An investigation into the relationship between illness representations, coping and quality of life amongst a UK sample of adults with sickle cell disease

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Introduction to this portfolio

This portfolio contains assessed* work that has been completed over a three year period. It is divided into three parts:

The academic chapter is comprised of 5 essays. These essays cover both 'core' and 'specialist' subjects.

The clinical chapter contains details of all placements and summaries of case reports from those placements (with the exception of the Forensic placement).

The research chapter is comprised of a small scale research project (year 1), a literature review (year 2), and a large scale research project (year 3).

Each chapter of this portfolio is presented in chronological order to reflect the developmental nature of the course.

* Denotes that the large scale research project has not been formally assessed.
Academic Chapter
Essay 1: Adult Mental Health

Compare the treatment roles of psychological therapies and psychotropic medication for an adult mental health problem of your choice.
What is schizophrenia?

The illness labelled schizophrenia continues to be a controversial construct which has been deconstructed (Boyle, 1990), criticised and dissected (Bentall, 1990a; Spaulding and Cole, 1984). The simplest model of schizophrenia is the traditional psychiatric 'disease model' in which the illness is defined as a disorder with a wide range of possible psychotic symptoms such as major disturbances in thought; disordered thinking in which ideas are not logically connected; faulty perception and attention, disturbances in motor activity, and flat or inappropriate affect. It causes the individual to withdraw from people and reality, often into a life of delusions and hallucinations (Davison & Neale, 1994). The disease model assumes that the condition bears no resemblance to normal functioning, thus the symptoms of the condition are abnormal, and signal the presence of a mental illness.

The range of symptoms exhibited by individuals is extensive, thus sufferers of the illness tend to differ from each other in terms of their presenting symptoms. The Diagnostic Statistical Manual of Mental Disorders-Version IV (DSM IV) determines how many symptoms must be present, and in which degree, to justify the diagnosis. DSM IV requires at least six months of disturbance for the diagnosis. This must include one week of at least two of the conditions Schnider (1959) described as first rank symptoms (positive symptoms) - delusions, hallucinations, disorganised speech, disorganised or catatonic behaviour, and secondary symptoms (negative symptoms) - alogia, anhedonia and flat affect. Problems during either phase include social withdrawal, impaired role functioning, blunt affect, vague speech, impairment in hygiene, odd beliefs and unusual perceptual experiences.

Alternative models of schizophrenia include that of Foulds & Bedford (1975), who proposed a hierarchical model in which schizophrenia is seen not as a separate disease entity, but as representing the most severe form of psychological disorder, encompassing classes of illness lower down the hierarchy e.g. depression, obsessional compulsive disorder, states of anxiety etc.
Claridge (1985), proposed a dimensional model in which certain areas of functioning are conceptualised as on a continuum from normality to dysfunction, representing a vulnerability dimension. The state of malfunction is defined depending on the individual’s position along the continuum, so that in its mild form the definition of the illness is not clear cut. The cause is multiple, arising from an interaction between an underlying disposition and a range of developmental trigger factors which combine to push the individual along the continuum beyond normal functioning to dysfunction.

Boyle (1990) and Bentall (1990b) are prominent among psychologists who have argued that the concept of schizophrenia should be abandoned and replaced with the study of individual symptoms of psychosis. Boyle (1990) argued that the concept is unreliable and invalid as a disease identifiable from other acute psychological disorders, and that the diagnosis has proven to be a poor predictor of aetiology and response to treatment. Birchwood and Tarrier (1992) summarise Boyle and Bentall’s main arguments as follows: i) There are no common symptoms which everyone who has the diagnosis presents with; ii) symptoms thought to define the illness appear in other disorders, this means that the diagnosis is less informative than it should be to clinicians; iii) the onset and prognosis is extremely mixed and difficult to predict - the aetiology remains unknown; iv) there is not enough research evidence to warrant grouping a set of symptoms into one category and labelling it schizophrenia because the scientific requirements which warrant this so far is absent.

Aetiology of schizophrenia

Medical approaches to the study of schizophrenia have tended to be unimodal such as the genetic approach of Gottesmann, McGuffin & Farmer (1987) who support the notion that a predisposition for schizophrenia can be transmitted genetically. Their theory fails to acknowledge social learning theories. For example the disturbing behaviour of a schizophrenic parent may have
a stressful effect on the development of a child, resulting in learned mannerisms from the parent. Therefore environmental and learning influences cannot be discounted.

In the last 20 years the work of Seidman (1983) emphasised the need to continue research on brain abnormalities as the cause of schizophrenia. His research found that a percentage of patients (number unknown) have been found to have observable brain pathology. Examination of the brains of deceased schizophrenics revealed structural problems in the limbic areas, the diencephalon, and the prefrontal cortex (Seidman, 1983). Images obtained from MRI and CAT scan studies also revealed that male schizophrenics in particular, have enlarged ventricles, which suggests deterioration of brain tissue, particularly in the limbic areas (Andreasen, Flaum, Swayze, Tyrrell & Amdt, 1990). The theory fails to explain why the prevalence of brain abnormality is most noticeable in the male brain, even though the same symptoms are exhibited by both sexes.

The biochemical explanation for the aetiology of schizophrenia points at the dysfunction of neurotransmitters, in particular, dopamine situate in the limbic areas of the brain (Davidson and Neale, 1994). However, the introduction of ‘atypical’ drugs such as Clozapine which are weak antagonist of dopamine, and yet are effective in treating the illness has shown that the dopamine hypothesis provides only half the answer to the aetiology of schizophrenia.

Zubin and Spring (1977; cited in Birchwood and Tarrier, 1992) offer a psychological perspective in the form of a vulnerability model of schizophrenia. The vulnerability model is a multifactorial model which integrates several aetiological perspectives. The model postulates that schizophrenia is a episodic disorder. They argue that the majority of schizophrenics return to normal functioning in between episodes. Long term disability is attributed to excessively prolonged episodes, frequent acute episodes, or to poor premorbid functioning which may be exacerbated by the social consequences of the symptoms. The model postulates that episodes of schizophrenia are
triggered by challenging environmental stressors such as high levels of expressed emotion and stressful life events (Brown and Birley, 1968: cited in Birchwood and Tarrier, 1992). If these stressors exceed a threshold, determined by the individual's level of vulnerability, then an episode may be triggered. Zubin & Spring (1977: cited in Birchwood and Tarrier, 1992) argue that vulnerability may be both inherited and environmentally acquired.

The role of psychotropic drugs in the treatment of schizophrenia

There are a number of possible causes of psychotic illness as discussed above, but the single most important as far as drug treatment is concerned is the 'dopamine hypothesis' which stems from the biochemical model of schizophrenia. The 'dopamine hypothesis' model attributes the symptoms of the illness to an excessive transmission of dopamine in various parts of the brain (Davis, Kahn, & Davidson, 1991). The standard antipsychotic drugs are potent dopamine antagonist (blockers) and are therefore thought to reduce symptoms by reducing the effects of excess dopamine.

The role of antipsychotic drugs is to give rapid relief from distress and agitated behaviour and control the acute phase of an illness by removing symptoms enough to allow the individual to function and engage in psychotherapy. After the acute phase has been brought under control, neuroleptics are used to maintain the individual's mental health and prevent further acute relapse. The first antipsychotic drug Chlorpromazine (Largactil) paved the way for effective drug treatment of a significant number of people with the illness. The large number of other neuroleptic drugs developed since chlorpromazine e.g., Haloperidol, have not proven to be any more effective in treating positive symptoms of schizophrenia, neither are they effective in treating negative symptoms. The new atypical drugs such as Olanzapine, Clozapine, Resprimidol are effective in the treatment of both positive and negative symptoms, and produce fewer side effects (Conley, Schulz, Baker, Collins & Bell, 1988). The atypical drugs have been shown to be most effective
with treatment resistant patients. Research by Conley et al., (1988) supports the view that atypical drugs such as clozapine is significantly more effective than chlorpromazine in patients unresponsive to other neuroleptics.

The choice of drug for a patient depends on: i) their psychotic symptoms; ii) their physical condition; iii) their history of response and compliance. The choice between drugs is largely based on the different side effect profiles of the drugs themselves, e.g. a sedative drug may be chosen for someone acutely psychotic, aggressive or violent, but a less sedative drug for an individual less disturbed and wanting to return to work. As with all prescribed drugs, neuroleptics produce side effects because they affect a number of different transmitters in the brain, and also enter various parts of the brain that control different body systems producing a number of unwanted side effects:

1. by blocking receptors of the transmitter acetylcholine they can cause dry mouth, blurred vision, constipation
2. by blocking noradrenaline receptors they can produce postural hypotension
3. by blocking the transmitter histamine they can produce drowsiness and sedation
4. by blocking dopamine receptors they can produce prolactin causing sexual dysfunction and movement impairments

They can produce a whole range of effects; of these, movement side effects are often the most obvious and most distressing. They fall into four main types:

i. Akathisia (restless leg)
ii. Parkinsonian effects
iii. Acute dystonia
iv. Tardive dyskinesia

In spite of the numerous side effects of psychotropic drugs in the treatment of schizophrenia, they play a very important role in the long run. Medication reduces florid symptoms, facilitates cognitive functioning, and improves patient’s ability to learn from their treatment environment and utilise
other therapies. Lindstrom (1989) reported that his patient's quality of life improved with 39% able to return to work within 2 years of being treated with Clozapine (it is unknown whether drug treatment was administered alongside psychotherapy). Furthermore, research by Donaldson, Gelenberg & Baldessarini (1983) revealed that that 65-70% of patients relapsed within a year of medication being stopped and also reported a relapse rate of 5-10% per month for those not taking maintenance medication.

**Psychological interventions for schizophrenia**

As mentioned earlier, neuroleptic drugs (with the exception of the atypical drugs) are relatively ineffective in the treatment of negative symptoms of schizophrenia, and a considerable number of patients will continue to experience residual positive symptoms (Silverstein and Harrow, 1978). Negative symptoms - apathy, a-motivation, flat affect, anhedonia and social withdrawal, impairs the individuals abilities to establish and maintain themselves in the community. Social skills deficits prevent them from successfully engaging in everyday activities, establishing friendships and relationships, self managing their illness and finances. This has led to a number of different psychological and psychosocial approaches to working with people disabled by their negative symptoms.

*Behavioural approaches* - In the 1960's psychologist began to develop behavioural interventions. There are numerous behavioural approaches but must note worthy are those concerned with developing skills - 'token economy' approach (Allyon and Azrin, 1968: cited in Davidson and Neale, 1994), and modifying disruptive, aggressive behaviour e.g. 'time out'. Behavioural programmes in general are based on manipulating rewards and punishment contingent on specific behaviour. Contingency management can also be used to decrease the behavioural correlates of hallucinations and delusions (Paul and Lentz, 1977). However the behavioural approach by itself falls short in that: i) improvements are not long lasting; ii) improvements do not generalise to
other settings (ecological validity); iii) implementation is most amenable to institutional settings and not community settings. Overall, behavioural interventions only have a worthwhile role when combined with other interventions (Perkins and Repper, 1996).

Skills-based approach - Over the last decades it has been noticed that many schizophrenic patients are unable to use old and acquire new skills as a result of their florid psychotic symptoms and disuse of premorbid skills. These negative symptoms in recent years have been combated with social skills training (Wallace and Liberman, 1985). The skill based approach has developed from the psychosocial stress vulnerability model which emphasises that vulnerability can be curbed by: a) strengthening personal resources e.g. maintenance drugs and social skills; b) controlling personal environment - low expressed emotion. Ideas about developing skills and skills training are based on identifying a person's skills and deficits. The things necessary for a person to learn are then broken down into components and intervention takes the form of building up competency largely within a behavioural framework. This type of approach helps interventions to be systematic and organised and offers a clear direction for work. The skills approach however has certain pitfalls akin to the behavioural approach: i) it can only be used when there is an identifiable skill that can be taught (Shepherd, 1977); ii) acquired skill will not always generalise to all settings; iii) social competence requires more than the acquisition of simple behavioural tasks; iv) it is necessary to judge what behaviour is required in any situation and adapt on the basis of the feedback we get from others; v) it can lead to the inappropriate prioritisation of interventions; a mismatch situation could arise between the things that the patient and staff consider important.

Psychological approaches for the treatment of positive symptoms has been the focus of cognitive and cognitive behavioural therapies over the last 20 years. Belief modification a form of cognitive therapy seeks to modify patients' delusional beliefs and attitudes. The symptoms model adopted by Chadwick, Birchwood & Trower (1996) integrates the principle of Beck's cognitive therapy and
Ellis' rational emotive therapy in addressing individual symptoms. They incorporate the ABC model but adapt the model slightly by including all cognitions under B. 'A' stands for activating events, B for beliefs about the activating event, and C for the emotional or behavioural consequences that follow from B given A. Chadwick et al., (1996) argue that the cognitive ABC model offers a helpful framework within which to understand the experience of positive symptoms. Their approach to treating individual symptoms focuses on weakening beliefs associated with delusions, voices and paranoia as a means to ease distress, based on the assumption of continuity between psychotic and non psychotic phenomena, and a rejection of the traditional disease model of discontinuity.

The theory that family environments have a role to play in the relapse of schizophrenic patients has been well documented (Falloon, McGill & Boyd, 1984). The focus lies in family environments precipitating and maintaining relapse as a result of their interaction with the patient. Work on expressed emotion by Brown, Birley & Wing (1972) revealed that the presence of critical, hostile or emotionally over involved attitudes of family members is a powerful predictor of subsequent relapse. Awareness of the burden of care on families led to the advent of therapies designed to help families cope with caring for a family member suffering from schizophrenia. Most studies focus on relapse rates as evaluation of treatment. The factor most salient in such intervention studies is high expressed emotion as postulated by Brown et al.,(1972) and Tarrier, Barrowclough, Vaughn, Bamrah, Porceddu, Watts & Freeman (1988). A common characteristic of family intervention studies is the inclusion of both patient and relative in therapy, and the encouragement of maintenance medication by the patient. The overall rationale for family intervention is to modify family environmental factors that can be identified as a contributing cause of relapse. Birchwood and Tarrier (1992) recommend that family interventions involve giving advice to relatives on caring for their ill relative through educating them about schizophrenia. Interventions are advised by Birchwood and Tarrier (1992) to include sessions on stress management, coping responses and goal setting. Support for family intervention stems from research by Goldstein,
Rodnick, Evans, May & Steinberg,(1978) which involved 104 young first and second episode schizophrenic patients who were randomly allocated to either moderate or low dose medication, and to either psychosocial intervention or standard after care. After 6 weeks significant differences in readmission rates were observed. For the moderate dose/ family therapy group 0% were readmitted compared to the low dose /standard care group in which 24% were readmitted. After 6 months there was still 0% admission rates for the family therapy group.

Some of the problems encountered with the theory of expressed emotion and subsequent family intervention programmes is the emphasis laid on the family being the cause of relapse in their relative. It must also be emphasised that symptom factors such as chronicity and severity, including behavioural disturbances may well contribute to the development of problems within the family leading to high expressed emotion. It is also misleading to characterise all low expressed emotion families as calm effective carers who are able to provide a convalescing environment for their relative. Given the severity and unpredictability of the illness at times, it should not be assumed that low expressed relatives cope all the time.

With regard to the intervention programmes, it has been revealed that not all interventions are successful owing to the problems of engaging family members. Some families may be unwilling to take part, others may be quite difficult to sell the programme to. Smith and Birchwood (1990) found in their study that 38% of relatives declined the offer of help, 16% withdrew in the early stages of assessment comprising an overall non engagement rate of 54% (families consisted of low and high expressed emotion relatives). McCreadie, Phillips, Harvey, Waldron, Stewart & Baird (1991) reported a 73% non engagement rate and postulated that reasons for non engagement could be due to i) denial of family needs; ii) stigma and embarrassment; iii) resignation to the situation; iv) resentment for being held responsible for well being/relapse of schizophrenic relative.
The last psychotherapeutic intervention to be mentioned briefly is that based on early intervention. The World Health Organisation (1979) revealed that each schizophrenic relapse increases the probability of future relapse, residual symptoms and social disability. The aim of early intervention programmes is to improve care by helping patients and family members identify individual relapse signatures (prodromes). Brier and Strauss (1983) presented evidence that patients are able to recognise early signs of relapse and how to initiate methods of self control. Birchwood (1992) suggested ways in which Clinical psychologists in particular could be instrumental in early intervention programmes. These include; i) offering a range of psychosocial interventions with vulnerable groups at risk of long term disability and chronicity; ii) engaging and educating patient and carer about early warning signs of relapse; iii) interviewing for prodromes which can be used to prime the early intervention system; iv) monitoring vulnerable individuals. More research is needed to support the effectiveness of this new intervention.

Conclusion

It would appear that a multifaceted approach of combining pharmacology and psychosocial/psychological techniques is the way forward for the treatment of schizophrenia. Drug treatment alone stands the risk of ignoring psychological components that are necessary for effective long term relief, and likewise, ability to engage in psychotherapeutic work relies heavily on bringing under control florid psychotic symptoms that otherwise make it impossible for the patient to function adequately. Biological and psychological approaches need to be integrated for many reasons:

- non compliance of drug regime due to side effects of neuroleptic drugs increases the revolving door contact with the system, and the sufferer becomes increasingly disabled by the disorder.
- Neuroleptics are ineffective in combating the negative symptoms of the illness or controlling residual symptoms. Even the atypical drugs still leave the patient predisposed to reacting abnormally to later stressful situations. Psychotherapies are most useful in controlling behavioural
deficits and helping patients to learn or relearn ways of interacting with their world, and dealing with the emotional challenges that all people face as they negotiate life.

- The family intervention work with high expressed emotion and the early intervention work emerging alerts us to the importance of combining pharmacological therapy and psychological/psychosocial therapy.

To conclude, logic and experience dictate that comprehensive treatment should be both biological and psychological (Davison and Neale, 1994).
REFERENCES


Essay 2: Learning Disabilities

What were some of the driving forces behind the move towards care in the community for people with a learning disability and what is the role of the clinical psychologist in resettlement?
To answer the first part of the question ‘what were the driving forces behind the move towards care in the community’ it is important to discuss how the mentally retarded became victims of institutional care to begin with. This essay will therefore begin by giving a brief history of the development of institutions and the laws of the land that encouraged and maintained their existence. The driving forces behind deinstitutionalisation is discussed next, focusing on contributions of psychological research in highlighting the capabilities of this client group, and criticisms of their hospital care. The impact of such research on the laws pertaining to the mentally disabled is also discussed. The essay concludes by discussing the role of the clinical psychologist in resettlement.

The development of institutions for the mentally disabled.

People with a learning disability have been described as different from the rest of society because of their inability to cope satisfactorily in their community (Malin, 1995), compounded by their low intelligence. Malin (1995) argued that before the industrial revolution the learning disabled were not considered ‘abnormal’ or ‘disabled’ due to the simple technical and educational demands of a non industrial society. However Malin argued that the industrial revolution required people who could be measured by their ability to cope with the demands of a developing country. This period in time demanded more abstract skills such as reading and writing. Education therefore was fast becoming the means for individuals to secure employment and status.

The learning disabled began to increasingly stand out as being cognitively, socially and practically of low competence. Although research on mental handicap was limited in the early 1800’s the attitude and mood was positive in academic arenas concerning the educability of those individuals classified as ‘idiots’ stemming from Itard’s work with the wild boy of Aveyron (1801: cited in Malin, 1995). Itard’s one year programme included attempts to teach the ‘wild boy’ to speak and socialise him into the community through teaching by imitation. Although Itard’s programme was
unsuccessful, his pupil Seguin took his theories further and proposed that ‘idiots and imbeciles’ had use of their intellectual faculties but lacked the power to apply them because of an inability to resist competing stimuli’. Itard and Seguin’s theory led to the development of institutions designed as places where people with a learning disability could be kept in conditions that would facilitate their training and education. Although this unintentionally gave rise to the birth of asylums and institutions, the premise of these institutions was that given suitable and adequate attention and training, the learning disabled were capable of learning simple tasks sufficient to enable them live and contribute to society. The ensuing years brought many changes in the laws concerning the learning disabled. This essay will now mention those most pertinent to the institutionalisation of the learning disabled.

The laws that led to the institutionalisation of the mentally disabled

Following Seguin’s work with the wild boy of Aveyron, the future for the learning disabled seemed promising in spite of the ambiguous terminology of the Lunatic Asylums Act of 1853, and the Idiots Act of 1886 (cited in Malin, 1995). The Lunatics Act of 1853 instructed justices of every county to provide asylums for the “pauper, lunatics and thereof”. A lunatic under this act was every person of unsound mind and every person being an ‘idiot’. However, the Idiots Act of 1886 states that idiots or imbeciles did not include lunatics and vice versa. Many authorities complied with the 1853 Act to provide care, education and training in special asylums by putting all their mentally disordered people in the same institutions that housed the learning disabled. The situation was compounded further by the 1890 Lunatic Act (cited in Malin, 1995) defining a lunatic as an ‘idiot’ or person of ‘unsound mind’.

The future for the learning disabled began to look bleak in the early 1900’s when research began to suggest that learning disabilities were a genetic phenomenon and therefore inherited. The impact of such research was exacerbated by further findings suggesting that the capabilities of such
disabled individuals could not be remarkably improved with training. These contributing factors to the institutionalisation of the learning disabled are considered next.

_Eugenics and the rise of intelligence testing_

The future of training institutions for the learning disabled declined at the turn of the 19th century by a change in opinion of those in the medical and research world. The change regressed from an optimistic view about the potential for education and training, to a belief that such capabilities were limited. In the opinion of the professionals, the learning disabled would always be a burden to society. Tizard (1958) argued that two major events caused this change in opinion; i) the science of genetics, ii) the development by Binet (1905) of a standardised instrument measuring intelligence, and the idea that intelligence is unaltered and is unaffected by training or education. Binet's view was adopted by the eugenists who produced research evidencing the inheritance of mental defect. This led to Tredgold (1908) publishing a paper recommending that the only way to protect society was to segregate the learning disabled from the rest of society to prevent their reproduction. These views gave rise to the Mental Deficiency Act of 1913 (cited in Malin, 1995) which divided the learning disabled into four groups: idiots, imbeciles, feeble minded persons and moral detectives. This act proposed facilities for keeping people in institutions once they had been admitted, and encouraged compulsory certification as a way of ensuring such people remained captive. After the first world war more people were committed to institutions under the 1913 Act. The size of the institutions grew which led to the construction of institutions large enough to hold approximately two thousand patients.

After the second world war research findings began to shift the opinion regarding the potential for employment of people with learning disabilities. Psychologists produced findings suggesting improvements were possible at all levels of defect. This combined with direct observation and several inquiries into the state of institutions in the 50's led to a optimistic change in opinion.
regarding the capabilities of the learning disabled, and criticism of the inadequacy of service provision. This led to the view that there should be community care rather than segregation and hospitalisation. The psychology research findings and the inquiries into institutionalised care will now be reviewed in turn.

The move towards care in the community

Psychological research into the capabilities of the learning disabled

The work of Tizard, O'Connor and the Clarkes dominated a number of studies on the potential of the learning disabled and the higher than expected IQ levels to be found amongst patients of mental hospitals. O'Connor & Tizard (1954) surveyed a 2% sample of patients in 12 mental institutions. The average IQ of the feeble minded was over 77 and 50% were reported as not requiring special nursing or supervisory care. This survey highlighted the authors' criticism of existing training methods in hospitals as being irrelevant to outside employment, and as seriously underestimating the potential of the client for working in the community (Tizard & O'Connor, 1952).

The criticisms were supported by evidence from Hilliard (1954) who observed 175 female defectives in a ten year experiment to find them work in the community. Hilliard concluded that given the appropriate training learning disabled persons could make a valued contribution to society, and that certification was a waste of potential. Hilliard found in another study of admissions to a large hospital that higher than expected IQ levels existed amongst patients (Hilliard & Mundy, 1954), and again concluded that hospitals were not the right place for many of these people and called for more accurate diagnoses and more effective rehabilitation.

The Clarke's after challenging the suggestion of permanent defect as measured by an IQ test (Clarke & Clarke, 1953) set up a series of experiments to examine the learning ability of the uneducable, imbeciles and idiots. Their studies showed this population capable of various assembly and other industrial work not related to IQ, and that such capabilities improved by
incentives. The Clarkes research not only demonstrated the potential of the mentally handicap but also criticised the facilities for care in existence during the 1950's. More studies by the Clarkes (e.g. Clarke & Clarke, 1959) began to find associations between the environmental background (e.g. environments that offer physical and mental stimulation) with IQ and other measures of ability.

The change of mood amongst researchers evidenced by their findings which suggested that the learning disabled could make a useful contribution to society was firmly established in the 1950's. This mood however did not generalise to those who worked directly with the learning disabled, nor those who held power over administration and discharge in hospitals. The major cause of the post war laws pertaining to the care of the learning disabled and subsequent deinstitutionalisation was due mainly to the reported conditions in hospitals for the mentally ill and the allegedly wrongful detention of certain people.

**Reports into hospital conditions**

The bad conditions reported included impoverished physical environments, block treatment and inflexible routines, isolation from the community and their families, overcrowdedness, understaffing, poor physical and therapeutic care. These bad conditions were reported in terms of general inhumanity to patients rather than a lack of opportunity for rehabilitation. This was the motivation behind the pressures for change given in the evidence to the Royal Commission (1957).

Psychologists however continued to publish studies reaffirming the criticisms of existing institutions and pleas for more stimulating environments e.g. Tizard's (1966: cited in Malin, 1995) experiment in which 16 learning disabled patients were moved from a hospital to be cared for in small family group homes. They recorded improvements in behaviour, and an increase in IQ which they put down to a more caring and stimulating environment. Research into the conditions of long stay hospitals for example Morris's (1969) study of 35 subnormality hospitals emphasising the
appalling conditions such as lack of material resources, no treatment, and overcrowding, supported Tizard's plea for deinstitutionalisation. On a more practical level was work by King & Raynes (1968) criticising hospital care and contrasting it with local authority hospital care. They identified four characteristics of hospital care based on Goffman's (1961) observations of total institutional care in asylums namely rigidity, block treatment, depersonalisation and social distance between staff and client. The study by Morris (1969) and King & Rayne (1968) were important in that they openly proposed an alternative to the hospital system, that of rehabilitation and care in the community.

Rehabilitation

Although the Royal Commission initiated steps towards community care, the Mental Health Act of 1959 abolished compulsory detention of patients except in certain clearly prescribed cases. The act also required local authorities to care for mentally disordered people providing accommodation, training or occupation for children and adults with learning disabilities. However the 1959 Act remained unpopular because it maintained the status quo of the large hospital as the alternative to small group homes.

In the meantime psychologists continued to publish research on the success of rehabilitation and progress of handicapped people on acquiring skills given adequate attention and training (e.g. Gunzburg, 1961). The medical profession on the other hand opposed the infringement on the right of the clinician to decide the provision of services and viewed with alarm the planned number of hostels being allowed in a ten year plan for England and Wales (Ministry of Health, 1962). Under this ten year plan 'hostels' were defined as residential accommodation in small units. Tizard (1964) recommended that such residential care for the mentally handicapped could be based upon small units closely associated with the day care services of a particular area. The units would cater for all grades of defect and replace hospital approaches with nursing care only provided for
chair and bed-fast patients. Tizard estimated that the latter group could be housed in a 20-40 bedded hospital annex of a normal hospital. The proposed size of these hostels were determined by several factors such as economics, and in some cases the design of hostels were influenced by Tizard's recommendation and the Slough experiment (Baranjay, 1971) which provided a comprehensive social and industrial training centre for community care of people with a learning disability.

In support of the Slough experiment and a major contributor to the social training programmes for the learning disabled was Gunzburg (1968). Gunzburg believed that rehabilitation and resettlement involved improving the quality of life of the learning disabled individual, and this in turn depended very much on the individual's ability to acquire/reacquire adaptive and social skills to enable them gain some semblance of an independent life. With this view in mind he developed the Progress Assessment Chart (PAC) to measure levels of social skills attainment. His early version of the PAC appeared in the 1960's and by the time his detailed work on the subject of resettlement appeared (Gunzburg, 1968) the charts were in wide spread use.

In summary therefore, the experiments of the 1950's had demonstrated the ability of people with a learning disability to learn social and industrial skills given adequate training. A principle known as 'Normalisation' which according to Nirje (1969) means "making available to the mentally subnormal patterns and conditions of every day life which are close as possible to the norms and patterns of the mainstream of society" became the catchphrase of those seeking change in service delivery in the 1960's. The 1960's was a time marked for the debate on the desirability of rehabilitation, a joint approach to care, and the appropriate training to be carried out than for any real changes in the pattern of direct patient care. However towards the end of the 1960's the system moved towards a radical solution. The report of the Seebohm Committee (1968) and subsequent legislation set up social care ie community care should become the responsibility of local
authorities, and abolished the idea of ineducability. This was implemented in the 1970 Education (Handicapped Children) Act which led to junior training centres being taken over by education authorities with the provision that all children must be educated.

The 1971 White Paper - Better Services for the Mentally Handicapped gave credit to the principle of rehabilitation in the community and stressed that hospitals are for treatment not residential care. This paper also recommended a variety of services which should be made available to this client group and their families such as coordinated advice, support and practical help, residential accommodation when necessary provided by local authorities in small units. The final section of this essay looks briefly at the implementation of these recommendations and the role of the clinical psychologist in resettlement.

Resettlement and care in the community

Between 1971 and 1990 emerged a host of reports and committee's recommending and suggesting improvements in the care of the mentally disabled. The two most pertinent obtained and discussed is the 1979 Jay Report and the Community Care Act 1990. The Jay Report proposed a model of care based on the principles of normalisation. It recommended the ending of a dual system of hospital and local authority care with a transfer to the latter, and social work rather than nursing training for staff of all residential care homes. The Community Care Act (1990) incorporated the principles of normalisation ie it intended to enable people to live as normal a life as possible in their own homes or in a homely environment in the local community. It also proposed providing the right amount of care and support to help people achieve maximum independence by acquiring basic living skills to achieve their full potential, and to give people a greater individual say in how they live their lives and the services they need to help them do so. Finally the Act proposed a proper assessment of need and good care management within a multidisciplinary team to be provided by local authorities.
The role of the clinical psychologist in resettlement

Resettlement means deinstitutionalisation and move from hospital care to community care. When the Community Care Act of 1990 came into force incorporating the principals of normalisation, it was hoped that it would change the way community care was conceived and delivered. The proper assessment of needs and good care management within a multidisciplinary team was seen as the cornerstone of the new way forward.

A core member of the multidisciplinary team for the learning disabled is the clinical psychologist. In addition to the traditional role of a clinical psychologist of assessment intervention and evaluation, clinical psychologist working with the learning disabled are instrumental in implementing the proposals set out in the Community Act of 1990, that is, reinforcing the principals of normalisation by aiding the team to work towards providing the learning disabled with a better quality of life in their new homes. Quality of life reflects the degree to which there is a match between an individual's wishes, desires, abilities and living conditions.

In preparing for resettlement, clinical psychologists are involved in offering support and the systematic training of staff in the principals of normalisation and social role valorisation. They are instrumental in preparing a clear planning and implementation strategy which involves a focus on comprehensive community services, as well as resettlement. With regard to the client, they contribute to the planning of continuity of care and preparation of both client and family for residential and future day care services. This is implemented by consultation with the client's family and by assessing the client's adaptive and social skills, needs and special risks in a community. When matching them to the appropriate environment consideration is given to their level of mental and physical disability (Hogg & Sebba, 1986).
Clinical psychologists also evaluate the conformity of residential and day care services to the principles of normalisation and social role valorisation, i.e., evaluating whether the relationship of the client with others in society counteracts the processes of social devaluation. For example, Williams (1986) used Programme Analysis of Service Systems (PASS: Wolfensburger & Glenn, 1975; Wolfensburger & Thomas, 1983) to evaluate 52 residential services divided into 9 categories. He found institutional provision of care failed badly in adhering to the principals of normalisation followed closely by small homes within institutional grounds and village communities. He found that ordinary housing and social services hostels approached but did not reach the level of minimum acceptability in terms of normalisation, and concluded that ordinary housing that involved 'lifesharing' with non-disabled was the only provision to exceed minimally acceptable practice.

As core members of a multidisciplinary team, clinical psychologists are involved in overall service planning and delivery; identifying strengths and weaknesses of the service through observation, audit and research. Where weaknesses are identified, they communicate their findings to the team and offer support where needed. This support could be in the form of supervision or workshops in which they share their expert knowledge of psychology with other members of the team, e.g., giving behavioural guidelines in terms of managing challenging behaviour, and acting as consultants with regards to matters such as individual programme planning.

**Conclusion**

The role of a clinical psychologist in resettlement is not exhausted by all means, but much depends on the philosophy and resources of the trust they work for. They have made useful contributions to the study of learning disabilities by way of research, demonstrating the capabilities of this client group given the appropriate level of care and stimulation. Although care in the community is now in place, it has not been without its problems. It has been slow to implement and has encountered problems with funding. There is the danger of some homes in the community
becoming mini institutions in their own right with residents losing touch with relatives and friends (Malin, 1995). The closure of hospitals in itself has been said to be a waste of resources. Nevertheless community care is here to stay and the role of the psychologist will continue to centre on helping individuals to live as normal a life as possible.
References


Childhood bereavement has a less deleterious effect upon children's psychological outcome than does marital discord and divorce. Discuss
Bereavement and divorce is a time of anxiety, social withdrawal and sadness for children of all ages. This essay assumes the position that the extent to which both types of loss have deleterious effects on children depends on various factors such as the age, gender and timing of the ‘loss’. This paper reviews the literature on the short/long term effects of bereavement and divorce, and the various mediating factors from a psychodynamic and cognitive/developmental perspective. The next section looks at the research evidence supporting the view that both ‘losses’ can have similar deleterious effects on children. The essay concludes with recommendations for further research.

Psychodynamic model of bereavement

Attachment Theory

It is important to discuss the nature of children’s emotional attachments to fully understand the effect of bereavement and divorce on children.

At the very foundation of normal development is the child’s emotional tie to its parents and their bonding (Bowlby, 1980). Bowlby (1980) suggested that attachment behaviour is an instinct in its own right with the function of survival as its main aim. He postulated that attachment is “any form of behaviour that results in a person attaining or retaining proximity to some other... preferred individual” (Bowlby, 1980, p.39). Bowlby (1969: cited in White & Woollett, 1992) suggested that secure attachments are important because problems with attachment may have severe consequences; children who do not learn to trust and use their main carer(s) as a secure base may have less confidence to explore and to engage in close relations with others.

Erikson (1965) took a similar view and proposed that the essential task of infancy is the development of basic trust in others. He believed that during the early months and years in life, children learn about security - whether the world is a good or bad place to live in. As infants are
totally dependent for so long, they need to know that they can depend on the outside world. This trust and sense of dependability is sorely threatened during bereavement and divorce.

Bowlby (1969: cited in White & Woollett, 1992) suggested that the manifest behaviours that encompass grieving and mourning are attempts on the part of the individual to re-establish a relationship with the lost object. Insecure attachments, for example children/adults who have not sufficiently differentiated and do not have a firm sense of their identity and separateness from their lost object, may experience conflicting emotions over unresolved issues between themselves and their lost parent, resulting in pathological grief (Palombo, 1981).

From the attachment theory point of view, one could argue that a child's experience of losing a parent through bereavement or divorce would produce similar emotional reactions such as separation anxiety. Furman (1983) however, described death as unique and loss through death as unique. This fact, Furman argues is often overlooked when bereavement is grouped with separations, divorce and other kinds of 'loss'.

In comparison to divorce, Furman (1983) argues that death is unique in the special threat it poses for all humans and in its total finality, thus making it especially hard to cope with. Furman further argues that there are alleviating factors; for example, in contrast to divorce, death can happen only once to a loved one and if properly understood, unlike divorce, does not imply a rejection.

**Psychodynamic research on bereavement**

Furman (1983) and her group found in their psychotherapeutic work with young children who experienced both divorce and bereavement, that repeated contacts with the non custodial parent raised false hopes and created a nagging feeling making it difficult to cope with the divorce, whereas bereavement could be mastered. However this does not imply that divorce has a more
deleterious effect.

Furman (1983) found that the mental work of coping with loss through bereavement consisted essentially of three parts: i) understanding and accepting the reality of the death, and this includes the meaning of "dead" in concrete physical terms; ii) mourning i.e. the internal process of adaptation to the permanent unavailability of the deceased loved object; and iii) resuming functioning in accord with one's developmental stage in life.

Furman (1983) argued that these three tasks of grieving should follow each other, with success depending on the sufficient degree of achievement at each stage. Failure could occur at any stage, for example failure at the first stage to understand and accept the death results in the whole process becoming arrested and mourning proper cannot begin. Likewise the inability to undertake or complete the second stage (mourning) is said to interfere with the resumption of normal functioning. Furman argues that the unresolved difficulties with the first or second parts manifest themselves clinically only in failure with the last part. Since the resumption of normal daily living includes progressive personality development, the child's symptoms surface at the time when the task of a new developmental phase has to be coped with. Furman (1983) gives the example of a child bereaved in early latency experiencing emotional problems several years later during the prepubertal period.

Wolfenstein (1966) argued that the capacity to mourn is simply not present in children until the completion of the adolescent process. Wolfenstein postulated that in adolescence, a phase appropriate mourning reaction occurs when adolescents leaving childhood behind, confront their separateness from parental figures, mourn the fact that they are unattainable as objects for Oedipal strivings, give up these childish longings, and move on to adulthood. This differentiation from the parents make it possible then to experience others as love objects and to mourn their loss. Prior to adolescence, Wolfenstein maintained that children are too dependent on their parents
for narcissistic supplies, and fear their own disintegration should they lose a parent. If a parent
does die, one sees multiple defences being brought into play. The child may split up the ambivalent
feelings and idealise the deceased parent while making the surviving parent the recipient of hostile
feelings. Wolfenstein's (1966) point of view is consistent with the view held for the same reasons
that children do not suffer from depression. Mendelson (1974) summarises Wolfenstein's thinking
by saying that children cannot mourn because of i) insufficient differentiation of the ego; ii) lack of
object constancy; iii) short sadness span with the incapacity to sustain mourning; iv) extensive
use of denial or reversal of affect and v) lack of full development of reality testing and reality
awareness.

Furman (1974) argued against the position that children are not able to mourn because of lack of
object constancy. She argued that since the stage of object constancy is reached in the second
half of the first year of life, the proposition is modified to say that mourning is possible following i)
achievement of the stage when the love object does not interfere with cathexis of those functions
and activities required for mourning - memory, perception and object constancy, and ii) the child's
self investment is sufficiently autonomous and independent that they can survive mentally and
accept substitutes to provide care.

This paper has looked very briefly at the similarity of the experience of loss from a psychodynamic
perspective, and the conflicting views about children's ability to grieve and mourn the loss of a
parent. The next section looks at studies on the effects of bereavement on children. Both studies
when compared to the divorce literature, suggest that bereavement can have similar deleterious
effects on children.
The psychological effects of bereavement on young children

In both bereavement and divorce, symptoms in response to parental loss can be shown immediately, or may emerge after a delay of some months and possibly years. Some studies have reported that the physical and emotional impact of parental loss does not become obvious until two years after the bereavement. For example, Worden & Silverman's (1996) study assessed a sample of bereaved children four months, one year, and two years after bereavement. Immediately following the bereavement, none of the children showed disturbance of clinical severity. By the second year follow up, 21% of the bereaved children in contrast to 3% of the matched controls were evidencing emotional and behavioural problems of probable clinical significance.

Studies that have looked at children's adjustment within a year after the death of a parent have yielded mixed results. Weller, Weller, Fristad & Bowes (1991) reported on the depressive symptoms in prepubertal children 8 weeks after the loss of a parent. They found that when parent and child reports were combined, 26% of the children were reported as meeting the DSM III criteria for depression. Weller et al., (1991) failed to use a control group in their study. Fristad, Jedel, Ronald, Weller & Weller (1993) studied the effects of parental death eight weeks after the bereavement. They found bereaved children's psychosocial functioning to be similar to normal children and significantly better than inpatient depressed children.

Other studies have found high rates of dysfunctional symptoms e.g. Van Eerdewegh, Bieri, Parrilla & Clayton's (1982: cited in Worden & Silverman, 1996) longitudinal study found that bereaved children when assessed one month after the death, showed more depressed mood and deterioration of school performance than did controls.

Kranzler, Shaffer, Wasserman & Davies' (1990) study reported on the acute bereavement reactions of a cohort of twenty six 3 to 6 year old children who experienced the death of either
their mother or father. The study which was carried out 6 months after the bereavement suggested bereaved children showed significantly higher rates of disturbance than controls on both parent and teacher Child Behaviour Check List (CBCL) reports (Achenbach, 1983). The total CBCL scores for bereaved boys was higher than the scores for controls. The total CBCL scores for bereaved girls were no different than controls. Bereaved boys were rated significantly higher on both externalising and internalising factors and bereaved girls scored significantly higher than controls on the internalising, but not the externalising factors of the CBCL. The 3-4 year old boys, were the most symptomatic sub group and were the least able to discuss sad feelings in connection with their parents.

Kranzler et al., (1990) emphasised the importance of both preexisting and post death relationships between the child and his/her parents. The surviving parent's ability to cope with their own grief and their capacity to provide for the emotional needs of their young children was found to be critical. Depression in surviving parents was found to be the most powerful predictor of child disturbance. These very young acutely bereaved children exhibited a variety of symptoms, including anxiety symptoms such as high levels of clinginess, and frequently expressed concern about the well being of their surviving parent. This supports Bowlby's (1980) description of separation anxiety symptoms in young children and the importance of the surviving parent's capacity to care for their children.

The conclusion of Bowlby (1980) and Furman (1974) that grieving is possible even in early childhood is supported by Kranzler et al's (1990) study. Contrary to the contention of Wolfenstein (1969), the evidence from the affect interview in the Kranzler et al., study showed that children, particularly girls, even as young as three, express the emotions of grief and engaged in 'grief work'. Kranzler et al., (1990) argued that compared to adult grief, the emotional response in bereaved children is less pervasive, more intermittent and more situation specific.
Kranzler et al., (1990) commend the fact that their study is unique in its focus on recent bereavement in preschool age children and in the direct assessment of these children. However, they acknowledged that the study is not without its flaws, for example the study is limited by its use of a non representative sample of self referred and re-referred families. Thus they say the sample may have included a disproportionate number of both successful help seekers as well as more disturbed bereaved parents and children. It would also have been desirable to obtain data on bereavement responses at different times within the 1-6 month period in which the data was collected. The authors also acknowledged that the small sample size limited the power and scope of the data analyses.

