The role of cognitive-behavioural therapy in the management of pain in patients with sickle cell disease

Veronica Nicky Thomas BSc PhD DipNRGN DipCouns CPSYCHOL
Senior Research Fellow, Department of Nursing Studies, Kings College London and
Chartered Health Psychologist, Department of Haematology, St Thomas’ Hospital

Jenifer Wilson-Barnett BSc MScPhD DipN RGN FRCN
Professor and Head of Nursing Studies, Department of Nursing Studies, Kings College,
London University

and Frances Goodhart MA MSc CPSYCHOL
Chartered Clinical Psychologist, formerly of ‘Input’, Pain Management Unit,
St Thomas’ Hospital, London, England

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INTRODUCTION

Like many other chronic disorders, sickle cell disease (SCD) involves impending threat of an early and sudden death, unpredictable, severe illness and pain. It is therefore not surprising that sickle cell disease presents many psychological challenges for the individual sufferer and his/her family. This in turn has consequences for the inpatient management of sickle cell disease pain. Over the past two decades, research undertaken by behavioural scientists has vastly improved our understanding of the ways in which psychosocial factors contribute to the
experience and management of pain (Rosenthal & Keefe 1983, Hurtig & White 1986, Thomas & Rose 1991, Thompson et al. 1992, Thomas et al. 1995). The cognitive-behavioural perspective has been shown to be enormously effective in a range of acute and chronic pain syndromes, its success being largely due to the fact that it takes account of the multidimensional nature of pain. The current management of pain in sickle cell disease focuses on the physical aspects of pain alone (Alleyne & Thomas 1994). In this paper we will describe the problem associated with sickle cell disease and present a rationale and some preliminary evidence based on work in progress which suggest that the utilization of the cognitive-behavioural perspective approach is suitable for the management of pain in this patient group. This paper therefore represents work in progress.

**SICKLE CELL DISEASE**

SCD is an inherited haemoglobin disorder which primarily affects the Caribbean and African population and also small numbers of people from India, the Mediterranean and the Middle East (NAHAT 1991). There are no accurate figures for the numbers of people in the United Kingdom with sickle cell disorders but the estimates range from 5000–6000 (Modell & Anionwu 1996). Recent evaluation data based on population modelling revealed that there are 9000 people with SCD in London alone (Streetly et al. 1997). This figure is expected to rise to 12 500 by the year 2011.

SCD is characterized by the production of a proliferation of haemoglobin S (HbS) which is structurally different from normal haemoglobin because of the substitution of a single amino acid in the beta chain. This changes the solubility of deoxygenated HbS and causes the red blood cell to become sickle shaped (France-Dawson 1990). The complications of SCD include acute chest syndrome, aseptic necrosis of the hips and shoulders, infections, splenic sequestration, anaemia sickle cell retinopathy, leg ulcers, priapism and cerebral vascular accidents (Serjeant 1992). SCD patients live under the threat of an early and sudden death related to the disease (Midence et al. 1993). In addition, these acute and chronic complications contribute to lifelong suffering (Gil et al. 1992).

Bone marrow transplantation (BMT) offers the only possibility of a cure. However, a decision to undertake BMT involves weighing up the risks of early mortality from an unsuccessful transplant and long-term side effects against the quality of life (Midence & Elander 1994). Vermlymyn et al. (1991) and Kirkpatrick et al. (1991) have reviewed the results of first 21 BMT cases and the results appear to be encouraging. The majority of the recipients are alive and well 3–5 years post-transplantation. In general it appears that greater medical understanding and more effective measures against complications has increased life expectancy, nevertheless, recent research conducted in the USA (Platt et al. 1994) has revealed the average age of deaths to be 42 years old for males and 48 years old for females.

Prashar et al. (1985) first drew attention to the national picture of inadequacy of care for this group and since this time there have been improvements in both the inpatient and outpatient care, screening facilities, health education information, counselling and in-service education for health care personnel. The Standing Medical Advisory Committee (SMAC) made recommendations to ensure that a more comprehensive health care policy and optimal provision of health care services are available for the growing numbers of people with SCD (SMAC 1993).

