawn regarding the efficacy of family therapy in the treatment of patients with bulimia nervosa (Dare et al., 1990). Randomly controlled research studies which allow such conclusions to be drawn, appear largely absent from the research literature.

The lack of research examining the effectiveness of family therapy in treating bulimia nervosa may have occurred due to a number of reasons. For example, due to the abundance of evidence supporting the effectiveness of CBT as the first choice treatment for bulimia nervosa, or due to this disorder having a later onset implying patients will be less likely to want or feel able to involve their family in treatment.

Schwartz et al., (1985) suggest understanding bulimia nervosa within the family system is just as important as with anorexia nervosa. They have shown family therapy to be effective in treating bulimic symptomatology. Their results showed 66% of their patients to be
nearly always in control of their eating with one of fewer episodes per month of bingeing and purging after an average of 33 sessions of family therapy. Similarly Dodge, Hodes, Eisler and Dare (1995) reported significant reductions in bulimic behaviours and an improvement in eating attitudes, after family therapy. These improvements were maintained at follow-up.

In contrast other studies have failed to observe the efficacy of family therapy with patients with bulimia. Russell et al., (1987) reported a high drop out rate of 44% and poor outcome obtaining an abstinence rate of only 9% in their bulimic sub-group treated with family therapy.

In general there appears to be a lack of controlled research considering the effectiveness of family therapy in bulimia nervosa. Although some studies do exist they suffer major methodological flaws, having small samples, no comparison control groups and biases in referral process (Dodge et al., 1995). There is a definite need for further exploration and research examining family therapy in treating bulimia nervosa, before conclusions regarding effectiveness can be drawn.

**Conclusion**

The quantity and quality of research addressing the effectiveness of CBT in the treatment of anorexia and bulimia nervosa differs significantly. Overall CBT for bulimia nervosa has been extensively evaluated and findings have concluded this intervention to be extremely effective and the first line treatment of choice (Wilson, 1999a). In contrast little evidence exists for the effectiveness of CBT in treating anorexia nervosa. Research that has been conducted is poor and allows no firm conclusions to be drawn regarding its effectiveness (Fairburn et al., 1999).

In contrast more research has been conducted considering the effective treatment of anorexia nervosa following a family therapy approach. Studies have supported the effectiveness of family therapy in treating younger anorectic patients (Russell et al., 1987, Dare et al., 1990; Robin et al., 1994). The evidence of this approach in treating older
patients is less clear (Dare & Eisler, 1997), and it is generally believed individual psychotherapy is more effective (Russell et al., 1987).

Research into the effectiveness of CBT in relation to bulimia nervosa is ample and has lead Wilson (1999a) to conclude, ‘CBT for bulimia nervosa stands as one of the most intensively researched and empirically well-established methods in all cognitive behaviour therapy for adult clinical disorders’ (Wilson, 1999a, p.82).

In comparison controlled studies into the effectiveness of family therapy for both anorexia and bulimia nervosa are sparse. Research within this field has been hindered by a number of practical and professional difficulties. On a practical level the incidence of anorexia nervosa is lower than bulimia nervosa, so is more difficult to gain participants for research trials. Similarly differences in the type of family therapy implemented make it difficult to conduct controlled research (Dare et al., 1990).

Unfortunately practical difficulties are only part of the reason explaining the lack of research into the effectiveness of family therapy. Clinicians in the field have criticised the process of systematic evaluation of family therapy as being limiting, restrictive of intervention and reductionist. Clinicians holding such beliefs therefore strongly oppose research trials and fail to monitor the effectiveness of their interventions (Dare et al., 1990).

With the introduction of Clinical Governance the need for self-regulation is likely to encourage clinicians to conduct research to measure the effectiveness of their treatment interventions. Based on the findings and conclusions of this future research, the effective treatment of anorexia and bulimia nervosa will continue to be established. Such research is crucially required within the field of family therapy in assessing effectiveness in treating both anorexia and bulimia nervosa. Similarly further research is required to assess the effectiveness of CBT in the treatment of anorexia nervosa. It appears the effectiveness of CBT in the treatment of bulimia nervosa has been established and clinicians can be fairly confident in gaining successful outcomes following this approach to treatment.
References


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

June 2000
Introduction

The ability to communicate effectively is directly related to quality of life (Van der Gaag, 1998) and is central to an individuals’ psychological well being. Being able to communicate with others, gives an individual status, a positive self image and an understanding of the world and the cultural rules and values of the society in which they live. Communication allows participation within the day to day functioning of society and gives access to education and employment. Further it enables individuals to have choice in deciding with whom to form relationships and to have some control over their level of involvement. Overall the ability to communicate is extremely powerful. It gives an individual some control over their life, in their decision making, their ambitions and desires.

In contrast, lack of communicative ability or difficulties in communication, contributes to many psychological problems, including ‘low self esteem, social isolation, learned habits of compliance, lack of trust, frustration and anger, disempowerment’, (Van der Gaag, 1998, p.88) and disruptive and challenging behaviours (Bott, Farmer & Rohde, 1997). Having the ability to communicate does not guarantee these problems will not be experienced, but increases the likelihood of an individual overcoming such difficulties and feeling understood.

Difficulties with communication ‘represent one of the most pervasive problems among’ people with learning difficulties (Campbell & Schwartz 1983, p.411). The difficulties that are experienced can range from ‘slight problems in speech production to a total absence of speech and functional communication’ (Campbell & Schwartz, 1983, p.411). The influence of communicative difficulties depends greatly on the nature and extent of the disability. Individuals with severe disabilities may have profound communication problems and may find themselves excluded from the ‘educational, cultural and societal influences that allow most of us to make some sense of our lives’ (Remington, 1999, p.231).
Prevalence of communication difficulties
Communication difficulties in people with learning disabilities are widely reported. McQueen, Spence, Garner, Pereira and Winsor (1987: cited in Van der Gaag, 1998) estimated 66% of the learning disabled population to have some form of speech and language difficulty. Blackwell, Hulbert, Bell, Elston, Morgan, Robertshaw and Thomas (1989: cited in Money, 1997) considered the specific types of communication difficulties individuals were presenting. Findings identified 62% of the population to have communication problems, 29% who were non-verbal, 25% with marked problems and 8% with some other level of verbal difficulty. Overall surveys estimate the prevalence of communication difficulties in people with learning disabilities to be between 73 and 89% (Van der Gaag & Dormandy, 1993).

What is communication?
In the past, there has been a dominant bias towards teaching people with learning disabilities speech, following a belief that communication should involve language (Campbell & Schwartz, 1983). Spoken communication was in the past regarded as superior and non-spoken forms of communication were to a certain extent disregarded. This view was strongly reinforced by the process of normalisation and the misunderstanding of the term. Professionals believed normalisation involved ‘making’ individuals with learning disabilities the same as those individuals without such disabilities. A real fear existed that teaching individuals a non-speech form of communication would go against the concept of normalisation, enhancing differences.

Over the last two decades this view has shifted. Evidence has suggested that providing people with learning disabilities with an effective means of communication, either verbal or non-verbal, has produced a positive effect. The introduction of non-verbal communication has decreased much difficult and challenging behaviour. Providing individuals with an effective means of communication has decreased the frustration and anger they previously experienced (Campbell & Schwartz, 1983). Emphasising the positive use of non-spoken
communication has lead staff and carers to be more receptive in the teaching and use of non-spoken forms of communication (Bartlett, 1997).

Communication is now firmly regarded as more than speech. There has been a move to consider the actual function of the communication when assessing an individual's communicative ability (McLean, Brady & McLean, 1996: cited in Remington 1999). Functional or intentional communication is no longer perceived to have to involve language. Intentional communication is now regarded as any 'deliberate action that has the function of social influence and control' (Remington, 1999, p.232).

Theories of Language Development

Before discussing the impact of others' expectations on the communicative abilities of people with learning disabilities, it is important to briefly outline theories of language acquisition (Price, 1989). The theories explaining language acquisition have changed dramatically over the years. Initially language was conceptualised as genetic in origin with the ability to learn language explained as being genetically predetermined through a 'Language Acquisition Devise' (Chomsky, 1957: cited in Price, 1989).

The more recent view perceives language as 'essentially a social phenomenon' (Price, 1989, p.189) developing out of interactions with significant others. Adult responses to the child's actions and words, leads the child to recognise that their actions can influence others. In turn this leads to the emergence of the intention to communicate and the desire to learn new methods of communication (Vygotsky, 1962: cited in Messer 1998). The Transactional model (Sameroff, 1975: cited in Nind & Hewett, 1994) further emphasised the social process of communication, stressing that communication will only occur if it serves a purpose. It follows that children will only learn to communicate if they have a 'reason to communicate and someone meaningful to communicate with' (Price, 1989, p.188), who in turn is able to acknowledge and respond appropriately to their communicative attempt.
The impact of parental expectations and responses to early communication

Following the social interactionist perspective of language (Bohannon, MacWhinney & Snow, 1990: cited in Warren & Yoder, 1997) the process and development of communication begins in infancy (Tucker & Kretschmer, 1999). For interactions at this early stage to be successful both adult and child must have the ability and knowledge to respond to each other's communication cues. Adults also have the additional role in that they must provide the child with models so they learn the most useful communication cues. For this task to be most successful adults should present cues in a way in which the child can reproduce them.

Similarly, adults must be able to recognise, respond to and elaborate communication cues that are used by the child. In reinforcing the child's efforts and emphasising particular cues through imitation, adults teach the child the most important communication cues. Adult beliefs of the importance or appropriateness of the communication cue given by the child are paramount in relation to what communication cues will be reinforced. Adults highlight sounds that they believe are culturally meaningful. This helps the child to learn communication that they will require for future interactions.

The development of 'normal' communication is largely dependent on the ability of adults to pick up and respond to the child's attempts at communication. Parents have certain expectations of how the child will communicate and focus on picking up such expected cues. Problems in the development of communication arise when parents fail to identify and respond to a child's communication cue. This is prevalent in the communication development of a child with learning disabilities (Tucker & Kretschmer, 1999).

Children with learning disabilities develop different ways of communicating which parents are not familiar with nor expecting. Verbal speech cues may not be available to the child. Instead they rely on eye blinks and non-speech vocal efforts as ways to communicate (Hanzlik, 1990: cited in Tucker & Kretschmer, 1999). If parents do not perceive such cues as appropriate communication and fail to respond to, elaborate on, and reinforce the
child's efforts through imitation, the child will not learn the value of the communication cue and fail to use such cues as communication in the future (Tucker & Kretschmer, 1999). From infancy, the child with learning disabilities learns little value or gain exists in attempting to communicate.

If individuals with learning disabilities are to develop the ability to communicate and be motivated to continue to develop communication skills throughout their lives, their early experiences of interaction with their parents need to be of a positive nature. This implies parents must change their expectations of what constitutes a socially meaningful communication cue and learn how to recognise and respond to their child’s individual attempts to communicate. Parents must learn to perceive eye blinks, back arching and other unusual behaviours as forms of communication and respond accordingly. Parents must model these behaviours and provide new communication cues that the child can pick up and intimate, entering into a more complex system of communication (Tucker & Kretschmer, 1999).

**Intervention - ‘Right From The Start’**

It appears that a gap exists between parental expectations and their knowledge of how their child with learning disabilities will communicate and acquire communication skills (McConkey, 1994). Clinical psychologists have to be skilled in sharing knowledge with parents and altering their expectations. They must work in partnership with parents (Davis, 1993) to inform and educate them, in relation to their child’s individual way of communicating. Parents need to be taught how to recognise and respond to communicative behaviours in a manner that will continue to foster and encourage communication attempts in their child.

Similarly parents also require assistance in learning to maximise the communicative attempts of their child. They need guidance in learning to allow sufficient time for their child to respond, not too use too many questions and directives, and to be sensitive to non-verbal forms of communication (Wootton, 1989). McConkey (1994) suggests the use of
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videos in achieving some of these goals, and in helping to alert parents to the specific behaviours that their child uses in order to communicate. In videoing the child, parents are able to perceive the child’s strengths as a communicator (McConkey, 1994). Videos are also effective in evaluating child-parent interactions and allow clinical psychologists to give parents guidance. This enables parents to learn how to modify their interactive styles, and become more involved and engaged in their child’s interactions (Clark & Seifer, 1983: cited in Nind & Hewett, 1994).

Clinical psychologists have an important role when working with parents to address their expectations of their child’s communicative ability. Studies have found that without help parents can fail to adapt their expectation of their child communicating verbally (Tucker & Kretschmer, 1999) and continue trying to communicate verbally with little or no success. It has been suggested that fathers have greater difficulty in adapting their expectations of verbal communication, especially to a son who has a low level of communication ability (Frey, Greenberg & Fewell, 1989: cited in McConachie, 1994). This suggests fathers may need greater direct help, in learning how to observe their child’s attempts at communication and in developing skills to interact with their child at a more appropriate level (McConachie, 1986: cited in McConachie 1994). Teaching parents to focus on communicative abilities drawn from their child’s own repertoire will aid communication and enhance a more positive experience for both parties (Tucker & Kretschmer, 1999). The positive feedback the child experiences will act as a powerful re-enforcer to continue making meaningful communication and develop more complex communication skills.

How the news of a child having a learning disability is broken to parents and the following discussion of the implications this will have on the child’s future, has a major impact on the expectations and coping strategies parents develop (Davis, 1993). Being informed at the earliest appropriate time, of the possibility their child may not develop verbal communication, may prevent parents forming inappropriate expectations regarding their child’s future communicative ability.
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The impact of staff expectations on communication

In the past the issue of communication difficulties had been regarded as the responsibility of the individual themselves. An assumption was made that the problems of communication were the result of the individuals' lack of competence and skill (Leudar, 1989). With the introduction of the social interactionalist perspective and the understanding of communication being a two way process, set in a social context, communicative competence is no longer regarded as the sole responsibility of the individual with learning disabilities. It is now widely acknowledged that some communication difficulties are exacerbated by the environment in which they occur (Leudar & Fraser, 1985: cited in Money, 1997).

In considering the communication environment, one is really focusing upon the interactions occurring within a set context. The interactions, which occur in any context, are dependent upon both the individual's expectations as to how the interaction will develop and the communicative ability of both individual's involved in the interaction.

Staff expectations of clients' communicative abilities directly affect the nature of the interaction. Problems occur when staff hold an inaccurate expectation of the clients' communicative ability and as a result, fail to adjust their communication to maximise the clients' ability to communicate effectively within the interaction (Purcell, Morris & McConkey, 1999).

Impact of Low Expectations

A communication environment that comprises staff members who expect clients to have limited communication skills, will fail to initiate or elicit effective interactions between staff and clients. In this environment, any communication skills the client with learning disabilities has developed will be under-utilised (Van der Gaag, 1989). The lack of opportunity to practice communication implies existing communication skills may fall into disuse and higher order communicative skills may never develop (Kenefick, 1986: cited in Kenefick, 1988).
The failure of the communication environment to provide opportunities for a successful and positive communication experience, acts as a powerful reinforcer to clients to stop trying to learn, how to effectively communicate with others (Butterfield & Arthur, 1995). The differences in the communication environments in which people with learning disabilities live, have been described as ‘systematically distorted’, (Leudar, 1989) in that they fail to provide the same communication and interaction opportunities as those without disability. An explanation for the difference is due to others expecting people with learning disabilities to have low levels of communicative ability and lack the understanding to allow participation within meaningful interactions.

Evidence for the ‘Systematically Distorted’ Environment

Much evidence is presented for the existence of a distorted communication environment for people with learning disabilities. Research has shown that although people with severe disabilities predominately initiate communication (Ogletree, Wetherby & Westling, 1992: cited in Butterfield & Arthur, 1995), staff are very poor at recognising the initiated behaviours (Houghton, Bronicki & Guess, 1987: cited in Butterfield & Arthur, 1995). Staff have also been observed to spend very little of their time directly interacting with clients. Landesman (1988) reported that the amount of time staff spent in social interactions with clients averaged only 10-15% of their total job time. The overwhelming majority of staff explained this lack of interaction time with clients as due to staff shortages. In reality increasing the number of staff would not significantly increase the interaction time spent with clients (Landesman-Dwyer, 1984: cited in Landesman, 1988).

Another misconception identified by Landesman (1988) to explain the limited social interaction between staff and clients is the ‘unresponsive resident’. Landesman (1988) explains staff expect clients not to have the skills required, to allow them to understand communication. As a result staff fail to initiate communication and to develop any communicative attempts initiated by clients. When staff do interact with clients, a difference in the type of communication style used between staff members, and staff and clients has been noted. Kenefick (1986:cited in Kenefick, 1988) reported approximately
two thirds of comments between staff were comprised of exchanges of information and discussions of personal happenings. In contrast when talking with clients, about 70% of the communication were directives. This had a direct effect on the communication clients used when communicating to each other, with about two-thirds using directives. Most of the clients' remarks to staff consisted of partial sentences responding to the constraints of orders, requests and questions by staff (Kenefick, 1986: cited in Kenefick, 1988).

**Impact of the 'Systematically Distorted' Environment**

The 'systematically distorted' communicative environment (Leudar, 1989) in which people with learning disabilities live has a massive impact on the development of their overall communicative ability. As highlighted earlier a direct link exists between available interactions and the opportunity to learn, practice and develop different types of communication skills. The failure of staff to provide clients with appropriate interactions means existing communicative abilities may fall into disuse and more advanced communicative skills may fail to develop (Kenefick, 1986: cited in Kenefick 1988). The length of the interactions staff have with clients also has implications. People with moderate to severe learning difficulties are not given the length of time they require, to allow them to develop communication skills that will enable them to enjoy meaningful interactions (Markova, Johoda, Cattermole & Woodward, 1992: cited in Chatterton, 1998).

The tendency of staff to fail to respond to or recognise clients' communicative attempts may eventually lead to further developmental and behavioural problems. If the communication environment has failed to provide clients with the attention and support required to develop and practice communication skills, they may become frustrated and lose their motivation to try and communicate using appropriate means. Accordingly clients may develop behavioural problems and challenging behaviours (Ceci, 1986: cited in Chamberlain, Chung & Jenner, 1993). This may be perceived by the individual as a more effective means of communication (Durand, 1990: cited in Thurman, 1997; Reichle &
Wacker, 1993: cited in Thurman, 1997) as the client usually gains an instant reaction from staff if displaying challenging behaviour.

**Impact of High Expectations**

In contrast to having low expectations of the communicative abilities of people with learning disabilities, some staff have high expectations. The impact of having high expectations and over estimating an individual's communication ability can also have a detrimental effect on the individuals' overall development and self esteem (Bartlett, 1997; Brown, 1998).

The concept of normalisation has had some influence in producing high expectations and an overestimation of the communicative ability of people with learning disabilities (Bartlett, 1997). The expectation of people with learning disabilities to have normal adult levels of communication has lead individuals, to be given opportunities to engage in high functioning interactions, above an appropriate level. Being placed within such interactions may lead people with learning disabilities to make mistakes and fail to respond appropriately in the given situation.

Mistakes are often intensified as throughout the communication people with learning disabilities are not only trying to participate within the interaction, but also trying to protect their self esteem by presenting an image of competence (Sabsay & Platt, 1985: cited in Leudar, 1989; Kernan & Sabsay, 1989). The pressure to present as competent is increased by the desire to please others and a need to fulfil the expected level of communication. If mistakes and inappropriate responds are made within the interaction the individual with learning disabilities has a tendency to blame themselves (Robinson, 1986: cited in Beveridge, 1989). This may result in poor self esteem, a desire to avoid future communication opportunities and a desire to restrict the use of communication skills, to those which feel safe and are well established in their communication repertoire. The tendency to avoid interactions and use only those communication skills that are well practised and rehearsed may prevent the development of higher communication skills.
Avoidance of social interactions may lead to isolation and 'exclusion from communication partnerships' (Bartlett, 1997, p.150).

**Intervention**

Clinical psychologists can intervene at a number of levels to overcome the impact of people’s inaccurate expectations, of the communicative abilities of people with learning disabilities. Initially clinical psychologists need to administer good assessments of measuring communicative abilities e.g. Communication and Symbolic Behaviour Scales (Wetherby & Prizant, 1990: cited in Warren & Yoder, 1997), Reynell Developmental Language Scales (Reynell, 1985: cited in Remington, 1999). Studies have shown staff have difficulties making an accurate assessment of clients communicative abilities, for example overestimating the clients ability to understand verbal language and underestimating the value of non-verbal forms of communication (Purcell, Morris & McConkey, 1999). Using psychometric assessments enables the individual’s actual level of communication to be established. This allows for a firm understanding of the individual’s communication strengths, their needs and the basic ground rules required for effective communication to be established (Chatterton, 1998).

As well as establishing the actual communicative ability of the individual, clinical psychologists also need to consider the environment within which the communication is taking place. In considering the environment the clinical psychologist is removing the responsibility for the communication difficulty from the client and placing it within the system. The environment and system itself needs to provide appropriate support for people with learning disabilities, if their communication skills are to benefit and be enhanced (Money, 1997). Research has demonstrated a high correlation between increased environmental opportunities and improved communication ability amongst clients with learning disabilities (Blackwell, et al., 1989: cited in Money, 1997).

Clinical psychologists need to aim at increasing the environmental opportunities of those with communication difficulties. The initial step is to work in partnership with staff.
Psychologists should run in collaboration with speech and language therapists, communication workshops. This forum should be used to increase staff awareness of their expectations, to increase their knowledge regarding verbal and non-verbal forms of communication and how to apply this knowledge in their future interactions with clients.

**Communication Workshops and Staff Training**

Current research into the effectiveness of staff training in the area of communication is varied (Money, 1997). Chatterton (1998) reported positive effects on the communication environment of adults with severe learning disabilities following staff communication training. After training, staff showed an increase of interactions with clients lasting for longer than 10 seconds and a decrease in interactions lasting for less than 10 seconds. An increase in all forms of non-verbal communication, particularly in the use of Makaton signs and gestures by staff was also observed. Encouragingly, a decrease in the number of attempts clients needed to make in order to gain a response from staff was also reported. This was explained, as staff were more aware of what constituted an attempt at communicating, and were more sensitive to non-verbal forms of communication. The earlier responses from staff resulted in fewer opportunities for clients to become frustrated. Communication workshops have also been effective in reducing the likelihood of staff overestimating clients' ability to understand verbal communication and increasing staff ability to identify and respond appropriately to non-verbal forms of communication (Purcell, Morris & McConkey, 1999).

**Direct Strategy**

Communication workshops have had positive outcomes in aiding the communicative ability of clients', by working towards changing the behaviours and expectations of staff within the communication environment (Cullen, 1988: cited in Brown, 1998). However studies have reported although staff morale and positive communication strategies with clients increases immediately after such workshops, there is little ongoing and further development of staff communication strategies (Brown, 1998). Direct intervention has
been suggested as a further method clinical psychologists can implement to alter staff expectations and develop their communicative behaviours.

Direct intervention comprises techniques such as: modelling, prompting and positive reinforcement, discussion and written feedback (Brown, 1998). For example, the technique of prompting and positive reinforcement involves the clinical psychologist shadowing the staff member interacting with clients. They suggest alternative communication strategies either verbal or non-verbal and give positive reinforcement to staff when this is achieved. Implementing direct intervention after completion of communication workshops, demonstrated staff had developed a greater understanding of the communicative ability of their clients. The number of complex utterances staff used had significantly dropped, with staff re-phasing sentences when they realised what they had said was too difficult. The use of augmentative communication had also increased (Brown, 1998).

**Alternative and Augmentative Communication**

Clinical psychologists should actively encourage the use of alternative forms of communication, promoting flexibility in use of communication mode in the homes of people with learning disabilities (Remington, 1998). Being flexible regarding the communication mode maximises the opportunities of people with learning disabilities to communicate effectively within their environment, regardless of the severity of their disability.

Clinical psychologists need to work closely with staff, presenting alternative forms of communication in a positive way, emphasising the increased quality of life, clients will enjoy if their communication, in whatever mode, is understood. Further psychologists should be involved in educating staff, with an aim to change the expectation that communication should consist of speech. A much needed message needs to be promoted, that all forms of intentional communication should be valued. Psychologists need to promote the relative ease at which clients can learn to make manual signs in contrast to trying to elicit a meaningful speech sound (Remington, 1998). Similarly they should
promote the ease of being able to understand the meaning of the communication through a
sign, emphasising the increased likelihood of the real communicative need being
transmitted.

A fear exists that in teaching non-verbal forms of communication, speech will not develop.
Clinical psychologists have a role in educating staff that signs and symbols are not
regarded as an alternative to speech communication, but a way in which to supplement
communication. For example the Total Communication approach combines speech and
signs to enable the client to pick up on cues used in either mode (Remington, 1998). This
increases the ability of the client to understand and to be understood, enhancing the clients
overall psychological well being and development.

**Working with the Individual**
As suggested earlier not being able to communicate effectively with staff and carers can
have a major impact on an individual’s psychological well being. Not having the ability to
communicate their needs, being frightened they may respond inappropriately and not
knowing how to recognise, regulate and express emotion, (McAlpine, Kendell & Singh,
1991: cited in Black, Cullen & Novaco, 1997) can potentially cause a number of
psychological problems. These include low self-esteem, social isolation, anger, (Van der
Gaag, 1998) and challenging behaviours (Bott, Farmer & Rohde, 1997).

Clinical psychologists also need to work directly with individual’s with learning disabilities
to overcome these emotional difficulties. This work should be along side their role in
promoting a more effective communication environment through their work with parents
and carers. Clients with low self esteem who experience anxiety in social situations will
continue to avoid social interaction if they persistently hold the belief they will respond
inappropriately or they are ‘no good’. Continued social isolation over time may lead to
clinical depression. Similarly unless clients are taught how to express and resolve feelings
of anger and frustration, challenging behaviours will continue persist even when the
communication environment is more effective at recognising the intentional
communication. It follows that as well as considering communication difficulties, the emotional disorders that may present, as a direct consequence of the communication difficulty must also be addressed.

Clinical psychologists can employ a number of psychological interventions working one-to-one with people with learning disabilities. Interventions and procedures that are used within adult mental health to address anxiety, depression and anger difficulties can be transferred to people with learning disabilities. Therapy follows essentially the same principles and components, but requires adaptation to reflect the ability level of the client (Lindsay, Neilson, Lawrenson, 1997). When addressing anger and frustration difficulties for example, clients with learning difficulties may benefit from the techniques of cognitive-behavioural therapy, such as self-monitoring, self-instruction, impulse control, relaxation training, and social problem solving (Reed, 1997).

The use of psychological interventions in addressing emotional disorders in people with learning disabilities has been largely neglected in recent years. As a result many of the interventions are at an early stage (Reed, 1997). The increased presence of emotional disorders in people with learning disabilities have been identified in clinical observations. This highlights the need for the continual development of effective psychological interventions for treating emotional disorders in people with mild to severe learning disabilities (Reed, 1997).

**Conclusion**

The expectations held by carers regarding the communicative abilities of people with learning disabilities has been highlighted as having major implications. Others' expectations have been shown to have an impact at two levels. Firstly in relation to an individuals' overall psychological and emotional well-being, and secondly in relation to the individuals' development of communication skills and the potential to learn further and more advanced skills in which to communicate effectively.
The importance of clinical psychologists working in partnership with parents to reduce the gap between their expectations and their knowledge of how their child will communicate has been stressed. Similarly the need to teach parents how to recognise their child’s individual communicative attempts and to respond appropriately has been demonstrated, as important in reducing the impact of inaccurate expectations. Clinical psychologists working in partnership with parents will help parents to formulate more appropriate expectations of their child’s communicative ability. This support will foster and encourage communication attempts in their child and help to prevent the child developing a view that there is little to be gained from trying to communicate.

The impact of staff expectations have also been discussed and shown to have similar implications. The impact of staff expectations on the communicative abilities of people with learning disabilities, has lead Van der Gaag and Dormandy (1993) to conclude ‘staff training is no longer an optional but an essential, ongoing commitment.’ (Van der Gaag & Dormandy, 1993: cited in Money, 1997, p.450). Continued staff training identifying staff expectations of the communicative abilities of their clients and raising awareness of the impact this has on clients, is paramount in trying to create effective communication environments, which promote and encourage communication from all clients, regardless of the severity of their disability.

Although collaboration of work between clinical psychologists and speech and language therapists has only been mentioned briefly here, it should be noted working closely with speech and language therapists is important for successful intervention when working with clients who have communication difficulties. Finally throughout their work in this area clinical psychologists should bear in mind their own expectations regarding the individual and their communicative ability. This awareness will reduce the likelihood of their own expectations impacting on their work with clients and their carers.
References


People with Learning Disabilities Essay


Psychiatric classification is irrelevant to the understanding and treatment of mental health problems in childhood and adolescence. Discuss.
Introduction

The prevalence of children and adolescents with mental health problems is reported to vary from 4 per cent to 23 per cent depending on geographical location (Carr, 1999). The mental health problems that children and adolescents are presenting to child and family mental health services are vast, as are the interventions employed by clinicians to treat these problems. The focus here is to consider the contribution and relevance of psychiatric classification to the understanding and treatment of mental health problems in childhood and adolescence. Before considering the use and contribution of psychiatric classification to clinical practice, the history of how child classification systems developed is briefly outlined. The categorical, dimensional and multiaxial classification schemes are then highlighted, followed by an introduction to the two main systems of classification used in current clinical practice. Methodological and ethical issues of psychiatric classification are also considered. Finally the contribution and relevance of psychiatric classification in the understanding and treatment of mental health problems in childhood and adolescence are discussed. The psychiatric disorders of separation disorder and anorexia nervosa are used to illustrate points throughout this discussion.

History of Child Classification

The first modern classification system of mental health problems started with Karepelin’s attempt in 1896, to differentiate between schizophrenia and manic-depressive disorder (Karepelin, 1896: cited in Mack, Forman, Brown & Frances, 1994). This classification system along with the later developed, but more official classification systems, of the Diagnostic and Statistical Manual (DSM) (American Psychiatric Association, 1952) and the International Classification of Diseases (ICD), (World Health Organisation, 1967) focused mainly upon disorders experienced in adulthood (Cantwell & Rutter, 1994). Throughout the 1960’s it became apparent this was unacceptable and a classification system for mental health problems occurring in childhood and adolescence was urgently required (Rutter, 1965).

Anna Freud (1965) was the first to develop a system to classify childhood disorders (Freud 1965: cited in Cantwell & Rutter, 1994). This system classified children on a
developmental profile, based on psychoanalytic concepts. This was followed by a system proposed by the Group for the Advancement of Psychiatry (1966) (Group for the Advancement of Psychiatry, 1966: cited in Cantwell & Rutter, 1994). This system aimed to be more descriptive in classification, but was once again heavily influenced by psychoanalytic thinking. Theoretical concepts, particularly those following psychoanalytic models, were at this time dominating classification. This led to confusion and disorganisation as the theories lacked empirical justification and widespread disagreement existed regarding which theory should be followed (Cantwell & Rutter, 1994). It became clear, psychiatric classification of childhood disorders ‘based on patterns of symptomatology, rather than on theories that lacked empirical substantiation’ was required. (Feighner, Robins, Guze, Woodruff, Winokur & Munoz, 1972: cited in Cantwell & Rutter, 1994, p.3) It was thought classification systems based on symptomatology would lead to greater diagnostic consistency among clinicians and as a result be of greater use in clinical practice (Cantwell & Rutter, 1994).

Types of Classification

Categorical Classification

Traditionally mental health problems have been classified by placing them into categories (Gelder, Gath & Mayou, 1991). Categorical classification is based on the assumption that psychiatric disorders are discrete entities that form discrete categories (Jablensky, 1998). The categories are defined in terms of the symptom-patterns and the progress and outcome of each disorder. The symptom-patterns are described by a single diagnostic term, allowing a large quantity of information to be summarised in a simple form. They also include an implicit hierarchy of categories, implying that if more than one diagnoses is made, one diagnoses will take priority over the other(s). As most clinical decisions are categorical in nature and many every day concepts are classified categorically, this method of classification follows a simplistic and familiar methodology (Klein & Riso, 1993: cited in Cantwell & Rutter, 1994). Although, categorical systems are widely used they are criticised for the high prevalence of patients who firstly, fail to meet diagnostic criteria and need to be placed in boundary categories and secondly, can be diagnosed with more than one diagnoses (Mack, Forman, Brown & Frances, 1994). These practical problems
of poor coverage and co-morbidity are discussed in more detail below.

**Dimensional Classification**

Dimensional classification dismisses the use of discrete categories, preferring to classify disorders on a dimensional continuum. This method of classification was employed by Achenbach (1991) in conceptualising children's problems (Achenbach, 1991: cited in Carr, 1999). Achenbach (1991) noted that only extreme scores on the internalising and externalising dimensions, of the Child Behaviour Checklist, would gain ICD and DSM diagnoses. Those children obtaining scores towards the middle of the extremes would be regarded as unclassifiable in relation to categorical classification.

Dimensional classification systems are extremely efficient in identifying and classifying syndromes that comprise many symptoms, but are poor at identifying rare syndromes such as autism (Cantwell, 1996), or syndromes that have only one symptom, for example, encopresis. These syndromes are best identified by categorical classification systems (Cantwell & Rutter, 1994). Dimensional classification systems have advantages over the categorical systems, as they can describe multiple symptom-patterns. Further, in comparison to categorical classification systems, dimensional systems are described as being more statistically reliable and extremely useful in research (Cantwell, 1996). However, within clinical practice dimensional classification systems have been described as difficult to apply and therefore have failed to be fully utilised (Gelder, Gath & Mayou, 1991).

**The Multiaxial Approach**

The multiaxial approach refers to systems of classification that code several different facets of a condition. Coding in this way elicits more elaborate information and allows comparisons of cases based on more than just symptoms (Gelder, Gath & Mayou, 1991). The multiaxial approach has become the favoured system. DSM-III (American Psychiatric Association, 1980) was the first official classification system to follow this method; DSM-III-R, (American Psychiatric Association, 1987) DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1996) have
continued to adopt this approach to classification.

**Systems of Classification**

The International Classification of Diseases- tenth edition (ICD-10) and The Diagnostic and Statistical Manual- fourth edition (DSM-IV)

Both DSM-IV (American Psychiatric Association, 1994) and ICD-10 (World Health Organisation, 1992; 1996) contain schemes for classifying mental health problems displayed in childhood. Disorders that present in adolescence are classified partly within these schemes and partly within the categories used for classifying adult mental health problems (Gelder, Gath & Mayou, 1991). In total there are seven recognised groups of childhood psychiatric disorders; Adjustment reactions, pervasive developmental disorders, specific developmental disorders, conduct disorders, hyperkinetic disorders, emotional disorders and symptomatic disorders.

As the mental health problems that exist in childhood and adolescence cannot be allocated to a single category, multiaxial approaches of classification are implemented. Both ICD-10 (World Health Organisation, 1996) and DSM-IV (American Psychiatric Association, 1994) are multiaxial, and contain five axes. Clinicians are required to make five different judgements about a child. Like single-axis categorical systems, both ICD-10 and DSM-IV code the presenting behavioural and emotional problems the child or adolescent displays, but in addition incorporates further axes on which to code general medical conditions, adaptive social functioning and general intellectual functioning. The situations in which the child or adolescent and their family present, is also coded on an axis considering psychosocial and contextual adversity. This system of classification allows rich and detailed information about the child or adolescent’s psychological problem and other contributory factors to be coded simply and briefly, without losing important information that is lost with single-axis categorical classification (Carr, 1999).

The two classification systems of ICD-10 and DSM-IV are similar on a number of accounts. However, discrepancies do exist in the diagnostic criteria for particular disorders. Such a discrepancy exists between ICD-10 and DSM-IV, for
differentiating autism from asperger's syndrome (Howlin, 2000). The difference between the two classification systems leads to confusion among clinicians regarding what constitutes autism, higher functioning autism and asperger's syndrome. The difference between the two systems also has implications for research. Classification systems are described as aiding and contributing to research, allowing for a global understanding of symptoms that constitute each disorder. However disagreement in diagnostic criteria between ICD-10 and DSM-IV for the same disorder, acts to confound rather than aid research (Howlin, 2000).

**Problems of Psychiatric Classification**

Although DSM-IV and ICD-10 are widely used, both have a number of methodological, and ethical issues that question their creditability and clinical usefulness in understanding and treating mental health problems in childhood and adolescence.

**Methodological Issues**

**Reliability**

Within research, most studies have observed acceptable reliability amongst clinicians for major psychiatric disorders (Cantwell & Rutter, 1994). Unfortunately, this has not been observed in relation to the more narrowly defined subcategorises. For example, in research diagnosis of the overall category of anxiety disorder has been found to have a high degree of reliability. In comparison, the subcategorises of anxiety disorder have been shown to be less reliably diagnosed (Cantwell, 1996).

With regard to clinical practice, concern is raised regarding poor inter-rater reliability. Poor inter-rater reliability exists in both ICD-10 and DSM-IV classification systems. The issue of poor inter-rater reliability exists within clinician practice, as clinicians are not trained to make diagnoses in a standardised way. Researchers on the other hand, follow standardised procedures in making diagnoses, which aid inter-rater reliability (Prendergast, Taylor, Rapoport, Bartko, Donnelly, Zemetkin, Aherarn, Dunn & Wieselberg, 1988: cited in Cantwell, 1996). The problem for clinicians is increased as they gain information from more than one source. The clinician's diagnosis is based on how they personally
understand and prioritise the information gathered, and how they think the information contributes to the overall problem.

Where standardisation has been applied to clinical practice, encouraging results have been obtained. Standardised interviews such as; the Diagnostic Interview for Children and Adolescents (Reich, Herjanic, Welner & Gandy, 1982: cited in Waldman & Lilienfeld, 1995) and the Diagnostic Interview Schedule for Children (Costello, Edelbrock, Duncan & Karlas, 1984: cited in Waldman & Lilienfeld, 1995) have been observed to exhibit moderately to very high levels of inter-rater reliability. Using these interviews clinicians have been more reliable in diagnosing disorders, such as, conduct disorder, attention deficit disorders, major depression and anxiety disorders (Hodges, Cools & McKnew, 1989). The levels of reliability obtained tend to be higher for the externalising disorders of conduct disorder and attention deficit disorders compared to the internalising disorders of depression and anxiety disorders (Waldman & Lilienfeld, 1995). This difference is likely to exist as the externalising disorders are characterised by diagnostic indicators that are more observable than internalising disorders.

The issue of reliability remains problematic for both systems of classification. However it should be noted that the reliability obtained for most psychiatric disorders in children are comparable to those of medical conditions (Spitzer, 1975: cited in Waldman & Lilienfeld, 1995). This is a point that critics of psychiatric classification systems often fail to mention.

Validity

For DSM-IV and ICD-10 to be considered valid classification systems, children who are classified within the same diagnostic category must share common characteristics in their predisposing, precipitating, maintaining and protective factors (Carr, 1999). Unfortunately, research has failed to identify any diagnostic categories where validity has been met on all four of the required factors (Carr, 1999). From a psychological perspective this finding does not seem surprising. The predisposing, precipitating, maintaining and protective factors experienced by children and adolescents will differ depending on their personal situation and circumstances (Volkmar & Schwab-Stone, 1996; Sonuga-Barke,
Psychological difficulties are not specific 'disease-like categorical entities' (Carr, 1999, p. 74) as suggested by the classification systems. The differences in predisposing, precipitating, maintaining and protective factors and the influence of interactional patterns, begins to highlight the importance and contribution of systemic models in understanding and treating mental health problems in children and adolescents.