The large clinical literature on childhood bereavement is controversial, and all the arguments about the effects on children cannot be reviewed in this essay. The general lack of consensus about the effect of bereavement on children is in part due to methodological flaws. Worden & Silverman (1996) argue that some studies failed to use a demographically matched non-bereaved control group. Without this it is not clear whether the observed behaviour is due to bereavement or due to age, gender or to developmental differences. A second problem is the use of non standardised assessment tools which make it difficult to compare across studies. The use of of parent/teachers as the informant instead of direct interviews with the children risks the possibility of the parent’s grief and mental health influencing their observations. As with both studies reviewed and many other studies on bereavement, the use of small samples, and different age cohorts, reduces the significance and generalisability of these studies to the wider population of bereaved children.

The effect of bereavement on adolescents

Birchnell (1970) argued that the capacity to sustain sad affect becomes commoner around puberty and so does the ability to express grief directly rather than through bodily symptoms or behavioural disturbances. The adolescent’s biological and psychological drive towards greater
autonomy conflicts with the tendency to become more dependent when bereaved and this may give rise to a seeming indifference or lack of feeling.

Freudenberger & Gallagher (1995) addressed loss, abandonment, and resultant depression in adolescents following the loss of a parent. They evaluated 24 parochial school children between the ages 8 and 16 who experienced the death or loss of a parent during infancy, early childhood, or latency. Each was referred for psychological evaluation because of manifest school dysfunctions.

Freudenberger & Gallagher (1995) found feelings of abandonment and depression to be the two major symptoms, either expressed or felt by the adolescents evaluated. They found that the initial loss was eventually accentuated by apathy or withdrawal which manifested itself in their lowered school grades and affective distancing from peers. Another manifestation found was poor expressive language skills. This they attributed to the children's diminished interest and involvement in interaction and communication. In view of the fact that the study's participants were drawn from a referred sample, and the authors' failed to use a control group, it is questionable whether these results generalise to the wider population of bereaved adolescents.

Long term effects of bereavement on children

The long term effects of childhood bereavement will be considered in relation to depressive illnesses since the psychoanalytic literature suggests that depression is the most likely outcome following parental loss (Bowlby, 1969). Empirical studies of the relationship between early parental death and psychiatric illness is controversial. Some studies suggest that adults bereaved as children have an approximately double risk of developing depression, especially if they experience a subsequent loss (e.g. Brown et al., 1971; Birtchnell, 1972a). Both these studies have been criticised for their methodological flaws in both Tennant, Bebbington & Hurry (1980) and Crook and Eliot (1980). Both reviews conclude that the current status of knowledge indicates that
parental death in childhood on its own has little impact upon the risk of depressive illness in adulthood. This conclusion is based on a number of methodological flaws in the research reviewed.

Firstly, sample selection was influenced by accessibility of participants and so participants came from psychiatric inpatients and outpatient populations. Such studies were flawed because findings were primarily related to psychiatric illness behaviour (or referral practices). Tennant et al., (1980) argue that only community based studies where non referred ‘cases’ are assessed can establish the relation between childhood bereavement and adult morbidity. Both Crook et al., (1980) and Tennant et al., (1980) highlight the problems of control groups. The possibility of psychiatric morbidity in control groups was not usually assessed and so the distinction between controls and experimental group was blurred.

Secondly, Dennehy (1966; cited in Crook & Eliot, 1980) noted that several factors that influence early adult mortality were not controlled for. For example the probability that an individual experienced the early death of a parent is strongly influenced by age, the age of his parents at his birth, and social class of the family of origin. The failure of many studies to control for factors such as age and social class has further contributed to the controversial nature of research in this area.

Thirdly, Tennant et al., (1980) argue that since childhood bereavement is considered pathogenic because of its psychological effects, it is important to exclude or study separately those cases where parental death is by suicide as this may indicate a substantial genetic risk for depression. None of the reviewed studies excluded parental suicides from their samples.

Fourthly, Munro & Griffiths (1968; cited in Tennant et al., 1980) found that adults recalled their immediate response to parental loss as less severe than expected; only 25% of subjects who had lost a parent during childhood recalled being emotionally disturbed at the time. In this light, the
difficulty of demonstrating long term adverse effects such as psychiatric morbidity becomes evident. Tennant et al., (1980) suggest that factors such as the attitude of the surviving parent, the stability of the family afterwards, and whether the parent remarries needs to be considered. Family stability and the child’s experiences following parental death are likely to moderate the impact of the bereavement; they are not confounding variables.

The question remains whether the symptoms and duration of psychopathology in children following bereavement is less deleterious than the impact of divorce and marital conflict. The next section will now answer that question by comparing the short and long term effects of divorce with the effects of bereavement.

The impact of divorce on children
During the first two years following divorce, children evidence physical and emotional problems and experience a host of stressors related to loss, conflict and change, Hetherington (1984). Two years post divorce, the majority of families have made significant adjustments Hetherington (1984). The research literature on divorce (e.g. Hetherington, 1987, Chase-Lansdale & Hetherington, 1990) like bereavement, suggests that long term adjustment is related to the age of the child, gender, and timing of the transition, and ensuing relationship with the custodial parent. Behaviour problems tend to persist in young boys in non married mother-custody homes for as long as six years (White & Woollett, 1992). Girls recover fully during elementary school years, but at the onset of adolescence show a variety of socio emotional problems (White & Woollett, 1992).

Short term effects of divorce on children
Children of all ages find the news of divorce profoundly upsetting. All children are acutely distressed even when aware of long term conflict in the marriage. The majority of children maintain fantasies of parental reconciliation (Wallerstein & Kelly, 1980; Furman, 1983). Emery (1982:cited in
White & Woollett, 1992) suggests that the short term reaction to divorce, like bereavement, depends on the child's own maturity, developmental stage and gender.

Wallerstein & Kelly (1977) conducted a study from a developmental point of view looking at how the experience of divorce affected the psychological and social development and especially the parent child relationship of children and adolescents. Sixty families with 131 children were referred to the project by attorneys, school psychologists, teachers and other sources. None of the 131 children had any prior history of psychological difficulty or psychiatric treatment.

Mothers had custody of the children in all but one family. Clinical interviews were carried out at the time of parental separation, and at one and four years after that time. Information was gathered about the quality of the marriage and family life, the events and feelings that preceded the decision to divorce, the personal history of each spouse, the impact of the divorce on each parent and the child, the relationship of each parent with the child and parent's perception of how their children understood and were coping with the divorce. These interviews and observations of the children as well as information about play behaviours and fantasies were used to understand how each child experienced his/her parent's divorce.

Wallerstein and Kelly (1977) found that parenting capacities deteriorated, and that the first year following divorce was the most stressful and critical time for the custodial parent and child. The relationship of the non custodial father both to the former spouse and to the child was a critical factor in the child's adjustment. The most distressed children were found to be those who became the focus of their parent's conflict; those whose custodial parents were themselves most distressed, and those whose parents received little emotional support from family and friends, a factor also evident in the bereavement literature (Kranzler et al., 1990).
Wallerstein & Kelly (1977) found that children of pre school age typically reacted with denial and they showed limited ability to understand divorce, hence tended to blame themselves. They showed intense separation anxiety and fear of abandonment by both parents, symptoms similar to those found by Kranzler et al., (1990) in their study of bereaved pre schoolers. Elementary children (7-8years) were less able to use denial than younger children and showed pervasive sadness, anxiety, depression, worry, loyalty conflict, guilt, and anger at one or both parents for the divorce. The 9 and 10 year olds felt shame and anger but were able to use a variety of mechanisms to deal with their feelings. At one year follow up, nearly half of the pre school group, over one third of the early latency, and half of the later latency children either were still displaying the dysfunctional behaviours observed in the initial interviews or were in an even more deteriorated psychological condition.

Kurdek & Berg (1986: cited in Chase-Lansdale & Hetherington, 1990)) suggested that the short term reactions of children to the separation of their parents vary as a function of their age. Infants and toddlers up to two years show their distress by failing to form secure attachments to their custodial parent. Pre school children were likely to worry about their own contribution to their parent's departure, to believe the separation is temporary, and to be confused by a parent reassuring them of their love yet moving away. The 6-8 year olds could understand that their parents might be incompatible and incapable of living together. The 9-12 year olds were more likely to experience conflict of loyalty and also to be ambivalent about both parents and to view their home and family environment negatively.

The attention to the different reactions of children at different developmental levels is one of the positive features of these studies. However, there were some notable methodological flaws in the designs akin to those found in the bereavement studies. Levitin (1979) noted specifically, in the Wallerstein & Kelly (1977) study the lack of representativeness or bias of samples and the lack of
control groups. When age and sex controls were used, the sample size become quite small, reducing the significance of the data. Finally the clinical interviews were not easy to replicate, and data collection and interpretation appears to rely heavily on subjective judgments and clinical skills.

The effect of divorce on adolescents

The divorce literature suggests that adolescents are initially anxious and upset by divorce, but they are on the whole more capable of coping, and many show significant growth in maturity (Wallerstein & Kelly, 1980). Kurdek & Berg (1983: cited in Chase-Lansdale & Hetherington, 1990) found higher rates of psychological adjustment among teenagers than late pre adolescent children in divorced families, and Zill & Peterson (1983) found no difference between adolescents whose parents recently divorced and those in non divorced families in rates of seeking or needing psychological help. In addition to advanced cognitive/emotional development, they have the advantage of deriving emotional support from peers and adults in other settings which may buffer the effect of divorce and facilitate adjustment Hetherington (1984). A substantial number of teenagers respond to divorce by becoming disengaged from the family and immersed in groups and activities outside the home. If these are prosocial groups and constructive activities, this may be a successful strategy in dealing with an aversive home situation. If these groups and activities are anti social, deleterious outcomes for the adolescent is more likely (Hetherington, 1989).

In the longer term however, akin to the bereavement literature which suggest some bereaved adolescents later experience depression in adult life (Jacobson, 1971; Birtchnell, 1971), Wallerstein, Corbin, & Lewis (1988) suggest that in the longer term it may be older children who have the greatest adjustment problems. Wallerstein et al., (1988) found Children aged 9-18 at the time of separation showed fewer signs of distress at the time of the break up. However, ten years later these adult children of divorce look back on the break up as a time of great personal unhappiness. They considered the divorce had a powerful influence on their lives and saw their
idealised childhood as having been snatched away from them. Children of separated or divorced parents may look inappropriately for explanations of any current unhappiness/depression in terms of family break up whereas children from intact homes have to find alternative explanations if they feel unhappy and dissatisfied with their lives (White & Woollett, 1992).

The effect of marital conflict on children


Chase-Lansdale & Hetherington (1990) reported that parents, teachers and clinicians described boys from conflict ridden homes as showing high rates of undercontrolled behaviour, aggressiveness, anti social behaviour and impulsiveness. Girls were reported as experiencing distress too, but were said to react in a more sexually stereotyped fashion e.g. being quiescent or trying to model good behaviour in the hope of promoting harmony in the home (Emery 1982: cited in Chase-Lansdale & Hetherington, 1990), and because of this internalised behaviour the distress of the girls is often not noticed by teachers and parents.

Cummings, Iannotti & Zahn-Waxler's (1986) study showed differences in the reactions of pre school (2 years) girls and boys who witnessed experimental manipulated conflict. Boys were said to respond aggressively towards peers following observation of the conflict, whereas girls showed more distress, were likely to withdraw and be quiescent afterwards. In addition, they found that there was a developmental progression, where younger children showed distress in response to their parents' conflict, while older children showed soothing, care taking behaviour in an attempt to
diminish the conflict, a pattern that is more marked in girls than in boys.

Hetherington et al., (1982) noted high rates of non compliant, aggressive and dependent behavior in pre schoolers after divorce and argued that because these patterns of behaviour were well established they may reflect both stress of divorce and long term impact of conflict preceding divorce. Hetherington's findings were supported by a longitudinal study by Block, Block & Gjerde (1986) of initially intact families of pre schoolers who were followed for 15 years. They compared children whose parents subsequently divorced with children whose parents stayed together. Boys whose parents later divorced showed high rates of undercontrolled behaviour at age 3, 4, and 7 than boys of the same age whose parents subsequently remained married. The effect of deteriorating marriages and family functioning remained evident for as long as 11 years prior to divorce. Block, Block & Gjerde (1986) found the impact on girls to be less marked.

Several lines of evidence converge to explain why boys show more marked effects of marital conflict than girls. Chase-Lansdale & Hetherington (1990) argue that boys are inclined towards aggressive behaviour to begin with due to biological propensities as well as cultural expectations. Boys are more likely to be allowed to witness marital conflict than girls, and so are more likely to imitate conflictual behaviour observed from the father (Emery 1982: cited in Chase-Lansdale & Hetherington, 1990). They are also in need of more discipline, yet this discipline is inconsistent due to parental conflict. Inconsistent discipline is also associated with conduct disorder in boys and to some extent over-control in girls (Block, Block & Gjerde, 1986).

The divorce itself may exacerbate ongoing behavioural difficulties in the immediate aftermath. For example Wallerstein & Kelly (1980) and Hetherington et al., (1982 ) found that the escalation of parental conflict post divorce was likely to contribute to significant deterioration in children's psychological functioning over the course of the first year or so. However, if divorce provides an
escape from conflict and does not lead to subsequent stressful events, children are eventually able to recover (Chase-Lansdale & Hetherington, 1990)).

However, Hetherington et al., (1982) noted that boys in both high and low conflict divorced families were still functioning less well at 2 years after divorce than boys in low conflict non divorced families. In contrast adolescents from low conflict divorced were equivalent in adjustment and school performance to those from low conflict non divorced families (Long & Forehand, 1987).

Long term effects of divorce

Over the long term, conclusions regarding the long term effects of divorce is limited to factors of gender and age of the child as well as timing of parent's marital transitions. If divorce occurs early in children's lives, and if the custodial mother does not remarry, behaviour problems seem to persist for boys for as long as 6 years after divorce (White & Woollet, 1992). Girls in non remarried mother custody families appear to recover completely during elementary school years, but at the onset of adolescence they may show a variety of problems, including heightened conflict with mother, increased anti social behaviour, disturbance of self esteem, and problems in heterosexual relations and behaviour.

If their parents remarry, younger boys socioemotional development is likely to improve; however elementary school-aged girls may be negatively affected. If the mothers marriage occurs in children's early adolescence, both boys and girls may show heightened levels of psychopathology beyond the 2 year adjustment period. In adulthood, young women from families of marital disruption are more likely to experience divorce themselves (Chase-Lansdale & Hetherington, 1990).
Conclusion

This essay has argued from the viewpoint that bereavement does not have a less deleterious effect on children than divorce and marital conflict. Although there are no studies to date that directly address this issue, the conclusion is drawn from the literature on both short and long term effects of both bereavement and divorce. We know from the psychodynamic literature that the experience of any form of parental loss is followed by separation anxiety, other physical/psychological reactions depend on the age (stage of cognitive development; ability to comprehend the loss), and the gender of the child, (boys more prone to externalising behaviour e.g. aggression). Other mediating factors include the nature of support networks available to the child, the relationship of the child with the surviving/custodial parent, and the parent's adjustment to the loss of their partner.

Further research is clearly needed following bereaved children and their families for longer periods of time than is presently done. Unless such research and subsequent longitudinal research comparing children who have experienced either loss is performed the question as to whether bereavement has a less deleterious effect remains controversial.
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Specialist Essay 4: Health Psychology

Critically evaluate the use of Cognitive Behaviour Therapy in the management of chronic pain for adults.
In order to answer the question the essay will begin by briefly discussing theories of pain and chronic pain, and how combined physical and psychological theories of pain gave rise to the development of cognitive and behavioural therapies for chronic pain. The essay will then discuss some of clinical research trials of cognitive behavioural therapies for chronic pain, and end by critically evaluating the usefulness of cognitive behaviour therapy for chronic pain.

**Definition of pain**

Sternbach (1968: cited in May, 1991) defined pain as an abstract notion which refers to; i) a person’s subjective experience of the sensation of hurt; ii) a harmful internal or external stimulus which may indicate present or imminent tissue damage and; iii) a succession of responses which act to protect the individual from harm. May (1991: cited in Pitts & Phillips, 1991) argued that this definition is based on a linear model which postulates that pain is triggered by tissue damage, and that the alleviation of pain will occur following the removal or repair of the damage. May argued that the model is not supported by clinical research, and cites the work of Beecher (1959) whose research provided evidence that tissue damage does not always determine pain sensation. The research reported that of a sample of seriously wounded combat soldiers returning from the second world war, merely a quarter said they needed an analgesic. Far more pain was reported by soldiers who had sustained much smaller wounds. Beecher explained these findings as follows: those with serious injuries were more positive about their wounds because they knew they would provide a ticket to safety, while the slightly injured soldiers believed that they would be returned to action, so such injuries were viewed more negatively. In a related investigation, Beecher (1956: cited in Skevington, 1995) found that the less severe wounds of civilian surgery were associated with greater pain than the more severe wounds of war, which were painless in some cases. Only 32% of the war wounded wanted analgesia, compared with 83% of civilian surgery patients. Beecher’s studies suggest that the severity and intensity of pain sensation depends on the meaning attached to the pain rather than the presence and extent of tissue damage. Further
evidence against Sternbach's (1968) model of pain comes from people's experience of phantom limb pain i.e. pain in the absence of a harmful stimulus and subsequent tissue damage. These reports challenge the assumption that pain is triggered by tissue damage, and suggest that an alternative explanation is needed to explain the sensation of pain.

**Pain theories**

Two early physiological theories of pain postulated that pain sensation was the result of stimulation of nerves endings. The specificity theory (cited in May, 1991) suggested that pain perception was the result of the stimulation of particular receptors or free nerve endings at the periphery. However excitation of particular receptors and nerve endings produced various sensations as well as pain sensation. May (1991: cited in Pitts & Phillips, 1991) argued that the lack of evidence to support this theory led to a second theory called the pattern theory of pain which suggested that excessive peripheral nerve stimulation of any kind would cause pain. Melzack & Wall (1965: cited in Skevington, 1995) incorporated this view along with psychological aspects into what they called the 'gate theory'. Melzack and Wall (1965: cited in Skevington, 1995) defined pain as an experience whose severity and intensity is influenced by the individual's unique past history of experience of pain, the meaning the individual attaches to the current pain producing situation, and by the individual's state of mind.

Melzack and Wall's (1965) gate theory proposed that situated in the dorsal horns of the spinal cord is a gating mechanism which regulates pain by monitoring the activity of certain myelinated and unmyelinated peripheral nerve fibres. Myelinated A- delta fibres control sudden or sharp pain, and unmyelinated C fibres and A-beta fibres control dull, diffuse or aching pain. When these fibres enter the spinal cord via the dorsal horns they are packed into layers which contain cells that are stimulated by the activity of these fibres. The unmyelinated A beta fibres activates the cells of the substantia gelatinosa which inhibits the firing of the central transmission cells, in other words,
‘closes the gate’. The myelinated A-delta fibres and unmyelinated C fibres block the firing of the substantia gelatinosa which then activates the central projecting transmission cells, in other words, ‘opens the gate’. The fibres then fire to areas of the brain responsible for the sensory aspects and expression of pain and areas of the brain responsible for the experience of aversive - cognitive - motivational and emotional reactions. Finally the response to pain is experienced following the descension of fibres from the brain on ‘the gate’. The pain experience that follows is influenced by the individual’s evaluation of the pain which in turn is influenced by past experience. In summary pain is experienced following the firing of specific nerve fibres and the evaluation/perception of the sensation that follows. The individual’s evaluation of the sensation will be influenced by the individual’s emotional state, and their past experience and reaction to pain. The possibility of experiencing pain in the absence of tissue damage according to the gate theory is due to A-Beta fibres inhibiting the activity of the central projecting transmission which closes the gate, together with other cognitive and behavioural factors, such as the memory of previous experiences and the meaning attached to the pain. These memories of past experiences influence anxiety levels at the time, making pain less or more intense and severe. In spite of its many criticisms Melzack & Wall’s gate theory provided the bases for understanding pain as an experience mediated by the integration of sensory, affective and cognitive factors.

Having briefly discussed various theories of pain the next section of will focus on chronic pain.

The role of cognition in chronic pain

Chronic pain is mostly defined as any pain lasting six months or more (Tan & Leucht, 1997). The problems of chronic pain patients’ are frequently much complex than the pain itself. Pain that individuals’ find hard to control causes immense suffering and hardship, and can have a detrimental on patients’ families. Presently, medical and surgical approaches have had little success in treating chronic pain (Morley, Eccleston, Williams, 1999). This fact, together with a growing interest in the role of psychological factors in pain, led to major developments in intervention. For most
individuals the degree of disability, pain, and psychological distress increases with greater severity of injury or illness, but research suggests that other factors influence adjustment. For example, Waddell, Newton, Henderson, Somerville & Main (1993) demonstrated that only 25% of the variance of disability responses to chronic low back pain could be accounted for by physical impairment. Thus the nature and severity of physical injury or disease did not account fully for the impact of chronic pain, which suggest that other factors were involved. Patients may begin to observe how their pain varies in relation to psychological and physiological states such as mood, boredom, fatigue and stress.

It seems likely that there is an association between poor psychological adjustment and pain. Persistent pain affects daily functioning and some individuals may respond with symptoms of depression and anxiety (Gil, Abrams, Phillips, & Williams, 1992). It is possible that mood state may influence the level of pain people experience with negative mood producing increased self reported pain levels (Gil et al., 1992, Spence, 1993). Pain can become the focus for unpleasant internal experiences, and a variety of psychological states may be interpreted and lumped under the label of ‘pain’. For example, pain may appear a more convincing reason for requiring support from others, than a complaint of depression (Morley et al., 1999).

Another factor which may impact on disability associated with chronic pain is patients’ attitude and beliefs about their pain. It is clear from research (Keefe, Salley & Lefebvre, 1992) that a person’s beliefs about their pain and coping abilities have a great effect on their adjustment. Beliefs which concern the degree to which patients believe that their pain is made worse by increased activity, avoid activity in order to promote healing or pain relief. Unfortunately such inactivity is likely to bring about a deterioration in their physical condition (Linton, 1985), and the psychological effect of avoidance undermines the patient’s confidence and reduces his/her ability to find the limits of the pain. The patient’s inactivity can lead to boredom, depression and lowered...
self esteem, all of which contribute to pain experience. Inactivity can also lead to an enhanced preoccupation with bodily sensations, which may be interpreted by the patient as an undetected and unresolved painful episode (Pennebaker, 1982). Patients' belief about perceived control and self efficacy also influences functioning in chronic pain. Keefe, Block, Williams & Surwit (1987: cited in Spence, 1993) demonstrated perceived control to be more strongly associated with better physical and psychological functioning in osteoarthritis patients than physical measures of disease status from x-ray. Self efficacy has also been shown to be important in determining adjustment and response to pain. This is also true for self efficacy expectations regarding the likely effectiveness of coping strategies, treatment, and ones ability to perform particular activities. Lazarus and Folkman's (1984) model of stress appraisal and coping, suggests that the use of coping strategies is influenced by the individual's appraisal of their own coping strategies.

Several studies have tried to identify the type of responses which influence adjustment to chronic pain. Various responses have been shown to be associated with poor adjustment. These include passive responding, catastrophising, praying and hoping (Gil et al., 1992). Good adjustment is associated with increased activity or attentional coping methods such as engaging in activities like reading, diverting attention and using coping self statements (Spence, 1993). Jensen, Turner, Romano, & Lawler (1994), investigated the correlates of improvement in multidisciplinary treatment of chronic pain for 94 chronic pain patients. They found that improved functioning and decreased health care use were associated with changes in beliefs about pain and cognitive coping strategies. However they did not find a strong relationship between improvement and changes in the use of some behavioural coping strategies such as increases in aerobic exercise, keeping busy, relaxation and decreases in pain contingent rest and opioid medication use. They tentatively concluded that improvement following treatment may be more related to changes in what chronic pain patients think about their pain than in what they do about their pain. They noted that although their data were correlational and not causal in nature, their findings were consistent with a cognitive
behavioural model for chronic pain control.

It is clear that cognitive processes play an important part in determining how people respond to chronic pain. It is also evident that a variety of environmental and biological factors have a contributing role which also needs to be considered during psychological intervention. Spence (1993) postulates that there are two main forms of cognitive therapy that are likely to be beneficial in the management of chronic pain. The first approach involves cognitive restructuring methods which suggest that distorted or maladaptive thoughts, attitudes and beliefs are associated with poor adjustment. Cognitive restructuring aims to increase beliefs regarding one's ability to control pain and to reduce fear/avoidance beliefs. The second approach involves techniques relating to the teaching of cognitive skills. These include relaxation imagery, biofeedback and attention diversion.

The next section reviews clinical trials of these methods in the management of chronic pain.

Clinical trials of cognitive behavioural therapy for chronic pain

Cognitive behavioural therapy (CBT) for pain control has also at times been referred to simply as cognitive therapy for pain. Cognitive behavioural therapy for chronic pain evolved from the development of CBT for behavioural and psychiatric disorders. All the cognitive approaches to these disorders and chronic pain usually involves teaching patients to use cognitive coping skills such as distraction, imagery techniques, and calming self talk, and to modify or reduce negative self statements and catastrophising thoughts. In addition, the most comprehensive treatments usually include other behavioural interventions such as relaxation, biofeedback, desensitisation, external contingency management or operant conditioning, modelling, and social skills training (Tan, 1982). This makes it difficult to know what role cognitive therapy plays in the effectiveness of such treatment, and whether improvements in adjustment are associated with changes in cognition.
Numerous cognitive interventions have been developed for a variety of chronic pain problems such as lower back pain and rheumatoid arthritis. Although the interventions vary in some way, cognitive pain interventions all share essential components such as education, discussion of the medical and psychosocial consequence of pain, and skills acquisition e.g. relaxation, biofeedback and pain relief imagery. In a controlled study of 81 patients with chronic lower back pain, Turner & Clancy (1988) randomly assigned patients to one of two therapeutic conditions (operant Vs. cognitive) or to a waiting list control group. The patients had had back pain exceeding 6 months, (with an average of 14 years) and were able to participate in aerobic exercises. Patients were treated in small groups for 2 hours a week for eight weeks. The cognitive group received training in systematic progressive relaxation and imagery, supplemented by home practise, identification of maladaptive thoughts and emotions associated with pain and stressful events. The results showed that the operant group benefited more than the cognitive group at the end of treatment. However both treatment groups showed significant improvements especially in the reduction of cognitive errors, but neither group reported significantly less pain than the control group at the end of therapy, so that after 12 months the two groups were no different. However questionnaires completed showed that the CBT group were more satisfied with their treatment and found it most helpful. Without the inclusion of these subjective measures, the value of the CBT programme would have been lost.

Spence (1991) in her clinical trial of CBT for chronic occupational upper limb patients showed that CBT on either a group or an individual basis produced significant reductions in depression and perception of pain during treatment, and these gains were generally maintained at a 2 year follow up. The study also showed continued reductions in disability, distress, and interference in daily living across the two year period. Although coping skills shifted from a passive coping style towards more active coping strategies during the treatment period, and were maintained at 6 month follow up, there was a tendency for coping strategies to shift back towards a passive style by the
two year follow up. Bradley, Young, Anderson, Turner, Agudelo, McDaniel, Pisko, Semble & Morgan (1988: cited in Gatchel & Turk, 1996) evaluated their treatment of rheumatoid arthritis patients over 15 weeks. They compared the use of CBT to the effects of standard medical treatment and found that CBT in comparison produced significant reductions in pain behaviour and disease activity at post treatment. CBT also produced a significant reductions in pain intensity ratings at post treatment. However a 1 year follow up assessment revealed that only the reduction in pain intensity ratings were maintained following termination of treatment.

From these studies it is not clear what contribution the cognitive therapy component made to the management of pain. Turner & Jensen (1993) tried to tease out the cognitive from the behavioural components of intervention. Their results demonstrated that cognitive therapy and relaxation training were both effective in reducing depression, disability, pain behaviour, and pain. They concluded that the two were equivalent in terms of reducing pain, (which indicates that the less costly treatment of relaxation training might be more profitably used). These benefits were maintained at 12 months follow up with no differences evident between treatments (relaxation, cognitive therapy or the two combined), and no additional effects for a combined cognitive-relaxation training approach. The Turner & Jensen (1993) study reported that behavioural therapies on their own produced changes in cognition, without any direct attempt to modify thoughts, attitudes, or beliefs. This view is supported by Spence (1992) who compared the benefits of EMG biofeedback, relaxation training and a combined procedure in the management of chronic pain. The study reported that changes in pain beliefs occurred without requiring cognitive therapy.

Turner & Jensen (1993) postulate that behavioural methods such as relaxation training forms an important part of pain management. Hillenberg & Collins (1982) reviewed 26 different relaxation procedures in 80 studies and concluded that the more sessions attended, the more effective relaxation tends to be. However they found considerable diversity in the quantity and style of
relaxation training carried out and little attempt to report these procedures in detail or to standardise them. With the research focus on the better management of pain, they found theories about how relaxation works absent.

Biofeedback as a CBT component has frequently been employed to assist feedback about levels of muscle tension during relaxation training. Keefe et al., (1987) found that back pain patients who attended 10 sessions of biofeedback with home practise reported significant reduction in pain, tension and EMG activity at the completion of training, but attempts to distinguish improvers from non-improvers were confounded by different initial levels of pain in the two groups. In a smaller but well controlled study of chronic rheumatic back pain patients where EMG biofeedback was compared with two conditions of pseudotherapy and conventional medical treatment, Flor, Haag & Turk (1986) found that patients in the biofeedback group did better and maintained these benefits on cognitive and behavioural measures. Biofeedback patients saw treatment as effective, furthermore, those who improved most said that they had continued to use relaxation to control their pain and tension because it gave them an increased sense of control. In contrast those who did not improve reported more helplessness, hopelessness and greater feeling of dependency on medical help.

Critical evaluation of research on CBT for chronic pain

Tan & Leucht (1997) point out, there is no one cognitive technique that has been found to be effective with all chronic pain patients. Psychological treatment of chronic pain is complex and variable, and outcome is mediated by various factors. Nevertheless clinical findings continue to support the efficacy of CBT for chronic pain control.

In a systematic review and meta-analysis of 20 randomised controlled trials of CBT for chronic pain, Morley et al., (1999) concluded that CBT including biofeedback was more effective relative to
waiting list control conditions. CBT produced significant changes in measures of pain experience, mood, affect, cognitive coping and appraisal, reduction of negative coping and increase in positive coping, pain behaviour, activity level, and social functioning. When compared across the same range of outcomes with other treatments or control conditions the authors found that the efficacy of CBT was of a smaller size and limited to the outcomes of pain experience, positive coping and social role function. The authors commented on the quality of the trials (which include most of the trials mentioned in this essay), in their opinion most were statistically under powered. This they found not to be surprising given the difficulty of administering complex treatment programmes to large numbers of patients over a long period of time. They also felt that some studies could be regarded as too complex with multiple treatment and control groups. They recommended the use of simple two armed trials with sufficient numbers, comparing a treatment group with a suitable control group. Morley et al., (1999) argued that control groups need careful consideration; patients assigned to a waiting list in one trial may continue to receive treatments such as physiotherapy, pharmacotherapy which may be equivalent to the treatment control in another trial. Unless expectations of efficacy were monitored, they argued that it would be a mistake to make assumptions about equivalence in terms of patients experience. They also found variability within the class of treatment controls from continuing previously ineffective treatments to starting a treatment with demonstrated benefit, such as 'pain' education.

In most studies the long term comparison of treatment and control groups was rendered difficult by the use of waiting list controls. Patients in these groups were commonly entered into an active treatment group or dropped out of the trial. When treatments were considered across both treatment control and waiting list control groups, there was considerable variability on quality and quantity of treatment as reported in the results. In some studies Morley et al., (1999) found that while some authors gave explicit accounts of the treatment procedures with reference to manualised interventions which were appropriately monitored, others did not. Morley et al., (1999)
discovered that in nearly all the studies they reviewed, data were sparse on health service use, drug intake, uptake of additional treatment, and change in work and occupational status as a consequence of treatment. The over reliance on self report measures was also noted. While many of the measures were psychometrically reliable the extent to which they were influenced by measurement reactivity was often unknown.

It appears that whatever psychological treatment approach is used; the benefits tend to be similar. Remarkable changes in physical and psychological adjustment to chronic pain appear to be produced whether the treatment involves cognitive therapy, operant/behavioural methods, cognitive-behavioural methods, relaxation training or biofeedback. Spence (1993) in her review concludes that there is a need to investigate the relative effectiveness of cognitive vs. behavioural components of interventions for pain. It has been suggested that all CBT approaches produce positive results because the mode of influence is via changes in perceived control rather than through specific behavioural or physiological changes. In support of this argument, Holroyd (1984: cited in Spence, 1993) reported that reductions in pain following EMG biofeedback training were associated with clients' expectancies regarding the success of training, with increases in self efficacy and internal locus of control. In the light of Holroyd's findings Spence (1993) suggests that it would be interesting for future research to focus on methods of restructuring attitudes and maladaptive pain and control beliefs directly, rather than focusing on changing the maladaptive cognitive errors relating to depression, such as catastrophising, personalising and overgeneralising. In most of the studies mentioned it has been difficult to show that CBT generates long term benefits. There remains a need to develop an approach that is cost effective, and demonstrate that CBT produces improvements that patients can maintain long term following completion of treatment.
Conclusion

Psychology has come a long way since the early 1960s when Melzack and Wall outlined the Gate Control theory of pain and opened the way to examine psychological influences on the experience of pain. Since that time, a great deal of evidence has accumulated to suggest that cognitive factors play a significant role in determining how people adjust to chronic pain. Attitudes to and beliefs about pain, injury, and ability to use coping skills are particularly relevant in determining emotional and behavioural responses to persistent pain. Cognitive behavioural therapy on the whole in its various forms has been efficacious in addressing these factors. Although treatment effects appear short lived, this highlights the need for chronic pain patients to have continued access to psychological services following attendance of a pain management programme.
REFERENCES


Essay 5: Older Adult

Critically evaluate the evidence for the effectiveness of treatments for depression in older adults.
This essay will focus only on the evaluation of psychological treatments for depression and will not include bipolar depression. The essay will begin by outlining the presentation of depression and its associated risk factors in older adults. The application of Behavioural, Cognitive and Psychodynamic therapies in the treatment of depression in older adults is discussed next, followed by a critical evaluation of clinical research on the efficacy of psychological intervention for depression in older adults. The essay concludes with recommendations for future research.

Depression in older adults

Depression is said to be the most common psychiatric problem in older adults (Koder, Brodaty & Anstey, 1996). It is said to be akin to depression in younger adults except it can be more complex owing to central nervous system (CNS) and non CNS problems common in old age (Gallagher & Thompson, 1982), such as dementias and slow information processing. Therefore it cannot be assumed that older people will respond to psychological therapies in the same way or at the same pace as younger adults (Woods & Roth, 1996). The presentation of depression is another area of complexity as depression in older adults may be masked by the presentation of anxiety, panic, somatic complaints such as pain, and physical illness (Bergmann, 1982). Teri & Wagner (1992) argue that the prevalence of depression in the elderly is masked by the exclusion of people with dementia. Furthermore, research tends to focus on community samples, ignoring the very high prevalence of depression in residential settings.

Several factors put an older person at risk of depression including: adverse life events such as loss of a partner; pain associated with physical illness and disability; poverty; loneliness and a previous history of depression (Roth & Woods, 1996). Older adults with psychiatric problems are often inadequately managed by primary and secondary services, with a probability of being diagnosed as suffering from dementia rather than depression (Roth & Woods, 1996). When older adults are referred to psychiatric services they are less likely to be referred to psychology
services, and more likely to receive biological treatments such as ECT and medication (Koder et al., 1996).

**Psychological therapies for depression in older adults.**

A growing body of evidence suggests that psychological therapy is effective in alleviating depression in adults. Research by Blackburn, Eunson & Bishop (1986) suggest that CBT has long term effects in preventing relapse, and Kovacs, Rush, Beck & Hollon (1981: cited in Gallagher-Thompson et al., 1990) reported that 56% to 70% of young adults with depression sustained remission after psychotherapy for over one year.

Psychological interventions for the elderly is very much the same as for younger adults except for a few modifications. For example, Koder et al., (1996) suggest reducing the rate of conversational flow of each session allowing the patient time to process information (Morris & Morris, 1991). Cognitive, sensory and perceptual impairments should be addressed by the use of large printed material, frequent review of progress, bright lighting, low background noise and sitting close to the patient (Thompson et al., 1986). Koder et al., (1996) suggest that beliefs about etiology of depression may need to be challenged as the elderly may be more likely to take a passive role by relying on the physician for symptom relief or cure (Thompson et al., 1986), or they may or fail to acknowledge physical symptoms as a feature of depression. Some may begin therapy believing that they are too old to change. Thompson et al., (1986) recommend tackling such views directly and reframing the task of therapy, for example describing CBT as helping them to cope better with depression as opposed to therapy as a cure for depression. Various psychological interventions have been used to treat depression in the elderly including cognitive behavioural therapy, behaviour therapy and psychodynamic therapy discussed next.
Cognitive-behavioural therapy

This form of therapy is based on Beck, Rush, Shaw & Emery's (1979) theory of depression which regards thought processes as causative factors in depression. They postulate that people become depressed because they negatively interpret events which cause them to think negatively about themselves, the world and the future. Cognitive therapy emphasises the importance of restructuring unhelpful negative thoughts and counterproductive assumptions and attitudes in order to alter negative feelings and behaviour. Depression is alleviated through therapy by 4 main strategies: 1) identifying negative thoughts and feelings; 2) evaluating and challenging evidence for thoughts and beliefs; 3) adopting more helpful and realistic positive thoughts and responses; 4) modifying dysfunctional attitudes. The technique is combined with behavioural components such as role play, graded task assignments and increasing daily activities which all aim to break the cycle of depression and give the individual a sense of control and achievement. Gallagher & Thompson’s (1982) cognitive therapy for older adults involved giving participants a booklet explaining the rationale for therapy stressing the importance of the cognitive triad ie negative view of self, world and future in the maintenance of depression. Patients were taught to use diaries to monitor their thoughts on a daily basis and were shown the association between negative thought patterns and mood state. Patients were encouraged to alter their unhelpful thoughts by generating and experimenting with more adaptive ideas. The aim of cognitive therapy is to help patients become aware of the habitual nature of negative thoughts and to help them develop a greater flexibility in thinking so that future events can be interpreted in a more productive way. In later sessions patients were helped to identify repetitive themes related to distorted fundamental beliefs and to see how cognitive strategies learned in therapy could be generalised to other areas in their lives and be applied in the future.
Behaviour therapy

Lewinsohn's (1974; cited in Thompson et al., 1982) description of behaviour therapy for depression focused on social learning and the role of reduced reinforcement in the etiology and maintenance of depression. Behaviour therapy involves reinstating positive behavioural patterns and creating new activities to compensate for some of the losses that the elderly experience. The focus of the therapy with older adults is to increase the frequency of positive experiences and minimise negative experiences. Gallagher et al.'s (1982) study on psychological interventions for depression in the elderly included giving patients pamphlets at the beginning of therapy explaining the rationale for therapy. Patients were then taught to use a diary to monitor their mood and behaviour daily, and the results were plotted on a graph produced by the therapist which showed the patient the association between mood and pleasant and unpleasant events on a daily basis. Patients were then introduced to techniques such as relaxation, social skills training and problem solving as a skill designed to increase or decrease events that were powerful determinants of mood for the client. Patients were also given homework which was used to focus the direction of subsequent sessions so that learning was reinforced and generalised.

Psychodynamic therapy

This therapy for the elderly is best explained from an object relational position which focuses on the older adult's relationship with significant others as the basis for psychopathology (Turner, 1992; Papouchis & Passman, 1993). The approach draws on Bowlby's (1973:cited in Papouchis & Passman, 1993) attachment theory which postulates that loss is a central factor in psychopathology. Loss is a common theme in old age and may include loss of physical health, partner or status. Papouchis & Passman argue that the experience and reaction to loss is a crucial determinant of how the aging process is interpreted by the individual. Bowlby argued that needs are related to different stages in life and that the attachment phenomena continues throughout life. Therapy therefore must consider the developmental task that older adults are dealing with, and the
environmental factors which play a critical role in their ability to achieve these developmental tasks (Papouchis & Passman, 1993). In other words therapy involves addressing uncompleted tasks from earlier life so that work can begin on later life issues. For example Liptzin (1985:cited in Turner, 1992) found the issues of trust Vs. mistrust needed to be addressed and resolved before integrity Vs. despair could be addressed. This view is supported by Pollock (1986:cited Papouchis & Passman, 1983) who argued that later life is a time of mourning for what one has failed to achieve, and that unless this work of mourning is mastered, an older person is at risk of turning rage and despair into himself and become depressed. The fundamental task of therapy is to help the individual mourn, come to terms with their losses, adapt to them, and reintegrate a different sense of self (Lazarus 1988: cited in Papouchis & Passman, 1993).

Group therapy

Cognitive-behavioural group therapy approaches employ cognitive and behavioural strategies to the group setting (Leszcz, 1990), with the aim of therapy being similar to individual therapy. Psychodynamic group therapies for the elderly include reminiscence or life review work (Butler 1974:cited in Leszcz, 1990). The psychodynamic approach aims to restore and stabilise the individual's sense of self in the face of life events that are common with the aged. Group therapy aims to increase self esteem and provide an environment where narcissistic injuries to the self may be addressed and resolved via the provision of relationships that may serve self object functions in addition to real objects for relatedness (Schwartzman, 1984:cited in Leszcz, 1990)). Other advantages of group therapy include the avoidance of isolation, reduction in loneliness, enables people to see that others have similar problems, enables them to offer something to others, group environment offers support from others. Furthermore it is cost effective.
Clinical research on psychological interventions for depression in older adults.

The first question we must ask is, do psychological therapies for depression in the elderly work?, and how do they compare to waiting list controls.

Scogin & McElreath (1994) in a quantitative review of 17 studies set out to examine the effectiveness of psychosocial treatments for geriatric depression and to compare the effectiveness with treatments for other age groups. They reported that at post treatment, subjects who received either group or individual psychological treatment (which could include cognitive, behavioural, psychodynamic or reminiscence) were significantly better on outcome measures than their no treatment and placebo counterparts. Four of the studies which focused on the elderly with major depression reported that subjects showed significantly less posttreatment depression than their no treatment or placebo-control counterparts. They also found that no particular model of therapy was superior to the other in the treatment of depression in the elderly. Based on studies that totalled 765 participants, they concluded that psychological therapy was effective in the treatment of depression. The overall effect size for treatment Vs. no treatment or placebo control was .78 which compared favourably with the mean effect size of .73 obtained by Robinson, Berman, & Neimeyer (1990) in their review of psychotherapy for depression across all adult ages. The results of the Scogin & McElreath (1994) study further suggests that psychological intervention is effective for both major and subclinical depression. The authors acknowledged that the number of studies reviewed were small, and that the study failed to acknowledge the absence of evidence to show that therapeutic gain was maintained over time.

