Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

and

Research Portfolio

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Evaluation of Client and Staff Satisfaction with a Goal Planning Project Implemented with People with Spinal Cord Injuries

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Summary

This study assesses client satisfaction, and canvasses staff opinions concerning the first year of a Goal Planning rehabilitation programme implemented with inpatients who had suffered spinal cord injuries. Questionnaires were completed by 33 patients. As a keyworker system is an integral part of Goal Planning, separate questionnaires were completed by 13 staff/keyworkers. The results indicated that patients believed Goal Planning to be informative about their injury and helpful in promoting a sense of control over their rehabilitation. In addition, a positive, and statistically significant association was found between perceived informativeness and control and the implications for successful rehabilitation are considered. Staff also gave favourable feedback regarding the perceived benefits of Goal Planning for patients, relatives and staff, although they acknowledged the increase in their workload as a result.

Key words: spinal cord injury (SCI); rehabilitation; control.

Evaluation of Client and Staff Satisfaction with a Goal Planning Project Implemented with People with Spinal Cord Injuries

Introduction

The British Government publications *The Health of the Nation*[1] and *The Patients' Charter*[2] both stipulate the importance of fully involving and informing patients about their treatment. In the area of rehabilitation, increasing patient participation and control has been linked to favourable outcomes across a wide range of health care settings[3]. Specifically amongst people with spinal cord injuries, Norris-Baker et al [4] have shown inpatient involvement in rehabilitation to be the best predictor of medical and behavioural outcome status. In particular, these authors found that patients who participate in active rehabilitation are more likely to be independent after discharge from hospital and less likely to be readmitted with medical complications.

Based on such findings, Kennedy et al [5,6] have developed "Goal Planning": a needs driven approach with the aim being "to empower people with a spinal cord injury to preserve, develop and reintegrate quality life goals, through appropriate scientifically-based interventions, a needs-determined service and responsive staff support" (p.17). With an emphasis on involving patients in decision making and minimising institutionalisation and dependency, Goal Planning focuses not only on the physical aspects of a person's injury, but on a wide range of skills necessary for reintegration to the community. They point out that "these necessary skills will only be acquired if individuals understand the rehabilitation process, are fully involved in decisions about this process, agree key goals, and play an active part in their rehabilitation" (p.17).

The Goal Planning process begins with a detailed needs assessment and then uses a behavioural change strategy originally developed by Houts and Scott [7] for working with people with learning disabilities. This approach is characterised by a recognition of the importance of client involvement and an emphasis on needs and strengths rather than weaknesses and disabilities. It attempts to specify goals in clear behavioural terms and set realistic targets while recognising the importance of professional input from a trained multi-disciplinary team. Goal Planning operates on the premise that providing patients with information about their condition and their rehabilitation, and promoting autonomy in choice and decision making, facilitates effective coping and thus facilitates rehabilitation. Kennedy et al [5] have shown that where a Goal Planning approach has been formally adopted with spinally injured patients, they spend more time in therapy areas during the day, less time in solitary activity and more time in verbal interaction. Thus Goal Planning may be an effective way of maximising the therapeutic potential of the rehabilitation environment.

This study attempts to assess client satisfaction in the first year of a Goal Planning programme which was used to direct the rehabilitation of patients with spinal cord injuries admitted to the Queen Elizabeth National Spinal Injuries Centre (QUENSIC) in Glasgow. Although there are perhaps methodological limitations and theoretical difficulties in interpreting data from customer feedback, Trinder[8] points out the importance of considering service users' views on a particular service as their needs and opinions may be quite different from those which service providers might expect. Given this, Bucknall[9] suggests that the appropriate place for consumer opinion surveys is "as an indicator of which aspects of the service might be changed to improve clients' responses".

The aims of the present study are threefold:

1. To assess whether the aims of Goal Planning as outlined by Kennedy and Pearce[6] have been met at QUENSIC. Specifically, whether patients considered the Goal Planning approach to have been helpful in providing information about their condition, whether they felt it increased their sense of control over their rehabilitation and whether there were any areas of their rehabilitation they felt Goal Planning did not cover.

2. To investigate the relationship between information provision and control with the aim of clarifying those factors which foster participation in rehabilitation.

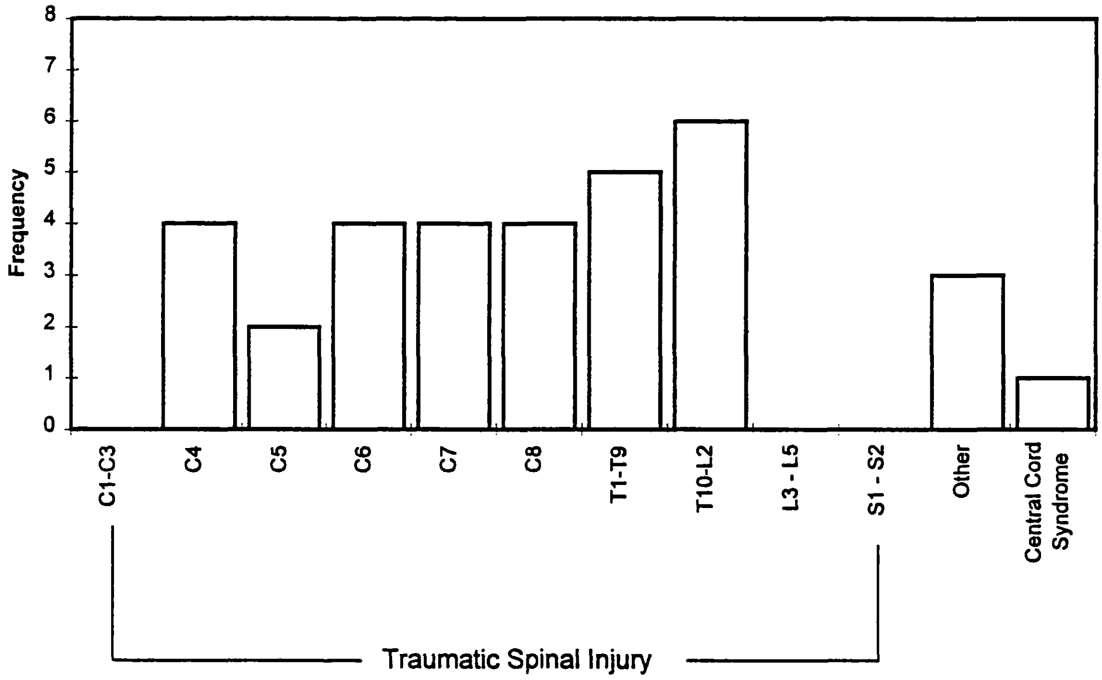
3. To assess staff perceptions of Goal Planning in terms of its usefulness, its impact on their workload and their ideas about areas where their training, or the system as a whole, might be improved.

Methods

Subjects

Patient Group. The sample consisted of 33 patients with spinal cord injuries who participated in Goal Planning during their hospital admission. Of these patients, 27 (82%) were male and 6 female and the age range was from 16 to 72 years (mean age of 38.6 years). Patients came from a fairly representative cross section of regions within Scotland, with the majority (42%) from Strathclyde region. Figure 1 shows the distribution of level of injury of patients. Fourteen (42.%) patients had an injury from C7 or above. One patient had a central cord syndrome and, of the three patients represented on the graph in the "other" category, one had spinal tuberolosis, one had a tumour and the third had "Locked In" syndrome. The modal injury category was between T10 and L2. Almost two thirds (21) of these injuries were complete. Two thirds (22) of the patients who had participated in Goal Planning had been discharged by the end of the assessment period. Of these, the mean length of admission was 21.3 weeks (range = 7 - 37). The first Goal Planning meeting was held on average 7.1 weeks (range = 2 - 18 weeks) after admission.

Figure 1 : Distribution of Level of Patients' Injury



Complete : n = 21
Incomplete : n = 12

Staff / Keyworker Group. A total of thirteen staff members participated in the study, nine (69%) of whom were female. Seven (54%) were nursing staff and the remaining six were split equally between physiotherapy and occupational therapy.

Measures

Patient and staff views were elicited using specially constructed questionnaires (see **Appendix 1.2**).

Procedure

Prior to the introduction of Goal Planning, the Centre's multidisciplinary staff team all underwent keyworker training directed by the Centre's clinical psychologist and using a training package based on that of Kennedy [5].

Upon admission to the Centre, patients were allocated a member of staff to be their keyworker. The keyworker was responsible for completing an initial needs assessment[1] and organised and facilitated subsequent Goal Planning meetings as well as acting as an advocate for the patient where necessary. The frequency of Goal Planning meetings varied from weekly to monthly according to individual needs and circumstances and was at the discretion of the therapists involved. However, the average frequency of meetings was fortnightly. Goal Planning finished when the rehabilitation targets identified as a result of the original needs assessment were achieved. The needs assessment was again completed at this point as a safety check to ensure that nothing had been missed. Although at this point, the patient was deemed to have completed rehabilitation, discharge was not always possible for a variety of practical reasons such as delays in re-housing and housing adaptation.

Towards the end of Goal Planning, the Centre's psychologist administered questionnaires to patients and assisted those who were unable to complete them. The patients for whom the

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[1] The Needs Assessment covers 14 key areas in SCI rehabilitation and was based on a similar document used in Stoke Mandeville Spinal Injury Centre and adapted for use with patients in QUENSIC. The schedule used can be obtained from the author.

psychologist had been keyworker (n=4) were omitted from the final sample as they may have felt particular pressure to give socially desirable responses.

In addition to the information obtained from the patient questionnaires, demographic details were obtained from a detailed review of case notes.

Keyworkers also completed questionnaires assessing their views on the Goal Planning process once Goal Planning had been completed.

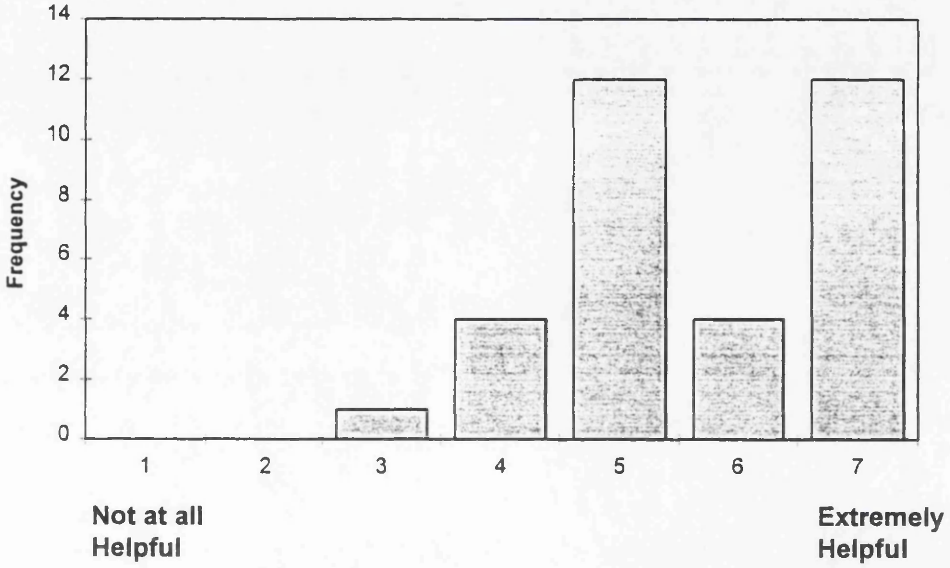
Results

Patients' Responses.

Perceptions of Goal Planning: Patient ratings of informativeness.

All patients reported being aware that a Goal Planning programme was being used in their rehabilitation. Figure 2 illustrates patients' ratings of how helpful they found Goal Planning to be in providing information about their condition. As we can see, 36% (7) people found it to be "extremely helpful" in this respect. The modal response on the scale from 1 ("not at all helpful") to 7("extremely helpful") was 5, indicating that patients generally seemed to find Goal Planning to be informative about their condition.

