The Effect of Psychosocial Adjustment on Pain and Compliance in Juvenile Chronic Arthritis

and

Research Portfolio

Submitted in Partial Fulfilment of the

Degree of Doctor of Clinical Psychology

within the Faculty of Medicine, University of Glasgow.

John J Marshall

September 1996

Acknowledgements

My thanks go out to staff at the Department of Psychological Medicine. I also thank Ms Sita Picton, Professor David Cooke, Ms Florrie Gullion and Dr Mary Ray in providing much valued advice and guidance for several parts of this portfolio.

Lastly, a big shout for Karen and the 3rd year psychology posse of 96 for their hugely appreciated encouragement, support and great nights out.

Contents

Appendices

Chapter One

LITERATURE REVIEW

Psychological Aspects of Juvenile Chronic Arthritis

Target Journal: Journal of Paediatric Psychology (See Appendix 1.1)

INTRODUCTION

Despite misguided hopes the public and media have of advances in the field of Paediatric Medicine they are unfortunately not likely to witness cures for many childhood chronic diseases into the next century. Children with chronic diseases therefore face a life-time of appointments at hospital, various diagnostic procedures and sometimes painful management interventions. The characteristics of chronic diseases present with a number of unique challenges to children, their families and the services involved in their care. It has, for example, been estimated that 10-15% of children under the age of 16 years are affected to some degree by a chronic long term condition (Weiland, Pless and Roughmann, 1992). Consequently these problems are faced by large proportions of the population.

Families of children with a chronic disease have to reorganise their lives when their child becomes suddenly ill. The restrictions placed upon a child's life greatly impinge upon quality of life indices. These may be a direct consequence of the disease where children feel tired or ill so that there are less likely to attend school or enjoy activities outwith school. In addition to social restrictions, there may be more indirect restrictions due to parental anxieties and lack of knowledge. A more extreme example of this were parents of boys with haemophilia who limited their children's experience of dangerous objects such as knives and scissors. When the children did have to use these implements they were more likely to injure themselves (Markova, Mcdonald and Forbes, 1980). It is clear that stability and predictability of a disease are important aspects in determining family coping and adjustment (Eiser, 1993).

Chronic diseases also vary in their threat to life. Advances in medicine have led to improvements in life expectancy among such diseases as cancer and asthma. Diseases such as Juvenile Chronic Arthritis (JCA), where there is minimal public awareness, mortality may actually rise to 14% after 15 years of disease in systemic onset. The common causes of death for this JCA sub-group are infection, myocarditis and renal failure (Leak, 1991).

Chronic Diseases also vary in their complexity and in the demands of treatment regimes. This can range from children taking medication only when an asthmatic attack feels imminent. In contrast children with Juvenile Chronic Arthritis (JCA) can face complex treatment regimes consisting of steroidal and non-steroidal anti inflammatory drugs, intense physiotherapy and splinting. Treatments of diseases such as cancer differ in that they may be aggressive and painful but are largely carried out in hospital, taking away much responsibility from children (Eiser, 1993). In the case of JCA there is considerable scope for increasing individual responsibility of children in adhering to management interventions.

The course of a chronic disease should also be considered against notions of child development. This creates difficulties for researchers where assessments are made against a background of change and non-predictability. These challenges are faced by researchers in the field of Juvenile Chronic Arthritis (JCA). A disease which is itself characterised by great unpredictability, concomitant physical and social restrictions.

The role of clinical psychology in dealing with these multifaceted problems has been to increase children's quality of life in relation to disease by health promotion. There have also been developments in health education, prevention of emotional difficulties and minimising the impact of disease on child development (Eiser, 1993). These improvements have taken pace at different speeds among a range of diseases such as asthma, diabetes and cancers, however, due to the uncertainties of children's adjustment to JCA psychological interventions for Juvenile Chronic Arthritis have lagged behind these more prominent diseases (Ross et al, 1993).

How Can a Child be Arthritic ?

Incidence and Prevalence

In a review of UK incidence and prevalence data an annual incidence of new cases was found to be 0.12 to 0.19 per 1000. Point prevalence estimates of up to 1.13 per 1000 have also been identified (Benjamin, 1990). The British Paediatric Rheumatology Group Data Base suggest that JCA is responsible for 30% to 50% of new cases referred to a specialist paediatric Rheumatology clinic over a one year period. JCA is therefore a comparatively rare disease in relation to common childhood disease such as diabetes or asthma, but, JCA is the most common of the connective tissue disorders.

Diagnosis and Classification

Historically known as Still's Disease, Juvenile Chronic Arthritis is a disorder of connective tissue in children's joints. It is characterised by swelling, heat and musculoskeletal pain. Classification depends on the presence of at least two symptoms from pain, swelling and limitation, in at least one joint for 3 months in a child under 16 years of age.

Three main sub-types of JCA exist. Pauciarticular JCA effects 4 joints or less and is the most common onset type. Polyarticular refers to 5 effected joints or more. The Systemic Onset classification is an acute phase of onset with symptoms of fever and the classic Still's rash.

Various complications are associated with JCA for example blindness resulting from chronic uveitis and other occular difficulties. Gastrointestinal and respiratory tract infections as well as arthritic psoriasis are also commonly found. Symptoms of JCA include failure to play using hands, limping or a reluctance to walk and stiffness. The signs of JCA such as soft tissue swelling, pain and tenderness of joints are usually associated with these limitations of movement.

Aetiology

Great uncertainty exists about the causes of JCA, however, theoretical mechanisms have been postulated which may involve genetic predisposition's and viral insults. These may result in abnormal immune responses which actually attack connective tissue. Immunological markers can be found among some children with JCA, for example Anti Nuclear Antibodies (ANA) in 30% of cases (Leak et al, 1991). Aetiological uncertainties do not yet allow for treatment interventions into the disease, however a great deal of research focuses on increasing the efficacy of symptom management.

Management of the Disease

Pharmacological management of JCA involves non-steroidal anti-inflammatory drugs such as aspirin, anti-rheumatic drugs and corticosteroids. Careful monitoring of drugs of this nature are required when side effect profiles are considered. These vary from gastrointestinal disturbances and ulceration to growth retardation.

Non pharmacological management primarily involves exercise programmes where children can be taught specific techniques with the aim of reducing muscle atrophy. Night splints and Working Splints are also commonly employed to help prevent physical deformities. JCA is unpredictable and can remit and recur. It requires adherence to complex management procedures to avert pain experiences, joint contortion and deformities as well as muscle wastage.

The fact that JCA is not treatable has important questions about the nature of psychological adjustment difficulties, however, among modern standard medical texts which cover non pharmacological management of JCA no mention is made of psychological interventions.

Psychological Adjustment Among Children with JCA

In spite of their sometimes chronic disabling and painful condition many children with juvenile chronic arthritis, who mostly attend mainstream schools, are expected to develop normally in terms of their academic and social experiences. Children with JCA face real practical mobility problems which stretch coping resources. This in turn correlates with levels of general psychosocial functioning (Stoff et al, 1987).

Practical difficulties have been identified in a needs assessment of 64 school aged children diagnosed with JCA. Of this group 34 had difficulties climbing stairs, waiting in line, handwriting, taking part in physical education and poor attendance (Stoff et al, 1987). These researchers also identified poor levels of understanding among teachers and school peers of the problems faced by children with JCA. Although there is general agreement about the practical limitations found among children with JCA there is less consistency in studying levels of psychosocial adjustment and the relationship between disease severity and adjustment. Relationships have varied between positive to negative to no association (McCarney et al, 1974, Litt et al, 1982 and Miller et al, 1982).

In one of the largest samples of children with JCA (n=363), Ungerer et al (1988) found that regardless of the severity of their illness, JCA children were no different to normal children in their view of themselves. By way of contrast, Billings et al (1987) compared the functioning of 43 children with severe JCA, 52 with mild JCA to 93 healthy matched controls. These researchers found that severity of disease was associated with depressive and anxious problems. In addition, children with mild JCA participated in fewer peer activities.

Different conclusions reached by these authors may have reflected the use of less reliable and valid measures of childhood adjustment of chronic disease (Wallander 1988). These researchers employed the Child Behaviour Checklist CBCL (Achenbach and Edelbrock, 1983, 1992), which is a broad measure of emotional and behavioural problems in children. Wallander (1988) indicated that the JCA group did not have psychological difficulties in contrast to other conditions such as juvenile diabetes. Out of a total of 270 children assessed only 9 were diagnosed with some form of JCA.

When similar assessment procedures were applied to a larger group of JCA patients (n=106), Vandvik (1990) concluded that mild to moderate affective and/or anxiety disorders were common among children with JCA. Unfortunately, included in this study were children with unconfirmed diagnosis of JCA. This puts into doubt how these findings can be generalised to a JCA population. Unanswered questions about the actual extent and nature of adjustment problems for children with a definitive JCA diagnosis remain.

Parental Adjustment to JCA

Few studies have concerned themselves with parental adjustment in JCA (Jarwouski, 1993), however, affective difficulties as measured by the Profile of Mood States were associated with JCA children's behavioural problems (Daltroy et al, 1992).

In the first longitudinal study into risk and resistance factors implicated in childhood psychosocial functioning it was concluded that clinicians should focus more on parental adjustment as a means of reducing behavioural disturbance in JCA patients (Timko et al 1993). The follow up of 172 JCA patients across four years allowed researchers to identify a number of predictors of poor psychosocial adjustment in terms of JCA behavioural problems. Mothers risk factors such as depressive problems and resistance factors; the presence of social supports and confidants were important predictors of patient outcome at one year. The researchers speculated that the aetiological mechanism for JCA maladjustment related to depressed parents engaging in more negative, hostile parenting. In contrast, mothers and fathers who were more socially active had children who were more socially competent at 4 year follow up (Timko et al, 1993). Confirmation is required as to the extent of parental adjustment to JCA in addition to whether parental distress is associated with negative parental interactions with JCA children.

Juvenile Chronic Arthritis: The Painful Challenge

In contrast with a medical tradition which relatively recently recognised the complexity of pain among children, current theoretical approaches to pain now employ socio-ecological models. These models recognise the importance of social, affective and cognitive factors in parsimoniously explaining the subjective experiences of pain (Melzack and Wall, 1983).

In the case of childhood chronic disease this model implies that disease characteristics alone cannot explain the frequency, intensity and duration of a child's pain. It also leads to the notion that psychological factors are implicated in pain perception and, crucially, are amenable to psychological interventions to decrease pain. Non pharmacological pain management of children has been grossly neglected (Ross, 1993). This fact is important because chronic pain is associated with functional outcomes such as quality of life (Eiser, 1993). In the case of Juvenile Chronic Arthritis, disease severity has not sufficiently explained reported levels of pain among JCA patients. Two earlier studies found no relationship between pain and disease severity (Scott et al, 1977, Beale et al, 1983).

Two groups of more recent researchers assessed the associations between disease activity, such as inflammation, morning stiffness and pain perception (Thompson et al, 1987, Ross et al, 1989). In contrast to the Thompson et al 1987, the second group found no association between disease activity and pain reports on visual analogue scale (VAS) ratings. Differences in these findings may be attributable to psychological effects mediating pain perception (Ross, 1993). Disease variables have, for example been found to only predict one quarter of the variance of reported pain (Ross, 1993). Psychological variables have been found to account for over one half of the variability of children's pain ratings (Ross et al, 1993).

Thompson et al 1987 examined more carefully the contribution of childhood adjustment on reported pain. No conclusive findings were made about the relationship between adjustment and pain. By way of contrast, Ross et al 1993, concluded that greater childhood emotional distress was related to higher reported pain. Salient aspects of childhood distress implicated in pain perception were child's anxiety and depression.

The differences between the two studies may reflect approaches to measuring pain. The study by Thompson et al 1987 employed a visual analogue scale at one point in time, whereas the severity of JCA can vary in terms of inflammation and stiffness on a daily basis (Leak et al, 1991). The uncertainties of relationship between psychological adjustment and pain focused upon by these two researchers require further clarification. More definitive conclusions about correlates of pain may suggest a real need for routine psychological interventions to ameliorate pain among this group.

The Scope for Increasing Treatment Compliance

Medical non-compliance, or "the extent to which a persons behaviour coincides with medical advice" (Haynes et al ,1979), has been estimated to range from 20-80 percent in paediatric settings (Eiser ,1993). Non-adherence has been shown to relate to the length and complexity of treatment (Haynes et al, 1979); experience of side-effects (Smith et al, 1979); difficulty experienced in managing side-effects and when child development is being compromised (Freidman and Litt ,1986). Conditions that are not highly visible in terms of the threat to life to those afflicted or among the public in general, such as diabetes can lead to minimisation of the disease among children and parents (Eiser 1993). Treatment of more serious chronic diseases such as cancer can, surprisingly, be dogged by poor compliance levels (Tebbi et al, 1986), however, compliance studies have tended to concentrate on diabetes and cancer and have severely neglected JCA (Eiser, 1993).

The issue of compliance is important due to the increased physical and psychological dangers of reduced adherence to management regimes. In a JCA drug outcome study dissimilarity in the efficacy of two drugs reflected different levels of compliance and not the therapeutic value of each drug (Fernstein,1979). Increased inflammation and pain result from reduced adherence to pharmacological and exercise programmes. This would result on limitations to mobility and would have severe ramifications for social activities and development. Reduced compliance to joint splinting in JCA increases the likelihood of severe deformation occurring (Leak et al, 1991). This in turn would effect a child's self concept and emotional development leaving them at great risk of future adjustment problems.

Research which considers compliance in JCA have been single case in nature (Rapoff et al 1984) and have, for example, considered specific salicylate treatments by measuring blood serum among small numbers of JCA patients (Litt and Cuskey, 1981). In a study of JCA family functioning and compliance (n=25) Chaney and Paterson (1989) found that medication compliance was high (96%), nevertheless, increased family stress was associated with decreased compliance. Crucial issues related to exercise and splinting compliance were completely ignored in this study. In addition, compliance was clumsily measured by asking parents and children to estimate the number of doses they had taken over the previous week. This retrospective information about compliance was combined with 3 week diary returns.