The second question is, if therapy works, do patients maintain therapeutic gain over time?.

Gallagher & Thompson (1982) reported on a study which aimed to explore the effectiveness of three types of interventions (behavioural, cognitive and brief relational/insight), and their
comparative value in the treatment of depression in older adult outpatients. The authors hypothesised that the two structured therapies (behavioural & cognitive) would be more useful with older adults given the nature of the problems they experience that may trigger depression. Thirty participants were involved aged 59-80 with a diagnosis of non-psychotic major depression for at least one year, 30% had previous admissions for depression. The participants were randomly assigned to one of the three individual therapy conditions for 16 sessions over 12 weeks. Eight participants dropped out before the third week (one from cognitive, two from relational/insight and five from the behavioural condition) and were replaced. Participants classified as endogenous subtype accounted for half of the sample and were distributed evenly across the three conditions. Evaluation occurred before and after therapy and four times during a one year follow up. The study reported improvements from pre to post therapy in all three groups via observer and self-report measures of distress (Beck's Depression Inventory and Hamilton Rating Scale for Depression). The follow up report suggested that participants in the cognitive and behavioural therapies maintained therapy gains more than the participants in insight therapy. The results suggested that structured therapies were more effective and beneficial than the unstructured therapy which the authors argued was due to skill acquisition. In interviews with participants to determine what skills were still being used in their everyday lives, two thirds of those in the structured groups indicated that skills such as mood and thought monitoring were used on a regular basis. In contrast only one third of the insight therapy participants reported use of knowledge or skills acquired in therapy. The authors argued that the study suggests depressed older adults maintain clinical improvements when they engage in therapy that provides a rationale for their depression and helps them learn skills for coping with depression after treatment has ended. The study demonstrated that psychological therapies without patients being on medication were effective in alleviating depression in the elderly. However, the research contains a number of limitations. First, the study did not state the number of participants who were self-referred. A large number of self-referrals would suggest that the study involved participants with some insight into
their difficulties and who were motivated to confront their problems. Second, owing to the small number of participants the results cannot be generalised to the wider population of depressed older adults, and third, the high rates of attrition makes it difficult to draw a reliable conclusion about the long term benefit of therapy.

In a later study Gallagher-Thompson, Hanley-Peterson & Thompson (1990) aimed to examine the frequency with which new episodes of depression were experienced by older adults over a 2 year period within three therapy modalities - brief cognitive, behavioural and psychodynamic therapy. The study involved 91 older adult (mean age 67.7 years) out patients diagnosed as having a current episode of major depression using the Research Diagnostic Criteria (RDC). Less than one third reported no previous history of depression, 52% reported one prior episode, and 17% reported two episodes or more. The average duration of current depressive episode was 2.8 years. Participants were randomly placed in one of the three therapy modalities or a waiting list control group. The three therapies offered 16-20 sessions of individual therapy over 4-6 months. Depression was measured using the Schedule for Affective Disorders (SADS), The Hamilton Depression Inventory and the Beck Depression Inventory. At the conclusion of therapy 52% of the sample were no longer clinically depressed, however 30% still met the RDC for major depression, and 18% minor depression. There were no significant differences between the three therapies in terms of outcome. At one year follow up ten people refused to be interviewed, 58% of those interviewed were not depressed, 27% met the criteria for major depression and 15% minor depression, there were no differences amongst the therapies. At two year follow up 17 people refused to be interviewed, 70% of those interviewed were not depressed, 22% were diagnosed as having major depression and 8% minor depression. Once again there were no differences among the therapies. In conclusion the study suggests that short term therapy is efficacious in the treatment of major depression in the elderly. As noted by the authors, relapse rates were not dissimilar from psychological interventions with younger depressed adults. The authors argued that
despite stressful life events and life changes following therapy the elderly who benefited most from therapy initially were able to maintain therapeutic gain as well as younger depressed adults. They hypothesised that this was due to such patients learning specific skills in therapy that were useful in addressing potentially depression triggering life events and situations that occur more frequently with advancing age. All three therapies emphasised encouraging patients to take more control over their feelings and activities and to develop a sense of self efficacy which is associated with positive emotional and behavioural change. They further suggest that predisposing factors and individual differences such as length of episode of depression, social support and personality determines patients' reaction to brief therapy. These factors they say may also be responsible for maintenance or relapse. Unlike their earlier study there was no evidence of differences in outcome between the three therapy modalities, all were effective in alleviating depression in the long term. Despite the encouraging and somewhat controversial results of the study, it failed to examine the wide generation and developmental span of the older population by not including those in their 80s and above. The original number of participants (n91) were not all included in the outcome evaluation as some refused to participate and one participant died, therefore the sample was reduced to 74 participants by the two year follow up and so the study was hasty in concluding that therapy was beneficial in the long term.

The third question is, do psychological therapies work better than medication?.

Beutler, Scogin & Kirkish (1987) reported on the comparison of pharmacological treatment with CBT for depression. Fifty six older adult participants were assigned to one of four groups - alprazolam, placebo, cognitive therapy plus alprazolam, cognitive therapy and placebo. Compared to the medication group the attrition rate was low in the group therapy condition during the 5 months of treatment. The study reported that no differences were noted between the medication and placebo groups. In contrast patients in the cognitive therapy groups showed consistent improvements on the BDI and clinical ratings on the HRSD three months after the termination of
therapy. However the efficacy of CBT was difficult to evaluate as the drug alporazolam was not widely used as an antidepressant at the time and did not perform well in the trial.

The final question is which therapies works best? Gallagher & Thompson’s (1982) study suggests that structured therapies (cognitive and behavioural) were more effective owing to skill acquisition, than unstructured insight therapy groups. However in a later study (Gallagher-Thompson et al., 1990) concluded that there were no differences between cognitive, behavioural and psychodynamic interventions. In a more recent study Gallagher-Thompson & Steffen (1994) recruited 66 older adult caregivers of patients with dementia and randomly assigned them to either brief psychodynamic or cognitive behavioural therapy. All participants met the criteria for major, minor or remittent depression and had been caring for their demented relative for 49 months on average. At the conclusion of therapy 71% no longer met the criteria for depression and there were no differences between the therapies. However when the results were carefully examined an interaction between therapy modality and length of care giving was observed. Those who had been providing care for less than 44 months appeared to benefit most from dynamic therapy and long term care givers benefited most from CBT. The authors suggested that CBT may have provided caregivers with skills needed to better manage and cope with their relative who is more likely to suffer pronounced deficits. Koder, Brodaty & Anstey (1996) reported on the efficacy of cognitive therapy for depression in the elderly via the review of 18 research articles. The review found that across four studies (Gallagher & Thompson, 1982; Thompson & Gallagher, 1994; Steuer et al., 1984 & Thompson, 1987) the combined effect size translated to percentages demonstrated that cognitive therapy was 66% more effective than psychodynamic therapy, 60% more effective than behaviour therapy, and 89% more effective than waiting list control groups. This is in contrast to the Scogin & McElreath review earlier mentioned where they found no difference in treatment efficacy between the treatment modalities. Finally in line with Scogin & McElreath (1994) they argued that group and
individual therapy for older adults with depression appear to be similar in efficacy.

Steuer, Mintz & Hammes (1984: cited in Leszcz, 1990) in a report on the use of psychodynamic and CBT group therapies for older adults argued that all models of group therapy whether structured and cognitive behavioural, or unstructured and interactional were equally effective in reducing symptoms of depression, improving interpersonal and social functioning and increasing self esteem. Both models of therapy were effective in reducing scores on the HRSD and the BDI. However patients in the CBT groups reported lower self rated scores on the BDI. In both the Steuer et al., study of 1984 and the Beutler et al., (1987) beneficial changes related to group therapy was reported.

Treatment of depression in patients with comorbid dementia

In the introduction to this paper it was mentioned that depression sometimes co-exists with dementia. Teri & Wagner (1992) reported that approximately 30% of patients with Alzheimer's disease also fulfill the criteria for clinical depression. Teri (1996) argues that depression may exacerbate the presentation of dementia and add to the patient's disability. Teri (1996) called this "excess disability" ie disability that exists beyond that caused by dementia itself. Patients with dementia and depression tend to have significantly more dysphoric mood, catatonic, social withdrawal and other symptoms of depression (Teri & Wagner, 1992). They are also likely to experience psychotic episodes and increased levels of disturbed behaviour (Teri, 1996). Teri & Wagner (1992) suggest that behavioural therapy is efficacious in alleviating depression in dementia. Lewinsohn's model of behavioural therapy for depression suggests that lack of reinforcement and increased aversive interactions are related to depressed mood. Depressed people become withdrawn, lose their motivation and end up decreasing their level of activity. Teri (1996) argues that the same is true for patients with dementia who due to organic impairment eventually lose the ability to engage in pleasurable activities. The less pleasurable activities they engage in the more
depressed they become. Teri further states that by identifying and encouraging patients to reengage in their pleasurable activities and by maximising their level of independence, based on their degree of cognitive and functional impairment, frequency of negative experiences may be reduced and their depressive mood and behaviour alleviated.

**General limitations of clinical research on depression in older adults**

In Koder, et al's (1996) review the authors commented on the marked methodological differences between most of the clinical studies. They noted that referral sources varied from self referral, outpatients to nursing home in-patients, with severity of depression varying amongst the sample groups. They reported that rates of attrition varied widely amongst the studies from 13.8-74.6%, making it difficult to evaluate the true impact of the interventions. The review reported that the average length of treatment (16.5 weeks) was longer than therapy in younger adults (6.9 weeks) suggesting that there is a difference in the process of therapy between younger and older adults, with older adults needing more sessions to achieve the same results as the younger adults. Most of the studies reviewed failed to discuss the content of therapy with regard to the behavioural and cognitive components, with most studies not clearly distinguishing between the two. Morris & Morris (1991) argue that behavioural and cognitive therapy overlap in theoretical background and implementation owing to the fact that both therapies focus on patients acquiring skills to help them cope with stressful life events and situations that trigger depression. Both therapies involve the collaboration of the patient e.g. negotiating setting tasks and goals to be achieved in the course of therapy, and both involve monitoring thoughts and mood by the patient. The overlap of the two therapies in some studies limits comparison of findings and explanation of the mechanisms that facilitate change. Most of the studies excluded older adults aged 80+ therefore efficacy of psychological treatment for this group is unknown. Most studies did not include follow up data reviewing the long term effects of therapy and booster sessions therefore it is unclear whether psychological therapy is effective in the long term. Koder et al., (1996) argue that good outcome in
most studies relied on intact cognitive functioning particularly in the area of memory and concept formation and absence of delusional symptoms and personality disorder. They linked severity of depressed mood to poorer outcome, and poor social network and stressful life events were linked to failure to benefit from cognitive therapy.

The efficacy of psychological interventions appears to be comparable to the success of interventions for younger adults. Coming to this conclusion is debatable owing to the fact that the length of therapy sessions and therapy techniques were modified in all the studies to take into account old age and age related cognitive changes. Comparison studies are limited to a few studies where participants all reported quite low BDI/HRSD scores to begin with in comparison to younger adult studies (Koder et al., 1996). In addition to this, the use of these measures is questionable. Morris & Morris (1991) point out that there is a slight tendency for patients who received cognitive therapy for depression to show more improvement on the BDI which loads heavily on items such as hopelessness, and self criticism that are affected directly by cognitive behavioural therapy. In addition the BDI lays emphasis on the experience of somatic symptoms common in old age e.g. sleep loss. More appropriate measures might include the Geriatric Depression Scale.

For all the research discussed, one must question whether the success or failure of an intervention in a research study mirrors its application in general clinical practice. Woods & Roth (1996) argue that in evaluating clinical interventions, a distinction must be made between efficacy of a therapy, results of which were drawn from clinical research trials, and its effectiveness in routine clinical practice. Woods and Roth argue that clinical research trials assess efficacy of a strictly adhered to programme which may not reflect the quality of that intervention in general clinical practice. They argue that it is also possible that general clinical practice may be enhanced by creative procedures not found in clinical trials. They further state that the gap between research and routine practice is
made more complicated by 3 factors i) individual difference in therapist client relationship which will impact on patients response to treatment; ii) severity and duration of the problem at time of presentation iii) Confounding variables such as economic, social and cultural factors which may complicate the delivery of therapy. However, it is acknowledged that first one must establish whether an intervention works in a well adhered programme and if so, then address whether it works in routine practice.

Finally, the question arises as to why G.Ps' and psychiatric services fail to acknowledge the efficacy of psychological interventions for depression in the elderly, and why psychology has been slow in coming forwards with regard to clinical research in this area. One possibility is historically older adults were deemed not psychologically minded. Freud (1905: cited in Turner, 1992) commented that people approaching the age of 50 and beyond lack the elasticity of mental information processing on which therapy as a rule depends. In spite of the fact that this view was challenged by others, for example Abraham (1919: Cited in Turner, 1992) who following a report on a series of successful psychoanalyses with older adults, argued that the age at which difficulties present is of greater importance for the success of therapy than the age at which treatment is started. The attitudes of therapists remain one of reluctance to treat older people whom they view as being more physically ill, more likely to suffer organic problems and may be close to death. These views contend that a therapist's own fear of aging and death makes it difficult to relate to and work with the very old (Woods & Roth, 1996). It is also possible that older people may lack awareness about psychology making them less likely to seek referral to psychology services. Following this is the possibility that older people themselves hold similar negative beliefs about the effectiveness of 'talking' therapies. Finally the question arises as to why older adults are not referred to psychology services in comparison to younger adults. Possible answers include misdiagnosis of depression as dementia (Woods & Roth, 1996), and ignorance about the effectiveness of psychological interventions for depression in older adults.
Conclusion

To conclude existing research supports the view that psychotherapy for depression in older adults is efficacious. Although differences between therapies are reported in various studies, evidence suggest that both structured and unstructured group and individual therapies are effective in alleviating depression.

More research is needed to document the efficacy of psychological interventions for depression alone and in comparison with medical approaches such as ECT and medication across a full range of depressive states.

It is not clear as to whether cognitive or behavioural therapy is more effective than any other type of therapy or pharmacotherapy in the long run. Research is needed to look at long term outcome, the rates of lapses and relapses and patients preference for therapy. It is also important to clarify which components of therapy patients find useful in helping them engage in therapy, and cope with their depression. For example Koder et al., (1996) found that techniques such as self monitoring were less useful with older adults compared to more more practical strategies. This contradicts Gallagher et al's (1982) study where the long term success of individuals who remained depression free was attributed to their ability to draw on techniques to combat future episodes of depression such as self monitoring thoughts and feelings.

In order to overcome the problem of under referral of older adults to psychology services, clinicians clearly need to educate referring agents and multidisciplinary teams about the service they offer and present evidence for the efficacy of the therapies they offer. Older adults could also be made more aware of psychology by the availability of literature informing them about talking therapies.
References


Clinical Chapter
Summary of clinical experience.

Purpose of summary:
To illustrate breadth of clinical experience gained from the four core placements and two specialist placements completed.

Core Placement 1: Adult Mental Health
Trust: South West London and St George's NHS Trust.
Supervisor: Ian Petch and Sara Meddings.
Summary: This first placement provided experience working with male and female clients presenting with a range of psychological difficulties (n=12). These included: post traumatic stress disorder, eating disorders, obsessive compulsive disorder, depression, panic disorder, anxiety disorder, and long term mental health difficulties.

Additional experience: Observation of a clinical psychologist and a community practice nurse in therapy and on duty in the community. The placement also involved a visit to a day and occupational therapy center for people with mental health difficulties.

Core Placement 2: Learning Disabilities
Trust: Thames Gateway NHS Trust.
Supervisor: Stephanie Wood.
Summary: This placement provided male and female clients (n=6, and group work-6 one hour sessions) with a range of disabilities and psychological needs. These included: functional analysis of challenging behaviours, behaviour and anger management, and cognitive assessments.

Additional experience: This placement also provided me with the opportunity to develop my presentation skills in teaching psychological ideas to other professionals. Furthermore, I was able
to visit and interact with staff and clients at a number of day centers for people with learning disabilities.

Research: Whilst on this placement I carried out my first year service related research project - A survey of staff emotional reactions to and beliefs about challenging behaviour.

Core Placement 3: Child, Adolescent and Family
Trust: Invictor NHS Trust.
Supervisor: Marion Levick and Elizabeth Croft.
Summary: This placement provided a wide range of male and female clients (n=18), who presented with a variety of psychological difficulties. These included: sleep difficulties, conduct problems, cognitive assessments, encopresis, enuresis, depression, ADHD, social anxiety, school refusal, and bereavement.

Additional experience: Whilst on this placement I visited a school for children with autism, a residential home for adolescents with behavioural difficulties, and a nursery for children with developmental problems.

Specialist Placement 4: Health Psychology
Trust: Guy’s and St Thomas’ NHS Trust.
Supervisor: Amanda Williams and Nicky Thomas.
Summary: This specialist placement provided specifically patients with sickle cell disease (n=11), presenting with a variety of psychological difficulties. These included: depression, health anxiety, adjustment to physical disability and stroke, cognitive assessments, pain management, and family work.

Additional experience: Whilst on this placement I helped organise a conference on sickle cell disease. I also gave a talk at the conference on the role of the psychologist in a sickle cell team.

Academic: I attended several haematology and health psychology seminars.
Core Placement 5: Older Adults

Trust: South West London and St Georges NHS Trust.

Supervisor: Lynn Beech.

Summary: This placement provided the experience of working with, and understanding organisations set up for male and female older adults (n=7), aged 75 years and above. The patients presented with a variety of psychological difficulties. These included: adjustment to old age and physical difficulties, depression, and health anxiety. A number of patients presented with memory problems requiring a neuropsychological assessment.

Additional experience: Whilst on this placement I carried out a dependency survey of adults who attended a day center for people with dementia. I also observed a community practice nurse on his visits to people with dementia living in the community.

Specialist Placement 6: Forensic Psychology

Trust: South West London and St Georges NHS Trust.

Supervisor: Paula Duncan and Sharon Prince.

Summary: This placement provided me with generic forensic experience working with male and females. Outpatient work included assessment of sex offenders and anger management difficulties. Inpatient work included helping patients address and understand their mental illness and offending behaviour.

Additional experience: Whilst on this placement I observed clinical psychologists, psychiatrist and a CPN perform risk assessments of sex offenders, and generic forensic offenders awaiting transfer to medium security. I also attended various forensic academic seminars and case presentations.
Core Placement: Adult Mental Health

Supervisor: Ian Petch and Sara Meddings.
Placement location: Springfield Hospital
Glenburnie Road
Tooting Bec
South West London and St Georges NHS Trust.
CONTRACT FOR ADULT MENTAL HEALTH PLACEMENT

Name of Clinical Psychologist in Training: Helen Idusohan

Name of Supervisors: Ian Petch, Principal Clinical Psychologist
(Adult Mental Health)
Sara Meddings, Clinical Psychologist
(Rehab & Continuing Care)

Start Date: 15 October 1997
Finishing Date: 3 April 1998

Supervision Day and Time: Wednesday 3.30 - 5.00 pm - Ian Petch
Thursday 4 - 5 pm

General Description of Placement: To provide supervised experience of working with adults with a range of mental health needs. The placement days will be divided in the ratio of 2/3 Community Mental Health and 1/3 Rehabilitation and Continuing Care Services.

AIMS AND OBJECTIVES

(A) Induction and Orientation

(1) Helen will spend the first few weeks of placement observing supervisors in direct work with clients and in team meetings related to the working of each of the services.

(2) Helen will arrange to spend one session with a representative of each discipline from the CMHT or continuing care team (sessions may occur at any point within the first 10 weeks of placement).

(3) Helen will arrange to meet with service providers related to the working of the CMHT and Rehab Team within the first four weeks and meet with these within the first 10 weeks of her placement.

(4) Helen will arrange to meet with Key Psychology personnel to gain an overview of the managerial structure of the Psychology Service.

(B) ASSESSMENT TECHNIQUES

(1) Cognitive Assessment

Aim: To complete a minimum of one formal psychiatric assessment independently.

Helen to observe a fuller assessment carried out by a clinical psychologist who specialises in neuropsychology.
(B) Other Assessment Techniques

**Aim:** To undertake a range of assessment and interview procedures and gain familiarity with a range of standardised assessment tools.

**Method:**
- Helen will observe supervisor(s) using a range of interview procedures and standardised assessment tools.
- Helen and supervisor(s) will jointly select and use measures and interview procedures.
- Helen will undertake interviews independently, selecting appropriate measures for assessment.

(C) Range of Client Work

**Aim:** To undertake direct and indirect clinical work, providing appropriate assessment, intervention and valuation for adults with a range of mental health needs. This will involve work on a maximum of 10 people and a minimum of 6.

The range of clinical presentation will include a minimum of

* one case of depression
* one case of an anxiety disorder
* one neuropsychological assessment
* one case involving adjustment and adaptive difficulties.
* one client with continuing mental health needs (present for more than two years)
* one client with severe mental health problems (in addition to client with continuing needs).

The placement will aim to give Helen experience of working with clients from a range of social, ethnic and cultural backgrounds and in outpatient, inpatient and community settings.
(D) Clinical Interventions and Approaches to Therapy

**AIM:** Helen will undertake a range of approaches to clinical work. This will include:

* basic counselling techniques.
* cognitive therapy.
* basic skills in behavioural approaches.
* use of non-individual approaches (couple, family, carer etc)

**Method:** Helen will observe supervisor(s) undertaking a range of clinical interventions.

Helen and supervisor(s) will jointly identify suitable therapeutic approaches and outline intervention plans for individual cases.

Helen will identify suitable therapeutic approaches and outline intervention plans in supervision.

Helen will undertake various clinical approaches independently, under supervision with feedback in supervision sessions, direct observation by supervisor and audiotape.

(E) Indirect Clinical Work

**Aim:** For Helen to contribute to indirect clinical work.

**Method:** Helen to observe supervisor(s) in multi-disciplinary team meetings.

Helen and supervisor(s) to discuss in supervision, the role and methods of indirect work.

Helen to attend multi disciplinary team meetings to contribute towards the development and review of multi disciplinary care programmes.

(F) Settings and Systems

**Aim:** To gain familiarity with the process by which clinical psychology services are provided within the context of a multi disciplinary team.

**Method:** Helen to attend multi disciplinary team meetings and Business Meetings to gain exposure to the process of planning service delivery.

Helen to attend Department Meetings and Divisional Meetings.

Discuss in supervision the role of Clinical Psychology and the nature of service delivery in the CMHT and continuing care and Rehabilitation service.
(G) **Professional Development**

**Aim:** For Helen to have a broader understanding of the place of psychology.

**Method:** For Helen to attend a Special Interest Group meeting.

(H) **Visits**

**Aim:** To gain an understanding of the role of related services.

**Method:**
- For Helen to visit the User Employment Project
- For Helen to visit local statutory and voluntary sector services as appropriate.
- For Helen to develop other relevant professional activities eg. DCP, MSF, academic services.

(I) **Report Writing and Correspondence**

**Aim:** For Helen to prepare a range of formal reports and correspondence appropriate to the needs of the referring agent, the need to convey psychological information to others and requirements of other professional involved.

**Method:**
- Supervisor(s) will make available a range of reports and other forms of correspondence.
- Helen and supervisor(s) will jointly identify appropriate forms of correspondence.
- Helen will prepare appropriate forms of correspondence for feedback in supervision.

(J) **Arrangements for Ending of the Placement**

**Aim:** To enable Helen to achieve the above aims by establishing clear criteria for the completion of each piece of work undertaken.

**Method:** Supervisor(s) will regularly review progress in each area of work.

At mid-placement review, supervisor(s) will establish completion dates for each area of work still ongoing.

Signed: [Signatures]

**Clinical Psychologist in Training**

**Supervisor**

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Case report summary 1: Adult Mental Health

A case of a young woman with generalised anxiety disorder, depression and a phobia of driving.

All identifiers have been removed or altered.
Case report summary 1: A case of a young woman with generalised anxiety disorder, depression and a phobia of driving.

**Reason for referral:** Ms. B was a Caucasian woman referred to the community mental health team by her GP for an assessment of her anxiety following a driving accident.

**Presenting difficulties:** Ms. B's symptoms had impacted severely on her life. Her mobility was reduced and so was her contact with friends. She also reported difficulties interacting with her family.

**Assessment:** Ms. B's presenting difficulties were assessed via a standard cognitive behavioural clinical interview.

**Formulation:** Ms. B's presenting difficulties were formulated within a cognitive behavioural framework. It was observed that her early life experiences such as her experience of her parent's marital discord, her separation from her parents due to hospitalisation for her congenital hip dislocation, left her vulnerable to the experience of anxiety and depression. Her recent life difficulties (car accident, continuing conflict between her parents, and pain in her hip) triggered and reinforced negative beliefs about herself, others, and her future. Furthermore, her catastrophic interpretation of hip pain reinforced her experience of anxiety. Her problems were maintained by subtle avoidance and safety behaviours which served to reduce her anxiety, but prevented her from driving confidently. Her depression was reinforced by her negative thoughts and appraisal of life events and experiences.

**Intervention:** Cognitive behaviour therapy was provided over 14 sessions, one hour a week. The sessions aimed to help Ms. B overcome her fear of driving by following a structured session plan.
which involved:

1) Teaching her to become aware of the cycle of her anxiety by instructing her to keep a
daily diary of situations, thoughts, feelings and behaviours that triggered her anxiety.

2) Teaching her relaxation techniques, which prepared her for exposure work.

3) Encouraging her to challenge her negative thoughts and avoidance behaviours via a series
of graded exposure tasks.

Outcome: Sessions with Ms. B were erratic owing to pain in her hip which required her to rest.
Nevertheless when she was able to attend sessions she engaged well. Her emotional and
physiological state were evaluated pre and post therapy. Her intermediate scores on the Beck’s
Depression Inventory and the Beck’s Anxiety Inventory suggested that therapy was successful in
reducing her general level of anxiety and depression, but had little effect on tackling her fear of
driving. It was her wish not to immediately engage in therapy with another psychologist when the
placement drew to an end. She said she wanted the opportunity to practice by herself the skills
she had learned in therapy, and would like a further session to discuss her progress in 3 months.
Year 1

Core Placement: Learning Disabilities


Supervisor: Stephanie Wood.

Placement Location: Rochester Health Centre
Delce Road
Rochester
Thames Gateway NHS Trust
PLACEMENT CONTRACT.

Trainee : Helen Idusohan
Supervisor : Stephanie Wood
Placement : Learning Disabilities
Placement dates : April 22 - September 29, 1998
Placement address : Rochester Health Centre, Delce Road, Rochester, Kent.

Supervision :

Sessions will be on Wednesday afternoons, 3.00 - 5.00, and will be in a room other than the Team room at the base. Emergency phone calls only will be permitted. Each session will have an agreed and prioritised agenda to which both parties will contribute items. Should this not be possible e.g. sickness, case reviews arranged prior to placement, an alternative slot will be agreed.

Clients :

1. Appropriate referrals from the adult team will be allocated for independent and joint working.

2. Client work will involve no more than six clients at any stage (counting jointly led groups as 1-2 clients); these will be arranged to include:
   - at least one female client;
   - at least one adolescent;
   - at least one older adult;
   - at least one behavioural intervention;
   - at least one psychotherapeutic-style intervention;
   - work direct with the client, with the family and via carers;
   - experience of different levels of disability.

3. There will be joint appointments with other team members (community nurses, speech and language therapists and psychiatrist) to see their working.

4. Observation of a psychiatric clinic will be negotiated with the team psychiatrist.

5. Participation in one Team-led group will be pursued : anger management has been identified as a preferred area (date to be confirmed with the nurses at Thames Gateway West).
Teaching:

A suitable opportunity for teaching will be identified by the end of May, probably within the area of challenging behaviour/behavioural assessment.

Research:

One small scale project will be required, the topic to be identified no later than the end of May.

Case Report:

One suitable case to be identified by mid-June, with a plan.

Organisation:

By the end of May, Helen will:

have the relevant Trust/Department charts and have talked through them;

be acquainted with the members and Operational Policies of both STALD and the learning disabilities services in the Western patch;

be informed of, and complying with, Team and Department working practices and quality standards;

have identified any additional people/roles within the Trust she would benefit from knowing more about.

Meetings:

Unfortunately, both Department and STALD meetings fall on Helen's study days, as do the multidisciplinary meetings of the Western staff. Helen will, however, be expected to attend:

the joint meetings of East and West during May and June (comparing resources, skills, services available, training needs, etc.) to consider the best evolution possible within the new Trust;

the STALD Awayday in July;

at least one joint meeting with a Social Services Disability Team, with the Community Nurse as STALD representative;

and, preferably, the Special Interest Group (Psychology of Learning Disabilities) in June.
Observations:

Helen will have the opportunity to observe Steph in initial assessment and ongoing work as well as other Team members in typical activities.

Skills:

The aim of the client work is to promote the following:

- transfer of previously acquired skills in interviewing, therapy and assessment to clients/families/settings where learning disability is a key feature;

- development of specific skills and understandings, as:
  - use of relevant assessments (e.g. SACS, FPR, BAB);
  - functional analysis;
  - planning, implementing and monitoring a behavioural intervention;
  - management of problems in people with autism;
  - co-ordination of multi-disciplinary approaches to people with multiple handicaps;
  - the roles available to a psychologist in learning disabilities.

Visits:

To be arranged:

MLD FE unit
SLD FE UNIT
Further Education College
Crisis Intervention Service
SEC (traditional)
Medway Day Opportunities Service

and others identified as placement progresses.

Own Training:

Should specific areas of need be identified during placement which are not part of the Course (e.g. Makaton signing) Steph and Helen will seek to build in such training within the placement.

Signed: ___________________________ Date: ____________

Signed: ___________________________ Date: ____________
Case report 2: Learning Disabilities


All identifiers have been removed or altered.

**Reason for referral:** Mr. C was a Caucasian man referred to the support team for adults with learning disabilities by his community nurse for an assessment of his challenging behaviour. The behaviour reported as challenging for staff at his social education center included smearing himself with grease from a boiler, destroying property, and physical aggression towards others.

**Pre-Assessment:** A functional analysis was carried in order to establish the factors responsible for Mr. C's behaviour. Information was gathered from his residential manager, his key worker at the social education center, his care manager, support staff diaries and psychometrics.

**Assessment:** Antecedent- Behaviour-Consequence charts were supplied to staff at the education center for completion over a period of 6 weeks, and Mr. C's Key worker completed the Motivation Assessment Scale to ascertain the extent to which his behaviours occurred under particular stimulus conditions.

**Formulation:** Mr. C had a moderate learning disability, fragile x syndrome, and epilepsy. As a result of these difficulties he had limited communication skills. He was prone to social anxiety as a feature of his fragile x syndrome, and challenging behaviour, owing to his learning disabilities. He had never received intervention to address his communication or behavioural difficulties and as a result, his behaviour was his medium for communicating his wants, needs and dislikes. His reported challenging behaviours were triggered by anxiety, frustration and boredom of inactivity. His communication and behavioural difficulties were maintained and reinforced by inconsistent response styles of staff.
**Intervention:** Work with staff involved:

1) That staff would devise an activity programme for Mr. C that they would consult during specified times known to trigger his behaviours.

2) That when Mr. C engaged in a specified activity instead of engaging in one of his challenging behaviours, staff were to praise him and chat with him for a while.

3) That staff were to ignore him when he engaged in challenging behaviour, and with the minimum of fuss, ask him to return to his scheduled activities.

**Evaluation:** Mr. C's progress charts revealed that although the frequency of his behaviours had increased, the total average duration of time spent engaging in challenging behaviour had decreased.
Year 2

Core Placement: Child, Adolescent & Family


Supervisors: Liz Croft and Marion Levick.

Placement Location: Homoepathic Hospital

Tunbridge Wells

Kent.

Invictor NHS Trust
PLACEMENT CONTRACT

Trainee: Helen Idusohan

Supervisor: Liz Croft & Marion Levick

Placement: Child & Adolescent Psychology


Placement address: Homoeopathic Hospital, 41 Church Road, Tunbridge Wells, Kent, TN1 1JU.

Supervision:

Sessions will be on Wednesday afternoons at 3.00pm-4.30pm and Thursday mornings at 11.30am-12.30/1.00pm. Emergency phone calls only will be permitted. Each session will have an agreed and prioritised agenda to which both parties will contribute items. Should this not be possible because of e.g., sickness, case reviews arranged prior to placement, an alternative slot will be agreed.

Clients:

1. Appropriate referrals from the team will be allocated for independent and joint working.

2. Client work will involve no more than six clients at any stage. These will be arranged to include:
   - at least one under 5 client;
   - at least one child of primary school age;
   - at least one adolescent;
   - a reasonable balance of boys and girls;
   - at least one family therapy case (alone or jointly);
   - at least one psychotherapeutic-style intervention;
   - work direct with the client, with the family and indirect via other professionals;
   - experience of different levels of complexity

3. There will be joint appointments with other team members to experience their working.

Teaching:

A suitable opportunity for teaching will be identified by the end of December, probably within the area of challenging behaviour/behavioural assessment halfway through the placement at the latest, probably with Health Visitors and focused on a particular problem area e.g., behaviour management, sleeping or feeding problems.
Case Report:

One suitable case to be identified by end of January with a plan.

Organisation:

By the end of December, Helen will:

- be familiar with the relevant Trust/Department structures and have talked through them in more depth;
- have met individually with all the members of the Tunbridge Wells Child and Family Mental Health Service;
- be informed of, and complying with, team and Psychology Service working practices and quality standards;
- have identified any additional people/roles within the Trust she would benefit from knowing more about.

Meetings:

Unfortunately, both CAFMHS team and Psychology meetings fall on Helen's university days. Helen will, however, be expected to attend if at all possible:

- At least one Psychology meeting on Tuesday morning.
- At least one CAFMHS meeting on Monday morning.
- At least one quarterly CAFMHS Team Day.
- If possible, an Invicta Child Psychologists meeting (monthly) and/or an Invicta Psychologists professional meeting (2 – monthly).
- Any appropriate inter-agency/inter-departmental meetings.

Observations:

Helen will have the opportunity to observe and co-work with Liz, Marion and other Psychologists in initial assessment and ongoing work as well as other team members in typical activities.

Skills:

The aim of the client work is to promote the following:

- transfer of previously acquired skills in interviewing, therapy and assessment to clients/families/settings where child, adolescent and family problems are the key feature.
- development of specific skills and understanding in the Child Specialty, such as use of relevant psychometric assessments (e.g., WISC, WORD, WIPPS I); behavioural analysis; developmental difficulties and implementing interventions from a range of therapeutic perspectives - behavioural, systemic, psychodynamic, consultative.
- co-ordination of multi-disciplinary approaches to child and family problems.
- the roles available to a psychologist in the child specialty.
Visits:
- Ravensdale
- Valence

To be arranged:
- Health Visitor consultation
- Halstead Place
- Family Support Unit
- Cage Green Autistic Unit
- Mainstream nursery & school

and others identified as placement progresses.

Own Training:

Should specific areas of need be identified during placement which are not part of the Course, Liz, Marion and Helen will seek to build in such training within the placement.

Signed:.................................................. Date:..........................
Year 2

Case report 3: Child, Adolescent & Family


All identifiers have been removed or altered.
An adolescent male with psychological problems: A multimodal (combined treatment) approach to assessment and treatment

Reason for referral: AA a 16 year old boy of Bangladeshi origin was referred to the Child and Family Mental Health Team by his GP regarding his obsession with washing his hands.

Assessment: The assessment involved separate clinical interviews with AA and AA’s father. Information collected included: AA’s health history, his psychological adjustment in Bangladesh and following his move to England, his difficulties as perceived by himself and his father.

Presenting difficulties as described by his father:
- That AA was obsessed with washing his hands
- That AA urinated excessively during the day
- That AA wet the bed (primary enuresis)
- That AA experienced difficulty relating to his peers

Presenting difficulties as described by AA:
- That he wet the bed
- That he urinated excessively during the day
- That he found it difficult relating to members of his family
- That he was confused and troubled about peer relationships, especially with girls in view of his culture and religion

Clinical interview and AA’s behavioural diaries revealed that AA did not appear to have a compulsion to wash his hands, except in response to his many trips to the toilet which was appropriate. AA did not think his hand washing was cause for concern, rather the difficulties he listed was what he wanted to address in therapy.
**Formulation:** A number of factors explain AA’s primary nocturnal enuresis. First, his family’s attitude and inconsistent management practices played heavily in maintaining AA’s anxiety about his bed wetting. Second, AA’s father wet the bed into his teenage years therefore AA’s family revealed a history of this difficulty. Third, AA’s bed wetting seemed to be functional, a response to his adjustment difficulties. His excessive urinating stemmed from his fear of losing control of his bladder, and wetting himself during the day as he did at night.

His difficulty relating to his peers and family resulted from numerous family moves to and within different countries. AA was unable to settle and form meaningful peer relationships, and furthermore he found it difficult balancing the expectations and norms of the host country in which he resided with those expected of him by his family, culture and religion.

**Intervention:**

1) AA was given a psychological explanation of his difficulties which he completely agreed with. He was encouraged to keep a diary of his enuresis and was asked to reward himself with special treats when he stayed dry.

2) AA was given the opportunity to talk about his excessive urinating in detail, and his beliefs about his low self efficacy were challenged and restructured via behavioural experiments. These experiments required him to test his beliefs by gradually reducing his trips to the toilet throughout the day.

3) AA’s confusion about peer relationships was discussed in great detail. He revealed a number of distorted and unhelpful beliefs about male and female relationships which were challenged and restructured during the sessions.

4) Family sessions were arranged to address AA’s interaction with his family.
**Outcome:** AA's bed wetting decreased at the end of therapy, but follow up session revealed the problem reemerged following invalidating responses from his family. Reports from his school about his socialisation were positive. Unfortunately, his father refused to allow the family therapy sessions to continue.
Specialist Placement 1: Health Psychology

Placement dates: April 1999 - October 1999

Supervisor: Dr. Nicky Thomas and Amanda Williams

Placement location: St Thomas Hospital
Department of Haematology
Lambeth Walk, London
Guy's and St Thomas' NHS Trust
PLACEMENT CONTRACT

Trainee: Helen Idusohan

Supervisors: Dr Nicky Thomas / Dr Amanda Williams

Placement: Specialist Health Psychology- Haemoglobinopathies; Sickle Cell Disease

Placement Dates: April 21- 1st October, 1999

Placement Address: Department of Haematology, St Thomas Hospital,
London SE1 7EH.

SUPERVISION:

Supervision will be undertaken jointly by Dr Nicky Thomas and Dr Amanda Williams on Wednesday morning 9-10 am and Thursday morning 10-11 am. The sessions with NT will be concerned with case material relevant to particular patients and issues relevant to Helen's research.
ALL RESPONSIBILITIES

Development of specialist sessions using a range of psychological therapies such as cognitive behavioural therapy for use in one to one work with clients and (and individual family members) as required.

Assessing patients/family members for individual assessment and interventions and making necessary arrangements for referral to other agencies.

Administering psychological/ neuro-psychological assessments.

DRAFTING and evaluating behavioural contracts for A&E and ward staff in the management of difficult and challenging behaviour in individual patients.

Working with the running of group education sessions for patients within a therapeutic model, giving individual written feedback to patients on their use of cognitive techniques taught.

Assist with the development of collaborative protocol (with NT & Laura Dinsom, child psychologist) that will facilitate transition of adolescents into sickle cell services.

Working with employers and educational establishments as indicated by individual needs.

TAKING

Collaborating closely with Nicky Thomas to teach medical, nursing, and other therapy staff about psychological components of SCD and cognitive-behavioural approaches to pain management and chronic illnesses.

TAKING psychological support /debriefing of ward & the staff in A&E treatment within a group setting.
• Providing education and guidance to health care professionals when dealing with difficult and challenging behaviour.

OBSERVATION
Helen will have the opportunity to observe Nicky in initial assessment and ongoing work. She will also shadow Neill Westerdale & Tina Adepegba Sickle Cell Nurse practitioners in the course of their clinical activities.

RESEARCH
One large scale research project and the topic is concerned with examining the relationship between coping, illness perception and quality of life in SCD. Sample size calculations indicate that 65 subjects are required. Ethics application is currently being prepared.

ADMINISTRATIVE RESPONSIBILITIES
Writing letters and reports, keeping clinical records.
Attending multidisciplinary meetings and case conferences
Undertake the administrative duties associated with the clinical responsibilities.

PERSONAL DEVELOPMENT
To attend haemoglobinopathy lectures and conferences.
SKILLS

The aim of this placement is to promote the following:

Application of previously acquired skills in assessment and intervention with clients/families with sickle cell disease.

Applying clinical skills and awareness of ethnic minority issues in the application of CBT.

To develop specific skills in the application of CBT to sickle cell disease.

To develop behavioural contracts in the identification and management of behavioural problems in-patients with sickle cell disease.

To develop protocols/guidelines that will facilitate psychological consistency in the delivery of care.

To develop a good understanding of the multidisciplinary approach to SCD.

Client Case Load

A minimum of 6 adult male and female patients (18 and above). Where possible for Helen to observe clinical psychologist in paediatric sickle cell service.

Health Psychologist's Signature: ___________________________ Date: 20/6/99

Clinical Psychologist: ___________________________ Date: 7-6-99

Trainee's Signature: ___________________________ Date: 20/5/97 124
Case report summary 4: Health Psychology

Coming to terms with Hemiplegia: A case study of a young woman with sickle cell disease.

All identifiers have been removed or altered.
Coming to terms with Hemiplegia:

A case study of a young woman with sickle cell disease.

**Reason for referral:** The Haematology psychology service adopted a self referral system as well as accepting referrals from the Sickle Cell Team. Ms. N was a 20 year old African (Ghanian) woman born in England. She was a self referral who wanted help addressing her difficulties adjusting to her physical disability, sickle cell disease, and family problems.

**Assessment:** Assessment consisted of a clinical interview and administration of thought monitoring diaries and questionnaires such as Beck's Depression Inventory, and Coping Strategies Questionnaire for adults with sickle cell disease.

**History of presenting difficulties:** Ms N was born with sickle cell disease, inherited from both her parents who carried the disease trait. Her disease was not diagnosed until she was 9 years old and experienced sickling in the brain which caused a stroke, and subsequent left side partial paralyses. Her parents who were already experiencing marital problems, separated following her illness, and her mother was left to care for 4 children. Ms N reported feeling and being treated differently to her siblings because of her disease and disability. Family expectations of her she though were low, and she reported a lack of emotional support from her mother. Ms. N was determined to live as normal a life as possible, but was unable to accept the limitations her disease and disability imposed on her. Although her depression inventory scores were low, her self report and thought diaries revealed depressive thoughts and negative reactions to life stresses commonly reported by individuals living with sickle cell disease.