Figure 2 : Patients' Ratings of How Helpful They Found Goal Planning to be in Providing Information

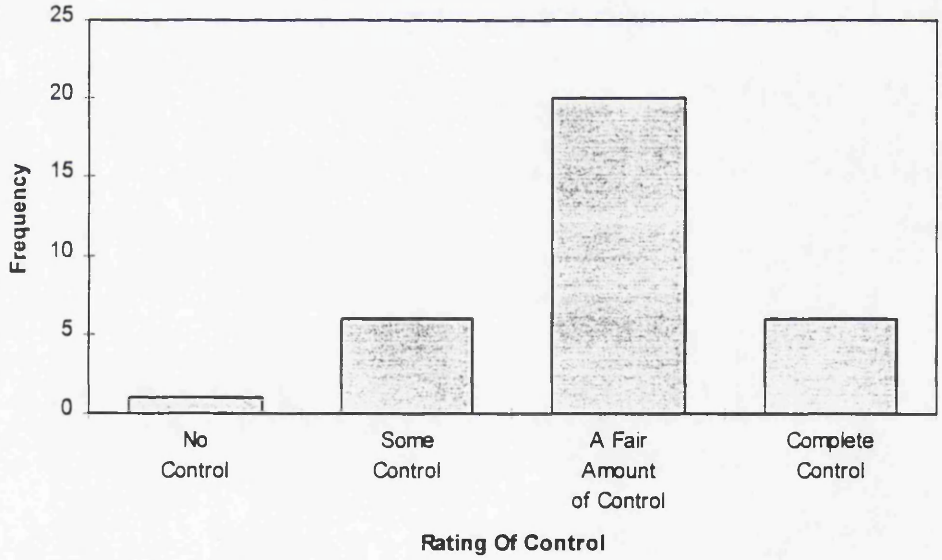


When relatives or friends were involved in the Goal Planning process (i.e. they attended Goal Planning meetings regularly), they were requested to indicate how helpful they had found Goal Planning to be in helping them understand rehabilitation. In just over half of cases (18), relatives or friends completed this part of the questionnaire. Of these, 8 (44%) relatives/friends indicated that they had found Goal Planning to be "extremely helpful" in this respect, with the remainder of responses falling within the "helpful" half of the rating scale.

Patient ratings of control over rehabilitation.

Figure 3 illustrates patient perceptions of control over planning their rehabilitation. The majority of patients (61%) felt they had "a fair amount of control", while 6 patients (18%) felt Goal Planning offered "complete control". One patient felt it offered no control.

Figure 3 : Patients' Perceptions of Control Over Planning Their Rehabilitation



The basic premise of the Goal Planning approach is that by increasing patient information about their condition and rehabilitation, perceived control is improved and thereby rehabilitation is facilitated. As the data in question is ordinal scaled, it necessitated the use of a non-parametric correlation and Kendall's Tau B was chosen on the basis that there was likely to be a substantial number of tied ranks [10]. A Kendall's Tau B correlation produced a correlation coefficient of .44 ($p < .002$) indicating that there is a significant relationship between the provision of information and control over rehabilitation.

Kendall's Tau B correlations were also carried out in order to assess whether perceptions of informativeness or control were associated with level of injury. Correlation coefficients of .06 and .09 were obtained between level of injury and informativeness and control, respectively, indicating that there were no significant associations (at $p < .05$ level of significance) between either of these two variables and level of injury.

Mann-Whitney tests were used to compare ratings of informativeness and control for those with complete and those with incomplete injuries. In terms of perceived informativeness, mean ranks of 17.10 and 16.83 were found for those with complete ($n = 21$) and incomplete ($n = 12$) injuries, respectively (high scores indicative of high perceived informativeness): $U = 124.0$, $W = 202.0$, exact two-tailed probability - $p = .9559$. Thus, those with complete and those with incomplete injuries did not appear to differ significantly in their perceptions of how informative they found Goal Planning to be concerning their injury.

Neither were there significant differences found in perceived control over rehabilitation for individuals with complete and incomplete injuries: Mann-Whitney tests gave mean ranks of 18.57 and 14.25 for those with complete and those with incomplete injuries respectively (a high score is indicative of high perceived control): $U = 93.0$, $W = 171.0$, exact two-tailed probability - $p = .2276$.

As length of admission was determined by factors other than the efficiency or otherwise of rehabilitation (e.g. housing issues), this relationship was not considered.

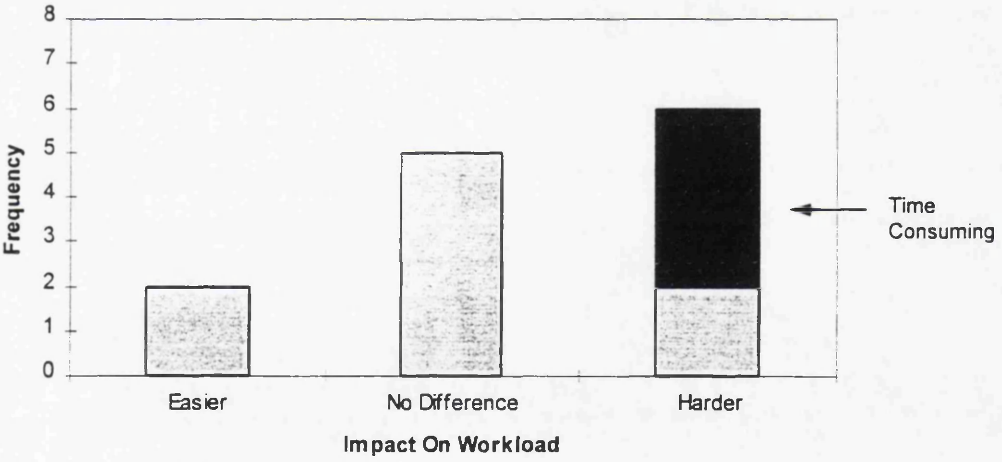
Qualitative information was also sought concerning patients' views on any areas they felt their rehabilitation programme did not cover. Four patients (12%) reported feeling that there were areas of rehabilitation which Goal Planning did not cover. Answers provided were disparate and included "medical problems", "sexual issues", "paralysis", "sweating under arms" and "payment for bed". No two patients mentioned any one of these areas.

Keyworker responses

Twelve keyworkers (92%) reported feeling that Goal Planning was "useful in every case" in spinal injuries management, and the remaining keyworker indicated that they felt it to be "sometimes useful". All keyworkers responded that they felt Goal Planning to be beneficial to patients, staff and relatives.

It was felt that an important factor in determining staff satisfaction with a new form of intervention might be their beliefs about how it impinged on their workload. As Figure 4 illustrates, two keyworkers (15%) reported feeling that it made their workload "easier", five (39%) that it made "no difference" and six (46%) that it made their workload "harder". However, of the latter six keyworkers, four specifically commented that Goal Planning did not make their workload "harder" *per se*, but that it tended to be time consuming.

Figure 4 : Keyworkers' Perceptions of Impact of Goal Planning on Workload



More qualitative information was obtained by asking keyworkers open ended questions concerning their views on how training and the system as a whole, might be improved. Six keyworkers (46%) maintained that the training did not require alteration. Of the seven keyworkers who suggested changes, two proposed the use of role-play and individual keyworkers made the following suggestions: the introduction of training "up-date" sessions, more teaching on negotiation and counselling skills, the provision of more practical information about programme implementation, the introduction of a mentorship scheme, and initially being allowed to sit in on Goal Planning meetings without being expected to contribute.

Concerning more general system changes, 69% of keyworkers (9) made no suggestions or commented that they felt the existing system was adequate as it stood. Individual suggestions included earlier involvement with community services, more regular input from medical staff, the involvement of an associate worker in addition to the main key worker and attempts to try to alleviate a burgeoning case load.

When keyworkers were given the opportunity to try to sum up their thoughts on the use of Goal Planning in spinal cord injury rehabilitation, their responses revealed a number of themes. Almost half (46%) commented that Goal Planning increased patient knowledge about spinal cord injury and 39% of keyworkers felt their own knowledge had been improved. Other positive aspects of Goal Planning mentioned included increased patient control over rehabilitation, the provision of a forum for discussion, and the fact that Goal Planning directed patient care. In addition, 15% of keyworkers believed that Goal Planning increased staff accountability. No negative comments were made.

Discussion

It would appear from patients' responses that the Goal Planning programme implemented at QUENSIC provided patients with helpful information on their condition and that this was associated with patients feeling they had control over their rehabilitation. When relatives or friends were involved in the Goal Planning process, they also seemed to find the programme useful in understanding rehabilitation. Although previous research[11] has shown differences between those with complete and incomplete lesions in terms of their adjustment to their condition, the present study found no significant differences between these two groups on either perceived informativeness or control. Neither was there a significant association between level of spinal injury and perceptions of informativeness or control.

The results relating to keyworker perceptions of Goal Planning, although mostly qualitative in nature, suggest that they tend to view it as a useful intervention of benefit to patients, relatives and staff. Goal Planning was believed to cause no extra work in many cases, although a number of keyworkers felt that it was a time-consuming form of rehabilitation. It is possible that this is a reflection of the fact that the programme represents a new and different way of working which may become less time consuming and labour intensive as staff become more accustomed to it.

Training was generally felt to be adequate, although suggestions for the use of role play and a more gradual assumption of responsibility were suggested, i.e. the introduction of a mentorship scheme, and being allowed to sit in on Goal Planning meetings prior to participating in them. Many of these suggestions are currently being adopted in the training of new keyworkers. More generally, keyworkers commented that they felt the existing system would operate more effectively given earlier involvement with community services, more regular input from medical staff, and the involvement of an associate worker to ease individual workload. These comments validated existing concerns within QUENSIC.

A number of methodological limitations inherent in the present study may be worth considering when evaluating the results and attempting to draw conclusions. Social desirability is a problem inherent in customer satisfaction evaluations and may be pertinent here. Although efforts were taken to minimise "pressure to please" by omitting those patients for whom the psychologist administering the questionnaires was key worker, it is possible that patients were aware of the key role the psychologist had in the training and overseeing of the Goal Planning programme. Also, as McPhee et al[12] point out, it is inadequate to ask if patients are "satisfied" in general terms and this criticism may be levied here: it might have been helpful not only to ask "how informative" or "how much control", but "what" was the most informative or helpful or provided the most control, and to provide patients with checklists.

Nevertheless, the results of this study suggest that patients found Goal Planning to be informative and that this was associated with patients feeling that they had control over their rehabilitation. It was not possible to conclude whether the implementation of Goal Planning necessarily resulted in shorter admissions or a decreased rate of re-admission as various medical and social factors confound the situation, e.g. often inadequate housing arrangements were the reason for discharge delays, despite early liaison with community agencies.

Partridge and Johnston[3] have highlighted the importance of other potential mediating variables which may help explain the variance in recovery from physical disability, including individual differences in coping style. Rotter[13,14] distinguished between those with an internal locus of control (i.e. believe that rewards are contingent upon their own behaviour) from those with an external locus of control (i.e. believe that positive or negative events in their lives are unrelated to their behaviour and determined by forces outside of themselves). Subsequent work using this construct[11,15] has shown that amongst people with spinal injuries, an internal locus of control is predictive of better psychological adjustment and better functional outcomes.

However, Strickland[16] suggests that health care approaches are most effective when tailored to an individuals' expectations. Therefore, one might expect that internal patients will tend to respond best to a regime promoting personal autonomy, choice and decision making (like Goal Planning), whereas more external patients may respond optimally to a more structured and controlled treatment environment. Thus it seems that choice and perceived control may not be beneficial per se, but perhaps only when "meshed" with an internal coping style.

Morrison, Johnston and MacWalter[17] have also highlighted the importance of self-efficacy beliefs in determining rehabilitation outcomes. Self efficacy beliefs refer to a person's perceived ability to successfully carry out a given response. Thus, it is possible for a person to have an internal locus of control, i.e. believe that what they do is important for their recovery, but may feel unable to successfully perform the necessary actions to take that control. It would therefore seem important for future research to ascertain whether rehabilitation efforts such as Goal Planning foster greater internality and enhanced self-efficacy beliefs and to investigate the effects of these variables on psychological and behavioural outcomes.

Conclusions

Given the limitations of social desirability and the inherent statistical restrictions, this study provides a preliminary attempt at canvassing both patient and staff views on the first year of Goal Planning within the area of spinal injuries rehabilitation. It represents an attempt to evaluate customer satisfaction with the programme and to assess the mechanism by which improvements might be gained. The results have indicated that patients generally feel Goal Planning to be informative about their injury and helpful in promoting a sense of control over rehabilitation, and also suggests that these two factors may be linked. In addition, staff appear to have favourable views on the benefits of Goal Planning for patients, relatives and staff, although they acknowledge the impact it has on their workload.