One study which considered medication and exercise compliance found 95% and 67.2% self-report levels of compliance, respectively (Hayford and Ross, 1990). The researchers commented on the worryingly low levels of compliance with exercise. No data was available as to potential correlates of reduced compliance to medication or exercise. Splinting, an important ingredient in non-pharmacological management to prevent deformities was again ignored. Information was based on diary returns only. It remains to be determined what childhood adjustment factors relate to the complete range of pharmacological and nonpharmacological compliance issues in JCA.

Summary

A survey of the limited literature on JCA indicates the need to address a number of adjustment, pain and compliance issues. Firstly, differing methodological approaches to measuring childhood adjustment and the inclusion of non JCA children in studies leave open the question of whether JCA children represent a distinct group in terms of emotional and behavioural adjustment. Confirmation is also required as to levels of parental adjustment and whether or not parents report negative interactions with JCA children. Secondly, great uncertainty remains about the relative contribution psychological adjustment has for reported pain due to contradictory evidence. Finally, the effects of psychological adjustment on compliance to the whole range pharmacological and nonpharmacological management approaches has yet to be properly considered.

References

Beales, G, Keen, J.H and Lennox Holt, P.J (1983) the Child's Perception of the Disease and The Experience of Pain in Juvenile Chronic Arthritis. *Journal of Rheumatology*, 10, 61-65.

Benjamin C.M Review of UK Data on the Rheumatic Diseases - Juvenile Chronic Arthritis. *British Journal of Rheumatology* 29: 231-233.

Billings A.G, Moos R.H, Miller J.J and Gottlieb J.E (1987) Psychosocial Adaption in Juvenile Rheumatic Disease: A Controlled Evaluation. *Health Psychology*: 6, 343-359.

Daltroy, L.H, Larson, M.G, Eaton H.M et al (1992) Psychosocial Adjustment in Juvenile Arthritis. *Journal of Paediatric Psychology* 17, 277-289.

Eiser,C (1993) *Growing up with a Chronic Disease,The Impact on Children and Their Families*. Jessica Kingsley Publications, London.

Hayford, J.R and Ross C.K (1990) Medical Compliance in Juvenile Rheumatoid Arthritis. *Arthritis Care and Research*, 1, 4, p190-97.

Haynes, R.B., Taylor,D.W. and Sacket,D.L (1979) (eds) *Compliance in Healthcare*, Baltimore and London: John Hopkins University Press.

Jaworski, T.M (1993) Juvenile Rheumatoid Arthritis: Pain Related and Psychosocial Aspects and their Relevance for Assessment and Treatment. *Arthritis Care and Research*, 6, No4 December 187-196.

Leak, A.M (1991) Topical Reviews: Juvenile Chronic Arthritis. *Rheumatism Council For Research.*

Litt, I.F, Cuskey W.R (1981) Compliance with Salicylate Therapy in Adolescents with Juvenile Rheumatoid Arthritis. *American Journal of Disability Child Research*, 135: 434-436.

Litt, I.F, Cuskey W.R, Rosenberg A (1982) Role of Self-Esteem and Autonomy in determining medications Compliance among Adolescents with Juvenile Rheumatoid Arthritis. *Paediatrics*, 69, 15-17.

McAnarney E.R, Pless I.B, Satterwhite, B (1974) Psychological Problems with Children with Juvenile Arthritis. *Paediatrics*, 73, 169-174.

Markova,I, Mcdonald,K and Forbes,C (1980) Integration of Haemophelic Boys into Normal Schools, *Child Care Health and Development*, 6, 101-109.

Melzack, R and Wall, P.D (1983) *The Challenge of Pain*, New York, Basic Books.

Miller, J, Spitz, P and Simpson, U (1982) The Social Functioning of Adults who had Arthritis in *Childhood. Journal of Paediatrics*, 100; 378.

Rapoff, M.A, Lindsey C.B, Christopherson, E.R.(1985) Parent Perceptions of Perceptions of Problems Experienced by their Children in Complying with Treatments for Juvenile Rheumatoid Arthritis. *Archives of Physical Medicine Rehabilitation*. 66, 267-269.

Ross, C.K; Lavine,J.V; Hayford-Dyer, A and Pachman, (1989) Validity of Reported Pain as a Measure of Clinical State in Chronic Juvenile Arthritis. *Anals of Rheumatic Disease*,48, 817-819.

Ross, C.K; Lavine,J.V; Sinacore, J.M and Pachman, L.M (1993) Psychological Factors Affecting Reported Pain in Juvenile Rheumatoid Arthritis. *Journal of Paediatric Psychology*, 18, 5, 561-573.

Scott, P.J; Ansell, B.M and Huskisson E.C (1977) Measurement of Pain in Juvenile Chronic Polyarthritis. *Annals of Rheumatic Disease*, 36. 186-187.

Stoff.E, Molock SD, White PH (1987) A Needs Assessment of Children with Rheumatic Diseases, *Journal of School Health* 57, 162-4.

Thompson, K.L., Varni, J.W., & Hanson, V. (1987) Comprehensive Assessment of Pain in Juvenile Chronic Arthritis, *Journal of Paediatric Psychology*, 12, 2, 241-255.

Vandvik .I H (1990) Mental Health and Psychosocial Functioning in Children with Recent onset of Rheumatic Disease. *Journal of Child Psychology and Psychiatry* 31: 961-971.

Wallander,J.L., Varni, J.W., Babani, L., Banis, H.T., & Wilcox, K.T (1988) *Family Resources as Resistance Factors for Psychological Maladjustment of Chronically Ill and Handicapped Children,* Manuscript Submitted for Publication, Sparks Centre, University of Alabama at Birmingham.

Weiland, Pless and Roghmann (1992) Chronic Illness and Mental Health Problems in Paediatric Practise: Results from a survey of Primary Care Providers. *Paediatrics*, 89, 445-449.

Major Research Proposal

Applicants

John J Marshall, Department of Psychological Medicine, Garnavel Royal Hospital, Glasgow.

Dr Goel, Consultant Paediatric Rheumatologist, Royal Hospital for Sick Children, Yorkhill.

Dr Mary Ray, Senior Registrar, Royal Hospital for Sick Children, Glagow.

Title

Psychosocial Factors Effecting Reported Pain and Medical Compliance in Juvenile Chronic Arthritis.

Summary

The main aim of this study is to identify the effects adjustment problems of children and their parents with Juvenile Chronic Arthritis (JCA) have on compliance and pain perception. The study will take place at an arthritis clinic in the Royal Hospital for Sick Children, Yorkhill. Areas of specific interest are parental stress as well as childhood emotional and behavioural difficulties.

This study will involve parents of children diagnosed with some form of juvenile chronic arthritis completing a number of questionnaires, as well as parent/child ratings of pain and compliance. Information about diagnosis was taken from case files or provided by clinicians.

Compared to other disorders , for example asthma or diabetes, the risk and resistance factors which contribute to psychological adjustment of children with JCA is only being investigated in more recent times. Psychosocial risk factors such as the presence of emotional and behavioural disorders in children has been linked to increased pain experience (Ross et al 1993).

Crucial to clinical management of this disease is adherence to medication, exercise and in some case the wearing of splints (Chaney and Peterson 1989). It would be useful to identify whether psychosocial factors interfere with adherence and the scope for clinical psychological intervention to improve compliance.

Introduction

Inflammatory arthropathy in children , or JCA is a disorder of the connective tissues in children' joints. It is characterised by swelling, heat and/or musculoskeletal pain. There are three specific subtypes of the disorder relating to onset and the number of joints involved. Systemic onset refers to sudden onset with the presence of rash, fever, Pauciarticular to four or fewer joints and Polyarticular to 5 or more joints.

Given the consequences of prolonged joint inflammation and pain in reducing mobility, as well as the potential for joint deformities in some children, the role of analgesics, anti inflammatory drugs, exercise and the wearing of splints in managing the disease becomes all important.

There is great uncertainty ~~between~~ about the relationship between childhood psychosocial adjustment and levels of pain experienced (Thompson et al 1987). However, it is the rationale of social-ecological models of pain that psychological variables come to the fore in providing explanations for severity of pain experienced.

The area of pain assessment is limited by methodological problems, for example few patients, measures at one point in time and a lack of children with definitive JCA diagnoses. In addition no study to date has considered the implication of parental adjustment and child pain experience.

As far as compliance issues are concerned it has been highlighted that older children comply with medication and exercise more readily than younger (Hayford and Ross 1989). There is, however, no information on the potential effect child and adult adjustment variables have with compliance to medication, exercise and the wearing of splints.

This study assesses the effect psychological variables have on these important management issues, improving on scant information and some aspects of previous methodologies. This may increase the impetus for clinical psychological involvement with this group with the aim of improving the child's quality of life.

Aims and Hypothesis

(1) To determine whether increased emotional/behavioural disorders in JCA and parenting stress is associated with increased pain reporting.

(2) To determine whether increased emotional/behavioural disorders in JCA and parenting stress is associated with decreased compliance.

Plan of Investigation

Subjects

60 children and their parents/ guardians will be approached at a clinic for JCA. Subjects included in the study are those with a definitive JCA diagnosis from ages 4-16 years. Those with uncertain diagnosis of JCA and other non-arthritic connective tissue disorders will be excluded.

Measures

Assessment of emotional and behavioural disorders

(1) Child Behaviour Checklist, Parent completed, (Achenbach and Edelbrock 1991).

Assessment of Parenting Stress

(1) Parenting Stress Index (Abidin 1990).

Assessment of Compliance

(1) Medical Compliance Questionnaire.

(2) Medical Compliance Diary.

Assessment of Reported Pain

(1) Visual Analogue Pain Measure.

(2) Visual Analogue Pain Diary.

Design and Procedure

Two stages of data collection would be required. Each child and parent/guardian would be contacted at the arthritis clinic and/or physiotherapy. They would receive a letter explaining the study and a verbal explanation would be offered (see appendix 2.1). In addition, an informed consent form would be given to indicate whether they and their child wished to participate.

The first stage involves parents completing the Child Behaviour Checklist and Parenting Stress Index. Children and parents will complete compliance questionnaires and report pain experienced. The second stage would involve giving parents and/or older children and adolescents one week pain and medical compliance diaries, with a stamped addressed envelope.

All questionnaires would be completed at the arthritis clinic or physiotherapy. From an initial pilot of 10 subjects it was found that a maximum of 45 minutes would be required to complete the first stage of data collection. In addition, it was found that the Child Behaviour Checklist had to be used in its interview format due to parental anxiety about completing questionnaires and difficulties with reading. Demographic information, such as fathers occupation will be gathered in order to take account of socio-economic status.

Data Analysis

Three JCA diagnostic categories can vary greatly in severity within each type. It is unlikely that differences between the dependant variables will reflect diagnostic sub-groups, but, it will be useful to confirm this by tests of group differences.

The hypothesis relating to potential links between the independent psychological variables and dependant compliance and pain variables are associations. Data analysis would primarily consist of correlation's between these continuous variables. Data will be stored on computer files, but, no personally identifying information will be stored.

Practical Application

In assessing the effect psychosocial adjustment on compliance and pain experience the potential scope for clinical psychological interventions may become clearer. An underlying service aim of providing evidence for the potential need for clinical psychological interventions with this group may ultimately lead to improvements in quality of life.

Time Scale

From 29/06/95 there were be prototypal implementation of the project to determine difficulties which may occur in the data gathering process, for example understanding of questionnaires and likely diary response rate. Following this data will be gathered at weekly clinics and physiotherapy sessions for up to 5 months.

Ethical Approval

Ethical Approval has been granted by Yorkhill Sick Children's Hospital Ethics Committee on 09/06/95.

References

Abidin, R.R., (1990) The Parenting Stress Index, University of Virginia.

Achenbach, T.M., & Edelbrock, C.S., (1991) ***Manual for the Child Behaviour Checkilist (Ages 4-16),*** University of Vermont.

Chaney, J.M & Peterson, L., (1989) Family Variables and Disease Management in Juvenile Rheumatoid Arthritis, ***Journal of Paediatric Psychology***, 14, 389-403.

Hayford, J.R and Ross, C.K., (1989) Medical Compliance in Juvenile Rheumatoid Arthritis: Problems and Perspectives, ***Arthritis Care and Research***, 1, 4, 190-197.

Ross, C.K; Lavine,J.V; Sinacore, J.M and Pachman, L.M (1993) Psychological Factors Affecting Reported Pain in Juvenile Rheumatoid Arthritis. ***Journal of Paediatric Psychology***, 18, 5, 561-573.

Thompson, K.L., Varni, J.W., & Hanson, V. (1987) Comprehensive Assessment of Pain in Juvenile Chronic Arthritis, ***Journal of Paediatric Psychology***, 12, 2, 241-255.

Chapter Three

MAJOR RESEARCH PROJECT PAPER

The Effect of Psychosocial Adjustment on Pain and Compliance in Juvenile Chronic Arthritis

Target Journal: Journal of Paediatric Psychology (see appendix 3.1)

Address for Correspondance

John J Marshall BA(Hons) Msc

Dept. of Psychological Medicine

Gartnavel Royal Hospital

Glasgow.

Abstract

This paper examines the relationship between the psychosocial adjustment of children with Juvenile Chronic Arthritis (JCA), parenting stress, and, child/parent reported pain and compliance . Whilst statistically controlling for somatic complaints increased child hood adjustment difficulties was found to be significantly asociated with increased pain. Parenting stress was also associated with increased pain. Children with JCA comply poorly to exercise and splinting treatments. Decreased compliance with exercise and splinting treatments were significantly associated to increased parenting stress and childhood adjustment problems respectively. The findings clearly imply that more attention should be paid to nonpharmacological management of pain as well as psychological interventions to increase compliance.

Key words: **Psychosocial Adjustment, Reported Pain, Compliance, Juvenile Chronic Arthritis.**

Introduction

In tandem with reduced public awareness of Juvenile Chronic Arthritis (JCA) there is relatively little psychological research which considers this childhood disease. Psychological research has begun to consider psychosocial adjustment, compliance to complex treatments and pain perception. These three aspects of JCA are important as they may be amenable to psychological interventions thereby increasing quality of life.