**Formulation:** Ms. N became aware of her disease at the age of 9 years, a time in life were children develop a sense of industry or as sense of inferiority. Her adaptation to her disability and
chronic illness at this stage depended on her family's ability to help her learn and develop life skills, exercise self expression, establish rewarding peer relationships, and develop independent values. Her family's difficulty adjusting to her illness made her increasingly aware of her limitations and she developed a sense of inferiority rather than a sense of industry. Her sense of being invisible and unheard at home drove her to succeed intellectually (which is to her credit). However her drive became dysfunctional owing to her underlying beliefs about her self worth which was attached to academic prowess. Her traumatic experience of a near fatal stroke at age 9, and her perceived family reaction to her disease, caused Ms.N to deny and avoid discussing the severity of her condition. And as such she denied the limitations her illness imposed, and was non compliant with the self help management strategies sickle cell disease sufferers are advised to follow. As a result of her difficulties Ms. N experienced emotional loneliness, depression and health anxiety.

Intervention: A combined cognitive-behavioural treatment was chosen to help her restructure her beliefs about herself, and her family. She received psychoeducation on her disease, and was encouraged to write about her early life experience of the disease. Behavioural tasks included experimenting with new patterns of verbal communication with her family, and encouraging her to learn independent living skills.

Outcome: Ms. N reported an improved relationship with her family. She restructured her beliefs about what she needed to do to feel valued by her family, and became comfortable with 'good enough' grades at university. She had begun to cook and clean for herself which increased her self confidence. However, she never fully accepted her disability, and continued to believe and work towards gaining the full use of her left side via physiotherapy.
Year 3

Core Placement 5: Older Adults and Organisations

Supervisor: Lynn Beech.
Placement location: Older Adult Mental Health Team
Sutton Hospital
Sutton
South West London and St Georges NHS Trust.
PLACEMENT CONTRACT

CORE PLACEMENT

The Organisation of Services for Older Adults over the Age of 75 years

Trainee: Helen Idusohan

Supervisor: Lynn Beech, Consultant Clinical Psychologist

Placement: 12 October 1999 – 23 March 2000

Overall Placement Aims

1. The trainee will gain the relevant experience to meet essential Older Adult Placement requirements. The trainee will gain the relevant experience to meet desirable Older Adult placement requirements. Where possible (see placement handbook for details of essential and desirable experience).

2. The trainee will gain relevant experience in the following areas in order to meet identified learning needs.

   i. Neuropsychological assessment with older people.
   ii. Service development and evaluation within a multi-disciplinary service.
   iii. Promoting an understanding of the role of a psychologist within a multi-disciplinary team via offering limited consultation to team members and holding joint seminar sessions with supervisor.

3. The trainee will have the opportunity to development assessment, formulation and intervention skills appropriate to the varied and often complex needs of this client group.

Clinical Objectives

1. The trainee will carry out assessment and treatment with male and female elderly clients (and family members/carers as required).

2. The trainee will undertake neuropsychological assessment using a range of assessment tools (eg. Cape, WAIS III, AMIPB).

3. The trainee, where possible, will work and observe clients in a range of different settings, including in-patient settings, residential/nursing homes, and client’s own home.

4. Trainee will undertake indirect work with clients with dementia.
5. The trainee will gain direct experience of applying a range of treatment approaches including Behavioural, CBT and verbally based / psychotherapy models with older people in addition to intervention approaches specifically designed for older people.

**Organisational Objectives**

1. Promoting within the multi-disciplinary team psychological awareness and skills required to provide good psychological care via joint seminars with Lynn Beech, Consultant Clinical Psychologist.

2. Trainee to develop knowledge of the role of other disciplines through observation of MDT work and joint Clinical work as appropriate.

3. Trainee will participate in service development via assessing and evaluating services for clients with dementia.

4. Trainee will attend team meetings and offer a psychological perspective on client and organisational issues.

5. Trainee will offer consultation on the development of group treatment for Older Adults within multi-disciplinary service.

**General Placement Guidelines**

1. The trainee will have two hours supervision per week, generally Wednesday 3-5pm.

2. The trainee to use alternate Thursdays for clinical study time.

3. Trainee to observe supervisor and other MDT members conducting assessment and intervention sessions as appropriate.

4. Trainee to attend and participate in relevant meetings.

5. The trainee to be familiar with and follow service policies.

6. The development of the trainee skills to be monitored through observation of sessions by supervisor.

7. A review date to be arranged, prior to the mid-placement review to review progress towards placement objectives and identify any gaps/further training needs.

[Signatures]

Trainee

Supervisor
A neuropsychological assessment of intellectual and frontal lobe functioning in a 76 year old man with clinical depression.
A neuropsychological assessment of intellectual and frontal lobe functioning in a 76 year old man with clinical depression

Reason for referral: Mr. B was a 76 year old Caucasian man admitted to the elderly psychiatric ward, suffering from severe depression and aggression towards his wife. A neuropsychological assessment was requested to provide a profile of his cognitive functioning and inform his behavioural difficulties.

Presenting concerns. Mr. B's history notes revealed that he had been suffering from severe depression for over 40 years, and had received 16 courses of ECT as a psychiatric in-patient. Mr. B also had a history of hypertension, and stomach difficulties. Although his CT scan and EEG revealed no abnormalities, he reported experiencing memory problems, and his wife via his day centre key worker reported increased violence towards her.

Assessment: The assessment comprised of reviewing Mr. B's history notes, discussions with his key worker, and neuropsychology assessment. Tests administered over two sessions included: WAIS III, AMIPB, NART-R, Stroop, Gibson Spiral Maze, and a test of verbal fluency

Results: In interpreting the results, Mr. B's low educational achievement and long history of severe depression was taken into consideration. His test profile indicated global intellectual deterioration, impaired visual and auditory memory, and new learning skills to such an extent as to suggest organic pathology. However given the severity of his depression at the time of testing and the absence of comparative data, the results were considered unreliable.

Recommendations: It was recommended that Mr. B should be reassessed in 6 months time for comparison purposes, and that in view of the extent of his impairment, he and his wife should receive support to help them adjust to his disabilities.
Year 3

Specialist placement 2: Forensic Psychology
Clinical Psychology Placement Contract – Helen Idusohan

Placement: Forensic
Supervisors: Paula Duncan and Sharon Prince
Placement base: South West London & St George's Mental Health NHS Trust
Shaftesbury Clinic
Springfield University Hospital
Glenburnie Road
Tooting
SW17 7DJ
020 8682 0033
Placement dates: April 12th – September 7th 2000

Summary and aims of specialist forensic placement

Helen will work within a multi-disciplinary team. Her placement will include completion of comprehensive forensic assessments with in-patients in a medium secure setting and with forensic out-patients. She will also undertake therapeutic interventions with forensic patients. Her placement will incorporate work with patients with a range of ethnic backgrounds, ages and presenting problems. The placement will provide Helen with a broad experience and understanding of issues relating to psychology and the law, including assessment and treatment of offenders. It is hoped that she will gain experience of various professional, legal, moral and ethical issues arising when working with this client group.

1. Induction

   a) Arranging meetings with multi-disciplinary professionals to gain an understanding of their role.
   b) Shadowing a senior forensic nurse to gain an understanding of their role and a perspective into the patient’s experiences of living in a medium secure unit.
   c) Gaining familiarity with the environment, the practical working arrangements and timetables followed in the department.
   d) Gaining familiarity with the in-patient backgrounds and psychological issues, from the team to which you will be attached.

2. Clinical work

   a) The assessment and treatment of a range of patients referred for psychological treatment to the Forensic Mental Health Service. Presenting problems will include perpetration of sexual and physical abuse, anger management, sexual deviations, psychosis and personality disorders.
Clinical work (continued)

b) Assessment experience will include functional analysis, personality, cognitive and neuropsychological assessment.

c) Treatment experience will include preparation and co-facilitation of a cognitive-behavioural group for in-patients.

d) Drafting reports for in-patient case conferences and to multi-agency referrers. Providing verbal and written correspondence about clients where necessary.

e) Attendance at ward rounds and referral meetings to negotiate psychological input regarding patients and present feedback from psychological interventions.

f) Observation and discussion regarding other team member’s roles and undertaking joint work with other disciplines.

g) Opportunities to observe the supervisors’ work and to be observed by the supervisors, followed by discussion within supervision.

h) Familiarity with working practices particular to a service for difficult and offender clients. Developing knowledge of issues involved in (and the practice of) security arrangements with this population and with regard to legislation.

3. Development of presentation skills

Participating in presentation of a clinical case to a multidisciplinary forensic audience.

4. Attendance at academic meetings

There is a full academic programme including research, journal and case presentations. Attendance is encouraged where possible in relation to other placement commitments. The academic opportunities within the department will provide:

a) Academic and theoretical understanding of work with mentally disordered offenders.

b) A working knowledge of the implications of the Mental Health Act (1983); the criminal justice system and basic criminal law.
5. Visits

Visits will be arranged by the trainee to hospitals providing a range of levels of security in the treatment of mentally disordered offenders, such as - Henderson Hospital, Broadmoor Hospital, Hume Ward, a close supervision unit, prison, the courts and other facilities as appropriate.

6. Other meetings and service development

a) Department and Trust Psychology meetings
b) Attendance at departmental policy group meetings as appropriate
c) Attendance at a risk management panel, child-protection case conference and Mental Health Review Tribunal, to observe or participate as appropriate.
d) Regional special interest group meetings

7. Supervision

Formal supervision will be offered each week, for an hour, by each supervisor. Additional supportive supervision will be available as appropriate.
Research Chapter
Service Related Research on Placement:

A Survey of staff emotional reactions to and beliefs about challenging behaviour.
1.1 ABSTRACT:

Those who work and live with people with learning disabilities who engage in challenging behaviours, confirm that such behaviours can often arouse strong emotional feelings (Hastings & Remington, 1995). These feelings together with their beliefs about the causes of the challenging behaviour will influence the way in which people respond (Bromley & Emerson, 1995). However, the role of affect and beliefs in the process of care for people with challenging behaviours is an area that has undergone little research.

Objectives: The purpose of the present study is to review the literature on staff's emotional reactions to challenging behaviour and to describe a small scale survey which partially replicates Hastings & Remington's (1995) study on the emotional response of staff to challenging behaviour.

Method: The survey involved 32 male and female qualified and non qualified support/nursing staff. Each participant read a short vignette depicting one of three types of challenging behaviour; stereotyped behaviour, aggression, and self injurious behaviour. They then completed a questionnaire regarding their emotional response to and beliefs about the behaviour. It was hypothesised that compared with unqualified staff, qualified staff would show less negative emotional reaction to challenging behaviour, and would attribute the behaviour to more external causes (eg, learned behaviour). It was further hypothesised that unqualified staff would show more negative responses to challenging behaviour and would attribute the causes of the behaviour to more internal causes. (e.g. biological/emotional problems).

Results: Contrary to prediction, the results suggested that qualified staff showed significantly more negative emotional reactions to challenging behaviour. Both qualified and unqualified staff held similar beliefs about the causes of challenging behaviour with the majority of all participants attributing behaviour to external causes - learned behaviour that had been positively reinforced.

Conclusion: The prevalence of high levels of negative emotions amongst staff may have implications for the service. For example such emotions may mediate the way staff respond to service users, thus affecting the quality of service delivery. Future research therefore might look at staffs' response to challenging behaviour. A further implication for the service may include the need for advanced training addressing staff's emotional reactions to the learning disabled.
1.2. Introduction:
The term challenging behaviour has been defined as "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is likely to be placed in serious jeopardy, or behaviour which is likely to seriously limit use of, or result in the person being denied access to, ordinary community facilities". (Emerson, Cummings, Barrett, Hughes, Mecool & Toogood, 1988).

Previous research has postulated that the behaviour and characteristics of people with learning disabilities may influence staff performance in a number of ways. For example, the personal appearance and mannerisms of clients may cause staff to either approach or avoid contact (Bromley & Emerson, 1995). Those clients who engage in challenging behaviours are likely to receive a disproportionate amount of time and attention from staff who may respond in ways that are likely to maintain challenging behaviour in the long run (Bromley & Emerson, 1995).

Challenging behaviours shown by clients may also produce various positive but in most cases negative emotional reactions in staff which may mediate their response to challenging behaviour. For example, Hastings (1993: cited in Hastings & Remington, 1995) identified five different staff emotional reactions; anger, fear, annoyance, anxiety and feelings of depression. Fifty percent of the participants in Hastings' (1993) study said their emotional responses affected the way in which they dealt with service users' behaviours. Bromley & Emerson (1995) found that in addition to experiencing a variety of emotional reactions, staff also held diverse views on the reasons for, or causes of, challenging behaviours. These ranged from medical/biological causes to attention seeking or communication difficulties.

Emerson & Bromley (1995) argue that patterns of emotions thought to be experienced by staff varied according to the type of challenging behaviour; aggression is thought to elicit annoyance
and sadness; self injury feelings of sadness and despair, and other behaviours e.g. screaming, elicited annoyance. This view is further supported by Hastings & Remington (1995) who found that self injurious behaviour and aggressive behaviour were associated with more negative emotions than stereotyped behaviour. The case for the argument that challenging behaviour elicits negative emotion is strengthened by various studies using observational and experimental methodologies. One of such studies include Hall and Oliver (1992:cited in Emerson, 1995) whose study involved observations of a man with self injurious behaviour. They observed that levels of staff attention varied depending on the presence or absence of self injurious behaviour. For example the amount of staff attention the man received was low when he did not self injure, attention from staff increased when the man self injured, and staff withdrew their attention when the man stopped self injuring. The authors hypothesised that staff contact with the man increased because of their experience of negative emotion caused by the man's challenging behaviour.

Recent research suggests that experienced staff have less intense or qualitatively different reactions to challenging behaviour. Hastings & Remington (1995) found that experienced staff found challenging behaviours less disturbing and rated 'feeling nothing' as a more likely response, and 'fearful' as less likely than inexperienced staff. Their study suggests that negative emotions become less intense with experience. However, in an earlier study Fallon (1983) found that although emotional reactions to challenging behaviour did change with experience and length of time in service, the reactions did not necessarily become less intense. Fallon(1983) suggested that staff who worked with clients with self injurious behaviour initially reported feeling empathy, optimism, curiosity and fear, and after a few months this changed to feelings of frustration, anger, detachment and guilt.

The extent and nature of staff's emotional reactions and belief systems employed to help them understand challenging behaviour is very important. Strong emotional reactions may result from
the beliefs staff hold about a particular behaviour, which in turn may mediate their response to that behaviour. Both emotional reaction and belief about the cause of a behaviour may compound the delivery of effective support by undermining treatment plans (Fenwick, 1995).

It is not clear how staff form their beliefs or why they experience the emotions they do, or how both reactions influence motivation towards interventions. Fenwick (1995) argues that Weiner's (1985) theory of motivation and emotion may help explain the relationship between causal beliefs staff have about challenging behaviour and their feelings. Weiner (1995) argued that the outcome of an event and its perceived causes (internality, stability, controllability) influence the emotions experienced with the dimensions of internality and controllability being involved in the genesis of interpersonal emotions such as pity and anger. Anger may be experienced when a person's bad behaviour is attributed to a controllable cause e.g. request for attention. Pity is more likely to be experienced when behaviour is attributed to uncontrollable causes e.g. mental illness.

Evidence supporting Weiner's theory comes from work on expressed emotion. Brewin, MacCarthy, Duda, & Vaughn (1991) examined the level of expressed emotion in relatives of schizophrenics and found that perception of the causes of the illness as personal to, and controllable by the client was associated with greater criticism and hostility by relatives. This suggests that staff's causal attribution of challenging behaviour is likely to generate different emotional responses, depending on whether the behaviour is perceived as being personal to, and controllable by the individual. Fenwick (1995) suggests that challenging behaviour may be influenced by factors such as severity of learning disability which is likely to influence judgment about control and intentionality. Severe/profound individuals would therefore be seen as less responsible and not in control of their behaviour (internal attribution) and mildly disabled persons would be seen as responsible for and in control of their behaviour. A likely consequence is that staff feel less pity and more anger towards the latter group.
1.3. Aims of the study:

The aim of the present study was to survey qualified and unqualified staff’s emotional affect and beliefs about challenging behaviour.

1.4. Hypotheses:

1) That qualified staff as a result of their training, would show less negative emotional reaction to challenging behaviour than unqualified staff.

2) That qualified staff would hold beliefs about the cause of challenging behaviour in line with existing causal models of challenging behaviour such as aspects of behavioural models dominant in the research and intervention literature.

The outcome of the survey may have implications for both staff and service delivery. For instance it may help staff identify for themselves areas in their work where they require further support. Implications for service delivery could include the need for advanced training focusing on emotional reactions to the learning disabled, and helping staff develop parallel beliefs about the causes of challenging behaviour based on the literature. Prevalence of high levels of negative emotions would signal the need for further research looking at staff’s response to challenging behaviour, their stress levels, perceived ability to cope, and their appraisal of the support received from management.

2. Method

2.1 Participants

Forty members of staff were approached to participate in the study following permission being given to conduct the survey. Ten were support workers from a challenging behaviour unit, and thirty were nursing staff working in support homes. Thirty-two members of staff in all completed the questionnaires (ie the response rate was 80%). The thirty two who completed the
questionnaires were a mixture of qualified and unqualified staff. It was not possible to gather information on the eight members of staff who did not respond because the researcher was not involved in distributing the questionnaires to individual staff members. The demographic information of the 32 participants who took part in the study is presented in Table 1.

Table 1.

Demographic information on the 32 participants in the survey.

<table>
<thead>
<tr>
<th></th>
<th>Qualified staff</th>
<th>Unqualified staff</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>9</td>
<td>6</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Mean years of work experience</td>
<td>19.6 (SD9.3)</td>
<td>8 (SD9.05)</td>
</tr>
<tr>
<td>Range of years of experience</td>
<td>6-37 years</td>
<td>2 mths-27 years</td>
</tr>
<tr>
<td>Percentage of staff with formal training in challenging behaviour</td>
<td>75%</td>
<td>50%</td>
</tr>
</tbody>
</table>

2.2. Measures

*Emotional Responses to Challenging Behaviour Scale*

This scale was developed by Mitchell & Hastings (1998) as a measure of caregiver’s emotional responses to challenging behaviours in people with learning disabilities. The scale was chosen in order to replicate in part the original study, and also because from the literature reviewed it appeared the most appropriate. The scale consists of 15 items rated on a 4 point scale, anchored from ‘No, never’ =0 to ‘Yes, very frequently’ =3 (see Appendix A). Each item is scored according to the numbers shown on the scale (i.e. increasing frequency associated with higher numbers). The data collected produces two subscales Fear/Anxiety feelings and feelings of Depression/Anger. (see Appendix A for details of which items make up the sub scales). The authors do not state whether or not these sub scales are derived from factor analysis. An additional question was included asking staff to list any other emotions they experience with this client group. The authors’s published findings are presented in Table 2 on page 147.
Mitchell & Hastings (1998) argue that correlations between the sub-scales and measures of care staff psychological well-being have provided support for the concurrent validity of the scale. In a study of 83 care staff, the Emotional Responses sub-scale scores were correlated with GHQ-12 scores, (Depression/Anger subscale .26) the Maslach Burnout Inventory-Emotional Exhaustion (Depression/Anger .44) Maslach Burnout Inventory-Depersonalisation (Fear/Anxiety .22, Depression/Anger .42). Mitchell & Hastings (1998) argue that these data support the concurrent validity of the Depression/Anger sub scale especially. Although it should be noted that the correlations obtained are low.

The Challenging Behaviour Attribution Scale

The Challenging Behaviour Attribution Scale (CHABA) (Hastings, 1997) was developed as a self completion rating scale that measures staff causal models of challenging behaviour (see Appendix B). The scale consists of 33 items (see Appendix B for sub scale items and scoring method) divided into five sub scales relating to five causal models: learned behaviour (8 items); medical/biological factors (9 items); emotional factors (8 items); aspects of the physical environment (8 items); and self stimulation (6 items). The questionnaire's design is concerned with staff application of causal models of challenging behaviour in particular circumstances. These circumstances are described within case vignettes about challenging behaviour.

The authors tested the reliability of the questionnaire for internal consistency using Cronbach's alpha coefficient for each of the sub-scales. The alpha values were shown to have a moderate to good level of reliability for all the sub scales. The sub scales and alpha values are: Biomedical 0.65; Physical environment 0.87; Learned Behaviour 0.76; Learned Positive 0.73; Learned Negative 0.65; Emotional 0.75; Stimulation 0.69. There is at present no validity data available.
Views on the emotions and beliefs associated with dealing with challenging behaviours were obtained by asking participants to read one of three vignettes (Hastings & Remington, 1995) describing a fictitious young man's challenging behaviour. They were then asked to complete both questionnaires described above. The three versions of the vignette (see Appendix A) described self-injurious behaviour, aggression and stereotyped behaviour. Each was based on a topographical definition of the behaviour derived from research literature on challenging behaviour (see Hastings & Remington, 1995).

2.3. Procedure

A brief visit and talk on the purpose of the survey was given to three supported houses, and support staff in the behavioural unit. The questionnaire was briefly described and guidance on completion given. The staff were reassured that the demographic information required revealed no information about their identities.

Replicating Hastings & Remington's (1995) procedure, one of three types of vignette were attached to each set of questionnaires (i.e., the Emotional Response Questionnaire and the CHABA). A member of staff from each residence and the behavioural unit was designated to distribute questionnaires to participants. The participants were given two weeks to complete the questionnaire and return it to the designated member of staff whose job it was to return all questionnaires in an envelope provided. Thirty-two sets of questionnaires (80%) were returned fully completed. It is acknowledged that the collection of questionnaires by a member of staff may have created doubt about the true confidentiality of the questionnaires, and in turn affected participants' responses to the questionnaires e.g., they may have been more likely to be less negative about challenging behaviour. Although as already stated the questionnaires were completed anonymously.
3. Results

*Emotional Response to Challenging Behaviour Scale*

The descriptive scores suggest that on both sub scales (Fear/Anxiety, Depression/Anger), qualified staff showed more negative emotional response to challenging behaviour. The descriptive results are summarised in Table 2 below. The mean and standard deviation scores are compared with published findings (Mitchell & Hastings, 1998) in Table 2 below.

### Table 2.

<table>
<thead>
<tr>
<th>ERCBS</th>
<th>Qualified</th>
<th>Unqualified</th>
<th>Mitchell &amp; Hastings</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n=16</td>
<td>n=16</td>
<td>n=83</td>
</tr>
<tr>
<td>Depression/Anger</td>
<td>10.75 (SD 6.25)</td>
<td>4.31 (SD 3.43)</td>
<td>6.87 (SD 3.33)</td>
</tr>
<tr>
<td>Fear/Anxiety</td>
<td>8.31 (SD 5.12)</td>
<td>3.12 (SD 2.89)</td>
<td>3.33 (SD 2.54)</td>
</tr>
</tbody>
</table>

The results were statistically analysed using the Mann Whitney *U* test. A non parametric test was chosen because the author could not assume normal distribution of the data. The test produced significant results (Depression/Anger *U*=46.5, *p*<0.001, Fear/Anxiety *U*=45.5, *p*<0.001) suggesting qualified staff showed more negative emotional responses on both sub-scales.

The responses were further analysed according to the one type of challenging behaviour each participant responded to. The mean and standard deviation scores of participants' emotional response to one of three types of challenging behaviour suggested that on the 'fear/anxiety' sub-scale, unqualified staff showed more negative emotional reaction to self injurious behaviour than qualified staff. Qualified staff however, showed more negative emotional response to stereotyped behaviour and aggressive behaviour. On the 'depression/anger' sub-scale, qualified staff showed more negative emotional response to all three types of challenging behaviour. A summary of the
The descriptive results is presented in Table 3.

**Table 3.**

The mean scores of qualified and unqualified staffs' emotional response to one of three types of challenging behaviour.

<table>
<thead>
<tr>
<th>ERCBS</th>
<th>Self injurious behaviour</th>
<th>Sterotyped behaviour</th>
<th>Aggression</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean/SD</td>
<td>Mean/SD</td>
<td>Mean/SD</td>
</tr>
<tr>
<td><strong>Fear Anxiety</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualified staff</td>
<td>(n=7) 3.85 (2.11)</td>
<td>(n=5) 5.5 (5.12)</td>
<td>(n=4) 3.75 (3.5)</td>
</tr>
<tr>
<td>Unqualified staff</td>
<td>(n=7) 4.75 (4.32)</td>
<td>(n=4) 1.75 (2.36)</td>
<td>(n=8) 3 (1.51)</td>
</tr>
<tr>
<td><strong>Depression/Anger</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Qualified staff</td>
<td>(n=7) 10.57 (6.29)</td>
<td>(n=5) 10.6 (8.87)</td>
<td>(n=4) 11.25 (3.3)</td>
</tr>
<tr>
<td>Unqualified staff</td>
<td>(n=4) 9.25 (6.75)</td>
<td>(n=4) 6.25 (6.13)</td>
<td>(n=8) 8.87 (4.15)</td>
</tr>
</tbody>
</table>

The results were statistically analysed using the Mann Whitney U non-parametric test. The results were not significant for self injurious behaviour (Fear/Anxiety; U=12.5, p=0.788, Depression/Anger; U=13, p=0.927), stereotyped behaviour (Fear/Anxiety; U=7.5, p=0.556, Depression/Anger; U=5.5, p=0.286), and aggression (Fear/Anxiety U=8.5, p=0.214, Depression/Anger U=14, p=0.808).

Although the study did not predict that years of work experience gained as either a qualified or unqualified member of staff might influence staff's emotional response to challenging behaviour, descriptive statistics in Table 1 and further statistical analysis suggested that the difference in years of work experience was significant. Qualified staff who had been shown to display higher levels of negative emotional reaction to challenging behaviour were also found to have considerably more years of work experience than the unqualified staff (t=3.58, df=30, p=0.001).
The Challenging Behaviour Attribution Scale (CHABA)

One qualified participant indicated that they had no idea of the causes underlying a person's challenging behaviour, and three unqualified participants gave equal ratings to two sub-scales. The results of the CHABA were interpreted by looking at which factor participants thought was the most likely cause of challenging behaviour. The results suggest that both qualified and unqualified staff held similar beliefs about the causes of challenging behaviour. Both qualified and unqualified staff thought of challenging behaviours as operant in the sense of acting on the environment. For example, six qualified and six unqualified staff attributed challenging behaviour to learned behaviour that had been positively reinforced. Three qualified and three unqualified staff believed lack of stimulation was the most 'very likely' cause of problematic behaviour, and one qualified and three unqualified participants rated the client's physical environment as the most 'very likely' cause of challenging behaviour. Five unqualified participants and four qualified participants attributed challenging behaviours to emotional problems (internal causes). Both qualified and unqualified participants rated biological/medical reasons the least likely cause of challenging behaviour. Attempts were made to statistically analyse these results. However, owing to the lower than minimum expected cell count of 5 in four of the cells, statistical analysis was not possible.
4. Discussion

**Emotional response to challenging behaviour**

The results of the survey suggest that qualified staff experienced significantly more negative emotional responses to challenging behaviour than unqualified staff, and were found to have spent significantly more years working in the field of learning disability. There were no statistically significant differences between the two staff groups in their emotional response to three types of challenging behaviour; self injurious behaviour, stereotyped behaviour and aggression. There was a trend for unqualified staff to display more negative reactions to self injurious behaviour than qualified staff. Qualified staff were more likely to display negative reactions to stereotyped behaviour and aggression.

Recent literature suggests that qualified experienced staff tend to show less negative emotional responses to challenging behaviour than unqualified inexperienced staff (Hastings & Remington, 1995), suggesting that negative emotions become less intense with experience. The results of this survey appear more in line with research by Fallon (1983) suggesting that although emotional reactions to challenging behaviour may change with experience and length of time in service, the reactions may not become less intense. This would explain a finding of no difference between groups - but qualified staff with a considerable length of service were becoming more negative. In the light of informal discussions with staff before the study commenced, reasons for staff becoming more negative may be due to ‘burn out’ as a result of staff recruitment/retention problems, and the perceived lack of supervision and continuous training.

**Beliefs about the causes of challenging behaviour**

Both qualified and unqualified staff held similar beliefs about the causes of challenging behaviour, clearly thinking of the behaviours as operant in the sense of acting on the social environment. Several authors have suggested that a behavioural approach might be helpful in understanding...
challenging behaviours - with positive reinforcement for example hypothesised as a maintaining factor of challenging behaviour (McBrien & Felce, 1992). Both groups failed to identify the role of biological factors in the determination of challenging behaviours consistent between certain syndromes and types of challenging behaviour e.g. fragile X syndrome and social anxiety, Lesch-Nyhan syndrome and self injury.

**Implications for staff and service delivery**

The findings of the present study raises a number of issues. Firstly, it highlights that negative affect is not restricted to certain types of challenging behaviour, both qualified and unqualified staff were found to report negative emotions associated with all three types of behaviour included in this study. This supports the view that concern over staff emotional responses should not be limited to ‘severe’ challenging behaviours (Hastings & Remington, 1995). Secondly, both qualified and unqualified members of staff typically experienced a range of diverse negative reactions which may cause staff to either avoid a client or terminate as quickly as possible any episode of challenging behaviour (Bromley & Emerson, 1995). Such quick solutions are likely to maintain behaviour in the long run owing to staff's inconsistent response to challenging behaviour. It is equally possible that staff who experience negative affect may be inclined not to follow behavioural programmes, especially when such programmes may lead to extinction bursts of challenging behaviour (Hastings & Remington, 1995). Thirdly, the question arises as to whether the less negative response reported by unqualified staff is due to the degree of support they are more likely to receive or the fact that they have considerably fewer years of work experience in the field. Conversations with staff and data from the emotional response questionnaire suggests that both qualified and unqualified members of staff need specific (and perhaps intense) support and counselling to enable them to maintain positive relationships with service users. Very little is known about the stress and strain staff experience working with people who engage in challenging behaviour, therefore it is important to monitor the management of staff in services for people with learning disabilities. One
way would be to carry out in depth qualitative studies of staff's experiences to indicate the type of support required to reduce 'burn out' and improve staff retention in an area which suffers recruitment and retention problems.

Finally, the construct employed by staff to understand a client's challenging behaviour may mediate their response to the client's behaviour, the probability of staff seeking internal or external support, and the probability of them appropriately implementing any advice given by peers, managers and other professionals (Hastings & Remington, 1994). The present data indicate that staff's beliefs about the cause of challenging behaviour concerned mostly external factors over which both client and staff exercise some degree of control. This has important positive implications for practice. Attribution theory suggests that staff who attribute challenging behaviour to internal causes e.g. emotional/biological states may perceive that they are unlikely to be able to change the behaviour (Fenwick, 1995). We can deduce from participants' attributions of challenging behaviour to more external controllable causes a willingness to seek advice from other professionals, and a willingness to implement behavioural programmes as advised.

Limitations of the present study

Power calculation

The interpretation of the statistical results of the survey presented in this paper needs to proceed with a degree of caution. Although the study produced several significant results, attempts to further compare the data within groups (comparison of responses dependent on type of challenging behaviour) proved non-significant owing to the small sample size. An a priori power calculation would have provided information on the number of participants necessary to run this study. Clearly it would have been important to have done this before starting the study, but the sample was in any case limited by the number of staff employed and the response rate.
Reliability & Validity

*Emotional Response to Challenging Behaviour Scale*

The test-retest reliability of the Depression/Anger sub-scale is not as good as that of the Fear/Anxiety sub-scale. Mitchell & Hastings (1998) hypothesise that this may be because these feelings are subject to greater change with levels of general or work related stress amongst staff. The predictive validity of the scale has not been investigated e.g. high fear/anxiety scores may be associated with avoidance behaviour, and depression/anger might be associated with punitive intervention responses. Hastings (1998) the author of the CHABA commented that the validity of the tool is difficult to establish given the lack of objective external validation criteria. At present there are no validity data. The CHABA may not be a sufficient measure of staff attributions. Therefore, participants' response to the CHABA may not completely reflect their beliefs about challenging behaviour.

*General criticism of the survey*

Firstly, there is a possibility that if newly qualified staff are separated from the rest of the qualified group, their data may show less emotional reaction to challenging behaviour, suggesting that number of years in service irrespective of whether staff are qualified or not may be a contributing factor to experiencing negative emotions. Secondly, the scales used tended to be a forced choice between expressing a negative emotion or no negative feeling rather than a choice of both negative and positive feelings which may have given a more balanced view of staff's feelings towards clients who engage in challenging behaviour.
CONCLUSION

The present survey examined the emotional responses of qualified and unqualified staff to challenging behaviour, and their beliefs about the causes of challenging behaviour. The results of the study suggest that both groups of staff showed negative emotional responses to challenging behaviour. When compared to published data, unqualified staff scores were lower than the norms, qualified staff scores on both scales were higher than the norms. It was also found that the qualified staff had significantly more years of work experience in the field of learning disability. Both groups tended to attribute the cause of challenging behaviour to learned behaviour that had been positively reinforced, however both groups did not see the relevance of biological/medical factors.

The negative emotions experienced by both groups of staff, especially qualified staff could be an indication that such staff require support and further training. It seems likely that such negative feeling towards challenging behaviour affects morale of staff and their perceived ability to cope when faced with distressing behaviour. In view of the results of this study which suggest that staff are experiencing negative emotions working with the learning disabled, it is important that staff receive ongoing support and training exploring the relationship between their beliefs and emotional response to clients in their care to ensure that such clients receive the best possible service.

The study also highlights the importance of clinicians examining staff causal beliefs and emotional responses as part of their functional and ecological analysis. Intervention plans should provide the opportunity for continuing discussion of staff feelings and beliefs about a client’s behaviour which may conflict with the programme he/she is advised to implement.

No doubt the results of this small scale survey cannot generalise to all staff within the service.
The results of this exploratory analysis may be considered of value in generating hypotheses for future, and more rigorous investigations.
References


APPENDIX A

*Demographic information sheet

*Emotional Response To Challenging Behaviour
Questionnaire and scoring procedure
**Demographic information**

Please circle your answer where appropriate.

Sex:  F / M

Are you working as a qualified member of staff e.g. do you have nursing qualifications or other professional qualifications?  YES  NO

How long have you worked with people with learning disabilities?  ......years........months

Have you received formal training on challenging behaviours?  YES  NO

**NB**

I should be grateful for all questionnaires to be returned by Thursday, 9 July 1998.

Overleaf is a short vignette describing a particular challenging behaviour. Please read the vignette and answer all the questions that follow.
Emotional Response to Challenging Behaviour Scale

James Robinson

1)* James is learning disabled. Sometimes, James stands in the middle of the floor and rocks his body. James' rocking always involves him putting his left foot behind his right and rocking from one foot to the other.

2)* James is learning disabled. Sometimes, James repeatedly hits himself around the head with his fists. This often leads to bruising and even bleeding.

3)* James is learning disabled. Sometimes, James stands in the middle of the floor and rocks his body. James' rocking always involves him putting his left foot behind his right and rocking from one foot to the other.

Instructions: Form a picture of what you think about the behaviour described. Keep James' behaviour in mind when you answer the questions on the questionnaire.

Emotional Responses to Challenging Behaviour

Below is a list of emotions that caregivers have said that they experience when they have to work with adults who display challenging behaviours. We want to know how you typically feel in this situation. Think about your own recent experience of clients like James you work with. Then consider each of the emotional reactions below and select the response next to each item that best describes how you feel when working with adults who display this particular type of behaviour.

<table>
<thead>
<tr>
<th></th>
<th>No, never</th>
<th>Yes, but infrequently</th>
<th>Yes, frequently</th>
<th>Yes, very frequently</th>
</tr>
</thead>
<tbody>
<tr>
<td>SHOCKED</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>BETRAYED</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>GUILTY</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>HOPELESS</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>AFRAID</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>ANGRY</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>INCOMPETENT</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Feeling</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>------------</td>
<td>---</td>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>SAD</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>FRUSTRATED</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>HELPLESS</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>DISGUSTED</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>NERVOUS</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>RESIGNED</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>FRIGHTENED</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>HUMILIATED</td>
<td></td>
<td></td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>

Please mention any other feelings you experience in this situation

* Please note that participants were presented with just one depiction of James Robinson.
Emotional Response to Challenging Behaviour Scale: Procedure for scoring

The scale consists of two sub scales: Fear/Anxiety feelings and feelings of Depression/Anger. To obtain these two scores, follow this procedure:

1. Each item is scored according to the numbers shown on the scale (i.e., increasing frequency associated with higher numbers).

2. Sum the scores for the following items to obtain the Fear/Anxiety sub scale score:
   FRIGHTENED, AFRAID, NERVOUS, INCOMPETENT, SHOCKED.

3. Sum the scores for the following items to obtain the Depression/Anger sub scale score:
   BETRAYED, ANGRY, SAD, HUMILIATED, HOPELESS, RESIGNED, HELPLESS, FRUSTRATED, GUILTY, DISGUSTED.
APPENDIX B

* The Challenging Behaviour Attribution Scale (CHABA)

* Sub scale items and scoring procedure
The Challenging Behaviour Attribution Scale (CHABA)

I am interested in why YOU think clients like James with learning disabilities engage in challenging behaviours. Consider how likely it is that each of the following statements are reasons for such behaviour. Simply think generally about the most likely reasons for people with learning disabilities behaving in this way.

Please give your response to each of the possible reasons, and use the scales below each reason to indicate your opinion. The key shows what the points on the scales mean.

VUL = Very Unlikely
UL = Unlikely
E = Equally Likely/Unlikely
L = Likely
VL = Very Likely

Please indicate your response by placing a circle around the appropriate point on the scale.

People with learning disabilities engage in challenging behaviours BECAUSE.....

1. They are given things to do that are too difficult for them VUL UL E L VL
2. They are physically ill VUL UL E L VL
3. They do not like bright lights VUL UL E L VL
4. They are tired VUL UL E L VL
5. They cannot cope with high levels of stress VUL UL E L VL
6. Their house/classroom is too crowded with people VUL UL E L VL
7. They are bored VUL UL E L VL
8. Of the medication that they are given VUL UL E L VL
9. They are unhappy VUL UL E L VL
10. They have not got something that they wanted VUL UL E L VL
11. They live in unpleasant surroundings VUL UL E L VL
12. They enjoy it VUL UL E L VL
13. They are in a bad mood VUL UL E L VL
Thank you very much for your cooperation.
<table>
<thead>
<tr>
<th>Item and number</th>
<th>Subscale</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. They are given things to do that are too difficult for them</td>
<td>L/LN</td>
</tr>
<tr>
<td>2. They are physically ill</td>
<td>BM</td>
</tr>
<tr>
<td>3. They do not like bright lights</td>
<td>PE</td>
</tr>
<tr>
<td>4. They are tired</td>
<td>BM</td>
</tr>
<tr>
<td>5. They cannot cope with high levels of stress</td>
<td>BM</td>
</tr>
<tr>
<td>6. Their house/classroom is too crowded with people</td>
<td>PE</td>
</tr>
<tr>
<td>7. They are bored</td>
<td>ST</td>
</tr>
<tr>
<td>8. Of the medication that they are given</td>
<td>BM</td>
</tr>
<tr>
<td>9. They are unhappy</td>
<td>EM</td>
</tr>
<tr>
<td>10. They have not got something that they wanted</td>
<td>L/LP</td>
</tr>
<tr>
<td>11. They live in unpleasant surroundings</td>
<td>PE</td>
</tr>
<tr>
<td>12. They enjoy it</td>
<td>ST</td>
</tr>
<tr>
<td>13. They are in a bad mood</td>
<td>EM</td>
</tr>
<tr>
<td>14. High humidity makes them uncomfortable</td>
<td>PE</td>
</tr>
<tr>
<td>15. They are worried about something</td>
<td>EM</td>
</tr>
<tr>
<td>16. Of some biological process in their body</td>
<td>BM</td>
</tr>
<tr>
<td>17. Their surroundings are too warm/cold</td>
<td>PE</td>
</tr>
<tr>
<td>18. They want something</td>
<td>L/LP</td>
</tr>
<tr>
<td>19. They are angry</td>
<td>EM</td>
</tr>
<tr>
<td>20. There is nothing else for them to do</td>
<td>ST</td>
</tr>
<tr>
<td>21. They live in a noisy place</td>
<td>PE</td>
</tr>
<tr>
<td>22. They feel let down by somebody</td>
<td>EM</td>
</tr>
<tr>
<td>23. They are physically disabled</td>
<td>BM</td>
</tr>
<tr>
<td>24. There is not very much space in their house classroom to move around in</td>
<td>PE</td>
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<tr>
<td>25. They get left on their own</td>
<td>ST</td>
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<tr>
<td>26. They are hungry or thirsty</td>
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<tr>
<td>27. They are frightened</td>
<td>EM</td>
</tr>
<tr>
<td>28. Somebody they dislike is near by</td>
<td>L/LN</td>
</tr>
<tr>
<td>29. People do not talk to them very much</td>
<td>ST</td>
</tr>
<tr>
<td>30. They want to avoid uninteresting things</td>
<td>L/LN</td>
</tr>
<tr>
<td>31. They do not go outdoors very much</td>
<td>PE</td>
</tr>
<tr>
<td>32. They are rarely given activities to do</td>
<td>ST</td>
</tr>
<tr>
<td>33. They want attention from other people</td>
<td>L/LP</td>
</tr>
</tbody>
</table>

L) learned behaviour (LP) learned positive; (LN) learned negative; (BM) biomedical; (EM) emotional; (PE) physical environment; (ST) stimulation.
Scoring the CHABA

Five main sub-scale scores are calculated from ratings of the CHABA items. Each rating is assigned a value of (-2) very unlikely; (-1) unlikely; (0) equally likely/unlikely; (1) likely or (2) very likely. A total score for each subscale is derived by summing the ratings on all of the items associated with the five causal models and dividing this score by the number of items in the subscale. A subscale score below zero suggests that the respondent considers the particular causal model is unlikely to apply to the rated behaviour. A total score above zero suggests that the particular causal model is viewed as applicable to the rated behaviour. Scores on individual subscales can also be compared directly. For example, a more positive scale score for emotional factors than biomedical factors indicates that the person views the former causal model as more applicable in a given situation.
Appendix C

*Feedback on service related research from Thames Gateway NHS Trust
Dear Helen,

Thank you for sending me the full and summary reports of the research work undertaken. I am indeed very impressed with the style and quality of your presentation. Regrettably the outcome of your research indicated that "qualified with more years work experience in learning disability services, significantly showed more negative emotional reaction to challenging behaviour than unqualified staff".