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Chapter 2

Major Research Project Literature Review

(Written for submission to ***Disability and Rehabilitation.***

See ***Appendix 2.1*** *for Notes for Contributors)*

Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

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Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

Summary

Given the huge variation in how people cope with acquired physical disability, researchers have moved away from stage models of adaption to consider the role of individual differences in personality, coping style and life experience in predicting adjustment to physically disabling conditions such as spinal cord injury (SCI) and multiple sclerosis (MS). Several cognitive factors have been identified as potential mediators between disability and psychological distress, including locus of control (LOC) and self-efficacy beliefs. Whilst, in general, the research on SCI suggests that an internal LOC is predictive of lower levels of depression and anxiety, this is not necessarily the case in MS due to the contrasting nature and demands of the condition. It also appears that the role of control cognitions may vary over time and across settings. Such findings have important treatment implications in terms of promoting mental health and for rehabilitation more generally.

Key words: spinal cord injury, multiple sclerosis, locus of control, self-efficacy, psychological disturbance

Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

Psychological Responses to Physical Disability

A review of the literature on adaption to acquired physical disability suggests a great deal of individual variation: whilst some people appear to cope well with their injury or illness, others exhibit a range of difficulties including anxiety, depression, poor self esteem, decreased quality of life, relationship problems and suicide attempts. In addition to the obvious inherent undesirability of these sequelae from a mental health perspective, these difficulties have implications for engagement in treatment and rehabilitation which, in turn, will affect eventual functional outcomes. For example, House[1] and Ebrahim et al[2] found that depression limited stroke patients recovery. Lawson[3] found a negative relationship between depressive behaviours and quality of spinal cord injury rehabilitation and Malec and Niemeyer[4] showed that spinal injured patients who were most depressed and distressed tended to require longer periods of rehabilitation and performed less well on specific self care behaviours. Heijn and Granger[5] concluded that rehabilitation success is determined by cognitive and emotional factors, and that the assessment and nurturing of these factors should receive the same degree of attention as do physical functions.

This review explores possible cognitive mediators of psychological disturbance in people with physically disabling conditions; specifically spinal cord injury (SCI) and multiple sclerosis (MS). The literature will be examined with particular reference to individual differences in coping style and adjustment and the implication of these for treatment and rehabilitation.

Stage Theories of Adaption

Historically, at least in the area of SCI, it has been assumed that depression and prolonged psychological distress are natural responses, to be expected, and even elicited, as the individual "works through" acceptance of his or her injury. Thus, adjustment to injury is conceptualised as a sequential staging process involving the progression through several naturally occurring emotional phases. Stewart[6] describes a three-stage model of coping and adaption which moves from denial through depression towards restitution. In the context of adaption to fatal illness, Kubler-Ross[7] highlighted the stages of denial and isolation, anger, bargaining, depression, and eventual acceptance, and Burnfield and Burnfield[8] reported a similar bereavement process based on their clinical experience of patients diagnosed with MS. However, it appears that stage theories of adaption have not been supported by empirical evidence[9-13] and have been challenged on a number of grounds, including:

1. The emphasis placed on adapting to disability as a process of working through a loss implies that the primary predictor of response is the injury itself rather than individual characteristics or responses concomitant to the injury. However, research in SCI has suggested that severity of injury, as indicated by level of lesion, tends to be of little prognostic value for psychological adaption.[3,4,14] Likewise, Boyle and Paty[15] have highlighted that an individual's psychological response to a chronic debilitating disease such as MS is not necessarily in proportion to the degree of physical disability experienced.

2. The assumption that the passage of time helps relieve psychological distress tends not to be supported by longitudinal research with many studies showing that initial levels of depression experienced by SCI patients are maintained several years after their injury.[16,17] Murray[18] reports that MS patients often report their greatest difficulty to be dealing with the unpredictable, uncertain nature of their illness as it necessitates not one, but repeated adjustments over their lifetime as circumstances continually change, usually in a downward direction.

Although SCI patients may well feel angry and depressed it cannot be assumed that these emotions are simple, direct responses to their injury.[10,13] Rather, patients may be angry at family or staff, or depressed that rehabilitation has been held up due to the emergence of pressure sores or the unavailability of necessary equipment. In the context of MS, Murray[18] notes that a particularly stressful time is the period during which patients' symptoms are being investigated and the cause has not yet been explained to them. As Allden[19] points out, the intrinsic danger of such a conceptualisation is that a patient's anger or depression is seen as a "stage he or she has got to go through in order to adjust", rather than something that could possibly have been avoided or that might, to some extent, be alleviated by a change in practise.

Individual differences in coping

Empirical evidence does not support stage models of adaption to events such as SCI, but indicates the greater importance of individual differences in personality, coping style and life experience.[20] As Lazarus[21] put it: "An emotion is aroused not just by the environmental demand, constraint or resource but by their juxtaposition with a person's motives and beliefs" (p.13). Lazarus and Folkman's[22] cognitive mediational approach to coping is centred on the concept of appraisal which is the process that mediates or, "actively negotiates" between the demands, constraints, and resources of the environment (*primary appraisal*) and the goals and personal beliefs of the individual (*secondary appraisal*). Several cognitive constructs have been identified as being key to the secondary appraisal process, including locus of control and self-efficacy beliefs.

Locus of Control

Researchers such as Ray et al[23] and Wallston et al[24,25] suggest that a concept of particular relevance to the study of coping is that of locus of control (LOC). This concept emerged from Rotter's[26,27] social learning theory and represents a generalised expectancy concerning the determinants of rewards and punishments in a person's life. The distinction is made between internal LOC, i.e. the belief that rewards are contingent upon one's own behaviour, and external

LOC, i.e. the belief that the occurrence of positive or negative events are unrelated to one's behaviour and determined by forces outside the individual.

Seligman[28] described a state of "learned helplessness" as the belief that there is no contingency between one's behaviour and environmental reward and maintained that a person would become helpless when an outcome occurred that was independent of his/her voluntary responses: "Our theory of helplessness suggests that it is not the loss of reinforcers, but the loss of control over reinforcers that causes depression" (p. 96). Accordingly, it is the belief in one's own inability to control the relevant reinforcers in life that is of critical importance in the development of depression. There are individual differences in one's susceptibility to this belief: people who have experience of exerting effective control over the sources of reinforcement in their lives are thought to be less vulnerable to depression than those whose lives have been characterised by helplessness in influencing those factors that relieve suffering and bring gratification. It may be that LOC accounts for a significant part of this variance. Trieschmann[13] suggests that this dimension of personality may influence the number of occasions that are needed to produce helplessness and depression (perhaps never in some Internals). It may also influence the type and schedule of reward, and the ability to delay reward in one person versus another.

A number of theorists have drawn attention to the utility of LOC in health related areas. Bulman and Wortman[29] found that among severe accident victims an internal LOC was associated with more effective coping and better adaption to disability than an external LOC. Partridge and Johnston[30] utilised LOC to predict recovery with adults recently disabled by a stroke or wrist fracture and found that in both groups greater internality was associated with faster recovery. They proposed that mood may mediate the relationship between control and recovery, i.e. external control might be associated with low mood and poor participation in rehabilitation activities. Other research on depression and locus of control cognitions suggests that low internal or high chance control cognitions will be associated with depression[31], and that depression which manifests itself in feelings of helplessness will result in low internal control.[32]

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Self-efficacy

Whereas LOC refers to relatively stable beliefs about one's ability to influence outcomes across a variety of circumstances[26], the self-efficacy construct refers to beliefs about one's ability to perform specific behaviours in specific situations.[33] Bandura's[34, 35] self efficacy theory maintains that perceived control of a situation is determined by two kinds of beliefs: (a) the expectancy that a given behaviour will lead to a given (favourable) outcome (*outcome expectancy*) and (b) the belief that the behaviour required to produce the outcome can be successfully executed (*self-efficacy expectancy*). According to Bandura, it is the level and strength of a person's self-efficacy beliefs which will largely determine whether or not a behaviour is attempted, the amount of effort expended, and persistence in the face of adversity.

The predictive utility of perceived self-efficacy has been demonstrated across a wide variety of health-related behaviours, including anxiety management[36], pain control[37,38], cardiac rehabilitation[35], and management of rheumatoid arthritis[39,40] and acquired visual impairment.[41]

Self-efficacy and LOC may interact in a number of ways: Morrison et al[42] have pointed out in the context of stroke patients, it is possible for a person to have an internal LOC, i.e. believe that recovery or progress is under their control, yet they may have low perceived self-efficacy; that is, they may feel unable to carry out the necessary actions. In such a case, a high level of cognitive dissonance and accompanying psychological distress might be expected.

Schiaffino and Revenson[40] found that amongst rheumatoid arthritis patients if the cause of a symptom flare was viewed as external, more limited in scope, and short-lived, perceptions of control (self-efficacy and outcome expectations) were not related to depression. In contrast, greater depression was experienced by individuals who perceived low control over their illness (low self-efficacy and outcome expectations) and attributed the cause of a recent symptom flare to a relatively permanent personal attribute (i.e. they made stable, internal attributions). Thus, they suggest that the relationships between cognitive appraisals and adaptional outcomes reflect a moderational rather than a mediational process.

Contrasting SCI and MS

As Burks[43] notes, the problems facing the MS patient are similar in many ways to those of the SCI patient: the disease often begins in young adulthood, has common impairments (e.g. weakness, sensory loss, spasticity and bowel, bladder and sexual dysfunction) and both groups of patients can lead long and productive lives given the necessary medical care and rehabilitation. In Burks' detailed review, however, he highlights the many more numerous ways in which MS and SCI differ and the resultant implications for service providers. These differences include demographic differences (e.g. MS patients are more likely to be female and SCI patients more likely to be male; MS patients often have a higher educational and socio-economic level than SCI patients; and MS patients with moderate to severe levels of physical disability are often older than the typical SCI patient at onset); differences in course (the relapsing-remitting or progressive course of MS versus the maximum disability with some recovery for the SCI patient); and linked to this, the fact that as regards MS, the timing of rehabilitation input and the specific goals are less clear. Given the contrasting nature and demands of these conditions, the remainder of this review will focus on the potentially differential mediating role of control and coping cognitions in predicting psychological distress.

Psychological distress and coping in SCI

Although the current research literature suggests that the psychological response to SCI is an individual one, studies report depression to be present in 20-45% of patients[44-46], with mean depression and anxiety levels elevated in comparison to able-bodied controls.[47] In addition, many studies have highlighted that initial levels of depression tend not to decrease over time. Stuckey[17] found that 1/5 of her SCI sample had clinically significant levels of anxiety and/or depression as many as 5 years post injury, with older patients and those with incomplete lesions more at risk of these type of problems. Frank et al[11] noted that people who had been injured longer were not necessarily less distressed than those who had been recently injured.

Schulz and Decker[48] identified the major predictors of depression in SCI patients to be health status, perceived control, social support, and satisfaction with social contacts. The studies by Stuckey[17] and Schulz and Decker[48] both showed that an internal LOC was linked to better adjustment and increased functional outcome, and that those with a more external LOC tended to be less well adjusted and exhibited a higher degree of emotional distress. Similarly, Dinardo[49] found that SCI patients with an internal LOC tended to have higher self-concepts and be less depressed than those with a more external LOC. Further, Externals who expressed their depressive feelings showed the poorest adjustment to their injury, whilst internal "repressors" showed the best adjustment.

Swenson[50] found that internal SCI patients compared with Externals spent less time in hospital with hygeine-related problems, were more satisfied with life, spent more time in work activities in the home, in educational activities, and in time outside their home and also that they spent more time in a combination of education, paid employment and community work. Swenson also notes the absence of a relationship between severity of disability and LOC or satisfaction with life. Thus, although a person with quadriplegia may in fact have less control over their immediate circumstances, this does not necessarily change the generalised expectancy of control over the rewards in life nor satisfaction with life.

Craig et al's[16] prospective longitudinal study identified factors which contributed to depression following SCI as the level of pain experienced at the time of measurement and an external LOC prior to hospital discharge. Other researchers[14, 51,52] have also identified an external LOC and pain to be important determinants of psychological upset within an SCI population. Summers et al[52] showed pain to be a significant problem for SCI patients and that pain interference was associated with emotional problems over and above that attributable to the injury itself.

To summarise, it would appear that not everyone with SCI is depressed or anxious. In addition, the incidence of psychological difficulties appears not to be related to level of lesion and also does not necessarily improve over time. The experience of depression in SCI, far from being necessary for successful adaption, tends to be associated with poor adjustment to spinal injury. People who sustain SCI are a heterogeneous group and it appears that individual differences in cognitive constructs such as LOC are likely to play an important mediating role between the injury and the development of psychological difficulties. Although many studies suggest that in SCI, an internal LOC is associated with reduced depression and better adjustment in comparison with those who are more externally oriented, others have not found such an effect.[11] Trieschmann[13] and many others have also highlighted the important role of pain in predicting adjustment to SCI.