Early research focused on the practical difficulties faced by Children with JCA such climbing stairs, hand writing, taking part in physical education and poor school attendance (Stoff et al 1987). Although there is general agreement about the practical restrictions placed upon a child with JCA there has been less consistency in studying levels of psychosocial adjustment.

One group of researchers who have considered psychosocial adjustment using standardised and broad measures of emotional and behavioural disturbance have found that the JCA group did not have increased psychological problems compared to a standardised norm group or other diseases such as diabetes (Wallander et al 1988). In contrast Vandvik (1990) concluded that mild to moderate affective and anxiety disorders were common among children with JCA. These studies have insufficient numbers of children with JCA and include those with unconfirmed diagnosis of JCA.

Few studies have concerned themselves with parent . adjustment in JCA (Jaworski 1993), but affective states as measured by the profile of mood states has been associated with JCA's child behaviour problems. Other studies which are concerned with the links between parent adjustment and JCA child's adjustment indicate the following poor predictors of JCA adjustment: mother's depressive problems; reduced resistance factors such as social supports and confidants (Timko et al 1993). These researchers speculated that the important etiological mechanism in JCA adjustment was dysfunctional child-parent interaction.

Studies which concentrate on the relationship between psychosocial adjustment and pain perception have traditionally been limited by pain estimates at one point in time only. JCA is a disease which has shown considerable variability in the extent of pain experienced (Beales et al 1983, Ross et al 1993).

Whilst it is agreed that from the theoretical standpoint of socio-ecological models of pain psychological factors have a role to play in pain perception, two groups of researchers have reached different conclusions whilst focusing on associations between measures of childhood psychosocial adjustment and pain (Thomson et al 1987, Ross et al 1993). Thompson et al (1987) used an estimate at one point in time for pain and found no relationship between psychosocial adjustment and pain. The second group used pain diaries and found that increased emotional problems were associated with increased pain (Ross et al 1993). There were a number of children in the latter study who had different forms of arthritis from the JCA types. Use of pain estimates at one point in time and prospective pain diaries may lead to more definitive conclusions about the psychosocial correlates of pain.

The third important area for JCA research concerns treatment compliance "or the extent to which a person's behaviour coincides with medical advice" (Haynes et al 1979). Much of the research on treatment compliance and JCA has used single case methodology (Rapoff et al 1984).

In a study of JCA family functioning and compliance, Chaney and Patterson (1989) found that although medication compliance was high, increased family stress was associated with reduced compliance with medication. Compliance was measured by asking parents and children to estimate the number of doses they had taken for the previous week as well as three week prospective diaries. The study ignored compliance to exercise and splinting, which are regarded as important aspects of the management of JCA (Leak 1991).

A study which has considered both medication and exercise compliance found 95% and 67.2% self-report levels of compliance, respectively (Hayford and Ross 1990). These researchers commented on the worrying low levels of exercise compliance. Splinting, an important ingredient of management to prevent joint deformities was again ignored. Information was based on diary return only. Uncertainty remains as to the psychosocial correlates of the whole range of treatment compliance issues for JCA.

This study will use a relatively large JCA sample and examine a number of relationships. This relates to the relationship childhood and parental psychosocial adjustment has with levels of pain reported. In addition the childhood and parental psychosocial correlates of compliance with medication, exercise and splinting will be explored.

Methods

Fifty four Children attending for follow up outpatient paediatric rheumatology clinic were seen over a period of 14 weeks. All children had a definitive diagnosis of Pauciarticular, Polyarticular and Systemic Onset types of Juvenile Chronic Arthritis.

Children were diagnosed by a Consultant Paediatric Rheumatologist, those with Spondiloarthropathies and uncertain diagnosis of JCA were excluded from the study. All children were seen who had appointments at the clinic therefore this can be construed as a random sample. Informed consent was obtained from parent(s) and child. One family had to leave during questionnaire filling and the data was discarded. A pilot study indicated that some parents were anxious about completing an adjustment questionnaire and had difficulty reading, therefore, the CBCL was used in interview format.

Of the JCA Children 23 were male and 31 were female. Children's age ranged from 4 to 16 years and 4 months. With an Average age of 10.9 (SD =3.16). Classification of Juvenile Chronic Arthritis from the sample included 3 (5.6%) with Systemic Onset, 37 (68.5 %) Pauciarticular and 14 Polyarticular (25.9%). Pauciarticular JCA is defined as 4 or fewer arthritic joints, Polyarticular is defined as 4 or more joints effected and Systemic Onset refers to the classic Stills rash and fever onset.

Social Class of child was categorised using father's occupation in accordance with Office of Population Census and Surveys: Classification of Occupations (1980). Classification was as follows: 11% of a sample of 54 children were classified as social class 1 (professional); 13% as social class 2 (intermediate); 15% social class 3 (skilled); 13% social class 4 (semi skilled); 11% as social class 5 (unskilled) and for 24% social class was unknown due to incomplete forms.

Measures

Figure one summarises measures (dependant and independent variables) used in the study. All data was collected in a paediatric rheumatology clinic except for pain and compliance diaries which were completed over a one week period following clinic appointment.

Figure One Summary of Measures (Dependent and Independent Variables)

Variable	Source of Data	Analytic Treatment
(Dependent Variable) Pain Reports	Estimate by VAS and Pain Diaries	Average score of ratings
Compliance measures	Self reported compliance and diaries	Percentage index of compliance
(Independent Variable)		
Childhood Psychosocial Adjustment	Child Behavior Checklist	T Score summary of Global Mean
Parental Adjustment	Parenting Stress Index	Global Parenting Stress Mean

Children's Reported Pain. Each child and parent completed a 10-centimetre visual analogue scale (VAS) at the clinic estimating their average pain experienced for the previous week (see appendix 3.2). Application of the VAS allows for the widest inclusion of age ranges in contrast to other forms of pain measurement (Thompson et al 1987). A high concordance rate between parent and child ratings of pain has been found (Thompson et al 1987). In addition to this retrospective measure children were given a one week pain diary to complete (See Appendix 3.3).

Compliance Measures. Parents and children were asked to estimate their rate of compliance to medication, exercise and splinting for the week prior to clinic appointment. They were given a number of statements (I take my medication as often as prescribed) and asked to circle a word (always, usually, sometimes, rarely, never) which they felt applied to this statement (See Appendix 3.4). Children and parents were also given diaries to complete. This involved recording medication taken, number of exercises completed for each day and whether or not a splint was worn (see appendix 3.5). Information from diary returns was compared to prescribed medication for each patient and/or exercise and splinting advise. This information was collected from case notes, clinicians and a physiotherapist. A percentage compliance rate was calculated from diary returns.

Psychosocial Adjustment of Child. The Child Behaviour Checklist (CBCL, Achenbach and Edelbrock 1983, 1991) provides parental reports of a child's behaviour. The measure provides an estimate of child's overall behavioural symptoms as well as subscales. It also gives a global estimate of child's competencies in a number of areas such as schooling, activity levels and social skills.

Parental Psychosocial Adjustment. The Parenting Stress Index (Abidin, 1990) provides an indication of the overall levels of parenting stress an individual is experiencing. It includes subscales relating to parental distress, parent-child dysfunctional interaction and whether a parent perceives their child as difficult.

Results

Childhood Psychosocial Adjustment

Fifty parents completed the Childhood Behaviour Checkilist (CBCL). No significant differences were found on the Child Behaviour Checklist by type of JCA diagnosis, (df=2, F-ratio =.3771, F prob = .6879). In addition, no significant differences were found on the Child Behaviour Checklist by sex (t=1.16, 2-tailed sig, n.s.) or socio-economic status (DF=4, F-Ratio=.9216, F-Prob=.4621).

The mean T scores on CBCL for the whole sample was 52.96 (SD=10.13). The mean T score for internalising behaviour problems was 55.9 (SD=10.98). The mean T score for externalising behaviour problems was 49.8 (SD=9.7). The mean competency score was 42.5 (SD=7.4). The distribution for each scale around the mean was essentially normal and not markedly influenced by extreme scores. For the mean T-score for the whole sample both Kurtosis (range = -.78 to + 3.98) and skewness (range -.22 to + .34).

In determining what proportion of the sample reported to be maladjusted depends on definition used. The authors of the CBCL (Achenbach and Edelbrook, 1983, 1992) recommend that a T score greater than 70 for behavioural problem scales and less than 30 for the competence scales represents clinical maladjustment. Therefore, 4% of the sample are maladjusted on the CBCL global scale. 12% are considered maladjusted on reported internalising behaviour problems. In contrast 2 % of this sample are considered maladjusted on their reported externalising behaviour problems. Table one indicates the frequency of clinically significant problems broken down by type of problem. Thirteen children were either too young for inclusion onto the competency scales of the CBCL or parents did not complete the scale. The results from the 41 completed competence scales of the CBCL were as follows: no children had scores which were indicative of significant maladjustment at school; 4 children (9.7%) received scores which indicated significant maladjustment in activity levels and 4 children were significantly maladjusted in terms of social competence (9.7%) , (See appendix 3.6). A more liberal interpretation of T score cut-off points (T>67 relates to clinically significant **borderline** clinical problems and T>33 indicative of significant maladjustment and **borderline** problems related to competency, (see appendix 3.7 and 3.8).

Table One: Frequency of Clinically Significant Problems.

Clinical Problem	Number of Children	Percentage
Withdrawn	3	6
Somatic Problems	11	22
Anxiety/Depression	3	6
Thought Disorder	2	4
Attention Disorder	4	8
Delinquency	1	2
Social Problems	4	8
Aggressive Behaviour	1	1.9
Sexual Problems	1	2.7
Externalising score	1	2
Internalising Score	6	12
Total T score	2	2

Parental Psychological Adjustment

Forty six parents returned completed Parenting Stress Index Questionaires. The mean raw score for the JCA sample on the Parenting Stress Index was 72.1 (SD=20.16). No significant differences were found between the child's sex when considering parenting stress scores, (t=1.13, df=1, n.s). One way analysis of variance indicates no significant differences on Parenting Stress Index score by JCA subtype (F= 0.34, df =2, n.s).

Table two highlights frequency of parental maladjustment on the parenting stress index. Tweny three point nine percent parents of children with JCA have clinically significant problems in relation to stress levels experienced within their role as parents.

Table Two: Frequency of Parental Maladjustment on the Parenting Stress Index

Parenting Stress Index	Number	Percentage
Parental Distress	5	10.8
Difficult Child	7	15
PCDI	8	17.4
Total Parenting Stress	11	23.9

Child and Parent Psychological Adjustment With Reported Pain

Eighteen (33.3%) children out of a possible 54 returned pain diaries. Mean child and parent visual analogue pain estimates for week prior to clinic visit were 3.53 (SD= 2.30). Mean child / parent prospective pain diaries for week following clinic were 3.23 (SD=2.71). No significant differences were identified on visual analogue scale by sex (F=.0208, df=1, n.s), diagnosis (F=.108, df=2, n.s) or socio-economic status (F=2.11, df= 4, n.s). No significant differences were found between retrospective clinic ratings and prospective pain diaries (t= -1.08, df=17, ns). Table three indicates correlation's between childhood psychosocial adjustment with retrospective pain ratings from clinic and pain diaries.

Table Three: Correlation Matrix of Psychosocial Adjustment with Pain Reports (n= 54)

	CBCL Total	CBCL Ext	CBCL Int	CBCL
Clinic Pain	.4605**	.3041*	.5935**	.1034
Diary Pain	.7027**	.6867**	.7375**	-.5906*

*p<.05, **P<.01 (One-tailed tests)

CBCL total T scores and internalising T scores are a summation of a number of sub scales measuring anxiety / depression and attention problems. Also included in these scores is the somatic subscale. This scale relates to the frequency of dizziness, tiredness, aches and pains. Table four displays partial correlation matrix between childhood adjustment and pain ratings controlling for somatic problems.

Table Four: Partial Correlation Matrix of Childhood Psychosocial Adjustment with Pain Reports Controlling for Somatic Problems

	CBCL Total	CBCL -EX	CBCL-INT	CBCL COMP
Clinic Pain	.4812*	.3350	.5129*	.1896
Diary Pain	.4298*	.4705*	.6992**	-.6096**

*p<.05, **P<.01 (One-tailed Tests)

Whilst controlling for somatic problems identified on the childhood psychosocial adjustment scale (CBCL) significant associations between increased adjustment difficulties and increased pain perception are still apparent. In addition reduced competence in areas such as schooling, activities, and social opportunities are associated with increased diary reported pain.

Largest correlates between subscales of the CBCL and clinic reported pain are anxiety/ depression, thought problems and withdrawn behaviour. The biggest correlates of diary reported pain are anxiety/depression, delinquency and school competency (See Appendix 3.9).

The correlation matrix shown between parenting stress and reported pain indicates significant associations between total parenting stress scores, clinic reported pain and diary reported pain. Parent-child dysfunctional interaction (PCDI) is the largest correlate with pain reports.

Table Five: Correlation Matrix Between Parenting Stress and Reported Pain

Pain Report	Total Parenting Stress	Parental Distress	PCDI	Difficult Child
Clinic Pain	.4958*	.0770	.2122	.3344*
Diary Pain	.2554*	.1652	.5402*	.3999

*p<.05, **P<.01 (One-tailed Tests)

Psychological Adjustment and Compliance

Thirty seven parents completed information about medication, 49 about splinting, 48 for physiotherapy attendance and 49 for exercise and gold injections. Children with JCA receive a variety of management interventions most frequently involving medication, exercise programmes to carry out at home and splinting (see table six).

Table Six: Type of Intervention Received By JCA Children

	Medication	Gold Injections	Attend Physiotherapy	Splinting	Exercise Programme
Number	36	5	24	29	40
Percentage	97%	10%	50%	59%	81.6%

Thirty one mothers (57.4%) were responsible for administering their child's medication, whereas only 4 (7.4%) of fathers made sure their child took their medication. 12 (22%) of children took responsibility for their own medication. Child / parent reported estimates of compliance for the week prior to being in clinic for a number of JCA management approaches are shown on table seven. Reduced compliance to exercise and splinting is most frequently reported.