The above finding has certainly given cause for concern in an effort to address the following issues:

1. The future range and appropriateness of challenging behaviour training for qualified staff.
2. The future role model of qualified staff towards unqualified staff in respect of the above finding.

May I take this opportunity to thank you for the valuable information provided and I would like to wish you a happy Christmas and a prosperous new year.

Yours sincerely,

Jacob Surroop
Manager, Target Unit
Literature Review

Illness perceptions, coping and functioning in adults with a chronic illness:
A review of research evidence.
Illness perceptions, coping and functioning in adults with a chronic illness

A review of research evidence

Introduction- Over the last 30 years health psychologists have studied peoples response and behaviour when faced with a health threat, and have proposed various social cognition theories and models from which this process could be understood. One such model is the Self Regulation Model (Leventhal, Meyer & Nerenz, 1980). The aim of this article is first, to briefly discuss and critically evaluate the self regulation model and its application in a variety of chronic illnesses. Second, to review and evaluate the evidence that the dimensions of illness representations postulated by the model generalise to all illness conditions. Third, to review and evaluate the evidence that illness representations mediate coping and outcome. The article concludes with suggestions for future research.

"The common sense" model of illness

It is known that people develop schemas, beliefs and representations of their world based on culture, family and social values to explain and predict events (Leventhal & Diefenbach, 1992). When people become ill they develop similar cognitive frameworks of bodily sensations and changes that reflect either familiar or unfamiliar symptoms (Weinman & Petrie, 1997). Leventhal & Nerenz, (1985) defined these illness schemas, beliefs and representations as 'a patient's own implicit common sense beliefs about their illness'. They argue that these common sense beliefs mediate how people understand and cope with their illness.

A number of social cognition theories have attempted to explain how patients' understanding of their illness and their evaluation of the threat it presents predicts various behaviours such as compliance and adherence to treatment. One such theory is the Health Belief Model (HBM) (Rosenstock 1974: cited in Conner & Norman, 1998) proposed that health practices are based on
the beliefs or perceptions an individual holds concerning a specific illness, such as: a) the perception of vulnerability to the illness; b) the perceived severity and consequences of the illness if contracted, and; c) the perceived effectiveness (benefits) and costs of performing the health behaviour. The cost benefit analysis in the HBM is plausible, but does not propose any cognitive mechanisms by which beliefs about the threat of illness and preventative behaviour are put into action. The model has also been criticised for explaining only 25% of the variability in health behaviour and that it may be difficult to separate knowledge about a disease from beliefs concerning it (Johnston, 1994: cited in Williams, 1997). In an attempt to address some of these issues, other models have been devised to try to account for health related actions as well as health related beliefs.

One such model is the Self Regulation Model - SRM (Leventhal et al., 1980) that was developed following a series of experimental studies examining how preparation for a noxious experience affected participants' emotional reaction and coping strategies. From these studies further open ended interviews were conducted and self report data collected to draw inferences regarding the attributes of illness representations. The inferences drawn were that individuals are motivated to reduce health threats in ways congruent with their perception of the threat the illness presents. Leventhal et al., (1980) proposed that to understand how people respond to the threat of illness an examination of these threats from the individual's perspective is necessary. Leventhal et al., (1980) proposed that this could be done by modelling the individual's representation of the threats, the strategies they use to manage the threats, and the criteria they use to appraise coping outcomes. Leventhal et al., (1980) also argued that it was important to identify the emotional reactions that emerge during illness threats, how these interact with illness representations, and how the individual copes and appraises the outcomes of these interactions. Leventhal, Diefenbach & Leventhal (1992) proposed a parallel response framework from which this dynamic process between cognitive and emotional elements could be understood. This conceptual framework was
The Parallel-Response Framework.
The Self Regulation Model (SRM) (Leventhal et al., 1970; cited in Leventhal et al., 1992) proposes two parallel processing systems, one is concerned with coping and appraising the objective health threat of the illness, the other is concerned with coping and appraising the management of the subjective emotional processing system. Both systems are influenced by culture, family and social values, and by schematic memories of past illness experiences and knowledge of illnesses. Together the two represent a self regulative system with each parallel processing system consisting of three stages. First the illness representation is generated and influences the formation and implementation of a plan of action which leads to the second stage—the use of coping strategies. At the third stage the coping strategies are appraised with respect to a set of expectations. Multiple feedback loops ensure that the three stages influence each other. The SRM is a dynamic model allowing illness representations, emotional and behavioural reactions to change over time. Leventhal et al., (1980) suggested that illness representations have at least five dimensions:

The first dimension is the individual's beliefs about the identity of the illness characterised by the label given to the experience of one or more familiar or unfamiliar symptoms.

The second dimension concerns the individual's beliefs about the causes of the problem e.g. an inherited disease or one caused by environmental stress.

The third dimension concerns the individual's beliefs about possible consequences of the illness; the impact of the illness on physical and psychological well being, and the social and financial costs of the disease.

The fourth, the time line dimension concerns beliefs about the duration of the illness and its
course. For example beliefs about whether the disease is acute, chronic or episodic.

The fifth dimension concerns the individual's beliefs about cure/controllability of the illness.

These five illness representations and have been researched and shown to have important implications for how patients' conceptualise and cope with their illness (Leventhal et al, 1992). For example, illness representations have been used to understand a range of illness behaviours from compliance with medical care (Meyer, Leventhal & Guttman, 1985), to rehabilitation (Petrie, Weinman, Sharpe & Buckley, 1996), and as a predictor of success when coping with chronic illness (Hampson, Glasgow & Toobert, 1990).

Despite current research reporting on the usefulness of the self regulation model, it has its limitations. First the model fails to report on the role of other beliefs e.g. beliefs about the self and others which may distort or interact with a person's beliefs about their illness. Belief about an illness may be distorted in order to maintain self esteem and cope with an illness by enhancing a sense of control and mastery over the illness (Williams, 1997). Williams (1997) argues that underlying beliefs about trust and relationships with authority figures can affect interaction with health professionals and have an important impact on health related behaviour. Thus beliefs about the self, others and the world may interact with illness perceptions. Williams (1997) argues that the omission of the self schema as a cognitive structure interacting with illness representations weakens the model's clinical utility. Second, it does not include an explicit appraisal stage and does not elaborate on the emotional reaction to illness. This is essential to any model of illness behaviour since there is a great deal of evidence that the appraisal of bodily sensations is an important factor influencing the experience of those sensations (Clark, 1989). Third, research supporting the structure of the generic dimensions of illness representations has been controversial. This controversy is examined next. This section of the review will begin with a brief overview of the research on the five dimensions and then focus on a number of studies and their
methodological limitations.

The generic structure of illness representations and chronic illness

Several studies involving different methodologies and measuring instruments across a range of different illnesses have confirmed the consistency and validity of one or more of the five dimensions co-occurring (Scharloo & Kaptein, 1997: cited in Petrie & Weinman, 1998). However, research has also shown that attempts to identify the five dimensions posited by the self-regulation model have offered less support for the existence of these as generic dimensions. The dimensions have been found not to be always well integrated and not necessarily complete as suggested by the model (e.g. Hampson, Glasgow & Zeiss, 1994), and in some studies only some of the dimensions have been found to be present or relevant (e.g. Heijman & de Ridder, 1998). Although Lau & Hartman (1983: cited in Leventhal et al., 1992) who added the cure dimension to the illness representation concept, noted that the cure dimension is more likely to be present in representations of acute illness were recovery is expected and may not be relevant in chronic diseases.

Moreover, the five dimensions may not be independent of each other. Hampson et al., (1994) found that the items developed to measure beliefs about the ‘cause’ and ‘consequence’ of diabetes to be highly correlated and therefore combined these two dimensions into a ‘seriousness’ dimension. Leventhal & Nerenz (1985) also found the timeline factor to be implicit in every dimension of illness representations, and so for some conditions the dimensions may be highly correlated and inseparable. It is also possible that difficulties may arise in determining what is an illness representation and what is a coping strategy e.g. “it is not serious” could be an illness representation or an avoidant coping strategy. Other studies report that the content of the representations vary across patients depending on the type of illness (Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman & Rooijmans, 1998; Hampson et al., 1990). Some dimensions may be
less relevant and some may merge together to form three or four dimensions or dimensions opposed to those identified in the self regulation model.

Evidence for the possible existence of other dimensions is reported by Hampson et al., (1990). They assessed and examined 46 women's personal representations of their non insulin dependent diabetes (NIDDM) using a variety of comprehensive open ended and fixed response questions developed to cover a wide range of beliefs including the five dimensions of illness representations. The results of the regression analysis identified four composite components to their understanding of illness representations - 'cause', 'symptoms', 'treatment effectiveness' and 'seriousness' (a merger of the consequence and time line dimensions). They found that illness representations contributed significantly to the prediction of dietary self management, and marginally to adherence to recommended exercise regime. For both diet and exercise, the 'Treatment Effectiveness' dimension was the most important predictor of level of self management. The Hampson et al., (1990) study demonstrated that the five dimensions of illness representations were present in patients with NIDDM yet simultaneously provided similar evidence to Turk (1986) that representations may not be independent of each other and may merge. For example, a meaningful distinction between the time line and consequence dimension could not be made by Hampson et al., (1990) resulting in the formation of a new dimension (seriousness). Another study by Hampson et al., (1994) examining the illness representations of patients with osteoarthritis also produced similar results with the time line and consequences dimensions merging together to form a 'serious' dimension. Both studies may suggest that i) illness representations are disease specific; ii) the time line and consequence dimension are measuring the same concept.

Similar results were reported in a recent study by Heijman & de Ridder (1998) who examined the structure and determinants of illness representations of Addison disease (AD) and Chronic fatigue syndrome (CFS) patients. They reported the 'consequences' and 'identity' dimensions to be
strongly related for AD patients but not for CFS patients answering the same questions. In a later study (Heijman & de Ridder, 1998) examined the structure of the illness representations associated with the same conditions but were interested in answering three questions: i) Whether the scales reflecting the five dimensions could be confirmed in a factor analysis using the original items and having no a priori hypothesis about the number and kind of dimensions present; ii) whether the observed structures would be the same for both CFS and AD patients and; iii) how the factor structures relate to coping and adjustment. The analysis produced factor structures different to the dimensions proposed by Leventhal (1980), in addition the dimensions differed slightly for the two patient groups. For the CFS patients a four factor solution was identified and labelled 'manageability', 'seriousness', 'personal responsibility' and 'external cause'. Personal responsibility correlated positively with manageability, while seriousness correlated positively with external cause. For both factors 'personal responsibility' and 'external cause' items relating to cure and cause were found to load on one factor. The pattern of correlation between beliefs about the cause of CFS and the consequence of CFS and between external cause and personal responsibility were consistent with findings in the Moss Morris, Petrie & Weinman (1996) study where CFS patients were shown largely to believe in a biological explanation for their illness and this belief was found to be associated with poor coping skills.

For the AD patients the factor analysis produced a different four factor solution labelled 'seriousness', 'cause', 'chronicity', and 'controllability'. The authors noted that chronicity and seriousness were negatively correlated, and argue that this may be due to the fact that AD sufferers' knowledge of the chronicity of the illness together with the knowledge of the effective management of the condition enabled patients to think and see their illness as not serious. The CFS group did not consider their illness to be chronic and the manageability dimension showed the strongest correlation with coping. The cure/control dimension was less relevant for the AD participants and was dropped from the factor solution. The authors explained that this may have
been due to patients’ trust in their medication and a lesser need to think of other ways to control their illness. Leventhal and Nerenz (1985) argued that the cure/control dimension should remain part of the self regulation model, but whether it should remain an attribute of illness representations itself or as a summary of expectations with respect to coping is open to debate. Given the nature of most chronic illness where a complete cure is unlikely, the cure dimension could be viewed as a measure of difficulty coming to terms with chronic illness or denial, therefore it would appear more useful to have the control dimension separated completely from the cure dimension for this reason. The ‘personal responsibility’ dimension for the CFS participants and the ‘cause’ dimension for the AD participants did not show significant relationships to either coping or adjustment, and therefore appeared less relevant for both groups. This supports the argument that the profile of illness representations may be disease specific i.e. some representations would account for a significantly greater proportion of the variance than others. In response to the three questions that the study set out to answer, theoretically derived scales reflecting the five dimensions were not found, neither were the observed structures found to be the same for CFS and AD participants. Therefore a generic structure common to the representations of all illnesses was not supported by the study. Dimensions of illness representations in this study merged according to the illness under study, resulting in dimensional structures that were applicable only in the light of the specific illness. The merger and formation of new dimensions leaves open to debate the possibility of the existence of other cognitive dimensions different to those identified by the self regulatory model. Hampson et al., (1990, 1994) argue that their studies on diabetes demonstrate that some changes to the five dimensions might be necessary. This article suggests that the inclusion of other possible dimensions rather than change is necessary.

The research on the self regulatory theory has been mostly informed by Western cultural tradition and has failed to incorporate non western illness beliefs. For example, Helman (1998) argued that some people from non Western society have ‘folk illnesses’ which are syndromes or diseases for
which their culture provides an aetiology, a diagnosis, preventative measures and regimens of healing. Matthews, Lannin & Mitchell (1994) in a qualitative study (method of qualitative analysis not mentioned) looking at advanced breast cancer in 26 black women in South America found that many of the women related their symptoms to ‘folk’ theory of disease. Of the 26 women 14 believed the symptoms were connected to or caused by a condition known as ‘bad blood’. Moreover segments of the ‘blood’ model were found in more than half of the black women with early and middle stage breast cancer, but were absent from all the accounts given by white patients regardless of stage of breast disease. This is a clear example of the cultural differences in the representation of the ‘cause’ of a disease. Many of the women drew connections between impurities in the blood and and what they described as lumps and knots in the body. These lumps and knots were said to be triggered by external factors e.g. sixteen of the women said their breast lump was triggered by blows or bumps to the breast area. Twenty two of the women delayed seeking treatment because of folk beliefs concerning the dire consequence of tampering with lumps. All 26 women believed that their condition could be exacerbated by tampering with lumps, especially if exposed to medical procedures (via x-rays) and air (via medical operation) which could result in the lump growing out of control. Many of the women struggled to evaluate and fit the medical diagnosis of cancer with their folk definition of the disorder and continued to believe that there was a difference between a lump/tumour and cancer. So if we are to fully understand the illness representations of our diverse multicultural society, we must be aware of the individual meaning given to symptoms within different cultural contexts and include them as alternative illness dimensions.

Methodological limitations

The results of the studies reviewed are to be interpreted with caution. The Hampson (1990) study cannot be generalised to the wider population of male and female diabetes sufferers because their study was based on a small sample of 46 female patients. The patients had all received a
diagnosis in the past year, therefore it is not certain that the representations would reflect the beliefs of women who had been diagnosed much longer. Given the dynamic nature of the model, one would expect illness perceptions of patients' who had been diagnosed much longer to become more positive or negative depending on the individual's appraisal of the illness and other illness related factors over time.

The Hampson (1990) and Heijman & de Ridder (1998) study may be interpreted as suggesting that there is no generic five dimensional structure to all illness representations or as suggesting that the five dimensions may be evaluated differently depending on the illness in question. Neither study has made an argument for either suggestion. The validity of the structured questionnaires constructed in both studies is questionable and may have failed to capture and discriminate completely the illness representations of diabetic patients in the Hampson study, and CFS and AD patients in the Heijman & de Ridder study, hence the merger of certain dimensions. In the Heijman & de Ridder study the 'cause' dimension was assessed differently for both diseases - AD patients were asked the extent to which they believed AD was caused by biological and psychological factors or fate. CFS patients were given a choice of 15 items. No doubt, such differences in the line of questioning makes it impossible to compare and draw inferences about the effect of the 'cause' dimension and its relationship to the other dimensions. The study also failed to control for background variables, the CFS patients were diagnosed in the last 3 years, AD patients in the last 11.4 years and had been ill longer. The AD patients' perception of their illness may have been influenced by years of having suffered from the disease. Both studies also failed to assess for comorbidity which may have influenced the way participants think and feel about their illness. In spite of the limitations of both studies they highlight the importance of recognising that different illnesses present with different representations, and in line with Turk et al., (1986) suggests the possibility of cognitive structures other than those described within the self regulation theory. The Mathews et al., (1994) qualitative study was part of a larger study investigating the
reasons why some women delay seeking treatment for breast cancer. It is recognised that the study cannot be generalised since the beliefs and behaviours of these women with advanced breast disease are not necessarily relevant to the behaviours of the majority of black women in America with breast cancer.

The next section of this article briefly discusses the literature on coping and then reviews studies reporting on the relationship between illness representations, coping and outcome. The section concludes highlighting the methodological limitations of the studies reviewed.

Illness representations, functioning and the role of coping mechanisms

According to the self regulatory model the influence of disease factors on emotional responses, coping behaviours and health outcomes should be mediated by illness representations. Models of stress and coping have been used to explain adjustment differences amongst chronically ill patients (Rosenstiel et al., 1983). In these models pain/illness is defined as a source of stress, whereas coping is defined as a purposeful effort to manage, avoid or reduce the negative impact of the illness (Lazarus & Folkman, 1984). The general cognitive model of coping postulates that the individual appraises both the situation with which they have to cope and the available coping resources at their disposal (Lazarus & Folkman, 1984). Cognitive appraisals and behavioural responses to deal with a potential illness threat are believed to play a central role in the coping process by influencing both the initiation of coping efforts and one's overall sense of well being (Lazarus & Folkman, 1984). Research suggests two major categories of coping behaviour: Problem focused coping (Lazarus & Folkman, 1984) which includes planning and instrumental behaviours to mitigate problems such as pain caused by disease e.g. pacing activities and: Emotion focused coping (Lazarus & Folkman, 1984) which includes strategies to manage thoughts and feelings associated with disease e.g. reinterpretation of the situation. Research has identified some of the appraisals most important in adaptation to chronic illness and pain.
Strategies such as self efficacy or control appraisal (the belief that one has the ability and resources to manage pain or illness) have demonstrated positive relations to indices of adaptive psychological functioning (Turner & Clancy, 1986; Gil, Abrams, Phillips & Keefe, 1989). Relations between control appraisals and activity level have also tended to be positive (Gil, 1989). Positive reframing, acceptance, social support have also been shown to be related to adjustment (Schussler, 1992). In sickle cell disease, Gil (1989) reported that strategies that involve 'passive' coping and catastrophising, self blame, emotional ventilation and avoidance have generally been related to poorer adjustment to sickle cell disease.

A number of studies have reported on the association between illness representation, coping and functioning. Moss Morris, Petrie & Weinman (1996) reported on the relationship between illness representation, coping and self reported daily functioning and well being of 233 patients with chronic fatigue syndrome. They found the identity dimension was positively related to both problem focused strategies - planning, and emotion focused coping - venting emotions and mental and behavioural disengagement. Belief that CFS had serious consequences was positively associated with planning, and belief in internal control was positively related to active coping, planning and positive reinterpretation. A strong belief in the illness lasting a long time was associated with coping by reducing daily activities. Both illness perceptions and emotional focused coping strategies were significantly related to functioning and psychological adjustment in the CFS sample. More important theoretically was the finding that the illness representations were more strongly associated with adjustment and well being than the coping sub scales which suggests that illness representations had a direct effect on functioning which was not mediated by coping strategies as the self regulation model posits.
Scharloo et al's (1998) study reported on the relationship between illness representations, coping and outcome in various chronic illnesses. The study involved three patient groups - 80 patients with chronic obstructive pulmonary disease (COPD), 80 patients with psoriasis, and 84 with rheumatoid arthritis (RA). The findings of the study suggested that illness perceptions, coping and medical variables were significantly related to functioning as indicated by the physical, role and social functioning sub scales of the Medical Outcomes Study Short Form General Health Survey (MOS) and disease specific Daily Activities of Life (DAL), Psoriasis Disability Index (PDI) and the Health Assessment Questionnaire (HAQ). Correlations were in the predicted direction with strong illness identity, 'passive' coping, belief in a long illness duration (timeline), belief in dire consequences, and an unfavourable score on medical variables were associated with worse outcome on disease specific measures of functioning. Coping involving seeking social support and belief in controllability/curability of the disease were significantly related to better physical and psychological functioning. In line with Moss-Morris et al., (1996), the study did not support the assumption of the self regulation theory that coping is a mediating factor between illness representations and outcome. When coping strategies were entered into the regression equation before illness perceptions, illness perceptions still explained more variance in functioning than coping. This indicates that illness perceptions had a direct effect on functioning that was not mediated by coping.

Heijmans & de Ridder (1998) mentioned earlier, despite finding cognitive dimensions other than those postulated in the self regulatory theory, found relationships between their dimensions and coping strategies. For the CFS patients the dimension named 'manageability' was shown to correlate with coping and adjustment. High manageability scores appeared to encourage problem focused coping, and support seeking. A strong belief in the condition being serious was associated with avoidance behaviour, such patients also experienced problems in physical and social functioning, mental health and vitality. The study suggests subsequent experience of problems in
physical and social functioning rather than the mediation of coping strategies. The pattern of correlations between beliefs about cause and consequence, and between external cause and personal responsibility were consistent with findings from research examining the role of cognitions in the perception of CFS. Moss Morris et al., (1996) found that CFS patients have been shown largely to believe in a biological explanation for their illness and this belief has proved to be an important predictor of higher levels of impairment and poorer outcome. For the AD patients strong beliefs in the seriousness of the illness led to problems in all aspects of functioning. Feelings of control correlated positively with fewer mental health problems and greater vitality. With regard to coping, strong beliefs in the seriousness of Addisons disease correlated positively with more cognitive and behavioural avoidance and venting of emotions. Chronicity was negatively related to seriousness and cause of the illness did not seem important in relation to coping or adjustment.

Methodological limitations
The Moss Morris et al., study (1996) has several limitations. Like the Hampson et al., (1990) diabetes study the participants were mostly women whose representations may differ to men. Therefore the results cannot be generalised to all diabetes and CFS sufferers. The age of participants ranged from 18-81 years, the study did not look at age/developmental stage differences and how this might impact on a patient's perception of their illness. Diagnosis of CFS was self reported without medical confirmation of the syndrome therefore the researchers were unable to confirm that patients met the criteria for CFS diagnosis.

Despite the results reported by Scharloo (1998) the study also had limitations. Certain sub scales were omitted - the 'consequence' dimension for the RA group and 'control/cure' for the Psoriasis group therefore contribution of these dimensions to the understanding of these illnesses is unknown.
Conclusion

The aim of the present article was to critically review the self regulatory model and review the evidence that there are illness representations common to all chronic illnesses, and that these illness representations mediate coping strategies people adopt.

Although the self regulatory theory and model has proven to be a useful tool in understanding how individuals perceive their illness. The model’s theory postulating that there are five generic dimensions of illness representations is controversial. Various studies have found the five dimensions not to be always well integrated, complete or relevant (Hampson et al., 1990, Heijman & de Ridder, 1998). Furthermore owing to variations in methodological procedures, reliability of questionnaires and open ended interviews used to elicit illness representations, it is possible that these measures may not have fully assessed illness representations and therefore were unable to discriminate between the dimensions. On the other hand, it is likely illness representations are not generic, and may be illness/disease specific, hence the discovery of dimensions not postulated by the theory.

There is some evidence to suggest that illness representations are associated with coping strategies that individuals adopt. Various studies have reported that illness representations and coping were associated with functioning and well being in chronic illness, and most importantly illness representations were more predictive of functioning and psychological well being than coping (Moss Morris et al., 1996, Scharloo et al., 1998). Both studies suggests that illness representations have a direct influence on functioning and mood that is not mediated by coping. As to which dimensions correlate the most with outcome depends very much on the nature of the illness being studied. Despite the short comings of the self regulation model it continues to be a useful starting point to understanding a variety of illness behaviour.
Suggestions for future research

First further research is need to clarify statements that are presently regarded as illness representations but could also be viewed as coping statements. Second the model needs to clarify questions about conceptual overlap of the dimensions e.g. the cause dimension for some conditions is unquestionable (e.g. sickle cell disease) what may be more important to such individuals is the factors that trigger symptoms of the disease. Finally, more rigorous testing of the relationship between the dimensions is also needed to understand the overlap of certain dimensions such as the time line and consequence dimension, and how these are influenced by views of the self.
REFERENCES


MAJOR RESEARCH PROJECT

AN INVESTIGATION INTO THE RELATIONSHIP BETWEEN ILLNESS REPRESENTATIONS, COPING AND QUALITY OF LIFE AMONGST A UK SAMPLE OF ADULTS WITH SICKLE CELL DISEASE.
Abstract:

Background: Patients' personal beliefs about their illness have been researched and shown to have at least five dimensions (Leventhal, Diefenbach & Leventhal, 1992). These include: beliefs about the identity of an illness, characterised by the symptoms associated with the illness; beliefs about the cause of the illness; beliefs about the duration of the illness; beliefs about the short and long term consequences of the illness; and beliefs about whether the illness can be cured or controlled. Research has revealed that these five cognitive representations of illness have important implications for how patients' conceptualise and cope with their illness (Leventhal et al., 1992). They have been used to understand a range of illness behaviours such as compliance with medical care (Meyer, Leventhal & Guttman, 1985), and as a predictor of success when coping with chronic illness (Hampson, Glasgow & Toobert, 1990). This study explored the relationship between illness representations, coping, and quality of life of 57 male and female adults with sickle cell disease, recruited from a Haematology out-patient clinic in London.

Method: Participants' self reported illness representations were assessed using the Illness Perception Questionnaire (IPQ) (Weinman, Petrie, Moss-Morris, & Horne, 1996), adapted for sickle cell disease. Pain coping strategies were assessed using the Coping Strategies Questionnaire (Gil, Abrams, Phillips, & Keefe, 1989), and quality of life was assessed using the SF36 Health Survey Questionnaire (Ware, Snow, Kosinski, & Gandek, 1993).

Results: The results demonstrated that illness representations were positively related to pain coping strategies, and negatively related to all aspects of quality of life. A series of regression analyses revealed that compared to coping strategies, illness representations, particularly the consequence and illness identity dimension, explained a significant proportion of the variance in quality of life. Participants with a strong illness identity, who believed their illness had dire consequences, experienced poor general and mental health, poor physical functioning, and frequent perception of bodily pain as measured by the SF36 questionnaire. Demographic variables such as gender and age, and cognitive coping strategies such as biased thinking (catastrophising) and behavioural isolation were also related to poor quality of life. The implications of these results for the management of sickle cell disease is discussed.
1. **Introduction**

Sickle cell disease represents the most predominant genetic blood disorder amongst African and African Caribbean people (Midence, Fuggle & Davies, 1993). The disease is also known to affect a small minority of people from the Mediterranean, Middle East, and Asia, (Midence et al., 1993). Despite advances in medical treatment there is no cure for sickle cell disease and many sufferers continue to experience pain and severe complications that pose a threat to their lives. Unpredictable severe painful episodes, and complications requiring short or long periods in hospital can significantly compromise the quality of life of the sickle cell sufferer (Midence and Elander, 1996). The impact of the disease on the lives of the adult sufferer has mainly been considered in terms of the psychosocial consequences of the disease (Davies, 1994; Barbarin & Christian, 1999), and the coping strategies of the sufferer (Gil, Abram, Phillips & Williams, 1992; McCrae & Lumley, 1997). Very few studies have reported on the health beliefs of sickle cell patients despite the growing body of research evidencing the role of patients’ illness beliefs in understanding and coping with their illness (see literature review p.182-185), and in regulating their behaviour (Leventhal and Nerenz, 1985). The present study aims to contribute to the literature by looking at, and examining the relationship between the adult sickle cell sufferer’s understanding and perception of their illness, and how this mediates their coping strategies and quality of life. A greater understanding of these factors will help to develop more effective interventions for this clinical population.

This introduction will firstly consider the nature of sickle cell disease and its prevalence. This will be followed by a discussion on the impact of sickle cell disease on the adult sufferer’s coping strategies, and their quality of life. The final section will integrate some of the cognitive factors identified in other chronic illnesses that may influence sufferers’ understanding and response to their illness.
1.1. **The nature of sickle cell disease**

Sickle cell disease (SCD) is a group of genetic blood disorders which affects predominately people of African and African Caribbean descent (Weisman and Schechter, 1992). There are several phenotypes of the disease, with sickle cell anaemia (HbSS) being the most prevalent type. Other variants of the disease include sickle haemoglobin SC disease (HbSC) and sickle Beta thalassaemia (SB Thal). In the Fair Shares for London Report (Streetly, Maxwell & Meija, 1997: cited in Thomas, Dixon & Milligan, 1999) the population estimate of sickle cell sufferers for greater London was 9,000 in 1996, and this is predicted to escalate to 12,500 by the year 2011.

Sickle cell sufferers produce haemoglobin S (HbS) which is structurally different from normal haemoglobin (HbA) (Holbrook and Phillips, 1994). Unlike normal haemoglobin, once sickle haemoglobin deoxygenates, it assumes a sickle shape, becomes rigid and crystallised causing vascular occlusion of small blood cells (Schaeffer, Gil & Porter, 1999). Vascular occlusion of the small blood vessels can result in various complications. The most prevalent and debilitating is recurrent and unpredictable pain in the affected areas such as the abdomen, back, chest, joints and extremities due to ischemic tissue injury secondary to the vascular occlusion (Schaeffer et al., 1999). The frequency, severity, intensity and duration of severe painful episodes is variable with some individuals experiencing very few severe painful episodes, others are more able to manage their pain at home, yet others may require frequent hospitalisation (Thomas et al., 1999).

Sickle cell disease is progressive in nature with more serious and life threatening complications occurring at different developmental life stages. For example childhood complications include anaemia, strokes (cerebral infarction) (Watkins, Hewes, Connelly, Kendall, Kingsley, Evans, Gadian, Vargha Khadem, & Kirkham, 1998), acute chest syndrome (bacterial or viral infection) which may result in hypoxaemia, and kidney dysfunction (Schaeffer et al., 1999). In adulthood,
complications may include anaemia, aseptic necrosis of the hip and shoulder, leg ulcers, sickle retinopathy, chronic organ damage (Thomas et al., 1999), acute chest syndrome and strokes (subarachnoid and intracerebral haemorrhages) (Schaeffer et al., 1999). The average life expectancy of female sufferers' is 46 years and males 42 years. However, owing to improved medical treatment over 50% of patients now survive beyond the age of 50 years (Platt, Brambilla, Rose, Milner, Castro, Steinberg & Klug, 1994). Nevertheless, sufferers continue to experience apprehension about the progression and prognosis of their disease. The threat of sudden death due to various disease complications such as organ damage or organ failure is part of the daily reality of patients with sickle cell disease, and affects their ability to formulate long term plans and goals. Sufferers's experience high levels of psychosocial disability and anxiety related to the unpredictable nature of their illness which negatively impacts on their ability to cope and manage their illness.

1.2. **The Impact of Sickle Cell Disease in Adulthood**

1.2.1. **Psychological impact**

The progressive and often fatal nature of the disease suggests that it has a detrimental effect on some sufferer's ability to cope and manage the disease, evidenced by clinical studies reporting on the psychosocial problems experienced by adults with sickle cell disease (Thompson, Gil, Abrams, & Phillips, 1992; Midence and Elander, 1996). Literature reviews on the psychological impact of the disease in adult sufferers tends to report on a small minority of patients who experience poor psychological adjustment (Ohaeri, Shokunbi, Akinlade & Dare, 1995), cope poorly and become overly reliant on health care services for their pain management (Vichinsky, Johnson & Lubin, 1982; Gil, Abrams, Phillips & Keefe, 1989), lead more limited lives (Midence and Elander, 1994), and experience depression, anxiety (Thomas et al., 1999), and a preoccupation with physical symptoms (Molock and Belgrave, 1994). Nevertheless sickle cell disease has pervasive psychosocial effects. Emotional disturbance is suggested to be due to a number of
factors. First, the stigma of the disease leads to poor self esteem, reduced achievement and reduced social and financial success (Holbrook and Phillips, 1994). Second, frequent hospitalisation affects family resources which result in reduced or completely eradicated family support (Brown and Lambert, 1999). Reduced family support includes not showing an understanding of the condition, and not providing encouragement to help sufferers live with the disease (Lewis and Kliewer, 1996; Famuyiwa and Akinyanju, 1998). The literature suggests that such individuals do not acquire the skills to help them cope with the disease and the demands of normal life, and develop low self esteem, self worth and self efficacy (Mattson, 1972; Pless & Pinkerton, 1975). They may become emotionally and physically disabled and fully reliant on social services for support (Chestnut, 1994). Third, death amongst same age friends and relatives with the disease renders the sufferer aware of the potential for a shortened life span (Chestnut, 1994).

A number of studies have examined depression in adults with sickle cell disease. Thompson, Gil, Abrams & Phillips (1992) reported that in a sample of 109 adults with sickle cell disease, more than half (56%) of the sample met the criteria for poor adjustment, with 40% showing signs of depression and 32% signs of anxiety. An earlier study by Damlouji, Kevess-Cohen, & Charache (1982) compared sickle cell patients with diabetic patients of the same race and socio economic group on measures of social disability, psychiatric morbidity, and physical complications. They found that 63% of the sickle patients and 50% of the diabetic patients had high levels of psychiatric morbidity, indicating a lowered sense of emotional well being; and 73% of sickle patients as compared to 57% of diabetic patients exhibited high levels of social disability. A more recent study by Schaeffer, Wilson, Gil, Burchinal, Kramer, Nash, Orringer & Strayhorn (1999) examined depression in 440 adults with sickle cell disease. They reported that being male, and having a poor family income were significantly associated with depression. Furthermore, patients who reported more painful episodes were more likely to report depressive symptoms. Conflicting evidence suggests the majority of sickle cell sufferers cope well, lead active lives, and are well
adjusted psychologically (Gil, 1994; Abrams, Phillips & Whitworth, 1994).

Originally it was assumed that children and adults with more severe disease (HbSS) would display more psychological disturbance (Lane, 1996; Platt, Thornington, Brambilla, Milner, Rosse, Vichinsky & Kinney, 1991), however Schaeffer et al., (1999) argue that adults with good psychological adjustment do not differ from individuals with poor adjustment on measures of disease severity such as phenotype of disease and number of complications or pain report. Furthermore, research has determined that factors such as family support and coping strategies were more predictive of poor psychological adjustment than disease severity variables (Thompson, Gil, Abrams, & Phillips, 1996; McCrae & Lumley, 1998; Brown and Lambert, 1999). Thompson et al., (1996) reported that good psychological adjustment to sickle cell disease in adulthood was associated with lower levels of perceived daily stress, higher self efficacy expectations, less reliance on palliative coping strategies, lower reports of negative thinking and fewer illness focused pain coping strategies.

A series of earlier studies reporting on the cognitive and behavioural coping strategies of adults with sickle cell disease (Thompson, Gil, Abrams & Phillips, 1992; Gil, Abrams, Phillips & Williams, 1992), suggested a relationship between coping strategies and adjustment to the disease. These studies demonstrated that coping strategies such as biased thinking (catastrophising) were associated with reports of pain and poor adjustment. Furthermore, McCrae & Lumley (1998) reported that passive adherence to typical medical recommendations such as taking fluids and resting appeared to be an ineffective means of coping. They reported a relationship between patients who adopted illness focused strategies and severe pain episodes, higher levels of psychological distress and more frequent hospital visits (Gil, 1989). Although cognitive coping strategies such as reinterpreting pain was not associated with less severe pain, it was associated with being more active during pain episodes (McCrae & Lumley, 1998). In line with Rosenstiel and
Keefe (1983), Thomas et al., (1999) argue that negative, passive, and illness focused strategies adopted by some sickle cell sufferers such as catastrophising, fear and anger self statements, and excessive resting, were reinforced by the unpredictable nature and reoccurrence of sickle disease pain and complications. Frequent pain and physical complications cause some patients to believe less in their ability to exert control over their symptoms and the impact the disease has on their lives. Therefore it is suggested that depression, anxiety and negatively biased patterns of thinking and coping with the disease impacts on the acquisition of life skills, and all aspects of the sufferers quality of life (Thomas et al., 1999).

1.2.2. Impact of sickle cell disease on quality of life

Dalky and Rourke (1973) defined quality of life as an individual's perception of well being, their satisfaction or dissatisfaction with life, and their feeling of happiness or unhappiness. Sickle cell disease impacts on all developmental aspects of adult life. Frequent hospitalisation interrupts peer socialisation, acquisition of social skills, and educational achievement (Barbarin and Christian, 1999). This in turn reduces career and employment opportunities. Furthermore, emotional distress resulting from employers' poor understanding of the disease, results in unemployment, reduced self confidence, reduced interest, incentive and motivation to seek employment (McCrae and Lumley, 1998). The sufferer's acquisition of effective positive coping strategies to enable them to adjust to and manage the demands of life, and cope with the disease is influenced by the degree of family support, social support via friends, health and social services (Abrams et al., 1994).

Midence, Fuggle & Davies, (1993) suggest that having sickle cell disease affects not only the individual's quality of marital relationship, but their interaction with their children, and the quality of their parenting skills. Children of such families where the sickle parent was isolated and used unhelpful coping strategies such as biased negative thinking, were found to increase the risk of maladjustment in their own children (Brown and Lambert, 1999). Such parents were reported as
experiencing high levels of parental anxiety, overprotection, and guilt associated with the hereditary nature of the disease, and depression as a result of their inability to cope with their child’s disease (Lewis and Kliewer, 1996).

Various studies have indirectly measured the quality of life of sickle cell patients. Black & Law (1986; cited in Midence & Elander, 1994) reported on the quality of life of 26 adult sickle cell patients living in Newham London. The study suggested that a wide variety of social activities precipitated sickling, and were treated cautiously or avoided by sufferers. These included drinking alcohol, physical exertion, swimming, getting wet or chilled, and even heavy meals. More than half of the participants interviewed were unemployed and experienced significant difficulties obtaining and maintaining employment. They believed they were restricted in the type of work they could do owing to the attitude and lack of knowledge and understanding of employers about the disease. Barrett, Wisotzek, Abel, Rouleau, Platt, Pollard, & Eckman (1988), reported that their sample of 89 adults with sickle cell disease experienced significant psychosocial distress in a number of areas such as employment and finances, sleeping and eating and performance of normal daily activities, and that men tended towards greater psychosocial dysfunction than women, with the greatest difference found in the area of social activity. Ohaeri et al’s (1995) study on the psychosocial problems of sickle cell sufferers, reported that out of 170 participants interviewed, the most common complaints were: the limitations the illness placed on their social lives with 24% feeling the illness had ruined their lives; labile mood on thinking about the illness; irritability; suicidal ideation during crises; 18% feeling frustrated at the lack of a cure for the condition; inefficiency at work; feelings of inferiority; loss of opportunities, and the burden of the illness on the family. The profile of the GHQ which was used as an indirect measure of quality of life, reported the most frequent items to be - feeling under strain (10%), lack of concentration (14%), feeling of not playing a useful role in life (13%), inability to face up to problems (12%) and not feeling reasonably happy (10%). The most commonly used coping strategies of those who completed the interview on
coping were: prayer (15.3%) distraction techniques such as reading (14.1%) and seeking seeking medical attention (8.2%).

The studies briefly reviewed had methodological limitations. First the studies recruited participants from out patient clinics, which suggests that these patients were relatively well and currently free from severe pain, compared to their counterparts in hospital. As a result the studies cannot be said to generalise to the larger population of sickle cell sufferers. Second the age of participants in these studies ranged from 11-70 years with little consideration for the developmental progression and manifestation of the disease. Third the studies failed to address cultural, and medical experiences of participants who come from diverse backgrounds, some of whom are immigrants from other countries. It is likely that their attitude towards their disease, and their experience of treatment in their country of origin, may influence their response quite differently to participants born and raised in the UK and America. Finally the studies indirectly measured quality of life which suggest the absence of standardised questionnaires developed to measure this entity. Furthermore the studies failed to define quality of life and the aspects of functioning that comprise their definition of quality of life.

The literature demonstrates that sickle cell disease impacts on the sufferer's psychosocial well being, and interacts with the coping strategies they adopt. The individual's experience of the disease and the response of family, friends and health professionals would appear to influence the sufferer's perception of themselves, their perception and beliefs about their disease, and its impact on their quality of life.
1.3. Health beliefs of adults with sickle cell disease

More recently, the literature has begun to focus attention on the importance of sickle cell patients' perception of their illness. For example, Broome and Monroe (1979) reported that of a 100 sickle cell sufferers surveyed, 45% reported feeling 'okay' when their disease was the topic of conversation with friends, and 20% felt embarrassed or ashamed about having their condition. This shame is thought to emanate from the stigma attached to the disease, e.g., 'bad blood' (Helman, 1998).

The stigma may arise also from years of being misunderstood by health professionals in G.P. and hospital settings resulting in perceived poor quality of care (Chestnut, 1994). Health professionals are aware that there are ways of delivering care which alleviate anxiety and depression in the sufferer, empowers them to become partners in decision making regarding their medication and treatment, and overall, improves their sense of self-efficacy. There are also ways of delivering care which disables and disempowers patients, increases their level of anxiety, exacerbates depression and increases their level of dependency on health care professionals. Furthermore, in rendering a medical model of treatment and care to sickle cell sufferers, it is possible that staff assess and treat the presenting complaints based on their own perception, and may fail to consider the perception and beliefs of the individual about which treatments work best and why. For example, Murray and May (1984: cited in Chestnut, 1994) reported on sickle cell sufferers perception of pain intensity during crises episodes, communication problems with medical staff, and problems of coping with their disease. Their findings suggested sufferers believed that medical staff misconstrued the amount of pain they experienced, and thus did not administer an adequate amount of analgesia. This study would suggest that health professionals need to consider patients' cognitive processing of what they believe and perceive their illness symptoms to be indicative of, based on their knowledge and experience and expectations of treatment. Failure to do so may jeopardise psychological adjustment to their illness (Chestnut, 1994), service utilisation, compliance, appointment keeping, and overall responsiveness to treatment (Meyer,
Leventhal & Guttman, 1985). The need to acquire knowledge about sickle cell patients’ health beliefs is therefore crucial because of the ethnic and cultural diversity of this patient group who may hold ideas and strong “folk illness” beliefs about their illness and what constitutes effective treatment and quality health care.

Furthermore, studies have shown that health beliefs interact with psychological adjustment and coping strategies (Scharloo, Kaptein, Weinman, Hazes, Willems, Bergman & Rooijmans, 1998). One study reporting from a Health Belief Model perspective on the health perceptions of patients with asthma and sickle cell disease (Bobo, Miller & Smith, 1989) suggested that compared to the asthma patients, sickle cell patients had poorer health outlooks, were more worried about their illness, were more susceptible to illness and sickness orientation, and rated their medical care lower for satisfaction than the asthma group. The studies reported by Murry and May (1984) and Bobo et al., (1989) illustrate an association between sufferers' health beliefs and their functioning, emotional well being, and perception of treatment. These results reinforce the need for further research in the area. The role of social cognition in health behaviours has been explored from a variety of models such as The Self Regulation Model (Leventhal, Meyer & Nerenz, 1980) which offers a useful frame work from which patients’ beliefs about their illness and the impact this has on their ability to cope and function can be understood.