**Coverage**

In order to improve reliability DSM-IV and ICD-10 narrowed the definitions of symptoms that constitute a particular disorder. Although helping to increase reliability, the problem of poor coverage has arisen (Carr, 1999). This refers to the situation when a child cannot be easily and clearly classified into a diagnostic category. Zinbarg, Barlow, Liebowitz, Street, et al., (1994) found 20% of patients in a psychiatric sample to have symptoms of depression and anxiety that caused functional impairment, but did not meet DSM-IV criteria for any of the depressive or anxiety disorders. Many clinicians think disorders in children are more common in practice, than DSM-IV or ICD-10 classification systems identify (Costelle, 1990: cited in Cantwell, 1996).

In order to address the issue of poor coverage the categories of Not Otherwise Specified and Unspecified, have been introduced in DSM-IV and ICD-10, respectively. Children who fall between two categories are given this diagnosis, for example, eating disorder not otherwise specified, conduct disorder unspecified. This method has been criticised for not adequately addressing the problem and creating a 'grab bag category to lump all disorders that do not meet criteria' (Cantwell, 1996, p. 5).

**Co-morbidity**

The problem of co-morbidity occurs in both classification systems and arises when a child's symptoms can be classified into more than one diagnostic category. It is common for a child with one diagnosis to have another diagnosis (Caron & Rutter, 1991; Costelle, 1990: cited in Cantwell, 1996). It appears to be most common in children who are aggressive, with either attention difficulties, depressive symptoms or anxiety disorders also being diagnosed. Similarly, children diagnosed with attention difficulties are
also commonly reported to have either depression or anxiety disorders. Finally children who are diagnosed with depression are also commonly diagnosed with anxiety disorders (Carr, 1999). The issue of co-morbidity is addressed quite differently by DSM-IV and ICD-10. DSM-IV encourages the use of multiple diagnoses when criteria for more than one diagnoses is met. In contrast ICD-10 combines categories, for example, hyperkinetic conduct disorder (Cantwell, 1996).

**Ethical Issues**

**Labelling**

Since the introduction of classification systems, concern has been expressed by clinicians of the effects of categorising childhood and adolescence mental health problems into diagnostic constructs. One of the main arguments against the use of classification and labelling of psychological difficulties presenting in childhood and adolescence, is the assumption the problem lies within the child or adolescent (Carr, 1999). This assumption ignores the interactional processes surrounding the child and the influence these processes have on the development and maintenance of the difficulty. The contribution of these interactional processes is discussed in more detail below.

Classification is further criticised as a diagnosis carries an implicit message regarding the way in which the child will present and behave. It is suggested this may lead to stigmatisation (Cantwell & Rutter, 1994). The effects such stigmatisation has on the future development and experiences of a child labelled at an early age causes clinicians concern (Cantwell & Rutter, 1994). This concern is heighten as some clinicians think it is not possible to conceptualise child or adolescent disorders as being different from normal development (Cantwell, 1996). There is a real fear children and adolescents will be labelled as having a mental health problem when in reality they are presenting symptoms that are part of a normal developmental phase. As a result clinicians need to be cautious when applying labels. This caution is observed with regard to the label of borderline personality disorder. Clinicians are not allowed to diagnose this disorder in adolescents under the age of 17 years, as many of the clinical features of borderline personality disorder reflect those displayed as part of the normal developmental phase of adolescence.
Finally, the application of a label to a child when they do not have the right to resist causes clinicians further concern (Carr, 1999). These concerns appear to suggest applying diagnostic labels to children and adolescents are fraught with negative effects. However it has been suggested the ‘harmful effects of psychiatric classification result from abuse of systems and not from the classification system per se’ (Cantwell, 1996, p.3).

**Contributions of Classification to Clinical Practice**

**Practical Relevance of Classification**

Classification does have practical contributions to make to clinical practice. Most importantly perhaps is the discourse it allows. Classification has been described as an ‘essential code of communication between clinicians. It provides a kind of language by which people can describe the disorders they investigate and treat’ (Rutter & Shaffer, 1980: cited in Werry, 1985, p.2). Classification also provides a means of bringing order and understanding to clinical practice, allowing groups of children and adolescents who share the same or similar clinical symptoms to be identified. This shared understanding has an important role in contributing to research and to the development of a body of expert knowledge (Carr, 1999). Without a shared understanding of disorders amongst clinicians, research on treatment and aetiology of disorders within childhood and adolescence would be impossible to conduct (Waldman & Lilienfeld, 1995). Research is important in allowing effective treatments to be identified and outcomes to be predicted (Gelder, Gath & Mayou, 1991).

**Clinical Relevance of Classification**

Classification has been observed to have a function in helping families to understand their child’s problem and in helping parents to cope with disruptive and difficult behaviours (Cantwell & Rutter, 1994; Werry, 1985). A diagnosis seems to reduce anxiety and uncertainty as ‘probabilistic statements about aetiology and prognosis’ can be delivered (Werry, 1985, p.2). Werry (1992) commented the best information provided by classification systems is prognostic. For example, parents whose child is diagnosed
with attentional deficit hyperactivity disorder, can be informed that research has found hyperactive children to do better after leaving school (Weiss & Hechtmen, 1986: cited in Werry, 1992). Having this knowledge, that their child is likely to do better after leaving school, may reduce parental anxiety regarding their child’s future and may help them to cope better with the present situation.

Classifying child and adolescent mental health problems into diagnostic categories has a major contribution to treatment, in relation to gaining funding for provision and resources (Cantwell & Rutter, 1994). For example, a diagnosis of attentional deficit disorder may lead the Local Education Authority to provide funding for a child to have a classroom assistant. Similarly, a diagnosis of autism may lead to a child receiving the specialist help they require (Rutter & Schopler, 1992). However, on the other hand, classification can be problematic, making funding for service provision and resources difficult to obtain. As classification leads to rigid and specific diagnostic criteria, it may lead to the exclusion of a child from a service, as they do not meet the strict diagnostic criteria set by the classification system (Howlin, 2000). For example, a child with autistic features may require funding to attend a special school for children with autism, but fail to gain the required funding, as they do not present with all the diagnostic symptoms of autism.

**Weaknesses and Criticisms of Classification**

There appears to be a number of significant weaknesses that make the psychiatric classification systems of DSM-IV and ICD-10 less than satisfactory (Cantwell, 1996), and discourage some clinicians from using them at all within the field of child and adolescent mental health (Graham 1986; Werry, 1985). Many clinicians believe ‘a particular diagnosis explains so little of the child and his world that ......it holds little practical value’ (Werry, 1985, p.1).

**Process of Psychiatric Classification**

The process of psychiatric classification is based on an interaction between the child and clinician (Spitzer, 1994). The interaction results in a formal understanding and description of what is ‘wrong’ with the child or adolescent. In understanding what is
'wrong' the clinician considers the child or adolescents, 'behaviour, speech, affect, thoughts, perception, intelligence and memory', (Spitzer, 1994, p.163) and based on the findings, makes a judgement regarding the nature of the problem (Spitzer, 1994). This judgement is based on an understanding of the problem being 'within the child' and that the child requires some kind of treatment to overcome their weakness or problem. From a psychological perspective, understanding and treating childhood and adolescent mental health problems in this way is unacceptable for two reasons. Firstly, clinicians adopting systemic, narrative and social constructivist models to guide their clinical practice, understand and treat mental health problems, in a manner that conceptualises problems as outside of the individual, for example, within the family, or within the interaction between the child/adolescent and family members, or the child/adolescent and wider society (Carr, 1999; Graham, 1986). Secondly, systemic models focus on the strengths of the child and family, working towards creating solutions to change the family system, rather than focusing on weakness and problems 'within the child' (Carr, 1997).

With some child and adolescent pervasive developmental disorders, such as autism, asperger's syndrome and retts syndrome, conceptualising the problem as being within the individual may be useful (Carr, 1999). However for the majority of child and adolescent mental health problems a number of clinicians would argue this was not a useful way in which to conceptualise mental health problems.

From a psychological perspective mental health problems in children and adolescents are perceived as arising from a complicated interactional process involving the individual, their family members and the social systems in which the family exist (Mikesell, Lusterman & McDaniel, 1996: cited in Carr, 1999), and not as an inherent characteristic of the child or adolescent. For example separation disorder is presented within the classification system of DSM-IV as being an inherent characteristic of the child. For separation anxiety to be diagnosed the child must show developmentally inappropriate and excessive anxiety relating to separation from home or the attachment figure (American Psychiatric Association, 1994). Exploration within the psychological assessment would usually uncover evidence of an interactional process existing between the child and
their mother, usually involving concerns about safety and an over-sensitivity to danger. Further exploration may uncover childhood anxiety in the mother or an event that has acted as a precipitating factor to the child’s separation anxiety. The psychological formulation would incorporate the predisposing, precipitating and maintaining factors in order to understand the problem and to guide treatment, rather than conceptualising the problem purely as an inherent characteristic of the child.

Nomothetic Versus Idiographic
Psychiatric classification is also criticised for its strong nomothetic tendency (Werry, 1985). A construct given to a child assumes a certain amount of knowledge and that this knowledge applies to all children diagnosed with the same particular construct. Within the psychological assessment it becomes clear that although children presenting with certain problems can share similar predisposing, precipitating and maintaining factors, this is usually not the case. Clinicians argue classifying children into constructs fails on two accounts. Firstly, it fails to treat each child as a unique individual and secondly, it fails to take into account the child’s unique interactions with their family and the wider society. In contrast systemic models are idiographic in nature, focusing on the uniqueness of the individual and their interactions with their family and the wider society (Werry, 1985). In classifying children and adolescents following nomothetic procedures there is a very real danger of losing individual differences. This may result in the loss of detailed personal information. It is this information that is paramount in gaining a real understanding of the child’s difficulty and being able to treat the problem effectively (Huschka, 1941: cited in Cantwell & Baker, 1988).

Aetiology and Treatment
A further criticism of psychiatric classification is the lack of information provided with regards to aetiology and treatment (Carr, 1999; Werry, 1992; Graham, 1986). A diagnostic construct offers a very limited understanding of how the problem arose and similarly, little guidance on what actions should be taken within clinical practice to treat the problem (Carr, 1999; Graham, 1986). For example, a diagnosis of anorexia nervosa, following DSM-IV diagnostic criteria, provides the clinician with information
that the individual is refusing to maintain their body weight, has an intense fear of gaining weight even though underweight, has a disturbance of body image and amenorrhoea in post-menarcheal females (American Psychiatric Association, 1994). Information explaining and leading to an understanding of why the problem has developed is not specified, nor is a specific guide or indication as to how the clinician should treat the problem.

It is the psychological formulation that allows the predisposing, precipitating and maintaining factors to be linked together to provide the clinician with a firm understanding of how the problem developed and the factors contributing to its maintenance. For example, in understanding anorexia nervosa, formulations drawing on family systems theories identify a number of family features and characteristics that may predispose and maintain the problem. Minuchin, Rosman and Baker (1978) identified families of adolescents with anorexia as enmeshed and rigid, being overprotective towards the child, lacking conflict resolution and involving the child in parental conflicts (Minuchin et al., 1978: cited in Carr, 1999). In contrast Weber and Stierlin (1981) suggested the predisposing factor of anorexia nervosa is the child’s fantasy that the parents will have nothing in common when the child reaches maturity and becomes independent. To avoid this happening the child aims to avoid maturity and independence through self-starvation (Weber & Stierlin, 1981: cited in Carr, 1999).

These two explanations and understandings of anorexia nervosa highlight the importance of the family system in the development and maintenance of the adolescent's difficulty. They also identify that there is not a sole explanation to understand the cause and maintenance of anorexia nervosa. The existence of different aetiological theories questions the assumption made by psychiatric classification systems, that all children sharing the same construct, share the same underlying knowledge attributed to that particular construct. This is clearly not the case. Systemic models have shown the idiographic uniqueness of each individual and their family needs to be explored in order to gain an understanding of why the problem developed and why it continues to present.

Additionally, the formulation also highlights protective factors, which can be drawn
upon during treatment to increase the likelihood of successful therapeutic change. Examples of protective factors for an adolescent with anorexia include; secure attachment with parents, family acceptance a problem exists, authoritative parenting and clear family communication. Psychiatric classification ignores the influence of these protective factors. Similarly, psychiatric classification also ignores the influence of interactional processes within the family system on the success of treatment and outcome. Classification systems indicate treatments that treat the child individually, following the assumption the problem is an inherent characteristic of the child. However, as systemic models highlight mental health problems experienced by children, exist within the family system. Treating only the individual child and not the system within which they live will lead to a less successful outcome. For example, the treatment of choice for anorexia nervosa is a highly structured family based treatment programme (Carr, 1999). The treatment of choice strongly indicates that the problem is perceived in the wider family context and as an interactional process between the child and their family. This indicates the whole family should be involved within the treatment process and all family members will be required to make some change in their behaviour if therapeutic change is to occur.

**Conclusion**

In conclusion psychiatric classification systems have been criticised for having a number of methodological problems, including, poor inter-rater reliability, poor validity, poor coverage and co-morbidity. Further these systems have also been criticised for labelling children from an early age and placing the problem within the child, ignoring the effects of interactional processes between the child and their family and the wider society.

However, psychiatric classification has been shown to make some contribution to clinical practice. Firstly, classification systems facilitate communication between clinicians. Secondly, they allow a shared understanding of disorders to exist. This is paramount within research and in the continued development of an expert body of knowledge. Thirdly, diagnoses gained from the classification systems, allow parents to make sense of their child’s symptoms, reducing their anxiety and offering them information relating to prognosis. Finally, the application of diagnostic constructs to a child’s
symptoms can help in gaining funding for service provision.

With regard to the relevance of psychiatric classification in understanding mental health problems within childhood and adolescence, the above discussion indicates psychiatric classification and diagnosis to be less relevant than the psychological formulation. Psychiatric classification gives a diagnostic construct to the child’s symptom-patterns, giving little information as to the predisposing, precipitating and maintaining factors. It is the psychological formulation, based on psychological models and theories, which links together the whole picture. The formulation incorporates the child’s family system and wider system, to provide the clinician with a firm understanding of the factors contributing to the development and maintenance of the problem. This is much more useful to the clinician in gaining an understanding of the mental health problem than purely naming symptom-patterns.

In considering the relevance of psychiatric classification in treating mental health problems in childhood and adolescence, the above discussion highlights diagnostic systems have some relevance and contribution to treatment. Classification systems allow standardised definitions of disorders to be established which are essential to research. Research allows an evidence base to be established, highlighting the most effective treatments. This allows the treatment of choice for specific disorders to be identified. However, this is based on the assumption that individuals are nomothetic and will respond equally to treatment. As has been presented above this is clearly not the case. Individuals are unique and experience different interactional processes that effect treatment. Classification systems tend to ignore the influence of the family and wider systems, placing the problem within the child, and as a result recommend treatments, which focus on overcoming inherent characteristics of the child. As illustrated above, in considering the treatment of children and adolescents the entire family system needs to be involved, actively engaging within treatment and making the required shifts for the structure of the family system to change. Only change in the whole family system will result in successful treatment of the child or adolescents mental health problem.
References


Examine the contribution of psychological models of health in the prevention and rehabilitation of coronary heart disease.

Specialist Health Essay
Year 2
Psych.D Clinical Psychology

June 2001
Introduction
The importance and contribution of the application of psychological theory and models to the area of health and illness has now been widely accepted (Edelmann, 1994). The contribution psychology has to make to health and illness has been increased as patterns of illness and disease have changed over the centuries. Society has seen a shift from contagious and infectious diseases, such as smallpox and polio to chronic diseases, such as heart disease, stroke and cancer (Pitts, 1998). These chronic diseases are to some extent a product of different lifestyles and health behaviours that were not evident in the 19th Century. Psychological models have been developed to aid understanding of health related beliefs and behaviours in an attempt to modify and change individual lifestyle practices in order to reduce the prevalence of chronic diseases.

Before considering the contribution of psychological models of health in the prevention and rehabilitation of coronary heart disease (CHD), the prevalence rates, pathology and risk factors of CHD are briefly outlined. The distinction between the biomedical model and biopsychosocial model is also addressed, emphasising the relevance and contribution of the biopsychosocial model in overcoming today’s chronic diseases. Cognitive models of health, focusing on the health belief model (Rosenstock, 1966: cited in Pitts & Phillips, 1998), Theory of planned behaviour (Ajzen & Madden, 1986) and the Self-regulatory model (Leventhal & Cameron, 1987) are then outlined and general criticisms of the models discussed. The contribution these models have in the prevention and rehabilitation of CHD is then addressed. Finally, interventions in the prevention and rehabilitation of CHD employed by psychologists are briefly highlighted.

Prevalence of Coronary Heart Disease
CHD is the largest single cause of death in England in men and women. In 1993, 170,000 deaths in England were caused by CHD, accounting for 26% of all deaths (Poulter, 1993). 50,000 of these deaths were premature occurring in individuals aged under 70 years (Timmis, Nathan & Sullivan, 1997). CHD has become costly for the NHS, accounting for 2.5% of the total NHS expenditure in 1991 (DoH, 1995). Due to concerns of increasing prevalence rates and NHS expenditure, CHD was identified as one of the five key target areas in the Governments Health of The Nation White Paper (DoH, 1992). In identifying CHD in this way, the Government highlighted the
importance of understanding the causes of CHD and investigating ways to significantly reduce CHD in this country.

In considering which groups are most at risk from CHD, research indicates CHD is predominately a male disease, accounting for 40% of all deaths in men aged between 45 and 64 years (Bennett, 1993). In contrast, CHD accounts for 10% of all deaths in women of the same age group (Bennett, 1993). With regard to ethnicity, CHD has a higher prevalence in individuals of South Asian origin in the UK than for Whites. The reason for this difference and susceptibility of South Asians to CHD has not been explained (Timmis, Nathan & Sullivan, 1997). The prevalence of CHD is also higher in the north of England and tends to be highest in social class V. The variations within social class and geographic location have yet to be adequately explained (Poulter, 1993), although differences in lifestyle have been put forward as a possible explanation.

Pathology
CHD is a chronic progressive disease affecting the arteries that feed the heart. It is a gradual process where metabolic by-products slowly build up within the artery walls. The collection of metabolic by-products acts to narrow and harden the vessels. This process is referred to as atherosclerosis. (Bundy, 1994). Atherosclerosis leads to the coronary arteries becoming blocked. This results in two major complications. Firstly, the heart muscle fails to gain its essential oxygen supply and secondly, the blood flow becomes blocked which damages the muscle tissue of the heart (Sheridan & Radmacher, 1992). A lack of oxygen to the heart muscle results in a condition known as ischemia, which can produce severe pain referred to as angina. It is estimated one million middle-aged men suffer with angina (Bundy, 1994). Angina is considered to be the least life threatening clinical manifestations of CHD (Bundy, 1994). In contrast, the clinical manifestation of myocardial infarction is extremely serious and life threatening. This occurs when the blocked blood flow damages the muscle tissue of the heart. It is more commonly known as a heart attack. Research indicates around 30–40% of people who have a heart attack die as a result (Sheridan & Radmacher, 1992).

Risk Factors
The exact cause of atherosclerosis is unknown (Timmis, Nathan & Sullivan, 1997), however a number of risk factors have been identified from epidemiological research
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(Bundy, 1994). Risk factors fall into two types, those that are irreversible and those that are considered potentially reversible. Risk factors are multiplicative (Bennett, 1993) the presence of two or more factors increases an individual’s risk of developing CHD. For example, a middle-aged man who smokes, has high blood pressure and high cholesterol level is six times more likely to have a heart attack than another male of the same age (Muir & Mant, 1996).

Irreversible factors
The risk of developing CHD increases with age and is greater for males than females. One-third of all deaths in men under 65 years are a result of CHD (Bundy, 1994). The presence of a strong family history of CHD also increases an individual’s susceptibility to the disease. Finally, diabetes has been identified as increasing the risk of CHD in both men and women, by a factor of two or four fold (DoH, 1995).

Reversible factors
Smoking has been identified as the single most important reversible risk factor for CHD (Bundy, 1994). The risk of developing CHD rises in proportion to the number of cigarettes smoked (Timmis, Nathan & Sullivan, 1997). Smoking is estimated to account for up to 18% of all CHD deaths (DoH, 1995). Giving up smoking has been identified as the single most effective way in which to reduce the risk of CHD (DoH, 1995). Obesity and poor diet are other important risk factors for CHD. Obesity as a risk factor is largely due to associated hypertension, hypercholesterolaemia and diabetes. Finally, physical inactivity and general unhealthy lifestyle practices lead to an increased risk of developing CHD.

It is important to emphasise all these risk factors are reversible as avoiding or correcting these risk factors may protect an individual against the development or the progression of CHD. Studies measuring the effect of lifestyle changes on CHD indicate changes in diet, stopping smoking, and introducing moderate exercise may significantly lower the risk of CHD (Ornish, Brown, Scherwitz & Billings, 1990). Findings have also indicated patients who make the greatest changes in their lifestyle behaviours show the greatest improvements in their health and in significantly reducing their susceptibility to CHD (Ornish, Brown, Scherwitz & Billings, 1990).
Controversial risk factors for CHD also exist; these include Type A behaviour (Friedman & Rosenman, 1959: cited in Snyder & Forsyth, 1991) and other psychosocial factors such as stress, social isolation, and depression (Scheidt, 1996). Although much has been written on these controversial risk factors, especially Type A behaviour, these will not be mentioned further.

**Biomedical Model Versus Biopsychosocial Model**

**Biomedical Model**
The biomedical model is the dominant model of medical science. This model considers only the biochemical factors of health and illness, its focus being solely on the biological elements of disease. The social, psychological and behavioural dimensions of the individual suffering with the disease are disregarded (Engel, 1980). The model promotes specialization and reliance on treatment and cure, which are provided and delivered by the medical profession. The responsibility for health and illness is placed firmly at the door of the medical profession and medical science (Gordon & Fadiman, 1984: cited in Sheridan & Radmacher, 1992). With regard to CHD the biomedical model is concerned with offering a cure and treatment for the disease or disease symptoms. Interventions include, surgery, for example, a coronary bypass or medication, for example, beta-blockers, nitrates and digitalis.

Although the biomedical model has dominated and been accepted without question for a number of years, recent years have seen a change in opinion and the biomedical model challenged. The ‘assumption that only biological factors of health and disease are worthy of study and practice’ has been questioned (Sheridan & Radmacher, 1992, p. 4). The influence and value of social, psychological and behavioural dimensions on health and illness have been acknowledged. This has lead to the development of the biopsychosocial model.

**Biopsychosocial Model**
The biopsychosocial model expands on the biomedical model, in that it accepts the importance of biological factors to health and illness, but highlights the importance and contribution of social, psychological and behavioural dimensions to health and illness (Engel, 1980; Jasnoski & Schwartz, 1985: cited in Sheridan & Radmacher, 1992). The biopsychosocial model is considered as being more acceptable when considering the contribution lifestyle plays in the development and progression of 21st
Century diseases. This is highlighted as behavioural and lifestyle factors have been implicated in seven out of ten, of today’s leading causes of death (Scheidt, 1996).

In considering CHD, the risk factors outlined earlier stress the contribution of social, psychological and behavioural factors in the development of the disease. Many of these risk factors for example, smoking, high blood pressure and obesity, are lifestyle factors, which are considered to be either reversible or preventable. The contribution of social, psychological and behavioural factors outlined by the biopsychosocial model highlights the role of and contribution psychological theory and models have to make within the health care system in addressing issues of physical health.

**Psychological Models of Health**

Epidemiological research has highlighted CHD is to a large extent mediated by a number of risk factors amenable to individual change (Bennett, 1993). Changes in individual health behaviours to reduce the risk of CHD can occur at the stage of prevention or rehabilitation. Psychological models of health have been developed to explore and understand the social, emotional and cognitive factors that influence the likelihood of an individual engaging in healthier lifestyle behaviours (Edelmann, 1994). Models considering the influence of cognitive factors have received the most attention. Psychological models focusing on cognitive factors consider the beliefs individuals hold regarding their health and how such beliefs influence their health behaviour.

**Health Belief Model**

The health belief model (HBM) (Rosenstock, 1966: cited in Pitts & Phillips, 1998) is one of the best-known psychological models of health. The model originates from the expectancy-value model developed from social learning theory (Rotter, 1966) and describes the relationship between an individual’s health beliefs and their health behaviour. The model primarily focuses on preventative health care, hypothesising that in the absence of disease the likelihood of an individual following and complying with preventative health care, is determined by a number of health beliefs held by the individual. The first of these beliefs is the extent to which the individual believes they are vulnerable or susceptible to the disease and secondly, how serious they believe the consequences of the disease to be. However, before engaging with and adopting preventative health behaviour the individual weighs up the perceived costs and
benefits of performing the health behaviour. The perceived benefits reflect the individuals beliefs surrounding the likelihood their actions will result in the desired outcome and reduce their risk of developing the disease. Perceived costs highlight the disadvantages and perceived barriers of engaging in preventative health behaviour. These would include for example, expense, time and difficulties in overcoming additions.

In reviewing the reliability of health beliefs in predicting patient compliance in implementing preventative health behaviours, Janz and Becker (1984) found the effects of susceptibility, benefits and costs to be fairly reliable. However, severity was found to be less reliable in predicting preventative behaviour. Overall, they conclude the HBM has only modest predictive power of compliance based on the four components of health beliefs. In contrast, other studies have highlighted the reliability and effectiveness of the HBM in predicting change in health behaviours in a number of areas, for example, vaccinations, screening for cancer and contraceptive behaviour (Harrison, Mullen & Green 1992: cited in Pitts & Phillips, 1998; Herold, 1983: cited in Pitts & Phillips 1998).

Criticisms of the model
Although the HBM has had success in some areas of clinical practice in altering individual health beliefs and encouraging compliance with preventative health behaviours, a number of problems exist with the model. The model is problematic, as it offers an explanation of health behaviour that assumes individuals make rational decisions about their health behaviour. In doing so, it fails to acknowledge the contribution and importance of emotions in the acceptance and adoption of preventive health behaviours (Eldemann, 1994). Further, the basic assumption of the model, that modifying health beliefs will increase an individual’s likelihood of compliance, is also problematic. The assumption does not take into consideration the issue of individual responsibility. Incorporated in the individual’s health belief is whether or not they see themselves as ultimately responsible for their health and whether they perceive themselves blameworthy if they become ill. Therefore the links between locus of control (Rotter, 1966) and health beliefs and health behaviours are not considered. The individual’s perception of locus of control and their responsibility for their own health need to be considered when discussing compliance with preventative health

**Self-efficacy**

Self-efficacy (Bandura, 1977) examines the individual’s beliefs in his or her own abilities and capacity to be able to change their health behaviour. The individual perceives the health threat and considers a range of coping strategies available to them. The choice of coping strategy they chose to follow is dependent upon their belief of what they are actually able to achieve. Therefore, the action an individual takes as a result of a health threat is a consequence of firstly, their belief they have the ability to perform the behaviour required to gain the desired outcome, and secondly, the individuals judgment that a specific behaviour will lead to the desired outcome (Bandura, 1977).

**Theory of Planned Behaviour**

The theory of planned behaviour (Ajzen & Madden, 1986) is based on the earlier theory of reasoned action (Fishbein & Ajzen, 1975). As with the HBM, the theory of planned behaviour is a central theory for health promotion and increasing compliance with preventative health behaviours. The model places intentions at a central point, stating intentions are the most important factors for determining behaviour. Intentions are described as comprising three elements. Firstly, the individual’s private attitude towards a behaviour. Secondly, the individual’s perception of socially determined norms, that influence their beliefs of how they consider others think they themselves should behave. Thirdly, the individual’s belief that they have the ability to carry out the planned and desired behaviour. For example, the individual believes they have the means to overcome any potential barriers to prevent them from carrying out the planned behaviour. This part of the model is strongly linked to the concept of self-efficacy (Bandura, 1977).

**Criticisms of the model**

The main criticism of the theory of planned behaviour is in relation to the direct link it applies between intention and behaviour. It is based on the assumption that all intentions are translated into behaviours. However, this is not always the case, as individuals can hold intentions about certain behaviours that fail to be translated into actions. Intentions may fail to turn into action, due to constraints such as, situation,
time, and expense or may just be suppressed (Pitts, 1998). A further problem with this model is the failure to take into account irrational decisions individuals make regarding their health (Edelmann, 1994) for example, continuing to smoke after a heart attack.

**Self-Regulatory Model**

The self-regulatory model (Leventhal & Cameron, 1987) of health can be conceptualised as a problem-solving model. It describes the individual as an active problem-solver, responsible for their own health state, who is motivated to regulate or minimize their health related risks and to act to reduce threats to their health. The basic premise of the model suggests individuals actively construct a representation of their illness and regulate their behaviour based on this representation.

The model proposes three stages that aim to regulate health behaviours during a phase that threatens an individual’s normal health. The stages are: cognitive representation, action planning or coping and finally appraisal. The first stage involves the individual developing a cognitive representation of what is actually wrong with them, what the causes of the symptoms are, how long the symptoms will last and the exact consequences of such symptoms. The second stage involves the individual planning how to deal with the health threat. This may involve coping strategies, such as seeking medical attention, and discussing with others methods they have used in the past to deal with the symptoms, or avoidance strategies, such as denial that a health problem exists and hoping it will eventually go away. The final stage of appraisal, involves the individual assessing and evaluating the effectiveness of the strategies employed during the second stage. This may lead to changes in the cognitive representation of what is wrong with the individual or changes in the ways to cope with the symptoms. This psychological model of health has been described as offering the widest framework to understand how individuals deal with the complex aspects of health, illness and disease (Earll, 1995).

**Critique of cognitive models of health**

These three psychological models of health have been valuable in identifying and understanding cognitive factors that influence and explain differential health behaviours. However, these models have suffered a number of general criticisms. For example, it has been suggested that the value-expectancy theories on which some
models are based, are the wrong theories on which to base models which try to derive cognitions to predict health behaviours and outcomes (Marteau, 1995). Silver and Wortman (1980: cited in Broome & Llewelyn, 1995) also challenge the theories on which the models are based, arguing the theories are not appropriate as they are not health specific theories.

Further criticisms have highlighted how cognitive models are to static and fail to explore the processes involved in an individual's decision to engage and participate in specific health behaviours. However, it is not only individual decision processes, which are disregarded. The contributions of environmental influences on an individual's decision to engage in health behaviours are also ignored. If environmental factors are ignored, there is a danger of detaching the individual from their social, economic and environmental context (Winett, 1985: cited in Broome & Llewelyn, 1995). This is a strong criticism made against the biomedical model.

Finally, cognitive models have been criticised for failing to consider cultural effects on the likelihood of an individual engaging with preventative health behaviours (Landerine & Klonoff, 1992). Ignoring cultural effects has huge implications for the likelihood of ethnic minority groups engaging in preventative health care practices. Failure to engage these groups will have implications for the future physical health of ethnic minorities in this country.

**Contribution of the models in the prevention and rehabilitation of CHD**

Despite criticisms relating to specific psychological models of health and criticisms levelled at cognitive approaches to health behaviour in general, these models do have a valuable contribution to make to clinical practice in the prevention and rehabilitation of CHD. Prevention of CHD through lifestyle change has always been noted as important. In contrast, risk factor modification and lifestyle change at the stage of rehabilitation is a more recent development (Maes, 1992). The aim of rehabilitation or secondary prevention is to encourage the patient to return to their former way of life, excluding risky lifestyle behaviours, for example, smoking, lack of exercise, poor diet. It is suggested these changes in health behaviours could prevent future complications of CHD, for example, a future myocardial infarction.
The psychological models of health outlined aid understanding of beliefs and cognitions that influence the likelihood of an individual engaging in healthier lifestyle behaviours. Although these models have primarily been devised to explain health behaviours at the level of prevention, they can also be adopted when considering the likelihood of individuals following medical advice and adopting alternative health behaviours after suffering the clinical manifestations of CHD. This is an increasing area of concern as on average about half of CHD patients fail to change health behaviours relating to smoking, physical activity, diet or weight reduction (Bar, Cluitmans, Elderen, Maes, Rutten, et al., 1990: cited in Maes, 1992).

The HBM asserts that modification of health beliefs can lead to changes in health behaviours. This has major implications for the future prevention and management of CHD. The aim of preventative intervention must be according to the HBM to change an individual’s health beliefs. According to the model, a change in health beliefs will lead to a change in health behaviour. The model highlights the importance of addressing health beliefs to gain change in behaviour, rather than trying directly to change the individual’s health behaviour. Consequently, preventative strategies, for example, health campaigns for reducing risk factors of CHD must focus on health beliefs that influence health behaviours. Preventative interventions must firstly, convince the individual, their behaviours and actions make them more susceptible to CHD and secondly, supply them with information of the serious consequences of CHD.

To increase the effectiveness of such interventions, health campaigns should focus on groups that are highly susceptible to developing CHD. Focusing campaigns at smokers, those who are overweight and physically inactive will produce far better results than focusing on the general population, which allows individuals to easily dismiss the idea they are susceptible. Raising awareness of an individual’s susceptibility to CHD in this way, will according to the HBM, increase the likelihood of compliance and change in health behaviour. Finally, campaigns should present the benefits of treatment in a manner that will overshadow the costs; to prevent individuals believing the changes in their behaviour will require too much effort and as a result become barriers to change.
The theory of planned behaviour is also strongly associated with increasing compliance with preventative health behaviours. According to this model changes in health behaviours are dependent on the individual's intentions. Preventative strategies for CHD, must aim to focus on and convert an individual's intention to change their health behaviour, for example, to give up smoking, to adopt a healthier diet, to start exercising, into action. The individual's belief that they actually have the ability to carry out the planned and intended behaviour is paramount to this model. If an individual intends to carry out a particular health behaviour but does not believe they have the ability to perform the behaviour, their health behaviours will remain unchanged. For example, an individual may intend to give up smoking, but fail to believe they have the will power to be successful. As a result they continue to smoke.

This highlights the importance of enhancing self-efficacy when attempting to change individual's health behaviours (Wulfert & Wan, 1993). Strategies for increasing self-efficacy and therefore increasing the likelihood of changes in health behaviours, focus on giving individuals information and support regarding how to be successful in reaching their intended health goal. This information and support can be delivered by professionals and can be transmitted via patient help lines, individual consultation, patient leaflets and patient groups, for example smoking cessation groups or exercise classes. Information and support in changing health behaviours can also come from other patients who have already successfully changed their behaviour. This may be in the form of patient support groups and patient newsletters. Finally, self-efficacy can also been increased through personal experience and practice and generating physiological arousal and psyching oneself up to do things (Bandura, 1977).

The self-regulation model explains individuals hold cognitive representations of illness and disease. An individual's health behaviours are dependent on the cognitive representation they hold of CHD and of the health related risks for developing CHD. Following this model, the presentation of information by professionals about CHD is critical. The information delivered by health professionals strongly influences the cognitive representation the individual forms of CHD and their own perceived risk of developing CHD. Further, information from professionals' influences the actions individual's plan to implement in reducing their risk of developing CHD or further reduce health complications due to existing clinical manifestations of CHD.
This model has implications for health promotion campaigns in preventing CHD. It suggests information regarding the development of CHD should be communicated concisely in a manner easily understood by the layperson and risk factors emphasised. To allow individuals to implement plans to reduce their risk and change their lifestyle behaviour guidelines should be outlined. These guidelines need to be communicated through a number of different modes, for example, written leaflets, television advertisements, professionals advising patients, health fairs and exhibitions. The information communicated should cater for differences in educational ability, language and culture.

**Psychological Intervention in the prevention and rehabilitation of CHD**

Although the biomedical model has interventions to treat the clinical manifestations of CHD, it is generally considered a disease that can be avoided, through changes in lifestyle. Therefore prevention at both the primary and secondary (rehabilitative) stage is regarded as the way forward, with regards to the management of CHD within the health care system.

**Prevention of Coronary Heart Disease**

The psychological models of health outlined here, highlight the importance of health education in preventing CHD. Health education is a very important element of health promotion. Health education programmes designed to prevent CHD include; providing information about CHD, exploring values and attitudes relating to CHD its causes and consequences, exploring how individuals make health decisions and finally, giving individuals the opportunity to acquire the skills to enable them to make the desired behaviour change and reduce their risk of developing CHD.

Although, health campaigns are frequently ineffective in producing behaviour change (Edelmann, 1994), employing psychological models and principles to this area, increases our understanding of the health beliefs individual’s hold and how such beliefs develop. Further, these models help to increase our understanding of factors, which prompt people to engage with preventative health care. Applying this understanding when devising health campaigns may help to increase their effectiveness in persuading individuals to change their lifestyle behaviours and adopt healthier lifestyle practices, which will significantly reduce their risk of developing CHD.
**Rehabilitation of Coronary Heart Disease**

Only 30-40% of individuals who have a myocardial infarction die as a result, the majority of individuals survive. As a result cardiac rehabilitation is required by a number of patients (Blumenthal & Emery, 1998). Traditionally, cardiac rehabilitation has concentrated on exercise-based programmes. However, controlled trials of exercise rehabilitation programmes have failed to demonstrate significant reduction in cardiac morbidity and mortality (Lipkin, 1991). Similarly, this intervention has failed to show any effects on getting people back to work (Bar & Vonken, 1990: cited in Maes, 1992). In contrast, a critical review showed psychological interventions, to have a beneficial effect on reported stress levels, return to employment, implementation of lifestyle change, for example, diet and nutrition, physical activity and smoking, and even morbidity and mortality (Bundy, 1989). As a result, it is now generally agreed that psychological interventions are probably most effective for rehabilitation and also for increasing compliance with changes in health behaviours and lifestyle (Bar, Cluitmans, Elderen, Maes, Rutten, et al., 1990: cited in Maes, 1992).

The current treatment of choice for cardiac rehabilitation includes a combination of psychoeducation and cognitive-behavioural skills training (Maes & van Veldhoven, 1990: cited in Maes, 1992). Psychoeducation includes information about CHD, diet, and maintaining a healthy lifestyle. The connections between physiological arousal and thoughts, feelings and behaviour are also highlighted. Skills training, includes, the use of bio-feed back, relaxation, assertiveness training and anger management.

Although, skills training are considered to be an extremely important part of rehabilitation, it is recommended that more time should be devoted to health education, in light of the influence of lifestyle behaviours in the development of CHD (Maes & van Veldhoven, 1990; cited in Maes, 1992). It is suggested rehabilitation programmes should aim to modify specific lifestyle behaviours, for example, smoking, diet, excessive body weight, lack of physical exercise and alcohol abuse (Maes & van Veldhoven, 1990: cited in Maes, 1992). In modifying lifestyle behaviours, psychological models of health can be applied, to aid understanding of the factors that influence the likelihood of an individual engaging in healthier lifestyle behaviours. This understanding will be fundamental to rehabilitation programmes with regard to the presentation of information to individuals regarding their condition and
the help, and support individuals are offered in trying to change their health behaviours.

**Conclusion**

The above discussion has outlined three psychological models of health, which can be used to explain, predict and change individual’s health behaviours. Although, these models have criticisms they can be successfully applied within a clinical context to assist professionals in changing individual’s health behaviours.

Psychological interventions at the preventative and rehabilitative stage of CHD have been highlighted to be valuable and effective. This demonstrates the role of psychology in the management of a medical condition, emphasising the need for psychologists to compliment the medical profession in addressing CHD. However, in practice there are few psychologists in cardiac rehabilitation. Previous research has found that in the UK there is less than one psychologist per one million inhabitants in the area of cardiac rehabilitation (Maes, 1992). Further research has concluded the number of psychologists who are active in the area of CHD is not reflective of the substantial interest given to psychological interventions in the CHD literature (Bundy, 1989).

These findings need to be addressed. More psychologists need to be attracted to work within the field of CHD. This concern is however felt within the area of physical health as a whole. Whether the present lack of psychological presence in physical health settings is a reflection of psychologists’ own perceptions of their role being predominantly within mental health or due to the medical professions hesitates to embrace psychology within its dominant medical model remains an interesting debate. However, the contribution of psychological models and interventions outlined here, stresses the effectiveness, contribution and understanding psychology and its models of health have to offer the medical profession in the prevention and rehabilitation of a serious and life threatening medical condition.
References


Critically discuss the argument that psychodynamic psychotherapy is inappropriate for older people when compared with other approaches.