Psychological distress and coping in MS

Emotional disorders are a common feature of MS[53,54], with rates of depression ranging from 27% to 54%.[55-57] There appears to be no consistent relationship between duration of illness and depressive symptoms[58,59] , and although some studies have suggested that patients with a greater degree of disability are more likely to experience depression[57,60] , many others have failed to show this relationship.[56,61]

Attempts have been made to link depression to brain pathology: Schiffer et al[62] found that cerebral involvement was positively correlated with depression, and Dalos et al[55] provided evidence that depressive episodes coincide with neurological exacerbation in many cases. However, Joffe et al[56] and Rabins et al[63] have failed to show such a relationship, and Rao et al[64] found that MS patients with mild to moderate cognitive impairment reported more depressive symptoms than those without cognitive impairment or those with severe impairment. A more recent study by Clark et al[65] found significant correlations between magnetic resonance imaging (MRI) ventricular measures and cognitive performance, but that Beck Depression Inventory scores were not correlated with either of these two variables. Thus, they suggest that cognitive impairment in MS is related to the disease process, but that the level of depression is not. They noted that, even with mild impairment or when the patient is in remission, there can be evidence of cognitive impairment, increased depression and ventricular enlargement, emphasising the commonly observed MRI finding that there may be significant evidence of change within the brain while at the same time the patient shows little or no symptomatic change.

Logsdail et al[66] also failed to find a positive relationship between the presence of psychiatric problems and lesions detected by MRI, and they maintained that social tension was a more likely explanation of patients' symptoms. Millefiorini et al[67] have suggested that at least in the early stages of MS, depression may be predominately "reactive" and more closely related to the degree of physical disability than to the extent of brain pathology. As Murray[18] has highlighted, because of the nature of depression, it tends to increase the distress and subjective perception of MS symptoms, as well as contribute to disruptions in personal, family and vocational functioning. A further confusing element is that many symptoms of MS are similar to those of depression, e.g. chronic and marked fatigue and memory and concentration difficulties, which may give the impression of depression when it is not in fact present. Thus, although one might expect that depression would be related to the neurological dysfunction of MS[59] as Minden and Shiffer[53] point out, it is likely to be the result of a more complex, multifactorial process involving both psychological and neurological factors.

Several studies have highlighted key factors affecting mental health and quality of life in MS patients, e.g. loneliness, fatigue, chronic pain, duration of symptoms, stressful life events, self-perceived cognitive deficits, and clinically assessed cognitive deficits.[18,68] Pain was often thought not to be a symptom of MS, however, recent studies have shown pain to be present in 54% to 75% of cases.[18,43] Although the literature suggests that, in general, effective psychosocial adjustment, the avoidance of depression and an active personal life all are related to an effective internal LOC, unfortunately, the fear of loss of control is constant for MS patients due to the uncertain nature of the disease. Lazarus[21] highlighted that the utility of any coping pattern "varies with the type of stressful encounter, the type of personality stressed, and the outcome modality studied" (p.9). He maintained that coping depends on appraisal of whether anything can be done to change the situation: if something can be done, problem-focused coping predominates (i.e. the use of strategies directed at managing or altering the source of the stress), but if appraisal says that nothing can be done, emotion-focused coping predominates (i.e. the use of strategies directed at regulating emotional responses and distress that occurs as a consequence of the problem). Many researchers have made the link between a problem-focused orientation and internal LOC and an emotion-focused orientation and an external LOC.[69,70]

Murray[18] reported that, in general, both problem-focused and emotion-focused strategies were used by people attempting to cope with MS. Hickey and Greene[71] reported elevated levels of depression and hopelessness in their MS sample relative to norms for the general population, another physically ill population and psychiatric in-patients, and they also found problem-focused coping to be positively correlated with an external LOC. Given Taylor's[72] contention that inadequate coping may result from the ineffective use of psychological defences, whereby an external LOC is combined with the use of problem-focused coping strategies, Hickey and Greene suggest that this may explain the elevated levels of depression and hopelessness in their sample.

Using a longitudinal design with MS patients exhibiting a phasic course, Lasar and Koetterba[73] examined the relationship between LOC and the pattern of relapse and remission. They found that external LOC beliefs were linked to an increase of episodes of MS, with an internal LOC being associated with a more favourable course of the disease.

Lazarus[21] suggested that in western cultures, taking action against problems is generally considered to be more desirable than reappraising their meaning, but there exists ample evidence that under certain conditions, rational problem solving can be counterproductive and likely to result in distress. In accordance with this, Burish et al[74] reported that amongst chemotherapy patients, maintaining a belief in personal control can be maladaptive in the face of repeated failures to gain control. Rothbaum et al[75] maintained that surrendering control to powerful others (a dimension of external LOC) is adaptive in situations where few opportunities for personal control are available and that maintaining a belief in personal control in such situations may lead to coping difficulties. Miller[76] postulated that personal control is valuable in so much as it can provide an upper limit on suffering and instil confidence in a predictable future. However, when allowing others to control significant outcomes is a more reliable means of achieving these ends, they should be preferred.

Reid[77] pointed out that living with a serious chronic illness creates unusual burdens for patients as people try to balance their need to maintain a sense of mastery over their lives with their need to surrender treatment of their disease to their heath care providers. In a study of people with rheumatoid arthritis (RA), Affleck et al[78] emphasised the importance of distinguishing among those aspects of chronic illnesses that are more or less subject to personal control in making predictions about the adaptive significance of control appraisals in a chronic disease. They maintained that rather than give up control completely, RA patients are likely to search for other opportunities for gaining control (i.e. control over their daily symptoms via participation in treatment decision making) in a selective and adaptive manner.

There are a number of similarities between RA and MS which render this study particularly relevant to an MS population: it is a progressive illness with a variable prognosis and most patients experience intermittent periods of disease flare and remission. As in MS, uncertainty about the course of the disease and the severity of the daily symptoms are often identified as the major stressors for sufferers.[79] The results of Affleck's study indicated that perceiving greater personal control over one's treatment was associated with positive mood and psychosocial adjustment, with negative mood being associated with the belief that providers had greater control over the patient's daily symptoms. However, patients who had a more severe form of the disease and expressed greater personal control over its *course* reported greater mood disturbance and showed poorer adjustment, but those who had relatively active symptoms and expressed greater personal control over their *symptoms* had less mood disturbance. The authors explained these findings by distinguishing between aspects of the illness that are more or less subject to personal control. This line of reasoning is in line with Reid's[77] contention that optimal adaption to a chronic disease depends on an individual's ability to come to terms with what he or she can and cannot control.

To summarise, although depression is fairly common in people with MS, the incidence of psychological difficulties within this population has not been consistently linked to brain pathology, duration of illness or degree of physical disability. As in the case in SCI, it is likely that cognitive factors such as LOC will mediate between the illness and adjustment. Indeed, Anderson et al[80] maintained that it is in illnesses such as MS - chronic, physically disabling illness characterised by their unpredictable nature - that perceptions of control over the illness are likely to have the greatest significance for psychological adaption. The literature suggests that an internal LOC may not necessarily be adaptive in the context of MS, as opportunities for exercising personal control seem to be less clear-cut than in the case of SCI.

Future research

Morrison et al[42] maintained that the role of control cognitions in predicting recovery from a physically disabling condition may vary according to (1) the nature, severity and prognosis of the condition and (2) the time point at which cognitions are assessed. The literature reviewed suggests that SCI and

MS may provide a useful contrast for exploring the perhaps differential role of LOC in predicting psychological distress and adjustment to physical disability. It would also seem important to explore the relationship between LOC and other more situationally-specific cognitive factors such as outcome expectancies and perceived self-efficacy: it may be that a person believes generally in their ability to control their environment, but if they remain unconvinced of the usefulness of their treatment or rehabilitation advice, or lack confidence in their ability to carry out the specific actions required, then this is likely to have implications for their psychological well being and their engagement in treatment and rehabilitation.

Lastly, future research might explore the relationship between LOC and distress across time and settings: in both MS and SCI, external beliefs, i.e. beliefs in "powerful others" such as doctors and therapists, may be adaptive in the acute phase of a condition, when the patient is hospitalised and thus under vicarious control. However, a more internal LOC may be linked to less distress following discharge from hospital, when the situation is more "over to them".

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Chapter 3

Major Research Project Proposal

Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

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Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

Summary

This study aims to examine patients' beliefs concerning the control they have over a physically disabling condition and their treatment, and their confidence in being able to carry out what is required of them in a rehabilitation setting. These factors will be investigated in terms of their influence on the psychological distress experienced by people facing two different types of disability: spinal cord injury (SCI) and multiple sclerosis (MS). Subjects will be drawn from in- and outpatient populations attending either the Queen Elizabeth National Spinal Injuries Centre (QUENSIC) or the Physically Disabled Rehabilitation Unit (PDRU), both within the Southern General Hospital. It is predicted that different perceptions of control (i.e. internal v external locus of control) may be differentially adaptive for these two conditions. It is also predicted that the influence of control and specific self-efficacy beliefs on mood and participation in rehabilitation may vary according to length and level of disability, residence (in- v outpatients) and pain experienced.

Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

Introduction

Psychological factors such as perceived control, self-efficacy expectations and emotions (anxiety and depression) have been found to be predictive of a wide variety of health outcomes. Rotter's (1966, 1982) locus of control (LOC) construct represents a generalised expectancy concerning the determinants of rewards and punishments in a person's life and distinguishes between internal LOC (i.e. the belief that rewards are contingent upon one's own behaviour) and external LOC (i.e. the belief that the occurrence of positive or negative events are unrelated to one's behaviour and determined by forces outside the individual). Partridge and Johnston (1989) utilised this construct to predict recovery with adults recently disabled by a stroke or wrist fracture and found that in both groups greater internality was associated with faster recovery. They proposed that mood may mediate the relationship between control and recovery, i.e. external control might be associated with low mood and poor participation in rehabilitation activities.

Other research on depression and LOC cognitions suggests that low internal or high chance control cognitions will be associated with depression (e.g. Crisson and Keefe, 1988), and that depression which manifests itself in feelings of helplessness will result in low internal control (e.g. Sinyor et al, 1986). Indeed, House (1987) and Ebrahim et al (1987) found that depression limited stroke patients recovery and Summers et al (1986) have reported that amongst arthritis patients, depression can decrease pain tolerance and contribute to patient inactivity. Thus, control cognitions may influence mood and this may have implications for rehabilitation efforts. Moreover, the potential influence of such a variable on patient distress levels is important in itself when considering the individual's overall psychological health, and not only in terms of their implications for rehabilitation.

Research by Bandura (1986, 1989) and O'Leary (1985) have demonstrated the predictive utility of perceived self-efficacy (self confidence concerning one's ability to successfully carry out a given behaviour) across a wide variety of health related behaviours. According to Bandura (1977,

1982) it is the level and strength of a person's self-efficacy beliefs which will largely determine whether or not a behaviour is attempted, the amount of effort expended, and persistence in the face of adversity. Thus provision of information and beliefs in the potential for personal control may not be sufficient for a person to actively participate in rehabilitation activities: people also need convincing that they are capable of carrying out the specific behaviours necessary for them to actualise their potential.

The stress and coping paradigm proposed by Lazarus and Folkman (1984) may provide a useful framework for considering control cognitions (LOC and self-efficacy) and psychological disturbance in the face of disability. This model proposes that a person's cognitive appraisal of events is crucial in predicting the coping response which will be made and the adaptation achieved. Thus, stress can be viewed as a response to an appraisal of an event as high in harm, threat or challenge (primary appraisal) and when secondary appraisal of resources/coping abilities to face it are low. Resources such as perceived personal control cognitions and self-efficacy beliefs feed in the secondary appraisal process and the coping response may mediate between the stressor and emotional distress and maladjustment.

Aims and Hypotheses

Aims

Morrison et al (1994) maintained that the role of control cognitions in predicting recovery from a physically disabling condition may vary according to the nature, severity and prognosis of the condition and to the time point at which the cognitions are assessed. This study therefore aims to elucidate the potential mediating role of LOC, and perceived self-efficacy in predicting levels of psychological distress in two conditions resulting in physical disability. SCI and MS differ in onset (traumatic v gradual), course (static v progressive) and prognosis (normal v shortened life expectancy).