**PSYCHOSOCIAL IMPACT**

Individuals with SCD vary in their ability to cope and the majority cope very well, lead active lives and are psychosocially well adjusted. This observation has also been made by Gil et al. (1989) about the American sickle cell population. The poorly adjusted individuals are often anxious and depressed and have become overly dependent on health care services for pain management. Due to repeated hospitalizations patients may learn to adopt a dependent style of coping which dominates their lives in and out of hospital (Shapiro 1989). Furthermore Gil et al. (1989, 1992) have found that individuals who have been assessed and found to have high levels of negative thinking and use a predominantly passive style of coping, experienced more severe pain, were more distressed and were high users of hospital services than individuals with active styles of coping.

In addition to looking at the relationship between styles of coping and the ability to cope with SCD, other researchers in the USA have tried to identify psychosocial problems in an attempt to develop appropriate interventions. It appears that adolescence is a critical time for these difficulties to occur (LePontis 1975, Hurtig & White 1986, Morgan & Jackson 1986, Ell & Reardon 1990). This is not surprising because adolescence is classically known to be a challenging phase of the human developmental cycle (Erikson 1978, Coleman & Hendry 1990) requiring a great deal of adjustment.

During this time there is tremendous physical growth as well as growth in cognitive potential with the accompanying sense of mastery and omnipotence. Sexual potency is rapidly escalating and there is a preoccupation with the need to be sexually attractive and for the adolescent with SCD this may give rise to distress arising from shame about their bodies as a result of the ‘side effects’ of disease process (LePontis 1975). These include ‘yellow eyes’ (jaundice), leg ulcers and delaying of physical development, and frequent hospitalizations that interrupt the formation of key relationships and achievement capabilities.
Many male adolescents and young adults also experience priapism which poses a great threat to sexual potency, resulting in the development of anxiety and depression.

There are other reasons why psychosocial problems may develop. First SCD is life threatening, and although the use of prophylactic antibiotics has reduced the incidence of deaths in childhood, deaths in early life due to SCD-related complications are still common. For the adolescent who has seen one of his/her friends die as a result of sickle-related complications, feelings of fear and helplessness are experienced very acutely. Thirdly, Gil et al. (1989) have argued that since SCD predominantly affects individuals of African and African-Caribbean origin, the ability to cope with this disease is likely to be influenced by racial discrimination which may give rise to feelings of anger, frustration, fear, anxiety and hopelessness. According to Gil et al. (1989) someone with SCD may face discrimination both because of race and as a result of chronic illness.

Finally the most frequent and intractable problem experienced is painful crises that results from ischaemia and which requires acute admission into hospital. In central London, painful crises are the commonest reason for hospital admission and account for 90% of all emergency admissions (Davies 1994), with an average length of stay of 7 days (Yardumian 1993). Many centres in the USA and United Kingdom have found that the vast majority of admissions are attributable to a minority of the patients who are poorly adjusted and have developed negative patterns of coping (Morgan & Jackson 1986, Ell & Reardon 1990).

Individuals vary in the number of painful crises experienced but most patients experience more than one severe episode which requires hospital admission for control. This inevitably causes severe disruption to the educational and social aspects of life which, in turn, has consequences for achievement capabilities and psychosocial adjustment.

PROBLEMATIC PAIN MANAGEMENT

Whilst it is recognized that the SMAC (1993) report may influence management in the future, the current management of sickle cell pain remains fraught with problems (Davies 1994, Alleyne & Thomas 1994, Waters & Thomas 1995, Anionwu 1996). Both patients’ expectations about pain relief and staffs’ attitudes concerning the provision of that relief contribute to the inadequacy of the situation (Weisman & Schecter 1992). Anionwu (1996) suggests that poor and inadequate management results from staffs’ stereotypical beliefs that patients with SCD are drug dependent. Staff also have negative attitudes, with a tendency to view these individuals as ‘difficult’ (Anionwu 1996).

Against this background of scepticism, Alleyne & Thomas (1994) found that British patients with SCD experience profound helplessness and consequently exaggerate emotional reactions in their attempt to gain adequate analgesia. These reactions however, may appear ‘over the top’, thus confirming the staff’s preconceived view of ‘difficult problematic patients’. Pallister (1992) has acknowledged that sickle cell patients frequently experience feelings of helplessness and depression which exacerbate pain and influence the manner in which pain is expressed.

As we have seen from the above discussion, for some individuals, SCD poses specific challenges to internal resources which when stretched to the limit result in anxiety and depression, dysfunctional coping and negative thought patterns. These variables can also be seen to contribute to inadequate pain management, since it is well known that these types of emotional states and styles of coping can intensify the pain experience (Melzack & Wall 1989, Thomas et al. 1995, Tyrer et al. 1989, Gil et al. 1989, 1992).