Older People Essay
Year 3
Psych.D Clinical Psychology

December 2001
Introduction
Psychotherapy with those over the age of 65 has tended to focus predominantly on behavioural and cognitive approaches, with very little input from psychodynamic models (Stern & Lovestone, 2000). The paucity of psychodynamic psychotherapy with older people appears to have stemmed from Freud’s (1898, 1905: cited in King, 1973) pessimistic view of applying psychoanalytic therapy to those over the age of 50. Unfortunately, Freud’s view continued to be influential throughout the 20th Century, with many therapists considering other approaches rather than psychodynamic models to be more appropriate for working therapeutically with older adults.

The focus here is to consider the appropriateness of using psychodynamic psychotherapy when working with and treating older adults. The appropriateness and effectiveness of psychodynamic psychotherapy with this population will be examined and compared with cognitive and behavioural models. As depression is common in old age, with between 30 and 60% of all people over the age of 65, suffering with mild depressive symptomatology (La Rue, Dessenville & Jarwick, 1985: cited in O'Leary, 1996) this diagnosis will be used to illustrate the discussion. Prior to comparing the three models, the development of psychodynamic psychotherapy with older people is outlined and themes that are specific in the treatment of older adults are highlighted. Specific criticisms of Freud’s original comments are noted and discussed in light of more recent research and therapeutic findings. Explanations as to why psychodynamic psychotherapy for older adults continues to be limited in clinical practice are also addressed.

History of Psychodynamic Psychotherapy with Older People
Freud in his paper ‘Sexual aetiology of the neuroses’ in 1898 first indicated psychoanalytic therapy was not suitable for all cases and noted some limitations. Freud wrote, psychoanalytic psychotherapy,

... fails with people who are very advanced in years, because owing to the accumulation of material in them, it would take up so much time that by the end of the treatment they would have reached a period of life in which is no longer attached to nervous health (Freud, 1898: cited in King, 1973, p. 23).
Older People Essay

Freud furthered his view of psychoanalytic therapy being inappropriate for older adults in his 1905 paper 'On psychotherapy'. Here he wrote:

The age of the patient has this much importance in determining their fitness for psychoanalytic treatment, that, on the one hand, near or above the age of fifty the elasticity of the mental processes, on which the treatment depends, is as a rule lacking – old people are no longer educable – and, on the other hand, the mass of material to be dealt with would prolong the duration of the treatment indefinitely (Freud, 1905: cited in King, 1973, p. 23).

In drawing such conclusions Freud had mistakenly believed mental cognitions were linked to sexual activity. He considered a change in the sexual activity of men and women over the age of 50, due to loss of sexual potency in men and menopause in women, reflected a decline in mental activity and cognition as well (Hildebrand, 1986). This decline in mental activity meant the over fifties lacked the flexibility in their mental processes to cope with the demands of therapy, leading Freud to conclude psychoanalytic psychotherapy was inappropriate for patients over 50.

Abraham challenged Freud’s position in 1919 in his paper ‘The applicability of psychoanalytic treatment to patients at an advanced age’. Abraham commented:

In my psychoanalytic practice I have treated a number of chronic neuroses in persons of over forty and even fifty years of age.... To my surprise a considerable number of them reacted very favourably to the treatment (Abraham, 1919: cited in King, 1973, p.24).

Abraham went on to note:

The prognosis in cases even at an advanced age is favourable if the neurosis has set in it’s full severity only after a long period has elapsed since puberty, and if the patient has enjoyed for at least several years a sexual attitude approaching the normal and a period of social usefulness .... In other words, the age at which the neurosis breaks out is of greater importance for the
success of psychoanalysis than at the age at which treatment is begun. We may say that the age of the neurosis is more important than the age of the patient (Abraham, 1919: cited in Gene & Cohen, 1981, p.348).

Abraham’s comments were extremely influential and led to a more positive and optimistic outlook for psychoanalytic therapy with those over the age of 50. This optimism grew in later years following the realisation that psychoanalysis focused heavily on the first five years of life and neglected the significant developmental aspects occurring in the later years (Wheelock, 1997). There was also recognition that firstly, the conceptual framework of early psychoanalysis had not been developed for working with and treating patients in the later decades of life (King, 1973) and secondly, that there had been a failure to consider that socio-biological changes in later life could lead individual’s to experience psychological difficulties (King, 1973).

Abraham’s earlier comments and this realisation led theorists in the 1950’s to extend psychoanalytic theory to cover life span developmental processes. Emphasis was placed on the notion that there were a number of developmental changes and life transitions, which occurred after the age of 50. Failure to deal with these developmental changes and life transitions effectively could cause individual’s to experience anxiety and concern that might develop into a chronic neuroses, requiring psychodynamic psychotherapy. Influential contributors to the development of psychodynamic theory for later life at this time included, Eriskson (1959) and Winnicott (1965). Although these theories highlighted difficulties that could be experienced in later life and advocated psychoanalysis to deal with such difficulties, Freud’s earlier comments remained influential and many patients over the age of 40 were refused psychoanalysis for many years to follow. For example, The British Psychoanalytic Society and The Tavistock Clinic, both rejected patients over the age of 40 for psychoanalysis until the late 1980’s (Hildebrand, 1986).

Themes specific to the treatment of older adults

The change in attitudes to treating older adults with psychodynamic psychotherapy was highly influenced by King’s 1973 paper ‘Notes on the Psychoanalysis of Older Patients’. King identified six developmental tasks that occurred in the later stages of
life, as a reaction to the reality of the physical, psychological and social effects of the ageing process. King hypothesised, difficulties adjusting to the issues covered by the developmental tasks may promote the individual to seek psychoanalysis. The six areas of concern were identified as, firstly the fear of diminution of sexual potency and capacity to have children, secondly the threat of redundancy or displacement in work roles by younger people, thirdly the fear of retirement, fourthly the illness or death of their own parents, fifthly the inevitability of their own ageing and finally the increasing possibility of their own death.

The identification and impact of specific concerns and issues related to the ageing process and importance of viewing each phase of the developmental life cycle as important to growth and development has since been acknowledged by a number of psychodynamic theorists (Nemiroff & Colarusso, 1985: cited in Turner, 1992). It is the acknowledgement of the need to address concerns that are specific to old age that seems to make psychodynamic psychotherapy an appropriate model for older people.

**Arguments against Freud's view**

As outlined earlier Freud (1905) stated psychoanalysis was inappropriate for adults over the age of 50 due to their lack of elasticity. However, more recent evidence has suggested that unless the individual has experienced brain damage, older people do have considerable flexibility in their mental processes, having the capacity to use experience in an imaginative and plastic way (Hildebrand, 1982). This would suggest older adults do have the mental capacity to benefit from psychodynamic psychotherapy in much the same way as younger adults.

Freud (1898, 1905) also indicated psychoanalysis was inappropriate for older adults due to the amount of material that therapy would have to cover and the considerable amount of time analysis would take. However, in reality this does not appear to be evident. It has been suggested older adults have a greater ability to be self-reliant compared to younger patients and as a result feel more comfortable having shorter therapy and being left to get on with things themselves (Hildebrand, 1982). Similarly, patients in later life seem to acquire a sense of urgency and a desire to get on with

It is suggested, the ability of older patients to get on with things and be able to make changes quickly is helped by their reduced need to maintain rigid defence systems and an ability and willingness to assimilate new ideas into their psychic structure (King, 1973). Older patients also appear to be more realistic in their expectations of psychodynamic psychotherapy, more direct in their comments and more open in expressing their emotions. They are also described as being less resistant to unpleasant insight and seem to have less difficulty accepting and integrating interpretations (Grotjahn, 1955: cited in Turner, 1992). Combined, these factors help to increase the progress made by older adults in a relatively short period of time and suggest psychodynamic models can be both useful and appropriate when working with individuals in the later decades of life.

**Why is psychodynamic psychotherapy for older adults lacking in clinical practice?**

Although, Freud's (1898, 1905) comments have been criticised by more recent research and therapeutic findings, a lack of work applying this therapeutic model with older adults remains apparent in the literature compared to cognitive and behavioural models. The reasons for this are explored below.

**Factors within the therapist**

Butler and Lewis (1982: cited in O'Leary, 1996) identified a number of reasons explaining the reluctance of therapists to implement psychodynamic psychotherapy in treating older adults. These factors are related to the therapists' own fears regarding the ageing process, for example, loss of control, illness and dying, which may be provoked when working with older adults. The therapists' fear and difficulty of facing the ageing process was highlighted by Bateman and Holmes (1995) who commented 'there is the continued requirement for the elderly to face up to the changes inflicted as a result of the ageing process.... facing these issues is painful, not only for the patient but also for the analyst.' (Bateman & Holmes 1995: cited in Stern & Lovestone, 2000, p. 501.) With this in mind it is often considered much easier for
therapists to work psychodynamically with younger people. This belief is enhanced as the therapist has usually been through and survived the issues and difficulties associated with a younger age group. In contrast, the ageing process and issues associated with old age are still the unknown for many therapists who have yet to reach the second stage of life (King, 1973).

A further reason outlined by Butler and Lewis (1982: cited in O’Leary, 1996) for the reluctance of therapists to engage in psychodynamic psychotherapy with older adults, stems from the possibility of therapy enhancing awareness of conflicts in the therapists’ own relationships with their parents. This may feel uncomfortable for the therapist and as a result be avoided by refusing to engage in long-term psychotherapy with those over the age of 65. Butler and Lewis, also identified a belief that exists amongst some therapists that psychodynamic treatment will be unhelpful for older adults as their problems result from untreatable organic factors, not from difficulties in their personal relationships. Such a belief will inevitably lead to other models of psychotherapy being considered more appropriate as mean of intervention. For example, the implementation of behavioural models rather than psychodynamic models in the treatment of dementia. Finally, Butler and Lewis suggested therapists may consider their skills and time to be wasted working with those who are nearing death or with those who may die while engaged in long-term psychotherapy.

Further reasons for psychodynamic psychotherapy failing to be implemented with older adults have also been presented. Cohen (1977: cited in O’Leary, 1996) explained the resistance of applying psychodynamic psychotherapy to older adults is due to the therapists’ underlying fear they might be overwhelmed by the amount and extent of the older persons presenting problems. This fear causes therapists to shy away from engaging in in-depth psychodynamic treatment with this population. Similarly, the therapists’ fear of failing when working with an older figure also tends to lead them to avoid offering psychodynamic treatment.

Finally, the unwillingness of therapists to implement psychodynamic psychotherapy in treating older adults may occur from conflicts that might arise as a result of differences in the therapists and older adults value systems. The value systems held by
older people become a central focus of therapy, due to changes in their work environment and retirement and due to death becoming a reality. Therapists may find it difficult to empathise and address these issues due to the non-exploration of their own values in these areas (O’Leary, 1996). Ultimately, ageist attitudes and beliefs that are predominant within society often relegates the older patient to less challenging models of psychological intervention, than that of psychodynamic psychotherapy (Porter, 1991: cited in Stern & Lovestone, 2000).

Factors within the patient
Butler and Lewis (1977) have also identified factors that exist within older patients themselves that may explain why older people are resistant to psychodynamic intervention. They suggested a desire for independence, fear of change and suspicion based on past experiences, makes older patients resistant to engaging within psychotherapy. Further, for some older patients psychodynamic psychotherapy is not implemented as it is considered they have an inability or lack the desire to confront difficult and irresolvable issues (Porter, 1991: cited in Stern & Lovestone, 2000). However, all these factors can also be applied to younger populations and should not be used as arguments to exclude older people from psychodynamic psychotherapy or to conclude the model is inappropriate for use with older adults. Older adults who remain capable of forming meaningful and significant relationships and seek new experiences should potentially be able to use psychodynamic psychotherapy in an active and beneficial manner (Stern & Lovestone, 2000).

Transference and Countertransference
Transference and countertransference are terms most commonly associated with psychodynamic psychotherapy (Knight, 1996). In classical terms transference refers to the process by which the patient transfers onto the therapist past experiences and strong feelings, which the patient previously experienced in relation to a significant person in their earlier life (Bateman & Holmes, 1995). In contrast, countertransference describes the thoughts and feelings experienced by the therapist that are evoked by the patients’ transference (Bateman & Holmes, 1995). Although, transference and countertransference are common to all age groups engaged in psychodynamic psychotherapy, it is generally believed the transference of older patients is more
complex than with younger patients (Colarusso & Nemiroff, 1987: cited in Turner, 1992) and maybe more intense (King, 1980). Similarly, the countertransference experienced by the therapist is also likely to be more powerful (Semel, 1993: cited in Knight, 1996). It has been suggested that it is because of the powerful nature of the countertransference experienced by therapists, that has led therapists to feel uncomfortable using this model with older adults and may explain why it has been considered inappropriate to work psychodynamically with older adults (Semel, 1993: cited in Knight, 1996). However, the complex and intense transference often observed in older adults seems to suggest this model of therapy is in its very nature, appropriate and beneficial in addressing and overcoming difficulties experienced in later life.

Transference
The four main types of transference experienced by older adults can be understood using a framework developed by Colarusso and Nemiroff (1987: cited in Turner, 1992). These include parental, son/daughter, peer/sibling/spousal and eroticised transference. The most common and best understood is the parental transference, where based on past experiences the patient reacts to the therapist as if they were their parent. Within the son/daughter transference the patient reacts to the therapist as if they were the patients own child, transferring unresolved expectations and disappointments felt towards their own child onto the therapist. The peer/sibling/spousal transference can occur when the therapist is seen as being similar to a person in the patient’s past with whom they had a close relationship. The erotic transference is rarely mentioned with older adults, but is in reality just as likely to occur as with younger patients (Knight, 1996). The erotic transference is more likely to occur when there is an decreased opportunity for intimacy in the patients’ life and accordingly the patient fantasies about a potential romance with the therapist (Turner, 1992).

Countertransference
Countertransference can be anxiety provoking for therapists working with clients from any age group. However, the issues which are confronted when working with older adults seem to be even more pertinent in evoking discomfort in therapists. Much of the unease involves the therapists’ own conflicts and anxieties surrounding the ageing
process (Knight, 1996) and unresolved hostility towards the therapists' own parents or grandparents (Turner, 1992). It has been suggested that therapists need to come to terms with their own feelings relating to the ageing process, dying and their own parents if they are to work effectively with older adults (King, 1980: cited in Turner, 1992).

**How appropriate are other models when working with older adults?**

The factors outlined above explain why psychodynamic psychotherapy with older adults may be limited in clinical practice. However, it is important to note the factors can equally be applied to cognitive and behavioural models of therapy. Regardless of the model implemented the therapist can be fearful of the ageing process and inexperienced in the issues associated with old age. Similarly, therapists following cognitive or behavioural models may think it is a waste of time or unhelpful to treat older adults. This could be due to an underlying ageist attitude towards old age and not related to the model of therapy. Likewise, the fear of being overwhelmed with the presenting problems and of treatment failure can also be applied to therapists implementing cognitive and behavioural therapy with older adults.

With regard to factors within the patient, older adults treated with any model of therapy may be resistant to change and to the model of therapy itself. Similarly, older adults who have an inability or lack the desire to confront and address difficult issues, will find any model of psychotherapy difficult to engage within and to use effectively in addressing and overcoming their presenting problems. Finally, transference and countertransference have also been highlighted as having a place within other therapies, having an important influence in the process and progress of all therapy with older adults (Dick, Gallagher-Thompson & Thompson, 1996). It is suggested the countertransference experienced when working with older adults can be difficult and uncomfortable for the therapist regardless of the model.

Applying the difficulties often associated with psychodynamic psychotherapy to other models of therapy seems to indicate little overall difference in the appropriateness of the three psychological models in treating older adults. The appropriateness of using
cognitive and behavioural models compared to psychodynamic models is discussed further below.

**Cognitive Therapy**
Cognitive therapy is one of the most widely used models in the treatment of depression in older adults. The process of treatment following the cognitive model for older people can involve giving the patient a leaflet outlining the treatment rationale and highlighting the influence of negative views regarding self, world and the future in maintaining depression. Patients are encouraged firstly, to keep a thoughts diary to monitor negative thinking and help patients to make associations between negative thoughts and mood, and secondly, to complete homework tasks to practice new skills learned in sessions. Finally, dysfunctional thought patterns, for example, catastrophising and generalisation are identified and the patient is encouraged to challenge these thought patterns and to generate more adaptive and positive thinking styles (Emery, 1981: cited in Dick, Gallagher-Thompson & Thompson, 1996).

Although, this model is widely implemented with older adults the appropriateness of the model maybe challenged. The structured nature of the sessions, the treatment contract, the process of identifying negative thought patterns, the focus on trying out new styles of thinking and behaving, and the need to complete homework tasks, may actually provoke anxiety in some older adults adding to their distress. Similarly, the nature of the treatment and the focus on challenging negative thought patterns in order to overcome their problems, may seem irrelevant to older people and seem inadequate and insensitive as a technique to address the existential and complex concerns that older adults often bring to treatment (Culverwell & Martin, 2000). Older adults presenting with depression due to underlying concerns with complex issues such as chronic illnesses, disabilities, loss of loved ones and the reality of their own death, may require the more unstructured, in-depth and sensitive approach offered by psychodynamic psychotherapy, rather than be presented with a model that aims to understand their depression in terms of faulty or negative thought patterns and suggests their difficulties can be overcome by simply thinking more positively.
**Behavioural Therapy**

Behaviour therapy is another model of therapy often applied to older adults in the treatment of depression. The aim of treatment following a behavioural model is to increase the number of positive experiences and activities in the older adult’s life and to reduce the number of negative events. The process of treatment following the behavioural model for older people, involves giving the patient a leaflet outlining the treatment rationale. The patients’ mood is then monitored in relation to the frequency of pleasant and unpleasant events and the association between events and mood plotted. Based on this monitoring, a structured programme is devised to decrease events associated with depressed mood and increase events associated with a more positive mood state (Gallagher, 1981: cited in Morris & Morris, 1991). The model also involves the teaching of specific skills, for example, relaxation training and social skills training which help the individual to feel more positive in mood.

Once again, although this model is widely implemented with older adults the appropriateness of the model maybe challenged. With regard to the existential and complex concerns that cause older adults to become depressed and present for treatment, one needs to address whether a behavioural approach can realistically be implemented and successfully decrease the number of negative events associated with depressed mood in older adults. Many of the concerns in old age cover issues of retirement, loss of loved ones and reality of ones own death. These events need to be addressed and the feelings of the individual experiencing such events explored, rather than the individual being given activities to complete that are expected to make them feel more positive about the situation. The behavioural model when applied to older adults seems to fail to address the fact, that the issues and concerns causing the depression still exist for the individual after the positive activity has been completed. In contrast, psychodynamic theories based on life span developmental processes are sensitive to the specific issues and concerns of older adults and accordingly, appear to be more appropriate for this client group.

**Effectiveness of psychodynamic psychotherapy versus other models**

Unfortunately, few models of therapy have been evaluated with older populations to the same extent as with younger populations (Stern & Lovestone, 2000). Research that
has been conducted seems to have focused predominantly on the application of cognitive behavioural therapy to older populations (Lovestone, 1993: cited in Stern & Lovestone, 2000). However, a small number of studies have been conducted comparing psychodynamic, behavioural and cognitive therapy in the treatment of depression in older adults. Studies have compared these models using one to one and group therapy.

**One to One Therapy**

In their study Gallagher and Thompson (1982) randomly assigned 30 elderly outpatients suffering with depression to one of three treatment conditions; cognitive, behavioural or psychodynamic therapy, for 16 sessions over a 12 week period. Participants’ depression was measured on the Hamilton Rating Scale for Depression (HRSD: Hamilton, 1967: cited in Gallagher & Thompson, 1982) and the Beck Depression Inventory (BDI: Beck, Ward, Mendelson, Mock & Erbaugh, 1961: cited in Gallagher & Thompson, 1982) before and after therapy. Results indicated participants from all three treatment groups showed comparable improvement in depression from pre to post treatment. Therefore, results support the use of all three psychological therapies in the treatment of older adults with depression.

The comparable effectiveness of all three therapies in treating depression in older adults was supported by Thompson, Gallagher and Breckenridge (1987). In their study 91 older adults were randomly allocated to one of the three treatment groups for 16 to 20 sessions. The HRSD and the BDI were implemented to measure level of depression pre and post treatment. At the end of treatment the measures indicated 70% of participants were either no longer suffering with depression or had improved significantly. Further analysis revealed there were no significant differences across the three treatment groups, suggesting psychodynamic therapy to be as equally effective as behavioural and cognitive therapy in treating older adults with depression.

With regard to maintenance of treatment gains over time, results indicated participants treated with behavioural or cognitive therapy retained improvements made at the end of treatment, at one year follow up better than those treated with psychodynamic therapy (Gallagher & Thompson, 1982). However, the reported superiority in
treatment gains at follow up for cognitive and behavioural therapy appeared to be marginal, indicating psychodynamic therapy to be only marginally less effective one year after treatment compared to the other two models (Morris & Morris, 1991).

Group Therapy
There has been a tendency for group therapy rather than individual therapy to be advocated for treatment with older adults (Hartford, 1980: cited in Steuer, Mintz, Hammen, Hill, Jarvik, McCarley, Motoike & Rosen, 1984). However, studies comparing different models of therapy in treating older adults in group settings appear to be limited. One of the few studies comparing two models in a group setting was conducted by Steuer, Mintz, Hammen, Hill, Jarvik, McCarley, Motoike and Rosen, (1984). The study considered the effectiveness of cognitive-behavioural and psychodynamic group therapy with older adults suffering with depression. Thirty-three participants were assigned to one of the two treatment groups, for a total of 46 sessions over a 9 month period. All participants completed the Zung Depression Scale (ZDS: Zung 1965: cited in Steuer, et al., 1984) and the BDI pre and post treatment. Results showed no clinically significant differences between the two treatment groups, suggesting psychodynamic and cognitive-behavioural group therapy are equally effective in reducing depression in older adults.

Conclusion
In considering the use of psychological models with older adults, there has been a tendency to focus on behavioural and cognitive approaches, with very little input from psychodynamic models (Stern & Lovestone, 2000). Previously the lack of psychodynamic therapy with older adults was explained due to the assumed inappropriateness of the model with patients in the later decades of life. However, it has been argued here that this assumption is incorrect and psychodynamic models have much to offer in the treatment of psychological difficulties of older people. The preferred models of cognitive and behavioural therapy have themselves been highlighted as having potential flaws in their application to older adults and the appropriateness of these models questioned.
Arguments presented suggest psychodynamic psychotherapy can be especially appropriate and beneficial to older adults due to more prevalent concerns associated with old age, for example, retirement, loss of loved ones and reality of one's own death. It is suggested these issues are better and more sensitively explored using a psychodynamic model, as an opportunity is provided which allows older adults to resolved issues in ways that other models do not (Canete, Stormont & Ezquerro 2000). The effectiveness of psychodynamic models compared to cognitive and behavioural models in treating depression in older adults has also been addressed. Studies have indicated no significant differences across the three models. This suggests psychodynamic therapy is just as effective and therefore appropriate for treating depression in old age as the preferred models of cognitive and behavioural therapy.

In conclusion, it would appear psychodynamic psychotherapy is appropriate for treating older adults in comparison with cognitive and behavioural models. It appears a shift is required in clinical practice for therapists to overcome biases that this model is inappropriate and ineffective for older adults and to offer older patients the opportunity to access psychodynamic psychotherapy to the same degree as younger patients. Therapists need to consider ‘not how old the patient is but is the patient suitable for psychodynamic psychotherapy’ (Stern & Lovestone, 2000, p.501). This falls in line with standard one of the National Service Framework for Older People (DoH, 2001) that outlines treatment and care should be based on the ‘individual’s health needs and not their age ...... Denying access to services on the basis of age alone is not acceptable’ (DoH, 2001, p.6).
References


CLINICAL DOSSIER
The clinical dossier contains summaries of the clinical experience gained over the three-year course and summaries of the five case reports submitted. Full versions of the five case reports and clinical documentation, including placement contracts, logbooks of clinical experience and placement evaluation forms can be found in volume 2 of the portfolio. Due to the confidential nature of the material it contains volume 2 is held within the Department of Psychology of the University of Surrey.
Summaries of clinical experience during training

Adult Mental Health
People with Learning Disabilities
Child and Young People
Chronic Pain – Specialist
Older People
Paediatric Oncology – Specialist

PsychD. Clinical Psychology

October 1999 – September 2002
Summaries of Clinical Experience During Training

Summaries of clinical experience

Adult Mental Health – Core Placement

People with Learning Disabilities – Core Placement
Summaries of Clinical Experience During Training

ADULT MENTAL HEALTH PLACEMENT SUMMARY

Supervisor: Mary Dobbin.
Trust: Mid Sussex NHS Trust.
Base: Linwood CMHT, Butler’s Green Road, Haywards Heath, West Sussex.

Presenting Problems: Depression, self-harm, psychosis, delusions of reference, anger, abuse issues, vomit phobia, social phobia, panic disorder, agoraphobia, memory problems and cognitive deterioration due to epilepsy and stroke.


Interventions: Cognitive-behavioural model was predominantly utilised in all interventions with clients. The author remained mindful of systemic issues with all clients. Joint working was carried out with another trainee clinical psychologist in the development, running and evaluation of a group for carers with relatives suffering from psychosis.

PEOPLE WITH LEARNING DISABILITIES PLACEMENT SUMMARY

Supervisors: Mel Smith and Jane Edmonds.
Trust: Eastbourne and County Healthcare NHS Trust.
Base: Woodside, The Drive, Hellingly Hospital, Hailsham, East Sussex.

Presenting Problems: Relationship difficulties, difficulties accepting disability, challenging behaviour, low self-esteem, communication difficulties within the family, bereavement, anxiety, sexuality issues, inappropriate sexual behaviour, obsessional behaviour and cognitive deterioration.

Assessments: Assessment for treatment interviews with clients/staff/relatives, functional analysis, dementia screening tool, BPVS, WAIS-III, Sex and Knowledge Questionnaire, Assessment of Adaptive Functioning, Staff monitoring forms and questionnaires and observational monitoring. Became familiar with: Halo and Vineland.

Interventions: Cognitive-behavioural, behavioural and systemic models were utilised in interventions with clients. Joint working was carried out with a social worker and child psychologist in the development, running and evaluation of a group for siblings of children with learning disabilities.
Summaries of clinical experience

Child and Young People – Core Placement

Chronic Pain – Specialist Placement
CHILD AND YOUNG PEOPLE PLACEMENT SUMMARY


**Supervisors:** Ele Jones and Jayne Wallace

**Trust:** Eastbourne and County Healthcare NHS Trust.

**Base:** Sturton Place, Hailsham, East Sussex.

**Presenting Problems:** Aggressive and disruptive behaviour, drug abuse, self-harm, anxiety and separation issues, school refusal, bullying, bereavement, depression, developmental delay, soiling and wetting, feeding and sleep problems, phobias, adjustment difficulties, eating disorders and conduct disorder.

**Assessments:** Assessment for treatment interviews with clients and parents for individual and family therapy, WISC-III, WOND, WORD, Parenting Stress Index, Burns Anxiety Inventory, TSCC and Bailey Scales of Infant Development. Became familiar with: BAS first and second editions, WIPPSI, WOLD, WRAT and assessment schedules to assess Autistic Spectrum Disorders.

**Interventions:** Cognitive-behavioural, behavioural and systemic models were utilised in interventions with clients. Opportunity was provided to build on understanding of systemic models including narrative, structural approaches, family therapy and being a member of a reflective team.

CHRONIC PAIN SPECIALIST PLACEMENT SUMMARY

**Dates:** 4th April 2001 – 21st September 2001

**Supervisor:** Hilary Rankin

**Trust:** Merton, Sutton & Wandsworth NHS Trust.

**Base:** Centre of Pain Education, Cotsworld Road, Sutton Hospital, Sutton, Surrey.

**Presenting Problems:** Persistent and ongoing pain with no medical explanation, low self-esteem, depression, fear avoidance, anxiety, poor body image, activity cycling, adjustment difficulties, loss issues, anger, sexual relationship difficulties and social isolation and epilepsy.

**Assessments:** Assessment for treatment interviews with clients for individual sessions and for pain management programme, Visual Analogue Pain Scales, Pain S-E Questionnaire, HAD, BDI, BHS, Pain Coping Questionnaire, Rosenberg’s Self-Esteem Questionnaire, CES-D Scale, Acceptance of Illness Scale, McGill Pain Questionnaire, UAB Pain Behaviour Scale, Sit to Stand Test, Walking Test, WAIS-III, AMIPB.

**Interventions:** Cognitive-behavioural model was utilised in interventions with clients both in individual and group sessions. Observation of a eight-week pain management programme. Opportunity to work with a range of clients from diverse social and cultural backgrounds and to gain further experience in neurological issues through observation of and discussions with the Neuropsychologist.
Summaries of clinical experience

Older People – Core Placement

Paediatric Oncology – Specialist Placement
OLDER PEOPLE PLACEMENT SUMMARY

Dates: 10th October 2001 – 22nd March 2002
Supervisor: Corrie Meesters.
Trust: Worthing Priority NHS Trust.
Base: 16 Liverpool Gardens, Worthing, West Sussex.
Setting: Psychology Department.

Presenting Problems: Memory and sequencing problems, difficulties adjusting to chronic illness and conditions, chronic pain, anger, low self-esteem, relationship problems, depression, anxiety, difficulties adjusting to retirement, fear of aging, sleep difficulties, dementia, phobia, complicated and unresolved bereavement issues and suicidal thoughts.

Assessments: Assessment for treatment interview with clients, NART, MEAMS, Raven, Rivermead, BADS, Doors and People, BDI, HADS, Adjustment to illness questionnaire, and monitoring of sleep pattern. Became familiar with: WMS-III, Dementia Rating Scales, Kendrick Scales and Mini Mental State Examination.

Interventions: Cognitive-behavioural, behavioural and client centred models were utilised in interventions with clients. A number of psychometric assessments were conducted. This gave the author experience of breaking bad news and informing clients of a possible diagnosis of dementia.

PAEDIATRIC ONCOLOGY SPECIALIST PLACEMENT SUMMARY

Supervisor: Lesley Edwards.
Trust: Royal Marsden NHS Trust.
Base: Royal Marsden Hospital, Downs Road, Sutton, Surrey.
Setting: Hospital based in and out patients.

Presenting Problems: Memory problems, identity issues, poor body image, depression, anxiety, OCD, phobias, eating problems, preparation for medical procedures, behavioural problems, issues of loss and coping.

Assessments: Assessment for treatment interviews with child and family, WISC-III, WOND, WOLD, WORD, WRAML.

Interventions: Cognitive-behavioural, behavioural, and systemic models were utilised in interventions with clients. A number of psychometric assessments were conducted. This placement gave the author the opportunity to work within a predominantly medical model and assess where psychological approaches fit within this model. The author also developed skills in working with terminally ill children and how to preserve with difficult to engage children. Opportunity was also given to work with a range of clients from diverse social and cultural backgrounds.
Summaries of case reports completed during training

Adult Mental Health
People with Learning Disabilities
Child and Young People
Chronic Pain – Specialist
Older People
References to the Summaries of Case Reports

PsychD. Clinical Psychology

October 1999 – September 2002

Please note that all client names and identifying details in this section have been changed to preserve anonymity.
ADULT MENTAL HEALTH CASE REPORT SUMMARY

THE ASSESSMENT, FORMULATION AND TREATMENT OF PANIC DISORDER WITH AGORAPHOBIA IN A 34 YEAR OLD WOMEN.

Presenting Problem
Miss W was referred to the Clinical Psychology Service by her GP, for treatment of Panic Disorder With Agoraphobia. Miss W reported she experienced anxiety symptoms including, palpitations, sweating, trembling, breathlessness, dizziness and feeling faint in a number of different situations, for example, in shopping malls, cinemas, car parks, crowded rooms and unfamiliar buildings. Miss W’s symptoms had become problematic and interfered significantly with her daily life for approximately six months.

Assessment Procedure
1. Assessment for treatment interview, drawing on the cognitive model of panic (Clark, 1986) and DSM-IV (APA, 1994) diagnostic criteria for Panic Disorder With Agoraphobia. The assessment was conducted over two sessions.
2. Weekly panic diary to elicit information relating to the nature of the panic, the feared sensation and the safety and avoidance behaviours implemented (Wells, 1997).
3. Psychometric tests: Beck Anxiety Inventory (BAI), Agoraphobia Cognition’s Questionnaire (ACQ), Safety and Avoidance Behaviours Questionnaire (SABQ).

Formulation
The cognitive model of panic (Clark, 1986) provided the theoretical framework from which the formulation was developed. According to the model, panic occurs due to the ‘catastrophic misinterpretation of bodily or mental events’ (Wells, 1997, p. 100). The individual interprets bodily or mental events as signs of immediate danger. Interpreting the bodily symptoms in such a way leads to heightened anxiety and this in turn increases the anxiety symptoms, increasing the belief of the impending danger. The individual becomes trapped within the vicious cycle of his or her own panic. Miss W initially experienced difficulties with her breathing and misinterpreted this as a sign she was suffocating. As a result she would panic further, experiencing other anxiety symptoms, her breathing would become more irregular throughout her panic attack. This provided Miss W with evidence she was in danger. Her physical symptoms continued to be misinterpreted as an indication she was suffocating and would eventually die. Miss W had developed in-situation safety behaviours and avoidance
strategies to help her cope with her panic disorder. Although appearing beneficial to her these behaviours acted to maintain her presenting difficulties.

**Intervention**

Following the assessment, the formulation was shared with Miss W and the therapeutic goals set. The cognitive-behavioural intervention aimed to identify and modify Miss W’s catastrophic interpretations, providing alternative explanations for bodily and mental sensations. Techniques employed included paired associates task, body-focus task and verbal reattribution. Behavioural experiments were also conducted, where Miss W would enter her feared situations to test out the validity of her beliefs relating to her symptoms. The behavioural experiments were based on a graded hierarchy of exposure agreed by Miss W. The experiments also encouraged Miss W to drop her safety behaviours. The final stages of treatment focused on relapse prevention and maintaining changes; identifying future difficulties and problem solving for solutions, highlighting the use of new skills in coping with future difficulties and presenting Miss W with a handout of skills and strategies learnt during treatment. A six-week follow up session was arranged to ensure continued maintenance of skills acquired.

**Outcome**

After the eight sessions spanning three months, Miss W had responded well to treatment and had managed to address and overcome her difficulties. The changes had been maintained at follow up. During her follow up session Miss W reported feeling more in control of her anxiety symptoms and more confident in entering previously problematic situations. Further, she had dropped all safety behaviours. Miss W’s psychometric test scores reflected her self-report of maintenance and continued progression. After the follow up session Miss W was discharged.
THE ASSESSMENT, FORMULATION AND TREATMENT OF A 22 YEAR OLD MALE WITH MILD LEARNING DISABILITIES, WITH LOW SELF-ESTEEM AND POOR SELF-CONCEPT.

Presenting Problem
S was referred by his GP to the Clinical Psychology Service, for treatment of agoraphobia. After a detailed assessment it was clear S’s difficulties were not agoraphobic in nature, but due to more complex reasons, encompassing his learning disability, previous negative experiences and low self-esteem. S had been increasingly isolating himself and withdrawing from all social activities. This behaviour was concerning as it could potentially impact on his emotional and psychological well-being, increasing his risk of becoming depressed and losing social and relationship building skills and opportunities for integration.

Assessment Procedure
1. Assessment for treatment interview. Five assessment sessions were conducted. With S’s consent his mother joined one of the assessment sessions, this allowed information to be clarified and an understanding of S’s difficulties from a family perspective to be obtained.
2. No formal psychometric measures were used during the assessment. This was due to a lack of instruments available. In general few instruments have been developed to measure the emotional states of people with learning disabilities (Benson & Ivins, 1992).

Formulation
The theory of Social Role Valorisation (SRV: Wolfensberger, 1983, 2000) provided the theoretical framework from which the formulation was developed. The basic principle of SRV refers to the understanding that an individual’s ‘welfare depends extensively on the social roles they occupy’ (Wolfensberger, 2000, p.105). The social role S was fulfilling fell into the devalued category and did not reflect the lifestyle of the majority of individuals his age. This had led to S developing low self-esteem and poor self-concept, which in turn are likely to lead to anxiety and depression (Leary, Schreindorfer & Haupt, 1995). For S to form a social network and develop an appropriate and valued social role he needed not only the knowledge and social skills, but also the opportunity to integrate with others. The lack of opportunity for social
intervention had implications for S’s social role and self-esteem. It also placed him at risk from losing his existing social and relationship building skills. Loss of these skills would be detrimental for S’s future social functioning and self-esteem.

Intervention
Following the assessment, the formulation was tentatively shared with S and his family and the areas of therapeutic work were identified. Although the dominant model within learning disabilities has been behavioural, it has become increasingly acknowledged that cognitive techniques can be used effectively in treating people with learning disabilities (Stenfert Kroese, 1997). Cognitive treatment aimed to identify negative thoughts and underlying assumptions and to modify these by generating alternative thoughts based on the outcome of behavioural experiments and discussions identifying S’s skills and abilities. Behavioural experiments were based on a graded hierarchy of tasks agreed with S, aiming to increase his self-esteem. Treatment also aimed to increase S’s social opportunities and social network, promoting a more valued social role, leading to increased self-esteem. A referral to Occupational Therapy was made to explore the opportunities and activities that were available to S. The final stages of treatment was to ensure therapy with the author ended appropriately to prevent S from feeling abandoned. A joint meeting with the new therapist was arranged. This allowed the opportunity for S and the author to hand over the work they had completed and highlight changes S had made.

Outcome
After 15 sessions spanning five months, S had responded well to treatment and had started to address some of his difficulties. He had started to increase his activities and was motivated to continue working on this with the Occupational Therapist. His self-confidence increased and he reported to feel better about himself. Treatment continued to be ongoing.
CHILD AND YOUNG PEOPLE CASE REPORT SUMMARY

THE ASSESSMENT, FORMULATION AND TREATMENT OF A 5 YEAR OLD BOY WITH BEHAVIOURAL PROBLEMS USING STRUCTURAL FAMILY THERAPY.

Presenting Problem
Tim was referred to the Clinical Psychology Service by his GP for behavioural difficulties. His mother reported finding his behaviour increasingly difficult to cope with. Having a request responded to with ‘wait’ or ‘no’ led to Tim screaming, shouting and stamping his feet. Tim constantly pushed boundaries with his parents, particularly his mother and this often led to his mother losing her temper. This was exacerbated by her own mother’s continued interference regarding her parenting skills. Mrs Smith was aware of the effect Tim’s behaviour was having on her and her inability to cope. She requested help in developing coping strategies and skills to deal more effectively with Tim’s behaviour. The frequency and severity of Tim’s tantrums had increased over the past 11 months and had prompted his mother to seek help.

Assessment Procedure
1. Assessment for treatment interview, drawing on Minuchin’s (1974) model of structural family therapy. The assessment was conducted over two sessions.
2. Subjective Measure – Each family member was asked how they would know when things were better. The indicators highlighted were; Tim would be happier and have fewer temper tantrums, it would feel calmer at home, Mrs Smith would feel more in control, Mr and Mrs Smith would no longer argue about Tim’s behaviour, Mrs Smith would not feel undermined by her own mother with regard to her parenting skills.
3. Psychometric test: Parenting Stress Index (PSI).