Research Questions

The present study takes Lazarus and Folkman's (1984) stress and coping paradigm as its theoretical starting point and directs its analyses towards the following questions:

1. Is an internal LOC control adaptive in the face of physical disability, i.e. is it predictive of decreased psychological distress (a) across conditions and (b) across time and setting?

(a) across conditions - Shulz and Decker (1985) and Stuckey (1993) have shown that amongst SCI patients, an internal LOC is linked to better adjustment and increased functional outcome. Stuckey (1993) found that 1/5 of her SCI sample had clinically significant levels of anxiety and/or depression as many as 5 years post injury, with older patients and those with incomplete lesions apparently more at risk of these type of problems. In addition it was found that those with a more external LOC are likely to be less well adjusted and have a higher degree of emotional distress.

However, this may not necessarily be the case for people with MS. As Reid (1984) has pointed out, living with a serious chronic illness creates unusual burdens for patients as they try to balance their need to maintain a sense of mastery over their lives with their need to surrender treatment of their disease to their heath care providers. Rothbaum et al (1982) maintained that surrendering control to powerful others is adaptive in situations where few opportunities for personal control are available and that maintaining a belief in personal control in such situations may lead to coping difficulties. Burish et al (1984) reported that amongst chemotherapy patients, maintaining a belief in personal control can be maladaptive in the face of repeated failures to gain control. To sum up, Affleck et al (1987) emphasised "the need to distinguish among aspects of chronic illnesses that are more or less subject to personal control in making predictions about the adaptive significance of control appraisals in a chronic disease" (p.277).

(b) across time and setting - It is also possible that the relationship between LOC and distress may be different across time and settings: as Morrison et al (1994) point out, external beliefs, i.e. belief in "powerful others" such as doctors and therapists, may be adaptive in the acute phase of a condition, when the patient is hospitalised and thus under vicarious control. However, a more internal LOC may be linked to less distress following discharge from hospital, when the situation is more "over to them".

2. How do self-efficacy beliefs impact on coping and psychological distress?

As Morrison et al (1994) point out in the context of stroke patients, it is possible for a person to have an internal LOC, i.e. believe that recovery is down to them, yet they may have low perceived self-efficacy; that is, they may feel unable to carry out the actions necessary for recovery. Thus, we might predict that in conditions such as SCI, where the literature suggests a positive relationship between internal LOC and adjustment, that an internal LOC combined with low perceived self-efficacy (as regards rehabilitation) might be associated with a high level of cognitive dissonance and increased psychological disturbance. The predicted interaction between these two variables in this population is illustrated in table 1.

Table 1: The combined effects of different levels of self-efficacy and LOC in predicting depression in SCI patients

		SELF-EFFICACY	
		High	**Low**
LOC	**Internal**	least depression	most depression
	External	intermediate level of depression	intermediate level of depression

3. Other important variables: The literature indicates that certain other factors may be important and interact with the main variables under investigation:

(a) Pain: Summers et al (1991) amongst others have shown pain to be a significant problem for SCI patients and demonstrated that pain interference was associated with emotional problems over and above that attributable to the injury itself. Recent studies have also indicated that 54% to 75% of MS patients experience pain (Burks, 1994; Murray, 1995). Thus it seems likely that the experience of pain may impact on distress and coping.

(b) Level of physical disability: Within SCI and MS, there is likely to be a range of physical disability, depending on the injury experienced in SCI (i.e. level and completeness of injury) and on the time since injury/diagnosis in both conditions. Variation on this variable may effect distress and coping.

Plan of Investigation

Subjects: Approximately 80 subjects (male and female, in- and outpatients) will be recruited on a voluntary basis from QUENSIC and the PDRU: approximately 50 SCI patients and 30 MS patients. SCI patients will be medically stable and able to sit in their wheelchair for a minimum of one hour per day. Subjects from either group will be excluded if they show significant levels of cognitive impairment.

Measures: Where possible, existing measures with demonstrated psychometric properties will be used:

1. Screening for cognitive impairment - Folstein et al's (1975) Mini-Mental State Examination (MMSE).

2. Locus of Control - Partridge and Johnston's (1989) Recovery Locus of Control (RLOC) Scale as developed by Morrison et al (1994).

3. Self-efficacy - Given Bandura's (1977) emphasis on the use of situationally-specific measures of self-efficacy, a new measure was developed specifically to apply to the rehabilitation settings under investigation. Designed according to Bandura's (1977) stipulations, it provides an indicator of the range of sources of rehabilitation advice available, as well as a measure of outcome expectancy

(i.e. how "good" the advice was perceived to be) and strength of self-efficacy beliefs (i.e. how confident patients were of being able to successfully carry out the advice) (see **Appendix 3.1**).

4. Psychological distress -

(a) Beck Depression Inventory (BDI) (Beck et al, 1967)

(b) Spielberger Trait Anxiety Inventory (STAI) (Spielberger et al, 1983)

5. Pain - The "Pain Severity" subscale of the West Haven-Yale Multidimensional Pain Inventory (WHYMPI) (Kerns et al, 1985) - designed for the comprehensive evaluation of chronic pain in clinical settings, and separate norms for subscales.

6. Level of disability - Barthel Activities of Daily Living (ADL) Index (Mahoney and Barthel, 1965).

7. Demographic details - including age, sex, occupational status, family support, medication, and details of hospital admissions.

Design and Procedure: An independent group design will be used with subjects varying in the length of injury/diagnosis and level of disability experienced. As far as possible subjects will be matched on level of disability. As it is anticipated that the number of patients with MS passing through the PDRU will be less than the number of patients with SCI accessible via QUENSIC, SCI patients will be allocated to groups according to their level of disability and one subject will be selected to match each subject in the MS group on this variable, thus allowing between group comparisons to be made. Within group analyses will also be made, and for this purpose the non-matched SCI patients will be added to the original SCI sample. Comparisons will also be made in terms of the length of injury / diagnosis.

Patients from both units will be approached directly and an information sheet will be provided and written consent sought (see **Appendix 3.2**). Anonymity and confidentiality will be assured. On completion, subjects will be fully de-briefed.

Settings and Equipment: All testing will be carried out in QUENSIC or the PDRU.

Data Analysis: Data will be stored on computer and analysed using SPSSPC+. Analyses will be directed at between group comparisons and where the criterion for parametric tests are met, t-tests will be carried out to compare scores on depression, anxiety, and pain, and to compare totals on LOC and self-efficacy scales. In- and outpatient samples will also be analysed separately.
Within group analyses will also be carried out for both groups, but due to possible limited availability of MS subjects, some of the more detailed analyses will be focused on the larger group of SCI subjects. Analyses will be mostly correlational and will examine possible associations between LOC and self-efficacy scores and levels of depression and anxiety. Regression analyses will be used to control for the effects of level and length of disability, as well as pain experienced. Given that sufficient numbers of SCI patients are obtained, possible interaction effects of LOC and self-efficacy will also be examined: analysis of variance will be used to compare depression and anxiety scores in each of four possible groups (i.e. Internal LOC/High SE, Internal LOC/Low SE, External LOC/High SE, External LOC/Low SE).

Purpose

The purpose of the present study is to explore the link between control and efficacy cognitions and the psychological distress experienced by people who are faced with two contrasting types of physical disability. Findings will have implications for psychological interventions aimed at reducing levels of anxiety and depression, and will also relate to wider clinical issues concerning engagement in rehabilitation and pain control.

Timescales

June - December 1995 - Data collection.

January - August 1996 - Analyses and write-up.

Ethical Approval

Ethics approval has been granted by the Southern General Ethics Committee.

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Chapter 4

Major Research Paper

(Written for submission to ***Disability and Rehabilitation.***

See ***Appendix 4.1*** *for Notes for Contributors)*

Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

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Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

Summary

This study examined the role of control cognitions such as locus of control (LOC) and self-efficacy, in predicting adaption to physical disability. These factors were investigated in terms of their influence on the psychological distress experienced by people facing contrasting physically disabling conditions, spinal cord injury (SCI) and multiple sclerosis (MS), across time and setting. Results indicated that although SCI subjects were more internally oriented than MS subjects, internality was not linked [illegible] to lower levels of depression or anxiety in either group. Within the SCI group, however, an external LOC was associated with increased depression and physical disability. LOC was also not differentially adaptive across time or settings for SCI subjects. However, results indicated that specific self-efficacy beliefs relating to one's ability to carry out treatment and rehabilitation advice were associated with lower levels of depression and anxiety across both conditions.

Keywords: spinal cord injury, multiple sclerosis, locus of control, self-efficacy, psychological disturbance

Coping and Psychological Disturbance in People with Physical Disabilities: Implications for Treatment and Rehabilitation

Introduction

The literature on adaption to acquired physical disability suggests a great deal of individual variation: whilst some people appear to cope well with their injury or illness, others exhibit a range of difficulties including anxiety, depression, poor self esteem, relationship problems and suicide attempts. In addition to the obvious inherent undesirability of these sequelae from a mental health perspective, these difficulties have implications for engagement in treatment and rehabilitation which, in turn, will affect eventual functional outcomes. For example, House[1] and Ebrahim et al[2] found that depression limited stroke patients recovery. Lawson[3] found a negative relationship between depressive behaviours and quality of spinal cord injury rehabilitation, and Malec and Niemeyer[4] showed that spinal injured patients who were most depressed required longer periods of rehabilitation. Heijn and Granger[5] concluded that rehabilitation success is determined by cognitive and emotional factors, and that the assessment and nurturing of these factors should receive the same degree of attention as do physical functions.

Lazarus and Folkman's[6] cognitive mediational approach to coping is centred on the concept of appraisal which is the process that mediates or, "actively negotiates" between the demands, constraints, and resources of the environment (*primary appraisal*) and the goals and personal beliefs of the individual (*secondary appraisal*). Several cognitive constructs have been identified as being key to the secondary appraisal process, including locus of control and self-efficacy beliefs.

Rotter's[7,8] locus of control (LOC) construct represents a generalised expectancy concerning the determinants of rewards and punishments in a person's life and distinguishes between an internal LOC, i.e. the belief that rewards are contingent upon one's own behaviour, and an external LOC, i.e. the belief that the occurrence of positive or negative events are unrelated to one's behaviour and determined by forces outside the individual. Bulman and Wortman[9] reported that among severe accident victims an internal LOC was associated with more effective coping and better adaption to physical disability than an external LOC. Partridge and Johnston[10] found that greater internality was associated with faster recovery in adults disabled by a stroke or wrist fracture and proposed that mood may mediate the relationship between control and recovery, i.e. external control might be associated with low mood and poor participation in rehabilitation activities.

Whereas LOC refers to relatively stable beliefs about one's ability to influence outcomes across a variety of circumstances[7], the self-efficacy construct refers to beliefs about one's ability to perform specific behaviours in specific situations.[11] Bandura's[12,13] self efficacy theory maintains that perceived control of a situation is determined by two kinds of beliefs: (a) the expectancy that a given behaviour will lead to a given (favourable) outcome (*outcome expectancy*) and (b) the belief that the behaviour required to produce the outcome can be successfully executed (*self-efficacy expectancy*). According to Bandura, it is the level and strength of a person's self-efficacy beliefs which will largely determine whether or not a behaviour is attempted, the amount of effort expended, and persistence in the face of adversity. The predictive utility of perceived self-efficacy has been demonstrated across a wide variety of health-related behaviours, including anxiety management[14], pain control[15,16], cardiac rehabilitation[13] , and management of rheumatoid arthritis[17,18] and acquired visual impairment.[19]

Morrison et al[20] maintained that the role of control cognitions (such as LOC and self-efficacy) in predicting recovery from a physically disabling condition may vary according to (1) the nature, severity and prognosis of the condition and (2) the time point at which cognitions are assessed. As Burks[21] has highlighted, spinal cord injury (SCI) and multiple sclerosis (MS) are two physically disabling conditions which vary along these dimensions and may therefore provide a useful contrast for exploring the perhaps differential role of LOC in predicting psychological distress and adjustment to physical disability. Although many studies[22,23] have suggested that in SCI, an internal LOC is associated with reduced depression and better adjustment, this may not necessarily be the case with MS where opportunities for exercising control appear less clear cut. Indeed, Rothbaum et al[24] maintained that surrendering control to powerful others (a dimension of external LOC) is adaptive in situations where few opportunities for personal control are available and that maintaining a belief in personal control in such situations may lead to coping difficulties.