INCORPORATING PSYCHOLOGY INTO MANAGEMENT OF PAIN IN SCD

It is now well established that the treatment of pain can be enhanced by approaches that incorporate psychological, social and behavioural components (Rosenthal & Keefe 1983) but in many British hospitals the focus is exclusively on the physical aspects of pain, ignoring the psychological and sociocultural dimensions. Although haemoglobinopathy counsellors and the newly created community nurse pain specialist, do provide some input to address the psychosocial components of pain in individual patients, it is frequently left to patients themselves to explore alternative strategies which are frequently met with disbelief and discouragement from many doctors (Davies 1994).

A growing body of research has demonstrated that cognitive factors such as appraisals, beliefs and expectations play an important role in exacerbating pain and suffering (Turk & Rudy 1992, Williams et al. 1993, Turk & Meichenbaum 1994). Research using systematic assessment of coping strategies in patients with SCD in the United States of America (USA) indicates that such strategies can be reliably assessed and are predictive of pain and adjustment (Gil et al. 1989, Thompson et al. 1992, Gil et al. 1992).

Other researchers (Thomas et al. 1984, Vichinsky et al. 1982, Burghardt-Fitzgerald 1989) have demonstrated that the use of psychological techniques to complement medical treatment already provided can be of long-term benefit. Vichinsky et al. (1982) demonstrated the benefits of a multidisciplinary approach in managing the pain associated with sickle cell disease. By providing adequate analgesic therapy and extensive counselling they were able to reduce morbidity and hospitalization. Most notable was a 58% decrease in casualty visits and a 44% decrease in admissions, for those with chronic pain. Similarly, Thomas et al. (1984) found that a variety of self-management skills involving progressive relaxation,
thermal biofeedback, self-hypnosis and cognitive strategies brought about a 50% reduction in casualty visits, hospital admissions and analgesic intake, and a reduction in accident and emergency visits and hospital admissions.

Similar research in this country is needed as a necessary first step in order to provide effective multidisciplinary pain management interventions for this population. The following discussion puts forward a rationale which suggests that the cognitive-behavioural perspective is wholly appropriate and likely to yield beneficial outcomes for patients and the standard of care which they will receive.

**COGNITIVE-BEHAVIOURAL THERAPY: A RATIONALE FOR THE MANAGEMENT OF PAIN IN SICKLE CELL DISEASE**

According to Turk & Meichenbaum (1994) the cognitive-behavioural (CB) approach in pain management developed from research on psychologically based problems such as anxiety, depression and phobias. The central features of the CB perspective include:

1. interest in the nature and modification of patients’ thoughts, feelings, beliefs and behaviours; and
2. some commitment to behaviour therapy procedures in promoting change (such as graded practice, homework assignments, relaxation and relapse prevention training) (see also Table 1).

Although cognitive behavioural therapy (CBT) may result in a reduction in the frequency and intensity of pain, pain relief is not the primary goal. Rather the aim is to help patients learn to live more effective and satisfying lives despite the presence of pain (Turk & Meichenbaum 1994). This is a particularly useful objective for the management of pain in SCD since pain is a severe and an ever present feature for which pharmacological agents are unable to offer long-lasting solutions. In addition the Report of a Working Party of the Pain Society (1996) on a Desirable Criteria for Pain Management Programmes, adds strength to this argument by suggesting that psychologically based approaches should be recommended for people whose pain remain unresolved by current available medical and other physically based treatment.

A particular strength of the CB perspective lies in its ability to take account of the multidimensional nature of pain as conceptualized by the gate control theory of pain (Melzack & Wall 1965). Both gate control theory and the CB perspective emphasize the important contribution of psychological variables such as perception of control, the meaning of the pain to the patient and dystrophic moods such as anxiety and depression. The therapist educates the patient about the complex nature of pain by attempting to alter the patients’ sensory construct of pain to one that includes cognitive, affective and psychosocial variables. In this way the patients are educated to think in terms of treatment that will provide greater personal control over their daily lives and ultimately improve their quality of life.

Since it seems that psychosocial problems develop in SCD because of a lack or loss of control, cognitive behavioural pain management interventions with the specific aim of enhancing personal control would seem to be eminently suited. The alternative coping strategies learnt can lead to empowerment and foster self-reliance, which in turn could reduce the impact that the distress has on individual sufferers and their families. In addition the use of a CB approach to manage sickle cell pain is likely to raise staff’s awareness about the psychosocial aspects of this disease and its multidimensional perspective might influence the way they think about and deal with sickle cell patients.