Formulation
Minuchin’s (1974) model of structural family therapy provided the theoretical framework from which the formulation was developed. This model ‘conceives of families as systems and subsystems, roles and rules, boundaries, power and hierarchy’ (Navarre, 1998, p.558). The model proposes effective family functioning is composed of a number of subsystems, which have clear boundaries, promote individual growth and have a structured hierarchy of power. The subsystems must be well defined, with regard to boundary and hierarchy, to allow members of each subsystem to carry out their functions effectively. Difficulties exist within family systems when boundaries...
are diffused and the hierarchies convoluted (Minuchin & Fishman, 1981). The Smith family displayed dysfunctional patterns as described by Minuchin (1974) and Reay (1988). The parental subsystem was not clearly defined and clear hierarchies were not evident between the parental and grandparent subsystems. The grandparent subsystem had taken on a role within the family, which caused the family to experience difficulties around clearly allocating responsibility for parenting and identifying clear boundaries around the parental subsystem. This confusion and stress had precipitated Tim's behavioural problems and continued to maintain the problem within the family system.

**Intervention**

Following the assessment, the formulation was shared with the family and the therapeutic goals set. The structural intervention aimed to promote change within the family structure. The author gained an understanding of the family system using a genogram. The use of this tool aided the author in joining the family. A number of therapeutic interventions were implemented to challenge the existing family structure including, enactment, marking boundaries, assigning tasks and support, and education and guidance. The family's perception of reality was challenged, by the author offering different ways to interact. This technique aided restructuring within the family system. The positive nature of the different ways to interact reinforced the new family structure. The final stages of treatment involved the author disengaging from the family when the family structure had altered.

**Outcome**

After the 12 sessions, spanning four months the Smith's family structure had altered and Mrs Smith had addressed her difficulties with her own mother and was now responsible for the role of parenting and felt confident about this role. Tim's behaviour had significantly improved, he was described as a much happier child and the atmosphere at home was calmer and more relaxed. Mr and Mrs Smith reported a change in their relationship, reporting they had become closer and were thinking about parenting issues together. The psychometric test score reflected the family's report and suggested the family no longer required psychological intervention. Tim and his family were discharged.
Summaries of Case Reports Completed During Training

CHRONIC PAIN SPECIALIST CASE REPORT SUMMARY

THE ASSESSMENT, FORMULATION AND TREATMENT OF A 41 YEAR OLD MAN PRESENTING WITH CHRONIC PAIN AND SECONDARY DEPRESSION USING COGNITIVE BEHAVIOURAL THERAPY.

Presenting Problem
Mr Jones was referred to the pain management service by the Consultant Anaesthetist, for urgent psychological assessment. He was referred with chronic pain syndrome with a very high stress component. Mr Jones reported pain in his arms, legs and neck. He had been experiencing these pain symptoms for approximately 18 months. Mr Jones also reported a change in his mood since the onset of his pain, describing how he felt very low and constantly worried about his future, worrying about the impact his pain would have on his ability to work. He was currently off sick from work. He was also feeling depressed that he was unable to participate in activities he had previously enjoyed because of his pain and felt he was not contributing at home as his pain prevented him from completing daily household chores.

Assessment Procedure
1. Assessment for treatment interview. The assessment was conducted over two sessions.
2. Pain diary.
3. Psychometric tests: Pain Intensity and Severity Rating Scale (Numerical rating scale), Beck Depression Inventory (BDI), Pain Coping Strategies Questionnaire (CSQ).

Formulation
From the assessment it was evident Mr Jones was suffering from chronic pain, which was exacerbated by stress and tension. His difficulties could be conceptualised within the biopsychosocial model (Engle, 1980) as the combination of physical, psychological and social factors were contributing to his current problems. The psychosocial disability factor (Mayer & Gatchel, 1988) provided the theoretical framework for how these factors interacted to contribute to Mr Jones overall pain and disability. The model proposes physical changes and the effects of such changes in the individuals’ social world, for example, changes in leisure activities and ability to work, can lead to psychological difficulties, for example, depression, stress, tension, anxiety and anger. Such emotional distress can substantially affect pain threshold and exacerbate pain symptoms. This feeds back and affects the pain experienced and...
ultimately the individuals' level of physical functioning. The emotional distress Mr Jones experienced was a consequence of a number of losses and changes that had occurred due to his pain. It was apparent he was having difficulties adjusting to and accepting these changes and coping with the increasing pain. These factors had caused him to become depressed. The treatment of secondary depression in chronic pain patients is via the treatment and management of their pain (Main & Booker, 2000). Giving clients back control over their pain and pain-associated incapacity, acts to reduce depressive psychopathology.

**Intervention**

Following the assessment, the formulation was shared with Mr Jones and the therapeutic goals set. The cognitive-behavioural intervention aimed specifically to address the stress-pain connection and adaptive coping strategies. Therapeutic techniques employed included, 1) psychoeducation and information, 2) introduction of coping strategies, for example a) relaxation, b) controlling and diverting attention, and c) activity pacing, planning and prioritising, 3) increasing daily activities and social role functioning, 4) cognitive restructuring, and 5) Relapse prevention and maintenance of change. A follow up session for one month after weekly sessions had stopped, was arranged to ensure continued maintenance of skills acquired.

**Outcome**

After the 12 sessions spanning four months Mr Jones had responded well to treatment. At his one month follow up he reported a significant reduction in pain, to have more control over his pain and to have adopted a number of effective coping strategies to manage his pain. As predicted his depressive symptomatology had decreased as his perceived ability to control his pain and implement effective coping strategies increased. His psychometric test scores also indicated a good response to treatment and continued progression. A further measure of Mr Jones’ progress in managing his pain was his plan to return to full time employment. At his follow up he reported he had met with his employers and had negotiated a graduated return to work. As Mr Jones recognised this could be a potentially stressful time, it was agreed he should be offered one further appointment so he felt supported during this transitional time. After this appointment it was envisaged Mr Jones would be discharged from the service. Unfortunately, due to the author leaving the service the final appointment was arranged with their supervisor.
OLDER PEOPLE CASE REPORT SUMMARY

THE NEUROPSYCHOLOGICAL ASSESSMENT OF A 73 YEAR OLD MAN PRESENTING WITH MEMORY AND SEQUENCING PROBLEMS.

Presenting Problem
Mr Edwards was referred for a neuropsychological assessment by the Consultant Psychiatrist. Mr Edwards was referred for an assessment of his cognitive abilities with the main query of examining complaints of worsening memory and difficulties in sequencing. These difficulties had got progressively worse over the last two years. His wife described how he took a long time to complete tasks, failed to listen instructions, often got confused, could not remember things and seemed to have experienced a change in his personality.

Assessment Procedure
1. Assessment clinical interview to gain background information. Mrs Edwards accompanied Mr Edwards to the appointment.
2. A full range of neuropsychological assessments were used in order to gain a complete overview of Mr Edwards' cognitive abilities. Mr Edwards was assessed for three sessions. One session of three hours in duration and a further two sessions each of two hours in duration. The tests used included: Wechsler Adults Intelligence Scale –III (WAIS-III), Middlesex Elderly Assessment of Mental State (MEAMS), Adult Memory and Information Processing Battery (AMIPB), Doors and People Test, The Behavioural Assessment of Dysexecutive Syndrome (BADS) and Simple Construction Drawings.

Findings
The findings of the assessment suggested that compared to adults of the same age and education, Mr Edwards was experiencing complex difficulties in some areas of his organic functioning. At a more specific level it was tentatively suggested Mr Edwards' neuropsychological profile supported the hypothesis that he was presenting with the early stages of Dementia Alzheimer's Type (DAT). The profile identified significant difficulties in memory, specifically episodic memory, signs of difficulties in visuoconstructive abilities, a significant decline in general intellectual impairment, problems in executive functioning, specifically in planning and coordinating and slight changes in his behaviour and personality, as reported by his wife. Mr Edwards' language ability appeared to have remained intact. However, a deterioration in his
language ability, particularly with word finding and naming would be predicted within the next year. It was important to note not all patients go on to develop full dementia (Folstein, 1997) therefore diagnosis at this stage remained tentative.

**Recommendations**

In light of the findings of the neuropsychological assessment a number of recommendations were made including, 1) the assessment is repeated in a year’s time, 2) Mrs Edwards is encouraged to contact the Alzheimer’s Society, 3) Mr Edwards is referred and allocated a Key Worker, to offer practical advice and support to him and his family in the future, 4) The findings and recommendations are discussed with Mr and Mrs Edwards and following this appointment a letter outlining the recommendations is sent to them.

**Feedback**

The decision was made to share the possible diagnosis of dementia with Mr and Mrs Edwards. Both Mr and Mrs Edwards showed considerable awareness of the situation, acknowledging that there was something wrong, but needed confirmation of this. Although in the past there has been a general avoidance of sharing information with the client for fear of causing them distress (Illiffe, 1995: cited in McWillaims, 1998), more recent research has suggested sharing a diagnosis can significantly improve psychological well being and adjustment and reduce distress (North, Cornbleet, Knowles & Leonard, 1992). The news that Mr Edwards was showing the first signs of a dementia process was delivered in a clear and sensitive manner, providing a contained and safe space for Mr and Mrs Edwards to hear and absorb the news. As suggested by North, et al, (1992) to allow maximum absorption and understanding Mr Edwards was sent a letter outlining what had been discussed in the meeting and the recommendations made. Giving feedback of this nature was difficult for the author and this was acknowledged and discussed in depth during supervision. When reflecting on the session, the author had initially felt uncomfortable with delivering the news, however, once the diagnosis was out in the open and the reaction of Mr and Mrs Edwards observed, the author felt much more comfortable and confident with the situation and was able to successfully contain the session. The session was observed by the author’s supervisor who fed-back the session had been conducted well and professionally.
References to the Summaries of Case Reports

REFERENCES TO THE SUMMARIES OF CASE REPORTS


INTRODUCTION TO THE RESEARCH DOSSIER

The research dossier contains the service related research project completed in Year 1, the literature review completed in Year 2 and the major research project completed in Year 3.
Use of Clinical Psychology in Primary Care from the GP's perspective: Implications for the future of Clinical Psychology.

Service Related Research Project
Year 1
Psych.D Clinical Psychology

July 2000
I would like to give my sincere thanks to Mary Dobbin for the encouragement and support she gave throughout this study. I would also like to thank Mary John and Michael Tossell for their constructive comments and suggestions throughout.

Further I thank all the GPs within the NHS Trust for participating within the study by completing and returning the questionnaires.
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Abstract

This is an exploratory study addressing the experiences General Practitioners (GPs) have of psychological services, the amount of psychology input received in primary care and GP perceptions of the role of clinical psychologists in primary care.

A non-standardised measure adapted from a questionnaire developed by Medlik (1999) was used. The questionnaire and covering letter were sent to 73 GPs working in General Practice Surgeries throughout the NHS Trust. To increase the response rate two mail-shots were used, with a time interval of one month. A 73% response rate was gained.

Findings indicate the majority of GPs have experience of psychological services and would like to receive more psychology input. GPs perceive the role of clinical psychologists working in primary care to be varied. Predominantly the perception is of clinical psychologists working individually with patients, but their skills in psychological assessment, consultation and running groups have also been identified. The involvement of psychologists in the education, training and supervision of staff is not considered by the majority of GPs as important. Implications for the planning of future service provision in this setting are discussed.
Introduction

The Government's recent white paper Health of the Nation (DoH, 1992) and the National Service Framework document (DoH, 1999), placed mental health in the forefront of service planning and development at all levels of the National Health Service (NHS). Services at the primary care level have been highlighted as a key area, in the planning and development of effective services for individuals with mental health problems (Dowrick, 1992). This follows from findings that show a large number of individuals who present to their General Practitioner (GP), have psychological problems (Newman & Rozensky, 1995). For example, Cummings (1991: cited in Rozensky, 1994, p.2) reported that '60% of all visits to physicians are by patients who have nothing physically wrong'. Further Cummings notes 'if you add to these figures those patients whose illnesses were stress related, 80-90% of all physician visits might be related to psychological issues' (Cummings, 1991: cited in Rozensky, 1994, p.2).

The combination of a large number of patients presenting with psychological problems in primary care, the poor detection rate by GPs and the illustrated effectiveness of psychological interventions over pharmacological approaches, in treating some psychological problems (Barlow, 1994: cited in Haley, McDaniel, Bray, Frank & Heldring et al., 1998), highlights the need for and importance of psychologists working in primary care settings.

In the past Clinical Psychology has been criticised for not examining its role in, or considering its contribution to, primary care (Medlik, Short & Marshall, 1987). More recently, however, this has changed and psychologists are now paying particular attention to how they can effectively contribute to the care of mental health problems in primary care settings.

With the introduction of Primary Care Groups (PCGs) a need has arisen to examine and evaluate the provision of clinical psychology in primary care (Medlik, 1999). Although finance plays a central role in how this is achieved, it is of primary importance to explore the GPs view of clinical psychology services and what is considered an acceptable service
when planning psychological provision at the primary care level.

In assessing the role of clinical psychologists in primary care, the way clinical psychologists have traditionally worked may alter to meet the changing priorities of the NHS. To be more effective clinical psychologists ‘may have to adapt their practice style to the unique characteristics of primary care’ (Haley McDaniel, Bray, Frank & Heldring et al., 1998, p.237). A move away from the provision of individual therapy to working more at an organisational level may be considered as a more desirable and effective use of psychological input by GPs (McPherson, 1991: cited in Medlik, 1999; Alexander 1996).

The present exploratory study aims:-

1. To explore what experience GPs have of psychological services provided across the Trust.
2. To consider how much Psychology input is currently received in primary care.
3. To assess GP perceptions of the role of clinical psychologists in serving primary care.
Method

Participants
The questionnaire was sent to 73 GPs working in General Practice Surgeries throughout the NHS Trust. Three sub-districts comprising the Trust were included in the study. GPs were approached by letter, which accompanied the questionnaire. (See appendix 3.)

Design
A postal survey was employed for the purpose of the study.

Procedure

Ethics
It was established from the Head of Adult Speciality and the Head of Psychology that no ethics approval was required for the study.

Measures
A non-standardised measure adapted from a questionnaire developed by Medlik (1999) was used. (See appendices 1 and 2.) In designing the adapted questionnaire the clinical psychologist working in primary care and the Head of Adult Speciality were consulted.

The questionnaire in the present study used questions originally devised by Medlik (1999) examining how many hours per week surgeries received from psychology services and how many hours would be ideal, but further examined how GPs would like this time to be used. The present questionnaire also identified psychological services GPs had experience of referring to and what improvements they considered could be made to these services. The role the GP perceives clinical psychologists to have in primary care was also explored. Finally the present questionnaire adapted and extended solutions proposed by Medlik (1999) to explore potential referral arrangements.

Once formulated the questionnaire and rationale of the research were presented at the Psychology Departmental Meeting and Adult Psychology Team Meeting to obtain
feedback before the questionnaire was circulated.

It should be noted that the questionnaire gained more information than is reported here. This occurred as the Psychology Department wished to consider other issues, for example, GP satisfaction of psychological services and GP opinion of potential referral arrangements. The opportunity to gain such information from one questionnaire was fully utilised.

Circulation of the Questionnaire
The questionnaire and covering letter explaining the aim of the study were sent to 73 GPs. The questionnaires were coded to allow the practice and the sub-district to be identified. This would allow for comparisons between GPs in different sub-districts. To increase the response rate two mail-shots were used, a time interval of one month was left between mail-shots. The questionnaire was sent again to all GPs with an accompanying letter. (See appendix 4.)

Feedback of Findings
The findings of the study were presented to the Clinical Psychology Department. (See appendix 5.)

Statistical Analysis

Descriptive statistics and crosstabulations
Descriptive statistics and crosstabulations were used to analyse the closed questions comprising the questionnaire. The use of crosstabulations allowed the differences in responses across sub-districts to be compared.

Content Analysis
The data obtained from the open questions was analysed by content analysis (Krippendorff, 1980). ‘Content analysis is a research technique for making placeable and valid inferences from data to their context.’ (Krippendorff, 1980, p.21.) This describes and
defines content analysis as a research method that allows data to be categorized and compared.

There has however been much concern for the validity and reliability of data analysed using content analysis. To ensure reliability of the content analysis performed within the study, the principle of Inter-Judge Consistency was implemented. Two individuals independently categorized the data, and later compared categories. Any discrepancies found were discussed and placed in an agreed category.
Results

Response Rate

Overall a good response rate was obtained, with 73% (53) of the questionnaires returned. 41% (30) were returned after the first mail-shot. A further 32% (23) were returned following a second mail-shot. 27% (20) of the questionnaires were not returned.

Of the 20 GPs who failed to return the questionnaire, 7 were from the sub-district A, 7 from sub-district B and 6 from sub-district C. A response was gained from all practices apart from two. These two surgeries had only one GP. Although the questionnaires were anonymous the practice was identifiable. This may explain the non-response from these particular surgeries. Of the remaining 15 surgeries included in the study all or at least half of the GPs based at each surgery completed and returned the questionnaire.

Table 1: Overall Return Rate

<table>
<thead>
<tr>
<th>PCG Sub-District</th>
<th>Total Returned</th>
<th>% of returned total</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>24</td>
<td>45.3%</td>
</tr>
<tr>
<td>B</td>
<td>17</td>
<td>32.1%</td>
</tr>
<tr>
<td>C</td>
<td>12</td>
<td>22.6%</td>
</tr>
<tr>
<td>Total</td>
<td>53</td>
<td>100%</td>
</tr>
</tbody>
</table>

Table 1 indicates the overall response rate, with the percentage of questionnaires returned from within each sub-district.

Table 2: Return Rate from each Sub-district

<table>
<thead>
<tr>
<th>PCG Sub-District</th>
<th>Total GPs Surveyed</th>
<th>Number Returned</th>
<th>% Returned</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>31</td>
<td>24</td>
<td>77%</td>
</tr>
<tr>
<td>B</td>
<td>24</td>
<td>17</td>
<td>71%</td>
</tr>
<tr>
<td>C</td>
<td>18</td>
<td>12</td>
<td>66%</td>
</tr>
<tr>
<td>Total</td>
<td>73</td>
<td>53</td>
<td>73%</td>
</tr>
</tbody>
</table>

Table 2 indicates the response rate considering the number of GPs that were surveyed within each specific sub-district.
1. Experience GPs have of psychological services offered across the Trust

Table 3: Psychological Services GPs have experience of referring to

<table>
<thead>
<tr>
<th>Psychological Service</th>
<th>Have experience of</th>
<th>Do not have experience of</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Frequency</td>
<td>Percentage</td>
</tr>
<tr>
<td>Child</td>
<td>51</td>
<td>96.2%</td>
</tr>
<tr>
<td>Pain Management</td>
<td>44</td>
<td>83%</td>
</tr>
<tr>
<td>Psychosexual</td>
<td>39</td>
<td>73.6%</td>
</tr>
<tr>
<td>Primary Care</td>
<td>39</td>
<td>73.6%</td>
</tr>
<tr>
<td>Older Adult</td>
<td>34</td>
<td>64.2%</td>
</tr>
<tr>
<td>CMHT Psychologist</td>
<td>23</td>
<td>43.4%</td>
</tr>
<tr>
<td>Neuropsychology</td>
<td>19</td>
<td>35.8%</td>
</tr>
<tr>
<td>Psychiatric Rehabilitation</td>
<td>17</td>
<td>32%</td>
</tr>
</tbody>
</table>

(For information of GP experiences of psychological services according to sub-district refer to appendix 6.)

2. Amount of Psychology input currently received

Table 4: Overall number of surgeries with clinical psychology input

<table>
<thead>
<tr>
<th>Does your surgery have Clinical Psychology input?</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>10</td>
<td>19.0</td>
</tr>
<tr>
<td>No</td>
<td>43</td>
<td>81.0</td>
</tr>
</tbody>
</table>
Table 5: Clinical Psychology input in surgeries according to sub-district

<table>
<thead>
<tr>
<th>Sub-district</th>
<th>Clinical Psychology Input</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Yes</td>
<td>Freq.</td>
<td>%</td>
</tr>
<tr>
<td>A</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B</td>
<td></td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>C</td>
<td>10</td>
<td>83.3</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>19.0</td>
<td></td>
</tr>
</tbody>
</table>

Tables 4 and 5 show only 10 GPs to have a clinical psychologist working within their surgery. All these GP surgeries are based within sub-district C.

Table 6: Hours per week surgeries have clinical psychology input

<table>
<thead>
<tr>
<th>Number of hours per week</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>No input</td>
<td>43</td>
<td>81.1</td>
</tr>
<tr>
<td>3 hours</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>4 hours</td>
<td>5</td>
<td>9.4</td>
</tr>
<tr>
<td>6 hours</td>
<td>3</td>
<td>5.7</td>
</tr>
</tbody>
</table>

Table 7: Number of hours per week surgeries have clinical psychology input according to sub-district

<table>
<thead>
<tr>
<th>Sub-District</th>
<th>No input</th>
<th>3 hours</th>
<th>4 hours</th>
<th>6 hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>A</td>
<td>24</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>B</td>
<td>17</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>C</td>
<td>2</td>
<td>2</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Total</td>
<td>43</td>
<td>2</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 7 indicates within sub-district C there is a difference amongst surgeries in the number of hours per week they receive clinical psychology input. The average number of hours per week is 4.4 hours. In contrast, surgeries in sub-districts A and B do not receive any direct clinical psychology input.
Table 8: Ideal number of hours per week to have clinical psychology input in the surgery

<table>
<thead>
<tr>
<th>Ideal Number of hours</th>
<th>Frequency</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Don't know</td>
<td>18</td>
<td>34</td>
</tr>
<tr>
<td>1</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>3</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td>4</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>5</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td>6</td>
<td>8</td>
<td>15.1</td>
</tr>
<tr>
<td>7</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>8</td>
<td>2</td>
<td>3.8</td>
</tr>
<tr>
<td>10</td>
<td>8</td>
<td>15.1</td>
</tr>
<tr>
<td>12</td>
<td>3</td>
<td>5.7</td>
</tr>
<tr>
<td>18</td>
<td>1</td>
<td>1.9</td>
</tr>
<tr>
<td>26</td>
<td>1</td>
<td>1.9</td>
</tr>
</tbody>
</table>

The ideal number of hours of clinical psychology input indicated by GPs is higher than the actual number of hours surgeries are receiving. The average ideal number of hours is 7 1/2 hours a week, with a range of 1 to 26 hours. From table 8 it is observed that most GPs would like 6 or 10 hours of clinical psychology input in their surgeries each week.

3. GP Perceptions of the role of clinical psychologist in serving Primary Care

Table 9: Overall indication of how GPs consider clinical psychology time should be spent in surgeries

<table>
<thead>
<tr>
<th></th>
<th>Yes Freq.</th>
<th>%</th>
<th>No Freq.</th>
<th>%</th>
<th>Don't Know Freq.</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Individual Therapy</td>
<td>38</td>
<td>71.7</td>
<td>3</td>
<td>5.7</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>Psychological Assessment</td>
<td>33</td>
<td>62.3</td>
<td>8</td>
<td>15.1</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>Consultation with GP's and other primary care staff</td>
<td>30</td>
<td>56.6</td>
<td>11</td>
<td>20.8</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>Group Therapy</td>
<td>28</td>
<td>52.8</td>
<td>13</td>
<td>24.5</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>Education &amp; training of staff</td>
<td>14</td>
<td>26.4</td>
<td>27</td>
<td>50.9</td>
<td>12</td>
<td>22.6</td>
</tr>
<tr>
<td>Supervision of staff</td>
<td>8</td>
<td>15.1</td>
<td>33</td>
<td>62.3</td>
<td>12</td>
<td>22.6</td>
</tr>
</tbody>
</table>

Table 9 indicates that GPs consider the role of clinical psychologists to involve; working
therapeutically with their patients on an individual basis, conducting psychological assessments, running groups and consulting with GPs and surgery staff. The education, training and supervision of staff is not considered by the majority of GPs as an appropriate role or use of clinical psychology. (For breakdown of GPs within sub-district see appendix 6.)

52.8% of GPs indicated Clinical Psychologists should be involved in the running of groups. The type of groups GPs would ideally like to be run in their surgeries are shown in table 10.

Table 10: Groups GPs would like in their surgeries

<table>
<thead>
<tr>
<th>Type of Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stress Management</td>
</tr>
<tr>
<td>Anxiety Management</td>
</tr>
<tr>
<td>Relaxation Groups</td>
</tr>
<tr>
<td>Autogenic Groups</td>
</tr>
<tr>
<td>Groups for Phobias</td>
</tr>
<tr>
<td>CBT Groups</td>
</tr>
<tr>
<td>Assertiveness Training</td>
</tr>
<tr>
<td>Somatisers Groups</td>
</tr>
</tbody>
</table>

GPs were also asked to complete an open question considering their perception of the role of clinical psychologists working in primary care. The results were analysed using content analysis. The themes that arose from the analysis are presented below in table 11. The themes are not presented in any particular order.

Table 11: GP perception of role of clinical psychologists working in primary care

<table>
<thead>
<tr>
<th>Clinical Psychologists Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treating anxiety</td>
</tr>
<tr>
<td>Receiving referrals for treatment</td>
</tr>
<tr>
<td>Conducting cognitive assessments</td>
</tr>
<tr>
<td>Running groups</td>
</tr>
<tr>
<td>Providing support</td>
</tr>
<tr>
<td>As an element of treatment package</td>
</tr>
<tr>
<td>Teaching</td>
</tr>
<tr>
<td>Advising</td>
</tr>
</tbody>
</table>
Conducting assessments
Monitoring and developing the Service
Having a different role to other members of the team
Dealing with general psychological problems
Providing treatment and intervention
Treating other groups

(Statements comprising each of the themes are presented in appendix 7.)

Content analysis was also employed to analyse suggestions GPs considered could be implemented to improve the psychological services that are currently provided. The themes that were constructed from this process are presented in table 12. The themes are not presented in any meaningful order.

Table 12: Suggestions provided by GPs to improve psychological services

<table>
<thead>
<tr>
<th>Suggestions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reduced waiting times</td>
</tr>
<tr>
<td>More financial provision and resources</td>
</tr>
<tr>
<td>More psychologists</td>
</tr>
<tr>
<td>More CBT</td>
</tr>
<tr>
<td>Increased accessibility and availability</td>
</tr>
<tr>
<td>Clearer referral guidelines</td>
</tr>
<tr>
<td>More counselling services</td>
</tr>
<tr>
<td>Some offered suggestions</td>
</tr>
<tr>
<td>Improvements specifically for Child Services</td>
</tr>
<tr>
<td>Improvements for other Services</td>
</tr>
</tbody>
</table>

(Statements comprising each of the themes are listed in appendix 7.)

With regard to direct suggestions made to improve psychological services, a number of ideas were elicited, e.g. the centralisation of services, integration with mental health services, psychologists providing regular community sessions, the reintroduction of practice based clinical psychologists, providing email feedback and finally having more CPN (Community Psychiatric Nurse) time within the surgery to free up psychology time.

Some improvements were suggested specifically for Child Services. The improvements included, providing more resources and provision, and considerably reducing waiting lists.
and time to first appointment. Improvements were also suggested which relate to other services, e.g. providing more resources for psychosexual services and providing a service in areas which are considered unmet e.g. survivors of sexual abuse and clients with eating disorders.
Discussion

A much higher response rate than the 30-40 per cent usually expected from a postal survey (McNeill, 1990) was observed in the present study. The response rate of 73% reflects that expected from face-to-face interviews (McNeill, 1990). The good response rate, implies the results are representative of GP opinion (De Vaus, 1991).

Over 70% of GPs surveyed had experience of child, pain management, psychosexual and primary care services, at some time or another. Many GPs indicated, that their experience of psychology in primary care had been very favourable, but the service had been stopped a number of years ago. It seemed the service previously provided by clinical psychologists had been replaced with CPNs. It was clear that although GPs wanted psychologists within their surgery, they did not want to lose the service provided by CPNs.

With regard to older adult services, 64% of GPs had experience of such services, 40% had experience of psychologists in Community Mental Health Teams and over 30% of GPs had experience of neuropsychology and psychiatric rehabilitation services. From comments made on the questionnaire, it is clear many GPs are unaware of neuropsychological services, expressing a desire to be informed of the service that is provided.

Based on previous experiences of psychological services findings indicate that GPs consider all psychological services to be under resourced, have too long waiting lists, implying difficulties with availability and accessibility, to be overly stretched, and not having enough time and money to provide a service that can be considered satisfactory. These results particularly applied to child, psychosexual and primary care services.

Although GPs have a tendency to view psychology within primary care in a negative light, due to lack of resources, findings indicate GPs do consider clinical psychologists to be beneficial and a useful addition to the services provided at the primary care level. The majority of GPs indicated they would like more psychological input within their surgery than they were currently receiving.
The way in which GPs consider clinical psychology time should be used within their surgeries, reflects their view of psychologists having a number of skills that can be utilised. Traditionally the role GPs perceive clinical psychologists to have in primary care, has involved seeing patients on an individual basis (Eastman & McPherson, 1982). Although findings indicate GPs still consider this to be the main role of clinical psychologists, they also note and value their skills in psychological assessment, consultation and in the running of groups. Psychologists running groups based in the GP surgery will have beneficial effects on the long waiting lists, increasing the accessibility and availability of treatment.

The involvement of psychologists in the education, training and supervision of staff was not considered by the majority of GPs as an important or useful role for clinical psychologists to undertake. This finding is disappointing. Allowing the opportunity to educate and supervise staff, especially the surgery based CPNs, would allow psychologists to transmit their skills. This would create a greater number of skilled therapists working within primary care, who are available to treat patients, reducing waiting lists.

Education within the GP surgery may promote an interest in psychological problems and interventions. GPs who are interested in psychological treatments have been found to refer less frequently, as they are more likely to treat their own patients (Verhaak, 1993: cited in Ross & Hardy, 1999). This would again reduce clinical psychology waiting lists. Most importantly perhaps are the benefits patients would gain from staff being educated in psychological problems. Education would allow increased recognition and detection of mental health problems at an earlier stage (Liese, Shepherd, Cameron & Ojeleye, 1995). Similarly education would also increase the probability of patients being offered psychological intervention rather than pharmacological treatments (Liese, Shepherd, Cameron & Ojeleye, 1995).

Waiting times were an issue GPs identified as requiring improvement, noting time to first appointment as unacceptable. The development and implementation of clearer referral guidelines may assist with this problem. This would aid GPs in making appropriate referrals to services, reducing inappropriate referrals that add to long waiting lists (Ross &
Hardy, 1999). Due to GPs requesting referral guidelines and the possibility of this leading to more appropriate referrals, the psychology service is considering devising referral guidelines for each of its services.

Overall GPs wish to have more psychological input available to them within their surgery. GPs perceive the role of clinical psychology in primary care to be varied and an extremely useful resource. The next stage is for PCGs to consider how they can meet this required need.

A proposal to meet this need has been developed by the clinical psychology department based on the findings of this study. The proposal includes the employment of one psychologist, to be split across surgeries comprising sub-district A. This is regarded as an initial response that will be built on over time. The post will initially offer generic mental health services; but the need for a child psychologist to be built into the structure has been acknowledged. It is predicted this will be the next stage in the development of this package of psychological provision at the primary care level.
**Conclusion**

Based on the findings of the study the role of the psychologist working in primary care, will predominately involve a traditional role of individual therapy, but add psychological assessment, consultation and group work. The move of psychology towards more of an organisational role does not appear, at this time to be required by GPs.

As the proposed psychological provision has been formulated based on the findings of the study, it is hoped GPs will consider this a move towards developing an acceptable psychological service, which aims to overcome some of the previous problems GPs have experienced and effectively meet the psychological needs of patients in primary care. The next step in the process will involve evaluating the interventions, which have been implemented to assess whether the demands have been adequately addressed and to monitor where the continued need for psychological provision lies.
References


Appendix One

Original questionnaire devised by Medlik (1999).
Psychology Services in Primary Care

1. How many hours per week does your surgery currently receive from clinical psychology, in the surgery?

2. How many hours per week do you think your practice needs?

3. With the formation of your PCG, which of the following options do you:
   A prefer to provide for your patients.
   B consider a likely compromise to match available resources.

(Please tick)

<table>
<thead>
<tr>
<th>A Prefer to provide for your patients</th>
<th>B Consider a likely compromise to match available resources</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Sharing psychological resources with other practices at a central community primary care location.</td>
<td></td>
</tr>
<tr>
<td>2) Making referrals to hospital-based clinical psychology departments.</td>
<td></td>
</tr>
<tr>
<td>3) Sending all psychological referrals to the CMHT for assessment and possible referral to a clinical psychologists if appropriate.</td>
<td></td>
</tr>
<tr>
<td>4) Keeping your psychologist in-surgery and having other practices within your PCG send their referrals to your surgery, probably increasing the number of sessions.</td>
<td></td>
</tr>
<tr>
<td>5) Sending your psychological referrals to be seen by a clinical psychologist based at another surgery with your PCG (but retaining overall patient management)</td>
<td></td>
</tr>
<tr>
<td>6) Using your psychology sessions more cost-effectively e.g. more consultation and less individual work.</td>
<td></td>
</tr>
<tr>
<td>7) Other - please enlarge</td>
<td></td>
</tr>
</tbody>
</table>
Appendix Two

Questionnaire devised for use in the present study.
Psychology Services in Primary Care

With the introduction of Primary Care Groups a need has arisen to review the provision of psychology to primary care (Medlik 1999). Throughout this process the view of the GP is essential. The following questions aim to explore your views on some of the important issues to be considered when planning future psychological provision at the primary care level.

Your individual responses are anonymous but localisable for research purposes to the practice and the PCG sub-districts.

Section 1
1. What psychological services do you have experience of? (Please tick)

<table>
<thead>
<tr>
<th>Psychological Service</th>
<th>Have experience of</th>
<th>Do not have experience of</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologists in Primary Care</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Psychology Services</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pain Management</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Older Adult</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychosexual</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychiatric Rehabilitation</td>
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<td></td>
</tr>
<tr>
<td>CMHT Psychologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropsychology</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Please list</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. Are you satisfied with the psychological services you have had experience of? (Please tick)

<table>
<thead>
<tr>
<th>Psychological Service</th>
<th>Yes</th>
<th>Yes but..... (please write comment)</th>
<th>No</th>
<th>Not experienced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychologists in Primary Care</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Child Psychology Services</td>
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<td></td>
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<td>Psychosexual</td>
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<td>Psychiatric Rehabilitation</td>
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<tr>
<td>CMHT Psychologist</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Neuropsychology</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other Please list</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If no in your view what improvements could be made to these services?

(please specify service and improvements)

3. What do you perceive to be the role(s) of the clinical psychologist in serving primary care?

Section 2

4. Does your surgery have clinical psychology input? Yes  No (if No please go to section 3)

5. How many hours per week does a clinical psychologist, spend in your surgery? _____________ hours

Section 3

6. Ideally how many hours per week do you think your practice needs? _______________ hours
7. How do you think this time should be used?

<table>
<thead>
<tr>
<th>Time used (please tick)</th>
<th>Number of hours</th>
<th>Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological Assessment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individual Therapy</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Group Therapy (specify)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Educational and training of staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supervision of staff</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Consultation with GPs and other primary care staff</td>
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<td></td>
</tr>
</tbody>
</table>

**Section 4**

8. With the formation of PCGs please consider and tick the following options.

<table>
<thead>
<tr>
<th></th>
<th>A Prefer to provide for your patients</th>
<th>B Consider a likely compromise to match resources</th>
<th>C Don’t know - not enough experience of Clinical Psychologists</th>
<th>D Not required</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Having a clinical psychologist in your surgery using sessions for:-</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) Individual work.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ii) Consultation.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>iii) Training and education of staff.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2) Making referrals to hospital clinical psychology departments.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3) Sending all referrals to the CMHT for assessment and possible referral to a clinical psychologist.</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td>4) Having other practices within your PCG send their referrals to a clinical psychologist in your surgery.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5) Sending your referrals to a clinical psychologist based at another surgery within your PCG, retaining overall patient management.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6) Any other options which you feel may be appropriate - please enlarge</td>
<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for completing this questionnaire. Please return to, Clinical Psychologist in Training, in the envelope provided.
Appendix Three

Letter sent to GPs for first mailshot.
All GPs in the NHS Trust

Re: Research examining the Use of Clinical Psychology in Primary Care from the GPs perspective. Implications for the future of Clinical Psychology.

With the recent developments in primary care we are keen to review Clinical Psychology Services. We are particularly interested in individual GP views on how to improve the accessibility and equity of Clinical Psychology Services. With this in mind we are surveying GP opinion and have enclosed a questionnaire.

It is envisaged the results will be referred to in the future planning of psychological input at the primary care level.

For the findings to be reliable and representative of GP opinion, a high response rate is required. It would be appreciated if you could spare 10 minutes to complete the attached questionnaire and return it, in the envelope provided.

Thanking you in advance for your co-operation.

Yours faithfully

Consultant Clinical Psychologist
Head of Adult Speciality

Trainee Clinical Psychologist
Appendix Four

Letter sent to GPs for second mailshot.
All GPs in the NHS Trust

Re: Research examining the Use of Clinical Psychology in Primary Care from the GPs perspective. Implications for the future of Clinical Psychology.

Recently you received a questionnaire surveying GP views and opinions on how to improve the accessibility and equity of Clinical Psychology Services within the Trust. At present thirty of the seventy-three questionnaires sent out have been completed and returned.

As it is envisaged the results of the questionnaire will be referred to in the future planning of psychological input at the primary care level, it is paramount to have a high response rate. This will ensure the findings are reliable and representative of GP opinion.

If you have not already completed and returned the questionnaire it would be appreciated if you could spare 10 minutes to complete the attached questionnaire and return it, in the envelope provided.

If you have already completed and returned the questionnaire please ignore this letter. We would like to take this opportunity to thank you for your time and sharing your views on the present Clinical Psychology Services.

Yours faithfully

Consultant Clinical Psychologist
Trainee Clinical Psychologist
Head of Adult Speciality
Appendix Five

Letter of confirmation stating findings have been presented to the service.
Dear Colleague,

Re: Claire Elphick - Adult Placement

I am writing to confirm that following the completion of the research project on placement, Claire formally presented the findings to the Clinical Psychology Department.

I would also like to add that both the project and the presentation were extremely useful for the department and formed a focus for our work with the PCG.

If you require any further information please do not hesitate to contact me.

Yours sincerely,

[Signature]

Consultant Clinical Psychologist.
Appendix Six

Crosstabulations
1. GP experiences of psychological services according to sub-district.

<table>
<thead>
<tr>
<th>Table 1 - Experience of child services</th>
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</thead>
<tbody>
<tr>
<td>Sub-district</td>
</tr>
<tr>
<td>--------------</td>
</tr>
<tr>
<td>A</td>
</tr>
<tr>
<td>B</td>
</tr>
<tr>
<td>C</td>
</tr>
<tr>
<td>Total</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2 - Experience of CMHT Psychology Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sub-district</td>
</tr>
<tr>
<td>--------------</td>
</tr>
<tr>
<td>A</td>
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<tr>
<td>B</td>
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<td>C</td>
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</table>

<table>
<thead>
<tr>
<th>Table 3 - Experience of Neuropsychology Service</th>
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</thead>
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<td>Sub-district</td>
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<tr>
<td>B</td>
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<tr>
<td>C</td>
</tr>
<tr>
<td>Total</td>
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</table>

<table>
<thead>
<tr>
<th>Table 4 - Experience of Older Adult Service</th>
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<tbody>
<tr>
<td>Sub-district</td>
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<td>--------------</td>
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<tr>
<td>B</td>
</tr>
<tr>
<td>C</td>
</tr>
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</table>
### Table 5 - Experience of Primary Care Service

<table>
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</thead>
<tbody>
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<tr>
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<tr>
<td>C</td>
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</table>

### Table 6 - Experience of Pain Management Service

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<tr>
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### Table 7 - Experience of Psychiatric Rehabilitation Service

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<th>Have experience of</th>
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<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
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</tr>
<tr>
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<tr>
<td>C</td>
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<td>12</td>
</tr>
<tr>
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### Table 8 - Experience of Psychosexual Service

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<th>Total</th>
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</thead>
<tbody>
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<td>A</td>
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<td>B</td>
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<td>4</td>
<td>17</td>
</tr>
<tr>
<td>C</td>
<td>7</td>
<td>5</td>
<td>12</td>
</tr>
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<td><strong>Total</strong></td>
<td><strong>39</strong></td>
<td><strong>14</strong></td>
<td><strong>53</strong></td>
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</table>
2. How GPs in each sub-district consider clinical psychology time should be used within Primary Care.