The relationship between LOC and distress may also vary across time and settings: in both MS and SCI, external beliefs, i.e. beliefs in "powerful others" such as doctors and therapists, may be adaptive in the acute phase of a condition, when the patient is hospitalised and thus under vicarious control. However, a more internal LOC may be linked to less distress following discharge from hospital, when the situation is more "over to them". This study therefore aims to explore whether an internal LOC is adaptive in the face of disability, i.e. associated with decreased psychological distress (a) across conditions (SCI v MS) and (b) across time and setting (acute v non-acute, inpatient v outpatient).

Morrison et al[20] also pointed out that it is possible for a person to have an internal LOC, i.e. believe that recovery or progress is under their control, yet they may have low perceived self-efficacy; that is, they may feel unable to carry out the necessary actions. Thus it is predicted that in conditions such as SCI where the literature suggests a positive association between internal LOC and adjustment, that an internal LOC combined with low perceived self-efficacy (as regards rehabilitation) might be associated with a high level of cognitive dissonance and increased psychological disturbance.

A review of the literature (see **chapter 2**) has also shown pain to be of particular importance in predicting psychological morbidity in SCI[25,26] and MS.[21,72] Thus, the influence of pain experience on psychological disturbance will also be investigated.

Method

Subjects

Subjects were 45 people with SCI and 25 with a diagnosis of MS. All of the SCI subjects attended a national resource for spinal injuries (Queen Elizabeth National Spinal Injuries Centre, QUENSIC) on either an in- or outpatient basis and were included only if medically stable and able to sit in a wheelchair for a minimum of one hour per day. MS subjects consisted of 17 inpatients attending the Southern General Hospital for rehabilitation and/or steroid treatment with a further 8 subjects attending a local MS Action group[*]. Subjects were excluded from either group if they exhibited significant levels of cognitive impairment (scored less than 23 on the MMSE, which according to Dick et al[28], is "suggestive of cognitive impairment"). Two SCI subjects failed to achieve criterion scoring on the MMSE and were therefore excluded from analyses. Tables 1 and 2 summarise the demographic and general characteristics of SCI and MS samples respectively.

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[*] Due to the limited numbers of MS patients passing through the original hospital unit targeted, it was necessary to widen sampling to encompass voluntary sector organisations. The MS Action Centre permitted access to their members on the proviso that questions relating to physical disability and possible cognitive impairment were asked in a circumspect manner in order to minimise distress. It was therefore agreed that subjects be asked about mobility, dexterity and bowel and bladder function in general terms, and only if they expressed difficulties should the formal Barthel checklist be carried out. Similarly, subjects were asked generally concerning memory, speech or reading problems, and the MMSE was completed only if they expressed difficulties in any of these areas. In three out of eight cases, subjects reported no physical difficulties at screening and a maximum Barthel score of 20 was assumed. In four out of eight cases, no cognitive difficulties were reported and a maximum MMSE score of 30 was assumed. It was felt that the inevitable compromise in reliability was necessary in order to access sufficient numbers of MS subjects. See **Appendix 4.6** for a discussion of the fuller implications of this change in sampling.

Table 1: Demographic and general characteristics of SCI subjects

		n(%)	mean	sd	range
Age		43 (100)	35.56	16.16	16-69
Sex:	male	31 (72)	-	-	-
	female	12 (28)			
Status:	inpatient (acute)	20 (47)	-	-	-
	inpatient (return)	4 (9)			
	outpatient	19 (44)			
Level of lesion:	C1-C3	3 (7)	-	-	-
	C4-C5	8 (19)			
	C6-C7	6 (14)			
	T1-T9	10 (23)			
	T10-L2	9 (21)			
	L3-L5	1(2)			
	S1-S2	1 (2)			
	other	5 (12)			
Completeness of lesion:	complete	20 (47)	-	-	-
	incomplete	23 (53)			
Time since injury (mths)	-	43 (100)	44.26	87.17	0.5-389
Total period of hospitalisation (wks)	-	43 (100)	20.38	18.31	0.5-96
Cause of injury:	RTA	14 (33)	-	-	-
	fall	14 (33)			
	sporting accident	5 (11)			
	other	10 (23)			
Living arrangements:	alone/sep/div	4 (9)	-	-	-
	partner	18 (42)			
	parent(s)	16 (38)			
	relative/friend	4 (9)			
	single parent	1 (2)			
Region:	Strathclyde	30 (70)	-	-	-
	Grampian	5 (12)			
	Lothian	3 (7)			
	Central	3 (7)			
	Fife	1 (2)			
	Dumf. & Gallow.	1 (2)			
Occupation (prior to injury)	professional	4 (9)	-	-	-
	intermediate	5 (12)			
	skilled non-man.	5 (12)			
	skilled man.	12 (27)			
	partly skilled	4 (9)			
	unskilled	5 (12)			
	school/student	5 (12)			
	unemployed	3 (7)			

Table 2: Demographic and general characteristics of MS sample

		n(%)	mean	sd	range
Age		25 (100)	39.36	7.77	29-58
Sex:	male female	9 (36) 16 (64)	-	-	-
Status:	inpatient MS Action	17 (68) 8 (32)	-	-	-
Category of MS	relapsing-remitting relapsing-progress. chronic progress.	10 (40) 7 (28) 8 (32)	-	-	-
Time since diagnosis (mths)	-	25 (100)	77.72	61.37	9-240
Subjective estimate of length of illness (mths)	-	25 (100)	100.72	79.45	9-276
Total period of hospitalisation (wks)	-	25 (100)	19.57	82.30	0-397
Living arrangements:	alone/sep/div partner parent(s) single parent	8 (32) 13 (52) 2 (8) 2 (8)	-	-	-
Region:	Strathclyde Central	24 (96) 1 (4)	-	-	-
Occupation (prior to MS)	professional intermediate skilled non-man. skilled man. partly skilled unskilled unemployed	2 (8) 7 (28) 2 (8) 5 (20) 3 (12) 1 (4) 5 (20)	-	-	-

Measures

1. *The Mini-Mental State Examination (MMSE)*[29] was used to screen for cognitive impairment (see **Appendix 4.2.1**).This measure was adapted for use with people who had impaired, or no use of their hands (see **Appendix 4.2.2** for details of adaption).

2. *The Barthel Activities of Daily Living (ADL) Index* [30] was used to assess level of physical disability. This is a well validated 10-item measure of ability to perform basic "activities of daily living" (e.g. feeding, dressing, walking, bathing, toileting and bladder and bowel function). Scores range from zero (maximum disability) to 20 (independence).

3. *The Beck Depression Inventory (BDI)*[31] is a well validated self-report measure consisting of 21 descriptive statements assessing symptoms of depression. Other research into depression following SCI has found it to be a good screening instrument for this population.[25,32,33]

4. *Spielberger Trait Anxiety Inventory (STAI)*[34] is a 20 item self-report measure of trait anxiety. It has been used in several studies in combination with the BDI to assess psychological morbidity within SCI populations[25,35] and has well demonstrated reliability and validity.

5. *The Recovery LOC Scale (RLOC)*[10] uses a 5-point Likert scale to measure two dimensions of personal control over recovery: internal LOC and external or chance cognitions. This scale has been found to have satisfactory internal reliability and predictive validity for stroke patients[10,20] and SCI patients[22] (see **Appendix 4.3.1**). Three additional items devised by Morrison et al[20] were included to measure belief in control by others, these items currently being validated in different patient populations including stroke patients, heart attack patients and spinal injuries (see **Appendix 4.3.2**).

Four LOC scores were therefore derived: firstly the original RLOC scale of five internal items and four external/chance items, coded in the direction of internality, i.e. external items were coded in the reverse so that strongly agreeing with an external item received a low score, thus representing low internality; secondly, the internal, external and others subscales were scored individually, with each being coded independently, i.e. strongly agreeing with any item on any of the three subscales achieved a maximum score of 5 (with the exception of the "friends and relatives" item on the others subscale which contains a double negative and was thus coded in reverse).

6. *Self-efficacy perceptions* were assessed using a new measure developed specifically to apply to the treatment and rehabilitation settings under investigation (see **Appendix 4.4**). Designed according to Bandura's[12] stipulations, it provides a measure of outcome expectancy (i.e. how "good" the advice was perceived to be) and self-efficacy beliefs (i.e. how confident they were of being able to successfully carry out the advice). Subjects were asked to indicate where they had received treatment or rehabilitation advice from a checklist of professional and non-professional "helpers".

They then rated how good the advice was on a five point visual analogue scale from 1("very poor") to 5 ("very good") and then rated each on how confident they were of being able to successfully carry out the advice using a similar scale from 1 ("not at all confident") to 5 ("very confident").

7. The "pain severity" subscale of the West Haven-Yale Multidimensional Pain Inventory (WHYMPI)[36] measured level of pain experienced. The WHYMPI has satisfactory reliability and internal validity, and there are norms available for clinical populations on each of the subscales (see **Appendix 4.5**).

8. A number of demographic details were collected including age, sex, occupational status, living arrangements, treatment procedures, and details of hospital admissions.

Design and Procedure

An independent group design was used with subjects varying in terms of the length and level of disability experienced. The final compliment of measures was administered using a semi-structured interview format. Interviews took between 30 mins and two hours to complete, following which subjects were fully de-briefed.

Pilot: The adapted MMSE and new self-efficacy scale were piloted on a small sample of SCI inpatients (n = 5) and resulted in a number of minor alterations to the scales.

Results

Descriptive Analyses

As tables 1and 2 indicate the proportion of males to females differed across conditions, with approximate ratios of males to females of 3:1 for the SCI sample and 1:2 for the MS group. As analyses indicated no significant differences between males and females on any of the dependent measures sex differences were ignored.

As table 3 illustrates, the distribution of Barthel scores is markedly different across SCI and MS groups: MS subjects are much less physically disabled as measured by the Barthel than are SCI subjects, with a much greater range of disability found within the SCI group (see **Appendix 4.6** for a discussion of the difficulties of applying a unitary measure of disability across conditions). As a result of the large disparity in the range of scores for the two groups, it was not possible to match each MS subject with a SCI subject according to Barthel score. Subsequent analyses therefore compared all 43 SCI subjects with the 25 MS subjects, and attempted to control statistically for the effects of level of disability within the SCI group.

Table 3: Distribution of Barthel scores for SCI and MS groups

Barthel Category	SCI (total n = 43)	MS (total n = 25)
	mean = 10.74 SD = 6.27	mean = 17.88 SD = 4.95
very severely disabled (0-4)	9	1
severely disabled (5-9)	10	1
moderately disabled (10-14)	10	1
mildly disabled (15-19)	10	6
independent (20)	4	16

Tables 1 and 2 also illustrate inter-group differences in length of injury/illness, with the mean length of SCI shorter than the mean length of time MS subjects had been diagnosed or their subjective estimate of length of MS. Although the mean length of hospitalisations are similar for both groups, the range and standard deviations are large especially for the MS group. Inspection of individual cases on the length of admission variable showed there to be a single outlier in both groups which corresponded to two elderly single women who were hospitalised because of care needs rather than treatment issues *per se* and were therefore not representative of the wider sample. When these cases were omitted the mean length of hospitalisations dropped to 18.43 weeks (range = 0.5 - 55, sd = 13.77) for SCI subjects and 2.41 weeks (range = 0 - 8, sd = 2.07) for MS subjects. However, both time since injury/diagnosis and length of hospitalisation variables remained positively skewed and logarithm transformations were therefore carried out to normalise these distributions. T-tests on the transformed variables showed that MS subjects had been diagnosed for significantly longer than SCI subjects had been injured (t = 5.58, df = 64.13, p < .001, two-tailed), and that MS subjects had significantly shorter periods of hospitalisation than SCI subjects (t = 7.89, df = 58, p < .001, two-tailed).

Pain was reported by 32 (74%) SCI subjects and in 9 (36%) of MS patients with mean pain severity scores of 2.80 (sd 1.18) and 2.41(sd 1.20).

As access to medical notes was limited, it was not possible to obtain reliable details about medication: although subjects tended to be clear about whether they received medication for pain relief, many were unsure whether they were taking anti-depressant drugs.

Main Hypotheses

1. <u>Influence of pain on depression and anxiety</u>

It was predicted that those experiencing pain would be significantly more depressed and anxious than those not experiencing pain, regardless of their condition.

Taking the overall sample (collapsing condition), those reporting pain (n = 41) were not significantly more depressed (t = .59, df = 66, p = .278, one-tailed) or anxious (t = .53, df = 66, p = .300, one-tailed) than those who did not report pain (n = 27). Within the pain suffering sample, pain severity did not correlate with depression (Spearman's r = .179, p = .131, one-tailed) or anxiety (Spearman's r = .058, p = .359, one-tailed).