Table Seven: Percentage Clinic Reported Compliance to Main Management Approaches

	Medication	Exercise	Splinting
Always	64.8	16.7	16.7
Usually	18.5	22.2	13.0
Sometimes	5.6	27.8	22.2
Rarely	3.7	11.1	1.9
Never	0	3.7	1.9
Missing	7.4	18.5	44.4

JCA patients and parents were given diaries to record medications taken, whether splints were worn and exercises carried out. One third of Compliance diaries (n=18) were returned by JCA patients and/or their parents. A percentage index of compliance was calculated from returned diaries. Mean diary index of medication compliance was 95.17% (SD=12.1), a 62.46% (SD=40.29) compliance rate was found for use of splints and 71.3% (SD=31.03) compliance rate for carrying out exercises.

Correlation matrix of childhood psychosocial adjustment with compliance diaries indicates that increased child adjustment problems are significantly associated with reduced splint compliance (see table eight).

Table Eight: Correlation's between Childhood Psychosocial Adjustment and Compliance Diaries

	CBCL Total	CBCL Externalising	CBCL Internalising	Competency Scores
Medication Diary	-.01497	.1026	-.1497	-.0482
Splint Diary	-.5634*	-.4668	-.3889	.5611
Exercise Diary	-.3157	-.1612	-.2003	.4818

*p<.05, **P<.01 (One-tailed Tests)

A correlation matrix of parenting stress and diary reported compliance indicates significant associations between parents perceptions of having a difficult child and reduced adherence to splint wearing.

Table Nine : Parenting Stress and Diary Compliance Correlation Matrix.

	Parenting Stress Total	PCDI	Parenting Stress	Difficult Child
Medication Diary	-.1590	-.3109	-.0203	-.0894
Splint Diary	-.2879	-.3680	-.1819	-.2438
Exercise Diary	-.2757	-.4449	-.1882	-.6320*

Qualitative Data of Parents Perception of JCA

Qualitative data is a useful adjunct to obtaining an insiders view of specific mental health or adjustment problems and is a generally neglected form of analysis (Nicolson 1995, Lewis 1995). The CBCL contains two open ended questions relating to parents greatest concerns about their child and the best thing they can describe about their child with JCA.

Thirty seven (68.5 %) parents completed the open ended questions, parents responses were categorised by independent raters. 9 parents were concerned about practical restrictions of JCA such as immobility, problems writing or dressing, 8 parents were concerned about uncertainties in relation to prognosis, 5 parents raised worries about pain experienced by their children, 5 about emotional problems, 5 at missing schooling, 1 about medication and 3 reported no concerns. For more detailed examples of parents comments see appendix 3.10.

Tweny seven (50 %) parents completed open ended questions about the positive aspects of their child with JCA. Sixteen parents highlighted positive parenting experiences with there child, 11 noted positive coping strategies to deal with the emotional impact of JCA and one parent described a coping strategy specifically linked to pain.

Discussion

Rates of overall childhood maladjustment in JCA do not differ from a community norm sample. Only 4% of JCA children are considered maladjusted on the CBCL global scale. This concurs with Wallander et al (1988), who found positive psychosocal adjustment among JCA patients compared to diabetes, spina bifida, cerebral palsy, haemophilia and community samples. These other childhood illnesses have a greater potential threat to life than JCA (Eiser 1993). It is also well known, for example, that mothers perceptions of severity of a childhood disease has an important bearing on childhood psychosocial adjustment (Eiser et al 1991). This study (n=54) in contrast with the 9 JCA patients from Wallander et al (1988) provides stronger evidence that JCA is not a significantly maladjusted population. Although overall adjustment does not appear different from a norm group, 12% of this sample have clinically significant somatic, depressive/anxious, withdrawn and attentional problems on the internalising scale of the CBCL.

Despite the fact JCA children did not have significant levels of maladjustment, strong associations between CBCL, retrospective and prospective pain diaries provide support for the notion that increased psychosocial maladjustment is strongly linked with perceived pain in JCA. Large associations are still evident when taking out the effects of somatic complaints on the CBCL. In particular increased maladjustment on the internalising scale of the CBCL is strongly associated (accounting for over half the variance) with reported pain.

Parenting stress is also strongly associated with child reported pain. Significant associations were found between global measures of parenting stress and pain reports.

There may be two pathways increasing pain perception. Firstly, there is evidence that a child's ability to cope with pain is influenced by parents pain beliefs and behaviours. In some cases when child-parent interaction is videotaped the interactional styles of the children who do not cope well with pain were characterised by conflict and contradictory advise (Dun-Geier et al 1986). The second pathway relates to parental adjustment, particularly in terms of depression leading to increased childhood maladjustment in JCA (Timko et al 1993). These researchers speculated that the etiological mechanism for childhood maladjustment may have concerned interactional styles. In this study measures of child-parent dysfunctional interaction was strongly associated with perceived pain.

Medication compliance does not appear to be a problem with this sample. In stark contrast, children with JCA have great difficulties in adhering to splinting and exercise interventions. Increased childhood maladjustment was significantly associated with reduced splint adherence. Similarly, associations were found for JCA children perceived as difficult on the parenting stress index and decreased exercise compliance. In other childhood diseases such as cancer compliance is affected by parent-child agreement on the following: agreed responsibility for medication; level of understanding of treatment instructions; treatment effectiveness and knowledge of how medication effects disease (Eiser, 1993).

Compliance has been related to mothers coping behaviours and father's satisfaction with life. Compliance in JCA may also be effected by a complex set of relationships within the family and not simply dependant on mothers' behaviour.

The importance of psychological variables such as depressive/anxiety symptoms have for pain reports in JCA and the lack of attention to non-pharmacological psychological pain management is cause for concern. There is no data available on the extent to which psychological pain management is offered as an adjunct to medical treatment for JCA. Methods of reducing child anxiety and maternal distress might be considered as part of a cognitive behavioural intervention. Qualitative evidence indicates that parents in this study frequently worry about their child's prognosis. There is also qualitative evidence of parental concerns about child's mobility. This would imply the use practical interventions aimed at increasing mobility.

Interventions to improve compliance in exercise and splinting in JCA may initially have to consider increasing childhood and parental adjustment. Specific interventions could attempt to enhance childhood parent agreement about the rationale for splinting and exercise regimes.

Methodological problems associated with this study concern parental perceptions of child behaviour. Parental perceptions are a function of child and parental characteristics. For example parents under stress have been found to overestimate inappropriate behaviour (Wallander et al 1988). On the other hand, a perceived advantage is the use of the CBCL with children with JCA. There is good validity data for using parental report on the CBCL as a measure of childhood adjustment (Achenbach and Edelbrock, 1983, 1991). Children with JCA and parents diary reports of pain were taken over one week. It is arguable that JCA is a variable disease and that a one week sample of pain does not reflect the true course of pain experiences, but, this still represents improvement on previous methodologies. Another difficulty relates to the possibility that children returning compliance diaries are inherently more compliant. One third of diaries were returned and children / parents retrospective compliance ratings showed similar difficulties adhering to exercise and splinting to those returning diaries.

These data strongly suggest the need for studies of pain treatment in children with JCA and evaluation of interventions designed to increase exercise and splinting compliance. Ultimately there may be a need to routinely incorporate psychological treatment into clinical care of JCA children.

References

Abidin, R.R., (1990) *Parenting Stress Index- Short Form,* Charlottesville, University of Virginia.

Achenbach, T.M., & Edelbrock, C.S. (1983,1992) *Manual For the Child Behaviour Checkilist.* Burlington, University of Vermont.

Beales, G, Keen, J.H., & Lennox Holt, P.J. (1983) The Child's Perception of the Disease and The Experience of Pain in Juvenile Chronic Arthritis. *Journal of Rheumatology,* 10, 61-65.

Billings A.G., Moos R.H, Miller J.J. & Gottlieb J.E. (1987) Psychosocial Adaption in Juvenile Rheumatic Disease: A Controlled Evaluation. *Health Psychology*: 6, 343-359.

Chaney, J.M., & Peterson, L. (1989) Family Variables and Disease Management In Juvenile Chronic Arthritis, *Journal of Paediatric Psychology,* 14, 389-403.

Eiser,C. (1993) Growing uo with a Chronic Disease, The Impact on Children and their Families, London, Jessica Kingsley Publications.

Eiser,C., Eiser, J.R., Town, C. & Tripp, J. (1991) Severity of Asthma and Parental Disciplince Practises, *Patient Education and Counselling,* 17, 227-233.

Hayford, J.R. & Ross C.K. (1990) Medical Compliance in Juvenile Rheumatoid Arthritis. *Arthritis Care and Research*, 1, 4, p190-97.

Haynes, R.B., Taylor,D.W. & Sacket,D.L. (1979) (eds) *Compliance in Healthcare*, Baltimore and London: John Hopkins University Press.

Jaworski, T.M. (1993) Juvenile Rheumatoid Arthritis: Pain Related and Psychosocial Aspects and their Relevance for Assessment and Treatment. *Arthritis Care and Research*, 6, 4, 187-196.

Leak, A.M. (1991) Topical Reviews: Juvenile Chronic Arthritis. *Rheumatism Council For Research*.

Lewis, S.E. (1995) A Search for Meaning: Making Sense of Depression, *Journal of Mental Health*, 4, 369-382.

Litt, I.F, Cuskey W.R. (1981) Compliance with Salicylate Therapy in Adolescents with Juvenile Rheumatoid Arthritis. *American Joournal Disability Child Research*, 135: 434-436.

Litt, I.F., Cuskey W.R. & Rosenberg A. (1982) Role of Self-Esteem and Autonomy in determining medications Compliance among Adolescents with Juvenile Rheumatoid Arthritis. *Paediatrics*, 69, 15-17.

McAnarney E.R., Pless I.B. & Satterwhite, B. (1974) Psychological Problems with Children with Juvenile Arthritis. *Paediatrics*, 73, 169-174.

Markova,I., Mcdonald,K. & Forbes,C. (1980) Integration of Haemophelic Boys into Normal Schools, *Child Care Health and Development*, 6, 101-109.

Melzack, R. & Wall, P.D. (1983) *The Challenge of Pain*, New York, Basic Books.

Miller, J., Spitz, P. & Simpson, U. (1982) The Social Functioning of Adults who had Arthritis in *Childhood. Journal of Paediatrics*, 100; 378.

Rapoff, M.A., Lindsey C.B. & Christopherson, E.R.(1985) Parent Perceptions of Perceptions of Problems Experienced by their Children in Complying with Treatments for Juvenile Rheumatoid Arthritis. *Archives of Physical Medicine Rehabilitation*. 66, 267-269.

Nicolson, P., (1995) Qualitative Research, Psychology and Mental Health: Analysisng Subjectivity. *Journal of Mental Health*, 4, 337-345.

Ross, C.K., Lavine,J.V., Hayford-Dyer, A., and Pachman,P,. (1989) Validity of Reported Pain as a Measure of Clinical State in Chronic Juvenile Arthritis. *Anals of Rheumatic Disease*, 48, 817-819.

Ross, C.K., Lavine, J.V., Sinacore, J.M., & Pachman, L.M. (1993) Psychological Factors Affecting Reported Pain in Juvenile Rheumatoid Arthritis. *Journal of Paediatric Psychology*, 18, 5, 561-573.

Scott, P.J., Ansell, B.M. & Huskisson E.C. (1977) Measurement of Pain in Juvenile Chronic Polyarthritis. *Annals of Rheumatic Disease*, 36. 186-187.

Stoff.E, Molock S.D. & White P.H. (1987) A Needs Assessment of Children with Rheumatic Diseases, *Journal of School Health* 57, 162-4.

Thompson, K. L., Varni, J.W., & Hanson, V. (1987) Comprehensive Assessment of Pain in Juvenile Chronic Arthritis, *Journal of Paediatric Psychology*, 12, 2, 241-255.

Timko, C., Baumgartner, M., Moss, R.H. & Miller, J.J. (1993) Parental Risk and Resistance Factors Among Children with Juvenile Rheumatic Disease: A Four Year Predictive Study, *Journal of Behavioural Medicine*, 16,6, 571-588.

Vandvick, I,H,. (1990) Mental Health and Psychosocial Functioning in Children with Recent onset of Rheumatic Disease. *Journal of Child Psychology and Psychiatry*, 31, 961-971.

Weiland,S.K., Pless I.B. & Roghmann K.J. (1992) Chronic Illness and Mental Health Problems in Paediatric Practise: Results from a survey of Primary Care Providers. *Paediatrics*, 89, 445-449.

Wallander, J. L., Varni, J.W., Babani, L., Banis, H. T., & Wilcox, K. T (1988) *Family Resources as Resistance Factors for Psychological Maladjustment of Chronically Ill and Handicapped Children,* Manuscript Submitted for Publication, Sparks Centre, University of Alabama at Birmingham.

Classification of Occupations (1980), Office of Census Population and Surveys (OCPS), London: HMSO.

Chapter Four

APPLICATION OF A NEW TEST OF FRONTAL LOBE DAMAGE

Single Case Research study (I)

Target Journal: Brain Injury (see appendix 4.1 for contributors notes).

Abstract

The need for a functional approach to deficits arising from frontal lobe damage prompted a number of researchers to recently publish a new assessment tool for dysexecutive syndrome. This paper considers how useful the Behavioural Assessment of the Dysexecutive Syndrome (1) is with a patient following subarachnoid haemorrage and resulting bifrontal brain damage. The practical benefit of the BADS is discussed with reference to rehabilitation interventions.

Introduction

Historically neuropsychological approaches to identifying relationships between brain structure and behaviour led to categorical terms such as 'frontal lobe syndrome'. It was potentially misleading to consider this a single syndrome. Deficits in the frontal lobes, once considered the 'seat of intelligence', vary greatly in terms of aetiology, severity, location and hence expression.

The complexity of the cytoarchetecture, neurochemistry and sheer number of intricate connections with the rest of the brain ensure that our knowledge of the various zones of the frontal lobes remains relatively scant since the seminal writings of Luria (2,3). Frontal lobe difficulties relate not only to damage sustained by a particular area but also by the associated interconnections between this area and functional brain systems. In some cases “the building blocks may be intact but what appears to be inhibited is the ability to initiate their use” (Burgess and Alderman, 1990, 4).