Table 17 - Psychological Assessment

<table>
<thead>
<tr>
<th>Sub-district</th>
<th>Yes</th>
<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
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Table 18 - Individual Therapy

<table>
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<tr>
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<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
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</thead>
<tbody>
<tr>
<td>A</td>
<td>18</td>
<td>1</td>
<td>5</td>
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Table 19 - Group Work

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<tr>
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<th>No</th>
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Table 20 - Education and Training

<table>
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<tr>
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<th>No</th>
<th>Don’t Know</th>
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<td>Total</td>
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Table 21 - Supervision of staff

<table>
<thead>
<tr>
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<th>No</th>
<th>Don’t Know</th>
<th>Total</th>
</tr>
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Table 22 - Consultation with GPs and staff

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<tbody>
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</table>
Appendix Seven

Content Analysis
1. What do you perceive to be the role of the Clinical Psychologist in serving primary care?

_Treating Anxiety_
Treatment of phobias.
Helping managing phobic type patients.
Treating phobic anxiety.
Treat behavioural problems, phobias and anxiety states.
Anxiety, phobic, obsessional behaviour treatment.
Mainly anxiety, phobias, obsessive states.
To see people with neurotic, obsessive anxious traits.
To treat anxiety and OCD.

_Receiving Referrals for Treatment_
Receiving referrals.
Secondary referrals from GP, CPN or Psychiatrist.

_Conducting Cognitive Assessment_
Assessment of cognitive functions.

_Running Groups_
Running groups.

_Providing Support_
Supportive, delivering ongoing support.
Availability, offering support, advice to patients and GP.
Essential support and advice in small number of cases.
As mainly supporting psychiatric services.

_As an Element of Treatment Package_
Part of a team approach to help people and families who have psychological/ mental illness.
Adjunctive - part of the team with GP, surgery based CPN and counsellor.
As part of CMHT.

_Teaching_
To educate PHCT on use of psychologist in surgery.
Teaching.
Educate PHCT i.e. appropriate referrals.
Advising
Advising i.e. management.
Available to discuss psychological aspects of cases at least monthly.
Providing information for cases with behavioural and psychological problems.

Conducting Assessments
Assessment and management of psychologically based problems.
Assessing psychological needs of a patient and then providing individuals therapy sessions.
Liaison, treatment, assessment.

Monitoring & Developing the Service
To actively explore new ways of using service.
To help audit / monitor other existing psychological services.

Having a Different Role to Other Members of the Team
Work in conjunction with CPN to manage extreme problems before they cause social disintegration.
Deal with more complex psychological problems beyond scope of CPN.
Treating patients that are currently referred inappropriately to CPNs e.g. neurotic or psychotic, worried well, existential stress, adjustment reaction.
To deal with more complex long standing problems which GP or CPN are not able to deal with themselves.
A large amount of GP work would be better done by Clinical Psychologist.

Dealing with General Psychological Problems
As a helpful referral resource for distressed people with symptoms based in psyche.
Management of difficult behavioural problems.
Need to be available and effective in managing psychological problems.
To deal with psychological problems.
Specific roles in assessing and treating specific patients.
Dealing with chronic psychological and behavioural problems.
To be available and treat appropriate patients.
Providing a service to a small number of selected patients who will benefit form the service.

Providing Treatment and Intervention
Proving CBT for intransigent depression, OCD and chronic pain management.
Psychodynamic / cognitive behavioural counselling.
Providing CBT, particularly for phobias, OCD cognitive problems.
Well defined problem focused work with adults.
To provide a therapeutic role.
Broadening the range of interventions available to out patients.
Treating other Groups
Would appreciate a role in eating disorders.
Help after abuse therapy for adults.
Short term intervention in crisis management.
Mental health/ illness prevention support.
2. In your view what improvements can be made to the psychology service offered?

Reduced Waiting Times
Shorter waiting times.
Shorter waiting times Waiting lists are hopelessly long.
Shorter waiting lists.
Shorter waiting lists.
Less delay.
Reduce waiting times.
Reduced waiting times.
Cut waiting lists.

More Financial Provision & Resources
More money.
More resources.
More provision.
More of the same.

More Psychologists
More staff.
More psychologists.
More staff.
More psychologists.
More trained staff.
Greater number of psychologists to reduce delay in appointments.
More psychologists.

More CBT
Need better access to CBT.
More CBT.

Some Offered Suggestions
Perhaps centralisation of services.
Integration with mental health services.
Offer regular community sessions.
Reintroduce practice based Clinical Psychologist.
Primary care referral to service.
Email feedback.
More CPN time.
Improvements specifically for Child Services
Offer assessment for ADH in children.
Child services need to be improved for access.
Actually have a child psychology service.
More availability of child services
Child and adolescent psychology service obviously need more psychologists so patients are seen quicker.
Increase provision especially more child services.
More child services.
More child facilities.

Improvements for Other Services
Services for unmet need e.g. previous sexual abuse and eating disorders.
More services - especially psychosexual and child.
If we had a service at all it would be an improvement on nothing.

Increase Accessibility & Availability
Easy access for assessment and treatment.
Open access.
More accessible.
Improved accessibility.
Increase accessibility.
Faster access.
Increase accessibility.
Easier access.
Faster access for limited consultation.
More availability.
More accessibility.
More accessibility.
Greater availability.

Clearer Referral Guidelines
Clear guidelines on who is appropriate to be referred and brief description of your job so patient is primed.
Guidelines for referral.
Clear guidelines for use for GPs.

More Counselling Services
Better services for counselling.
Need more counselling type support.
Use of counsellors in all surgeries wanting to free up CPN/ psychologists time and increase appropriateness of referral.
The Impact and Effect of Chronic Pain: The Partner's Perspective

Literature Review
Year 2
Psych.D Clinical Psychology

July 2001
Literature Review

Introduction

Chronic pain and the family has been the subject of much research over the last 25 years and has been studied from a number of different perspectives. Previous research has focused on the family in the aetiology and maintenance of chronic pain. Studies examining these two perspectives have been the subject of comprehensive reviews by Turk, Flor and Rudy (1987) and Payne and Norfleet (1986). Previous research has also explored the influence of involving family members in the treatment of chronic pain (Ranjan 1989; Flor, Turk & Rudy, 1987; Moore & Chaney, 1985). Finally, research has examined the impact and effect of chronic pain on the family itself. It is the impact on partners of chronic pain patients, which dominates the literature and accordingly is the focus here.

Chronic Pain

Chronic pain is defined as persistent pain that has been ongoing for a period of longer than six months and requires long-term management (Gonzales, Martelli & Baker, 2000). The most common sites of chronic pain are low back pain and neck pain (Nicholson, 2000). Although prevalence rates vary considerably, some research has suggested that as many as 46.5% of the general population have pain, with 15.8% describing their pain as highly disabling and severely limiting (Elliott, Smith, Penny, Smith & Chambers, 1999). Individuals between the ages of 45-64 years are most likely to report pain (Nicholson, 2000). When considering duration of pain, Turk, Flor and Rudy (1987) reported the norm for patients presenting to pain treatment centres is 8.8 years, with some patients reporting over 30 years pain duration.

Impact of Chronic Pain on the Partner

Chronic pain has a major impact on many areas of the pain sufferer’s life, for example, employment, social and leisure activities, family and personal relationships, psychological well being and general physical capability (Banks & Kerns, 1996). It has also been recognised that chronic pain is likely to have significant consequences for the family living with someone in chronic pain (Dura & Beck, 1988). This acknowledgement has led to a considerable number of studies exploring and examining the effects of chronic pain on partners of pain patients.
Marital Satisfaction

Research focusing on the marital relationship of chronic pain patients and their partners suggests that many partners experience dissatisfaction with the relationship. Unfortunately, the level of dissatisfaction compared to the general population is unclear due to the lack of control groups throughout the literature. Within the current literature the Locke-Wallace Marital Adjustment Test (MAT; Locke & Wallace, 1959) has been widely used to measure marital satisfaction. Findings using this measure appear to be consistent throughout the literature. Kerns and Turk (1984) assessed 30 male pain patients and their partners. Results indicated marital dissatisfaction in over half of pain patients and their partners, with approximately one third of the couples expressing severe levels of dissatisfaction. In another study using an all male pain sample, Flor, Turk and Scholz (1987) examined levels of marital satisfaction in 58 pain patients and their partners. Findings suggested 51% of partners were dissatisfied with their relationship. Subramanian (1991), using a smaller sample, measured marital satisfaction in 20 partners. Over one third of all partners reported marital dissatisfaction. A larger sample of 117 couples were involved in a study conducted by Ahern, Adams and Follick (1985). As well as having a large sample, this study also focused on one specific site of pain, chronic low back pain. Results indicated 35% of partners rated their relationships as maladjusted and 40% reported significant dissatisfaction within specific areas of their relationship. In a well-designed study by Romano, Turner and Jensen (1997), using a matched sample of 33 couples without chronic pain or any other disabling condition and 33 chronic pain couples, showed partners of pain patients were more likely to report less marital satisfaction than control partners. Thirty percent of pain patient’s partners fell in the dissatisfied range of the Dyadic Adjustment Scale (DAS; Spanier, 1976) compared to 12 % of controls.

Although rather limited in the chronic pain literature, qualitative studies provide further evidence that partners of chronic pain patients experience dissatisfaction with the relationship. Payne (1982) interviewed 47 couples attending a pain treatment programme. Twenty of these couples indicated they were currently less satisfied with their relationships than at any other time. Similarly, Snelling (1994) conducted a qualitative study using grounded theory to analyse interview data of 18 couples. Findings indicated that chronic pain could impinge on the relationship. Based on the analysis of qualitative responses, Snelling noted, the relationship may change from an
equal relationship to one where the pain patient is dependent on their partner for physical and emotional support. Snelling hypothesised, it is this change in the relationship, which leads to dissatisfaction. This supports earlier observations made by Bruhn (1977) who suggested that changes in the relationship might increase dissatisfaction. According to Bruhn partners of pain patients may feel burdened due to their increased responsibility regarding their partner and household chores and it is the increased responsibility that is likely to increase their dissatisfaction with the relationship.

**Evidence challenging a negative impact**

Saarijaervi, Hyyppae and Alanen (1990) provided some evidence to suggest marital dissatisfaction in partners of chronic pain patients is no higher than that of marital relationships in general. They conducted a large Finnish population study, comparing 63 chronic pain patients and their partners to 101 controls. Marital satisfaction was measured using The Marital Questionnaire (MQ). The questionnaire was designed specifically for their study, and comprised 14 items from the DAS, and 6 items from the Marital Communication Inventory (MCI; Bienvenu, 1970). The MQ was shown to be reliable and to correlate with the MAT.

Findings indicated that although sexual problems were more common in the chronic pain sample, with regard to marital satisfaction there were no significant differences between the two groups. One fifth of both groups reported conflict and dissatisfaction. They concluded the majority of chronic pain patients and their partners experience high marital satisfaction. However, it should be noted that 35 pain couples originally approached refused to participate. Saarijaervi et al., (1990) point out there is a possibility that the willingness of the couples that participated could reflect their marital satisfaction. Those who refused to participate may have been dissatisfied with their marriages. This potential explanation for the differences in participation rate is a major limitation of the study’s findings. A further limitation is the non-standardised measure used to assess marital dissatisfaction. However, Feinauer and Steele (1992) support Saarijaervi et al., (1990) earlier findings. Feinauer and Steele (1992) measured marital satisfaction in 141 couples using the MAT and found 71% of partners to report high levels of marital satisfaction and happiness. This was in spite of the high levels of reported interference with sexual activity that resulted due to their partner’s pain.
Methodological Critique

Overall the evidence indicates many partners of chronic pain patients report marital dissatisfaction. However, the research is methodologically poor and caution needs to be applied when drawing conclusions regarding the relationship between these two variables. For example, some studies have included only male pain patients and their partners. As Romano, Turner and Clancy (1989) suggest the reliance on male samples limits the generalizability of findings to female pain patients and their partners. Other studies have often included patients with dissimilar pain conditions, and have failed to consider the effects of differing sites of pain and symptom severity on the partner and relationship. Studies also suffer two major limitations due to their sample sizes. Firstly, a number of studies have very small samples, making it difficult to infer generalisations. Secondly, the difference in sample sizes makes it impossible to draw comparisons between studies and to conclude overall prevalence of marital dissatisfaction in partners of pain patients.

Further weaknesses are reflected in the measures used to assess marital satisfaction. The MAT has been widely used in studies of marital satisfaction of chronic pain patients and their partners. Although, the instrument has been proven to be a valid and reliable measure for assessing marital satisfaction (Ahern and Follick, 1985), studies drawing conclusions regarding the marital satisfaction of pain patients partners based solely on this measure should be treated with caution. As Ahern and Follick (1985) point out, the measure was not developed or initially intended for use in measuring marital satisfaction of pain patients and their partners. Further, the MAT is a self-report measure. This implies studies using the MAT suffer all the limitations associated with self-report measures. These include for example, response bias, social desirability, creation of forced answers, and failure to gain a real understanding of why an individual endorsed a particular response.

Studies are also problematic as the vast majority fail to have control groups, making it difficult to establish whether partners of pain patients experience higher levels of marital dissatisfaction in comparison to the population in general. Studies that have attempted to overcome this criticism for example, Saarijaervi et al., (1990) have unfortunately, as outlined earlier, suffered other methodological weaknesses. Similarly, studies have also failed to compare partners of chronic pain patients with partners of patients suffering with other chronic illnesses. If literature on chronic
illness in general is considered, findings indicate dissatisfaction with the relationship. For example, Schott and Badura (1988) found the increasing responsibilities of wives after their husband’s heart attack could lead to marital dissatisfaction. Isaaca, Neville and Rushford (1976: cited in Anderson, 1988) highlighted the effect of one partner having a stroke on the amount of satisfaction reported by the other. They concluded increased dependency upon one partner might contribute to increased conflict and hostility at home, which in turn may increase dissatisfaction with the relationship. In light of such research, the suggestion of caution in assuming partners of pain patients experience higher levels of marital dissatisfaction than the partners of chronically ill patients in general needs to be seriously considered (Turk, Flor & Rudy, 1987). Finally, Flor, Turk and Scholz (1987) note, the lack of information and baseline measurement relating to partners marital satisfaction prior to the onset of pain, means it is impossible to determine whether dissatisfaction is a consequence of living with someone in chronic pain or a situation that increases existing distress within the relationship.

**Sexual Satisfaction**

Although there has been some interest in exploring sexual satisfaction, overall research in this area of chronic pain appears to be limited. In comparison to the literature exploring sexual difficulties and satisfaction in pain patients (Labbe, 1988; Weiss & Harner, 1982; Infante, 1981; Maruta and Osborne, 1978) there appears to be a paucity of studies exploring this issue from the partner’s perspective.

Maruta and Osborne’s (1978) study is widely quoted within the literature when considering the impact of pain on the patient’s sexual activity. Their sample of 66 pain patients participated in interviews covering six general areas relating to sexual adjustment in the relationship and the effect of pain on the quality and frequency of sexual activity. Findings indicated 60% of pain patients experienced a reduction in sexual satisfaction, 58% reported a reduction in frequency and approximately half experienced sexual dysfunction after the onset of pain. Although the findings of the study reflect views of pain patients themselves, the results predict a profound impact on the sexual activities of partners within the relationship. Maruta, Osborne, Swanson and Hallwig (1981) investigated this further using the same set of questions to assess sexual functioning in 50 pain patients and their partners. Eighty-four percent of
partners reported significant reductions or elimination of sexual activity since the onset of their partner’s pain.

Similar findings have also been observed in qualitative studies. In Snelling’s (1994) study partners of pain patients described how their sexual relationship had become a ‘bone of contention’ causing many arguments. The nature of the study allowed the reasons for the reduction in sexual activity to be explored. In some cases the reduced sexual activity was a direct consequence of their partners pain. In some cases however, partners of pain patients found the way they felt about their partner had changed so withdrew from engaging in sexual activity.

**Methodological Critique**

The literature suggests many partners of pain patients experience sexual dissatisfaction. However, again research is methodologically weak. A major flaw within these studies is the lack of valid and reliable standardised measures available to assess sexual dissatisfaction. Studies have failed to implement any standardised measures and in some cases have used a limited number of questions to assess sexual dissatisfaction. Further difficulties exist as no baseline information or measurement of the quality and frequency of sexual activity prior to the onset of the pain problem is available. Retrospective self-reports of sexual activity prior to pain onset are compared to self-reports of current sexual activity. This is problematic for two reasons. Firstly, retrospective reports have been shown to be highly unreliable (Linton & Melin, 1982) and secondly, individuals may be more attuned to the belief their sexual relationship was more satisfying prior to the onset of their partners pain. This may result in partners of pain patients overestimating the quality and frequency of their previous sexual activity. This overestimation would produce a greater sense of reduction and dissatisfaction in the current sexual relationship.

Finally, difficulties exist as studies have failed to compare sexual dissatisfaction in partners of pain patients with couples in the general population. Studies, which have measured sexual dissatisfaction in the general population, note 59% of women and 49% of men, experience sexual dissatisfaction at some stage of their life (Sanders, 1987: cited in Bancroft, 1989). These figures suggest sexual difficulties and dissatisfaction are common in many couples at some point and it should not be assumed partners of chronic pain patients experience higher levels of sexual
dissatisfaction. Similarly, as research in the general population suggests, the presence of sexual difficulties, for example, premature ejaculation, erectile problems, orgasmic dysfunction, dyspareunia and vaginismus, does not necessarily imply sexual dissatisfaction. Golombok, Rust and Pickard (1984: cited in Bancroft, 1989), found in spite of a number of sexual difficulties, 97% of men and 77% of women rated their sexual relationship as satisfactory. Therefore, even though sexual difficulties may be common for pain patients (Labbe, 1988; Weiss & Harner, 1982; Infante, 1981; Maruta and Osborne, 1978), it may not mirror a view of sexual dissatisfaction in their partners.

Health
Evidence suggests partners of pain patients experience a number of physiological, physical, psychological and emotional reactions.

Physiological Responses
There is evidence that the physiological responses of partners of pain patients may be affected as a result of their partner’s pain. Block (1981) examined the effects of pain behaviours on 16 pain patients’ partners. Partners of pain patients were exposed to videotapes of their partner and actors portraying hospitalised patients, displaying painful and neutral facial expressions. Their phasic changes in skin conductance and heart rate were measured in response to each type of facial expression. Partners of pain patients showed an increase in skin conductance as a response to their partner’s, but not to the actors, painful facial expressions in comparison to neutral expressions. Results also suggested an increase in heart rate in response to painful facial expressions. Block (1981) concluded the data supports the hypothesis that chronic pain has a physiological effect on partners of pain patients.

Stampler, Wall, Cassisi and Davis (1997) furthered Block’s (1981) study examining the impact of patient pain behaviours on their partner, in the actual presence of their partner. Twenty-six couples engaged in a series of structured conversations. The first conversation involved the discussion of a mutually agreed neutral topic. The second conversation involved discussing the impact of chronic pain on the couple’s life. Measures of phasic skin conductance and heart rate were taken from the pain patient’s partner during each type of conversation. Partners showed increases in skin conductance and heart rate when listening and responding to the discussion of the
impact of chronic pain. Stampler et al., (1997) concluded this supports Block’s (1981) original finding that chronic pain has a physiological effect on partners of pain patients.

**Methodological Critique**

Although these studies are consistent in their findings caution needs to be taken when drawing generalisations from the findings. Both studies are based on small samples, fail to have a control group and have been conducted in an experimental setting. Further studies need to address these issues, examining the physiological responses of partners of pain patients in naturalistic environments.

**Physical Problems**

Previous studies have provided evidence to suggest partners of chronic pain patients develop pain symptoms and health problems of their own. Evidence has been presented highlighting a high incidence of pain problems and pain complaints in partners of pain patients. Mohamed, Weisz and Waring (1978) compared 13 patients with depression and pain to 13 patients with clear depressive symptoms but no somatic symptomatology. Patients in both groups and their partners completed the Personal History and Family History Pain Questionnaire (Mohamed, Weisz & Waring, 1978), a modified version of the McGill Pain Questionnaire (Melzack, 1975). The questionnaire measured pain symptoms and site of pain. The results indicated the partners of patients with depression and pain reported a significantly greater prevalence of pain problems than sets of matched partners from the depression only patient group. Further, the results showed a much greater similarity in the site of reported pain between patients and their partners in the depression and pain group than in the depression only group. In another study Flor, Turk and Scholz (1987) using the Wahler Symptom Inventory (Wahler, 1968) assessed a range of physical and psychophysiological symptoms. They found 86% of pain patient partners reported at least one pain symptom per week. Similar findings were found by Saarijarvi et al (1990). They used the Standardised Nordic Questionnaire (Kuorinka, Jonsson, Kilbom, Jonsson, et al., 1987) and found partners of pain patients were more likely to report having experienced musculokeletal pain symptoms over the past week than controls.
Partners of pain patients have also been reported as having a tendency to develop a number of more common health problems. Rowat and Knafl’s (1985) interviewed 40 partners. Qualitative analysis showed overall 83% of partners reported some kind of health difficulty, which they considered to be directly related to their partner’s pain. Twenty three percent of these difficulties related to physical health problems. These included disturbance in sleep and appetite, increased blood pressure, migraines and gastro-intestinal distress.

**Methodological Critique**

Turk, Flor and Rudy (1987) note, overall studies have failed to compare partners of chronic pain patients with partners of chronically ill patients and with partners of the general population. Failing to provide comparison groups highlights the need for caution when drawing conclusions regarding the physical effects of living with someone in chronic pain. Turk, Flor and Rudy (1987) argue the physical effects may be the same as living with a partner suffering from any chronic illness. This was illustrated by Klein, Dean and Bogonoff (1967) who reported 67% of partners of chronically ill patients showed increases in physical symptoms during the illness period. The physical symptoms most often reported were nervousness, and feelings of fatigue and tiredness. Further, Turk, Flor and Rudy (1987) point out, care should be taken not to assume the physical effects of living with someone in chronic pain are more severe than living with a patient suffering from chronic illness in general. The findings of Klein, Dean and Bogonoff (1967) indicate the presence of physical symptoms is common in a significant proportion of partners of all chronically ill patients.

Flor, Turk and Scholz (1987) begin to address the two criticisms put forward by Turk, Flor and Rudy (1987). In a well-designed study, they randomly selected and compared 20 (out of the overall sample of 58) partners of pain patients with a matched control group of partners of diabetic patients. Participants were matched on age, sex, education level, duration of illness, and duration of their relationship. Results showed partners of pain patients experienced significantly more pain symptoms than partners of diabetic patients. Findings indicated 86% of pain patient partners reported at least one pain symptom per week, compared to 45% of diabetic patient partners. This supports other findings, suggesting partners of pain patients experience a higher incidence of pain problems and pain complaints. However, with regard to physical
symptoms in general, Turk, Flor and Rudy (1987) reported no differences between pain patient and diabetic patient partners. Unfortunately, the study by Turk, Flor and Rudy (1987) is limited due to the relatively small sample. As a result further research comparing partners of chronic pain patients with partners of chronic illness patients needs to conducted before the relationship between physical health and living with someone in chronic pain can fully be established.

**Psychological and Emotional Problems**

Evidence has been presented that suggests the psychological and emotional health of partners of chronic pain patients is also affected. Rowat and Knafl (1985) reported 69% of partners interviewed made statements that reflected how their partner's pain had impacted on their own emotional health. Partners described how they felt sad, depressed, fearful, nervous, irritable, tense, anxious and isolated. They related the cause of these feelings directly to their partner's chronic pain.

Studies involving standardised measures have also emphasised an impact on partners of pain patient's emotional and psychological health. Shanfield, Heiman, Cope and Jones (1979) used the Symptom Check List-90 (SCL-90; Derogatis & Lipman, 1973) to assess the impact of patient pain on the psychological health of 44 partners. The global severity index (GSI) was the focus of analysis as it allows an indication of overall distress. The mean GSI scores of pain patients and their partners were compared against the norms for psychiatric outpatients and non-patients. Results showed both pain patients and partners to have significantly higher GSI scores than non-patients. Shanfield et al., (1979) concluded this finding illustrates the high levels of psychological distress, which are experienced by partners of pain patients as compared to the general population. Interestingly, younger partners had higher GSI scores, indicating higher levels of psychological distress than that experienced by older partners. In another study, Kerns & Turk (1984) assessed partners' mood using the Depression Adjective Check List (Lubin, 1967). The measure is a specific inventory of depression and has established reliability and validity (Lubin, 1967). The results showed over half of partners experienced significant depression. Other studies have also identified a relationship between living with someone in chronic pain and experiencing emotional problems. Ahern, Adams and Follick (1985) used the Depression, Psychasthenia and Mania scales from the Minnesota Multiphasic Personality Inventory (MMPI; Hathaway & McKinley, 1967) to measure emotional
distress in 100 partners. The results indicated a significant number of partner’s experienced high levels of emotional distress, with 20% of partners reporting depressive symptomatology. Depression was found to be the most common symptom reported followed closely by anxiety. Feinauer and Steele (1992) also used the MMPI, but reported a much higher rate of depression in partners. They found 77% of partners to show moderate to high levels of depression on their MMPI profiles. Flor, Turk and Scholz (1987) reported similar levels of depression as Ahern, Adams and Follick (1985). They found 26% of partners to be significantly depressed, as measured by the Beck Depression Inventory, (BDI; Beck, Ward, Mendelson, 1961). Similar findings were found by Schwartz, Slater, Birchler and Atkison (1991), who reported 28% of partners to have significantly depressed mood as measure by the BDI. Saarijaervi et al (1990) assessed partner emotional distress using the Brief Symptom Inventory (BSI; Derogatis & Melisaratos, 1983) a measure that has been shown to have good retest and internal consistency reliabilities (Derogatis & Melisaratos, 1983). They reported distress scores in partners of chronic pain patients to be higher than the control group. Scores were reported to be significantly higher on somatization, depression, anxiety, and hostility.

**Methodological Critique**

The literature tends be consistent in suggesting a negative impact on the emotional and psychological health of partners of chronic pain patients. It appears partners of pain patient’s are particularly susceptible to developing depressive symptomatology. However, caution needs to be raised due to the methodological weaknesses of the studies conducted within this area. The majority of studies have relatively small sample sizes, making the effect sizes questionable. A severe limitation is the lack of control groups. Partners of pain patients need to be compared with partners in the general population before a relationship between depression and living with someone in chronic pain can be fully established. Failure to compare partners with the general population makes it difficult to conclude this group of people experience higher levels of depression than the overall population. A lack of baseline measurement is also problematic, as the relationship between cause and effect cannot be established. Further, partner’s emotional and psychological health has been measured using a variety of different measures; this makes comparing findings across studies complicated. Finally, the appropriateness in administering many of the measures implemented within these studies is questionable. Many measures have been
inappropriately administered within the pain population, lacking sensitivity and specificity (Williams, 1995).

Conclusion

Summary of Methodological Weaknesses

Overall, studies assessing the impact of living with someone in chronic pain have lacked sophistication and suffered a number of methodological weaknesses. A major drawback of many of the studies outlined is the lack of control groups available to allow comparisons to be made with the general population or with other chronic illnesses. Further, studies have lacked baseline information and used non-standardised measures, many of which were not designed for use within the pain population. Studies have also implemented a variety of different measures to assess the same variable and then drawn comparisons between studies. With regard to samples, a number of studies have drawn conclusions based on extremely small samples that have in some cases been single sex samples, with differing sites and differing durations of pain. Several studies have failed to control for the effects these confounding variables may have.

Numerous studies have also relied on a convenience sample consisting of partners of pain patients attending pain management programmes. Although convenient and easy to gain access such studies are not based on a representative sample. The studies comprise the partners of pain patients who are coping least well in managing their pain (Flor, Turk & Rudy, 1987). This suggests partners included in studies may also be coping less well and have differing characteristics from partners of pain sufferers who are not attending pain management programmes. Such characteristics may influence the impact of their partner's pain. Therefore, the findings, which are outlined in the literature, may only be clinically relevant for a small portion of those living with a partner in chronic pain (Schwartz, Slater & Birchler, 1996).

Finally, the majority of research in this area has used quantitative methodology and data has been analysed using inferential statistics. Due to small samples many studies have analysed data inappropriately, applying methods that are only really suitable for use with samples, of over 100 participants. For example, Kerns and Turk (1984), Flor, Turk, and Scholz (1987), and Schwartz, Slater, Birchler, and Atkinson (1991) used multiple regression analysis on samples ranging between 29 and 58 participants. Due to small samples the majority of studies in this area have had no choice but to
implement analysis involving weaker statistical tests, for example, t-tests and chi-squared. Both these points suggest caution when interpreting the significance of findings and conclusions presented.

**Future Directions**

Although the current review aims to be thorough and comprehensive it does not claim to be exhaustive. However, there does appear to be an unequal balance of quantitative and qualitative studies in the literature. Quantitative methodologies appear to have dominated the research in this area and to have suffered many criticisms. Criticisms regarding the measures that have been used to assess the extent to which pain impacts on the lives of partners have recently been addressed by Sharp and Nicholas (2000). They have developed a number of valid and reliable psychometric measures to assess firstly, the responses of partners of pain patients to their partner's pain and secondly, to measure the extent to which pain impacts on the lifestyle and mood of partners of pain patients. It is hypothesised, these measures used with better-designed, representative and controlled studies will help to overcome some of the methodological weaknesses highlighted throughout this review.

With regard to qualitative methodology only three qualitative studies have been identified (Payne, 1982: cited in Payne & Norfleet, 1986; Rowat & Knafl, 1985; Snelling, 1994). These studies have added a different dimension to the literature explicitly exploring the personal meaning of living with someone in chronic pain. The paucity of studies using qualitative methods illustrates how rare it is to explore the personal meaning of living with someone in chronic pain. This represents a gap in both research and understanding. Further qualitative studies employing newer qualitative techniques, for example, Interpretative Phenomenological Analysis (IPA) (Smith, 1996; Smith, Jarman & Osborn, 1999) need to be employed in future research to address this issue. IPA was successfully employed by Osborn and Smith (1998), to explore the personal experiences of the pain patient. Using this method to gain an 'insider perspective' (Conrad, 1987) into the partners view of living with someone in chronic pain, exploring their experiences, cognitions and meaning-making (Coyle & Rafalin, 2000) would be valuable in gaining a greater understanding of the effects and impact of living with someone in chronic pain.
Final Comment

In conclusion, research suggests partners of pain patients are affected in significant ways by their partner’s pain. However, due to the inconsistencies and general weaknesses within the existing literature the exact impact remains unclear. Further investigation into the experience of partners of chronic pain patients is required before firm conclusions can be drawn. It is suggested this investigation is initially conducted and explored from a qualitative perspective, followed by more methodologically sound quantitative work based on findings derived from qualitative studies. Finally, it is hypothesised future studies considering the impact of living with someone in chronic pain may be useful in identifying issues and experiences that are shared by partners of pain patients. This knowledge may have clinical relevance and implications as it may highlight new ways in which partners of pain patients are involved in future pain management programmes with sessions included specifically addressing the needs of partners of pain patients.
References


The personal experiences of partners living with someone suffering with chronic lower back pain: An interpretative phenomenological analysis.

Major Research Project
Year 3
Psych.D Clinical Psychology

July 2002
ABSTRACT

This study explored the personal experiences of partners living with someone suffering with chronic lower back pain (CLBP). Semi-structured interviews were used to elicit an account of their experience. The interviews were transcribed verbatim and analysed using interpretative phenomenological analysis (Smith, 1996a). The standards and guidelines outlined by Elliott, Fischer and Rennie (1999) were applied to address issues of reliability and validity. The participants were partners of pain patients who had been referred to one of two pain management centres and comprised of five females and six males aged between 32 and 71 years. The analysis revealed three main themes, understanding and making sense of the pain, consequences and coping. The themes identified the importance for participants to have an understanding of their partner’s pain and how this possibly influenced their responses. Participants also showed understanding and awareness of the effects of the pain on their partners. Participants identified a number of consequences of living with someone with CLBP. These focused around changes and restrictions in their social life and leisure, sex life and identity, and development of their own health problems. Participants implemented problem-focused and appraisal-focused coping strategies to cope with the restrictions placed on them and the pain situation. Although these strategies helped, participants also identified a number of factors that acted as barriers to coping. The themes are discussed in relation to existing research and the methodological issues relating to the study are addressed. Clinical implications and directions for future research are outlined.
INTRODUCTION

Overview
This study is an exploration of the experiences of partners living with someone suffering with chronic lower back pain (CLBP). Previous studies have explored how CLBP affects the individual pain patient and the personal experience of living with CLBP from the patients' perspective (Osborn & Smith, 1998; Strong, Ashton, Chant & Cramond, 1994; Strong & Large, 1995). However, a paucity of research exists focusing on the effects of CLBP on partners of pain patients. The aim of this study is to discover how partners of patients attending a pain management programme think they are affected by, cope with and understand their experience of living with someone with CLBP.

The researcher became interested in this particular area of research after observing a relatives' session forming part of a pain management programme. In this session patients were invited to bring their partner. It was observed that partners often experienced difficulties in understanding and coping with the pain situation. The researcher was curious and interested in gaining further understanding, insight and knowledge of the partner's experience.

Understanding chronic health problems
Chronic illness refers to health problems that have a definite organic pathology, for example, coronary heart disease, respiratory illnesses or cancer. In contrast, chronic conditions refer to problems that are less easily diagnosed, less understood by the medical profession and have a less well-known organic pathology, for example, chronic pain, premenstrual syndrome or fertility problems (Schwartz & Ehde, 2000).

Traditionally, studies have focused on the experience of chronic illnesses and conditions from the perspective of the individual suffering with the health problem. However more recently, researchers have acknowledged that family members and partners are also affected, and have examined the experiences of chronic health problems from family members' and partners' perspectives (Anderson & Bury, 1988; Coyne & Smith, 1991; Fiske, Turk & Kerns, 1985; Rowat & Knafl, 1985; Snelling, 1994).
To experience one’s partner suffering with any chronic illness or condition is particularly stressful and requires the healthy partner to make considerable changes within their life (Schwartz & Ehde, 2000). However, it is perhaps chronic conditions, the conditions that are less understood in terms of pathology, that are likely to have a greater effect on partners, due to ambiguities and uncertainties surrounding the causality, chronicity, treatment and prognosis of the condition (Schwartz & Ehde, 2000).

**Understanding chronic pain**

Chronic pain is often a condition surrounded by ambiguities and uncertainties (Schwartz & Ehde, 2000). It is defined as recurrent or persistent pain that has been ongoing for a period of longer than six months and requires long-term management (Gonzales, Martelli & Baker, 2000). Three types of chronic pain have been proposed (Schwartz & Ehde, 2000). Chronic pain that arises due to a disease, for example cancer. Chronic pain that results from some clear pathological injury, for example, amputation. And finally, chronic pain that exists but has no detectable organic pathology or the level of organic pathology cannot explain the level of pain reported (Schwartz & Ehde, 2000). CLBP often fits into the latter category. More often than not, no organic pathological explanation can be offered to explain why the patient is experiencing CLBP or the level of pain they are reporting.

**Prevalence of chronic back pain within UK**

Chronic back pain is one the nation’s leading causes of disability with 1.1 million people being disabled by it, being unable to work (Labour Force Survey, 1998) and it continues to rise. Over a ten-year period between 1987-8 and 1997-8 the prevalence of reported back pain, (pain lasting for longer than one week) rose from 36.4% to 49.1% an increase of 12.7% (Palmer, Walsh, Bendall, Copper & Coggan, 2000). Back pain is extremely costly for the National Health Service, with 480 million pounds each year being spent on services used by people with back pain (Clinical Standards Advisory Group Committee on Back Pain, 1994).

**Effects of chronic pain on partners**

As well as a significant problem for society, chronic back pain is also a significant problem for individual sufferer. Chronic back pain has a considerable impact on the pain sufferer’s life, accounting for changes in physical, emotional, social and
occupational functioning (Schwartz & Ehde, 2000) and in family and personal relationships (Banks & Kerns, 1996). However, there is also a significant effect on family members. Family members often find themselves taking on increased responsibilities and find family roles and dynamics changed (Bruhn, 1977). Family members also have increasing demands placed upon them for emotional, physical and financial support (Snelling, 1994) and have to deal with uncertainties and worries surrounding the cause and recovery of the pain patient’s symptoms (Schwartz & Ehde, 2000).

Although all family members can potentially be affected by the patient’s CLBP the focus here is the effect on the patients relationship and partner. Limited literature reflecting the experiences of partners of CLBP patients is available. As a result the literature on chronic pain in general is discussed. This broader literature suggests significant difficulties for partners.

Previous research has highlighted that marital and sexual dissatisfaction are areas frequently identified as problematic for partners of pain patients (Ahern, Adams & Follick, 1985; Flor, Turk & Scholz, 1987; Kerns & Turk, 1984; Maruta & Osborne, 1978; Maruta, Osborne, Swanson & Hallwig, 1981; Romano, Turner & Jenson, 1997; Snelling, 1994; Subramanian, 1991). Literature reviews have consistently identified that partners of pain patients rate their relationships as poorer and as being less satisfying compared with controls (Payne & Norfleet, 1986; Turk, Flor & Rudy, 1987). Between 35% and 60% of partners of pain patients rate their relationship as being dissatisfying (Turk, et al., 1987). The variation seems to be dependent upon the measure and comparison sample used within individual studies (Schwartz & Ehde, 2000).

Decreased sexual activity and satisfaction have also been reported by couples of chronic pain (Maruta & Osborne, 1978; Maruta, et al., 1981). In comparison to the literature exploring sexual difficulties and satisfaction in pain patients (Infante, 1981; Labbe, 1988; Maruta & Osborne, 1978; Weiss & Harner, 1982) there appears to be a paucity of studies exploring this issue from the partner’s perspective. Studies that have explored the partner’s perspective have found that chronic pain may have a greater impact on the partner’s level of satisfaction than the patient him/herself. Maruta, et al. (1981) found 84% of partners to report significant reductions or elimination of sexual
activity since the onset of their partner’s pain. Snelling (1994) reported partners of pain patients described how their sexual relationship had become a ‘bone of contention’ causing many arguments within the relationship. The distress and dissatisfaction experienced by partners of pain patients has been suggested as being gender related. Romano, Turner and Clancy (1989) reported female partners had a tendency to report more distress and dissatisfaction with the sexual relationship compared to male partners.

Partners’ emotional and physical health has also been shown to be affected. Studies examining the emotional impact on partners have reported between 20% and 30% of partners may be experiencing depressive symptomatology (Ahern, et al., 1985; Flor, Turk & Scholz, 1987; Schwartz, Slater, Birchler & Atkinson, 1991). With regard to physical health difficulties, partners have been found to develop pain symptoms similar to that of the pain patients and to be more likely than controls to develop common health problems of their own, for example, disturbances in sleep and appetite, increased blood pressure, migraines and gastro-intestinal distress (Flor, Turk & Scholz, 1987; Mohamed, Weisz & Waring, 1978; Rowat & Knafl, 1985; Saarijarvi, Hyyppae & Alanen, 1990).