1.3.1. Illness representations and chronic illness

Health psychologists have been at the forefront of examining how people construe and react to mental representations of their illness, and have proposed several models from which illness beliefs can be understood. One such model is Leventhal, Diefenbach & Leventhal’s (1992) Self Regulation Model (see literature review p.g. 172-175) which posits that self regulation is a function of the representation of health threats and the targets for ongoing coping set by the representation, the procedures that regulate coping, and the appraisal of coping outcomes. The underlying
cognitive mechanisms are assumed to function at both concrete (symptom based schemata) and abstract levels (disease labels), and individuals often engage in biased testing while attempting to establish a coherent representation of a health threat. The model postulates that cognitive and emotional processes form partially independent processing systems. The coherence of the system is seen as crucial for the maintenance of behavioural change. The model proposes that illness representations are construed from personal knowledge and experience, culture, family and social beliefs, and these representations mediate how people conceptualise and cope with their illness. These representations are created along five dimensions: beliefs about the **identity** of the illness, characterised by the label given to the experience of one or more familiar or unfamiliar symptoms, a series of beliefs about the **cause** of the illness, beliefs about the social and economic **consequences** associated with the illness, and whether they believe the illness can be **cured/controlled**, and ideas about how long the illness will last ie illness **timeline**. Although the dimensions are distinct and can have specific effects on outcome, they are not necessarily independent and direct associations between the dimensions have been reported (Moss-Morris, Petrie, & Weinman, 1996).

Illness representations are the individual's way of making sense of the various threats and demands of illness, and change with disease progression, emergent symptoms and treatment response (Weinman and Petrie, 1997). Illness representations are considered to be guides to action and have been reported to directly influence behaviours associated with compliance with medical care (Meyer, Leventhal & Guttman, 1985), rehabilitation (Petrie, Weinman, Sharpe & Buckley, 1996) and as a predictor of coping with chronic illness (Hampson, Glasgow & Toobert, 1990), and via this with outcomes such as mood, physical and social functioning (Moss-Morris et al., 1996). Leventhal and Diefenbach (1992) suggest that it is important to understand illness representations as they reflect the individual's unique way of making sense of the various threats and demands of illness. Furthermore such representations are thought to guide action and directly influence behaviours associated with coping.
1.4. Rationale

There are no published studies to date that have applied the Self Regulation Model to adults with sickle cell disease. This study aims to consider if illness representations as postulated by the Self Regulation Model, may provide a base from which the illness perceptions of adults suffering from a genetic, chronic and often fatal illness like sickle cell disease can be understood. The study aims also to explore how these illness representations may affect quality of life via ability to cope with the disease, and thereby offer suggestions for refining interventions.

1.5. Aims of the study

1. To explore the content of the illness representations of a cross sectional sample of male and female adults with sickle cell disease.

2. To assess the relative importance of the contributions of illness representations to coping strategies and quality of life of the sample group.

3. To consider the clinical value of the Self Regulatory Model in understanding personal illness models of adults with sickle cell disease and how this knowledge might shape psychological interventions for patients with sickle cell disease.
1.6. **Hypotheses**

Based upon current literature which suggest that illness perceptions mediate coping strategies and outcome (Hampson, Glasgow, Zeiss, 1994; Moss Morris et al., 1996), it is hypothesised that:

1. Illness representations will be associated with the coping strategies that participants adopt, and their quality of life.

2. Illness representations will differ according to phenotype of disease. Participants with the most severe form of sickle cell disease (HbSS) will perceive their illness more negatively than participants with the less severe form of the disease (HbSC).

3. Illness representations will be a better predictor of quality of life than coping strategies.

1.7. **Power Analysis**

An a priori power analysis was conducted to determine the number of participants needed to conduct the study. This was calculated using 'G Power' (Erdfelder, Faul, Buchner, 1996), which is a power calculation programme. Based on the study's correlational design the researcher opted for a medium effect size (R=0.3). The desired power was set at 0.8 the criterion alpha at 0.05 based on a two tailed test. The computed actual power of the study based on a minimum sample of 82 participants was 0.8043.
2. **METHOD**

2.1. **Ethical approval**

Ethical approval was sought and gained for the study from the responsible community trust's ethics research committee. A copy of the letter granting ethical approval is included as Appendix 1. Following ethical approval, the professor of haematology was informed in writing (see Appendix 1) of the nature of the study. He granted access to patients, provided a list of names of all sickle cell patients who attended the hospital and their illness phenotypes.

2.2. **Design**

The study employed a within-group design to examine illness representations, coping strategies and quality of life measures in adults with sickle cell disease. Demographic variables such as gender was included in the analysis because it has been shown to be associated with episodes and severity of pain (Gil et al., 1989; Gil et al., 1992). Illness severity was also included because of the general belief that those with sickle cell anaemia (HbSS) have more problems throughout life than those with other sickle cell disorders (Holbrook and Phillips, 1994; Lane, 1996). These between group differences were examined using Independent t tests.

A correlational design was used to examine the associations between illness representations, coping strategies and quality of life measures, and regression analysis was used to assess the relative contribution of illness representations and coping strategies to quality of life.
2.3. Participants

Male and female adults who had been medically diagnosed with either sickle cell anaemia (HbSS) (which occurs when both inherited beta globin genes have the sickle mutation), sickle cell disease (HbSC), or sickle Beta thalassaemia (SB Thal) (which both occur when a sickle beta globin gene is inherited from one parent and another abnormal beta globin gene is inherited from the other parent) were included in the study. In-patients, and individuals with sickle cell trait, were excluded from the study because of the difficulty of recruiting patients experiencing painful crises and possible complications. Individuals with the trait were excluded because they do not experience pain or complications associated with the disease.

Holbrook and Phillips (1994) suggest that individuals with sickle cell disease experience disease severity along a continuum between severe and mild disease. Those with (HbSS) experience their disease anywhere from middle of the continuum to the severe end, those with (HbSC) fall close to the middle of the continuum, and those with sickle thalassaemia lie anywhere between mild and severe disease.

Seventy nine patients were approached by the researcher in the haematology out patient clinic over six months. Of these, fifty-seven participants successfully completed the study which represents a response rate of 72 percent. Bio-demographic information and socio-demographic information on the 57 participants who successfully completed the study is presented in Table 1 and Table 2 over leaf.
Table 1.

**Bio-demographic Characteristics of the 57 Participants**

<table>
<thead>
<tr>
<th></th>
<th>Male</th>
<th>Female</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>M (SD)</td>
<td>M (SD)</td>
</tr>
<tr>
<td>Participants</td>
<td>18</td>
<td>39</td>
</tr>
<tr>
<td>HbSS</td>
<td>14</td>
<td>24</td>
</tr>
<tr>
<td>HbSC</td>
<td>4</td>
<td>15</td>
</tr>
<tr>
<td>Age</td>
<td>30.7 (11.66)</td>
<td>29.5 (8.64)</td>
</tr>
</tbody>
</table>

Table 2.

**Socio-demographic Characteristics of the 57 Participants**

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Marital Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>16</td>
<td>28.1</td>
</tr>
<tr>
<td>Single/Divorced</td>
<td>41</td>
<td>71.9</td>
</tr>
<tr>
<td>Employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>31</td>
<td>54.4</td>
</tr>
<tr>
<td>Unemployed</td>
<td>26</td>
<td>45.6</td>
</tr>
<tr>
<td>Qualifications</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No qualifications</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>O Levels</td>
<td>25</td>
<td>43.9</td>
</tr>
<tr>
<td>A Levels</td>
<td>7</td>
<td>12.3</td>
</tr>
<tr>
<td>Undergraduates</td>
<td>13</td>
<td>22.8</td>
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<tr>
<td>Post Graduates</td>
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<td>10.5</td>
</tr>
<tr>
<td>Other qualifications</td>
<td>2</td>
<td>3.5</td>
</tr>
</tbody>
</table>

The number of hospital admissions in the last twelve months ranged from zero admission (20 participants) to 20 admissions (1 participant).

Of the twenty two patients who did not take part in the study, five patients refused to participate from the onset (four female and one male) owing to severity of pain and tiredness, or research participation fatigue. The remaining seventeen (8 male, 9 female) felt either too tired to complete the study in the clinic and opted to return the questionnaires by free post to the researcher (but failed to do so), or were called in for their appointment whilst completing their questionnaires, and
at the end of their appointment insisted on going home, promising to send their completed questionnaires by free post to the researcher. However they subsequently failed to do so.

2.4. Measures

The measures used in the study were specifically developed for use with adults and were chosen to obtain participants' self reports. The measures are presented in order of administration during the study.

**Coping Strategies Questionnaire-Revised (CSQ): Sickle Cell Disease Version for Adults.**


The CSQ (Appendix 2) was developed by Rosenstiel and Keefe (1983) as a measure of pain coping strategies. The questionnaire was revised by Gil et al., (1989) by adding several new subscales to the original subscales to assess cognitive, behavioural, and physiological strategies particularly relevant to sickle cell disease. The adapted questionnaire comprises 80 items. The first part consists of 13 subscales each comprising six items. Eight subscales assess cognitive strategies:

- Diverting attention
- Reinterpreting pain sensation
- Calming self statements
- Praying and hoping.
- Ignoring pain sensation.
- Catastrophising
- Fear self statements
- Anger self statements

Two subscales assess behavioural strategies:

- Increased behavioural activity
- Behavioural isolation.
Three subscales assess physiological illness focused strategies:

- **Taking fluids**
- **Resting**
- **Heat/cold/massage**.

Participants are asked to rate each item on a 7 point Likert type scale rated from 0 ("never do that") to 6 ("always do that") to indicate how often they used each pain coping strategy; item ratings were summed for each sub scale. At the end of the CSQ participants are asked to make two overall ratings of their perception of the effectiveness of their coping strategies; how much they are able to control pain, from "no control" (score of zero) to “complete control” (score of 6), and how much they can decrease pain, from “can’t decrease pain at all” (score of zero) to “can completely decrease pain” (score of 6). The CSQ yields measures as follows:

1. Eight cognitive coping strategy scores from zero to six with a higher score indicating frequent use of the cognitive coping strategy.

2. Two behavioural coping strategy scores from zero to six with a higher score indicating frequent use of the behavioural coping strategy.

3. Three physiological illness focused coping strategy scores from zero to six with a higher score indicating frequent use of the physiological coping strategy.

4. Perceived degree of control over pain score from zero to six with a higher score indicating a greater perception of control over pain.

5. Perceived ability to decrease amount of pain score from zero to six with a higher score indicating a greater perceived ability to decrease pain.
The internal reliability for the 13 sub scales of the CSQ are relatively high and range from 0.69 to 0.91 (Gil et al., 1989). The questionnaire has been validated in the UK in a recent trial of cognitive behavioural therapy for sickle cell disease (Thomas et al., 1999).

**Illness Perception Questionnaire (IPQ)** (Weinman, Petrie, Moss-Morris & Horne, 1996)

The IPQ (Appendix 2) is a thirty eight item self report scale developed for assessing cognitive representations of illness in a variety of medical conditions. The IPQ scale items were derived to reflect five theoretical dimensions of illness representations that have been found to underlie the cognitive representations of illness. The five IPQ scales assess:

- **Illness identity** - the symptoms the patient experiences and associates with the illness.
- **Cause** - the personal beliefs about the aetiology of the illness.
- **Timeline** - beliefs about the duration of the illness.
- **Consequences** - beliefs about the impact of the disease on the patient's life.
- **Cure/Control** - beliefs about how one recovers or controls the illness.

The IPQ allows the user to add items for particular patient groups or health threats, therefore three additional items were added to the 'consequence' dimension including the statements:

- "having sickle disease prevents me from getting the best out of myself"
- "having sickle cell disease has had a bad effect on my close relationships"
- "having sickle cell disease reduces my career options".

Therefore the IPQ used in the study comprised 41 items.

The identity (symptoms associated with the disease) subscale is comprised of 12 core symptoms that the patient is asked to rate for frequency as experienced as part of their illness on a four point scale ranging from "All of the time" to "Never" (scored 0-3). These symptoms include: **pain, nausea, breathlessness, weight loss, fatigue, stiff joints, sore eyes, headaches, upset**
stomach, sleep difficulties, dizziness and loss of strength The resulting scores on items endorsed at "occasionally" or greater are summed to give a weighted illness identity score ranging from 0-36.

The other twenty nine items were rated by the patient on a five point Likert scale ranging from "Strongly Disagree" to "Strongly Agree" (scored 1-5). After reverse scoring appropriate items (IP11, IP16, IP17, IP23 and IP25), the scores for Time line (3 items), Consequences (10 items), and Cure/Control (6 items) scales are obtained by summing all the scale items. For the 'Cause' scale (10 items) it is not appropriate to sum all of the items as each represents a specific causal belief (Weinman et al., 1996). The measures yielded and used from the IPQ are as follows:

1. Weighted illness identity score from zero to thirty six, a higher score indicating a greater illness identity.

2. Illness consequence score from one to five with higher scores indicating a greater perceived illness consequence

3. Illness control/cure score from one to five with higher scores indicating a greater perceived control over and cure of the illness

4. Illness time line score ranging from one to five with higher scores indicating longer perceived time line or duration of the illness

5. Illness cause score ranging from one to five with higher scores indicating a stronger belief in factors as causative on dimensions of: germ/virus, diet, pollution of the environment, hereditary, chance, stress, patient's own behaviour, other people being responsible, poor
medical care, state of mind.

The IPQ has been validated and standardised, and has established psychometric properties with internal subscale consistency ranging from 0.73 to 0.82. Test-retest reliability coefficients for the subscales range from 0.49 to 0.84 at one month and 0.34 to 0.54 at three months. (Weinman, Petrie, Moss-Morris & Hone, 1996).

Quality of life measures

Researchers have used a variety of measures in their attempt to assess quality of life. Some measures assess several dimensions, and in some cases several measures are used together to assess quality of life, but give no overall evaluation. There is at present no agreement regarding the number of aspects of life that should be included in a quality of life assessment.

Several measures were reviewed for use in this study. The first was the Quality of life index (QLI) (Ferrans & Powers, 1985), which was developed to measure the quality of life of healthy individuals and those experiencing illness. The questionnaire consists of 64 items that measure satisfaction with various domains of life, and the importance of the domain to the individual. The second measure was the Sickness Impact Profile (SIP) (Patrick & Erickson, 1993) which consists of 136 items measuring a wide range of specific dysfunctions. The third was the SF 20 from which the SF 36 was developed. The QLI and SIP questionnaires were not considered appropriate for use with sickle cell patients because of the length of administration and respondent burden. The SF 20 was also excluded because it failed to adequately assess levels and kinds of physical functioning limitations, such as lifting and carrying groceries; climbing stairs; and walking moderate distances.

The SF36 was chosen for several reasons. First, it is a generic quality of life measure because it assesses health concepts that represent basic human values that are relevant to every body's functioning and well being (Ware, 1990a). The measure is considered to be generic because it is not
age, disease or treatment specific, and as such, assesses health related quality of life outcomes known to be directly affected by disease and treatment. Second, owing to the difficulty of recruiting participants to complete lengthy questionnaires, this tool was considered more practical because it is shorter, requiring less respondent time, and can be self administered. Third, the SF36 attempts to reduce respondent burden without reducing measurement precision by constructing scales from more efficient items. For example in the Health Insurance Experiment (Ware, Brook et al., 1980) 25 items were necessary to define seven levels of physical functioning. With the SF36 only 10 items were necessary to define 21 levels of physical functioning.

**Short Form 36 Health Survey Questionnaire (SF36)** (Ware, Snow, Kosinski & Gandek, 1993)

The SF36 questionnaire (Appendix 2) was constructed to represent eight of the most important health dimensions included in the Medical Outcomes Study (MOS) and other widely used health surveys,(Ware et al.,1993). The questionnaire consists of 36 items measuring the following nine health dimensions (the item numbers are in brackets) including:

- **physical functioning (3a-3j)**
- **role limitations due to physical health problems (4a-4d)**
- **role limitations due to emotional problems (5a-5c)**
- **social functioning ( 6 & 10)**
- **mental health ( 9b, 9c,9d,9f,9h)**
- **vitality (9a,9e,9g,9 i )**
- **bodily pain (7 & 8)**
- **general health ( 1 & 11a-11d)**
- **change in health (2).**

The sub scales are either forced choice “yes” or “no” ( role limitations due to emotional and physical problems) or Likert scales ranging from three points (physical functioning), five points
(change in health, general health perception and one of the social functioning and bodily pain subscales) to six points (mental health, vitality and the remaining social functioning and pain subscales). Each quality of life area was assigned a score ranging from 0-100, with a higher score indicating enhanced quality of life in that area.

The SF 36 has been vigorously tested for its reliability and validity (Jenkinson, Layte, Wright, & Coulter, 1996). Internal reliability tests have shown that subscale items are highly correlated (Brazier, Harper, Jones, O’Cathain, Thomas, Usherwood & Westlake, 1992) and alpha coefficients range from 0.73 for social functioning to 0.96 for physical functioning, role limitation, physical, emotional, and vitality (Brazier et al., 1992).

Background information sheet
The background information sheet (Appendix 2) was devised by the researcher and used to obtain sociodemographic and medical information from the participant, and included questions on age, gender, ethnic origin, educational status, employment, marital status, and number of hospital admissions in the last year.

Summary of measures used in the study
1. Demographic variables
2. Illness severity (HbSS, SC, SB Thal)
3. Coping Strategies Questionnaire Revised: Sickle cell disease version for use with adults
4. Illness Perception Questionnaire
5. SF 36 (quality of life measure)
2.5. **Procedure**

2.5.1 **Recruitment of participants**

Participants were recruited from the weekly out-patient haematology clinic. Seventy nine patients in all were approached by the researcher after they had given a blood sample, and before they were called in for their appointment with the haematologist. The researcher introduced herself as a trainee clinical psychologist who had just finished a six month clinical placement in sickle cell, and was collecting data for her research project. The purpose of the research was explained as 'a study examining patients' beliefs about their sickle cell disease, how they coped with sickle cell pain and the effect this had on their quality of life'. The patients were told that participation involved completing three questionnaires and a background information sheet, all of which was completely confidential to the researcher. Patients were told that participation was voluntary, and that refusal to participate would not affect their treatment at the clinic. Patients who agreed to participate were instructed to read their consent form which explained the purpose of the study in more detail (Appendix 2) and were instructed to sign the consent form if they fully understood the information and were happy to continue. They were then given verbal and written instructions on how to complete the questionnaires which were stapled together in the following order;

Coping Strategies Questionnaire,
Illness Perception Questionnaire
Short Form 36
Background information sheet.

Participants were encouraged to approach the researcher (who remained seated in the clinic throughout) should they experience difficulties completing the questionnaires. Three participants requested that the questionnaire be read out to them, owing either to literacy problems (one participant) or sickle retinopathy (two participants). The recruitment of participants ran weekly for 6 months (October 1999 - March 2000).
Debriefing of participants

On completion of the questionnaires participants were thanked and offered the opportunity to discuss any aspect of the study or the questionnaires. As a result of the debriefing exercise, three female patients were referred on by the researcher to the sickle cell team's Health Psychologist for assessment and subsequent intervention. It is worth noting at this point that recruitment of participants which took place during the winter months is regarded by the sickle cell team to be a period of low clinic attendance by patients. This is due to the cold weather known to be a precipitant of sickling, which affects mobility and a willingness to attend routine clinic appointments.

2.6. Statistical Analysis

The data generated were a mixture of nominal and ordinal data. Nominal data included sickle cell phenotype (illness severity). Ordinal data included Illness Representations, Coping Strategies and Quality of Life measures. For the ordinal data the Kolmogorov-Smirniv test was used to determine the distribution of the data and suitability for parametric analysis. In the vast majority of cases the data was found to be normally distributed, and therefore parametric analysis was deemed appropriate. (Full results of Kolmogorov-Smirniv statistics are found in Appendix 3). Three variables included in the Kolmogorov-Smirniv test, were excluded from the reliability analysis and parametric analyses because the questions constituting these variables did not form distinct scales. These variables included the Transition variable from the SF36 questionnaire, and two questions assessing perceptions of overall ability to Control/Decrease pain, from the Coping Strategies Questionnaire.

With regard to the use of parametric analysis on ordinal data, it is argued by Bryman and Cramer (1997) "that parametric tests apply to numbers and not to what those numbers signify..." p.g.117. They argue that because the tests do not know what these numbers signify, ordinal data are
treated as interval scaling. Furthermore, they argue that the majority of psychological variables are ordinal in nature (e.g. attitude questionnaires) to which parametric tests are routinely applied.

The analysis was divided into seven stages:

Stage 1. Reliability analysis of measures used or developed for this study. The Cronbach Alpha statistic was used to determine the internal reliability of the IPQ and CSQ scales, and the SF36. The 'Cause' subscale of the IPQ scale was excluded because the questions do not form a distinct scale. The CSQ items, which assessed perception of ability to control and decrease pain, and the SF36 'health transition' item were also excluded from the reliability analysis because these items do not form distinct scales. It was considered necessary to retest the reliability of the questionnaires because they had never been used (except the CSQ, although reliability of use with UK population was not explored) with sickle cell patients.

Stage 2. Exploration of the inter-correlations between the IPQ subscales.

Stage 3. Unrelated t tests were used to test for differences between illness severity groups, and gender on measures of illness representation.

Stage 4. Pearson correlations were used to explore the strength and direction of relationships between illness representations and coping strategies. Scattergrams were performed to assess whether the relationships were linear or affected by outlying cases.

Stage 5. Pearson correlations were used to explore the association between illness representations and quality of life. Scattergrams were performed to assess whether the relationships were linear or affected by outlying cases.

Stage 6. Pearson correlations were used to explore the relationship between coping and quality of life. Scattergrams were performed to assess whether the relationships were linear or affected by outlying cases.

Stage 7. Significant correlations at p <= .01 from the univariate analysis were entered into a series of standard multiple regressions to determine the relative contribution of demographic indices,
illness representations, and coping strategies to measures of quality of life.

All analysis were carried out using the Statistical Package for Social Sciences for windows, version 9.0 (SPSS Inc., 1998). In view of the number of correlations used in this study it was decided to set a more stringent significance level of p<.01 to reduce the probability of significant results occurring by chance i.e saying there is a relationship between variables when there really is none.

3. Results

3.1. Reliability of measures:
Internal Consistency of the Illness Representations Questionnaire (IPQ)
The results of the reliability analysis and the mean ratings for IPQ are presented in Table 3

Table 3.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>M</th>
<th>SD</th>
<th>Alpha Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Illness Identity</td>
<td>14.94</td>
<td>6.08</td>
<td>0.7721</td>
</tr>
<tr>
<td>Illness consequence</td>
<td>33.01</td>
<td>9.27</td>
<td>0.8976</td>
</tr>
<tr>
<td>Control/Cure*</td>
<td>19.85</td>
<td>3.24</td>
<td>0.4021</td>
</tr>
<tr>
<td>Illness Timeline</td>
<td>11.73</td>
<td>3.27</td>
<td>0.8501</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Germ</td>
<td>1.91</td>
<td>1.21</td>
<td></td>
</tr>
<tr>
<td>Diet</td>
<td>1.68</td>
<td>0.8</td>
<td></td>
</tr>
<tr>
<td>Pollution</td>
<td>1.71</td>
<td>1.01</td>
<td></td>
</tr>
<tr>
<td>Chance</td>
<td>2.36</td>
<td>1.21</td>
<td></td>
</tr>
<tr>
<td>Medical care</td>
<td>1.87</td>
<td>1.1</td>
<td></td>
</tr>
<tr>
<td>Others</td>
<td>2.17</td>
<td>1.28</td>
<td></td>
</tr>
<tr>
<td>Self</td>
<td>1.63</td>
<td>0.81</td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>2.31</td>
<td>1.39</td>
<td></td>
</tr>
<tr>
<td>Hereditary</td>
<td>4.45</td>
<td>0.8</td>
<td></td>
</tr>
<tr>
<td>State of Mind</td>
<td>1.68</td>
<td>0.98</td>
<td></td>
</tr>
</tbody>
</table>
The reliability of three of the IPQ scales were comparable to other studies using the measure with adults (Weinman et al., 1996). The control/cure scale was found to have a low internal reliability with an alpha of .4021. This suggests that in this sample the questions comprising the control/cure subscale were not highly correlated and potentially measured different things. As a result of the subscale's poor reliability it was excluded from any further analysis. Compared to pain patients included in the Weinman et al. (1996) study, sickle cell patients achieved a higher mean score on the illness ‘Identity’ and ‘Timeline’ dimension. However pain patients achieved higher mean scores on the ‘Consequence’ and ‘Cure/Control’ dimension.

**Internal Consistency of the Coping strategies Questionnaire**

The results of the reliability analysis and mean ratings for the CSQ are presented in Table 4.

**Table 4.**

*Mean Rating and Alpha Coefficient for Each of the Coping Strategies Questionnaire Subscales*

<table>
<thead>
<tr>
<th>Subscale</th>
<th>M</th>
<th>SD</th>
<th>Alpha Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Cognitive strategies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diverting attention</td>
<td>13.28</td>
<td>7.76</td>
<td>0.7463</td>
</tr>
<tr>
<td>Reinterpreting pain sensation</td>
<td>7.56</td>
<td>6.71</td>
<td>0.7621</td>
</tr>
<tr>
<td>Calming self-statements</td>
<td>21.73</td>
<td>6.93</td>
<td>0.7962</td>
</tr>
<tr>
<td>Ignoring pain sensation</td>
<td>11.17</td>
<td>7.46</td>
<td>0.832</td>
</tr>
<tr>
<td>Praying and hoping</td>
<td>22.33</td>
<td>7.84</td>
<td>0.7119</td>
</tr>
<tr>
<td>Catastrophising</td>
<td>15.04</td>
<td>7.97</td>
<td>0.7899</td>
</tr>
<tr>
<td>Fear self-statements</td>
<td>14.72</td>
<td>7.57</td>
<td>0.7256</td>
</tr>
<tr>
<td>Anger self-statements</td>
<td>13.18</td>
<td>7.51</td>
<td>0.7544</td>
</tr>
<tr>
<td><strong>Behavioural strategies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased behavioural activity</td>
<td>13.44</td>
<td>6.78</td>
<td>0.6611</td>
</tr>
<tr>
<td>Isolation</td>
<td>14.26</td>
<td>9.87</td>
<td>0.9</td>
</tr>
<tr>
<td><strong>Physiological strategies</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Taking fluids</td>
<td>24.39</td>
<td>8.85</td>
<td>0.8791</td>
</tr>
<tr>
<td>Resting</td>
<td>25.67</td>
<td>5.66</td>
<td>0.6102</td>
</tr>
<tr>
<td>Heat/cold/massage</td>
<td>16.79</td>
<td>7.7</td>
<td>0.6051</td>
</tr>
<tr>
<td><strong>Perception</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Control</td>
<td>3.56</td>
<td>1.34</td>
<td>-</td>
</tr>
<tr>
<td>Decrease</td>
<td>3.01</td>
<td>1.54</td>
<td>-</td>
</tr>
</tbody>
</table>
The internal reliability of all the subscales of the CSQ were comparable to other studies using the questionnaire with adult sickle cell patients (Gil et al., 1989). Sickle cell participants included in the Gil et al., (1989) study achieved higher mean scores on all coping strategies, except on physiological coping strategies such as taking fluid and resting, where participants in this study achieved a higher mean score.

**Internal consistency of the Short Form 36 Health Survey Questionnaire (SF36)**

The results of the reliability analysis and mean ratings for the Quality of life Questionnaire -SF36 are presented in Table 5.

<table>
<thead>
<tr>
<th>Subscale</th>
<th>M</th>
<th>SD</th>
<th>Alpha Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical functioning</td>
<td>64.56</td>
<td>24.33</td>
<td>0.8796</td>
</tr>
<tr>
<td>Role-Physical</td>
<td>48.24</td>
<td>40.6</td>
<td>0.8257</td>
</tr>
<tr>
<td>Role-Emotional</td>
<td>55.36</td>
<td>40.98</td>
<td>0.7671</td>
</tr>
<tr>
<td>Bodily pain</td>
<td>47.29</td>
<td>30.32</td>
<td>0.887</td>
</tr>
<tr>
<td>Vitality</td>
<td>47.92</td>
<td>20.41</td>
<td>0.8107</td>
</tr>
<tr>
<td>Mental Health</td>
<td>66.49</td>
<td>20.41</td>
<td>0.8014</td>
</tr>
<tr>
<td>Social functioning</td>
<td>63.4</td>
<td>24.68</td>
<td>0.6571</td>
</tr>
<tr>
<td>General Health</td>
<td>46.42</td>
<td>22.94</td>
<td>0.7933</td>
</tr>
<tr>
<td>Health Transition</td>
<td>2.49</td>
<td>1.07</td>
<td>-</td>
</tr>
</tbody>
</table>

The results of the analyses showed good internal reliability, and was comparable to other SF36 studies (Brazier et al., 1992). Compared to a population of 13,042 British individuals who reported suffering from a longstanding illness, (Jenkinson, Coulter & Wright, 1993), sickle cell patients achieved lower mean scores on all aspects of quality of life as measured by the SF36.
3.2. **Inter-correlations between the Illness Perception Questionnaire subscales**

Initial exploratory analysis was performed on the IPQ subscales to explore the relationship between the illness representation components. The results are presented in Table 6.

<table>
<thead>
<tr>
<th>IPQ scales</th>
<th>Consequence</th>
<th>Timeline</th>
<th>Identity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequence</td>
<td>r=0.386 p=.003*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td>r=0.468</td>
<td>r=0.233</td>
<td>p=.000**</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>r=.377</td>
<td>r=.113</td>
<td>r=.226</td>
</tr>
<tr>
<td></td>
<td>p=.004**</td>
<td>p=.403</td>
<td>p=.091</td>
</tr>
<tr>
<td>Pollution</td>
<td>r=.276</td>
<td>r=.139</td>
<td>r=.073</td>
</tr>
<tr>
<td></td>
<td>p=.038*</td>
<td>p=.303</td>
<td>p=.590</td>
</tr>
<tr>
<td>Medicalcare</td>
<td>r=.293</td>
<td>r=.065</td>
<td>r=.068</td>
</tr>
<tr>
<td></td>
<td>p=.027*</td>
<td>p=.630</td>
<td>p=.614</td>
</tr>
<tr>
<td>Germ</td>
<td>r=.333</td>
<td>r=.039</td>
<td>r=.098</td>
</tr>
<tr>
<td></td>
<td>p=.011*</td>
<td>p=.773</td>
<td>p=.466</td>
</tr>
<tr>
<td>Hereditary</td>
<td>r=.176</td>
<td>r=.223</td>
<td>r=.060</td>
</tr>
<tr>
<td></td>
<td>p=.190</td>
<td>p=.095</td>
<td>p=.659</td>
</tr>
<tr>
<td>Chance</td>
<td>r=.198</td>
<td>r=.114</td>
<td>r=.007</td>
</tr>
<tr>
<td></td>
<td>p=.139</td>
<td>p=.397</td>
<td>p=.959</td>
</tr>
<tr>
<td>Self</td>
<td>r=.032</td>
<td>r=.057</td>
<td>r=.169</td>
</tr>
<tr>
<td></td>
<td>p=.816</td>
<td>p=.675</td>
<td>p=.208</td>
</tr>
<tr>
<td>Others</td>
<td>r=.193</td>
<td>r=-.129</td>
<td>r=-.008</td>
</tr>
<tr>
<td></td>
<td>p=.150</td>
<td>p=.338</td>
<td>p=.953</td>
</tr>
<tr>
<td>Diet</td>
<td>r=.149</td>
<td>r=.070</td>
<td>r=.040</td>
</tr>
<tr>
<td></td>
<td>p=.296</td>
<td>p=.607</td>
<td>p=.768</td>
</tr>
<tr>
<td>Mind</td>
<td>r=.092</td>
<td>r=.162</td>
<td>r=-.092</td>
</tr>
<tr>
<td></td>
<td>p=.494</td>
<td>p=.228</td>
<td>p=.495</td>
</tr>
</tbody>
</table>

*p<=.05  **p<=.01

As shown in Table 6, a strong illness identity (or number and extent of the symptoms participants associated with their disease) was positively associated with the belief that having sickle cell disease had serious consequences. Participants who believed that the disease would last a long
time also held strong beliefs that the illness had serious consequences. External attributions such as believing that the disease was caused by germs, pollution and poor medical care, and psychological attributions such as believing that sickle cell disease was caused by stress, were positively correlated with the belief that the illness had serious consequences. Surprisingly, attributions to the hereditary nature of the disease were not associated with any of the illness dimensions. These correlations are similar to those reported by Weinman et al., (1996). They found that patients with a strong illness identity were more likely to perceive their illness as lasting longer, and having more serious consequences.

3.4. Differences in illness perceptions between illness severity groups HbSS and HbSC

Descriptive statistics and an independent T-test were used to describe and compare illness representations of participants with blood type HbSS and HbSC. The mean scores and results of statistical analyses are presented in Table 7.

Table 7. Mean and standard deviation scores of illness severity groups on the Illness Perception Questionnaire

<table>
<thead>
<tr>
<th>Illness Perceptions</th>
<th>HbSS (n=38)</th>
<th>HbSC (n=19)</th>
<th>t test</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequence</td>
<td>33.92 (9.33)</td>
<td>31.21 (9.13)</td>
<td>1.041</td>
<td>55</td>
<td>0.303</td>
</tr>
<tr>
<td>Timeline</td>
<td>11.78 (3.49)</td>
<td>11.63 (2.85)</td>
<td>0.17</td>
<td>55</td>
<td>0.985</td>
</tr>
<tr>
<td>Identity</td>
<td>15.26 (6.05)</td>
<td>14.31 (6.26)</td>
<td>0.551</td>
<td>55</td>
<td>0.584</td>
</tr>
</tbody>
</table>

The descriptive statistics suggest that participants with blood type (HbSS) experienced more illness symptoms associated with their disease. They also believed that their illness would last longer, and perceived their illness as having more dire consequences than participants with blood type (HbSC).
3.5. Gender differences and illness perceptions

Descriptive statistics and an independent t-test were used to describe and compare gender differences on perceptions of illness. The mean scores and results of statistical analyses are presented in Table 8.

Table 8.

Mean and standard deviation scores of males and females on the Illness Representation Questionnaire

<table>
<thead>
<tr>
<th>Illness Perceptions</th>
<th>Males(n=18)</th>
<th>Females(n=39)</th>
<th>t test</th>
<th>df</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequence</td>
<td>38.00(7.42)</td>
<td>30.71(9.21)</td>
<td>-2.936</td>
<td>55</td>
<td>0.005</td>
</tr>
<tr>
<td>Timeline</td>
<td>12.77(1.86)</td>
<td>11.25(3.66)</td>
<td>-1.658</td>
<td>55</td>
<td>0.405</td>
</tr>
<tr>
<td>Identity</td>
<td>15.94(5.83)</td>
<td>14.48(6.21)</td>
<td>-0.838</td>
<td>55</td>
<td>0.103</td>
</tr>
</tbody>
</table>

The descriptive results suggest that males experienced more illness symptoms compared to females. Male participants also perceived their illness lasting longer and believed their illness had more serious consequences compared to female participants. Further statistical analysis using independent t-test suggest significant differences between males and females on their perception of the consequences of their illness ($t=-2.936$, df=55, $p=.005$) with men believing that their illness had more serious consequences than women.
3.6. **Association between illness representations and coping**

Correlations were computed to explore how participants' perceptions of their illness related to the coping strategies they adopted. The results are presented in Table 9.

**Table 9.**

**Correlations of Illness Representations with Coping Strategies**

<table>
<thead>
<tr>
<th>IPQ</th>
<th>Anger statements</th>
<th>Isolation</th>
<th>Catastrophising</th>
<th>Fear statements</th>
<th>Reinterpreting</th>
<th>Cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequence</td>
<td>$r = .562$</td>
<td>$r = .325$</td>
<td>$r = .415$</td>
<td>$r = .440$</td>
<td>$r = .044$</td>
<td>Stress</td>
</tr>
<tr>
<td></td>
<td>$p = .000^*$</td>
<td>$p = .014$</td>
<td>$p = .001^*$</td>
<td>$p = .001^*$</td>
<td>$p = .744$</td>
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</tr>
<tr>
<td>Identity</td>
<td>$r = .214$</td>
<td>$r = .242$</td>
<td>$r = .236$</td>
<td>$r = .200$</td>
<td>$r = .148$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .110$</td>
<td>$p = .069$</td>
<td>$p = .077$</td>
<td>$p = .136$</td>
<td>$p = .271$</td>
<td></td>
</tr>
<tr>
<td>Timeline</td>
<td>$r = .011$</td>
<td>$r = .147$</td>
<td>$r = .083$</td>
<td>$r = .120$</td>
<td>$r = .022$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .933$</td>
<td>$p = .277$</td>
<td>$p = .542$</td>
<td>$p = .376$</td>
<td>$p = .869$</td>
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<tr>
<td>Cause</td>
<td>Stress</td>
<td>$r = .345$</td>
<td>$r = .423$</td>
<td>$r = .215$</td>
<td>$r = .209$</td>
<td>$r = .132$</td>
</tr>
<tr>
<td></td>
<td>$p = .009^*$</td>
<td>$p = .001^*$</td>
<td>$p = .109$</td>
<td>$p = .119$</td>
<td>$p = .329$</td>
<td></td>
</tr>
<tr>
<td>Germ</td>
<td>$r = .471$</td>
<td>$r = .221$</td>
<td>$r = .277$</td>
<td>$r = .351$</td>
<td>$r = .310$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .001^*$</td>
<td>$p = .099$</td>
<td>$p = .037$</td>
<td>$p = .007^*$</td>
<td>$p = .019$</td>
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</tr>
<tr>
<td>Others</td>
<td>$r = .252$</td>
<td>$r = .182$</td>
<td>$r = .149$</td>
<td>$r = .312$</td>
<td>$r = .371$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .058$</td>
<td>$p = .175$</td>
<td>$p = .267$</td>
<td>$p = .018$</td>
<td>$p = .004^*$</td>
<td></td>
</tr>
<tr>
<td>Chance</td>
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<td>$r = .174$</td>
<td>$r = .153$</td>
<td>$r = .298$</td>
<td>$r = .419$</td>
<td></td>
</tr>
<tr>
<td></td>
<td>$p = .171$</td>
<td>$p = .195$</td>
<td>$p = .256$</td>
<td>$p = .025$</td>
<td>$p = .001^*$</td>
<td></td>
</tr>
<tr>
<td>Pollution</td>
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<td>$r = .277$</td>
<td>$r = .180$</td>
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<td>$r = .286$</td>
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<tr>
<td></td>
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<td>$p = .037$</td>
<td>$p = .180$</td>
<td>$p = .060$</td>
<td>$p = .031$</td>
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<td>$r = .111$</td>
<td>$r = .218$</td>
<td>$r = .194$</td>
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<td>Diet</td>
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<td>$r = .161$</td>
<td>$r = .158$</td>
<td>$r = .222$</td>
<td>$r = .248$</td>
<td></td>
</tr>
<tr>
<td>Medicalcare</td>
<td>$r = .289$</td>
<td>$r = .019$</td>
<td>$r = .120$</td>
<td>$r = .329$</td>
<td>$r = .289$</td>
<td></td>
</tr>
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<td></td>
<td>$p = .029$</td>
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<td>$p = .373$</td>
<td>$p = .012$</td>
<td>$p = .029$</td>
<td></td>
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<tr>
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<td>$r = .211$</td>
<td>$r = .183$</td>
<td>$r = .223$</td>
<td>$r = .216$</td>
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</tr>
<tr>
<td>Self</td>
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<td>$r = .026$</td>
<td>$r = .126$</td>
<td>$r = .064$</td>
<td>$r = .172$</td>
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<td>$p = .818$</td>
<td>$p = .850$</td>
<td>$p = .352$</td>
<td>$p = .637$</td>
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</tr>
</tbody>
</table>

*P < .01
Table 9 continued

**Correlations of Illness Representations with Coping Strategies**

<table>
<thead>
<tr>
<th>IPQ</th>
<th>Calming Statements</th>
<th>Ignoring</th>
<th>Praying &amp; Hoping</th>
<th>Massage</th>
<th>Relaxation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequence</td>
<td>$r = -0.093$</td>
<td>$r = -0.044$</td>
<td>$r = -0.009$</td>
<td>$r = 0.179$</td>
<td>$r = 0.026$</td>
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<tr>
<td></td>
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<td>$p = 0.747$</td>
<td>$p = 0.945$</td>
<td>$p = 0.183$</td>
<td>$p = 0.848$</td>
</tr>
<tr>
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<td>$r = -0.018$</td>
<td>$r = -0.144$</td>
<td>$r = -0.076$</td>
<td>$r = -0.026$</td>
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<tr>
<td></td>
<td>$p = 0.986$</td>
<td>$p = 0.893$</td>
<td>$p = 0.286$</td>
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</tr>
<tr>
<td>Timeline</td>
<td>$r = 0.077$</td>
<td>$r = 0.044$</td>
<td>$r = -0.325$</td>
<td>$r = -0.018$</td>
<td>$r = 0.023$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.568$</td>
<td>$p = 0.743$</td>
<td>$p = 0.014$</td>
<td>$p = 0.897$</td>
<td>$p = 0.864$</td>
</tr>
<tr>
<td>Cause</td>
<td>Stress</td>
<td>$r = -0.024$</td>
<td>$r = -0.012$</td>
<td>$r = 0.131$</td>
<td>$r = 0.051$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.861$</td>
<td>$p = 0.931$</td>
<td>$p = 0.332$</td>
<td>$p = 0.705$</td>
<td>$p = 0.177$</td>
</tr>
<tr>
<td>Germ</td>
<td>$r = -0.039$</td>
<td>$r = 0.008$</td>
<td>$r = -0.307$</td>
<td>$r = -0.088$</td>
<td>$r = -0.074$</td>
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<td>$p = 0.774$</td>
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<td>$p = 0.516$</td>
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<tr>
<td>Others</td>
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<td>$r = 0.257$</td>
<td>$r = 0.281$</td>
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<tr>
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<td>$p = 0.933$</td>
<td>$p = 0.575$</td>
<td>$p = 0.016$</td>
<td>$p = 0.054$</td>
<td>$p = 0.034$</td>
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<td>Chance</td>
<td>$r = 0.166$</td>
<td>$r = 0.156$</td>
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<td>$r = -0.178$</td>
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<td></td>
<td>$p = 0.217$</td>
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<td>$p = 0.184$</td>
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<tr>
<td>Pollution</td>
<td>$r = 0.078$</td>
<td>$r = 0.103$</td>
<td>$r = -0.136$</td>
<td>$r = -0.171$</td>
<td>$r = 0.052$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.563$</td>
<td>$p = 0.444$</td>
<td>$p = -0.312$</td>
<td>$p = -0.024$</td>
<td>$p = 0.702$</td>
</tr>
<tr>
<td>Hereditary</td>
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<td>$r = 0.094$</td>
<td>$r = -0.015$</td>
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<td>$r = 0.038$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.272$</td>
<td>$p = 0.489$</td>
<td>$p = 0.911$</td>
<td>$p = 0.234$</td>
<td>$p = 0.779$</td>
</tr>
<tr>
<td>Diet</td>
<td>$r = -0.063$</td>
<td>$r = 0.078$</td>
<td>$r = 0.141$</td>
<td>$r = 0.176$</td>
<td>$r = 0.074$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.641$</td>
<td>$p = 0.566$</td>
<td>$p = 0.294$</td>
<td>$p = 0.190$</td>
<td>$p = 0.582$</td>
</tr>
<tr>
<td>Medicalcare</td>
<td>$r = 0.052$</td>
<td>$r = 0.042$</td>
<td>$r = -0.151$</td>
<td>$r = 0.333$</td>
<td>$r = -0.004$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.702$</td>
<td>$p = 0.758$</td>
<td>$p = 0.261$</td>
<td>$p = 0.011$</td>
<td>$p = 0.978$</td>
</tr>
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<td>Mind</td>
<td>$r = 0.036$</td>
<td>$r = -0.080$</td>
<td>$r = -0.067$</td>
<td>$r = -0.325$</td>
<td>$r = 0.250$</td>
</tr>
<tr>
<td></td>
<td>$p = 0.791$</td>
<td>$p = 0.552$</td>
<td>$p = 0.620$</td>
<td>$p = 0.014$</td>
<td>$p = 0.061$</td>
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<tr>
<td>Self</td>
<td>$r = -0.024$</td>
<td>$r = -0.020$</td>
<td>$r = 0.301$</td>
<td>$r = -0.334$</td>
<td>$r = 0.050$</td>
</tr>
<tr>
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<td>$p = 0.885$</td>
<td>$p = 0.023$</td>
<td>$p = 0.011$</td>
<td>$p = 0.710$</td>
</tr>
</tbody>
</table>

*P<.01
Table 9 continued

**Correlations of Illness Representations with Coping Strategies**

<table>
<thead>
<tr>
<th>IPQ</th>
<th>Taking fluid</th>
<th>Diverting attention</th>
<th>Increased activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Consequence</td>
<td>r= -.026</td>
<td>r= .074</td>
<td>r= -.054</td>
</tr>
<tr>
<td></td>
<td>p=.849</td>
<td>p= .587</td>
<td>p= .691</td>
</tr>
<tr>
<td>Identity</td>
<td>r= -.083</td>
<td>r= .026</td>
<td>r= .050</td>
</tr>
<tr>
<td></td>
<td>p=.542</td>
<td>p= .846</td>
<td>p= .710</td>
</tr>
<tr>
<td>Timeline</td>
<td>r= .176</td>
<td>r= .124</td>
<td>r= .269</td>
</tr>
<tr>
<td></td>
<td>p=.189</td>
<td>p= .359</td>
<td>p= .043</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>r= .148</td>
<td>r= .228</td>
<td>r= -.036</td>
</tr>
<tr>
<td></td>
<td>p=.272</td>
<td>p= .088</td>
<td>p= .792</td>
</tr>
<tr>
<td>Germ</td>
<td>r= .149</td>
<td>r= .326</td>
<td>r= .092</td>
</tr>
<tr>
<td></td>
<td>p=.267</td>
<td>p= .013</td>
<td>p= .498</td>
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<td>Others</td>
<td>r= -.102</td>
<td>r= .224</td>
<td>r= -.017</td>
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<tr>
<td></td>
<td>p=.450</td>
<td>p= .094</td>
<td>p= .899</td>
</tr>
<tr>
<td>Chance</td>
<td>r= .078</td>
<td>r= .181</td>
<td>r= .103</td>
</tr>
<tr>
<td></td>
<td>p=.566</td>
<td>p= .177</td>
<td>p= .445</td>
</tr>
<tr>
<td>Pollution</td>
<td>r= .108</td>
<td>r= .169</td>
<td>r= -.094</td>
</tr>
<tr>
<td></td>
<td>p=.424</td>
<td>p= .209</td>
<td>p= .489</td>
</tr>
<tr>
<td>Hereditary</td>
<td>r= -.043</td>
<td>r= -.235</td>
<td>r= .015</td>
</tr>
<tr>
<td></td>
<td>p=.752</td>
<td>p= .078</td>
<td>p= .911</td>
</tr>
<tr>
<td>Diet</td>
<td>r= .058</td>
<td>r= .120</td>
<td>r= .025</td>
</tr>
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<td></td>
<td>p=.671</td>
<td>p= .374</td>
<td>p= .849</td>
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<tr>
<td>Medicalcare</td>
<td>r= -.079</td>
<td>r= .196</td>
<td>r= .155</td>
</tr>
<tr>
<td></td>
<td>p=.558</td>
<td>p= .144</td>
<td>p= .248</td>
</tr>
<tr>
<td>Mind</td>
<td>r= .063</td>
<td>r= .020</td>
<td>r= -.126</td>
</tr>
<tr>
<td></td>
<td>p=.639</td>
<td>p= .835</td>
<td>p= .350</td>
</tr>
<tr>
<td>Self</td>
<td>r= .151</td>
<td>r= .205</td>
<td>r= .017</td>
</tr>
<tr>
<td></td>
<td>p=.262</td>
<td>p= .125</td>
<td>p= .901</td>
</tr>
</tbody>
</table>

*P=<.01

Owing to the large number of correlations and the risk of suggesting a relationship between variables when there really is none, only correlations significant at p=<.01 were analysed further.