Impaired frontal lobe integrity is associated with a diverse array of problems. Impairments are commonly noted in attention, language (particularly verbal fluency), visuo-spatial functioning and personality functioning. Significant adynamia is associated with massive frontal damage, orbito-frontal damage has been associated with restlessness and prefrontal damage with impaired attention. Memory can be significantly impaired by attention problems and increased sensitivity to interference. Behavioural perseveration is also commonly associated with frontal damage (5).

Until now there have been no assessment batteries which are specifically designed to test the range of executive functioning, cognitive, behaviour and emotional/ personality changes associated with dysexecutive problems and frontal brain damage.

The Behavioural Assessment of Dysexecutive Syndrome (BADS) attempts to improve upon previous assessments of dysexecutive and other frontal problems by asking patients to plan their behaviour over longer time periods and set priorities when facing competing tasks. Some of the more widely used tests of executive functioning such as the Wisconsin Card Sort, the Stroop Test and the Reitan Trail Making Test can be performed normally by some patients with obvious impairments of executive functioning. In the case of the widely used Wisconsin Card sort test it has been concluded that " the evidence that frontal patients perform more poorly than nonfrontal patients is weak" (6).

The BADS is made up of 6 subtests, a self report questionnaire and a relatives questionnaire. The Role Shift Card Test is similar to the Wisconsin Card Sort as a means of measuring persevaritive responding. The action programme sub-test was designed to give subjects a novel, practical task that requires a specific course of action to solve a problem. It requires physical manipulation of water, wire and a cork to solve the problem. The subject is required to screw a lid onto a container to allow them to fill up a test tube with water and retrieve a cork inside the test tube by keeping to a number of rules. The key search is a planning task which relates to a real life scenario of losing keys. The temporal judgement test involves questions about common place events which are measures in seconds and minutes. The zoo map test involves planning a route whilst keeping to a number of rules. The modified six elements subtest involves the subject being given instructions on how to do three tasks (dictation, picture identification and arithmetic). The point of the subtest is whether subjects can plan , organise and monitor their behaviour. Finally, the dysexective questionnaire covers four broad areas of likely change following frontal damage. These are emotional and/ or personality changes, behavioural changes and cognitive changes. The following single case research describes a neuropsychological assessment utilising the BADS and discusses implication for rehabilitation.

Patient L.G

L.G is a right handed 32 year old lady who suffered a subarachnoid haemorrage and underwent surgery for clipping of an anterior communicating artery aneurysm. She developed post-operative vasospasm and CT scan revealed bifrontal ischaemic changes. One month following haemorrage L.G was described as having fluctuating levels of communication, poor attention/ concentration, initiative and insight. Although L.G was conscious throughout she remained disorientated indicating very severe level of brain damage. There was evidence of a mild right sided weakness following surgery.

L.G was a senior production manager at in an electronic firm. Although she had no formal qualifications, she had progressed from being a machinist to this responsible post. She also taught at a horse riding school and tended to work very long hours. She had left school with two higher grades and trained as a riding instructor. She lived with her partner who had tended to take responsibility for running the household. Her employer had kept her post open pending rehabilitation outcome

During assessment L.G was alert and co-operative, Her affect and behaviour were appropriate to situation. Her memory difficulties made it difficult for her to give a full history, but she had insight into this, as with most of her difficulties. The main difficulties listed by L.G following haemorrage were memory problems, difficulty with language such as wandering off the subject and poor concentration. L.G reported that memory for names, details of events (e.g. from the previous day) and things people said to her. She denied any emotional problems following this neurological event. She also noted that in company she was more likely to speak her mind. Her aims were to return to work. Table One indicates results on formalised neuropsychological testing.

Figure One: L.G's Neuropsychological Test Results

Test Used	Test Result
Verbal Fluency (FAS)	10-14th percentile
NART	IQ equivalent 105
WAIS-R Subtests	
Comprehension	IQ equivalent 105
Similarities	IQ equivalent 85
Block Design	IQ equivalent 85
Digit Symbol	IQ equivalent 75
Digits forwards	14th percentile
Digits backwards	61st percentile
WMS-R	
Logical Memory (immediate)	16th percentile
Logical Memory (delayed)	1st percentile
Verbal Paired Associates (immediate)	raw score 9
Verbal Paired Associates (delayed)	raw score 2
BADS	Standardised score 75 (borderline)
Rey Complex Figure Test (copy)	25th-50th percentile
Rey Complex Figure Test (immediate recall)	25th-50th percentile
Hospital Anxiety and Depression Scale	
Anxiety	10
Depression	13

Discussion of L.G's Assessment

A brief language screen indicated no gross impairments of comprehension and expression, but there was significant impairment of verbal fluency with verbal disinhibition and rule-breaking. From L.G's occupation, educational background and NART error scores premorbid functioning was estimated to be in the average to high average range.

Her scores from selected subtests of the WAIS-R indicate current intellectual functioning is impaired by comparison. Attentional, executive functions were particularly effected. L.G's scores were often lowered by poor error checking, distractibility and difficulty in maintaining task "set". L.G showed impairment of abstract verbal reasoning whilst social reasoning appeared intact.

Significant impairments of verbal and visual memory were confirmed by scores on logical memory and verbal paired associates test and the Rey Complex figure. L.G's recall of spoken passages (Logical Memory) scored at the 16th percentile on the immediate trial, falling to 1st percentile after delay. New learning ability was markedly impaired; while L.G learned all 4 "Easy" associations on the Paired Associate task by the second trial and could retain two of them after delay, she only learned one "hard" association after the sixth trial. L.G's copy of the Rey Complex figure was executed in a highly disorganised and piecemeal fashion but nevertheless scored within normal limits. Immediate recall was just within normal limits, but much lower than would be predicted from premobid level of intellectual functioning.

Formal measures of attention revealed impairments consistent with L.G's performance in other tests. Her immediate attention span (Digits forwards) was 6, falling at the 14th percentile. L.G's score on the more demanding digits backwards was 7, at the 61st percentile; this discrepancy itself is suggestive of attentional difficulties.

L.G's scores on the Behaviour Assessment of Dysexecutive Functioning (BADS) were within the borderline range. Particular difficulties were with temporal judgement, action programme, ability in planning routes and following specific instructions. On the action programme subtest of the BADS, L.G attempted to fill up the container without screwing a lid onto it, the result being she was unable to fill the container with water.

She then used the lid of the container to laboriously fill the test tube with water. Once L.G solved the problem, albeit in a unconventional fashion, she immediately then screwed the lid onto the container. When asked if what she had just done would be a better way of solving the problem, L.G looked at the container and screwed on lid and replied - “no”.

The Dysexecutive Questionnaire completed by L.G and partner indicated severe difficulties in planning, lethargy, difficulty making decisions, impulsivity and temper. There were no differences between self rating and partner rating indicating that L.G had some insight into her executive difficulties. A questionnaire measure of affective symptomatology (Hospital Anxiety and Depression Scale) indicated caseness levels warranting therapeutic intervention. In contrast to her level of insight into cognitive problems L.G appeared to have reduced insight into these emotional difficulties.

In summary, L.G sustained a very severe brain insult leaving a range of cognitive and emotional disturbances. These primarily consisted of executive and attentional functioning, e.g. poor action planning/organisation, temporal judgement, sustaining attentional and regulating responses. Observations in a neuropsychological rehabilitation unit indicated that L.G had significant difficulties in initiating behaviour and required frequent and detailed prompting. This pattern is consistent with bifrontal damage suffered.

It is expected that L.G will continue to show improvement, but, the severity and nature of cognitive and behavioural disturbances mean that one must be guarded about the likelihood of L.G returning to her previous job. Intensive rehabilitation would be beneficial to L.G particularly targeting executive, memory and attentional difficulties.

Discussion

Subarachnoid Haemorrage accounts for 15-20% of cerebrovascular disease (7). The pathological process of atherosclerosis leading to the deposition of plaques can ultimately lead to occlusion of various major cerebral vessels. Effects of occlusion of a blood vessel depend on whether collateral channels are available, rate of occlusion, blood pressure and difficulties with circulation (7). The conclusions reached from L.G' case have to be tempered with the difficulties in generalising from patients with subarachnoid haemorrage due to theses individual differences.

The BADS in combination with traditional neuropsychologcial assessment and observation provided useful confirmation of L.G' s severe executive, attentional problems and impairment of intellectual and memory functions. Difficulties with intellectual and memory functioning were exacerbated by executive problems. The BADS allowed more detailed conceptualisation of initiation problems, route planning, action sequencing and monitoring of behaviour. Ecological examples of executive difficulties related to L.G requiring detailed instruction on the actions required when searching for a phone number. In addition, people phoning her at home had to prompt her to pick up the phone when speaking on her answer machine. On one occasion she had attempted to get a train with minimal planning and randomly chose a platform at the station. This information was useful in applying more focused neuropsychological rehabilitation programme and long term goal planning.

In positive practical terms the BADS took 30 minutes to administer. The presentation of tasks made it interesting and L.G was able to sustain her concentration throughout. However, some parts of the BADS, such as the modified six elements subtest involves relatively complex instructions. This may require patients who are functioning within the average range of intellectual reasoning making the BADS difficult to apply across a wider range of ability. From a testers point of view the BADS is relatively mobile and easy to administer.

Cognitive rehabilitation's central tenets of retraining, behavioural compensation and prosthetic compensation were applied to L.G's case. It was apparently unlikely that L.G would return to work in her previous capacity as manager. L.G's performance was reduced on logical memory and paired associate learning. These tests have a high degree of validity in predicting return to work (8,9).

Although numerous cognitive programmes have been developed for the remediation of executive problems research into these programmes has been limited (10). The main thrust of L.G's rehabilitation involved problem solving training at group and individual levels, behavioural programmes to encourage the consistent application of memory aids such as PQRST, descriptive cueing, daily activity schedules and timetables. In addition L.G was encouraged to make written plans for travel, verbalise and practise them. Successful treatment of impaired planning ability has been demonstrated in head injury cases with this technique (Cicerone and Wood, 1987). Social skills groups and video role play were used to address her abrasive social manner and to encourage L.G to monitor her own behaviour more closely. From inpatient rehabilitation plans were made for a seamless transition for rehabilitation to continue in the community with the emphasis placed on structure for L.G.

To assess a patient with neurological damage with assessments that have little ecological validity is self defeating in terms of planning appropriate rehabilitation. The BADS goes some way in using everyday tasks (e.g. devising a plan to look for a lost key, estimating time for daily events) to providing clear targets for cognitive rehabilitation.

References

1. Wilson, B.A., Alderman, N., Burgess, P.W., Emslie, H. & Evans, J., *Behavioural Assessment of Dysexective Syndrome*, 1996, Thames Valley Test Company, Bury St Edmonds, England.

2. Luria, A.R, *The Working Brain*, 1972, Allen Lane Penguin Press London.

3. Luria, A.R., Frontal Lobe Syndromes. In: Winken P.J Bruyn G.W (eds) *Handbook of Clinical Neurology,* North Holland, Amsterdam, Vol 2, Chap 3.

4. Burgess, P.W., & Alderman, N.M. *Rehabilitation of Dyscontrol Syndromes Following Frontal Lobe Damage*: A Cognitive Neuropsychological Approach, in R. LI, Wood & and I. Fussey, 1990 (eds) Cognitive Rehabilitation in Perspective in Perspective (pp- 183-203), Basingstoke: Taylor and Francis LtD.

5. Anderson, R.M., *Practitioners Guide to Clinical Neuropsychology*, 1994, New York, Plenum Press.

6. Mountain, M.A., & Snow, W.G., Wisconsin Card Sort Test as a Measure of Frontal Pathology : A Review. *The Clinical Neuropsychologist*, 7, 108-118, 1993.

7. Walsh, K.W., *Understanding Brain Damage: A Primer of Neuropsychological Evaluation*, 1991, Second Edition, Melbourne, Churchhill Livinstone.

8. Brookes, D.N., McKinley,W., Symington,C. et al, Return to work within seven years of head injury, *Brain Injury*, 1: 5-19, 1987.

9. Brookes, D.N., Campsie,I., Symington, C et al: The five year outcome of severe blunt head injury: a relatives view. *Journal of Neurology, Neurosurgery and Psychiatry*, 46: 760-770, 1986.

10. Von Cramon, D.Y., & Matthes-von Cramon, G.: *Frontal Lobe dysfunctions in patients- therapeutical approaches.* In R.L Wood & Fussey (Eds), Cognitive rehabilitation in perspective (pp.164-179), London, Taylor Francis.

11. Cicerone, K.D., & Wood, J.C.: Planning disorders after closed head injury: A case study, *Archives of Physical Medicine and Rehabilitation*, 68, 111-115, 1987.

Chapter Five

Treatment of Severe Poverty of Speech

Single Case Research Study (II)

Target Journal: British Journal of Learning Disabilities (Notes for Contributers, See appendix 5.1).

Abstract

People with learning disabilities do not have a powerful voice to influence important decisions taken about their day to day lives. This can be compounded by the presence of psychiatric problems leading to dual diagnosis. In hospitals people with learning disabilities and concomitant psychiatric problems can be seen as the most difficult patients. Traditionally this group have had less opportunity for appropriate mental health provision. This paper highlights clinical psychological intervention into severe poverty of speech related to Schizophrenic (Residual Type) Disorder. Speech output increased during intervention allowing a more appropriate conceptualisation of the problems presented. The implication of increased speech conferring greater individual choice is discussed against a background of changing service philosophy driven by humanistic principles such as social role valorisation.

Individuals with learning disabilities are vulnerable to a range of mental health problems which can often be unidentified and therefore not responded to with the appropriate service. Traditionally having a learning disability reduces the opportunity for an appropriate mental health service (Reis 1992). Dual diagnosis is an important consideration in any attempts to increase quality of life.

Schizophrenia has been identified as a significant problem in the learning disabled population with point prevalence rates estimated at 3.5 percent (Reid 1985). There may be a tendency to view these figures as an underestimate due to the underdeveloped knowledge base relating to dual diagnosis and the fact that individuals with learning disabilities may not be able to express a disorder of thought or perception (Turner, 1989). Particular areas of uncertainty relate to differentiating some symptoms of learning disability from those associated with a severe schizophrenic state. These include social withdrawal, slowness of thought, poverty of speech and emotional blunting (Murray 1986).