**Effects of partners on chronic pain**

As well as being affected by chronic pain, partners themselves have been shown to have an impact in the development and maintenance of pain and disability in patients. Much of the research involving partners has examined how their responses influence the patients’ pain and pain behaviours. Fordyce (1976) proposed a behavioural-operant model of chronic pain. The model highlighted the influence of the partners’ responses to the patients’ pain and pain behaviours on the nature and course of the patients’ condition.

Fordyce describes pain behaviours as the verbal and non-verbal behaviours that the patient displays to inform others they are in pain, for example, grimacing, holding a part of the body, refraining from speaking, complaining about the pain or taking medication. The behavioural-operant model proposes that pain behaviours are subject to reinforcing factors in the environment, for example, attention, sympathy and avoidance of an activity. Such reinforcement may actually act to maintain the pain behaviours.
According to Fordyce in reinforcing the pain, partners use one of three types of responses; solicitous, negative and facilitative. A partner responding in a solicitous manner is attentive to the pain and the patients needs. Partners frequently worry that the pain patient is ‘overdoing it’ and have a tendency to underestimate the patient’s abilities, preferring to do things for them, rather than run the risk of them ‘paying for it later’ (Schwartz & Ehde, 2000). Studies have shown solicitous responses by partners are associated with increased pain and disability by pain patients (Flor, Kerns & Turk, 1987; Kerns, Haythornthwaite, Southwick & Giller, 1990; Schwartz, Slater & Birchler, 1996).

In contrast, negative responses by partners, for example, irritation or criticism have been shown to reduce pain behaviours and levels of disability (Flor, Kerns & Turk, 1987). However Schwartz, et al., (1996) report contradictory findings, reporting that punitive responses to pain behaviours are related to higher pain intensity and greater psychosocial and functional impairment. They proposed a clinical model of conflict management, describing a negative cycle of marital conflict, avoidance, pain behaviour and disability. The model suggests that marital conflict may increase pain behaviours, which may in turn be associated with negative or punitive responses by the partner that may lead to increased patient disability. They conclude that it might be useful for couples to assess the conflict within their relationship and also to address the partner’s feelings and behavioural responses to the pain and pain situation.

Fordyce (1976) describes facilitative responses by partners as responses that reinforce well behaviours, such as, exercising, participating in family activities, completing household chores and working. Attention and praise given to well behaviours has been shown to have a positive affect on increasing physical functioning in patients and reducing levels of reported pain (Cairns & Pasino, 1977; White & Sanders, 1986).

**Relationship changes initiated by chronic back pain**

The average age of onset of chronic back pain is between 45-64 years (Nicholson, 2000). Therefore, it is likely that many patients developing CLBP will have been with their partner for a number of years prior to onset. Thus, both partners would have experience of the relationship without CLBP. The onset of CLBP during the course of the relationship implies that both partners will have to adapt to the changes and challenges imposed by the chronic health problem.
Lyons and Meade (1995) suggest that chronic conditions such as CLBP can pose a threat to the relationship and changes within the relationship may be required if it is to survive. Lyons, Sullivan, Ritvo and Coyne (1995) argue that if the relationship remains unchanged the chronic condition may have an negative impact on the couples lifestyle, for example, reducing contact with others, increasing marital difficulties, reducing meaningful activities, for example, work and sport. They suggest this can potentially lead to a dysfunctional relationship with little shared activity, communication or intimacy. They propose further difficulties may arise within the relationship due to changes in reciprocity of support and care between partners. They explain that although the support and care given by the healthy partner may allow adjustment to the chronic condition by the couple, the lack of balance of support and care within the relationship may actually destroy the relationship. According to exchange and equity theorists (Clark & Mills, 1979) reciprocity and balance within a relationship are pertinent to the maintenance and survival of the relationship. Individuals who do not perceive their relationships to be reciprocal may leave the relationship (Roloff, 1981).

To avoid the relationship becoming dysfunctional, unbalanced and dissatisfying, Lyons and Meade (1995) suggest partners must remodel their relationship. This usually involves partners making substantial lifestyle adaptations and changes to accommodate the chronic condition and enhance the quality of the relationship. Although remodelling allows the relationship to be re-balanced and become more reciprocal, an alternative view suggests reciprocity within close relationships does not need to be immediate. Rather reciprocity is regarded by partners to cover the life span (Antonvcci & Jackson, 1990; Clark & Reiss, 1988). This now proposes that as long as a long-term sense of balance is present within the relationship it is not an issue that one partner is giving more support at one time, as long as that partner has received support from the other partner some time in the past. This explanation of reciprocity may explain why partners stay in relationships that are not immediately equal.

**Future Directions**

In summary, much of the research focusing on partners of pain patients has explored how the partners’ responses influence the patients’ pain behaviours and the levels of pain reported. Although, some attention has been paid to the impact of chronic pain on partners it is recognised that much more research is required to fully explain and...
understand the experience and effects of chronic pain on partners (Ahern & Follick, 1985; Schwartz & Ehde, 2000). Studies have however, provided evidence of relationship and sexual dissatisfaction, emotional distress and physical health problems in partners of pain patients. Unfortunately, many of these studies have lacked sophistication and suffered a number of methodological weaknesses, for example, studies have lacked control groups, used non-standardised measures not designed for use with the pain population and used extremely small samples that have in some cases been single sex samples with differing sites of pain (Payne & Norfleet, 1986). This has lead to inconsistencies within the literature and the exact impact of chronic pain on partners remaining unclear. Therefore, further investigation is required before firm conclusions can be drawn regarding the experience of living with someone suffering from chronic pain. The researcher suggests this investigation is initially explored from a qualitative perspective, followed by further quantitative studies based on findings derived from qualitative studies.

With the exception of a few studies (Rowat & Knafl, 1985; Snelling, 1994) the majority of studies considering the effects of living with someone in chronic pain have used quantitative methodology and data has been analysed using inferential statistics. Studies implementing qualitative methodologies have added a new and different dimension to the literature as they have explicitly explored the personal meaning of living with someone in chronic pain. Rowat and Knafl (1985) found the themes of helplessness and uncertainty to be central to the distress experienced by partners of pain patients. Partners were distressed and felt helpless at being unable to affect or change the level of pain their partner reported. With regard to uncertainty, partners were uncertain of the nature of the chronic pain itself, how the pain would affect family life and how to manage their partner's pain. Snelling (1994) concluded that social relationships, for example, marital relationships, sexual activity, contact with friends and relatives and roles were reported by partners to be affected greatly by the pain situation. This led to distress in partners. It is hoped the current study will add to this limited literature base, employing a qualitative methodology to provide a richer account of how individuals think, understand and cope with living with someone with CLBP.
The present study

Clinical Relevance of the study

Little research exists examining how partners make sense of their partners’ CLBP and how they cope with the social reality created by the pain situation. Recently, Osborn and Smith (1998) explored the personal meaning of CLBP, from the patient’s perspective. Their study produced some interesting and useful findings that have thrown light on new ways in which to manage pain in individuals suffering with CLBP. The four themes that emerged from their study (searching for an explanation, comparing this self with other selves, not being believed and withdrawing from others) highlighted the importance of and need to ‘attend to the psychological processes and constructs that the patients’ in chronic pain live through and bring to the pain clinic’ (Osborn & Smith, 1998, p.80). Osborn and Smith suggest that pain management programmes need to expand their focus, addressing the pain patients psychological processes and constructs as well as providing them with an understanding of their pain and helping them to acquire coping strategies to manage their pain. They conclude that if pain management programmes fail to address the anxieties and psychological difficulties experienced by pain patients this might jeopardize their future success in managing their pain effectively.

With regard to the current study it is hoped studying the phenomenon from the partners’ perspective will have similar implications for partners and highlight new ways in which partners could be involved to improve the treatment of patients with CLBP. At present the involvement of partners in pain management programmes varies considerably between different programmes and little consensus exists regarding how to involve partners in the process of change (Gold, 2000). If similar personal experiences were identified amongst partners of pain patients, this may have implications for how partners are involved in pain management programmes in the future. In may be considered beneficial to involve partners more, to address particular psychological issues and difficulties many partners appear to be experiencing or to set up their own support group. It may be hypothesised that focusing on and addressing partners experiences of living with someone with CLBP may produce a more supportive and relaxed home environment and a greater understanding of the pain situation and how to adapt to it effectively. This may in turn be beneficial for patients, contributing to more effective pain management and successful outcome.
Aims of the study
The overall aim of the study is to explore the participants’ personal world examining how they make sense of their partner’s pain and the social reality the pain situation has created. More specifically the study aims to:

a) Examine changes the participant believes have occurred due to their partner’s pain.
b) Examine ways in which the participant copes and adapts to the situation and changes in their lives.
c) Examine the participants understanding and assessment of the pain situation.
d) Examine how participants respond to their partner’s pain.

The aims will help address the overall research question: What is it like living with a partner suffering with CLBP?
METHOD

Research Design

Rationale for the methodology

The paucity of research exploring how partners of pain patients understand and make sense of their experience meant this research was conducted as an exploratory investigation. A qualitative methodology was implemented to allow meanings of the phenomenon under investigation to be elicited rather than to produce generalisable quantified rules.

Description of Interpretative phenomenological analysis

The qualitative methodology of Interpretative Phenomenological Analysis (IPA) comprises two intellectual orientations, phenomenology and symbolic interactionism (Smith, 1996a). The phenomenological approach (Schutz, 1962) is concerned with gaining an understanding of social reality based on a personal and subjective account of the individual’s experience, emphasising that to some extent the account reflects their beliefs of the phenomenon under investigation. Symbolic interactionism (Blumer, 1969) recognises that the meanings the individual has to make sense of the phenomenon are based on their individual interpretations of the event being studied (Smith, 1996a).

Although IPA is committed to understanding the individual’s perspective it acknowledges that it is only possible through the ‘interpretative analytic work of the investigator’ (Osborn & Smith, 1998, p.67). Therefore findings based on IPA are considered a ‘co-construction between participant and analyst in that it emerges from the analyst’s engagement with the data in the form of the participant’s account’ (Osborn & Smith, 1998, p.67).

In comparison to other qualitative methodologies IPA is positioned close to grounded theory (Glaser & Strauss, 1967) but distant from discourse analysis (Potter & Wetherell, 1987). IPA has been described as adopting ‘a broadly similar perspective’ to grounded theory (Smith, 1995, p.18) and as sharing ‘much of its analytic terminology’ (Willig, 2001, p.69).

In contrast, IPA is radically different to discourse analysis (Smith, 1996a). The difference stems from the understanding of the status of cognitions. IPA considers
cognitions, what participants think and believe about the phenomenon under investigation, can be represented in the participants’ verbal responses. It emphasises that verbal responses should be the focus of analysis, as the participants’ beliefs can be understood through the analysis of the verbal reports. In contrast, discourse analysis considers verbal reports to be behaviours in their own right and strongly opposes the view of being able to map verbal responses onto underlying thoughts and beliefs (Smith, 1996a).

Discussions have taken place as to whether IPA is actually required as another method of qualitative inquiry; bearing in mind it’s similarities with grounded theory and the established critical literature associated with grounded theory. Willig (2001) suggests two reasons for the development of IPA. First, grounded theory was devised to study social processes and therefore is argued to be better applied to address sociological questions. In contrast, IPA has been specifically developed for psychological research and gaining an insight into the personal experience of the individual. Second, grounded theory has overtime developed many different versions. Researchers must now make difficult decisions regarding which version of grounded theory is most suitable for their research question. In contrast, IPA is a new and developing approach implying researchers are not drawn into such theoretical and controversial debates, instead enjoying the freedom to be more creative with the approach (Willig, 2001).

**Why Interpretative phenomenological analysis**

IPA was used to analyse data within the current study, as it is a method devised specifically for use with psychological research. It allows a detailed exploration of the participant’s view of the topic under investigation to be established, aiming ‘to explore the participant’s experiences, cognitions and meaning-making’ (Coyle & Rafalin, 2000, p.27), uncovering as far as possible an ‘insider’s perspective’ (Conrad, 1987) of the issue being studied. However IPA acknowledges that this process is ‘dynamic’ (Smith, 1996a), recognising that the qualitative analysis is the result of ‘an interaction between the participants’ personal accounts and the researcher’s interpretative framework’ (Coyle & Rafalin, 2000, p.27). This open acknowledgement of the interaction and influence of the researchers own values, beliefs and assumptions on the analytic process is a key strength of IPA.
The Sample

Sampling method

The very nature of qualitative research is to reflect diversity within a given population, rather than to seek generalisability and representativeness of the population as a whole (Barbour, 2001). Due to the small sample sizes used within qualitative research ‘it makes little sense to think in terms of random or representative sampling’ (Chapman & Smith, 2002, p.127). Instead IPA implements purposive sampling, attempting to select a homogenous sample for whom the research question is relevant and who will be able to ‘provide specific instantiations of the psychological experience’ (Osborn & Smith, 1998, p.68) of the phenomenon under investigation.

Criteria for inclusion in the study

Partners of pain patients were approached to be included in the study. To be involved in the study the following inclusion criteria had to be met:

a) The participant must have lived with the person with CLBP for at least six months.

b) The pain patient must have been suffering with CLBP for at least six months.

c) The pain patient must have been referred to a pain management programme.

Ethical approval

Ethical approval was sort and gained from three different bodies. Two NHS Trust Local Research Ethics Committees and from the University Advisory Committee on Ethics. See appendices, 1, 2 and 3 for copies of letters confirming ethical approval.

Recruitment of participants

The participants were recruited via a number of methods, depending on the stage the pain patient was at in the pain management programme. Partners of pain patients who had completed the pain management programme and were part of the patient support group were recruited via a letter. These letters were sent via the patient to ensure their support and cooperation in including their partner in the study (See appendix 4). If patients were in agreement, they were asked to give their partner a further letter of invitation, an information sheet outlining the study and an acceptance form. (See
appendices 5, 6, 7.) Fifty-one partners were approached using this method of recruitment and nine recruited.

Pain patients who were still completing the pain management programme during the recruitment phase, were asked face to face if they would pass the information to their partners. Thirty-seven partners were approached in this way with no up-take. A poster was then put up outlining the study. If pain patients expressed an interest they asked for further information to give to their partners. Approximately 50 partners were made aware of the study in this way with one recruited. Finally, a poster was placed in the waiting room, aiming to recruit partners of pain patients that had not yet completed the pain management programme but were at the assessment stage. Approximately 30 partners were made aware of the study using this method with one recruited.

Approximately, 168 pain patients were approached and asked if they agreed to pass the information to their partners. This resulted in 11 participants (partners of pain patients) being recruited for the study, eight from one pain management centre and three from another centre. Initially, the aim was to recruit all participants from one centre. However, due to difficulties in gaining the required participants another centre was involved at a later stage. The difficulties in recruiting the sample and implications this may have for the study's findings are addressed in the discussion.

**Participant Group**

**Demographic data**

The sample consisted of 11 participants, five females and six males aged between 32 and 71 years (mean age 57 years, s.d = 11.08). In terms of their ethnic origin, nine (82%) were White UK, one (9%) Anglo Indian and one (9%) Black Caribbean. With regard to occupational status two (18%) were self-employed, one (9%) worked part-time, three (27%) worked full-time, one (9%) worked at home (household chores) and four (36%) were retired. Ten participants were married (91%) and one (9%) cohabiting. In terms of their partners' pain, all participants reported the pain patient suffered with CLBP. Ten (91%) reported their partner also suffered with other types of chronic pain as well, for example, upper back pain, shoulder pain, leg pain, abdominal pain and headaches. With regard to the length of time the pain patient had suffered with CLBP, participants reported between two and 40 years (mean number of years 16 years, s.d = 11.23).
Data Collection

Semi-structured interview

Semi-structured interviews are used within research to ‘gain a detailed picture of a respondents’ belief about or perceptions or accounts of, a particular topic’ (Smith, 1995, p.11). They are comprised of a set of questions on an interview schedule that acts as a guide rather than dictating topics to be covered. This allows more flexibility than structured interviews, giving the researcher the opportunity to follow up particularly interesting points, gaining a fuller picture and understanding of the participants experience.

This form of interviewing does have drawbacks. It reduces the control the researcher has over the interview situation, suffers from possible interviewer effects, lacks generalisability due to small samples, is both labour and time intensive and is harder to analyse in comparison to structured interviews. However, in light of the advantages of the semi-structured interview and the predominant use of semi-structured interviews in research employing IPA (Smith, 1995), the researcher decided to implement the semi-structured interview as the method of data collection for the current study.

Constructing the interview schedule

In constructing the interview a number of resources available to the researcher were fully utilised. Initially, the researcher met and spoke informally with two experts in chronic pain. The aim of the meetings was to allow the experts to highlight important issues that they believed might be pertinent for partners of pain patients. Their information and knowledge was based upon issues that were sometimes raised in the relatives’ session of the pain management programme, where both the patient and their partner attended the session. As suggested by Smith (1995) the researcher also consulted previous literature that had considered the experiences of partners living with patients of other chronic illnesses (Anderson & Bury, 1988), to identify key areas and devise questions for the interview schedule. Once devised the interview schedule was discussed and checked with the two experts and alterations made based on their constructive comments.

The main areas which the final interview schedule covered were 1) gaining a description of the participant’s perception and understanding of their experience 2)
examining how participants believed their lives have changed and how they cope with the changes 3) ascertaining participants understanding and assessment of the pain situation and 4) exploring participants reactions to their partners pain. See appendix 8, for interview schedule.

**Conducting the interview**

The interview process followed interview guidelines outlined by King (1996) and Elmes, Kantowitz & Roediger (1995) ensuring ethical considerations of informed consent, no deception, right to withdraw, debriefing and confidentiality were adhered. Written consent was obtained from the participants (See appendices 9 and 10). Participants were asked to complete a short booklet containing demographic questions (See appendix 11). Participants were not paid for their involvement in the study.

Eleven partners of pain patients were interviewed. The interviews were conducted either in an office at the pain management centre or at the participants home depending on which setting the participant preferred. In all cases the researcher tried to ensure participants felt at ease, making every effort to promote a relaxed environment with no interruptions. The interviews lasted approximately one hour.

All 11 interviews were audio taped and transcribed verbatim. As the focus of IPA is on the content of the interview only, the non-linguistic features of the speech were not transcribed (Willig, 2001). The researcher transcribed all the interviews and checked the transcripts for accuracy prior to analysis. The verbatim transcripts served as the data for the analysis. See appendix 12, for an example of a transcript. This transcript has been randomly selected. Copies of all transcripts are available on request from the author.

**Analytic Process**

IPA (Smith, 1996a; Smith, Jarman & Osborn, 1999; Willig, 2001) was used to analyse the 11 verbatim transcripts. For qualitative research to be considered ‘good’ the process of analysis should be transparent (Smith, 1996a). In line with the notion of transparency the analytic procedure implemented in the current study is outlined below.
The first step involved taking a transcript and considering it in detail. The researcher chose a transcript from an interview with a participant who had seemed at ease and very capable at putting their thoughts and feelings into a verbal account. The transcript was read through a number of times and notes were made on the transcript relating to key phrases and processes. Emerging themes were also noted on the transcript. The themes referred to keywords that ‘captured the essential quality of the findings in the text’ (Smith, et al., 1999, p.221). The emerging themes were then listed on a separate sheet of paper and connections between the themes considered. Themes that were considered to be similar were combined, reducing the number of overall themes. Care was however taken to ensure the emerging themes were both consistent with and illustrated by the data. At this stage a list of master themes started to emerge. All master themes were represented in the verbatim transcript. Themes which no longer seemed to fit or lacked evidence within the data were at this time dropped.

As the analysis continued other transcripts were read and further examples of the identified themes were highlighted and illustrated within these transcripts. However, the researcher remained mindful of the possibility of new themes being identified from the subsequent transcripts. Any new themes that did emerge at this stage were added to the list of master themes. Previous transcripts were then re-read and checked for examples of any new themes that had emerged. Finally, all themes were checked to ensure they were illustrated in the data. As suggested by Coyle and Rafalin (2000) the themes were then ordered in a manner that allowed a logical and coherent research narrative.

While every effort was made to ensure themes and master themes developed from the analytic process, it was not possible to avoid the influence of the interview schedule itself on the analysis (Coyle & Rafalin, 2000). Therefore, some of the themes reflect the general content of the interview schedule. It is also recognised the analysis process involved a certain ‘degree of subjectivity as it is shaped by the researchers interpretative framework’ (Coyle & Rafalin, 2000, p.28).

**Researcher’s Interpretative Framework**

As research is a ‘dynamic process’ (Smith, 1996a) the interpretative framework the researcher brings to the analysis will have an effect on the overall research process. Accordingly, it is imperative to note and make explicit this interpretative framework.
The researcher had personal experience of working at a pain management centre for six months, participating in one of the eight-week pain management courses. During the course the researcher had observed the relatives’ session and listened to five couples having a limited discussion regarding their personal lives. This took place after the interview schedule had been constructed but before any of the interviews with partners had been completed. Similarly, observing the patients in the other seven sessions, occurred before the interviews were conducted. The researcher was aware having access to patients and partners in this way affected her knowledge and understanding of the issues faced by partners of pain patients and also influenced her belief system. The researcher was aware they believed it would be difficult to live with someone with CLBP, as it would interfere with many aspects of a partner’s life. It is acknowledged these factors would have influenced the researcher’s interpretative framework.

**Evaluative Criteria**

Acknowledging the subjective nature of the analysis and the influence of the researcher’s interpretative framework on the generation of data and analysis implies that traditional criteria devised for evaluating the quality of quantitative studies are not appropriate (Elliott, Fischer & Rennie, 1999; Henwood & Pidgeon, 1992). However, the need for criteria to evaluate qualitative research has been regarded as invaluable in reassuring traditional quantitative researchers of the methodologically rigor of qualitative studies and also in legitimising qualitative research (Elliott, et al., 1999). A number of alternative evaluative criteria specifically for qualitative research have been suggested (Barbour, 2001; Elliott, et al., 1999; Smith, 1996b). Although, a number of suggested criteria have been presented no firm criteria for the evaluation of qualitative research has been agreed by researchers within the field of qualitative research (Smith, 1996b).

For the purpose of this study the standards and guidelines outlined by Elliott, et al., (1999) were applied to address issues of reliability and validity.

**Owning one’s own perspective**

The researcher made explicit her interpretative framework and belief system and the impact this might have on her understanding of the data and the interpretations being made.
Situation the sample
Basic descriptive information about the participants and their life circumstances is presented to allow the reader to assess the applicability of the findings.

Grounding in examples
Interpretations are illustrated by and grounded in examples from the raw data, allowing readers to ‘interrogate the interpretation’ (Smith, 1996b, p.192) being made and ‘assess the persuasiveness of the analysis for themselves.’ (Coyle & Rafalin, 2000, p. 28).

Proving credibility checks
To provide a credibility check one transcript was taken and looked at independently by five colleagues familiar with IPA. This led to a group discussion of emerging themes. This allowed the researcher to check the agreement of themes before moving onto the analysis of the remaining transcripts. The researcher then met with one of the group members (a research psychologist) to discuss theme categories in detail and to provide a check on the analytic workings of the emerging account. This allowed validation of the researcher’s interpretations of the data and ensured the themes were illustrated by the data. As Osborn and Smith, (1998) suggest, in conducting these checks the aim was ‘not to produce a single definitive reading’ (Osborn & Smith, 1998, p.68) but to allow some verification that the analysis followed a systematic process and was supported by the data. Finally, to ensure creditability, a transparent systematic process of analysis was followed and outlined, to allow readers to understand how the researcher made the interpretations and to allow other researchers to follow the same process (Barbour, 2001).

Coherence
The research is presented following a coherent and consistent structure.

Accomplishing general versus specific research tasks
The findings of the research are limited to this group of partners and demonstrate how they make sense of their personal experiences. The study aims to provide information regarding the experience of living with someone with CLBP. However, it does not claim it’s findings to be generalisable to or representative of other individuals in the same situation.

Resonating with readers
The findings are presented in a manner that allows the reader to clarify and expand their understanding and knowledge in this area.
RESULTS

Overview
Interpretative phenomenological analysis focused on identifying the themes most relevant to gaining an understanding and insight into the specific aims outlined for the current study. These were to examine a) changes in the participant’s lifestyle, b) how they cope with the situation, c) their understanding and assessment of the pain situation and d) how they respond to their partner’s pain. Three superordinate themes emerged through the analysis – Understanding and making sense of the pain, Consequences, and Coping. Within these were further subordinate themes that encapsulated the participants’ experiences and illustrated the development of the superordinate themes through the transcripts.

Summary of Themes
The findings presented illustrate how participants understand and make sense of their partner’s pain. This understanding develops through knowledge of the cause and the kind of pain their partner experiences. Their understanding of the pain appears to influence how they respond to the pain and the impact they believe the pain has had on their partner. The findings also highlight the consequences of living with someone with CLBP. Participants experience a number of restrictions in their social life with their partner and also on their own leisure time. Similarly, participants talk of a restricted sex life and how in some instances this has led to a change in self-identity. Some participants also identify problems with their own health. To cope with these consequences and with the overall pain situation participants draw upon a number of coping skills. These include problem-focused and appraisal-focused coping strategies.

Presentation of themes

1. Understanding and making sense of the pain
Participants were asked how they understood their partner’s pain. They were asked to outline how the pain was caused and to give a description of the pain their partner experienced. They were also asked how they could tell when their partner was experiencing a lot of pain and having a ‘bad’ day and how they reacted when their partner was in pain.
Understanding the cause

Participants were able to give an explanation outlining why their partner’s pain started. Some explanations appeared to be factual, explaining how an external event had resulted in their partner developing pain. In all such cases external events were blamed for causing the pain, none of the participants placed any blame on their partner for being involved in the event. Helen explained:

Well, it was twenty five years ago, ...he had an accident at work, so it was sort of sudden and err he's sort of been suffering ever since really. (Helen)

For others, like Emily there was a sense of not knowing exactly what had caused her partner’s pain. However, she still needed to be able to understand and try and make sense of the situation. She offered a number of possible explanations as if she was trying to think back and search for an understanding of why this had happened to her partner.

It started quite gradually, umm, we don't really know exactly, exactly what caused it, umm, there was a time when my husband slept in my son’s bed because my son wasn’t well and he slept in with me that time and I think the bed wasn’t really suitable and umm, I think it was lifting my son, you know swinging him about like you do with young children. (Emily)

In contrast, others like Mike explained they did not have an understanding of what had caused the pain, but did go on to give an explanation. He did not believe an external event had triggered the pain, but believed that the differences in people’s health made some people like his partner more susceptible to health problems. For Mike the cause of his partner’s pain was due to internal factors.

To be quite honest I wouldn't know what caused it but if you take there are some people like me who are very healthy... and unfortunately some people aren’t and it's just a deteriorating factor of the illnesses they have acquired over the years and this has just got worse and worse. (Mike)

In order to make sense of their partner’s pain and the pain they experienced the group often drew upon their own past experiences of pain, as Helen illustrated:
About ten years ago we put a shed up and umm, I umm did my back in, fortunately it was only temporary, it was only bad for about a week, but I was in absolute agony, I mean I’d never really understood the pain he was in before but you know when I got that I, I just could not move, ...I was crawling on all fours, I was in absolute agony and ever since then I think I appreciate his pain a bit more. (Helen)

**Describing the pain**

Participants were asked to describe their partner’s pain. All participants except Mike and Helen were able to give descriptions of their partner’s pain. Mike again spoke about the differences between people’s health and used this reasoning to explain why he was unable to describe his partner’s pain.

*I would say because you can't feel pain for anyone, you can feel empathy but you just can't put yourself in their position and having said I am blessed with very good health I cannot put myself in that position.* (Mike)

The remaining participants were able to describe their partners’ pain, often giving dramatic and powerful descriptions, using words such as drilling, tearing, pinching, nagging and gnawing. As Emily, Daniel and Phillip described:

*It’s like having an electric drill, dentist drill, screwed into you.* (Emily)

*It is a pretty tearing pain, it’s as though there is a contraction all the time, so someone is crippling her spine or whatever in a particular place and pinching, pinching, pinching and pinching for hours or days on end.* (Daniel)

*I’d have to think of it as a sort of nagging, gnawing, sort of wearing down sort of pain, constantly there in the back of her mind, a gnawing pain I suppose.* (Phillip)

These descriptions indicate how painful the participants believe the pain must be for their partner and highlight a real sense of empathy and understanding. Participants who were unable to give an exact cause of their partner’s pain were often able to give elaborate and vivid descriptions of the pain experienced. This suggests most participants have a good understanding of the pain their partner is experiencing.
In contrast to the others although being able to offer a description of the pain, George and Bob’s descriptions seemed less dramatic, as George explained.

It’s a pain that’s there that moves and she can feel it. (George)

Reactions to the pain – Past and Present

How the participants described their partner’s pain seemed to have some influence on how they reacted when their partner was in pain and the amount and type of support they offered. All the participants were able to identify when their partner was in a lot of pain or having a ‘bad day’. The signs or indicators were mainly associated with their partner’s face, eyes and colour, as George and Sarah described:

It shows in her face, it gets drawn and in her eyes, she kind of frowns and her eyes crumple up. (George)

I can tell by his colour when he is really bad, cos he gets very pale, umm he goes quiet. (Sarah)

For others like Maggie they also relied on changes in their partner’s concentration as a sign they were in pain.

Yeah, I mean, yeah, his quiet and umm doesn’t, he can’t concentrate as much ... I can see in his face and just the way he holds himself, I can tell and you in a room chatting and he slowly drifts off, his voice trails off a little bit, umm and you can see his eyes glaze a little bit. (Maggie)

Participants who gave powerful descriptions of their partner’s pain often responded in a solicitous manner, possibly reinforcing and maintaining their partner’s pain behaviours, by persuading their partner to lie or sit down, stop what they were doing, take painkillers or have a back rub, as Daniel and Sharon described:

Well I try to persuade her to lie down or don’t do whatever it is she’s currently doing whatever that may be, to sit down or to go to bed. (Daniel)
"I'll rub his back for him, I tell him to lie down for a little while, take some painkillers. (Sharon)"

Others like Emily and Sarah seemed to respond in a negative manner, describing how they felt resentment, suspicion, a lack of sympathy and frustration towards their partner when they were in pain. They spoke of resenting having to take on the extra responsibilities that had been placed upon them when their partner was lying on the sofa or watching television. They thought their partner could be doing more and were often suspicious that their partner used their pain to get out of completing activities and chores. This appeared to lead these participants to be unsympathetic towards their partner, and to want to say ‘shut up about your back’. Frustration was experienced at the realisation that the pain wouldn’t go away and both their lives had changed, as Helen explained:

*There are times when it gets you frustrated and you know think, oh why are there things you can't do? (Helen)*

It is interesting to note that it was predominantly the female participants who reacted with these negative responses. This may have implications for how well they are coping with the situation in comparison to the male participants.

In contrast others like Bob, whose description of his wife’s pain lacked intensity and severity, seemed to have a different way of responding. His responses seemed to be more facilitative. He appeared to try and gain a balance between letting his wife participate in activities, encouraging her to keep her independence and yet at the same time ensuring when she does need help that he is there to support her to prevent her feeling like an invalid.

*I try to let her be independent... But I don't let anybody try and feel they're an invalid, if she says ‘Bob, give us a hand here’ yes I'll be there but you feel you can cope fine by me, but the minute you start taking away somebody's independence then they might be thinking what's the point. (Bob)*

It should be noted that this is only one interpretation of how the descriptions given by participants might influence their responses. It may be that participants respond in a...
facilitative or negative manner, as this is the most effective response for the participant and their partner in order to manage the situation. This needs to be followed up with further research.

Many participants talked about a change in their reaction to their partners’ pain as time had progressed, considering themselves to be more sympathetic, as Sarah commented:

*I think I’m a bit more sympathetic now because I didn’t appreciate at the time just how bad he was, umm when he first started I thought, oh God typical man, you know what they’re like, but as the years go on you realise just how bad they are, so I think you get more sympathetic*. (Sarah)

Although, considering herself to be more sympathetic now in comparison to the past, Sarah recognised that it was not possible for her to be sympathetic all the time.

*You can’t be sympathetic all the time you know sometimes you, you feel like saying ‘oh shut up about your back, I’ve got my problems as well you know*. (Sarah)

Others, like Emily, talked about feeling more able to cope with the pain situation and as a result considered themselves to be more supportive:

*I’ve got used to it, I think more at first I used to be really frightened I just wondered what would happen ... now I’ve to get used to it now I know and I think I’ve been a bit more support*. (Emily)

However, although believing she was more familiar with the situation Emily was still struggling with some aspects, being resentful and suspicious of her partner:

*Well I think I’ve had this sort of feeling, because my husband isn’t able to do a lot, he sits around, I get, I get this kind of resentment, I think why should I be doing this. She later went to explain: Sometimes I must admit I do wonder, I mean is he making more of it than it is you know*. (Emily)
Bob and Mike seemed to have contrasting views about how their reactions had changed. Bob felt he initially did too much and changed to allow his partner to do more things for herself. In comparison, Mike felt at first he had left his partner to get on with things and changed to volunteer more help.

_When she just started I was more for her to sort of push my way in to help but now I understand it ... not to take away anything from her, I let her get on with what she can do and that's it._ (Bob)

_I just let her get on with it and tried to be there if she needed anything, so umm I didn't understand it and my motto's always been if you need help ask and I've learnt to volunteer now as I can see the pain in her eyes, so I've learnt to volunteer._ (Mike)

Bob and Mike's experiences illustrate the struggle participants have in finding the right balance, between doing too much and not doing enough to help their partner.

**Understanding effect on partner**

Participants had an understanding and awareness of how the pain had impinged on their partner's life. Understanding that changes had occurred in their partner's activities and that their partners' personality or temperament had altered as a result of being in constant pain. The group understood that their partners could no longer engage in activities they used to enjoy because of their pain, as Sarah explained:

_He can't do what you used to do, he used to absolutely love walking and going to the country and walking in the fields, walk around, hills, anywhere as long as he was walking he was happy, can't do that now you know, umm and just generally sort of you know walking anywhere now even to walk down the end of the road._ (Sarah)

Many participants thought their partner was frustrated with no longer being able to get on with activities they use to enjoy and their partner now having to do these activities instead, as Sharon described:

_He loved his umm, gardening and he, he gets frustrated that he can't do it and that I have to do it._ (Sharon)
This often led participants to experience a sense of frustration for their partner, as Mike explained:

I get frustrated for her knowing that she used to enjoy doing things, but now you can see after about half an hour, fifteen minutes she’s had enough and she has to come back in. (Mike)

Others felt frustrated at not being able to do anything to help, Helen commented:

I think it’s the frustration of not being able to do anything to help ... umm because you know that whatever you do it won’t change anything. (Helen)

There was also an awareness of a loss in playing a specific role and an understanding that this was upsetting for their partner as they were not able to fit the role adequately, as they failed to perform the necessary tasks associated with the role. This led to a sense of knowing their partner was different compared to others, as Sarah and Maggie commented:

He can’t play with them (grandchildren) how he’d like to, I do but umm he can’t keep on all the time ... it does upset him cos he’d like to be like other granddads running about playing football but he can’t. (Sarah)

He’s got two small nieces who he would love to throw around all the time and he feels that he perhaps doesn’t take, he tries as much as he can but there are times when he can’t have such an active role an uncle and godfather, as he would like. (Maggie)

In contrast to the other participants George did not believe his partner was stopped from doing things because of her pain commenting:

No, she’s adapted, most of the things she’s doing now she was doing before, no I don’t think she’s really been stopped from doing anything. (George)

Participants were also aware of changes in their partners’ personality or temperament, noting changes in their mood and self-confidence, and describing them as being more irritable and less outgoing, as Sarah and Helen illustrated:
He always used to be full of fun, laughing and joking but now he’s lost all that sort of twinkle and he gets very irritable. (Sarah)

I think he’s a bit more irritable than he used to be, not so tolerant, umm, he’s just not so outgoing as he used to be, basically he seems to lack confidence, in fact since he’s been at home for the last ten, fifteen years he’s certainly lost a lot of confidence in himself. (Helen)

Again, in contrast to the other participants George did not think his partner had changed much at all and put this down to her having a high pain threshold.

I don’t know if she’s changed terribly much, she’s dealt with and coped well because of her pain threshold. (George)

Summary
In order to make sense of and understand their experience of living with someone with CLBP it appears important for participants to have an explanation of the cause. Some participants have a clear understanding, while others have a number of possible explanations. The majority of explanations are based on external causes. Participants draw on their own pain experiences to help their understanding and compassion towards their partner. Participants also have different ways of describing their partner’s pain and it is tentatively suggested that this may be linked to how they respond to their partner’s pain. However, it is noted that this is only one interpretation and additional research is required to explore this tentative finding further. Participants’ show an understanding and awareness of the effects of the pain on their partners, recognising that their partners can no longer participate in activities they used to enjoy and that they have become more irritable and less outgoing.

2. Consequences
Participants were asked to describe ways in which they thought their partner’s pain had affected themselves. Participants identified a number of areas they thought had been affected as a consequence of their partner’s pain. These areas all focused around changes and restrictions that had been placed on the participant’s lives, comparing life before and after their partner’s pain. The main areas that participants had experienced restrictions were in their social life and leisure, and sex life and identity. Another
consequence for participants was the development of their own health problems. These are discussed in turn below.

2.1 Restrictions

Social life and leisure

With regard to their social life most participants acknowledged some restrictions in the activities they were now able to do with their partner. Restrictions were often due to the length of time their partner could sit for, making it impossible to go to the cinema or theatre and to eat in restaurants. Phillip commented:

*It restricts going to places like the cinema, the nature of the seats in cinemas means that she chooses not to go ... anything that involves sitting for more than a couple of hours is a problem.* (Phillip)

There was also an acknowledgement of the pain restricting social plans and arrangements and having to cancel social engagements at the last minute due to their partner’s pain, as Helen explained:

*Social life, we have had in the past to cancel, umm sort of social engagements if he’s been really bad, normally only things with friends you know, if we’re going out to dinner or whatever, if we’re just going out things like that.* (Helen)

Other participants identified restrictions around being spontaneous and being unable to plan future social events and activities like they used to, due to uncertainty regarding their partner’s pain on a day-to-day basis or knowing how long a flare up might last, Sarah commented:

*You can’t say oh I think we’ll go so and so today or we’ll go to tomorrow because you don’t know how he’s going to be tomorrow. I mean one day he can be fine, today he’s not to bad, tomorrow he can be really bad, so you just can’t plan like you used to.* (Sarah)

Others identified the need for careful planning of activities and events if their partner was to be involved, Chris noted:
The other difficulty we have of course is having to make a lot of special arrangements... it’s a lot more effort to think, well can we take the car and park it, ... for example, a few weeks ago we wanted to go to a concert and we couldn’t get information over the telephone about disabled parking spaces, ... so I said look I’ll go and have a look to see what disabled parking spaces were available, before we went there. (Chris)

As well as being restricted in the types of activities they could do with their partners, participants were also aware that there would be times when they would have to do things alone as their partner’s pain would be too severe, as Maggie described:

*I think we have to plan sort of weekends away more carefully and things always have to have, have an open mind that you may not do it, you know there’s a family gathering, a wedding or things like that and you have to have it in the back of your mind that it may not be a possibility for us both to go.* (Maggie)

The group seemed to accept the need to do things on their own and emphasised the importance of maintaining and developing their own interests and not allowing their partners pain to become the main focus of their life, as Sharon described:

*Well, I have to get on with my life in a way, I can’t, I feel that I can’t run my life completely round him, umm, umm, I would do nothing, my life would be washing, cooking, cleaning, shopping, gardening, you know, umm, watching television and I’m sorry but that’s just plain boring to me.* (Sharon)

There was also an understanding that although maintaining their own interests was important there would be times when arrangements may need to be altered in light of their partner and the pain situation. Arrangements were often altered to keep the peace or to prevent the participant feeling guilty. Arrangements were then re-arranged for a time when their partner would be occupied and this was regarded as compensating for missing out before, as Bob explained:

*If I’m going out and she say’s it’s alright, the way she comes over it makes me feel as if she doesn’t want me to go, she doesn’t want to be here by herself and it makes me feel guilty for leaving her because I know I’ll be gone four, five, six hours and she’ll be here, so for peace, I’ll say oh I can’t be bothered I can always go another time.*
she's going to spend the day with one of the kids then I'll say right I can go out for the day and they'll bring her round in the evening, so it compensates for not going the day before. (Bob)

In contrast to the other participants George did not consider his social life to have been restricted at all by his partner's pain, he still thought he was able to socialise with his partner in the same way as before.