Five out of the nine MS subjects who reported pain received medication, four of whom reported pain relief and one reported variable relief. Of the 32 SCI subjects reporting pain, 26 were receiving medication for pain relief. Nine of them reported that medication helped, nine that it gave variable relief, and eight that it did not help at all. Separate oneway analyses of variance were used to compare (a) the mean BDI and (b) the mean STAI scores for SCI patients reporting these three levels of effectiveness of medication and a fourth group ($n = 6$) reporting pain but not receiving medication. Non-significant F ratios of 1.51 and 2.13 (at $p < .05$) were found for the BDI and STAI respectively.

2. Is an internal LOC adaptive in the face of disability, i.e. is it predictive of decreased psychological distress (a) across conditions ?

It was predicted that an internal LOC would be associated with lower levels of depression and anxiety within the SCI group, but not necessarily within the MS group.

Mean scores on each of the psychological measures are shown for SCI and MS groups in table 4. Results indicated that SCI subjects did not differ significantly from MS subjects in terms of the overall levels of anxiety and depression experienced (see **Appendix 4.7** for distribution of BDI and STAI scores across groups). SCI subjects scored higher on the internal subscale and RLOC total, indicating that they are significantly more internally orientated than MS subjects. (**Appendix 4.8** contains within group comparisons on the BDI and STAI for the SCI group.)

Table 4: Means, standard deviations and t-test significance for psychological test scores for SCI and MS groups.

Variable	N	Mean	SD	t-value	DF	Sig (p < .05) two-tailed
BDI:						
SCI	43	11.00	7.89	1.45	66	N.S.
MS	25	8.28	6.57			
STAI:						
SCI	43	38.67	11.28	1.11	66	N.S.
MS	25	41.68	9.86			
RLOC:						
SCI	43	37.21	4.65	2.21	66	p =.031
MS	25	34.56	4.97			
Internal:						
SCI	43	22.33	2.88	2.56	66	p =.013
MS	25	20.40	3.19			
External:						
SCI	43	9.12	3.15	.92	66	N.S.
MS	25	9.84	3.05			
Others:						
SCI	43	9.05	2.46	.14	66	N.S.
MS	25	8.96	2.41			

Correlational analyses were directed at the relationship between LOC and depression and anxiety (see **Appendix 4.9** for the rationale for choosing correlation measures).Tables 5 and 6 show the correlations between BDI, STAI, Barthel, time since injury/diagnosis and LOC scores for the SCI and MS subjects. As there was a broad range of disability (as measured by the Barthel) within the SCI group, the effects of level of disability were partialled out where appropriate for the SCI sample.

Table 5: Correlations between BDI, STAI, Barthel, time since injury and LOC scores for SCI subjects (n = 43) (Barthel variance partialled out except for correlations with Barthel)

	Barthel	Time	BDI	STAI	Internal	External	RLOC	Others
Barthel		.112	-.073	-.071	-.004	-.222*	.149	-.261*
Time			-.306*	-.168	-.150	-.093	-.034	-.218
BDI				.850***	.027	.334*	-.206	.197
STAI					.090	.197	-.074	.041
Internal						-.168	.753***	.084
External							-.775***	.140
RLOC								-.039

**p < .05, ** p <.01, ***p < .001 (two-tailed level of significance used with Barthel and time, one-tailed level used for remainder)*

Table 6: Correlations between BDI, STAI, Barthel, time since diagnosis and LOC scores for MS subjects (n = 25)

	Barthel	Time	BDI	STAI	Internal	External	RLOC	Others
Barthel		-.303	-.168	-.189	.508***	-.060	.352*	-.139
Time			.042	.162	-.048	-.181	.080	.126
BDI				.738***	-.280	.335	-.386	.228
STAI					-.152	.350	-.312	.184
Internal						-.267	.806***	-.372
External							-.786***	.629***
RLOC								-.626***

** p < .05, ** p <.01, *** p < .001 (two-tailed tests)*

As tables 5 and 6 show, internality was not associated with lower levels of depression or anxiety for SCI or MS subjects, although, there was a non-significant trend with depression within the MS group. Severity of depression was, however, positively correlated with external LOC for SCI subjects and external LOC was associated with increased levels of disability. There was also an association between externality and level of depression within the MS group, however the correlation was not significant at p < .05. A belief in control by others was positively correlated with an external LOC and negatively correlated with RLOC for MS subjects, but this was not the case for SCI subjects.

3. Is an internal LOC adaptive in the face of disability, i.e. is it predictive of decreased psychological distress (b) across time and setting ?

It was predicted that an external LOC and a belief in others would be linked to lower levels of depression and anxiety in the acute phase of an illness or injury, when a person is hospitalised and thus under vicarious control, but that an internal LOC would be linked to lower levels of psychological distress following discharge.

From tables 5 and 6, it can be seen that time since diagnosis was not significantly correlated with BDI or STAI scores for the MS group. However, within the SCI group, depression scores were negatively correlated with time since injury.

SCI subjects were divided into those who were in the acute phase of their injury (i.e. still hospitalised following their injury) (n = 20) and those who had left hospital, but were receiving outpatient treatment (n = 19). Four SCI inpatients were excluded from this analysis as they constituted re-admissions. As expected, those in the acute phase of their injury had been injured for significantly less time (t = 5.10, df = 23.8, p < .001) and were significantly more physically disabled (t = 4.64, df = 37, p < .001) than those in the non-acute phase. As table 7 illustrates, acute subjects were found to be significantly more depressed and anxious than non-acute subjects.

Table 7: Means, standard deviations and t-test significance for BDI and STAI scores for SCI patients in acute and non-acute phases of their injury

Variable	N	Mean	SD	t-test	DF	One-tailed significance
BDI:						
acute	20	13.15	8.56	1.70	37	p = .048
non-acute	19	8.89	6.91			
STAI:						
acute	20	41.50	10.60	1.64	37	p = .055
non-acute	19	35.79	11.16			

In order to investigate whether an external LOC was more adaptive for acute subjects and an internal LOC for non-acute, BDI and STAI scores were correlated with internal, external and others scores for these two groups separately, partialling out the variance associated with level of disability. As tables 8 and 9 show, an external LOC or belief in others was not associated with decreased depression or anxiety in the acute condition; neither was an internal LOC associated with decreased distress in the non-acute condition.

Table 8: Correlations between BDI, STAI and LOC scores for SCI subjects in acute phase of injury (n = 20) (Barthel variance partialled out)

	LOC		
	Internal	**External**	**Others**
BDI	.009	.310	.164
STAI	-.004	.131	-.043

All non-significant at p < .05 (one-tailed)

Table 9: Correlations between BDI, STAI and LOC scores for SCI subjects in non-acute phase of their injury (n = 19) (Barthel variance partialled out)

	LOC		
	Internal	**External**	**Others**
BDI	-.019	.304	.002
STAI	.104	.228	-.025

All non-significant at p < .05 (one-tailed)

It was not possible to clearly group MS subjects into in- and outpatient groups, given that inpatient admissions were typically very brief, and that the subjects accessed via MS Action could not be readily identified as "outpatients" *per se*. Although an attempt was made to categorise MS subjects according to relapse, remission and progressive courses, subjects found it difficult to identify their disease status. The poor reliability of this classification prohibited further analyses.

4. How do self-efficacy beliefs impact on coping and psychological distress ?

It was predicted that low perceived self-efficacy as regards rehabilitation would be associated with increased depression and anxiety, and that in conditions such as SCI where a positive association has been found between internal LOC and adjustment, that an internal LOC combined with low perceived self-efficacy might be associated with a high level of cognitive dissonance and increased psychological distress.

As the range of available advice varied across subjects, self-efficacy and outcome-expectancy scores were obtained for each subject by summing their individual ratings and dividing them by the total number of sources of advice accessed. As table 10 shows, SCI subjects typically accessed more sources of advice. However, self-efficacy and outcome expectancy scores are comparable for SCI and MS groups. Kendall's tau correlations of .394 (p < .001, one-tailed) and .178 (p = .111, one-tailed) were found between self-efficacy and outcome-expectancy scores for SCI and MS subjects, respectively. Self-efficacy scores were not correlated with RLOC scores for SCI (tau = .080, p = .467, two-tailed) or MS (tau = .014, p = .925, two-tailed) groups.

Table 10: Medians and ranges of number of sources of available advice, outcome expectancy and self-efficacy scores for SCI and MS subjects

Measure	Median	Range
No. of sources of advice:		
SCI	7	3 - 11
MS	5	2 - 10
Mean outcome expectancy score:		
SCI	4.22	3.00 - 5.00
MS	4.00	2.25 - 5.00
Mean self-efficacy score:		
SCI	3.90	2.67 - 5.00
MS	3.62	2.00 - 5.00

Among SCI subjects self-efficacy correlated negatively with BDI (tau = -.175, p = .053, one-tailed) and STAI scores (tau = -.262, p = .007, one-tailed). Similar results were found for MS patients (tau = -.282, p = .027, one-tailed, for BDI and tau = - .331, p = .011, one-tailed, for STAI).

Interaction effects of LOC and self-efficacy were examined within the SCI group using a two-way ANOVA. SCI subjects were divided into four groups on the basis of a median split on RLOC and self-efficacy: external/low self-efficacy, external/high self-efficacy, internal/low self-efficacy, internal high self-efficacy (8 cases sat on the medians and were therefore excluded from the analysis). Tables 10 and 11 show the mean BDI and STAI scores for each group. No significant main effects of self-efficacy or RLOC were found for BDI scores. For STAI scores F ratios of 3.04 (p = .062) and 5.232 (p = .029) were found for RLOC and self-efficacy respectively, indicating a main effect of self-efficacy. There was no significant interaction found.

Table 11: Mean BDI scores for SCI subjects falling into groups of external/low self-efficacy, external/high self-efficacy, internal/low self-efficacy, internal high self-efficacy

		RLOC		
		External	**Internal**	**Total**
Self-efficacy	**Low**	13.10 (n = 10)	11.29 (n = 7)	12.35
	High	10.50 (n = 8)	6.40 (n = 10)	8.22
	Total	11.53	8.41	

Table 12: Mean STAI scores for SCI subjects falling into groups of external/low self-efficacy, external/high self-efficacy, internal/low self-efficacy, internal high self-efficacy

		RLOC		
		External	**Internal**	**Total**
Self-efficacy	**Low**	41.80 (n = 10)	40.43 (n = 7)	41.24
	High	34.38 (n = 8)	31.60 (n = 10)	32.83
	Total	38.50	35.24	

Discussion

The results of the present study suggest that although SCI subjects were significantly more internally oriented than MS subjects, contrary to prediction an internal LOC within this group was not associated with lower levels of depression. Internal LOC did not correlate significantly with BDI scores for either group, although there was a non-significant trend for a negative correlation for MS subjects. Although SCI subjects tended to be somewhat less anxious than MS subjects, anxiety level was also not associated with internality. Levels of depression and anxiety were highly correlated for both groups.

The greater internality found within the SCI sample may be related to the implementation of the Goal Planning rehabilitation programme[37,38] in QUENSIC over the past couple of years. This programme attempts to foster in patients a sense of self-direction and control over their rehabilitation, which is in contrast with the more piecemeal treatment and rehabilitation that the MS sample received. Although previous studies[37] have found Goal Planning approaches to be associated with positive outcomes including increased engagement in rehabilitation, the results of the present study suggest that rehabilitation which attempts to promote an internal LOC does not necessarily reduce psychological distress.

Although there was no association between internality and depression or anxiety for SCI subjects, externality was, however, significantly related to depression. It is of course impossible to determine the direction of the relationship between these two variables, as it may be that the more depressed a person is, the more likely they are to rely on external supports. However, these results suggest that although an internal LOC is not necessarily psychologically adaptive in the face of SCI, an external LOC appears to be maladaptive. This finding is in keeping with many other studies[22,23] which have documented an association between externality and poor psychological adjustment in SCI. Given that within the SCI sample, external LOC was associated with increased levels of both depression and functional impairment, it may be as Partridge and Johnston[10] have suggested that mood mediates the relationship between an external LOC and rehabilitation outcomes.

The correlation between externality and depression approached significance for MS subjects and, in addition, there was a slightly stronger association (although also non-significant) between internality and adjustment for MS than for SCI subjects. While the non-significant associations limit the conclusions that can be drawn, these results at least suggest that an internal LOC is not necessarily maladaptive in the face of more unpredictable, chronic disabling illnesses such as MS.