People with a dual diagnosis can be viewed as the most difficult, violent and self injurious patients within a hospital setting (Forest and Ogunremi 1974). How an individual is perceived, for example with minimal speech and apparently few expressed preferences may influence the level at which they are included in decisions about their own lives, such as goal planning. Providing conditions conducive to improving social interaction and speech output ultimately raises the likelihood of increased assertion in making fundamental life choices.

Mr M: Background

This 27 year old man was referred to psychology services by the Consultant Psychiatrist for assessment for 'bereavement counselling'. Mr M was diagnosed as having a mild learning disability. From limited medical information it appeared that the learning disability related to birth complication in terms of umbilical cord asphyxiation and anoxia. Apart from this event his medical history was unremarkable. He had been admitted twice to a hospital for people with learning disabilities over a 3 year period due to psychotic symptoms. In addition, his father died of cancer 6 years prior to psychological involvement.

A survey of Mr M's medical notes indicated that he suffered a distressing psychotic episode at the age of 22, prompting the first admission to hospital. Mr M reported hallucinations ("seeing monsters"); delusions of reference ("the TV talks to me"); paranoia ("my family are not real") and grandiose delusions ("I've been brought back to life"). In addition to formal thought disorder Mr M also displayed neologisms such as "I have telescope psychic eyes". Mr M was diagnosed as suffering from schizophrenic disorder.

At this time there was some tentative evidence for a co-morbid depressive disorder when Mr M spoke of "crying inside my head". There was also evidence of initial insomnia, early wakening and weight gain.

Following admission Mr M suffered two further relapses with the presence of florid psychotic symptoms. After the first relapse Mr M suffered dramatic deterioration in expressive communication and he began to speak in a monosyllabic manner. A great deal of uncertainty was expressed about the aetiology of his current difficulties and consequently the future scope of clinical intervention, but, care staff speculated on the possibility of complicated bereavement overlaying schizophrenia. Other formulations expressed related to selective mutism.

Mr M's father died 6 years prior to psychological involvement. He had a good relationship with his father. Mr M attended the funeral and appeared to grieve appropriately. He had a strong social support network within close and extended family. These circumstantial factors associated with loss reduce the likelihood of complicated bereavement (Worden 1993).

Due to local policy of impending community placement for Mr M psychological assessment and intervention was required. Primarily this was aimed at determining the nature of Mr B’s difficulties and the scope for increasing verbal communication. This would enable Mr B to take part in future planning.

Researchers in the field of dual diagnosis emphasise the importance of getting the history right. This includes the timing of onset of symptom profile no matter how 'feigned' or 'bizarre' they appear (Turner, 1989). The mean age of onset for psychotic symptoms in people with mental retardation is in the early 20's. This contrasts with 26 for those not learning disabled (Meadows et al, 1991). This might be because the etiological mechanisms in those with dual diagnosis may be more reflective of some neurodevelopmental disorder. Alternatively people with learning disabilities may have more functional difficulty in coping with their subjective experiences psychosis, hence presenting earlier. There is no available evidence as yet to refute either of these hypotheses.

Researchers have highlighted the idea of a general misconception that people with learning disabilities with low verbal I.Q's would not be able to express elaborate conceptual and linguistic aspects of the first rank symptoms of schizophrenia (Meadows et al, 1991). The epidemiological focus of research in the 1970's and 80's has neglected phenomenology of types of hallucinations and delusions.

Psychological Evaluation

Assessment mainly concerned itself with primary (face to face) and secondary levels, namely environmental, social and physical context (Dickens, 1991). At the time of carrying out primary levels of assessment there were difficulties due to the low frequency of verbal utterances from Mr M. At the secondary level of assessment Mr M was observed in work (Occupational Therapy); leisure (outing to a bowling alley) and ward situations. Mr M was able to carry out sophisticated instruction for example, couched in an 'if- then' format. He would also sometimes smile and laugh appropriately in response to subtle humour. This contrasted sharply with reduced verbally expressive communication. There was little initiation of speech except when instrumental, for example "go ...out", with rising intonation. Responses were monosyllabic and he demonstrated a great deal of compensatory gestures such as pointing and thumbs up. Care Staff tended to readily accept these alternative means of communication and would verbalise his gestures. The implication here is that Mr B's problems were at least being maintained by contextual factors.

Mr M displayed reduced motivation, where, a great deal of coaxing was required to involve him in any activities. He would lie on his bed for significant proportions of the day. He attended Occupational Therapy only twice a week due to availability.

Mr M' presentation did not conform to that of selective mutism, which is a failure to speak in certain social situations. Selective mutism is rare, being found in fewer than 1% of mental health settings, onset is usually in childhood, associated disorders such as social phobia are commonly found and speech output differs across situation (DSM IV, 1994). This was not in keeping with Mr M's presentation.

A greater understanding of the nature of Mr M's difficulties is apparent when considering renewed research interest into schizophrenic typology. Some researchers have identified three main factors in schizophrenia - a psychotic factor, a disorganisation factor and a negative factor (Liddle 1987, Miller et al 1993). The negative symptoms such as poverty of speech, latency of response, attentional impairment and avolition are robustly associated with Type II Schizophrenia. A substantial body of literature links Type II schizophrenic presentation with abnormal brain structure, impaired cognitive function and poor outcome (Miller et al 1993). As in Mr M's case Type II Schizophrenia is associated with periods of negative symptoms, recurrent severe florid psychotic symptoms and neuroleptic resistance (Hwu et al 1995).

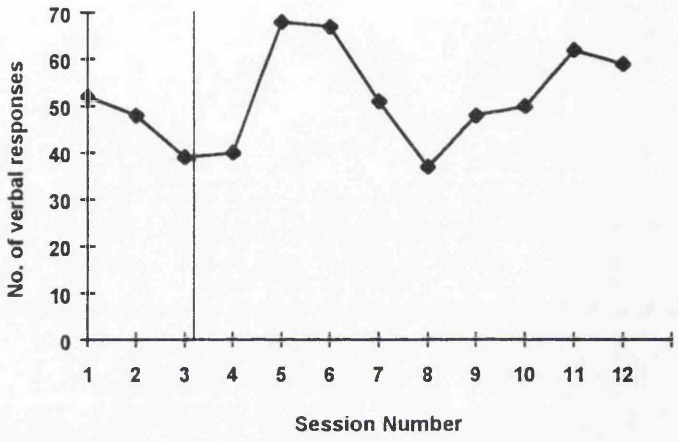
Intervention

Prior to intervention a simple mean baseline measure of spontaneous utterances and verbal responses were collated during a sample time of thirty minutes in work, leisure and ward contexts. Speech responses and speech initiation was noted verbatim during treatment sessions. Given that there were no apparent difficulties with daily living skills, Mr M was more formally and globally assessed using the communication domain of the Vineland Adaptive Behaviour Scales (Interview Edition, Expanded Form, 1989).

Intervention was designed with the aim of increasing Mr M's verbal communication, increase motivation by for example providing more structured activities as well as to gather more evidence from Mr M to refute hypothesis relating to bereavement difficulties. Findings from observational studies of care staff working with people with learning disabilities indicate that only 10% of their day is spent in social interaction with clients. Interactions are brief, for example up to half being 10 seconds and two thirds of interactions have been found to be neutral in style (Hastings and Remington 1994). The rationale for interventions to improve Mr M's quality of life involved modifying of staff behaviour to ignore Mr M's alternative methods of communication such as gesturing, increase positive interaction, encourage and reward speech. Individual psychology input was aimed at increasing speech. Changing regressive contexts which can be associated with difficulties in engendering prosocial behaviour was seen as a crucial part of intervention.

Results

Graph one highlights speech responses from Mr M. Sessions one to four involved baseline measurement. Increases in speech are apparent immediately following intervention, but this had dropped to base levels by session 7. It is arguable that emotionally sensitive discussions relating to his fathers funeral may have been associated with decreased verbal output. This was something that he had never previously spoken about. From session 7 to 10 speech output remained around baseline levels but increased by session 11 (See Graph One).



Graph One: Verbal Response Count

From table one the frequency of spontaneous speech is very low, but increases during intervention.

Table One: Frequency of Verbal Initiation

Session Number	Verbal Initiation
1	0
2	0
3	0
4	1
5	0
6	1
7	2
8	0
9	2
10	0
11	2
12	2

Table two shows raw Vineland Adaptive Behaviour Rating Scale scores before and after intervention. Raw scores were used due to the fact that when large changes occur using this scale from 'no spontaneous speech' to 'spontaneously initiates speech' an additional raw score of one is given and no change occurred in terms of percentile scores. Raw scores more accurately reflected change in Mr B's presentation. Table two displays raw Vineland Adaptive Behaviour Scale raw scores.

Table Two: Vineland Adaptive Behaviour Rating Scale (Communication Domain) Before and After Intervention.

Time of Assessment	Raw Receptive Communication Score	Raw Expressive Communication Score
Before Intervention	26	58
After Intervention	27	63

A number of qualitative changes were noted. Mr M spoke of leisure activities which he enjoyed. He spontaneously asked to be able to go out of the ward and if a member of staff wished to play pool. He also for the first time talked of his fathers death and funeral offering little phenomenological evidence of complicated bereavement. Anecdotal accounts from staff indicated that Mr M was more pro social and had for example spontaneously cuddled a member of care staff, something which he had never done during his stay.

Discussion

The humanistic principles of social role valorisation implies that the highest goal is to create and support valued social roles for individuals who are at a high risk of being socially devalued. This practically involves enhancing personal competencies and social image via relationships and groupings as well as activities and programmes (Wolfensberger, 1983). Intervention to increase Mr M's communication enabled him to express a number of preferences. He expressed a wish return to his family not to a community unit as planned. In addition, he reported leisure interests in football. This allowed goal planning to develop with Mr M's views and preferences.

Assessment and formulation of Mr M's difficulties was in terms of severe negative symptoms associated with Schizophrenia (Residual Type), (DSM IV, 1994). This frame of reference motivated staff to change and maintain style of interaction with Mr M. It also meant that future moves from the ward may have to be staged gradually due to the previous history of psychotic break down associated with stressors.

Mr M's case has implications for the tertiary level or how a person receives services in relation to dual diagnosis. As services are located in the community there is a growing recognition that emotional problems associated with dual diagnosis need to be identified and treated in these settings (Sturmey and Steven 1993). This may reduce the chances of poorer quality social interaction historically associated with institutional environments.

References

Forrest, A.D. & Ogunremi, O.O. (1974) The prevalence of Psychiatric Illness in a Hospital for the Mentally Handicapped. Health Bulletin, 32, 198-202.

Meadows,G., Turner, T., Campbell,S.W., Lewis,M.A., Revely & Murray, R.M. (1991) Assessing Schizophrenia in Adults with Mental Retardation: A Comparative Study. British Journal of Psychiatry, 158, 103-105.

Reid, A.H. (1985) Psychiatric Disorders in Mental Deficiency. In The Changing Outlook. Edited by A.M Clark, A.D Clark and J.M Berg, Cambridge University Press. UK. 78-96

Sturmey, P. & Sevin, J. (1993) Dual Diagnosis: An Annoted Bibliography of Recent Research. Journal of Intellectual Disabilities, 37, 437-448.

Warden, J. (1993) Grief Counselling and Grief Therapy: A Handbook for the Mental Health Practitioner. Second Edition Spriger Publications. London.

Wolfensberger, W. (1983) Social Role Valorisation: A Proposed New Term for The Principle of Normalisation. Mental Retardation, 21, 6, 234-259.

Hwu, H.G., Tan,H., Chen,C.C. & Yeh, L.L. (1995) Negative Symptoms At discharge Predict Poor Outcome in Schizophrenia, British Journal of Psychiatry, 166, p61-67.

Liddle, P.F. (1987) The symptoms of Schizophrenia: A re-examination of the positive-negative dichotomy. British Journal of Psychiatry, 158, 317-322.

Miller, D.D., Arndt,S & Andreason, N.C. (1993) Alogia, Attentional Impairment and Inappropriate Affect: Their Status in the Dimensions of Schizophrenia. Comprehensive Psychiatry, 34,4, pp221-226.

Murray, R. (1986) Schizophrenia. In Essentials of Postgraduate Psychiatry, edited by P.Hill, R. Murray and A. Thorley. Grune and Stratton: London.

Peralta,V, Cuesta, M.J & Leon, D,J. (1992) Formal Thought Disorder in Schizophrenia: A factor Analytic Study. Comprehensive Psychiatry, 33,2, 105-110.

Reiss S. (1992) Assessment of a Man with Dual Diagnosis. Mental Retardation 30, 1-6.

Turner, T.H. (1989) Schizophrenia and Mental Handicap: An Historical Review, With Implications for Further Research. Psychological Medicine, 19, 301-314.

Chapter Six

MANAGING THE TRANSITION OF A SEXUALLY ABUSED CLIENT FROM LEARNING DISABILITY TO ADULT MENTAL HEALTH SERVICES

Single Case Research Study (III)

Target Journal: Journal of Intellectual Disabilities (see appendix 6.1 for contributors notes).

Abstract

This case refers to a young woman who disclosed that she had been sexually abused prior to her inclusion in special schools and subsequently a learning disability service. Formalised assessment revealed a number of primary mental health problems and little evidence of learning disability. The case is described with reference to the difficulties of transferring clients from a learning disability service to adult mental health provision.