Another feature of the CB perspective that lends itself well to pain management in sickle cell patients is the ease with which this method can be used within community settings. A community focus for pain management offers another opportunity for patients to learn to relinquish some of their dependence on hospital services. Research has shown that these patients are ready to take a more active role. For example Waters & Thomas (1995) found that amongst hospitalized patients with sickle cell disease, the majority expressed a wish for more personal involvement in the management and control of their pain. Using visual analogue scales, these patients indicated minimal levels of perceived personal control over their own pain, which was reduced even further when hospitalization became necessary. It therefore seems to be an opportune moment to utilize pain control measures which fulfils this need.

Both the lack of psychological involvement in the daily pain management strategy and in research endeavours in this country, led us to initiate a multi-centred research project (involving four centres in London) to evaluate the

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<th>Table 1 Primary objectives of cognitive-behavioural treatment programmes (as outlined by Turk &amp; Meichenbaum 1994)</th>
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<td>To combat demoralization by assisting patients to change view of their pain and suffering from overwhelming to manageable.</td>
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<td>To teach patients that there are coping techniques and skills that can be used to help them adapt and respond to pain and the resultant problems.</td>
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<td>To assist patients to re-conceptualize their views of themselves from being passive, reactive and helpless to being active, resourceful and competent.</td>
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<td>To help patients learn the associations between thoughts, feelings and their behaviour and subsequently to identify and alter automatic, maladaptive patterns.</td>
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<td>To teach patients specific coping skills and, moreover, when and how to utilize these more adaptive responses.</td>
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<td>To bolster self-confidence and to encourage patients to attribute successful outcomes to their own efforts.</td>
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<td>To help patients anticipate problems proactively and generate solutions, thereby facilitating maintenance and generalization.</td>
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effectiveness of a community-based cognitive behavioural therapy intervention. This research is currently in progress and the following discussion is a brief summary of the pilot study which forms the basis for the current project. Clearly one cannot generalize from this preliminary work; however, it demonstrates that CBT is both feasible and acceptable to this patient group and therefore adds some potency to our claim that CBT is useful in the management of pain in SCD. It also raises some interesting issues for further exploration in the main study.

PURPOSE
Since cognitive behavioural therapy represents a completely new and unknown modality of pain control for this patient group, the main purpose of the pilot study was to determine the feasibility of implementing this method and to assess patients’ acceptability of this approach. A number of clinicians and nurses suggested that patients with SCD may have problems adjusting to the philosophy inherent in this treatment approach and consequently expressed doubts about these patients’ ability to adhere to the treatment procedure. Therefore we designed this study to assess the specific methodological issues of patient recruitment, compliance and acceptance.

PILOT STUDY METHOD
Recruitment of patients
This pilot study involved 30 patients (14 females and 16 males) with sickle cell disease whose ages ranged from 15 to 35 years and who were recruited from two hospitals in south east London. In terms of disease severity, all patients had sickle cell anaemia (HbSS genotype) and had had three or more hospital admissions for painful crises in the previous calendar year. The patients were recruited from out patient clinics, hospital wards and hospital-based sickle cell support groups. The consultant haematologists and haemoglobinopathy counsellors assisted the recruitment process by alerting the researchers to the patients who fulfilled the above criteria. Written consent was obtained from all subjects and from parents where appropriate. Immediately after patients had signed the consent agreeing to participate in the study, they were randomly assigned to one of the following treatment groups.

Group 1: CBT for the management of chronic pain
Patients allocated to this group (n = 10) attended weekly 1-hour sessions for 6 months, with a qualified cognitive therapist who taught the following: cognitive therapy and relaxation training. Chronic pain management was the focus for CBT because in addition to acute painful crises, it is now clear that patients with SCD also experience significant amounts of chronic pain as well. The CBT was tailored for SCD patients by building on the adaptive coping strategies that they normally use. The therapist taught the group using a very structured teaching approach which followed the basic CB therapy treatment structure (according to the objectives outlined in Table 1) (see Turk & Meichenbaum 1994 for a fuller discussion). Patients were given homework assignments to practise the use of the skills that they had learnt each week.