No we still do the things we used to do. We weren't very outgoing or going to lots of parties, things like that it's not really our scene, what we did was go round to socialise with friends and we still do that. (George)

Along with restrictions in engaging in social activities with their partner, participants also indicated restrictions in their own free time and time for relaxation. Due to their partners' pain and having to take on increased responsibilities at home they felt they had little time for themselves and doing activities they used to enjoy. Male participants described how they were taking on more of the household responsibilities as a direct result of their partners' pain. As illustrated by Chris:

I've had to do a lot more things, like the housework, I do the vacuuming, cleaning all that sort of thing and umm, changing the beds and umm, oh there's washing and all that sort of thing I'm doing a lot more. (Chris)

In contrast, the female participants were already fulfilling the majority of the household responsibilities but did have to take on more of a role in outdoor activities and decorating, as Sharon explained:

I'm having to do a lot more in the garden now which he used to do, he always did the garden and I'm not a gardener really, you know I find I'm doing all the work. The other thing is decorating he used to do it but now I do it or have to get someone else in to help. (Sharon)

Participants also identified added responsibilities due to their partner's physical dependence on them. Partners often needed help and assistance in performing their
personal activities such as getting out of bed, bathing and dressing and participants perceived this as an added pressure, as Daniel described:

*She needs help getting in and out of bed, possibly standing, err possibly she can getting out of the bath, or even the shower ... that's a bit stressful, trying to support a nine stone person, umm, making sure I don't drop her umm so that's a bit stressful.* (Daniel)

Daniel also seems to have concerns and worries surrounding his own abilities to deal with the situation and give his wife the care she requires which adds to his stress and difficulty in coping.

The extra chores and responsibilities around the home and in giving physical care to their partner leads to a sense of always being on the go and of having to fit more into a day, as Bob explained:

*The biggest thing that has changed for me is that I'm always on the go, always doing something, no time to sit down and say I'm getting bored.* (Bob)

For Mike, Emily and Chris there was a realisation of not being able to do the activities they used to do, due to their added roles and responsibilities, as Mike and Emily explained:

*Everyday life has changed where I could sit back and watch a television programme or read a golf magazine or something I've got to prepare the veg or err like make the beds or help her with the washing and so on and so forth.* (Mike)

*I don't feel able to go and do something that I would like to do, I mean it's even like going round the shops, something that I used to do, spend three or four hours walking round, going in all the shops I liked and now I can't get the time to do it.* (Emily)

Sex life and identity

Many of the female participants talked about the restrictions their partner's pain had placed on their sex life. For these women their sexual relationship had been an important part of their relationship, a part they had previously enjoyed and described
as a good aspect of the relationship. The loss of sexual relations with their partner had initially been considered a great loss, causing the women to feel depressed and neglected, as Sharon and Emily commented:

Well, the physical side of life is non-existent, because he can't cope with it, which ok, I mean, I've accepted but I was a bit depressed about that to begin with, I mean we still love each other, he's a dear man but it's umm it has changed from the point of view that you know we haven't got the physical side of our relationship. (Sharon)

He couldn't show the same affection to me, we couldn't sort of have cuddles because he was in pain and all the sort of usual things you do and err, I mean, I have felt really neglected. (Emily)

However, over time the women explained how they came to accept the restrictions placed on their sex life. Being able to accept the change in the nature of their relationship, overcoming their sadness and sense of loss and learning to perceive sexual relations as only one aspect of their relationship, as Sharon explained:

I was depressed about it to begin with but umm, I've learnt to live with it, you know it's sad in a way, it's the one thing I think is a shame, but there you are, it doesn't make me love him any less, it's just one aspect of a relationship. (Sharon)

Sarah commented on wishing for the intimate times again, but at the same time acknowledged sex was only one aspect of a relationship and described other ways that her partner showed his affection. She appeared to examine her relationship as a whole weighing up the restriction of her partner's pain on their sex life and comparing this to the benefit, of still having him around. She was also aware that her husband tried to compensate for the lack of intimacy, showing his affection to her in other ways. However, she was still left wanting the physical side but was resigned to the fact she was unable to have everything she wanted in her relationship.

Your sex life's ruined, I can tell you, you don't have any of that, well I mean that sort of thing's gone and you do miss that sort of side of things and the intimacy, you know, to have a nice cuddle, but umm, you know, you wish that you could have those times back, ... but obviously you can't that's it but I still love him there's more to a
relationship than just sex as long as I know he's around, I've got him that's all that matters, he's good to me, he shows affection with chocolates and flowers I think, but obviously it's nice to have the physical side where you get a cuddle, but you can't have everything. (Sarah)

Although emphasising that they had accepted the change in their sexual relationship and no longer felt depressed or neglected, the lack of physical relationship seemed to have further implications for some of the female participants. For Emily and Sarah both indicated a change in their sense of identity. They perceived themselves to have shifted from being a wife to that of carer, as Emily and Sarah commented:

*I mean really my role has altered from being a wife to more of a carer making sure he's alright and running round doing everything and getting everything he needs and it's changed to being a carer. (Emily)*

*I'm more of a carer now, cos you don't have a sort of close relationship like we had before. (Sarah)*

It seems for Sarah and maybe for Emily the change in identity from wife to carer is connected to the loss of a sexual relationship with their partner. The sexual relationship that has

*... definitely lessened off and it's just, I mean now it's gone to absolutely, it doesn't exist any more, it's disappeared (Emily) has led to a change in self-perception and identity in these two women.*

In contrast, only one male participant, Bob indicated a restriction in his sexual relationship with his partner due to her pain. Similarly, he also expressed acceptance of this and viewed sex as being only one part of a relationship.

*The only changes we've got are when it comes onto sexual relationships with your wife, that is the only changes but I can live with that, that's not love is it, that's just a feeling two people get for each other. (Bob)*
Although, the restricted sexual relationship appears to be an area that has been a major consequence for female participants, they may have been more likely to discuss this issue with the female researcher than the male participants. The effect of the researcher on the research will be addressed in the discussion.

2.2 Development of own health problems

With the increased responsibilities and reduced time for relaxation participants talked about feeling more tired. Emily, Sharon, Sarah and Daniel, commented that they do get more tired. With the exception of Emily and Maggie participants did not report that their health had been significantly affected. However, Emily and Maggie indicated they had experienced some serious health problems, which they believed were a direct result of their partners' pain, including depression for which they had been prescribed antidepressants, anxiety, and irritable bowel syndrome, as Maggie explained:

*It's affected my health I get irritable bowel and I'm sure part of that is to do with that (partner's pain) and I've had a period of depression where I had to go on antidepressants umm part of that was not knowing what to do (about his pain).*

(Maggie)

For Emily the depression and anxiety had initially been triggered by the loss of sexual intimacy within the relationship but had persisted due to her fear and uncertainty as to what might happen and what she wants in the future:

*I think it does stem from fear of the future of what might happen, although I feel at the moment I don't want to live with him and I'd rather be out of this situation in some ways, I'd also be scared stiff to lose him.* (Emily)

Summary

Participants identified a number of consequences of living with someone with CLBP. One of the main areas affected is the participant's social life and leisure time with a number of restrictions placed on activities with and without their partner. Participants accept the need to do things on their own and emphasise the importance of maintaining their own interests, rather than being stuck in a life of pain. However, at the same time they recognise the need to be flexible regarding their own
arrangements, otherwise they are left feeling uncomfortable and guilty in being able to have a life of their own. Restrictions are also placed on the participant’s own leisure and free time due to the extra chores taken on and the added responsibility in taking care of their partner’s physical needs. Another, restriction identified was with regard to their sexual relationship. This was particularly relevant for the female participants who talked of feeling depressed and neglected at first, but had now accepted the absence of sex, explaining that sex was only one aspect of their relationship. However, the restricted sexual relationship had influenced two of the female participants self-identity, from wife to carer. The final consequence identified considered the development of the participants own health problems. The majority of the group commented that they were more tired, but in general their own health had not be significantly affected. Two female participants indicated their own health had been seriously affected.

3. Coping
Participants were asked to explain how they coped with the restrictions that been placed on their life as a result of their partners’ pain and how they coped in general living with someone suffering with CLBP. A number of coping strategies were elicited. Strategies were either problem-focused (Seeking external support, Gaining information and Communication), or appraisal-focused (Reciprocity, Perception of partner as coping, and Acceptance). Some of the coping strategies were more widely drawn upon than others, although all strategies were implemented by at least two of the participants.

3.1. Problem-focused coping

Seeking external support
The group often relied on external support to help them cope. Support was received from family, friends, work colleagues and religion. The support from family and friends seemed to be at more of a practical than emotional level as illustrated by Mike:

*We have family who help, our daughters and grandchildren, like if they are going out shopping they might phone up and say is there anything you want from the shops, they give practical help which makes it easier.* (Mike)
Work colleagues were especially important for Sarah, who used them as a resource to talk over her difficulties.

I've got companionship there (at work) people to talk to and we are quite close in the office and we really get on well, it's nice to have somebody to talk to. (Sarah)

For Bob, Sharon and George religion and the church was a source of support and perceived to give strength to cope, as Bob explained:

But believe you me, thank the lord for giving me the strength to cope, you know. (Bob)

Gaining information
To increase understanding of their partners' pain and to help them cope with the situation participants thought it was important for them to be included in medical consultations and have access to information, as George explained:

I think it is important and partners should always be included and given some information as it helps you understand. (George)

The information was sought from either the medical profession or from participants using their own resources, as Mike explained:

Talking to friends, some friends that are nurses and discussing pain, umm and it's a greater understanding, reading about it, watching programmes on television and seeing how they cope and come to terms, umm, I suppose I've just gone into that routine myself, I've applied it, accepted it. (Mike)

Although participants often wanted information and perceived this as important most of the participants believed they had not been given any information by the medical profession, as Sharon explained:

I can understand it because I've been in the profession, but umm, no I don't think I've been given information just looking back I don't think I've ever been spoken to about it, about his pain. (Sharon)
To gain an understanding participants relied on reading the information that had been
given to their partner and on their partner sharing this with them, as Helen and Emily explained:

_I don’t think I have been given any information, I’ve just read all the stuff that his
been given, it’s always been given to him and then I tend to read it._ (Helen)

_Umm, to be honest I don’t think I’ve had a lot of information ... I’ve always read
anything he’s had and umm if he’s had any treatment he tells me about it._ (Emily)

Mike and Sharon both commented on the session at the pain management programme
that they had been invited to attend with their partner, finding this session useful.
Sharon thought this should be taken further, with the partners of pain patients being
offered a session on their own.

_I mean they’re very good here at the pain management programme ... I mean whether
they should have a session just for the partners could be quite a good idea, to say to
them look what are your problems and umm perhaps give them an explanation of how
pain works and ways that they can umm, the different ways they help to treat pain._
(Sharon)

Communication
The female participants recognised the benefit of good communication and how this
could help themselves and their partner cope, as Maggie explained:

_I suppose really it’s probably communicating as well about his problem ... and he
realises a bit more the benefits of it._ (Maggie)

Although recognising how important good communication was and how this could
help them to cope with the situation some female participants felt they were unable to
communicate their true feelings to their partner, as they were worried they would
upset them, as Sharon described:

_My husband is someone who can’t take a lot of criticism or negative remarks, he’s a
lovely man, but umm, he’s easily you know, oh umm you always blame me for_
everything, if I say anything he doesn’t take it constructively so I tend to keep quite and just not say anything. (Sharon)

Others, like Sarah, Emily and Maggie talked about the difficulties in getting their partners to communicate about their pain and how this had a negative affect on their own mood and ability to cope with the situation, as Sarah described:

I get ratty with him because I say why don’t you know we have a little chat or something you know, I’m getting ratty with you because you’re not doing something but you won’t say why you’re not doing something, it’s like a vicious cycle all the time. (Sarah)

Maggie also talked about the difficulty in getting her partner to understand that she wanted him to communicate with her about his pain:

I find it incredibly difficult because partly because he doesn’t want to talk about it, but it’s trying to get him to talk about things like that, make him understand that I actually want to know, he just assumes people don’t want to know. (Maggie)

Participants were aware of the advantages of communication but in reality this coping strategy was not implemented appropriately. On the one hand participants failed to communicate thoughts and feelings to their partners as they tried to protect their partner from how they really felt about the situation. On the other partners also refused to communicate with the participants. Participants perceived this negatively wanting their partners to tell them how they were feeling, as they thought this would increase their understanding. However, it is suggested that partners may not have communicated such thoughts and feelings as they also wanted to protect the participants from knowing how they were really affected by the situation.

3.2 Appraisal-focused coping

Reciprocity

Bob and Mike both talked about being able to cope with the situation as they considered now being a time to look after their partners as their partners had looked after them in the past.
I'm always been saying if it wasn't for the wife that I've got I wouldn't be where I am today, so I wouldn't knock her, when she was fit she helped a hell of a lot, she worked hard, so I think I should repay her, I don't look at it as favour but you got married for better or for worse, sickness and in health. (Bob)

I was lucky I didn't even have to make a cup of tea, I got a cup of tea in bed and everything I was the envy of my friends to be honest, you don't look at it as paying her back just as a time when I have to do more in the house and I'm quite prepared to do that. (Mike)

Perception of partner as coping
Participants who perceived their partner to be coping well with their pain and having learnt to live with the pain seemed to be coping extremely well themselves. This was definitely seen with George. George did not think his life had undergone any significant changes due to his partners' pain or consider his partner to have experienced any losses or change in her personality due to the pain. Instead he perceived his partner to be coping and not letting the situation get on top of her and this appeared to have a positive effect on him and his ability to cope.

She thinks she should try and get on with it, cope with it and not let it get on top of her. (George)

He later emphasised this point again, commenting:

I mean it's a lot to do with who you are and what effect you let it have on you, if you let it take over you, but not her she's not that sort of person. (George)

Although they did mention some changes in both their own lives and their partners Chris, Phillip and Bob also perceived their partners to be coping well and to have adjusted to the pain situation, noting how this helped them adapt to and cope with the situation, as Phillip explained:

I think she copes extremely well and that helps. (Phillip)
In contrast to the male participants, only one of the female participants perceived her partner to be coping with the pain and to have learned to live with it. Helen explained:

*I think when it first happened, umm, he used to moan a lot about it, but I think he’s accepted it now, much more now, that umm it’s not going to change, it’s not going to get better and he’s learnt to live with it in his self a lot more, he doesn’t complain about it as much now as he used to, and that makes it easier for me. (Helen)*

Emily and Sharon perceived their partners not to be coping with the situation, Sharon commented how her partner tended to dwell on his pain, and Emily described how her partner would go to bed:

*He is in bed so much ...now I just sort of feel he’s more or less permanently in bed. (Emily)*

Emily also described how her partner was bad tempered a lot of the time and this was usually because he couldn’t cope with something, she explained:

*He gets bad tempered now if things aren’t right because he can’t cope with them. (Emily)*

She acknowledged that him being bad tempered made it difficult for her to cope and she was left feeling:

*Kind of screwed up, you know, tense, sometimes I can understand and sometimes I can’t. (Emily)*

Acceptance

A number of participants spoke of accepting the changes in their lives and the increased responsibilities that had occurred due to their partner’s pain. They noted how their acceptance and having adapted to this new way of life, just getting on with things made it easier to cope, as Mike and Sharon explained:

*I just accept it, I don’t think back and feel I could be doing something else and have to do this, I just accept it because it’s my way of life. (Mike)*
I think I've learnt to accept it now and just get on with life. (Sharon)

However there was acknowledgement that further increases in responsibilities, particularly around the house would be increasingly difficult to cope with, as Sharon explained:

Well, I suppose if he gave up doing anything because I couldn't cope with that, at the moment he still does, I mean he will do the washing up and he does still clean the downstairs rooms for me ... but if he stopped doing that and those sort of things, I had to do all the cleaning, I couldn't cope with all the work. (Sharon)

Participants also talked about the implications of a dual role and how this could act as a barrier to coping. Bob, Chris, George and Sharon were all retired and reflected on their situation in light of their retirement and having more time now, noting how much more difficult it was to cope before they retired when they were juggling roles, Bob explained:

Also because of her I used to have a lot of stress going to work I used to do shift work, you know, I would sort of come in at one thirty in the morning, she's asleep and I would have to get up early, make her tea, make the bed, tidy the house, do the hovering, do all the washing and then I might have to start work at one o'clock in the afternoon, by then I started to feel tired and I have gotta go and drive the trains for eight hours and that was affecting me terribly ... it's since I've retired I don't let it worry me. (Bob)

Bob went on to illustrate the flexibility his retirement gave him and how this made coping much easier:

How do I cope, I just do, it's got to be done. It's not to say I've got to do it and then think oh I've got to get ready for work, I've got all day, if I feel oh right I've done the ironing now and I'm suppose to do the washing and I think oh I can't be bothered, I'll leave that for tomorrow it's no problem. (Bob)

Chris compared the situation with his wife now to a time before when he was working and his wife had previously experienced back pain.
She did have an episode of back pain before when I was working and she couldn’t stand and that was very much more difficult for me then, I mean I had to do things at home and then turn round and go to work. (Chris)

In contrast participants who were working described how difficult it was balancing going to work and caring for their partner. Maggie described how she thought her own health problems had developed from her dual role.

When he was in bed a lot and I was having to sort of, I was coming into work late because I was having to help him out of bed ... I was always in a rush, umm, I didn’t want him to do things like go shopping and umm do the cleaning ... I was trying to do to much which is where I think the problem came from. (Maggie)

**Summary**

In order to cope with their situation and the consequences of living with someone with CLBP participants talked about implementing two main types of coping strategies, problem-focused and appraisal-focused coping. Although these strategies helped participants to adapt and cope with their experience a number factors were identified that acted as barriers to coping. These included, further added responsibilities, perception of partner as not coping, having a dual role and being unable to communicate effectively with their partner.

**Concluding Remarks**

Participants who believe few restrictions or changes have occurred in their own or their partner’s lives and consider their partners to be coping well seem to respond in a facilitative manner and appear to have adapted and cope with the pain situation well. This is demonstrated by George’s experience and to a certain extent Bob’s and Mike’s. In contrast, participants who think their relationship and partner have altered dramatically as a result of the pain, consider their partner to be having difficulties coping, perceive themselves to have much added responsibility and to have difficulties communicating with their partner are more likely to react negatively towards their partner and to have difficulties coping with the situation. This is highlighted in particular by Emily and Sarah’s experiences.
DISCUSSION

Overview

The three main themes - Understanding and making sense of the pain, Consequences and Coping - that emerged from the analysis will be presented and discussed. As suggested by Charmaz, (1995) new literature will be introduced to examine where the findings fit with the existing literature. Methodological issues associated with the study will be discussed and the study’s strengths and weaknesses outlined. Finally, clinical implications and directions for future research will be addressed.

Examination of themes in light of existing research

Self-regulatory model of illness behaviour
Leventhal and Cameron (1987) introduced a model of illness behaviour to examine the relationship between an individual’s cognitive representation of their illness and their consequent coping behaviour. The model is based upon problem solving approaches and suggests individuals understand and deal with their illnesses in the same way as they do other problems. First, they interpret and make sense of the situation; second, they cope with the situation, aiming to re-establish normality and third, they appraise how successful their implemented coping strategies have been.

From the current analysis it was clear that the findings could be linked to and presented in a manner that reflects the self-regulatory model. The findings illustrated how partners of pain patients understand and cope with their experience of living with someone with CLBP. Participants tried to make sense of the situation and establish coping strategies to help them deal with the situation more effectively. Although participants did not appear to appraise these coping strategies or evaluate how good they were, they were able to offer examples of situations and events that would make coping with the pain situation more difficult.

Following the model, participants attempted to interpret and make sense of the situation, by identifying and describing their partner’s symptoms and trying to establish the cause. Even when a specific cause was not available, participants suggested a number of explanations, emphasising the importance for participants to
have their own understanding of the cause. Participants often relied on their own previous experiences of pain to aid their understanding. Participants also expressed an understanding of the impact the pain had on their partner’s lifestyle and personality. Finally, the group identified the consequences of living with someone with CLBP. This was mainly in terms of restrictions in specific areas of their lives and the development of their own health problems. In order to cope with the pain situation and the consequences participants implemented various coping strategies.

**Understanding and making sense of the pain**

Rowat and Knafl (1985) found that many partners did not understand and were unable to give a description of their partner’s pain. In contrast, in the current study participants showed some understanding of their partner’s pain and were able to offer a description of the pain. The descriptions of their partner’s pain differed between participants in relation to the intensity and severity. It is suggested that this may influence how participants respond to their partner’s pain.

The role of partners in the maintenance and exacerbation of pain behaviour has been the subject of much research (Payne & Norfleet, 1986; Turk, Flor & Rudy, 1987). Findings have shown that partners’ reactions may have an impact on the development and maintenance of pain and disability in patients (Fordyce, 1976). The findings of the current analysis suggest that participants who give graphic and dramatic descriptions of their partner’s pain often react with either negative or solicitous responses. In contrast, participants who give very limited descriptions seem more likely to respond in a facilitative manner, encouraging their partners to participate in activities and maintain their independence. This may suggest that participants who hold representations of their partner really suffering with pain, may be over empathetic and do everything they can for their partner to relieve the pain. On the other hand, they may feel overwhelmed with the situation, be uncertain as to what to do and as a result be critical or irritated by the situation. These are tentative explanations of why participants respond in different ways and further research is required to establish greater understanding in this area.

**Consequences**

The findings of the current analysis support those of previous studies, suggesting that many areas of partners’ lives change as a result of living with someone suffering with
Both qualitative and quantitative studies have revealed changes in partners’ social lives, sexual activity, physical and emotional health, leisure time and role (Ahern, et al., 1985; Flor, Turk & Scholz, 1987; Kerns & Turk, 1984; Maruta, et al., 1981; Rowat & Knafl, 1985; Schwartz, et al., 1991; Snelling, 1994). The findings suggest participants’ social lives with their partners are often restricted as a result of their partner’s pain. Many participants mentioned the loss of being able to do things together, having to do more things on their own and a loss in being able to plan events and activities together. However, this was heavily influenced by nature of the couple’s social life prior to the CLBP.

Chronic pain often affects the patient’s ability to function sexually, due to pain during or after sexual activity, or reduced sexual function or desire (Schwartz & Slater, 1991). However, even though such difficulties may have significant implications for partners, limited research had been conducted examining the effects on partners. In the current analysis the decline in sexual activity was considered by some female participants as being a great loss and had initially caused them to feel depressed and neglected. In comparison only one male participant mentioned a change in his sexual relationship. However, although all participants acknowledged how difficult the change was for them to accept and cope with initially, they recognised that intercourse was only one aspect of their relationship and over time focused on other areas to gain sexual expression (Renshaw, 2001), for example, talking, buying gifts and emotional closeness. Participants appeared to remodel their relationship (Lyons & Meade, 1995) and perception of sexual expression, in order to adapt to the situation and to enable the relationship to continue to function effectively. However, for two of the female participants this change in and lack of sexual relationship seemed to have triggered a change in self-identity, from that of wife to carer. There appears to be a paucity of research examining how partners’ identity may change as a result of caring for someone with a chronic health condition and is suggested as a further area of research.

In line with the previous literature, participants talked of their increased roles and their extra responsibilities, taking on activities that had been previously completed by their partner (Bruhn, 1977). In turn this influenced their own relaxation and leisure time, with participants complaining of having little time for themselves and being unable to participate in their own hobbies. This led many of the participants to complain of feeling tired. However, in general the participants did not talk of the significant
physical and emotional health difficulties that have been outlined in earlier studies (Ahern, et al., 1985; Feinauer & Steele, 1992; Rowat & Knafl, 1985). This supports the findings of Manne and Zaurta (1990) who also found spouses of individuals with chronic physical conditions not to be significantly distressed or to experience physical illness themselves. The two participants that did describe health problems reported those that have been outlined in previous research, depression, anxiety and irritable bowel syndrome (Ahern, et al., 1985; Feinauer & Steele, 1992; Rowat & Knafl, 1985). Both these participants were female and did not appear to be coping as well in comparison to the rest of the group. The symptoms they experienced could be described as spousal burnout (Ekberg, Griffith & Foxhall, 1986) as they expressed isolation, resentment and a desire to leave the relationship.

Coping

Lazarus and Folkman (1984) define coping as ‘the constantly changing thoughts and behaviours that people use in order to manage stressful situations’ (Lazarus & Folkman, 1984, p.154). Moos and Schaefer (1984) applied crisis theory to examine how individuals cope with the crisis of physical illness. They argued that physical illness can be considered a crisis as it represents a major change in an individuals’ life. For example, change in identity, location, role, social support and in the future. The extent of the illness crisis can be increased by factors such as the unpredictable nature of the illness, information being unclear, ambiguous meanings and limited prior experience.

Although, predominantly, this model has been applied to the individual suffering with the physical illness, certain aspects of the model are reflected in the findings of the current study. Some participants experienced a change in identity, for example, from wife to carer. Most experienced some change in role, for example, taking on increased responsibilities, and some experienced changes in social support, feeling less involved with their own social network and activities and an increased reliance on external social support for practical assistance. The model suggests that difficulties coping with the pain situation may have been exacerbated by the unpredictable nature of the pain, a lack of information given to the participants and the meaning of the pain being ambiguous due to uncertainties about its cause and prognosis and participants’ own limited experiences. In the current study other difficulties that may have exacerbated the situation were also elicited. These included; perceiving partner as not coping,
further added responsibility, having a dual role, and being unable to communicate effectively.

Once confronted with the crisis of physical illness individuals implement a variety of coping strategies to help them adapt to and cope with demands of the physical illness (Sezufa & Kuipers, 1999). In the current study participants were observed to implement a variety of coping strategies.

**Problem-focused coping**

Problem-focused coping involves using strategies that confront the problem, reconstruct it as more manageable and controllable (Moos & Schaefer, 1984). Skills include seeking information, gaining external support (Lazarus & Flokman, 1984) and communication (Cannon & Cavanaugh, 1998). In the current analysis participants often spoke of problem-focused coping strategies but often failed to gain control over the situation via these methods. Many participants identified the need to have information, as this was an important medium for them to gain an understanding of their partner’s pain and to learn how to manage and cope with the situation effectively. However, many participants felt that in reality they were often excluded from medical consultations and not given any information regarding their partner’s pain. This often led to participants feeling excluded and experiencing uncertainty with regard to how to manage and cope with the situation, and in turn to difficulties in coping. To aid coping participants suggested they should be involved in the dissemination of information, given time to talk through and address their own problems associated with the situation and to discuss ways they can help their partners cope with their pain.

It is important to note that all but one of the participants in the current study were partners of pain patients that had completed a pain management programme. Partners were invited to attend one session with the pain patient. During this session information about pain and methods of managing pain were discussed. The accounts of the participants in the current study suggest partners may require further input and may benefit from a session solely for partners. This issue is addressed in more detail below.
With regard to communicating about the pain and pain situation, female participants noted the benefit of good communication as a means of coping. However, in reality this strategy failed to be implemented effectively as participants avoided expressing negative feelings directly to their partner. As Schwartz and Slater (1991) and Flor and Turk (1985) explain, this may have occurred because of underlying guilt and worry surrounding expressing such feelings towards their partner who is already suffering or fears that negative comments would make the pain worse. Coyne and Smith (1991) referred to this as ‘protective buffering’. They noted this might lead to increased distress in the partner implementing the strategy. In other words participants may have increased their own distress and difficulties in coping through trying to protect their partner. This was observed in the current analysis, as female participants trying to protect their partners appeared to be coping less well.

All participants made effective used of external support in helping them to cope. This support came from family, friends, work colleagues and religion. Schaefer, Coyne and Lazarus (1981) suggested social support could be grouped into three categories, tangible assistance (running errands and helping out with gardening or decorating), information and emotional support. From the participants’ accounts it appears family and friends provide more tangible assistance and information and work colleagues and religion provide more emotional support. The amount and type of social support individuals receive has been associated with levels coping (Dunkel-Schetter, Folkman & Lazarus, 1987). This may explain the differences in levels of coping amongst participants in the current study, as some participants appeared to have more support structures in place than others.

**Appraisal-focused coping**

Appraisal-focused coping involves using strategies that allow an understanding of the illness and represents a search for meaning (Moos & Schaefer, 1984). According to Moos and Schaefer skills include acceptance and redefining the situation in a positive and more acceptable way.

Many of the participants talked about being more accepting of the pain situation and expressed acceptance of the changes that had been placed on their lives and the increased responsibilities that had resulted. Acceptance as a coping strategy has been associated with women more than men (Cannon & Cavanaugh, 1998). This was not
supported in the current study, with male and female participants both commenting on implementing the coping strategy. However, some participants noted they would not accept further responsibilities and were aware this would act as a barrier to coping.

Previous studies have shown that how the pain patient adjusts and copes to the pain situation may influence their partner’s ability to cope (Ahern, et al., 1985; Flor, Turk & Scholz, 1987). In the current study the participant’s perception of how well the pain patient was coping seemed to influence his or her own coping. Participants who believed their partner was coping well and was not restricted by their pain considered themselves to be coping well and to describe little change or restrictions. This highlights the influence of the participant’s perception of how their partner is coping on their ability to cope. The pain patient may actually be coping poorly, but if perceived to be coping well by their partner this will strengthen their partner’s ability to cope and vice versa. This finding was also observed in Ben-Zur’s (2001) study, exploring inter-spouses perceptions of coping among breast cancer patients.

Most of the participants spoke of difficulties with their increased responsibilities and a general lack of reciprocity of support and care between themselves and their partners. Some participants indicated that this created problems within their relationship and one participant hinted they might leave the relationship as a result. The lack of reciprocity in relationships did not have the same effect on all participants. It appeared to be less of an issue for male participants. They tended to be coping better and held a view of reciprocity not needing to be immediate, but as covering the life span. They had a long-term sense of balance and believed they had at some time in the past received the same care and support from their partner and this balanced the present situation (Antonvcci and Jackson, 1990; Clark and Reiss, 1998). This may explain why overall the male participants seemed to have adapted to and coped with the pain situation more effectively. This gender difference in view of life-span reciprocity and its influence on partners abilities to cope requires further investigation.

Similarly, participants who seemed to be coping well appeared to have been more successful in remodelling their relationship, making lifestyle adaptations to compensate for their partner’s pain. This supports the earlier findings by Lyons and Meade, (1995). However, although remodelling the relationship may obviously help
both the pain patient and partner cope with the situation, the success and need of remodelling appears to be dependent on the relationship prior to the CLBP and how much interference it now causes. In the current study one participant who coped well with the situation described how he and his partner were able to do much the same activities as before her CLBP. It is suggested that this was because many of the activities they enjoyed doing were home-based or going to friends who understood about her pain. Accordingly, their life continued in much the same way as before, requiring little remodelling. In contrast, participants who had an active social life were more likely to need to remodel their relationship. Therefore, the need to remodel the relationship is not a prerequisite to maintaining a successful relationship in the light of a chronic condition, as Lyons and Meade (1995) seem to suggest, but based on the nature of the relationship prior to the chronic condition.

The findings of the current study are presented as a working model in figure one, (over page) illustrating the partner’s experience of living with someone with CLBP.

**Methodological Issues**

**The study design**

*Limitations of IPA*

Willig (2001) suggests that although IPA is too new to have an established and credible published critical literature there are a few conceptual and practical limitations of this method. Willig notes that IPA relies on participants communicating their experience via language and this implies IPA has two main assumptions. First, that experience can be capture in language and second that the participant has the language to communicate the experience.

In considering the first assumption, Willig suggests that ‘language constructs rather than describes, reality’ (Willig, 2001, p.63). The language used tells us about the way a participant chooses to talk about an experience rather than about the actual experience. As a result, Willig argues IPA can be criticised for the manner in which it conceptualises language and it’s failure to consider the constitutive role of language.

For Willig, the second assumption highlights the importance of participants having the skills to express their thoughts and feelings verbally. In order to gain descriptions of
Figure One: Working model illustrating partner's experiences of living with someone with CLBP

**Understanding and making sense of the pain situation**

- Identify Symptoms
- Describe Symptoms
- Understand Cause – use of own explanations & experiences
- Understand impact on partner – activities & personality

**Responses to pain behaviour**

- Facilitative
- Negative
- Solicitous

**Coping Strategies**

- Problem-focused coping
  - Seeking information
  - Gaining external support
  - Communication
- Appraisal-focused coping
  - Acceptance
  - Perception of partners as coping
  - Reciprocity

**Consequences of pain situation**

- Restrictions
  - Social life with partner
  - Own leisure time
  - Sexual relationship
  - Identity

- Development of own health problems

**Barriers to coping**

- Dual role
- Lack of communication
- Added responsibility
- Perception of partner as not coping
participants' experience, participants must be capable of using language to communicate and describe their experience. Participants who cannot articulate and describe their thoughts and feelings about their experience will be unable to provide the kind of talk required for phenomenological analysis. Willig proposes this has implications for the applicability of IPA, suggesting it is not applicable to all participants, only those who can express and articulate their thoughts and feelings appropriately. With regard to the current study some participants were clearly more able to express themselves with greater ease and articulate expression. In contrast, other participants found this more difficult and at times produced more of an account of their experience rather than an evaluation of their thoughts and feelings. Due to these differences, the participants who were able to express themselves produced transcripts that provided richer data and contributed to the generation of themes to a greater extent.

The sample

Recruitment difficulties

There were difficulties in recruiting participants for this study. Two pain management centres had to be involved and a number of recruitment methods implemented. It is suggested the difficulties may have occurred as pain patients failed to pass on the information to their partners. This may have occurred for a number of reasons. First, pain patients may have felt uncomfortable with their partners talking about them and their pain. Second, pain patients may have considered the pain management centre as being their place of support and did not want their partner to be involved. Third, pain patients may have worried about confidentiality and the members of the pain management team having access to what their partners were saying about them. This may have arisen in spite of the researcher's attempts to stress confidentiality. Fourth, pain patients may have thought their partners already have enough to do and did not want to ask them to participate in the study and burden them further. Finally, partners themselves may have decided they did not want to participate in the study for reasons such as, lack of time, not wanting to talk about their experiences, thinking the study was not important or worrying about the outcome of what they might say regarding their partner.

The difficulty in recruiting partners has implications for future quantitative studies. Approximately 168 partners were approached via pain patients to be involved in the
study, with an up-take of only eleven. This was considered a good number for a qualitative study but would not be appropriate for a quantitative design. This issue of recruitment would need to be addressed if a quantitative study was to be implemented. For example, it may be appropriate to approach partners more directly allowing their consent to be gained independently. The low response rate in the current study may also have been due to the design of the study. More individuals may have been willing to complete postal questionnaires considering this less intrusive and time-consuming than being interviewed. For example, the questionnaires assessing partner’s responses and perceptions of chronic pain developed by Sharp and Nicholas (2000).

Weaknesses
Due to difficulties in recruiting participants all those who agreed to participate were involved in the study. The sample was therefore a convenience sample. It is of interest to note the mean number of years the participant’s partner had suffered with CLBP was 16 years. This is significantly higher than the mean of ten years that is reported by one of the pain management centres involved in the study. These factors may imply a bias within the sample, suggesting these participants may have been coping less well and felt they needed to talk to someone about their experience. However, as suggested by Kurz and Cavanaugh (2001) it is also possible that the participants were actually better adjusted and able to engage in the interview than those who did not participate. Perhaps non-participation reflected coping less well. It is of interest to note that many of the participants were retired and this may again have indicated a bias in the sample, reflecting individuals with more time available.

The sample only comprised partners of pain patients that had attended a pain management programme. Attending a pain management programme suggests the sample comprises partners of pain patients who are coping least well in managing their pain (Flor, Turk & Rudy, 1987). It would be expected that this would have implications for the impact of the pain on partners. Exploring the experiences of partners of pain patients who have not attended a pain management programme may produce very different findings, as would exploring the experiences of partners of pain patients who had suffered with their back pain for a significantly shorter period of time. Therefore the findings of this study may only be clinically relevant for a small portion of those living with a partner suffering with CLBP (Schwartz, et al., 1996). However, the aim of qualitative research is not to produce a generalisable account but
to provide information and findings that would not have been elicited through implementing quantitative methods. It is suggested that such information has been gained from the current analysis.

Strengths
Romano, et al. (1989) highlighted differential gender effects in the distress and dissatisfaction reported by pain couples. They found female spouses experienced greater emotional and relationship dissatisfaction and distress. The current analysis seems to lend further support for this finding. Based on Romano, et al. (1989) and the findings of the current study it is suggested that it is essential to include both male and female partners in the sample to gain a real insight into the experience of living with someone with CLBP. Schwartz, et al. (1996) noted that their reliance on male patients limited the generalisability of their findings to female pain patients and their spouses. The current study including similar numbers of male and female partners’ has allowed differences in male and female partners’ experiences to be discussed.

Schwartz, et al. (1991) suggested that studies that failed to choose one site of pain suffered methodological weaknesses. The focus on one site of pain, in the current study, has allowed the specific experience of living with someone suffering with CLBP to be explored and has overcome a difficulty highlighted in earlier studies (Ahern, et al., 1985; Flor, Kerns & Turk, 1987; Rowat & Knafl, 1985).

The interview
The interview schedule was developed specifically for the study and aimed to elicit insight into partner’s experiences of living with someone with CLBP. Although achieving its aim and providing rich accounts of partners experiences the researcher felt the interview schedule was long with too broad a focus. It is suggested it may have been better to have had a smaller number of questions and to have been more focused, allowing the researcher to have fully explored specific areas of the participants experience.

Some of the interviews were conducted at the participants homes at the request of the participant. In all these instances although the interviews were conducted in private, their partner was at home. The researcher noted that participants involved in interviews conducted at their homes seemed to talk less freely and speak less
negatively, compared to those who were interviewed at the pain management centre. This may have been due to fears of their partner overhearing and feeling uncomfortable with talking about negative aspects of their relationship. On the other hand they may actually have less negative experiences. The explanation for the noted difference in participant reaction according to context remains speculative but may be overcome in future studies by ensuring the interview context is consistent or ensuring partners are not at home when the interview is conducted.

**Impact of the researcher on the interview and research findings**

The researcher explicitly outlined her interpretative framework and belief systems and considered the impact this might have on her understanding of the data and the interpretations being made. The researcher tried to ensure she approached the data without preconceptions but openly acknowledges the analytical account is an interaction between her interpretative framework and the given accounts. This suggests that subjectivity is an influencing factor of the analysis and alternative interpretations of the data are possible. Similarly, the researcher recognises the findings cannot infer cause and effect or make claims about trends or predictions within the general population. The emphasis of the current study was to describe the personal experience of living with someone with CLBP and not to make generalisable predictions.