Introduction

Within the learning disabled population those categorised as borderline-mild disabilities are at higher risk of being abused than individuals diagnosed with severe-profound disabilities (Furey et al, 1994). Significant proportions of the general U.K adult population have also experienced sexual abuse (Ussher and Dewberry, 1995). Adult survivors of abuse can suffer a variety long term psychological consequences from loss of self esteem to generalised anxiety and chronic post traumatic problems to dissociative identity disorder (Hall and Lloyd, 1993). The chronic effects of sexual abuse intrude upon school life and the possibility exists that an individual perceived as failing in significant areas of adaptive and intellectual functioning below aged 18 years can be diagnosed as having a primary learning difficulty. These people may find themselves streamlined into special education services carrying implicit assumptions about intellectual functioning and adaptive behaviour. Individuals with primary mental health problems can ultimately becoming cemented within an adult learning disability service. This single case study relates to a young woman who was channelled into special education and learning disability services. This woman felt unable to disclose her experiences of sexual abuse which occurred prior to education failure, until she was 22 years old. No formalised assessment of intellectual functioning or adaptive behaviour had taken place in her adult life. In addition earlier assessments were not available. The case reflects the difficulties of managing the eventual transition to adult psychiatric services.

The Case

At the age of 22 years Miss I was referred by a community learning disability nurse to the team psychologist due to a number of long standing behavioural problems which greatly concerned Miss I and her mother. Miss I was at times aggressive towards her mother and staff involved in her care (community nurse and social worker). She would smash up ornaments and furniture in her mothers house. Less frequently she would rip the heads off her collection of bears and sew them back on. She suffered frequent nocturnal enuresis associated with unspecified nightmares and made suicidal gestures, for example locking herself in the bedroom with paracetomol after announcing she wished to kill herself. There was little evidence of genuine suicidal intent as these events did not result in harm coming to Miss I.

Miss I was diagnosed as having a mild learning disability, hence came under the auspices of learning disability services. She was diverted from mainstream education at the age of 13 to special schools due to severe difficulties in coping with school curriculum. Miss I was moved around a number of adult training centres for learning disabled clients due to her poor attendance and "difficult behaviour". Miss I frequently stated that she wanted a "normal job", and had gained a standard grade in English at level 3. This is the equivalent of a pass in Scottish O' grades and in itself raised doubts that Miss I should be included within a learning disability service. She also expressed an interest in word processing and secretarial skills.

Psychological Assessment

Assessment revealed evidence of a depressive disorder with depressed mood and occasionally tearful. Miss I reported feeling guilty in relation to 'things in the past' that she did not wish to initially discuss, difficulties with sleep onset, suicidal ideation and weight gain. Miss I was able to understand the Beck Depression Inventory and her responses fell within the moderate range.

Miss I also described symptoms of a chronic post traumatic stress disorder. She descried intrusive images, nightmares and occasional flashbacks but did not wish to elaborate on their content. Miss I reported anxiety and anger associated with these symptoms leading to aggressive behaviour. In addition, Miss I reported infrequent self injury, such as cutting into her upper arm. Miss I's self esteem was low describing herself as "ugly and rotten inside". Apart from social contacts through a day centre she had no friends outwith work.

At session three Miss I disclosed that at the age of 13 she was sexually assaulted en-route home from school by an older boy known to her at school. The assault itself was alleged rape and involved verbal threats and violence. Following these alleged events Miss I's school work deteriorated when she was assessed and diverted to special schooling. Miss I reported a significant degree of guilt at the time, she perceived that she was being moved due to having 'participated' in this assault and was unable to disclose these experiences at the time. Important factors prior to abuse related to the separation of her parents, she remembered frequent arguments before her father finally left home.

Supportive psychological intervention was carried out to allow Miss I to start to discuss traumatic memories, develop coping strategies to counter depressive and anxious symptomatology. Although it was apparent from clinical psychological assessment that Miss I was unlikely to fit criteria for a learning disability there was a service demand for formalised assessment.

The Weschler Adult Intelligence Scale -Revised was used (Weschler, 1981). Miss I had a full scale IQ of 73 (95% confidence interval, 68-78), a Verbal IQ of 75 (95% confidence interval 70-80) and Performance IQ of 71 (95% confidence interval, 63-79). Some conventions note that IQ from 50-55 to approximately 70 is found in mild "mental retardation" (DSM IV, 1994). Miss I's performance was reduced due to her emotional difficulties such as depressed mood. This performance was therefore likely to be an underestimate of her abilities. Clinical psychological assessment indicated Miss I had an obviously high level of adaptive skills, for example being able to make her own meals, however, her circumstances and emotional difficulties interfered with the application of these skills. She did not meet diagnostic criteria for learning disability.

Following discussions with a psychologist in an adult community mental health team Miss I was introduced to the psychologist and the team in conjunction with ongoing input from a learning disability team. Miss I reported great anxiety in changing services and worried about losing contact with familiar people. As Miss I became more comfortable with gradual this transition learning disability team input was phased out.

Discussion

Intrafamilial sexual abuse is the most common form of abuse, but, it has been estimated that up to 54% of children abused in the Northern Ireland Incidence Study were sexually abused by known persons not living in the home (Research Team, 1990). Apart from clinical samples, non clinical studies indicate that among abused children intrafamilal abuse is underrepresented.

There are a variety of negative effects following sexual abuse which transcend the identity of the perpetrator. Investigations into the effects of sexual abuse are limited by the effects of pre-existing or concurrent difficulties, such as family discord or social disadvantage (Smith and Bentovim, 1994). In Miss I's case pre-existing stressors related to the separation of her parents. Although previous stressors to sexual abuse are factors which influence the effects of abuse, a number of emotional and behavioural effects are more directly related to abuse experiences (Conte and Shuerman, 1987).

A history of sexual abuse is associated with considerable mental health and adjustment problems into adulthood long after abuse itself (Fromuth, 1986). Traumatic sexualisation, powerlessness, sense of stigma and enforced silence are particular etiological factors influencing the development of problems into adulthood (Hall and

Lloyd, 1993). A sense of responsibility for the abuse, as in this case, are commonly reported by other victims in clinical studies (Byrne and Valdeserie, 1982). Other emotional effects may relate to a difficulty in trusting others, this was a difficult issue when suggesting to Miss I that she may benefit from changing to a different service.

Depressed mood commonly associated with anger are frequently reported consequences of sexual abuse. Miss I did not wish her mother to know about abuse, but, this was an issue the mental health services planned to address. As in Miss I's case anger is commonly expressed by females to their mothers (Smith and Bentovim, 1994). Anxiety or post traumatic problems such as flashbacks, intrusive images and startle responses are part of the generally fearful picture following abuse. Common behavioural reactions to abuse are suicidal thoughts and activities such as burning with cigarettes and cutting wrists. There is speculation that these behaviours are attempts by victims to make themselves less attractive or block out memories of abuse.

A number of abuse factors influence long term psychological outcome for the victim. Physical violence and coercion result in short and long term negative consequences. In some research penetrative forms of sexual violence have been strongly associated with longer term negative effects (Ussher and Dewberry, 1995).

Models of treatment of sexual abuse relate to emotional and cognitive processing mainly involving exposure to memories of abusive acts within a safe and supportive environment. Concomitant psychological problems such as depression and low self esteem can also be effectively managed using cognitive behavioural approaches (Hall and

Lloyd, 1993). Discussions between professionals in learning disability and mental health teams agreed that the overriding concern was to address these problems from a mental health perspective. A key point about this case was that clinical psychological assessment indicated that Miss I was unlikely to be someone with a learning disability. Formalised intellectual assessment was therefore required to confirm that Miss I did not fit diagnostic criteria for learning disability.

Operational diagnostic criteria for learning disabilities traditionally emphasise combining intellectual functioning (eg IQ) but, there is a degree of artificiality with intelligence approaches to assessment. The notion that intelligence is a unitary concept and that I.Q tests actually measure this general mental ability with linguistic and cultural purity is up for debate. Intelligence theories tend to emphasise " a mosaic of mental abilities that are relevant to our world" (Kirby, 1991). To say someone is of normal intelligence is misleading as it may be more important to consider someone's skills and weaknesses. It is also highly questionable whether IQ offers anything of value to individuals with a learning disability. In Miss I's case due to the possibility of recommending inclusion in mainstream adult psychiatric/ psychology provision there was an implicit service demand to justify such a change hence the Weschler Adult Intelligence Scale was employed.

Miss I agreed to attend the community mental health team to 'test out' whether or not she was agreeable to change. The changeover was handled sensitively and gradually by members of both teams and involved giving a sense of control and self efficacy to Miss I. This was considered important due to the nature of her difficulties. This case highlights the importance of cross service communication and co-operation between professionals when managing the transition of clients between services. Having a long-standing involvement with particular service does not necessarily imply by default that it is the most appropriate for a persons needs.

References

Byrne, J.P. & Valdeserri, E.V. (1982) Victims of Childhood Sexual Abuse: A Follow up Study of a Non Compliant Population, *Hospital and Community Psychiatry*, 33, 938-940.

Conte, J.R. & Shuerman J.R. (1987) Factors Associated with Increased Impact of Sexual Abuse, *Child Abuse and Neglect,* 11, 433-442.

Fromuth, M.E. (1986) The Relationship of Sexual Abuse with later Psychological and Sexual Adjustment in a Sample of College Woman. *Child Abuse and Neglect*, 10, 5-15.

Furey, E.M. Granfield, J.M. & Karan, O.C. (1994) Sexual Abuse of Adults with Mental Retardation: A Comparison of Victim Characteristics. *Behavioural Interventions*, 9, No2, 75-86.

Kirby,J.R. (1991) Rethinking Learning Disability. *Development Disabilities Bulletin*: Special Issue, 19,2, 1-11.

Hall,L. & Lloyd,S. (1993) *Surviving Child Sexual Abuse: A Handbook for Helping Woman Challenge Their Past.* 2nd Edition, Falmer Press, London.

Research Team, (1990) *Child Sexual Abuse in Northern Ireland: A Research Study of Incidence*. GreyStone, Antrim, Northern Ireland.

Smith, M,. & Bentovim, A., (1994) Child Sexual Abuse, in *Child and Adolescent Psychiatry: Modern Approaches*, Edited by M., Rutter, E. Taylor, and Hersov, L, Blackwell Publications, London.

Weschler, D. (1981) *Weschler Adult Intelligence Scale- Revised Manual*, The Psychological Corporation, Harcourt Publishers.

Ussher, J.M. & Dewberry,C. (1995) The nature and long term effects of Childhood Sexual Abuse: A survey of Adult Woman Survivors in Britain. *British Journal of Clinical Psychology*, 34, 177-192.

Chapter Seven

Small Scale Service Evaluation Project

Evaluation of a Sex Education Group for Individuals with Learning Disabilities

Target Journal: British Journal of Learning Disabilities (See Appendix 7.1).

Author

John J Marshall

Department of Psychological Medicine

University of Glasgow

Gartnavel Royal Hospital

Glasgow.

Summary

This study evaluates the effectiveness of a sex education group known as the Healthly Relationships Course. Levels of knowledge in a number of Socio-Sexual domains were assessed prior to and following this intervention, as well as Socio-Sexual attitudes. In addition, clients satisfaction with the programme was surveyed. Increased levels of knowledge were identified following intervention, as well as shifts in attitudes in a more positive and flexible direction. Qualitative differences were identified between male and female participants. Clients positively evaluated the programme, however a number of negative aspects were identified. The results are discussed with reference to service implications.

Introduction

The ideological drive, pervading health authorities, social work departments and voluntary organisations, which emphasises that individuals with a learning disability should enjoy the same rights, responsibilities and opportunities as others has been found wanting in the area of sex education .

A number of factors have constrained the development of sex education programmes in the past. Legislation has been out of step with current positive influences. The legal status of people with learning disabilities is only recently becoming clearer and in many areas service providers may be obliged to work without really knowing what is right and wrong in the eyes of the law (Booth and Booth, 1992). Many adults with Learning

Difficulties have simply not had access to positive programmes of sex education (Craft, 1994).

Despite these difficulties there are a number of positive practical, philosophical and political pressures which are making it more likely that service providers develop guidelines for implementing strategies which consider the sexuality of their clients. The momentum of community care which is leading to comparatively more personal freedom is a situation which may be conducive to developing relationships. In addition, there are risks of exploitation in the community.

> "Sex education , to provide knowledge and understanding of ones own sexuality, what forms of behaviour are culturally andsocially appropriate and the right to say no to unwelcome advances, can empower an individual to make choices ". (Booth and Booth, 1992).

Libertarian notions of the philosophy of normalisation also underpin the growing provision of appropriate and structured sex education.

> "It is now agreed that education is a better approach than repression, segregation or incarceration " (Gath, 1988).

The increasing publication of guidelines by service providers bring discussions of sexuality into the open, are a public statement , allow a framework for consistency, give protection to staff and may foster more positive attitudes and practices (Booth and Booth, 1992). In addition this has led to more recent improvements in the areas of client assessment, staff training and intervention in terms of sex education (Craft 1994).

Where Sex Education does take place it can be considered that the programmes are too narrow and the assessment of reliability, validity or effectiveness of programmes is infrequently carried out (Mcabe, 1993).An awareness of these issues is essential to good clinical practise when designing and implementing a sex education programme.

These external pressures as well as anecdotal evidence of difficulties relating to aspects of clients socio-sexual knowledge, attitudes and relationships prompted the service providers of a day centre run by Central Regional Council to request input from Clinical Psychology services. This was in order to initiate a plan in developing, conducting and evaluating a sex education programme.

Aims

The main objective of this study was to evaluate whether a group educational programme would increase service users levels of socio-sexual knowledge. In addition, to determine whether the educational group would be conducive to fostering more positive attitudes to socio-sexual matters. The study was also concerned with service users perceptions of this educational programme.

Increasing socio-sexual knowledge was seen as important in allowing service users to exercise more informed choices in relation to the sexual aspects of their lives. Service users who develop more positive attitudes about this very important aspect of themselves may benefit in terms of their levels of confidence and self worth. Finally, it is important to evaluate perceptions of such a programme to genuinely involve service users in the decision making process of how future programmes develop.

Methods

Content of Programme

A broad based programme was developed between Clinical Psychology services and staff at the centre (see table one). The rationale of the Healthy Relationships Programme was based in the notion of providing an atmosphere conducive to exploring everyday relationship difficulties, develop a problem solving approach and raise awareness of the emotional aspects of coping. In addition, the clear and unambiguous provision of information related to sex and sexuality allows individuals to make more informed choices about their lives.