Group 2: the attention placebo group
This group is included because it is possible that being with the cognitive therapist may alone result in improvement in patient outcomes. Richter et al. (1986) has highlighted the importance of a plausible placebo control that provokes similar expectancies to the treatment group. Patients allocated to this group (n = 10) also attended weekly 1-hour sessions, for 6 months, with a qualified cognitive therapist but these sessions were patient-led. Patients allocated to this group were told that the sessions were designed to provide them with an opportunity for the discussion of the types of problems they encountered in hospital and to explore the feelings associated with these problems.

The CBT and attention placebo groups’ sessions were held in a community hall. A total of 18 sessions were held for both groups over the 6 months.

Group 3: waiting list control
Patients in this group (n = 10) received conventional medical treatment only. This group allows for the effects of intervention with no intervention to be assessed.

Psychological measures
After patients had been randomly assigned to treatment conditions and before the intervention commenced, they completed a number of questionnaires (see Table 2) in order to assess anxiety and depression, pain coping strategies and pain experience. Information concerning the number of hospital admissions and accident and emergency visits and duration of hospital stay was also collected from each patient. These assessments were repeated again at the end of the 6 months intervention. Qualitative process data concerning the acceptability of the intervention for this group of patients were obtained via a questionnaire at the end of the intervention. Utilization and effectiveness of cognitive behavioural skills on pain and mood were recorded throughout the 6 months by the CBT intervention group. Patients were interviewed (via semi-structured method) about the usefulness of the method, their views about their pain experience and their experiences of pain management in hospital 6 months after the intervention. All patients were asked to keep a self-report diary of pain, the number of times they visited accident and emergency or were admitted to hospital for painful crises, including the length of time they spent in hospital when admission became necessary.
Table 2 Psychological questionnaires used

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<td>General Health Questionnaire 30 (GHQ; Goldberg &amp; Williams 1988)</td>
<td>anxiety &amp; depression</td>
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<tr>
<td>State Anxiety Questionnaire (ANX; Spielberger et al. 1983)</td>
<td>current state of anxiety/distress</td>
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<tr>
<td>Coping Strategies Questionnaire (CSQ; Rosenthal &amp; Keefe 1983)</td>
<td>6 cognitive coping strategies: diverting attention, re-interpreting pain, coping self-statements, ignoring pain, ‘catastrophising’, praying and hoping</td>
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<td>Belief About Controlling Pain Questionnaire (BPCQ; Skevington 1990)</td>
<td>belief in personal control, powerful others and chance events of controlling pain</td>
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<tr>
<td>Self Efficacy Questionnaire (PSEQ; Nicholas 1988)</td>
<td>patients felt about functioning in daily life despite pain</td>
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<tr>
<td>Short Form McGill Questionnaire (SFMPQ; Melzack 1987)</td>
<td>pain levels on a scale, least, average and worst ratings</td>
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Brief summary of pilot results

The issue of non-compliance did not prove to be a problem because all patients adhered to the format of the sessions and followed the therapist’s instructions as far as we were able to assess this objectively. Patients were observed practising the relaxation exercises and this is important because Turner & Jensen (1993) have argued that practising in front of the therapist is essential to its effectiveness. Non-attendance did occur, mainly due to the fact that patients were hospitalized as a result of painful crises. However, the best attendance occurred within the CBT group and of the 18 sessions, one patient attended 17 sessions, six patients attended 12 sessions, one patient attended 10 sessions, one patient attended eight sessions and one patient dropped out of the study after six sessions. The poorest attendance occurred within the attention placebo group and of the 18 sessions, one patient attended 18 sessions, four patients attended 11 sessions, three patients attended four sessions, and two patients attended one session only because of hospitalization due to painful crises.

Patients were on the whole very enthusiastic, motivated and committed to the philosophy of the CB therapy. They were particularly impressed with the fact the sessions were conducted outside the hospital, because when they are well they prefer to avoid hospitals.

The research team did not encounter any difficulties with the practical aspects of the research and as a feasibility initiative, this pilot study has provided some useful insights and good foundation for the main study. In addition, patients were generally very positive about this approach and claim that they are using the strategies they have learnt to manage the pain and its associated stress on a regular basis. This is indicated in the following response from a patient:

Although it wasn’t always a convenient time for me, I feel that I have benefited from the therapy. I have only been in hospital twice since the therapy and the time in hospital has been shorter. (Patient 4AH)

Although some patients felt that they were unable to use the strategies to make any impact on the severity of pain during a painful crisis, one patient indicated that cognitive strategies are very useful in these situations. However, it seems that because the strategies were being used effectively the staff failed to treat the report of pain seriously:

Its been very valuable and I find that I am using these techniques all the time. Since last April, I have had a lot fewer crises and the recovery has been faster. I think it is the therapy that has helped me to cope better because I do use the strategies that I have learnt. In fact I think I am using them ’too well’.