The belief that sickle cell disease had serious consequences was positively associated with unhelpful cognitive coping strategies, consisting of various forms of negative thinking adopted during episodes of pain. These strategies can be viewed as unhelpful because of their association
with maladaptive outcomes such as depression and anxiety. Unhelpful cognitive strategies included engaging in biased thinking (catastrophising), and self statements of fear and anger, such as “I worry that my disease is getting worse”; “I realise that most people don’t really care”. Further examination revealed an association between external attributions of illness and the coping strategies participants adopted. Participants who believed their disease was caused by stress was positively correlated with self statements of anger and behavioural isolation from others. Illness attributed to germs was negatively associated with self statements of anger and fear. External attributions such as believing sickle cell disease was caused by others or due to chance was positively related to helpful cognitive strategies such as reinterpreting pain sensations.

With regard to participants’ perception of their control over their pain resulting from the coping strategies they adopted, forty three participants (75.5%) believed they had some control over their pain (rating of either 3, 4 or 5 on a scale of 0-6), six participants (10.5%) believed they had complete control (score of 6) over their pain, while eight participants (14.1%) believed they had no control over their pain (rating of 0-2 on a scale of 0-6). Thirty three participants (57.9%) believed they had the ability to decrease their pain (rating of 3-5 on a scale of 0-6). Five participants (8.8%) believed they had the ability to decrease their pain completely, and nineteen participants (33.3%) believed they had very little ability to decrease their pain (rating of 0-2 on a scale of 0-6).
3.7 Correlation of illness perceptions with quality of life

Pearson correlations were computed to explore how participants’ perceptions of their illness related to their quality of life. The results are presented in Table 10.

Table 10.

Correlation of Illness Perceptions with Quality of Life

<table>
<thead>
<tr>
<th>IPQ</th>
<th>General</th>
<th>Social</th>
<th>Mental</th>
<th>Vitality</th>
<th>Bodily</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Health</td>
<td>Functioning</td>
<td>Health</td>
<td>Pain</td>
<td></td>
</tr>
<tr>
<td>Identity</td>
<td>r=-.543</td>
<td>r=-.433</td>
<td>r=-.315</td>
<td>r=-.420</td>
<td>r=-.266</td>
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<td></td>
<td>p=.000*</td>
<td>p=.001*</td>
<td>p=.017</td>
<td>p=.001*</td>
<td>p=.045</td>
</tr>
<tr>
<td>Consequence</td>
<td>r=-.742</td>
<td>r=-.430</td>
<td>r=-.500</td>
<td>r=-.484</td>
<td>r=-.383</td>
</tr>
<tr>
<td></td>
<td>p=.000*</td>
<td>p=.001*</td>
<td>p=.000*</td>
<td>p=.000*</td>
<td>p=.003*</td>
</tr>
<tr>
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<td>r=-.358</td>
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<td>r=-.178</td>
<td>r=-.189</td>
<td>r=-.213</td>
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<tr>
<td></td>
<td>p=.006*</td>
<td>p=.745</td>
<td>p=.186</td>
<td>p=.158</td>
<td>p=.112</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>r=-.347</td>
<td>r=-.230</td>
<td>r=-.422</td>
<td>r=-.412</td>
<td>r=-.416</td>
</tr>
<tr>
<td></td>
<td>p=.008*</td>
<td>p=.085</td>
<td>p=.001*</td>
<td>p=.001*</td>
<td>p=.001*</td>
</tr>
<tr>
<td>Germ</td>
<td>r=-.244</td>
<td>r=-.221</td>
<td>r=-.252</td>
<td>r=-.230</td>
<td>r=-.155</td>
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<tr>
<td></td>
<td>p=.067</td>
<td>p=.099</td>
<td>p=.059</td>
<td>p=.086</td>
<td>p=.248</td>
</tr>
<tr>
<td>Others</td>
<td>r=-.149</td>
<td>r=-.251</td>
<td>r=-.347</td>
<td>r=-.142</td>
<td>r=-.106</td>
</tr>
<tr>
<td></td>
<td>p=.270</td>
<td>p=.060</td>
<td>p=.008*</td>
<td>p=.294</td>
<td>p=.431</td>
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<tr>
<td>Chance</td>
<td>r=-.166</td>
<td>r=-.303</td>
<td>r=-.171</td>
<td>r=-.069</td>
<td>r=-.191</td>
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<td></td>
<td>p=.216</td>
<td>p=.022</td>
<td>p=.203</td>
<td>p=.611</td>
<td>p=.155</td>
</tr>
<tr>
<td>Pollution</td>
<td>r=-.189</td>
<td>r=-.033</td>
<td>r=-.142</td>
<td>r=-.059</td>
<td>r=.000</td>
</tr>
<tr>
<td></td>
<td>p=.159</td>
<td>p=.806</td>
<td>p=.293</td>
<td>p=.663</td>
<td>p=.997</td>
</tr>
<tr>
<td>Hereditary</td>
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<td>r=-.181</td>
<td>r=-.178</td>
<td>r=-.112</td>
<td>r=-.094</td>
</tr>
<tr>
<td></td>
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<td>p=.179</td>
<td>p=.186</td>
<td>p=.409</td>
<td>p=.488</td>
</tr>
<tr>
<td>Diet</td>
<td>r=-.196</td>
<td>r=-.197</td>
<td>r=-.247</td>
<td>r=-.211</td>
<td>r=-.213</td>
</tr>
<tr>
<td>Medicalcare</td>
<td>r=-.383</td>
<td>r=-.166</td>
<td>r=-.332</td>
<td>r=-.194</td>
<td>r=.057</td>
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<tr>
<td></td>
<td>p=.003*</td>
<td>p=.217</td>
<td>p=.012</td>
<td>p=.148</td>
<td>p=.676</td>
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<tr>
<td>Mind</td>
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<td>r=-.114</td>
<td>r=-.232</td>
<td>r=-.069</td>
<td>r=-.127</td>
</tr>
<tr>
<td></td>
<td>p=.375</td>
<td>p=.400</td>
<td>p=.082</td>
<td>p=.612</td>
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<tr>
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<td>r=-.090</td>
<td>r=-.173</td>
<td>r=-.032</td>
<td>r=-.126</td>
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<tr>
<td></td>
<td>p=.270</td>
<td>p=.505</td>
<td>p=.197</td>
<td>p=.814</td>
<td>p=.350</td>
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</table>

*P=<.01

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### Correlation of Illness Perceptions with Quality of Life

<table>
<thead>
<tr>
<th>IPQ</th>
<th>Physical Functioning</th>
<th>Role-Physical</th>
<th>Role-Emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Identity</td>
<td>r = -.483</td>
<td>r = -.418</td>
<td>r = -.304</td>
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<tr>
<td></td>
<td>p = .000*</td>
<td>p = .001*</td>
<td>p = .022</td>
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<tr>
<td>Consequence</td>
<td>r = -.411</td>
<td>r = -.494</td>
<td>r = -.479</td>
</tr>
<tr>
<td></td>
<td>p = .001*</td>
<td>p = .000*</td>
<td>p = .000*</td>
</tr>
<tr>
<td>Timeline</td>
<td>r = -.083</td>
<td>r = -.064</td>
<td>r = -.263</td>
</tr>
<tr>
<td></td>
<td>p = .538</td>
<td>p = .636</td>
<td>p = .048</td>
</tr>
<tr>
<td>Cause</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stress</td>
<td>r = -.265</td>
<td>r = -.322</td>
<td>r = -.344</td>
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<tr>
<td></td>
<td>p = .046</td>
<td>p = .015</td>
<td>p = .009*</td>
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<tr>
<td>Germ</td>
<td>r = -.050</td>
<td>r = -.320</td>
<td>r = -.378</td>
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<tr>
<td></td>
<td>p = .714</td>
<td>p = .015</td>
<td>p = .004*</td>
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<tr>
<td>Others</td>
<td>r = -.040</td>
<td>r = -.174</td>
<td>r = -.302</td>
</tr>
<tr>
<td></td>
<td>p = .766</td>
<td>p = .196</td>
<td>p = .022</td>
</tr>
<tr>
<td>Chance</td>
<td>r = -.118</td>
<td>r = -.185</td>
<td>r = -.203</td>
</tr>
<tr>
<td></td>
<td>p = .383</td>
<td>p = .168</td>
<td>p = .131</td>
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<tr>
<td>Pollution</td>
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<td>r = -.121</td>
<td>r = -.349</td>
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<td>p = .860</td>
<td>p = .371</td>
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<tr>
<td>Hereditary</td>
<td>r = -.063</td>
<td>r = -.071</td>
<td>r = -.031</td>
</tr>
<tr>
<td></td>
<td>p = .643</td>
<td>p = .601</td>
<td>p = .818</td>
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<tr>
<td>Diet</td>
<td>r = .034</td>
<td>r = -.290</td>
<td>r = -.251</td>
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<td>p = .803</td>
<td>p = .028</td>
<td>p = .059</td>
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<tr>
<td>Medicalcare</td>
<td>r = -.072</td>
<td>r = -.214</td>
<td>r = -.308</td>
</tr>
<tr>
<td></td>
<td>p = .595</td>
<td>p = .110</td>
<td>p = .020</td>
</tr>
<tr>
<td>Mind</td>
<td>r = -.072</td>
<td>r = -.042</td>
<td>r = -.192</td>
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<td></td>
<td>p = .595</td>
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</tr>
<tr>
<td>Self</td>
<td>r = .091</td>
<td>r = -.114</td>
<td>r = -.160</td>
</tr>
<tr>
<td></td>
<td>p = .502</td>
<td>p = .398</td>
<td>p = .233</td>
</tr>
</tbody>
</table>

Owing to the large number of correlations and the risk of suggesting a relationship between variables when there really is none, only correlations significant at \( p < .01 \) were analysed further.

Pearson correlations were computed to investigate the relationship between participants' perception of their illness and their quality of life as measured by the SF36. A strong illness identity (or the perception that many symptoms were associated with sickle cell disease) was associated with poor general health, low vitality, poor social and physical functioning.
functioning includes activities such as bathing and dressing). The belief that sickle cell disease had serious consequences was associated with difficulties at work and daily activities owing to emotional problems, poor physical functioning and problems with work or other daily activities as a result of physical health problems. Participants who perceived their illness to have serious consequences also experienced poor general and mental health, poor social functioning, low vitality and frequent perception of increased bodily pain. A strong belief in the illness lasting a long time was also associated with poor general health and difficulties at work and daily activities owing to emotional problems. Further examination revealed correlations between external attributions of illness and quality of life. Psychological attributions such as stress was associated with poor general and mental health, frequent perception of increased bodily pain, low vitality, and problems with work and daily activities owing to emotional problems. Attributing sickle cell disease to other people was related to poor mental health. Environmental illness attributions such as pollution was associated with difficulties at work or social activities owing to emotional problems. The belief that the disease was caused by poor medical care was associated with poor general health.

With regard to participants' perceptions of whether their health had improved or become worse over the last 12 months, 20 participants (35.1%) felt their health remained the same, 11 participants (19.3%) felt it had got much worse, 12 participants (21.1%) felt it was somewhat better, while 14 participants (24.6%) believed it was much better.
### 3.8. Correlation between coping strategies and quality of life

Pearson Correlations were computed to investigate the relationship between participants' coping strategies and their quality of life. The results are presented in Table 11.

#### Table 11.

<table>
<thead>
<tr>
<th>Coping Strategies</th>
<th>General Health</th>
<th>Social Functioning</th>
<th>Mental Health</th>
<th>Bodily Pain</th>
<th>Emotional Role-Functioning</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catastrophising</td>
<td>r = -0.349</td>
<td>p = 0.008*</td>
<td>r = -0.513</td>
<td>r = -0.389</td>
<td>r = -0.355</td>
</tr>
<tr>
<td>Fear statements</td>
<td>r = -0.470</td>
<td>p = 0.000*</td>
<td>r = -0.377</td>
<td>r = -0.458</td>
<td>r = -0.119</td>
</tr>
<tr>
<td>Anger statements</td>
<td>r = -0.407</td>
<td>p = 0.002*</td>
<td>r = -0.451</td>
<td>r = -0.364</td>
<td>r = -0.227</td>
</tr>
<tr>
<td>Isolation</td>
<td>r = -0.270</td>
<td>p = 0.042</td>
<td>r = -0.481</td>
<td>r = -0.320</td>
<td>r = -0.375</td>
</tr>
<tr>
<td>Massage</td>
<td>r = -0.227</td>
<td>p = 0.089</td>
<td>r = -0.293</td>
<td>r = -0.418</td>
<td>r = -0.089</td>
</tr>
<tr>
<td>Taking fluid</td>
<td>r = 0.21</td>
<td>p = 0.876</td>
<td>r = 0.28</td>
<td>r = -0.107</td>
<td>r = -0.073</td>
</tr>
<tr>
<td>Relaxation</td>
<td>r = -0.24</td>
<td>p = 0.857</td>
<td>r = -1.108</td>
<td>r = -1.183</td>
<td>r = -1.184</td>
</tr>
<tr>
<td>Calm statements</td>
<td>r = -0.058</td>
<td>p = 0.667</td>
<td>r = 0.033</td>
<td>r = -0.010</td>
<td>r = -0.092</td>
</tr>
<tr>
<td>Divert attention</td>
<td>r = -0.086</td>
<td>p = 0.524</td>
<td>r = -0.110</td>
<td>r = -0.085</td>
<td>r = -0.148</td>
</tr>
<tr>
<td>Reinterpreting pain</td>
<td>r = -0.272</td>
<td>p = 0.843</td>
<td>r = -0.209</td>
<td>r = -0.315</td>
<td>r = -0.011</td>
</tr>
<tr>
<td>Ignoring</td>
<td>r = -0.064</td>
<td>p = 0.635</td>
<td>r = -0.070</td>
<td>r = -0.085</td>
<td>r = -0.089</td>
</tr>
<tr>
<td>Praying &amp; Hoping</td>
<td>r = -0.244</td>
<td>p = 0.667</td>
<td>r = -0.002</td>
<td>r = -0.075</td>
<td>r = -0.106</td>
</tr>
<tr>
<td>Increased activity</td>
<td>r = -0.272</td>
<td>p = 0.435</td>
<td>r = -0.106</td>
<td>r = -0.361</td>
<td>p = -0.578</td>
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</tbody>
</table>

* P = <0.01
**Table 11. continued.**

**Correlations of Coping Strategies with Quality of life**

<table>
<thead>
<tr>
<th>Coping Strategies</th>
<th>Role-Physical</th>
<th>Physical functioning</th>
<th>Vitality</th>
</tr>
</thead>
<tbody>
<tr>
<td>Catastrophising</td>
<td>r = -.136</td>
<td>r = -.215</td>
<td>r = -.132</td>
</tr>
<tr>
<td></td>
<td>p = .312</td>
<td>p = .109</td>
<td>p = .326</td>
</tr>
<tr>
<td>Fear statements</td>
<td>r = -.112</td>
<td>r = -.254</td>
<td>r = -.196</td>
</tr>
<tr>
<td></td>
<td>p = .407</td>
<td>p = .057</td>
<td>p = .145</td>
</tr>
<tr>
<td>Anger statements</td>
<td>r = -.256</td>
<td>r = -.288</td>
<td>r = -.295</td>
</tr>
<tr>
<td></td>
<td>p = .054</td>
<td>p = .030</td>
<td>p = .026</td>
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<tr>
<td>Isolation</td>
<td>r = -.238</td>
<td>r = -.044</td>
<td>r = -.173</td>
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<tr>
<td></td>
<td>p = .074</td>
<td>p = .747</td>
<td>p = .199</td>
</tr>
<tr>
<td>Massage</td>
<td>r = -.111</td>
<td>r = .000</td>
<td>r = -.110</td>
</tr>
<tr>
<td></td>
<td>p = .411</td>
<td>p = .997</td>
<td>p = .416</td>
</tr>
<tr>
<td>Taking fluid</td>
<td>r = -.088</td>
<td>r = -.207</td>
<td>r = -.108</td>
</tr>
<tr>
<td></td>
<td>p = .517</td>
<td>p = .123</td>
<td>p = .426</td>
</tr>
<tr>
<td>Relaxation</td>
<td>r = -.218</td>
<td>r = -.056</td>
<td>r = -.192</td>
</tr>
<tr>
<td></td>
<td>p = .103</td>
<td>p = .678</td>
<td>p = .153</td>
</tr>
<tr>
<td>Calm statements</td>
<td>r = -.010</td>
<td>r = .103</td>
<td>r = -.075</td>
</tr>
<tr>
<td></td>
<td>p = .943</td>
<td>p = .446</td>
<td>p = .578</td>
</tr>
<tr>
<td>Divert attention</td>
<td>r = -.130</td>
<td>r = -.067</td>
<td>r = -.043</td>
</tr>
<tr>
<td></td>
<td>p = .335</td>
<td>p = .619</td>
<td>p = .750</td>
</tr>
<tr>
<td>Reinterpreting pain</td>
<td>r = -.142</td>
<td>r = -.078</td>
<td>r = -.214</td>
</tr>
<tr>
<td></td>
<td>p = .292</td>
<td>p = .563</td>
<td>p = .110</td>
</tr>
<tr>
<td>Ignoring</td>
<td>r = -.246</td>
<td>r = -.025</td>
<td>r = -.057</td>
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<tr>
<td></td>
<td>p = .065</td>
<td>p = .851</td>
<td>p = .673</td>
</tr>
<tr>
<td>Praying &amp;hoping</td>
<td>r = -.165</td>
<td>r = .013</td>
<td>r = -.016</td>
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<tr>
<td></td>
<td>p = .220</td>
<td>p = .921</td>
<td>p = .906</td>
</tr>
<tr>
<td>Increased activity</td>
<td>r = -.226</td>
<td>r = -.044</td>
<td>r = -.149</td>
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<tr>
<td></td>
<td>p = .091</td>
<td>p = .744</td>
<td>p = .268</td>
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</tbody>
</table>

*P =< .01

Owing to the large number of correlations and the risk of suggesting a relationship between variables when there really is none, only correlations significant at p =< .01 were analysed further.

Cognitive coping strategies such as catastrophising, and engaging in fear and anger self statements were negatively related to mental and general health, and social functioning. Behavioural coping strategies such as isolation, and anger self statements were negatively associated with the experience of pain and emotional problems. Catastrophising was also
negatively related to the experience of pain. Physiological coping strategies such as massaging painful areas of the body was positively associated with mental health.

4. **Relative contributions of demographic variables, illness representations and coping strategies as predictors of quality of life.**

The subscales of the Illness Representation Questionnaire and Coping Strategies Questionnaire which were significantly correlated (at p=<.01) with the subscales of the SF36 questionnaire (quality of life measure) at univariate level, were entered into a series of standard multiple regression analyses to determine and compare their relative contribution to participants' quality of life. Demographic variables such as age and gender were also entered into the analyses because of their relation to the incidence of painful crises (Gil et al., 1989). Illness severity (illness phenotype) was entered in the analyses because of the general belief that those with the severe form of the disease (HbSS) experience more health problems associated with the disease throughout life.

The use of multiple regression requires that several practical issues be addressed. For example Tabachnick and Fidell (1989) argue that when using multiple regression the number of cases to independent variables ratio has to be substantial. They suggest that for standard regression one should aim to have at least 20 cases per variable, and where this cannot be achieved “a bare minimum requirement is to have at least 5 times more cases than independent variables - at least 25 cases if 5 independent variables are to be used”...p.g. 129 (Tabachnick and Fidell, 1989).

Furthermore, they argue that if stepwise regression is to be used, the number of cases to independent variable ratio of 40 to 1 is reasonable because this regression analysis produces a solution that does not generalise beyond the sample unless the sample is large. So for this reason, standard regression was the choice of analysis.
4.1 Demographic variables and illness representations as predictors of quality of life

The illness representation dimensions Consequence, Identity, Timeline, and the Causal attributions that correlated with quality of life variables at univariate level, were entered into a standard multiple regression predicting General Health, Social Functioning, Mental Health, Role-emotional, Bodily Pain, Physical functioning, Vitality, and Role-Physical. The summary of these analyses is presented in Table 12.

Table 12.

Relative Contribution of Demographic Variables and Illness

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>B Value</th>
<th>B</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Health</td>
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<td>-0.265</td>
<td>.008**</td>
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<tr>
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<td>-1.124</td>
<td>-0.455</td>
<td>.000**</td>
</tr>
<tr>
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<td>0.245</td>
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<tr>
<td></td>
<td>Medicalcare</td>
<td>-4.93</td>
<td>-0.237</td>
<td>0.017*</td>
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<tr>
<td></td>
<td>Gender</td>
<td>-3.115</td>
<td>-0.664</td>
<td>0.502</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.164</td>
<td>-0.069</td>
<td>0.457</td>
</tr>
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<td>Illness Severity</td>
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<td>-0.096</td>
<td>0.316</td>
</tr>
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<td></td>
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</tr>
<tr>
<td></td>
<td>F=11.653**</td>
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</tr>
<tr>
<td>Social Functioning</td>
<td>Identity</td>
<td>-1.259</td>
<td>-0.31</td>
<td>.025*</td>
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<tr>
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<td>Consequence</td>
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<td>-0.245</td>
<td>0.1</td>
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<td></td>
<td>Gender</td>
<td>-8.627</td>
<td>-0.164</td>
<td>0.208</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>0.263</td>
<td>0.103</td>
<td>0.411</td>
</tr>
<tr>
<td></td>
<td>Phenotype</td>
<td>-0.0506</td>
<td>-0.001</td>
<td>0.994</td>
</tr>
<tr>
<td></td>
<td>Adj.R^2=.21</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>F=4.102*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mental Health</td>
<td>Gender</td>
<td>-2.369</td>
<td>-0.054</td>
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<td></td>
<td>Age</td>
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<td>-0.034</td>
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<td>Phenotype</td>
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<td>Consequence</td>
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<td>Stress</td>
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<td></td>
<td>Others</td>
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<td>0.055</td>
</tr>
<tr>
<td></td>
<td>Adj.R^2=.30</td>
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<tr>
<td></td>
<td>F=5.001**</td>
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</tbody>
</table>
Table 12. continued

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>B Value</th>
<th>B</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Role-Emotional</td>
<td>Gender</td>
<td>17.451</td>
<td>0.2</td>
<td>0.142</td>
</tr>
<tr>
<td></td>
<td>Age</td>
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<td>0.048</td>
<td>0.706</td>
</tr>
<tr>
<td></td>
<td>Phenotype</td>
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<td>0.001</td>
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<td>-0.433</td>
<td>0.004**</td>
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<td></td>
<td>Stress</td>
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<td>-0.082</td>
<td>0.558</td>
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<td>Germ</td>
<td>-4.618</td>
<td>-0.137</td>
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<td>Pollution</td>
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<td></td>
<td>Adj.R2= .24</td>
<td></td>
<td></td>
<td>F=3.637**</td>
</tr>
<tr>
<td></td>
<td>F= 5.151**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bodily Pain</td>
<td>Consequence</td>
<td>-0.568</td>
<td>-0.174</td>
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<td></td>
<td>Stress</td>
<td>-0.284</td>
<td>-0.426</td>
<td>.003**</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>1.378</td>
<td>0.021</td>
<td>0.866</td>
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<tr>
<td></td>
<td>Age</td>
<td>-1.019</td>
<td>-0.323</td>
<td>.011*</td>
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<td></td>
<td>Phenotype</td>
<td>-0.4054</td>
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<tr>
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<td>Adj.R2= .27</td>
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<td></td>
<td></td>
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<tr>
<td></td>
<td>F= 5.151**</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical Functioning</td>
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<td>0.163</td>
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<tr>
<td></td>
<td>Age</td>
<td>-0.696</td>
<td>0.294</td>
<td>.022*</td>
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<td>Illness Severity</td>
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<td></td>
<td>Consequence</td>
<td>-0.633</td>
<td>-0.241</td>
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<tr>
<td></td>
<td>Identity</td>
<td>-1.416</td>
<td>-0.354</td>
<td>.007**</td>
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<tr>
<td></td>
<td>Adj.R2= .30</td>
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<tr>
<td></td>
<td>F= 5.997**</td>
<td></td>
<td></td>
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<tr>
<td>Vitality</td>
<td>Gender</td>
<td>11.271</td>
<td>0.252</td>
<td>.033*</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.577</td>
<td>-0.265</td>
<td>.022*</td>
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<tr>
<td></td>
<td>Illness Severity</td>
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<tr>
<td></td>
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<td>-0.702</td>
<td>-0.311</td>
<td>0.029*</td>
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<tr>
<td></td>
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<td>-0.711</td>
<td>-0.243</td>
<td>0.052</td>
</tr>
<tr>
<td></td>
<td>Stress</td>
<td>-3.665</td>
<td>-0.243</td>
<td>0.052</td>
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<td></td>
<td>Adj.R2= .39</td>
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<tr>
<td></td>
<td>F= 7.176**</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Role-Physical</td>
<td>Gender</td>
<td>3.037</td>
<td>0.035</td>
<td>0.784</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.432</td>
<td>-0.102</td>
<td>0.408</td>
</tr>
<tr>
<td></td>
<td>Phenotype</td>
<td>-1.287</td>
<td>-0.015</td>
<td>0.902</td>
</tr>
<tr>
<td></td>
<td>Consequence</td>
<td>-1.658</td>
<td>-0.379</td>
<td>.012*</td>
</tr>
<tr>
<td></td>
<td>Identity</td>
<td>-1.567</td>
<td>-1.767</td>
<td>0.083</td>
</tr>
<tr>
<td></td>
<td>Adj.R2= .23</td>
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<td></td>
</tr>
<tr>
<td></td>
<td>F= 4.391**</td>
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The results suggest that illness representations dimensions and demographic variables were significant predictors of quality of life. Illness representations and demographic variables accounted for 60 percent of the variance in General Health. The illness identity and consequence dimension were the most significant negative predictors of General Health, followed by the belief that poor medical care was the cause of the disease. Demographic variables and illness representations explained 21 percent of the variance in Social Functioning. The illness identity dimension was the most significant negative predictor of Social Functioning. Demographic variables and illness representations accounted for 30 percent of the variance in Mental Health, with the 'consequence' dimension making the most significant negative prediction of Mental Health. Twenty four percent of the variance in Role-emotional was explained by illness representations and demographic variables. The consequence dimension made the most significant contribution to the negative prediction of problems with work and daily activities owing to emotional difficulties (Role-emotional). Demographic variables and illness representations accounted for 27 percent of the variance in the perception of frequent bodily pain. The belief that stress was the cause of sickle cell disease, and age were the most significant negative predictors of bodily pain, with younger participants reporting more bodily pain than older participants.

Demographic variables and illness representations accounted for 30 percent of the variance in Physical functioning. The experience of illness symptoms (illness identity) and age were the most significant negative predictors of physical functioning, with younger participants reporting more difficulties with physical functioning than older participants. Demographic variables and illness representation dimensions accounted for 39 percent of the variance in Vitality. Gender was a positive predictor of vitality, with females reporting more vitality than men, whilst age was a negative predictor of vitality, with participants aged 30 and below reporting less vitality. Believing that sickle cell disease had serious consequences was also a negative predictor of vitality. Twenty
three percent of the variance in Role-physical was explained by illness representations and demographic variables. The consequence dimension was the most significant negative predictor of Role-physical.

4.2. **Relative contributions of demographic variables and coping strategies as predictors of quality of life.**

Standard regression analysis was computed to examine the extent to which participants' coping strategies correlated with quality of life variables at univariate level, predicted quality of life after controlling for demographic indices. Coping strategies were significantly correlated with just five quality of life subscales at univariate level, and so regression analyses predicted in turn, General health, Social functioning, Mental health, Bodily pain and Role-emotional. The summary of these analyses are presented in Table 13.

**Table 13.**

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>B Value</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Health</td>
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<td>0.346</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.562</td>
<td>0.066</td>
</tr>
<tr>
<td></td>
<td>Phenotype</td>
<td>1.049</td>
<td>0.859</td>
</tr>
<tr>
<td></td>
<td>Fear statements</td>
<td>-0.96</td>
<td>0.076</td>
</tr>
<tr>
<td></td>
<td>Anger statements</td>
<td>-0.975</td>
<td>0.073</td>
</tr>
<tr>
<td></td>
<td>Catastrophising</td>
<td>0.295</td>
<td>0.625</td>
</tr>
<tr>
<td></td>
<td>Adj.R²=.24</td>
<td></td>
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</tr>
<tr>
<td></td>
<td>F=4.062**</td>
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</tr>
<tr>
<td>Social Functioning</td>
<td>Anger statements</td>
<td>-0.263</td>
<td>0.651</td>
</tr>
<tr>
<td></td>
<td>Gender</td>
<td>-0.452</td>
<td>0.949</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.469</td>
<td>0.153</td>
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<tr>
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<td>Phenotype</td>
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<td>0.541</td>
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<tr>
<td></td>
<td>Catastrophising</td>
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<td>0.076</td>
</tr>
<tr>
<td></td>
<td>Fear statements</td>
<td>0.226</td>
<td>0.689</td>
</tr>
<tr>
<td></td>
<td>Isolation</td>
<td>-0.802</td>
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<tr>
<td></td>
<td>Adj.R²=.27</td>
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<td></td>
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<tr>
<td></td>
<td>F=4.013**</td>
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</table>
Table 13. continued

Relative Contribution of Demographic Variables and Coping to Quality of Mental Health

<table>
<thead>
<tr>
<th>Dependent Variable</th>
<th>Independent Variable</th>
<th>B Value</th>
<th>B</th>
<th>P</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mental Health</td>
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<td>0.625</td>
<td>0.014</td>
<td>0.915</td>
</tr>
<tr>
<td></td>
<td>Age</td>
<td>-0.194</td>
<td>-0.091</td>
<td>0.485</td>
</tr>
<tr>
<td></td>
<td>Phenotype</td>
<td>7.39</td>
<td>0.172</td>
<td>0.179</td>
</tr>
<tr>
<td></td>
<td>Catastrophising</td>
<td>-0.0759</td>
<td>-0.03</td>
<td>0.892</td>
</tr>
<tr>
<td></td>
<td>Fear Statements</td>
<td>-0.553</td>
<td>-0.205</td>
<td>0.292</td>
</tr>
<tr>
<td></td>
<td>Anger statements</td>
<td>-0.377</td>
<td>-0.139</td>
<td>0.447</td>
</tr>
<tr>
<td></td>
<td>Massage</td>
<td>-0.647</td>
<td>-0.244</td>
<td>0.101</td>
</tr>
<tr>
<td>Adj.R² = .19</td>
<td>F = 2.943*</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

| Role               | Isolation            | -1.318  | -0.317 | .048* |
|                    | Anger statements      | -1.415  | -0.259 | 0.089 |
|                    | Gender               | 14.445  | 0.165 | 0.248 |
|                    | Age                  | -0.602  | -0.141 | 0.299 |
|                    | Phenotype            | 10.586  | 0.123 | 0.358 |
| Adj.R² = .12       | F = 2.660*           |         |     |   |

| Bodily Pain        | Gender               | 18.433  | 0.285 | .024* |
|                    | Age                  | -1.626  | -0.515 | .000** |
|                    | Phenotype            | 7.437   | 0.117 | 0.298 |
|                    | Catastrophising      | -1.284  | -0.338 | .010* |
|                    | Isolation            | -1.357  | -0.442 | .001** |
| Adj.R² = .36       | F = 7.513**          |         |     |   |

Coping strategies and demographic variables explained 24 percent of the variance in General Health, with none of the coping or demographic variables making significant contributions to the prediction of General Health. In comparison 60 percent of the variance in General Health was explained by illness representations and demographic variables. Coping strategies and demographic variables better explained the variance in Social Functioning. Together they explained 27 percent of the variance, compared to 21 percent explained by illness representations and
demographic variables. Behavioural isolation as a coping strategy was the most significant negative predictor of Social Functioning. Nineteen percent of the variance in Mental Health was explained by coping strategies and demographic variables. None of the coping or demographic variables were significant predictors of Mental Health. In comparison illness representations and demographic variables explained 30 percent of the variance.

Coping strategies and demographic variables explained 12 percent of the variance in Role-emotional. Behavioural isolation was the most significant predictor of difficulties with work and daily activities owing to emotional problems (Role-emotional). In comparison illness representations and demographic variables explained 24 percent of the variance in Role-emotional. Thirty-six percent of the variance in Bodily Pain was accounted for by cognitive and behavioural coping strategies and demographic variables. Age was the most significant predictor of Bodily Pain, followed by isolating oneself from others, engaging in catastrophic thoughts and gender. In comparison illness representations and demographic variables explained 27 percent of the variance in Bodily Pain.
5. **Discussion**

5.1. **General Discussion**

The discussion will focus on the main hypotheses of the study, followed by issues such as the theoretical implications and limitations of the study, and implications for clinical practice.

**Aims and Hypotheses**

The aim of the study was to explore the illness representations of adults with sickle cell disease, and to examine their association with quality of life via coping. Three hypotheses were generated, and the discussion will focus on the main findings related to these.

**H1. Illness representations will be associated with coping strategies and quality of life**

The Self Regulatory Model posits that coping is a mediating factor between illness representations and outcome. Therefore the model postulates a relationship between illness representations, coping, and outcome in various chronic illnesses. The study’s first aim was to report on whether these generic illness representations could be applied to genetic illnesses such as sickle cell disease, and whether they were associated with coping strategies and outcome as the model posits.

The study reported a positive relationship between the consequence dimension and three out of thirteen coping strategies participants adopted. The belief that sickle cell disease had dire consequences was positively related to cognitive coping strategies such as anger and fear self statements, and biased thinking (catastrophising). These findings are in line with current research on the illness representations and coping strategies of adults with chronic fatigue. Moss - Morris et al., (1996) reported that chronic fatigue participants who perceived their illness as having dire
consequences tended to engage in unhelpful strategies such as venting their emotions. The ‘identity’ and ‘timeline’ dimension (number of perceived symptoms associated with the disease) surprisingly were not significantly correlated with any of the coping subscales. In other studies (e.g. Hampson, Russell, & Zeiss, 1994; Moss-Morris et al., 1996), the identity dimension was found to be strongly related to behavioural disengagement (isolation) and frequent use of medical services. Scharloo et al., (1998) reported associations between the ‘timeline’ dimension and poor outcome on disease specific measures of functioning and role and social functioning. Attributing illness to psychological factors such as stress was positively related to anger self statements. Externalisation of the attribution of illness to others and chance was positively related to reinterpreting pain sensation. The belief that the disease was caused by germs was positively related to anger and fear self statements.

Attributing the disease to various factors such as stress, and external causes such as germs, other people, and chance was positively associated with cognitive strategies such as anger and fear self statements, behavioural isolation and reinterpreting pain sensation. The wide array of causal beliefs may reflect participants' personal controversy about the cause of pain associated with the disease, and the lack of medical clarification, rather than the actual aetiology of the disease. Furthermore, these external attributes may reflect beliefs about vulnerability to painful crises, and attempts to control this experience by minimising stress and exposure to germs and other people by reducing activity and isolating themselves.

The relationship between illness representations and coping suggests that beliefs about sickle cell disease impact on coping, or that coping responses influence how patients perceive their illness. The lack of associations between coping strategies and perceptions of timeline and illness identity would suggest that duration of the disease (which is hereditary) and number of illness symptoms have little impact on coping or shaping perceptions about the disease. Surprisingly, beliefs about
the genetic cause of the disease did not correlate with any of the other illness dimensions or coping strategies. This may reflect a number of things; firstly, limited knowledge about the cause of sickle cell disease; secondly, participants who had completed the questionnaire on coping strategies when in pain, may have responded to the illness perception questions thinking about the cause of sickle cell pain rather than the cause of the disease.

With regard to the association between illness representations and quality of life, illness representations, such as the identity and consequence dimension, were related to most aspects of quality of life. A strong illness identity (ie the perceived experience of illness symptoms) was strongly related to poor general and mental health, poor social, physical and role functioning, and low vitality. These findings support previous research by Moss-Morris et al., (1996) who argued that a strong illness identity may be perceived by patients as a sign of the presence of disease, and that it is the severity of the illness rather than perception of symptoms that is responsible for poor functioning. This view is supported by the descriptive statistics which revealed differences between the two illness severity groups. The HbSS participants scored higher on all three illness dimensions (consequences, timeline and identity). However these differences did not reach statistical significance. This is surprising, given that HbSC is a milder form of sickle cell disease, one would expect to find significant differences in the perceptions of these two groups. One hypotheses might be that the perceived stigma of the disease is pervasive to those with a milder form of the disease, therefore their perceptions and experiences of the disease is similar to that of patients with more severe forms of the disease.