Table One: Topics Covered in Healthy Relationships Course

Session Number	Session Title
1	Introduction to Range of Human Relationships
2	Appropriate Physical Contact
3	Freindships
4	Parenterships
5	Trust and Being Let Down
6	Our Bodies
7	Living With Our Bodies
8	Attractiveness
9	Sexual Relationships/ Contraception
10	Making Choices
11	Sexually Transmitted Diseases
12	Good Manners
13	Coping In Relationships
14	Evaluation of Course

Participants

Ten service users with mild learning disabilities were incorporated into the Healthy Relationships Programme. In terms of inclusion criteria all of the male service users displayed evidence of reduced levels of knowledge regarding Socio-Sexual matters and held quite negative attitudes about women. They also were or had been involved in relationships. In addition, there were frequent breaches of trust in relationships and arguments between service users. This was due to the reported number of other relationships male service users became involved in out with their regular partners.

Although the main focus for intervention was knowledge and attitude change, a number of male service users displayed inappropriate sexual behaviour, for example touching other service users, however knowledge and attitude change were seen as a fundamental prelude to changing these behaviours.

The men's group age ranged between 26 and 39, mean age was 24.8, n=5). They were selected by staff at the day centre. Evidence of reduced knowledge and negative attitudes toward socio-sexual matters was also a prerequisite for entry onto the Healthy Relationships programme for females at the day centre. There were, for example, prevalent myths in relation to contraception and sexually transmitted diseases.

The majority of female service users also lacked in assertiveness skills particularly in relation to sexual matters and a number were quite vulnerable in their current relationships. The woman's group ages ranged between 27 and 42 years, (mean age of 33.2, n=5).

Measures

The Brook Questionnaire (Brook Advisory Centre, 1988) and Socio Sexual Knowledge and Attitude Test (SSKAT, 1980) were employed in this study. Specific domains from each assessment were used. The strengths of the Brook questionnaire lay in its emphasis on assessing participants knowledge. Although the Brook questionnaire is not standardised it is relatively modern and as such has greater face validity.

In order to identify any attitudinal change the attitudinal components of a number of domains of the SSKAT were used. When evaluating service users views of the programme a number of open ended questions were employed to identify perceived positive and negative aspects of the course.

Format

It was decided to have separate male and female groups. Arguably, a mixed group would have not been conducive to increasing communication. For example the female service users felt that it may have made discussions about sensitive topics in relation to women's health more difficult.

The overall philosophy of the groups was one of openly encouraging weekly discussion on a number of topics highlighted by pictorial, video and slide media (Family Planning Association, 1993, Forth Valley Health Board 1985, 1988 ,1991).

Clinical Psychology input related to guidelines on the development and implementation of the programme as well as its evaluation. One Day Centre Manager and a Community Nurse conducted the group sessions. On occasion Psychologist (JM) was also involved in group work with specific topics, for example sexual arousal and masturbation.

Psychologist (JM) administered sub-domains of The Brook Questionnaire and SSKAT prior to the first session of the Healthy Relationships Programme and following the last session. In addition (JM) interviewed service users to determine level of satisfaction with the programme.

When surveying service users attitudes toward the Health Relationships Programme in order to minimise clients expectations of having to give favourable responses, service users were also asked: "if you were going to run the course again how would you make it better ?". All responses were classified by an independent rater.

Results

Mean percentage correct scores were calculated from female service users responses on a number of domains of the Brook questionaire. As can be seen from Table two, increases in the percentage of correct scores were found following the Healthy Relationships Course among all the domains assessed by the Brook questionnaire, for the female participants. However, greatest improvements in correct responses were found in the areas of Body Parts, Masturbation and Sexual Assault.

Table Two:Mean Percentage Correct Scores on Brook Questionnaire (Female Group, n=5)

Brook Sub-test knowledge area	Pre Intervention	Post Intervention
Human Relations	77.0	95.4
Body Parts	72.6	100.0
Female Parts	51.2	66.6
Male Parts	65.0	90.0
Masturbation	34.8	62.5
Social Behaviour	95.2	97.5
Sexual Assault	26.8	86.7
Intercourse	61.6	85.7
Total Correct	51. 5	85.8

In a similar fashion mean percentage scores were obtained from male responses on the Brook Questionaire. Table three indicates improvements in mean percentage correct responses, for male participants, following intervention in all domains assessed by the Brook Questionnaire. Areas of greatest change for male service users were Body Parts, Female Parts, Masturbation and Sexual Assault.

Table Three:Mean Percentage Correct Scores on Brook Questionnaire (Male Group, n=5)

Brook Sub-test knowledge area	Pre Intervention	Post Intervention
Human Relations	96.4	100.0
Body Parts	70.4	100.0
Female Parts	29.0	73.3
Male Parts	70.0	95.0
Masturbation	40.2	75.0
Social Behaviour	85.4	100.0
Sexual Assault	60.8	86.7
Intercourse	61.6	91.4
Total Correct	82.8	90.9

A mean index score relating to service users attitudes was calculated from the SSKAT assessment. Attitudinal changes are reflected in Table four where scores over 75 relate to more positive attitudes in the sub-domain assessed. Scores between 25 and 75 are associated with more neutral attitudes. Attitudes of male participants in all domains moved in a positive direction following the Healthy Relationships programme.

Male attitudes to masturbation prior to intervention were in a negative direction. This is particularly the case when it took place within the department of psychological medicine. There were greater shifts in attitude following intervention in relation to this sub-domain as well as in relation to the intimacy sub-domain.

Table: Four: Mean Attitude Index Score from SSKAT (Male group, n=5)

Sub-domain	Pre-intervention	Post-intervention
Dating	60.0	63.8
Intamacy	73.0	93.3
Intercourse	53.3	60.0
Masturbation	42.0	75.0

As far as attitudinal change is concerned for female participants Table five indicates change in a more positive direction for all areas assessed by the SSKAT, but as with the males greater change occurred in the areas of intimacy and masturbation.

Table: Five: Mean Attitude Index Score from SSKAT (Female group, n=5)

Sub-domain	Pre-intervention	Post-intervention
Dating	54.0	58.8
Intamacy	44.4	66.6
Intercourse	61.1.	70.3
Masturbation	41.3	61.5

In terms of the evaluation of service users perception of the Healthy Relationships Course, when asked "what did you think about the group over all ?" responses were classified by an independent rater and appear on Table six. The responses ranged from "it was okay", a neutral response, to "It was great, I liked it a lot" , an extremely positive response. The majority of service users gave positive responses.

Table Six: Service User Satisfaction with Healthy Relationships Course

Type of Response	Number of Clients Responding
Extremely Positive	2 counts
Positive	7 counts
Neutral	1 count
Negative	0 counts
Extremely Negative	0 counts

Table seven classifies service users responses in relation to positive aspects of the course which were identified when asked the question; "What was good about the Healthy Relationships course. ?".

A frequent response referred not to factors within the content of the course but to the social context in which the course occurred (see table seven). For example one service user said "we were altogether, talking about relationships, meeting people". Three of the female service users highlighted women's health information in their responses, for example "learning about the pill". Three others responded that the focus on relationships was important to them, for example " talking about boyfriends and girlfriends".

Table Seven: Positive Aspects of the Course Identified

Aspect of the Course	Number Responding
Talking with others	3 counts
Woman's Health Information	3 counts
Coping with Relationships	3 counts

Six service users listed a number of negative aspects of the healthy relationships course, 4 service users reported that they could not identify anything negative. The most frequent comment from the six service users related to embarrassment caused (see table eight). One response of a service user encapsulates this category of answers; "did not like talking about making love, dirty, I was embarrassed".

Table Eight: Negative Aspects of Healthy Relationships Course

Negative Aspect	Number of responses
Embarrassment Caused	5 Counts
Difficulty Understanding Material	1 Count
Too Much Information	4 Counts
Males service users not prioritised	1 Count
Not enough information on marriage	1 Count
Not enough people on course	1 Count
None Identified	4 Counts

In addition, there were 4 responses relating to the view that there should be less information, for example " it was sometimes difficult and there was a lot to remember". Amongst the six who identified negative aspects, one individual also hoped that there would be more service users in the group, another participant wanted more specific information about marriage and one service user also asked that the male group received priority before the female group in the day.

Discussion

Baseline data from the Brook questionnaire and SSKAT indicated lowered levels of knowledge and few positive attitudes among both female and male participants in relation to socio-sexual matters. Amongst this group the need for the provision sex education is abundantly clear. In particular, there were lowered levels in relation to knowledge about masturbation and sexual assault. One female service user, for example, responded that masturbation might lead to her becoming pregnant.

The implications for a learning disability service are clear. Services which aspire to create valued options in various aspects of service users lives should also be involved in developing satisfying and appropriate sexual behaviours (East Sussex County Council, 1992).

In contrast to the baseline knowledge of male service users, female participants displayed lower levels in relation to sexual assault. When shown the stimulus picture in the Brook Questionnaire of a sexual assault taking place one service user reported that they were boyfriend and girlfriend kissing. Although other female service users identified the aggressive intent of the assailant, they thought it unnecessary to report this to family, carer's or police.

When setting service standards for the implementation of sex education programmes it has been recommended that the essential elements are health education, increasing knowledge, feelings, attitudes and values (Craft, 1994). However, it is clear that issues related to confidence and assertiveness should also be fundamental targets for change.

Possession of assertiveness skills are necessary in order to exercise informed choices in relation to sexual matters.

Female service users responses on the SSKAT indicated more negative attitudes toward intimacy than male service users (Table five). Negative attitudes in this domain may have reflected some female service users consternation with physical contact with male partners due to previous negative experiences.

The issue of masturbation highlights the problem of negative and rigid Socio-Sexual attitudes. The majority of male participants were adamant that masturbation was detrimental to health, for example one service user stated "it is very bad and will make you ill" or "you will go blind". One may speculate that service users who openly reported that they did masturbate whilst holding negative concomitant attitudes were vulnerable to unnecessary levels of guilt and worry.

Structured, planned and broad ranging sex education in the form of the Healthy Relationships course reduces the likelihood of a reactive and crisis oriented service. It is clear that inclusion on the Healthy Relationships Course led to overall improvements in the knowledge of participants as well as the development of more positive and flexible attitudes. This confirms previous findings of the utility of sex education in terms of knowledge and attitude change (Thompson, 1991).

There were no large differences in quantitative improvements between male and female participants, however qualitative changes reveal more about differences between the baselines for both groups of service users.

Improvements in knowledge for male participants in the sexual assault domain related more to identifying limits to behaviour and the emotional impact inappropriate sexual approaches have on victims. For example one male participant when asked about sexual assault in the Brook Questionnaire before intervention, reported that " he is only trying to go out with her". During reassessment this service user stated that "this is rape, he should not do that, she should get the police to him".

Changes in the Sexual assault domain for female service users related to increasing assertiveness and in giving correct response as to how to deal with assault.

Common myths were apparently dispelled in relation to male service users knowledge about masturbation, for example when asked what happened after masturbation at follow up all the men totally refuted notions of negative health consequences and were accurately able to describe for example erection and ejaculation.

Increases in knowledge and attitudes amongst female participants to masturbation were not as great possibly reflecting wider reluctance to acknowledge this aspect of female sexuality.

Such views of sexuality originate amongst those mostly involved in the socialisation of service users. This would imply that a service addressing such problems should train their staff and increase their understanding of how their own attitudes and values can influence others.

One question related to this issue is who should carry out sex education programmes ? In this study the groups were conducted by a Day Centre Manager and Community Nurse with evaluation conducted by Clinical Psychology Services. All professionals were involved in developing the programme. A more accurate question may relate to who is comfortable and confident when implementing such courses ?

Systems of review for sex education and the training of staff are important in order to protect service users and staff involved. Service users should also be widely consulted on the content and implementation of any course. This makes the course more in tune to the individuals involved and may lead to greater knowledge and attitude change.

Service users tended to perceive the Healthy Relationships programme in a positive manner. It is of interest that although six service users identified aspects of the content of the course as beneficial, four service users noted that simply being in a group was important to them. This may have been generally indicative of restricted opportunities for developing other social relationships.

A number of service users identified the negative aspect of embarrassment caused to them when discussing more sensitive sexual topics. It may be that future courses need to take more account of this and present information more sensitively in these areas. Other responses that may affect future courses is the fact that a number of service users felt that the course lasted too long. Future courses may have to develop a more concise syllabus.

Although knowledge and attitudes were major targets for change, other problems such as some male inappropriate behaviour and reduced assertiveness among some in the female group were not directly assessed. However, anecdotal reports by staff indicate significant behavioural changes among a number of service users. One example relates to a female service user who appeared socially anxious in early sessions and displayed more confident and assertive behaviours following intervention.

However, groups of this sort are not appropriate places for addressing long standing behavioural problems. When identifying standards of excellence for implementing a sex education service staff should be aware that these kinds of interventions represent an appropriate starting point. Those involved in running sex education should not be expected to provide a quick fix for certain behaviours. Provision should be maintained for individual work, counselling couples and for drawing upon outside expertise.

References

Booth,T. & Booth,W. (1992) Practise in Sexuality Mental Handicap Vol 20, No 2.

Brook Advisory Centre (1988), Questionaire on Social and Sexual Knowledge, London: Brook Advisory Centre.

Craft, T (1994) Issues in Sex Education for People with Learining Disabilities in the United Kingdom, Sexual and Marital Therapy, Vol 9, No2.

East Sussex County Council (1992) Personal Relationships and Sexuality: Guidlines for Carers Working with Learning Disabilities (Brighton, East Sussex County Council).

Forth Valley Health Board (1988) Living Together.

Mcabe, M.P. (1993) Sex Education Programmes for People with Mental Retardation, Mental Retardation, Vol 31(6) 377-387.

Forth Valley Health Board (1985) Men and Women.

Forth Valley Health Board (1992) One to One HIV/AIDS Video.

Family Planning Association (1994) Periods, What You Need to Know.

Thompson,S.B.N. (1991) Sexuality Training in Occupational Therapy for People with a Learning Difficulty, British Journal of Occupational Therapy, August,54(8).

Wish, S., McColms,A. & Edmonson,M. (1980) Socio-Sexual Knowledge and Attitude Test, Stoeling Publication, Illanois.