(Patient 6AF)

Too well?

(Researcher)

Yeah, I am coping so well that hospital staff are not taking me seriously. Two months ago I went to casualty in a crisis, I used the techniques and was able to remain calm but it didn’t work because I had to wait 4 hours before I got any pain relief. In future when I am in crisis I don’t think I will be using the strategies.

(Patient 6AF)

This response highlights the double-bind that the clinical situation presents for some patients with SCD. If they use behavioural and verbal devices to attract attention to their pain, they are accused of being ‘over the top’, yet if they appear outwardly calm in their attempt to remain ‘in control’, this is taken as a sign that pain is not genuine. This finding also emphasizes the importance of educating nurses about individual differences in pain behaviour and of the significant role that distraction plays in coping with pain experience.

Patients who were allocated to the attention placebo group, also seem to have accrued benefits from having spent time with the cognitive therapist:

I really looked forward to those sessions, you see its the first time that I have had any positive input in the care system. It was really useful to share some of the awful problems but at the same time feeling that it was OK to do it without feeling that we are complaining yet again, I felt valued.

(Patient 3CC)

It was good to hear other people’s views. I learnt more about what some of the others went through — more shocking experiences
than I had. It was good to talk about it, once you joke about it, laugh it off, you can lose that fear, its a big relief. (Patient 2BA)

It is apparent from these responses that patients feel deprived of meaningful contact with health care professionals. The opportunity to share feelings of distress, loneliness and despair in a group with a qualified professional was both supportive and empowering.

The psychological data gained from this study do provide additional support for the assertion that CBT would be beneficial for patients with SCD. Non-parametric and parametric statistical tests were used to assess the relationships between psychological distress, coping strategies, pain experience and differences between treatment groups. In general the results revealed high levels of anxiety and depression, low levels of pain self-efficacy and an increase in the use of negative coping strategies among all patients. Correlational tests also revealed a positive relationship between anxiety, depression, pain and length of hospital stay. This suggests that patients who had high levels of anxiety and depression also experienced greater pain and a longer duration in hospital stay. Levels of psychological morbidity were high enough to warrant psychological intervention. For example, the average GHQ score was 11, much higher than the recommended cut-off threshold (3–4) for psychiatric disorder (Goldberg & Williams 1989). Although there were no significant differences found between the groups in terms of pre- and post-intervention psychological outcome measures, there is a most encouraging observation of a trend in the reduction of anxiety and depression after CBT intervention. Preliminary analyses have also provided some evidence for believing that cognitive therapy can help to speed the recovery process. Analysis of variance revealed that there is a significant difference between the groups in terms of post-intervention duration of stay (%5.2<0.001; post-hoc Scheffe test revealed that the longest period of hospital stay occurred within the waiting list control group at 6 months follow-up.

CONCLUSION

In this paper we have put forward a case for utilizing cognitive behavioural therapy in the management of sickle cell pain. The CB perspective aims to empower patients to become active participants in management of their pain and to reduce physical and psychological distress associated with their pain. Both the evidence from American studies and preliminary British evidence suggests that CBT is valuable in the management of SCD-related pain. Furthermore preliminary evidence from our pilot data suggests that the amount of psychological distress experienced by British sickle cell patients is quite profound. It is our contention that the purely physical approach employed to manage pain in a climate of such distress is bound to be deficient. It is well established that anxiety (Thomas et al. 1995) and depression (Tyrer et al. 1989) can intensify pain and only a pain management programme that takes account of such distress is likely to rectify the problems that currently exist in the management of pain in sickle cell disease. Cognitive behaviour therapy may provide the solution and whilst we recognize that CBT has cost implications (e.g. the costs of CBT therapist), the amount of benefit to be gained by individual patients and families could outweigh the costs. Moreover, there is potential saving for NHS trusts. If the preliminary finding of a reduction in the duration of hospital stay is substantiated by the work in progress then the saving for health authorities could be significant.

Acknowledgement

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References