Believing that the illness would last a long time was associated with poor general health. This result is not surprising given that sickle cell sufferers experience pain and complications from birth, and are likely to experience health problems throughout their lives (Barbarin & Christian, 1999). The consequence dimension was strongly negatively associated with all eight subscales of quality
of life, which suggests that the perceived consequences of the disease impacts on all aspects of life. This is in line with a study by Ohaeri et al., (1995) who reported that their sample of adults with sickle cell disease believed that their illness had negative consequences such as becoming a burden to their family, affected their relationship with others, and lowered their sense of self worth. It is also possible that the consequence dimension's strong association with all eight subscales of quality of life indicates that the consequence dimension measured the same factors as the quality of life variables.

With regard to the relationship between coping strategies and quality of life, cognitive strategies such as catastrophic thoughts about the meaning of pain, and fear and anger self statements were the most unhelpful and debilitating strategies participants used to cope with their illness, evidenced by their negative association with six quality of life subscales. This may suggest that participants who use these strategies experience a high degree of both psychosocial and functional impairment. These cognitive strategies were negatively related to poor general and mental health, frequent perception of bodily pain, low vitality, poor social functioning, and problems at work and other activities owing to emotional problems (Role-emotional). These findings are in line with Gil et al., (1989), and MacCrae & Lumley (1998), who reported that sickle cell patients who used cognitive strategies such as catastrophising, fear and anger self statements reported more pain episodes, were less active during pain crises, and had higher levels of psychological distress. Negative behavioural responses such as isolation during episodes of pain, was associated with poor health status such as poor social functioning, frequent perception of bodily pain and difficulties with work and daily activities owing to emotional problems (Role-emotional). MacCrae & Lumley, (1998) suggest that individuals who use this strategy tend to live limited lives, are often unable to work, and are preoccupied with their symptoms. Self help strategies such as massage was positively related to good mental health. A reason could be that participants who use this strategy achieve a sense of ability to control and decrease their pain.
H2. Illness representations will differ according to phenotype of disease.

Given the different levels of illness severity, it was hypothesised that participants with HbSS (the most severe form of the disease) would report more dire beliefs about their disease than participants with less severe forms of the disease. This hypothesis however was not supported in the study. Although descriptive analyses suggested a difference in illness representations of the two illness groups, these differences did not reach statistical significance. This is in line with Schaeffer et al., (1999) who argued that illness phenotype was not a predictor of psychological adjustment. However this result is surprising given that HbSC is a milder form of the disease, and as such, one would expect this group of patients to hold beliefs quite different to patients with the more severe form of the disease. One hypothesis may be that people with sickle cell disease, irrespective of blood type, are faced with the progressive nature of the disease, and the threat of sudden death. Furthermore, sufferers of the disease, irrespective of blood type may also experience the same stigma attached to the disease, and at various times in their lives are physically and socially disabled by the disease. Therefore participants with less severe forms of the disease may share the same fears, worries, and experiences of the disease as those with the more severe form of the disease, and as a result hold similar beliefs about their disease.

Although it was not hypothesised that illness representations would differ according to gender, significant differences were observed between males and females on their representations of illness. Male participants achieved higher mean scores on the identity, consequence and timeline dimension. Statistical analysis suggests that males perceived their disease as having significantly greater negative consequences, than did females. Ohaeri et al., (1995) also reported that males tended to express more negative opinions about their illness, and were more socially disabled by their illness than females. One hypothesis may be that physical complications are interpreted differently by males. Men may hold more negative views about the disabling physical effect of
their disease such as rendering them impotent, or preventing them from fathering children owing to priapism (sickling in the penis) and low sperm count (Midence & Elander, 1994).

**H3. Illness representations will be a better predictor of quality of life than coping strategies.**

Although no direct test of this hypothesis was conducted owing to the small sample size, a series of regression analyses were conducted in which illness representations and coping strategies were entered into separate analyses and compared.

The results of the analyses indicated that illness representations explained a significant proportion of the variance in all 8 subscales of the quality of life measure included in the study. On the other hand, of the five coping strategies found to be associated with five of the quality of life measures, only two coping strategies (isolation and catastrophising) significantly explained the variance in three of the five quality of life subscales.

Illness representations were the most significant predictors of general health, with the consequence dimension explaining most of the variance, followed by illness identity, and poor medical care. Although demographic variables (age, illness severity and gender) did not make a significant contribution to the prediction of general health, combined with illness representations they explained 60 percent of the variance in general health. Coping strategies on the other hand only explained 24 percent of the variance in general health. None of the demographic variables or coping variables (fear and anger self statements and catastrophising) were significant predictors of general health. This would suggest that participants' beliefs about their illness symptoms and the consequences of their disease, together with their perception of the quality of care they receive, were the strongest negative indicator of their general well being. Furthermore, these results suggest that coping strategies played a lesser role in how participants managed their
illness overall. These findings are in line with those of Hampson et al., (1994), Moss Morris et al., (1996), and Scharloo et al., (1998) who reported that illness representations were more strongly associated with adjustment and well being than coping sub scales. This suggests that illness representations have a direct effect on functioning that is not mediated by coping strategies as the self regulation model posits.

Demographic variables and illness representations explained 30 percent of the variance in mental health, with beliefs and thoughts about the consequence of the disease being the strongest predictor of poor mental health. Coping strategies and demographic variables explained only 19 percent of the variance in mental health, and none of the variables made a significant independent contribution to the prediction of mental health. These findings suggest other factors in addition to illness representations, coping strategies and demographic variables unknown at present play a more important role in the prediction of mental health in adults with sickle cell disease.

Illness representations and demographic variables accounted for 21 percent of the variance in social functioning, with severity of illness symptoms explaining the largest proportion of the variance and being the most significant predictor of social functioning. On the other hand, coping strategies and demographic variables accounted for 27 percent of the variance with behavioural disengagement (isolation) being the most significant predictor of poor social functioning.

Illness perceptions and demographic variables accounted for 27 percent of the variance in bodily pain. Age, and stress perceived as the likely cause of the disease were the most significant negative predictors of bodily pain. However coping strategies were the most significant negative predictor of perceived bodily pain as measured by the SF36 quality of life questionnaire, and together with demographic variables explained 36 percent of the variance. Age of the participants
was the most significant negative predictor of perceived frequency of bodily pain. This is in line with research suggesting that young adults (individuals in their twenties) report more severe pain than older adults (individuals aged thirty and above) (Platt et al., 1991). One hypothesis may be that sufferers in their thirties and over, as a result of more years of experience living with pain, adopt more helpful strategies to manage their pain. Behavioural isolation was the next most significant predictor of perceived frequency of bodily pain. One hypothesis is that isolation leads to lowered activity levels and less involvement in pleasurable activities. This results in an excessive focus on, and negative interpretation of bodily sensations, which in turn exacerbates the perceived experience of pain. The significant contribution of biased thinking (catastrophising) as a predictor of bodily pain supports the hypotheses that negative interpretation of pain exacerbates the perceived experience of pain. Gender also made a significant contribution to the prediction of bodily pain, which is in line with the Ohaeri et al. (1995) study in which males reported a more severe perception of pain than females.

Coping strategies and demographic variables accounted for just 12 percent of the variance in problems at work and other activities due to emotional difficulties (Role-emotional). Behavioural isolation was the most significant negative predictor of Role-Emotional. Illness representations and demographic variables better explained the variance in role-emotional, accounting for 24 percent of the variance. The consequence dimension was the most significant negative predictor of the role-emotional variance. One hypothesis is that emotional problems and isolation during painful crises results in frequent absenteeism from social activities and work and results in dismissal from work (Black and Laws, 1986). The perceived consequence of the disease might also impact negatively on sufferers willingness to seek or maintain employment and other activities owing to past negative experiences of employment (Chestnut, 1994; Barbarin & Christian, 1999).
Illness representations and demographic variables alone were significant negative predictors of vitality, physical functioning and problems at work and other activities owing to physical health difficulties (Role-physical). This result is surprising given the findings of other studies such as MacCrae & Lumley, (1998) who reported associations between coping strategies adopted by sickle cell patients and activity levels.

Demographic and illness representation variable accounted for 39 percent of the variance in vitality. Gender was the most significant negative predictor of vitality followed by the consequence dimension and age. One could hypothesise that the progressive nature of the disease renders sufferers feeling fatigued most of the time. It is also likely that the progressive nature of the disease results in high levels of chronic pain and disability owing to joint damage and internal organ failure. This would have a profound effect on sufferers perception of quality of life.

Demographic variables and illness representations accounted for 30 percent of the variance in Physical functioning and 23 percent of the variance in Role-physical. Illness identity (number of symptoms associated with the disease) and age were the most significant negative predictors of physical functioning. This suggests that the more illness symptoms sufferers experience, and fear exacerbating their pain, the more limited they are in performing daily independent living activities like bathing, dressing and shopping due to their physical health problems. In the pain literature there is evidence that cognitive factors especially fear of pain and fear of further damage resulting in pain and subsequent avoidance of activities are the strongest predictors of disability (Jensen, Turner, Romano, & Lawler, 1994). In line with the literature which suggests that young adults with sickle cell disease report more pain and social disability, age was a significant negative predictor of physical functioning, with young adults reporting poorer physical functioning than older sufferers.
The study supports the view of the self regulation model which posits a feedback loop between illness representations and coping strategies. However what was not supported is the view that illness representations mediate functioning via coping. In support of studies such as Moss Morris et al., (1996) and Scharloo et al., (1998) the present study concludes that illness representations had a direct effect on functioning that was not mediated by coping. Furthermore, illness representations were a better predictor of quality of life than coping strategies.

Theoretical implications
Illness representations in adults with sickle cell based on the IPQ, showed a lack of logical association between the dimensions as found in other adult studies. Given the fact that the disease is genetic in nature, only one illness attribution (stress) was found to correlate with beliefs about the consequences of the disease. Marteau and Senior (1996) argue that the extent to which a disease is unexpected and the time of diagnoses influences the extent to which people think about illness attributions. It is therefore possible that causal beliefs do not figure predominately in the perceptions of the participants because the cause of the disease is explicit- ie hereditary. What appeared to be more important were factors that triggered pain, of which stress seemed to be the most significant factor. Furthermore, no relationship was evident between the identity dimension and the timeline dimension as found in other studies (Moss-Morris et al., 1996; Weinman et al., 1996). This may be due to the fact that symptoms associated with sickle cell disease vary in duration and change over time reflecting the natural progression of the disease.

5.2. Discussion of Methodology
The response rate of 72. percent is not unusual in this type of study although the difficulty of persuading patients who were reticent about research from the outset to return questionnaires lowered the response rate. Furthermore, the sample were recruited from the haematology out
patient clinic, and as such included predominately adults who were compliant with care, and had experienced very few severe sickling crises in the last 12 months that required hospitalisation. A further limitation included the characteristics of the sample, which consisted mostly of females, and individuals with the severe form of the disease. This suggests that the results may not generalise to the greater population of sufferers. Furthermore, recruitment from in-patients would have enabled adults with current severe pain and complications to be included for comparison purposes.

The issue of reliability of the measures was a major consideration in the study. The discussion of the study’s methodology will consider the general issues of reliability, the measures used, their performance in this study, and statistical issues.

**General issues related to measurement**

Although great effort was taken to ensure that all questionnaires used in the study were standardised, none of the questionnaires had been tested for their reliability for use with sickle cell patients in the UK. As a result a difficulty arose when the control/cure dimension of the Illness Representation Questionnaire was found to have poor reliability (Chronbach Alpha.4021) and had to be excluded from the study. This was disappointing as it meant that the study was unable to report on this dimension and its relative contribution to the understanding of illness representations of adults with sickle cell disease. However, similar results were reported by Heijman and de Ridder (1998) in which the control dimension for patients with Addison Disease was excluded from the analysis due to poor reliability. It may be that given the genetic nature of sickle cell disease, which is not curable at present, and the unpredictability of pain associated with the disease, participants rely more on their medication and medical care, and believe less in their own ability to control their illness. In comparison the Coping Strategies Questionnaire and the Quality of life measure (SF36) performed well, and consistencies were found between this sample and those on which the
measures had been standardised. The coping strategies questionnaire was found to have several limitations. The first pertains to the confounding role of negative affectivity. Negative affectivity is defined as "the disposition to experience and report aversive emotional states." (Watson & Clark, 1984: cited in MacCrae & Lumley, 1998, pg. 38). Macrae & Lumley (1998) argue that several self-report measures of negative mood and emotions, such as depression and anxiety are highly inter-correlated and load together on the dimension of negative affectivity. They argue that this concern is relevant to pain coping strategies questionnaires where the Negative Thinking/Passive Adherence factor contents overlap with negative affectivity. Thus they argue that the association between negative thinking such as catastrophising and psychological maladjustment such as mental health may be explained by the influence of negative affectivity.

MacCrae & Lumley (1998) point out that because the Negative Thinking/Passive Adherence factor of the Coping Strategies Questionnaire appears to tap two different constructs. Three subscales they argue clearly assess negative thinking or negative cognitive/emotional responses to sickle cell disease pain (catastrophising, fear and anger self-statements) which may be viewed as appraisals or maladaptive outcomes, whereas the other subscales they argue reflect 'passive adherence' or physiological/medical behaviours (taking fluid, resting, massage), which appear to differ conceptually from negative thinking. MacCrae & Lumley (1998) argue that if this global factor encompasses two constructs, then the interpretation of negative thinking/passive adherence lacks specificity.

A further limitation of the study is the possibility of a conceptual overlap between certain measures. For example the strong correlations between the illness dimension 'consequence' and the quality of life subscales may indicate that both measures are assessing the same concept. Furthermore, the SF36 like many other outcome measures, fails to give an overall evaluation of
quality of life.

**Statistical Issues**

In view of the exploratory nature of the study and the large number of tests performed, it was decided to set a more stringent significance level at $\alpha<0.01$ to avoid Type I errors (i.e., saying there is a relationship when there really is none). However, adopting such a stringent level increased the probability of Type II errors. For example, significant associations detected at a less stringent level ($P<.05$) were excluded from further analysis.

In the multiple regression analysis only variables that were significantly correlated (at $P<.01$) with the quality of life subscales at univariate level were entered. Other variables that were not significant at univariate level may have become so at multivariate level. However, due to the small sample size it was not possible to run a regression analysis including all the variables. Moreover, the fact that in some of the analyses the variables did not in themselves reveal significant contributions suggests that there was either shared variance with other variables, or that factors other than those entered into the regression were more important predictors of quality of life. Furthermore, interpretations of the findings were limited and could not be generalised to the larger sickle cell population because of the small sample size, and the fact that the study did not include a control or comparison group. Given the progressive nature of sickle cell disease, the study failed to consider the differences in perceptions of younger versus older adults with the disease.

**5.3. Implications for further research**

This study represents an exploratory investigation into the illness representations of adults with sickle cell disease, and clearly methodological problems limited the interpretations of the findings. The poor reliability of the control/cure dimension would suggest that further research using qualitative methods is needed to ensure that a wide range of beliefs that participants hold regarding
this dimension are incorporated. One might also say that given the fact that the disease is genetic, complications begin soon after birth, and a cure does not exist for the disease at present, control rather than 'timeline' and 'cure' might be a more realistic and useful dimension to qualitatively investigate.

The results that emerged from the descriptive and regression analysis indicated differences in the illness perceptions of the two phenotype groups (HbSS and HbSC), and differences between genders, and that these variables in addition to age were significant predictors of some quality of life subscales. Future research would need to employ a larger sample to enable the study explore in more depth illness representations, coping strategies and perceptions of quality of life in different age groups.

The cross sectional and correlational nature of this study meant that the causal role of illness representations and coping could not be determined. For example, the impact of the disease on general and mental health could affect how sufferers construe their illness beliefs and appraise their coping responses, and also vice versa. The nature and progression of sickle cell disease is unpredictable, and a cross sectional study reduces confidence in the stability of the measures and patients' perception of illness. A longitudinal design would enable us to explore changes in illness perceptions, coping and quality of life over time. Furthermore the timeline and control dimension is perhaps biased in favour of more stable and less severe illnesses.

5.4. Implications for clinical practice

The IPQ needs to be adapted further to increase the reliability and validity of all five dimensions in order for it to become a useful tool for health professionals to use to assess and intervene in sickle cell disease and possibly other hereditary diseases.
The results of this study suggest that the illness perceptions of sufferers of sickle cell disease are very important. The consequence and illness identity dimension, especially, appear to be quite powerful in understanding how participants perceive and adjust to their illness. This would suggest a need for cognitive interventions to focus on problem solving and restructuring beliefs about the consequences of the illness. For example participants in this study perceived their disease as having a bad effect on close relationships, greatly reducing career opportunities, and prevented them from getting the best out of themselves. Interventions should include presenting simplistic models of the self regulation theory, educating patients about the association between the way they perceive their illness in particular the perceived consequences and its relationship with the coping strategies they adopt. A suggestion would also be to use a cognitive model of panic to teach patients to how to monitor and reduce their health anxiety by illustrating the association between the perception of illness symptoms (illness identity) and the adoption of unhelpful cognitive coping strategies such as catastrophic thinking and interpretations of these symptoms as reinforcers of poor quality of life evidenced by factors such as poor mental and general health. Knowing how adults with sickle cell disease construe their disease adds another level to our understanding of this wide spread, but poorly managed and misunderstood disease. It is also possible that one explanation for the short lived effects of therapy for this client group is the lack of emphasis on deconstructing and restructuring sufferers’ underlying illness perceptions. Further clinical research is needed to test this hypothesis.
References


Ware, J.E. (1990a). Measuring patient function and well being: Some lessons from the Medical Outcome Study. In K.A. Heitgoff & K.N. Lohr (Eds.). *Effectiveness and outcomes in health care: Proceedings of an invitational conference by the institute of Medicine* (pp107-119), Division of


APPENDIX 1

• LETTERS FROM RESEARCH ETHICS COMMITTEE

• LETTER TO HAEMATOLOGY CONSULTANT
Dear Ms Idusohan

EC99/106  An investigation to examine the relationship between illness representations, coping and quality of life amongst a UK population of adults with sickle cell anaemia

Ms H Idusohan, Dr N Thomas

Thank you for submitting the above application. This will be considered by the Ethics Committee on 29/06/1999 and you will be informed of the outcome shortly after that date. You will NOT be required to attend for interview.

Please note this project carries a protocol number noted above, which must be quoted in any future correspondence.

Yours sincerely

Stella Hirsch
Administrator
Research Ethics Committee
Ms H Idusohan
Haematology Department
St Thomas' Hospital

Dear Ms Idusohan

EC99/106  An investigation to examine the relationship between illness representations, coping and quality of life amongst a UK population of adults with sickle cell anaemia

Thank you for your correspondence dated 9.7.99 and for submitting a revised consent form as requested by the Research Ethics Committee. This is satisfactory and I am happy for the study to commence.

Please note that this project carries a reference number, noted above, which must be quoted in any future correspondence.

The project number and the principal investigator must be clearly stated on the consent form. If approval is given to named investigators only, these names must also be stated on the form.

In the case of research on patients, a copy of the consent form must be placed in the patient’s medical records, together with a note of the date of commencement of his/her participation in the research. A label must appear on the outside cover of the records when the patient is participating in the research.

The investigators must adhere to the published Guidelines of the Committee and provide the Chairman with annual progress reports and an end of study report. The research should start within 12 months of the date of approval.

The St Thomas' Hospital LREC is compliant with the ICH GCP requirements.

Yours sincerely

Dr G du Mont
Chairman,
Research Ethics Committee
Professor Pearson
Department of Haematology
4th Floor North Wing

Dear Professor Pearson,

Re: An Investigation to examine the relationship between illness representations, coping, and quality of life amongst a UK population of adults with sickle cell disease.

Ethics No: EC99/106.

As part of the training in clinical psychology, it is a requirement that all trainees conduct clinical research. Dr. Nicky Thomas has kindly agreed to supervise my research project (see abstract attached) which has just received ethical approval.

The study involves patients completing just three questionnaires which should take no longer than 40 minutes to administer. I will need to see at least 65 patients who will attend the Friday clinic between September 1999 - February 2000. I would be very grateful for advice on how to identify suitable participants (patients with HbSS) at the clinic.

Yours sincerely,

Helen Idusohan
Clinical psychologist in training

cc: Dr. Okpala
    Dr. N Thomas
    Tina Adepegba
    Neil Westerdale
5) PLACES WHERE THE RESEARCH WILL BE DONE

Are the patients to be admitted? NO

If so is their admission part of a routine clinical admission? N/A
If so will this research involve an extended stay in hospital? N/A
If so, how long will this extension of their stay be? N/A

6) BACKGROUND OF THE STUDY

Sickle cell disease involves unpredictable severe illness, pain, and threat of early and sudden death. Owing to the unpredictable course of the disease, it presents many psychosocial challenges to the individual. Adulthood is a critical time for these psychosocial problems to be salient (Holbrook & Phillips 1994). This in turn impacts on the way individuals' cope and live with their illness. Owing to the frequent experience of pain and hospitalisation, individuals may engage in high levels of negative thinking (Gil et al. 1989) and learn to adopt a dependent style of coping that dominates their lives in and out of hospital (Shapiro 1989). This inevitably causes severe disruption and has consequences for individuals' quality of life. Chronic illness such as sickle cell disease gives rise to a range of biopsychosocial problems the severity of which can vary from patient to patient with the same illness. Health psychologists have shown that in order to make sense of and respond to these problems, patients create their own models or representations of their illness. The most influential theoretical framework adopted in this work is the self-regulation model of Leventhal & Diefenbach (1992) which proposes that patients' illness models are based around distinct components that in turn determine coping. Thus each patient will have their own ideas about the identity of the illness, which includes the label and symptoms of the illness; the perceived cause of the illness; the time line or how long the illness will last; the consequences of the illness on the person’s life; and beliefs people have about the curability or controllability of the illness. Each of these components has been shown to have implications for patients with regard to adherence to treatment regimes (Leventhal et al., 1992), decision to seek health care (Baum et al., 1989), and the individual’s emotional responses to symptoms (Easterling & Leventhal, 1989). Morris et al. (1996) reported on the relationship between coping and illness perceptions in patients’ with chronic fatigue syndrome. They reported that illness representations explained a greater percentage of the variance in levels of disability and psychological well being than did coping strategies used by participants to manage their illness. The illness perception components of illness identity, emotional causes, controllability and consequences had the strongest overall association with adjustment, such that participants with strong illness identity, who believed their illness was out of control, caused by stress, and had serious consequences were most disabled and psychologically impaired. Disengagement coping strategies and venting emotions was associated with greater disability and poorer psychological well being, while positive reinterpretation and seeking social support were positively related to psychological well being. The results from this study suggest that illness perceptions and coping are a fruitful area of investigation in understanding a significant proportion of the variance in day to day functioning of patients’ with CFS. These variables have also been shown to influence adaptation in a similar fashion in a number of other chronic illnesses such as diabetes and rheumatoid arthritis (Weinman et al., 1996). Little is known about the illness representations of people with sickle cell disease. Given the progressive nature of the illness, it is possible that particular components; identity, controllability and consequences are strongly associated with quality of life via coping. This study therefore is concerned with how the relationship between illness cognitions and coping might influence functioning in adults with sickle cell disease.

7) AIMS OF THE STUDY

(Please include anticipated clinical use of outcomes, the potential benefit to the Patient and the potential benefit to medical science).

- The aim of the study is to provide data on the content of illness representations of a population of adults with SCD, and explore the relationship between the various illness components with coping strategies and quality of life.
- To assess the relative importance of the contribution of illness representations to the understanding of how this patient group adopt positive/negative coping strategies, and how this impacts on their quality of life.
- To consider the clinical value of understanding illness representations of patients' with sickle cell disease and how this knowledge might: i) inform future psychological interventions for this patient group e.g. interventions designed at encouraging some sense of control over their illness; ii) addressing more negative illness perceptions may be important in improving functioning and well being.
APPENDIX 2

• RESEARCH CONSENT FORM
• COPING STRATEGIES QUESTIONNAIRE
• ILLNESS REPRESENTATION QUESTIONNAIRE
• SF-36 (QUALITY OF LIFE) QUESTIONNAIRE
• BACKGROUND INFORMATION SHEET
**Title of Project:** An Investigation to examine the relationship between illness representations, coping and quality of life amongst an UK population of adults with sickle cell disease.

**Principal Investigator:** Helen Idusohan  
**Ethics Committee Code No.:** EC99/106

**Outline explanation:**

My name is Helen Idusohan and I am training to become a clinical psychologist. I am working in the hospital with patients with sickle cell and I would like to invite you to participate in a study exploring how people understand and manage their sickle cell illness, and how this affects their quality of life. I intend to use the study to look at ways of helping people who are finding it hard to cope with having sickle cell disease.

The study involves completing 3 questionnaires. This should take no longer than 30 minutes to complete. You do not have to participate in any part of this study, and whether you participate or not will not have any effect upon your treatment. At anytime you may withdraw your participation without giving a reason.

This research study is separate from the sickle cell clinic. The information you give will remain confidential to the researcher and will be stored in a locked cabinet. The information will not be shared with any doctors or nursing staff. Furthermore, all of the information collected during the study will be destroyed at the end of the study.

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I (name)  
of (address)

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

**SIGNED (Volunteer)_________________________**  
**Date_________________________**

**(Doctor)_________________________**  
**Date_________________________**

**(Witness, where appropriate)_________________________**  
**Date_________________________**

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3 copies required: one for researcher, one for patient/volunteer, one for patient's notes.
Coping Strategies Questionnaire-Revised
Sickle Cell Disease Version for Adults

Individuals who experience pain develop ways to cope or deal with their pain. These include saying to themselves when they experience pain, or engaging in different activities. Below are a list of activities that patients have reported doing when they feel pain. For each activity, I want you to indicate, on the scale below, how much you engage in that activity when you feel pain, where a 0 indicates you never do that, a 3 indicates you sometimes do that, and a 6 indicates you always do it when you are experiencing pain. Remember, you can choose any point along the scale.

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<tr>
<th>VER DO THAT</th>
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<td>I FEEL PAIN...</td>
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<td>1.</td>
<td>I try to get some sleep.</td>
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<td>2.</td>
<td>I imagine that the pain is outside of my body.</td>
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<td>3.</td>
<td>I take a hot or cold bath.</td>
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<td>4.</td>
<td>I think of things I enjoy doing.</td>
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<td>5.</td>
<td>I try to think years ahead, what everything will be like after I've gotten rid of the pain.</td>
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<td>6.</td>
<td>I read.</td>
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<td>7.</td>
<td>I avoid people.</td>
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<td>8.</td>
<td>I realize that most people don't really care.</td>
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<td>9.</td>
<td>I don't like to be with people.</td>
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<td>10.</td>
<td>I try to think of something pleasant.</td>
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<td>11.</td>
<td>I drink twice as much as I usually do.</td>
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<td>12.</td>
<td>I rub the parts of my body that hurt.</td>
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<td>13.</td>
<td>I increase my fluid intake.</td>
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<td>14.</td>
<td>I tell myself it doesn't hurt.</td>
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<td>15.</td>
<td>It is awful and I feel that it overwhelms me.</td>
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I feel pain.....

16. I try to drink some water or juice every hour.
17. I think it is not fair that I have to live this way.
18. I do something I enjoy, such as watching TV or listening to music.
19. I try to drink a lot of water.
20. I worry that I am having a heart attack or some other physical problem.
21. It is terrible and I feel it is never going to get any better.
22. I take a hot or cold shower.
23. I think no one wants to hear about my problems.
24. I go off by myself.
25. I go to bed.
26. I try to be alone.
27. I rely on my faith in God.
28. I count numbers in my head or run a song through my mind.
29. I worry that my disease is getting worse.
30. I know I need to get away from everyone.
31. I pretend it is not a part of me.
32. I massage painful areas.
33. I use ice packs to help relieve the pain.
34. I play mental games with myself to keep my mind off the pain.
35. I go to a quiet place where I won't be bothered.
36. I think of people I enjoy doing things with.
37. Although it hurts, I just keep on going.
I feel pain....

38. I think that if I can't be healthy then no one else should be.
39. I tell myself that I can overcome the pain.
40. I try to be around other people.
41. I ignore it.
42. I have faith in doctors that someday there will be a cure for my pain.
43. I think that I don't deserve this.
44. I just go on as if nothing happened.
45. I tell myself to be brave and carry on despite the pain.
46. I worry all the time whether it will end.
47. I just think of it as some other sensation, such as numbness.
48. I know others don't understand.
49. I don't pay any attention to it.
50. I drink five or more glasses of water or juice a day.
51. I worry that I am really going to get sick.
52. I relax my muscles.
53. I do anything to get my mind off the pain.
54. I am afraid I am going to die.
55. I lay down on the bed or couch in order to relax.
56. I try not to think of it as my body but rather as something separate from me.
57. I feel I can't go on.
58. I pretend it is not there.
59. I pray to God it won't last long.
60. I feel I can't stand it anymore.
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1. I feel pain....
2. I replay in my mind pleasant experiences in the past.
3. I do something active, like household chores or projects.
4. I try to feel distant from the pain, almost as if the pain was in somebody else's body.
5. I drink as much juice or water as I can.
6. I know I'll have to go to the hospital or see my doctor.
7. I spend time resting.
8. I know someday someone will be here to help me and it will go away for awhile.
9. I don't think about the pain.
10. I leave the house and do something, such as going to the movies or shopping.
11. I try to relax.
12. I am sure there is something wrong.
13. No matter how bad it gets, I know I can handle it.
14. I tell myself I can't let the pain stand in the way of what I have to do.
15. I use a heating pad.
16. I see it as a challenge and don't let it bother me.
17. I feel my life isn't worth living.
18. I pray for the pain to stop.
19. I don't think of it as pain but rather as a dull or warm feeling.
ased on all the things you do to cope or deal with your pain, on an average day, how much control do you feel you have over it? Please circle the appropriate number. Remember, you can circle any number along the scale.

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<td>Some control</td>
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<td>Complete control</td>
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ased on all the things you do to cope or deal with your pain, on an average day, how much are you able to decrease it? Please circle the appropriate number. Remember, you can circle any number along the scale.

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<td>Can't decrease</td>
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</tr>
<tr>
<td>it at all</td>
<td></td>
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</tr>
<tr>
<td>Can decrease</td>
<td></td>
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<tr>
<td>it somewhat</td>
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<tr>
<td>Can decrease</td>
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<tr>
<td>it completely</td>
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<td></td>
</tr>
</tbody>
</table>

277
## Illness Perception Questionnaire

### Your Views about Your Sickle Cell Disease

Please tick how often you experience the following symptoms as part of your illness.

<table>
<thead>
<tr>
<th>Symptom</th>
<th>All the Time</th>
<th>Frequently</th>
<th>Occasionally</th>
<th>Never</th>
</tr>
</thead>
<tbody>
<tr>
<td>Pain (e.g. chest, back, hip, etc.)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Breathlessness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weight loss</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stiff joints</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sore eyes</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Upset stomach</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sleep difficulties</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dizziness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Loss of strength</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
VIEWS ABOUT YOUR SICKLE CELL DISEASE (CONTINUED)

- We are interested in your own personal views of how you now see your illness.
- Please indicate how much you agree or disagree with the following statements about your illness.

<table>
<thead>
<tr>
<th>VIEWS ABOUT YOUR SICKLE CELL DISEASE</th>
<th>STRONGLY AGREE</th>
<th>AGREE</th>
<th>NEITHER AGREE NOR DISAGREE</th>
<th>DISAGREE</th>
<th>STRONGLY DISAGREE</th>
</tr>
</thead>
<tbody>
<tr>
<td>F1 A germ or virus caused my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F2 Diet played a major role in causing my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F3 Pollution of the environment caused my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F4 My sickle cell is hereditary; it runs in my family</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F5 It was just by chance I became ill</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F6 Stress was a major factor in causing my sickle cell disease</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F7 My sickle cell is largely due to my own behaviour</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F8 Other people played a large role in causing my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F9 My sickle cell was caused by poor medical care in the past</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F10 My state of mind played a major part in causing my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F11 My sickle cell will last a short time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F12 My sickle cell is likely to be permanent rather than temporary</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F13 My sickle cell will last a long time</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F14 My sickle cell is a serious condition</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F15 My sickle cell has had major consequences on my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F16 My sickle cell has become easier to live with</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F17 My sickle cell has not had much effect on my life</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F18 My sickle cell has strongly affected the way others see me</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F19 My sickle cell has serious economic and financial consequences</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F20 My sickle cell has strongly affected the way I see myself as a person</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F21 My sickle cell will improve in time with treatment</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F22 There is a lot which I can do to control my symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F23 There is very little that can be done to improve my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F24 My treatment will be effective in curing my sickle cell</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F25 Having sickle cell prevents me from getting the best out of myself</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F26 Having sickle cell reduces my earning opportunities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F27 Having sickle cell has a bad effect on my close relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F28 Recovery from my sickle cell is largely dependent on chance or fate</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F29 What I do can determine whether my sickle cell gets better or worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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THE SHORT FORM 36 HEALTH SURVEY
QUESTIONNAIRE (SF - 36)

The following questions ask for your views about your health, how you feel and how well you are able to do your usual activities. If you are unsure about how to answer any questions, please give the best answer you can and make any of your own comments if you like.

1. In general, would you say your health is:
   
   Excellent .............................................
   Very good ............................................
   Good ...................................................
   Fair ..................................................
   Poor ..................................................

2. Compared to one year ago, how would you rate your health, in general now?
   
   Much better now than one year ago.............
   Somewhat better now than one year ago........
   About the same .....................................
   Somewhat worse now than one year ago........
   Much worse now than one year ago............... (please tick one)
3. **HEALTH AND DAILY ACTIVITIES**

The following questions are about activities you might do during a typical day. Does your health limit you in these activities? If so, how much?

<table>
<thead>
<tr>
<th>Activity Description</th>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Vigorous activities, such as running, lifting heavy objects, participating in strenuous sports</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Moderate activities, such as moving a table, pushing vacuum cleaner, bowling or playing golf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Lifting or carrying groceries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Climbing several flights of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>e) Climbing one flight of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>f) Bending, kneeling or stooping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>g) Walking more than a mile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>h) Walking half a mile</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>i) Walking 100 yards</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>j) Bathing and dressing yourself</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Please tick one box on each line*

4. **During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?**

<table>
<thead>
<tr>
<th>Problem Description</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Cut down on the amount of time you spent on work or other activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Accomplished less than you would like</td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Were limited in the kind of work or other activities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) Had difficulty performing the work or other activities (e.g., it took extra effort)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(answer Yes or No to each question)
5. During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

   a) Cut down on the amount of time you spent on work or other activities.................................................................

   b) Accomplished less than you would like...........................................

   c) Didn't do work or other activities as carefully as usual.................................................................

   (answer Yes or No to each question)

6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

   Not at all.................................................................................................

   Slightly.................................................................................................

   Moderately.............................................................................................

   Quite a bit..............................................................................................

   Extremely.............................................................................................

7. How much bodily pain have you had during the past 4 weeks?

   None ........................................................................................................

   Very mild ................................................................................................

   Mild ........................................................................................................

   Moderate ..............................................................................................

   Severe ....................................................................................................

   Very severe
8. During the **past 4 weeks**, how much did pain interfere with your normal work (including work both outside the home and housework)?

   - Not at all
   - A little bit
   - Moderately
   - Quite a bit
   - Extremely

(please tick one)

These questions are about how you feel and how things have been with you during the **past 4 weeks**. (For each question please indicate the one answer that comes the closest to the way you have been feeling).

9. How much time during the **past 4 weeks**:

   | All of the time | Most of the time | A good bit of the time | Some of the time | A little of the time | None of the time |
--- | --- | --- | --- | --- | --- | --- |

a) Did you feel full of life?............

b) Have you been a very nervous person?............

c) Have you felt so down in the dumps that nothing could cheer you up?............

d) Have you felt calm and peaceful?
e) Did you have a lot of energy? □ □ □ □ □ □ □

f) Have you felt downhearted and low? □ □ □ □ □ □ □

h) Have you been a happy person? □ □ □ □ □ □ □

i) Did you feel tired? □ □ □ □ □ □ □

(please tick one box on each line)

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc.)?

All of the time: □ □
Most of the time: □ □
Some of the time: □ □
A little of the time: □ □
None of the time: □ □
11. How true or false is each of the following statements for you?

<table>
<thead>
<tr>
<th>Statement</th>
<th>Definitely true</th>
<th>Mostly true</th>
<th>Not sure</th>
<th>Mostly false</th>
<th>Definitely false</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) I seem to get ill more easily than other people.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) I am as healthy as anybody I know.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) I expect my health to get worse.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>d) My health is excellent.</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

(Please tick one box on each line)

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BACKGROUND INFORMATION SHEET

AGE........
SEX: MALE.....FEMALE.... please tick as appropriate

How would you describe your cultural or ethnic origin? Please tick as appropriate
i) African-Caribbean
ii) African
iii) Asian
iv) Other (please specify)......

Education: If you have any educational qualifications, please tick the highest qualification you have.

i) None.....
ii) GCSE's (O'Level)...........
iii) A' Levels..................
iv) Undergraduate Degree.........
v) Post graduate Degree...........
vii) Other (please specify)...........

Are You Employed/ Unemployed (please circle)

Marital Status:
Single..... Married........ Living with Partner......... Divorced...........

Hospital Admissions:

Have you had any hospital admissions in the past 12 months relating to your sickle cell disease?
No....Yes.....please specify how many admissions............

Sickle cell history:

How old were you when you were first diagnosed as having sickle cell disease...........

Thank you very much for taking part in this study.
APPENDIX 3

• RESULTS OF ONE SAMPLE KOLMOGOROV-SMIRNOV TEST
### Illness Representation Dimensions

<table>
<thead>
<tr>
<th></th>
<th>Identity</th>
<th>Timeline</th>
<th>Consequence</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>57</td>
<td>57</td>
<td>57</td>
</tr>
<tr>
<td><strong>Normal Parameters</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>14.947</td>
<td>11.7368</td>
<td>33.175</td>
</tr>
<tr>
<td>SD Deviation</td>
<td>6.084</td>
<td>3.2707</td>
<td>9.2765</td>
</tr>
<tr>
<td>Most Extreme</td>
<td>0.117</td>
<td>0.229</td>
<td>0.108</td>
</tr>
<tr>
<td>Differences</td>
<td>0.081</td>
<td>0.159</td>
<td>0.075</td>
</tr>
<tr>
<td>Negative</td>
<td>-0.117</td>
<td>-0.229</td>
<td>-0.108</td>
</tr>
<tr>
<td><strong>Kolmogorov-Smirniv Z</strong></td>
<td>0.887</td>
<td>1.731</td>
<td>0.812</td>
</tr>
<tr>
<td><strong>Asymp Sig (2 tailed)</strong></td>
<td>0.411</td>
<td>0.005</td>
<td>0.525</td>
</tr>
</tbody>
</table>

### Coping Strategies

<table>
<thead>
<tr>
<th></th>
<th>Ignoring pain</th>
<th>Diverting attention</th>
<th>Reinterpreting pain</th>
<th>Calming statements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>57</td>
<td>57</td>
<td>57</td>
<td>57</td>
</tr>
<tr>
<td><strong>Normal Parameters</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>11.1754</td>
<td>13.2807</td>
<td>7.5614</td>
<td>21.7368</td>
</tr>
<tr>
<td>SD Deviation</td>
<td>7.4693</td>
<td>7.7684</td>
<td>6.7189</td>
<td>6.9321</td>
</tr>
<tr>
<td>Most Extreme</td>
<td>0.072</td>
<td>0.087</td>
<td>0.158</td>
<td>0.102</td>
</tr>
<tr>
<td>Differences</td>
<td>0.072</td>
<td>0.078</td>
<td>0.158</td>
<td>0.074</td>
</tr>
<tr>
<td>Negative</td>
<td>-0.067</td>
<td>-0.087</td>
<td>-0.13</td>
<td>-0.102</td>
</tr>
<tr>
<td><strong>Kolmogorov-Smirniv Z</strong></td>
<td>0.543</td>
<td>0.66</td>
<td>1.194</td>
<td>0.77</td>
</tr>
<tr>
<td><strong>Asymp Sig (2 tailed)</strong></td>
<td>0.929</td>
<td>0.776</td>
<td>0.116</td>
<td>0.594</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Praying &amp; hoping</th>
<th>Catastrophising</th>
<th>Fear statements</th>
<th>Anger statements</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>57</td>
<td>57</td>
<td>57</td>
<td>57</td>
</tr>
<tr>
<td><strong>Normal Parameters</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean</td>
<td>22.3333</td>
<td>15.04</td>
<td>14.72</td>
<td>13.18</td>
</tr>
<tr>
<td>SD Deviation</td>
<td>7.8475</td>
<td>7.97</td>
<td>7.57</td>
<td>7.51</td>
</tr>
<tr>
<td>Most Extreme</td>
<td>0.136</td>
<td>0.124</td>
<td>0.134</td>
<td>0.108</td>
</tr>
<tr>
<td>Differences</td>
<td>0.069</td>
<td>0.057</td>
<td>0.134</td>
<td>0.093</td>
</tr>
<tr>
<td>Negative</td>
<td>-0.136</td>
<td>-0.124</td>
<td>-0.078</td>
<td>-0.108</td>
</tr>
<tr>
<td><strong>Kolmogorov-Smirniv Z</strong></td>
<td>1.027</td>
<td>0.934</td>
<td>1.014</td>
<td>0.815</td>
</tr>
<tr>
<td><strong>Asymp Sig (2 tailed)</strong></td>
<td>0.243</td>
<td>0.348</td>
<td>0.255</td>
<td>0.519</td>
</tr>
</tbody>
</table>
NPar Tests

One -Sample Kolmogorov-Smirniv Test

Coping strategies

<table>
<thead>
<tr>
<th></th>
<th>Increased activity</th>
<th>Isolation</th>
<th>Taking fluids</th>
<th>Relaxation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>N</strong></td>
<td>57</td>
<td>57</td>
<td>57</td>
<td>57</td>
</tr>
<tr>
<td>Normal Parameters</td>
<td><strong>Mean</strong></td>
<td>13.44</td>
<td>14.26</td>
<td>24.39</td>
</tr>
<tr>
<td></td>
<td><strong>SD Deviation</strong></td>
<td>6.78</td>
<td>9.87</td>
<td>8.85</td>
</tr>
<tr>
<td>Most Extreme Differences</td>
<td><strong>Absolute</strong></td>
<td>0.072</td>
<td>0.083</td>
<td>0.123</td>
</tr>
<tr>
<td></td>
<td><strong>Positive</strong></td>
<td>0.072</td>
<td>0.079</td>
<td>0.095</td>
</tr>
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SF 36: Quality of life scales

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### SF36: Quality of Life scales

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Appendix 4

• Characteristics of sample
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