The researcher is also aware that her gender may have had some influence on the accounts presented by the male and female participants. The current analysis tends to suggest the female participants coped less well with the situation, feeling more negative towards their partner and experienced more restrictions. However, it is also possible that the female participants felt more comfortable and spoke more openly and honestly about their experiences with the female researcher than did the male participants. The researcher’s gender may have had a particular effect on the ease at which male and female participants talked about the difficulties and changes in their sexual relationship with their partner. Thus the perceived differences in coping and experience of the situation amongst male and female participants may have been due to possible interviewer effects rather than actual experience (Breakwell, 1995). The use of questionnaires to measure sensitive topics that might not have been discussed by some participants face-to-face may have overcome this problem (Kurz & Cavanaugh, 2001). Method triangulation, combining interviews and questionnaires
has been suggested as a method of strengthening studies and corroborating and augmenting data collected by each method (Begley, 1996).

**Clinical implications and directions for future research**

1) The findings suggest partners of pain patients may themselves be in need of clinical attention. This supports the earlier recommendation of Schwartz and Slater (1991).

2) Pain management programmes may need to revaluate their involvement with partners. This may involve offering partners a) their own sessions, b) joint sessions with patients and c) their own support group. It is suggested these strategies will help partners to address their specific psychological and practical difficulties.

a) *Own Sessions* – Pain management programmes may be required to run sessions specifically for partners to provide education, in a number of areas. For example, the nature of chronic pain, its course and treatments, the cognitive, emotional and physical affect and impact of pain on themselves and the pain patient, ways in which to manage the situation effectively and positive ways of responding to pain behaviours, rather than reinforcing pain behaviours and disability. These recommendations were also highlighted by Schwartz and Slater (1991). In light of the current findings it is also suggested the programmes should address issues in self-identity, roles and sexuality.

b) *Joint Sessions* – The findings of the current study illustrate partners have difficulties in communicating with their partners about issues relating to the pain. Following Schwartz and Slater (1991) it is again recommended that pain management programmes offer partners and pain patients a joint session, focusing on teaching pain couples how to communicate more effectively around problem issues, specifically focusing on conflict resolution.

c) *Support Group* - The importance of social support outside of the marriage, in the form of support groups to help partners cope, has previously been highlighted by Ravenson and Majerovitz (1991) in examining the effects of rheumatoid arthritis on spouse's psychological well being and coping
skills. It is suggested pain management programmes may be required to facilitate and support partners in the setting up of such groups. The recommendation for the provision of support groups for partners is highlighted in the Government’s National Strategy for Carers (DoH, 1999).

These three strategies may help partners to cope more effectively. This is relevant to pain management programmes, as how partners adapt to and cope with their partners’ pain affects not only their own experiences of the pain situation but also exerts a potential influence on their partners’ coping and psychological adjustment (Manne & Zautra, 1989). It is suggested partners who are more equipped to cope may provide a more supportive home environment, have a greater understanding of the pain situation and how to react to their partners’ pain more effectively. This may in turn be beneficial for pain patients resulting in more effective pain management and outcome.

3) Medical professionals may need to be made aware of the difficulties partners experience and how having access to information helps them to understand and cope with the patient’s pain more effectively. This may be problematic with regard to patient confidentiality but having leaflets in pain clinics that have been written for carers may be a way in which to address this. Similarly, patients should be encouraged to share the information they receive from pain management programmes with their partners. This recommendation for access to wider and better sources of information for partners is emphasised in the Government’s National Strategy for Carers (DoH, 1999).

4) Prior to further involvement of partners in pain management programmes research needs to explore the experiences of partner’s of pain patients who have more recently started experiencing CLBP. It is hypothesised that the needs of this group of partners would be different, with more of a focus on a need to understand and make sense of the situation, than on how to manage the consequences and develop coping strategies.

5) Future research could also examine the experiences and role of children living with parents suffering with chronic pain. The Government has identified young carers as a disadvantaged and vulnerable group, highlighting the difficulties they may experience due to the responsibilities and expectations placed upon them (DoH, 1999). The report *Something to Think About* (Social
Services, 1995) revealed some serious disadvantages experienced by young carers. Studies that have examined the effects of parental chronic pain on children, have considered the effect on children's illness and pain behaviour and risk factors for maladjustment (Chaturvedi & Kanakalatha, 1988; Chun, Turner & Romano, 1993; Jamison & Walker, 1992; Ranjan, Thomas, Mogilevsky & Cook, 1994). As yet no study has examined children's perspectives of living with parents suffering with chronic pain utilising qualitative methods. It is suggested such a study may provide an in-depth understanding of the child's experience.
REFERENCES


Appendix One

Letter of ethical approval
Ms. C. Elphick

Dear Ms. Elphick,

re: The personal experiences of significant others living with people suffering with chronic lower back pain. An Interpretative Phenomenological Analysis

Thank you for your very helpful letter and enclosures of 25 May 2001. I am now happy to give full approval to this study on behalf of the Committee and wish you the best of luck with it.

LREC approval is given on the understanding that:

i) the study is commenced within the next 12 months. Should the start of the study be delayed beyond this time, a re-application to the Committee will be required.

ii) any change or amendment to the protocol will be reported to the Committee.

iii) the Committee should be sent one copy of any publication arising from your study, or a brief report after completion if there is to be no publication.

Yours sincerely,

[Signature]

Dr
Chairman
Local Research Ethics Committee
Appendix Two

Letter of ethical approval
12th March 2002

Miss Claire Elphick
Trainee Clinical Psychologist
Department of Psychology
University of Surrey
Guildford
Surrey, GU2 7XH

Dear Miss Elphick

Re: LREC NO. 02/02:
The personal experiences of significant others living with people suffering with chronic lower back pain. An interpretative phenomenological analysis

Thank you for your recent letter and revised participant information sheet relating to the above study. Your application, including the subject background information and consent form, can now be approved. Permission is granted on the understanding that:

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

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

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

iv) A brief report will be submitted one year after commencement, thereafter annually, and after completion of the study.

v) Approval is given for research to start within 12 months of the date of application. If the start is delayed beyond this time, applicants are required to consult the Chairman of the Committee.

vi) You are required to obtain separate approval for your project from your host body (e.g. Trust, PCG).

Good luck.

Yours sincerely

Chair
Local Research Ethics Committee
Appendix Three

Letter of ethical approval
31 July 2001

Ms Claire Elphick
Trainee Clinical Psychologist
Psych D Clinical Psychology
Department of Psychology
University of Surrey

Dear Ms Elphick

Re: The personal experiences of partners living with people suffering with chronic lower back pain. An interpretative phenomenological analysis
ACE/2001/59/Psych) – FAST TRACK

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

This letter of approval relates only to the study specified in your research protocol (ACE/2001/59/Psych) - Fast Track The Committee should be notified of any changes to the proposal, any adverse reactions, and if the study is terminated earlier than expected, with reasons

Date of approval by the Advisory Committee on Ethics: 31 July 2001
Date of expiry of approval by the Advisory Committee on Ethics: 30 July 2006

Please inform me when the research has been completed.

Yours sincerely

[Signature]

Secretary, University Advisory Committee on Ethics

cc:
Appendix Four

Letter of invitation to pain patients
Dear Sir/ Madam

Re: The personal experiences of partners living with people suffering with chronic lower back pain: An interpretative Phenomenological Analysis.

I am carrying out a study looking at the experiences of partners of chronic lower back pain patients and I am currently looking for partners to participate in the research. If your partner participated in the study they would be interviewed for about an hour about their experiences.

The research and study are separate from the pain management programme. The pain management team will not have access to the information given by your partner. The interview with your partner will be totally confidential. In writing up the interview their name will be replaced by a fictitious name and I am not allowed to reveal their true identity.

The study is important as the results may indicate partners of pain patients also require formal support. The results would help in the planning and development of such services.

If you are in agreement for your partner to participate in the research and talk to me about their experience of living with someone with chronic lower back pain, please give them the attached letter, information sheet and acceptance form. If you would like to discuss the study with one of the clinical team before passing on the information to your partner, please do not hesitate to contact the team.

Yours sincerely

Claire Elphick
Trainee Clinical Psychologist
Appendix Five

Letter of invitation to partners of pain patients
Dear Sir/ Madam

Re: The personal experiences of partners living with people suffering with chronic lower back pain: An interpretative Phenomenological Analysis.

I am carrying out a study looking at the experiences of partners of chronic lower back pain patients and I am currently looking for partners to agree to be interviewed. I would be extremely grateful if you would agree to participate.

I have enclosed a copy of the information sheet explaining the study and what is involved. I am happy to visit you at home to conduct the interview or for you to come to the hospital. The interview will last for about an hour.

The study is important as the results may have implications for the future planning of pain management programmes. The results may for example, indicate support and advice specifically for partners of chronic pain patients is required, as many partners share similar experiences. The study’s findings would be used in the planning and development of sessions for partners of chronic lower back pain patients. However, to gain detailed and meaningful results I need to interview as many people as possible.

If you are prepared to participate in the study, I would be grateful if you would complete the attached acceptance form and return it in the envelope provided. Please ensure you have indicated the best time for me to contact you, so I can telephone to discuss the study further and arrange the interview.

Yours sincerely

Claire Elphick
Trainee Clinical Psychologist
Appendix Six

Participant information sheet
Introduction
You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. A contact name and address is printed at the end so you can ask questions if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part in the study. Thank you for reading this.

Title of the Research
The personal experiences of partners living with people suffering with chronic lower back pain. An Interpretative Phenomenological Analysis.

Why do this research?
I hope this research will help psychologists and other professionals working with patients suffering with chronic lower back pain in understanding the wider implications of chronic lower back pain and the impact it has on the lives of those living with their patients. This will help us to plan and provide better services for patients and their families. I also hope those who take part in the research will find it helpful to talk about their experiences.

What does the research aim to do?
The aim of this research is to explore the experiences of partners of chronic pain patients, considering their coping strategies, and their underlying beliefs and cognitions surrounding their partner’s pain.

What will the research involve?
You will be asked to take part in an informal interview about your experiences of living with someone suffering with chronic lower back pain. The interview will last about an hour and be held at the Hospital or at your home depending on which is more convenient to you. The interview will be recorded on audiotape so that, in writing up the research, I can write people’s experiences directly.

Naturally, to protect confidentiality, I will not use any identifying details such as names and locations. In writing up the interviews, your name will be replaced by a
fictitious name, and I will not record the names of other people or places that may arise in the interview. Once the research is written up, I will destroy the audiotape recordings.

**Do I have to participate?**
No, participation is voluntary. If you do not wish to be involved in the research do not complete and send back the acceptance form.

**What if I agree to participate but then change my mind?**
You can withdraw from the research at any time. If for example, during or after the interview you decide you no longer want to be involved in the research, the audiotape will be destroyed immediately. Similarly, if after a few days you decide to withdraw from the research any interviews already written up will be destroyed. You do not have to give a reason for withdrawing from the research.

**Have I been given enough information?**
If you have any questions please ask the researcher. If you wish to discuss the research further before or after completing the interview, please do not hesitate to contact the researcher.

**Contact:**  
Claire Elphick, Trainee Clinical Psychologist  
Psych.D Clinical Psychology  
Department of Psychology  
University of Surrey  
Guildford  
Surrey, GU2 7XH

**What do I do now?**
If you have decided you would like to participate in the study complete and send the acceptance form back to the researcher in the stamped addressed envelope provided. The researcher will contact you within a few days to answer any remaining question you may have and to arrange a time to conduct the interview.
Appendix Seven

Participant acceptance form
Participant Acceptance Form

The personal experiences of partners living with people suffering with chronic lower back pain. An Interpretative Phenomenological Analysis.

I am interested in participating in the above research project and agree to be contacted by the researcher to discuss the research further.

Please complete the following details:

Name: ____________________________________________________

Date of Birth: ______________________

Address:
_________________________________________________________________
_________________________________________________________________
_________________________________________________________________

Contact Telephone Number: ________________________________

Times available to be contacted: ______________________________
_________________________________________________________________

Please return this form to the researcher in the pre paid envelope provided.
Appendix Eight

Interview schedule
**Interview Schedule: Partner’s experiences of chronic pain**

Introduce the research by providing and reading through the information sheet. Draw attention to confidentiality procedures on the consent form. Address any questions that the interviewee may want to ask. Obtain written consent to interview and audiotape the interviewee. Counter-sign consent form.

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

'As you are aware, this research is exploring the personal experiences of partners living with people suffering with chronic lower back pain. I will be asking a number of questions covering different areas so I can gain an understanding of your overall experience. I would like to start by asking about the time your partner began to experience chronic pain.'

1. When did your partner start to experience chronic pain?
2. Describe to me what it was like for you at this time?

'The next set of questions look at how your partner’s pain may or may not have affected you.'

3. How do you think your partner’s pain has affected you?
4. What things are different about your life now than before your partner’s pain?
5. Looking at your experience as a whole what is the most significant change in your life that has taken place as a result of your partner’s pain?
6. What aspect of living with someone in chronic pain do you consider being most problematic/stressful?

'Now I’d like to ask you a set of questions about coping.'

7. How have you coped with your partner’s chronic pain?
8. What has helped you to cope?
9. What circumstances make it more difficult for you to cope with your partner’s pain?
'The next set of questions concern your understanding and perception of your partners pain.'

10. What is your understanding of your partner's pain?

11. Can you describe your partner's pain?

12. How do you know your partner is in pain?

13. What do you do when your partner is in pain?

14. Do you react differently now compared to when they first experienced pain?

15. How do you think your partner's pain has affected them?

'Finally, I would like to ask you some questions concerning treatment.'

16. What do you think helps your partner's pain?

17. Do you think you have an effect on your partner's pain?

18. What information have you been given by professionals to help your understanding of your partner's pain and treatment?

Is there anything else that I have failed to ask you in the interview that is important for me to know?
Appendix Nine

Consent Form
CONSENT FORM

Title of Project:

The personal experiences of significant others living with people suffering with chronic lower back pain. An Interpretative Phenomenological Analysis.

Name of Researcher: Claire Elphick – Trainee Clinical Psychologist

Please initial box

1. I confirm that I have read and understand the information sheet dated ......................... (version ............) for the above study and have had the opportunity to ask questions.

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

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

_________________________________________  ___________________________  Date  Signature

Name of Person taking consent (if different from researcher)  Date  ___________________________

_________________________________________  Date  ___________________________

For the above study:  Date  Signature
Appendix Ten

Consent Form
CONSENT FORM

TITLE OF PROJECT: The personal experiences of partners living with patients suffering with chronic lower back pain. An Interpretative Phenomenological Analysis.

The (or parent/guardian for a paediatric study) should complete the whole of this sheet himself/herself

Please tick appropriate box

Have you read the Patient Information Sheet? YES □ NO □

Have you had an opportunity to ask questions and discuss this study? YES □ NO □

Have you received satisfactory answers to all of your questions? YES □ NO □

Have you received enough information about the study? YES □ NO □

Who have you spoken to? Dr/Mr/Mrs ..................................................

Do you understand that you are free to withdraw from the study:
• at any time?
• without having to give a reason for withdrawing?
• and without affecting your future medical care?

Do you agree to take part in this study? YES □ NO □

Signed by (or parent/guardian) .................................. Date ............

(Name in Block Letters) ......................................................................

Signed by Investigator ............................................... Date ............

(Name in Block Letters) .....................................................................
Appendix Eleven

Demographic information booklet
Participant Demographic Sheet

Please read each question carefully and then answer each one. Do not skip over any questions. If you believe that any question does not apply to you, rather than leaving it out, please note that this question does not apply to you by circling the number of that question. Please use the space at the end to add any additional comments that you wish to make.

The information that you give will not be used within the research to identify you in anyway because this research is entirely confidential. It will be used to give general information regarding all individuals who agreed to participate in the research and also as a means of reference in case I need to contact you.

Section One: You

1. Date: __________

2. Title: __________

3. Your name: _______________________________________

4. Address: _______________________________________

5. Contact telephone number: __________________________

6. Age: (in years) __________ 7. Date of Birth: __________

8. Sex: (Tick the appropriate answer)

   □ Male
   □ Female

9. Which of the following terms best describes you ethnic background? (Tick the appropriate answer)

   □ Black – African
   □ Black – Caribbean
   □ Black – Other
   □ Chinese
   □ Indian/ Pakistani/ Bangladeshi
   □ White UK
   □ White Other
   □ Other (please specify) ____________________________
10. What is your current employment status? (Tick the appropriate answer)

- Working full time (over 30 hours per week) - go to 11a
- Working part time (less than 30 hours per week) - go to 11a
- Working at home (i.e. household chores) - go to 12
- Self employed - go to 11a
- Unemployed - go to 11b
- Full time Student - go to 12
- Part time Student - go to 12
- Retired - go to 11b

11a. What is your current occupation? ___________________________

11b. If you are no longer working what was your last occupation? __________________

12. What is your current marital status? (Tick the appropriate answer)

- Married
- Living as Married
- Divorced/ Separated

12. What is your current living situation? (Tick the appropriate answer)

- Live with spouse/significant other
- Live with spouse/significant other and children
- Live with others, please specify ___________________________

13. Have you ever suffered with chronic pain yourself? (Tick the appropriate answer)

- Yes (please specify) ___________________________
- No

Section Two: Your Spouse (significant other)

1. Your spouse’s (significant other’s) name: ___________________________

2. How are you related to the patient? (Tick the appropriate answer)

- Husband
- Wife
- Partner
- Other (please specify) ___________________________

3. Age of patient : (in years) ____________ 4. Date of Birth: ________________

5. Sex of patient: (Tick the appropriate answer)
Major Research Project

☐ Male
☐ Female

6. Which of the following terms best describes the patient’s ethnic background? *(Tick the appropriate answer)*

☐ Black – African
☐ Black – Caribbean
☐ Black – Other
☐ Chinese
☐ Indian/ Pakistani/ Bangladeshi
☐ White UK
☐ White Other
☐ Other (please specify) _______________________

7. What types of chronic pain does the patient suffer from *(please tick all those which apply)*

☐ Headaches
☐ Shoulder pain
☐ Abdominal pain
☐ Facial pain
☐ Arm pain
☐ Lower back pain
☐ Upper back pain
☐ Chest Pain
☐ Leg pain
☐ Other (please specify) ______________________

8. How long have they had chronic pain? ________________________ (years)

*Section Three: Any additional comments that you wish to make.*
*You do not have to make additional comments*
Appendix Twelve

Example of an interview transcript – Selected at random
Interview Transcript

This transcript has been selected randomly

All identifying names and places have been changed to persevere anonymity.

R = Researcher
P = Participant

R: As you are aware the research is exploring the personal experiences of partners living with people suffering with chronic lower back pain, I'll be asking a number of questions covering different areas so that I can gain an understanding of your overall experience. I’d like to start my asking about the time your partner began to experience chronic pain, when was that?

P: Umm, well I put about, his had it for about fourteen years but possibly it did start, the pain actually started a while before that, but it wasn’t really chronic it came and went.

R: And how did it start?

P: Well, just really complaining of pain in his back, I mean things got difficult, it got more difficult to do gardening and things like that.

R: So it gradually developed and got worse.

P: Yes, it was gradual.

R: What was it like for you at this time?

P: Umm, well it wasn’t any problem really, because umm, I’d actually had a slipped disc and I’d been on my back for a long time and I was sympathising, but umm, it wasn’t a lot of problems at that point he still went to work so umm it didn’t effect us much particularly.

R: And as it got worse overtime did it start to affect you more?

P: Yes, umm it’s difficult to say exactly when but, time goes so quickly, I suppose about ten years ago it started to cause more problems.

R: In what way?

P: Umm, well it was limiting and he, he wouldn’t want to do things or go out and he started, his back was sort of beginning to rule his life.

R: Was that difficult for you?

P: It is difficult yes, yes. I mean I often find I have to go to places on my own, I mean for instance, recently perhaps more, he’s, he’s been, his best, his, the man he was best man to had his 40th anniversary and he really wanted him to be there but I ended up having to go on my own which was really very difficult.
R: So it's made you a lot more independent.

P: Yes, but I've always been independent anyway, I am an independent person, umm, but umm, we did, it is nice to do things together, particularly now we're retired but we don't which is a shame.

R: How does that make you feel?

P: Well I don't feel angry, but I must admit I do get frustrated at times, yes, because I'm not angry about it, as he can't help it poor man, it's really his fault, I'm not an angry person.

R: So the frustration where does that come from?

P: Umm, I think it's probably mostly the fact that I'm having to slug my guts out when his often lying on the sofa doing nothing, it's very difficult and I'm having to do a lot more in the garden now which he used to do, he always did the garden and I'm not a gardener really, you know I find I'm doing all the work, but I know he can't always help it, but he is very good, I mean he does do his best when he can and he, it isn't as if he sits and does absolutely nothing at all, he does make an effort but there are times when obviously his worse the others.

R: So there's been extra work and responsibilities for you that you have gradually taken on.

P: Yes, yes.

R: My next question is about things, which are different about your life now compared to before your partner developed his pain, you've spoken about the increased amount of responsibility on yourself and you say socially your more independent, what other things have changed?

P: Umm, well the physical side of life is non-existent, because he can't cope with it, which, ok I mean, I've accepted but I was a bit depressed about that to begin, with not that he knew, I didn't tell him because I thought that would only make him feel worse, my husband is someone who can't take a lot of criticism or negative remarks, he's a lovely man umm, but he umm, he's easily you know, oh umm you always blame me for everything, if I say anything, he doesn't take it constructively so I tend to keep quite and just not say anything.

R: So there's been a change in your relationship.

P: Yes, in a way but I mean it's not a bad, it's a change that's been there plus my husband has diabetes so that hasn't helped umm but umm I mean we still love each other, his a dear man but it's umm it has changed from the point of view that you know we haven't got the physical side of our relationship and umm he tends to dwell on his pain a lot so that doesn't help, you know wake up and his groaning and he hands me the cream to rub his back.

R: What do you think in that situation?
P: I think oh and then I keep quite.

R: So you prefer to keep quite than tell him how you’re feeling?

P: Yes, well there’s not much point in making a lot of fuss is there and also I mean I know that if roles were reverse he’d willing rub my back if I wanted him to it’s just that sometimes everyday he can get a bit much, but it’s part of life isn’t it?

R: Any other changes?

P: Umm, the only other change is that it limits, we don’t go on holiday I mean umm last year we were going away in September but I had to cancel it he really couldn’t of coped and he told me to go but I didn’t want to go on my own or I couldn’t taken some one with me but there was no-one I really wanted to take so umm I stayed at home and did a load of decorating, which was very handy.

R: So it sounds like what you can do is sometimes limited.

P: Yes, so we just stay at home, the only, where we do go, is my daughter lives in Wales and he’ll manage to get down there because he can relax, so we do go and see her, and my son lives in ...... so we go there once a year, but a holiday, holiday we haven’t had for ages not a proper holiday.

R: Any changes in how you see yourself, due to the change in roles you’ve taken on?

P: Umm, not really, I don’t think, so because umm in a way I’ve always been the one who’s taken the responsibility umm it’s been a bit like that because I mean for instance when my daughter was about thirteen I said look we’ve got to do something she can’t sleep in that room I think we’ll have to have a loft extension he wouldn’t have pushed it, he wouldn’t have done it, I’ve always been the one who has to suggest things and get on.

R: So now is an extension of how it’s always been.

P: Yes, it’s an extension of that really as he’s never been a man for pushing things forward, I mean he always agrees, he doesn’t make a fuss about it sort of thing, he doesn’t say oh know and he’s quite willing but it’s always been me that’s seemed to have had to take the thing forward, but it is just an extension of that.

R: If you look at your experience as a whole what is the most significant change in your life due to your partners pain?

P: I suppose our physical relationship basically, because we had a good relationship but now he just can’t cope.

R: And that’s because of the amount of pain he experiences.

P: Well because it seems to increase his pain and umm I think his diabetes has affected his ability so you know, there’s everything else isn’t there.
R: And how do you cope with that?

P: Umm, I was depressed about it to begin with but um I’ve learnt to live with it, you know it’s sad in a way, it’s the one thing I think is a shame, but there you are, it doesn’t make me love him any less, it’s just one aspect of a relationship.

R: The other things you’ve mentioned the increase in responsibility, changes in your social life how have you coped with those changes?

P: Well in a way I’ve just on with things, I am a very busy person, I run a ..... group, every week, which I’ve done for over twenty years, I still do the surgery bit of work which can sometimes can be a lot sometimes less, umm I do go to keep fit once a week and go to my friends, I go on day trips with my friend, I try to do my photos, I ‘m trying to do a family tree, my time just goes, I’m extremely busy. I can’t sit at home doing nothing.

R: So you’ve coped my making sure your busy with lots of interests.

P: Well, I have to get on with my life in a way, I can’t, I feel that I can’t run my life completely round him because umm, umm, I would do nothing, my life would literally be washing, cooking, cleaning, shopping, gardening, you know umm watching television and I’m sorry but that’s just plain boring to me, I’m to umm, I’ve got too active an mind to do that, I mean I do get extremely tired now and I have my own heart problem and thank God there’s tablets, if I didn’t take tablets I wouldn’t be able to do anything, I’m very fortunate really, but that’s one thing I don’t think he recognises, that I have a problem, I know that I’ve got a problem and that it’s, it is, it could be, probably will be potentially fatal in the end, but I’ve had it for years, I’ve had it since I was forty but things have got slightly worse, but umm I don’t tell him, I wouldn’t tell him how it is and what the problems are, although he knows I have angina, he knows I get angina yet he doesn’t recognise that it’s real and I do find I’m a lot more tired.

R: Your sort of protecting him aren’t you.

P: Yes in a way.

R: And why do you do that?

P: Because I don’t think he could cope with that, his a real worrier, I mean, I, again I suppose it’s partly my fault, but I have a tendency to do, he’s err, he, he won’t cope with things often very well.

R: So you deal with them for him.

P: In a way and also if he knew sometimes how I was feeling he would probably say oh you shouldn’t be doing this and you shouldn’t being doing that and I’d rather not be told that, I’d rather get on with my own thing.

R: And when you are out doing all these things how does that make you feel about your husband being at home?
P: Umm, well his very good I must admit he’s not a man, I mean I’ve got a friend whose husbands had a stroke, which is slightly different as he is more dependent and umm she finds is very difficult to get out because his so anti her leaving him umm so I’m very thankful he doesn’t mind, he say’s no, no, no, you’ve got to get on and do your thing and he’s good like that, I mean we do, do some things together but not as much as would be nice to I mean I go out on day trips with a friend but he won’t come because he can’t stand staying on the coach for ages this sort of thing we could go and do but he won’t because he can’t cope with the pain, which is a shame, it’s sad really and there’s lots of things, I mean the group I run I’ve asked him to come and he’d enjoy it if he came but he doesn’t want to because of the sitting, he’s never been a great socialiser.

R: So sometimes it may not be just because of his back problem but also maybe part of his personality.

P: Yes, I think it is.

R: So what things do you do together?

P: Umm, well we go to church together, he manages that, he didn’t for a long time, he had a bad year and umm so he didn’t come for ages but he seems to be trying to make more of an effort recently get back to just doing little things, occasionally we go walking, and not a lot really, I mean the evenings is a time when I do sit down I’m to tired to do anything so I’m afraid we are a bit of television addicts we sit down and relax, watch the TV so we’re always together in the evenings, umm if I’m gardening he’ll often potter, he’ll help me so if I’m gardening we’ll probably both be out there.

R: So there are some things that you still do together.

P: Yes.

R: And you mentioned about going to church and your fellowship group do you find that religion has helped you to cope have you used that as a strategy?

P: Probably yes, I have a strong faith, yes.

R: You mentioned that at times you get more tired have you noticed any other physical or health problems that you would put down to you extra roles?

P: Umm, No, No, I mean gardening gives you aches and pains, probably I would think, but no on the whole I’m very fortunate, I mean I keep extremely well considering, I’m very fortunate I’ve always had a lot of energy, I haven’t got as much now but I’m sixty-nine so you expect it.

R: You mentioned before that you have bee depressed, do you still feel that way at times?

P: No, no not really, ok, but I mean not sort of clinical depression, you know more sort of it’s a bad day today.

R: What circumstances would make it a bad day?
P: Well, probably if his feeling awful it doesn't help me, you know, I mean some days he's just, he goes around with his head in his hands and his holding his back, and I think, I have to get out, I can't just sit and watch him like that so I am most days doing something, but I'm glad to be out, umm he's not that bad all the time, but he has days, but you know when someone is continually complaining, it can get you down, but umm as I say he's just recently slightly better, he's just had some injections but they haven't helped, they cannot find the cause of this pain and I think that frustrates him that he doesn't know, I think it's just general muscular pain, I don't know.

R: That frustrates him how does it leave you feeling?

P: Well, I just think you have to take it on board, there's not much else we can do at the moment he's waiting for another scan, but I bet it won't show anything and umm so I think, I think the thing I possibly feel is that he has to try and a bit more, you know, make a bit more of an effort which I think he has been recently.

R: You do think it's been aware you've been thinking that?

P: I don't know, I mean we did go, I said to him at the beginning of the year why don't you go to a physiotherapist, because you know I think perhaps if you did some exercises it might help, and she was extremely good, she was a very nice girl, but the exercises just seemed to make it worse, because I feel his problem is muscular and if he works through the exercises he would probably feel better but he gave up. He said the exercises were making the pain worse so in the end this lady said look I don't think there's anything I can do for you and she's probably right.

R: Looking towards the future what things would make it more difficult for you to cope in the future?

P: Well, I suppose if he gave up doing anything because I couldn't cope with that at the moment, he does still, I mean he will do the washing up and he does still clean the downstairs rooms for me, because I said to him when I retired I'm not doing all the cleaning, you do the downstairs, I'll do the upstairs. He was quite happy to do it, he doesn't mind, he's very good, he does still do that which is a great help because I hate cleaning, so he'll do that and I'll cope with the upstairs, but if he stopped doing that and those sort of things, I had to do all the cleaning I couldn't cope with all the work.

R: So housework is a big thing you couldn't cope with doing.

P: Yes, yes. I mean I'm finding it difficult to cope with the garden, I do the basic minimum, I, I cut the grass and put the plants in and I don't mind, I quite enjoy doing it, but at times, but err it gets to much.

R: Would you find it more difficult to cope if your husband became more dependent on you?

P: Well, I suppose, I mean, I think you have to accept, I mean, you see the strange thing about it, is his not limited in movement he's got this pain but he can move around bend and stand, he's movement is not really limited, I mean, I feel really sorry for him because he will willingly want to do a lot more, if he could cope, he would do it, I mean he, he loved umm gardening and he, he gets frustrated that he can't do it and
that I have to do it you see, so he feels he’s putting pressure on me as well, it’s not all one sided he does worry about me.

R: The next set of questions concern your understanding and perception of your partner’s pain, you’ve already said that the cause is unknown, but how would you describe your husband’s pain?

P: Well it’s all encompassing really, I mean it does vary he does have a tendency to some days his obviously better than others, but if it’s a really bad day he looks ill, he, he feels sick, he can’t eat a lot because the pain is effecting his whole self and how his feeling, so I know that, umm, how it is to him, it’s very difficult to gauge other peoples pain because people have different pain thresholds, umm you really can’t gauge how much pain he is feeling but how he appears and how he is you know his in pain.

R: So you can tell his in pain by looking at him.

P: Yes, he looks really tired and drawn and he’ll tell me, his not quite about his pain, but I don’t mind that, he’s that sort of person, he can’t, I mean it’s not like women, women can often keep things to themselves, they have an ache or a pain, but they don’t make a big deal out of it, but I think men tend to tell a lot more anyway or most men not all men, but I mean he does do his best, it doesn’t happen all the time but you know, I can tell when his in pain his whole demeanour.

R: And what do you do when he is in pain?

P: Umm, well I can’t do a lot really because there’s nothing I can physically do, I’ll put his tens on, I’ll rub his back for him, I tell him to lie down for a little while take some pain killers, you know umm, go and take a walk, umm I can only suggest things.

R: And how does that make you feel?

P: Helpless really and frustrated, you know it is frustrating for both of us really, he gets frustrated because umm, he’s a lovely man really and he would like to be doing more it’s not that he doesn’t want to do it, but he really cannot, he does push himself at times, I mean his got a brother whose a bachelor so I do all his washing and I’ve also got a neighbour whose now in a nursing home who we try and go and visit twice a week and his very good at trying to go even if he’s got pain he will go and see her, so he’s very good in he doesn’t just sit and do nothing all the time he also does watercolour but he hasn’t had time to do that this year, and umm so he loves his watercolour but umm when his in pain like this he can’t do it, so his only done a little this year.

R: Thinking about when your husband first started to experience pain do you think you react differently now to back then?

P: I suppose I used to ignore it more and now I’m perhaps a little bit more sympathetic, but obviously you can’t be sympathetic all the time you know sometimes you, you feel like saying ‘oh do shut up about your back, I’ve got my problems as well you know’ but I don’t I wouldn’t hurt him like that umm I suppose I’ve always considered other people’s feelings and err I know he couldn’t cope if I said that so I just keep quite about it, but I am, I do you know get frustrated with him.
R: Would you say you get frustrated more now than at first?

P: No, not really. I think it frustrated me more about five years ago when I was still working he was retired and I think it umm frustrated me more then, but umm I was at work and I didn’t get a lot of support, I got support in the house, that sort of support, but I didn’t get any sort of mental support and I think I felt a lot more frustrated, I think I’ve learnt to accept it know and just get on with life.

R: So do you think it’s got easier since you’ve also been retired?

P: Umm, possibly yes although I still do quite a lot you know.

R: How do you think your husband’s pain affected him?

P: His probably a bit more introspective than before, you know, he, sort of everyday is a struggle, he gets up, I think feeling, you know another day of pain, which is understandable really and I think, yes he is a bit more introspective.

R: How do you think his coped?

P: I think his coped, I think in some ways it’s a good excuse for not doing things, now that sounds unkind but I don’t mean it like that, his never been a person who particularly wants to umm, go out and do a lot, umm we enjoyed our holiday and things but umm I think sometimes it can be a good excuse to not do anything which he probably doesn’t want to do.

R: And have you talked to him about that?

P: No, I’m a coward and it would upset him too much.

R: And what do you think will happen in the future with regards to your husband’s pain?

P: I umm, I don’t know, I can’t see it getting a lot better, umm it might not get worse it might stay the same, I mean it’s very difficult to gauge, you see I sometimes I think sometimes, I feel he could do more than he does, but umm then I can definitely see some days he is in a lot of pain other days he’s not so bad but he, when he’s not so bad he does try and get on and do things he doesn’t as I say, Sit around and do absolutely noting like some people do, he goes to see my friend in the nursing home oh and that’s the other thing, that recently his friend who’s a bachelor, and on Saturdays he always comes over and Douglas used to go and do a bit of shopping and bring it back, have lunch and they usually go to football only a local team but they’ve been going before the second world war, but for most of this year I’ve had to go and do jack’s shopping so that’s another extra thing I’ve had to do, go over do Simon’s shopping bring it back then drive them back to football, then drive back to collect them, so it’s all little things it all mounts up.

R: In the future what do you think your roles going to be?

P: I don’t know, I mean I would always support him and do whatever I can but I couldn’t close my life completely I think you have to have some outlet as well
otherwise you’ll go mad, I mean this is where these carers of people who are physically disabled, that must be, I mean it becomes a real burden and I think umm if that ever if it did become that he was, I mean the thing at the moment which is good is that he is not, he is able to walk and move, although he’s got the pain he is not physically unable to get on with things, so that’s a real blessing, I mean if it ever became that umm he err was really became more disabled well then I think we’ll just have to work round that, but make sure that you always have a bit of a life yourself. I’ve just brought myself a new computer so I am learning how to use it now, then when I’m older and can’t get out I’ll have something to do.

R: So you’ve already been planning ahead.

P: Yes, I think you do have to plan sometimes in this life and be prepared, yes.

R: You mentioned about the burden of caring do you see things as a burden now?

P: Yes, to a certain extent I do, because I’m having to do more, all the things Douglas used to do and yes it can, it is a bit of a burden at times you think life’s all work, but then it isn’t all work because I do make sure that I do other things that I enjoy, I mean I like going out on these coach trips with a friend and umm I enjoy, I’ve been to the theatre a couple of times, but again you see it would be nice to go with Douglas to the theatre that’s what I’d like, it would be nice to, but he can’t seem to cope with them.

R: Do you think your missing out at all?

P: Well, I suppose to a certain extent, but on the other hand I’m the sort of person whose quite content with my life, I can still enjoy life umm you know, I’m a positive person umm Douglas has always been a bit the other way, it’s always been a bit of a negative person and oh we shouldn’t do that because, he’s that sort of person but I’m much more positive, he’s more cautious.

R: Finally, I’d like to ask you some questions concerning your husband’s treatment, what do you think helps his pain?

P: The tens machine has been good but some times it works sometimes it doesn’t, I mean if the pains very bad it probably won’t touch it, but if it’s not too bad it’ll help, it does depend on where you put the pads, putting the pads on in the right place is a bit hit and miss really if you don’t know where to put them, but sometimes they do work, but sometimes they don’t work. I think the umm the rubbing his back, sometimes gives him a physical, umm sort of feel that your doing something but it actually doesn’t do a lot but it never hurts to give him a massage.

R: What affect do you think you have on his pain?

P: I don’t really think I have any affect on his pain, if his got it his got it, and anything, I mean I can cheer him up, perhaps make him feel better but I mean I don’t actually think anything I do has any effect on his pain whatsoever his either got it, his always got pain, always, some days it’s slightly better than others, if it’s not to bad he copes but when it gets very bad he just doesn’t cope.
R: Going back to when you were saying you sometimes don’t tell him things do you think you keeping things from him stops him from getting stressed and so helps to reduce his pain?

P: I mean there are lots of things I do talk to him about, but there are things better kept from him, like my heart problem and for instance I fell over the other day but didn’t tell him, I knew he would panic if he knew and he’d say you shouldn’t be doing this you shouldn’t be doing that. I didn’t say anything because it wasn’t important, if it was something important I would talk to him, but it wasn’t important enough to tell him so that’s the sort of thing I might not tell him because he’d just worry about it.

R: Thinking about information you as a partner have been given from professionals do you think information has been given to help you understand?

P: No I don’t think so, I mean my, I can understand it because I’ve been in the profession, but umm no I don’t think I’ve been given information just by looking back I don’t think I’ve ever been spoken to about it, about his pain.

R: Do you think partner’s need to be given more information to help them understand and be able to cope?

P: Yes, I think so, I mean there very good here at the pain management programme but umm, but the only one partners were invited to, was the one which a physio did, I mean whether they should have a session just for the partners could be quite a good idea, to say to them look what are your problems and umm perhaps give them an explanation of how pain works and ways that they can umm, the different ways they help to treat pain.

R: Finally, is there anything that I’ve failed to ask that you think would be important or useful for me to know about what it’s like to live with someone in chronic pain?

P: I don’t think so, I mean it’s the physical difficulties, sometimes the emotional difficulties, social difficulties there also associated with it a bit, I mean I’m very fortunate really I don’t have as many difficulties as some people do, the character that I am helps me to cope with a lot of it. As I say I did go through one phase when I was, I really felt a bit down, but I think you adjust don’t you and you sort of accept the situation and learn to work your way through them really and again I think I’ve made sure that I’ve had other outlets that I haven’t got introverted into his pain because I don’t think that helps the situation. I suppose lately it’s been the physical work that’s made me tired, I’d always hoped I wouldn’t have so much physical work to do and that has increased, I think that worries Douglas, I mean he does realise, he knows I’m doing a lot and that frustrates him, because he’d like to be doing it, its not because he doesn’t want to do it, I mean, I mean he may use his pain as an excuse for some things, but not for things around the house, he would be quite happy to carry on, that’s the other thing decorating he used to do it but I do it now or I have to get someone else in to help and that Douglas finds jolly difficult, so that’s another thing that frustrates him because he can see things, but he just feels he can’t cope with them, which is fair enough I mean if your in pain all the time it is difficult isn’t it, I mean it’s difficult for us when we don’t have pain to visualise what it is like to be in pain all the time.

R: Thank you for participating in the study.