Although previous studies[25,26] have identified pain in conjunction with an external LOC to be key determinants of psychological upset, the present study failed to find a significant relationship between psychological distress and pain: although pain was reported by approximately three quarters of SCI and one third of MS subjects, ratings of pain severity were one standard deviation below the mean obtained for Kerns et al's[36] chronic pain population, and those reporting pain appeared to be no more depressed or anxious than those not. Within the SCI group, perceived effectiveness of pain relief medication was also not associated with anxiety or depression. The lack of association between pain severity and psychological distress may be due to the relatively low level of pain reported by subjects. However, a more comprehensive, multi-dimensional measure of pain may have been more sensitive to the subtleties of the psychological impact of pain.

The results suggest that, regardless of the nature of the condition or subjects' LOC, if people feel confident of their ability to carry out treatment and rehabilitation advice, then they are likely to experience lower levels of depression and anxiety. Self-efficacy did not correlate with internality in either group and the expected interaction between LOC and self-efficacy within the SCI group was not found. Although it was not possible to assess whether self-efficacy expectations were linked with adherence to treatment or rehabilitation, there exists a wide body of evidence[15] that perceived self-efficacy predicts behaviours across a wide variety of health domains. Thus, it may be that those with high self-efficacy were more likely to engage actively in rehabilitation which may have reduced helplessness and resulted in lower levels of anxiety and depression. Of course, the correlational nature of the present analyses renders this speculative.

Neither time since diagnosis nor level of disability were associated with psychological morbidity for MS subjects, however the poor sensitivity of the Barthel as a measure of functional impairment for this patient group may have masked any effects of level of physical disability. Although there was a greater spread of Barthel scores among SCI subjects, the lack of association found between level of disability, on the one hand, and depression and anxiety on the other, in this study are in keeping with previous studies[3,4,39] which found severity of injury to be of little prognostic value for psychological adaption.

However, in contrast to previous studies in SCI[22,25] a significant relationship was found between time since injury and depression scores: the longer subjects had their spinal injury, the less depressive symptomatology they exhibited. This association between time and depression was not found in the MS sample. It appears that time since injury may have quite a different psychological significance for SCI subjects than time since diagnosis does for MS patients: for SCI subjects, time since injury is more akin to length of disability with level of disability being likely to stabilise or improve over time. However, people with MS can have the illness for a considerable period of time without experiencing significant levels of functional impairment, but, over time, functioning may fluctuate and eventually decline. Thus the pattern of progression of disability over time, and perhaps the anticipation of future disability, may be more important in predicting depression, rather than the level of disability *per se*.

The hypothesis that a belief in others and more external sources of control might be more adaptive when one is hospitalised in an acute phase of injury or illness, and internality more adaptive when discharged, was not supported by the present findings. However, analyses were restricted to the SCI group, as the inpatient/outpatient distinction appeared not to be meaningful within the final MS sample, and because subjects were uncertain of the status of their MS. Also important, is the fact that unlike SCI, an acute phase of MS is not necessarily associated with hospitalisation.

Intuitively, it would seem that the stage of MS, whether relapse, remission or progressive, would be important in considering the adaptiveness of different control cognitions. However, the poor reliability of subjects' reports meant that these analyses could not be carried out. Thus, the MS sample were treated as a single group and their heterogeneity was not taken into account. Future studies might involve medical professionals in the identification of different phases of MS and explore the adaptiveness of LOC cognitions across the different phases.

The adaptiveness of control cognitions across settings might also usefully be considered as a separate issue from the "acuteness" of the condition. It was beyond the scope of this study to investigate whether, as Morrison et al[20] have suggested, that flexibility of LOC across settings is optimally adaptive. Future studies might best test this using a more longitudinal design following subjects from hospital to home.

Conclusions

The results of the present study suggest that although an internal LOC is not necessarily linked to lower levels of psychological morbidity in people with SCI or MS, an external LOC is associated with depression and greater physical disability in SCI. In general, however, LOC does not appear to be differentially adaptive across conditions or across time or setting. The present findings do, however, point to the usefulness of the more situationally-specific self-efficacy construct in predicting anxiety and depression across both conditions. Thus, regardless of the nature of the condition or subjects' LOC, if a person feels confident of their ability to carry out specific treatment or rehabilitation advice, they are likely to experience less psychological distress.

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Chapter 5

Single Case Research Study

*(Written for submission to **The British Journal of Learning Disabilities.***

*See **Appendix 5.1** for Notes for Contributors)*

Treatment of a Dog Phobia in a Man with Down's Syndrome:

Working with a Mother's Agenda

A Case Report

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Treatment of a Dog Phobia in a Man with Down's Syndrome: Working with a Mother's Agenda

Summary

The case study presented highlights the importance of a thorough assessment incorporating wider family, developmental and life-span issues, and relates these to the development, maintenance and treatment of a dog phobia in a 27 year old man with Down's syndrome. The first twelve weeks of treatment are described. Assessment revealed that maternal needs and fears were important maintaining factors of the phobia and treatment was therefore aimed at using the mother as "co-therapist" and desensitising both her and her son to their fear of his contact with dogs. Graded exposure and cognitive therapy were used with both mother and son to challenge their catastrophic thinking in relation to dogs. However, in order to prevent future relapses, it was important to examine underlying relationship factors and separation anxieties which appeared to maintain the phobia.

Treatment of a Dog Phobia in a Man with Down's Syndrome: Working with a Mother's Agenda

Introduction

Whilst there is an extensive literature investigating phobias in the general population, there appears to be a dearth of research on the assessment and treatment of phobic disorders in adults with learning disabilities. However, several studies have highlighted the effectiveness of behavioural interventions with this population. For example, Guralnick (1973) reported the successful use of an "anxiety hierarchy" to treat an extreme fear of heights in a 21 year old man with Down's syndrome. Similarly, Peck (1977) treated an adult with a fear of rats, and Matson (1981) has reported the successful treatment of several adults with a range of phobias. Specifically relating to dog phobias, Dixon and Gunary (1986) and Jackson and Hooper (1981) have demonstrated the successful use of desensitisation, and Bryan and Weston (1987) the effectiveness of modelling. Lindsay et al (1988) described the success of exposure treatments with two women with dog phobias. Their multi-component package involved increasing contact with dogs using graded exposure and changing stimuli; eliciting anxiety from an early stage in the intervention; modelling nonanxious responses to dogs; developing control over feared situations; using relaxation; and promoting generalisation of coping behaviours.

When assessing and treating phobias in people with learning disabilities, certain issues need to be considered. Lindsay (1987) points out that in people with learning disabilities both the presentation of phobias and their reactions to them might be quite different from those of non-learning disabled people. Lindsay et al (1988) also notes the importance of achieving a comprehensive assessment of the behaviour and feelings of a person with a learning disability presenting with a phobia. Cognitive behavioural approaches to treatment (e.g. Butler, 1991) may also require adaption as the cognitive components may be difficult for some people with learning disabilities to grasp.

Traditional models of treatment such as Butler's, emphasise the importance of maintaining factors which serve to reinforce phobic behaviour and which therefore need to be addressed in order to treat the phobia. For many adults with learning disabilities who experience prolonged dependence on their families, the needs and desires of other family members or carers may be particularly potent reinforcers of behaviours, both adaptive and maladaptive. Klesges et al (1984) stressed the importance of parental behaviour on children in their successful treatment of a child with a dental phobia using the child's mother (who was also dental avoidant) as a model of appropriate behaviour. They suggested that improvements in the child's phobia were related to indirect graded exposure effects and some sort of mother-child "mutual modelling" effects. Thus, they conclude the need for a careful assessment of both parental and child variables contributing to childhood fears and phobias.

The case study presented highlights the importance of a thorough assessment incorporating wider family, developmental and life-span issues and relates these to the development, maintenance and treatment of a dog phobia in a man with Down's syndrome. The first twelve sessions of assessment and treatment are described and long term outcome is discussed in terms of the need to widen treatment focus to encompass the needs and concerns of significant others in the person's life.

Presenting Problem

Mr DM was a 27 year old man with Down's Syndrome with a longstanding dog phobia. D had received psychological treatment in the past (five years previously) when he had appeared reluctant to go out alone in case he encountered a dog. A programme of graded exposure had apparently been successful in ameliorating his fear and decreasing avoidant behaviours. Although D's keyworker from his resource centre reported that D coped fairly well with dogs by ignoring them without any overt anxiety, D's mother reported that D's ability to cope with dogs had gradually "slipped away again". She reported several incidents where D had appeared terrified by small dogs and she described how she would take D's arm and put herself between him and the dog. Mrs M was particularly worried that if D came across a dog when he was on his own he might panic and run into the road or, given that D had a heart condition, that the fear might provoke a heart attack. As a result Mrs M had minimised D's opportunities to walk unaccompanied.

D reported feeling "a bit shaky" when he saw a dog particularly if they were unleashed and barking or jumping which seemed to trigger thoughts of being bitten or overpowered. However, he described generally trying to ignore dogs and he recalled several incidents in the previous week when he had done just that. D appeared keen to show that he was coping and made no mention of the incidents which his mother had referred to. He reported that although he did not like dogs, this did not stop him from doing anything that he wanted to do.

Resource centre staff maintained that as a result of Mrs M's worry, and a general tendency to be "overprotective", she was opposing the centre's encouragement that D attend college courses and other activities out with the centre. Concern was voiced that D's development was being unnecessarily restricted because of his mother's fears and that this was beginning to "rub off" on D: although originally D had been keen to attend college, he had recently begun having second thoughts and voicing concerns about "not being able to cope".

Mrs M confided that she felt the centre tended "to push D too hard" and that they were generally unaware of his limitations. She was displeased that D was "forced" to travel outside the centre to do things and could not understand why the centre did not provide for all of D's needs. She worried that this might overly tire D and put pressure on his heart. Mrs M reported that although D was a "high grade Downs", the community integration the centre was trying to foster was unrealistic and unnecessary and may even put her son at risk. She believed that D had a full and busy life and was content with living at home and attending the centre.

When asked about his hopes for the future, D responded that he wanted to continue attending his current centre, feeling a job would be "too much" for him. D reported not wanting to move out of home because he couldn't cook and he believed he would be lonely.

Personal history

D lived at home with his 55 year old mother, a housewife, and his 59 year old father, an engineer. In addition to attending a local adult resource centre he attended three different clubs for people with learning disabilities, one of which his mother was on the organising committee for and attended with

D. Although all the clubs were local, Mrs M always accompanied D in the evenings and collected him afterwards. D also enjoyed snooker and bowls and attended local clubs with his parents.

D was born with heart problems and it was thought that he would die before he reached his 20's due to one of the valves in his heart not shutting properly. Corrective surgery was performed when D was 21 and D's GP reported that although the operation was largely successful and D's condition had stabilised, the ineffectual valve continued not to function as completely as it should. The GP also made it clear that she supported Mrs M's view that D should not be "pushed too hard" and agreed with her that the resource centre "should realise his limitations".

Measures of Assessment

1. Interviews with D alone and with his parents, D's keyworker and D's mother alone - Interviews were carried out within home and work contexts to gain an overall picture of the current status of D's dog phobia and to explore its impact, and any other possible limiting forces, on D's personal development. These interviews covered areas such as the development of the phobia, severity, symptoms, maintaining factors, existing coping strategies and previous treatment. The interviews were also used to elicit opinions from all parties concerning D's future and plans for his development.
2. Zung self-rating anxiety scale (SAS) (Zung, 1971) - This measure of generalised anxiety was adapted for use with people with learning disabilities by Lindsay and Michie (1988) and provides a measure of the presence of 20 anxiety symptoms. M indicated the presence of four anxiety symptoms, suggesting he experienced a fairly low level of generalised anxiety.
3. Graded hierarchies - Phobic behaviour was measured in two contexts: dealing with dogs in public places and interacting with "known" dogs, i.e. a friend's dog encountered in their house. Based on the method outlined by Butler (1991), two separate hierarchies of graded stimulus situations were developed (see **Appendix 5.2**). Anxiety was measured across treatment using the following subjective units of distress: "difficult" - "okay" - "easy". On the first hierarchy D reported that the first four steps would be "easy" and the last two "okay" and thus seemed fairly confident in his ability to cope with situations involving walking past dogs in public places. However, on hierarchy 2,

interacting with "known dogs", he reported being "okay" for steps one and two, but the remainder were perceived as "difficult". Mrs M believed that D was likely to panic in all of the situations in both hierarchies.

Formulation

Assessment revealed some discrepancy between D's and his mother's perceptions of his phobia: Mrs M significantly over-estimated the severity of symptoms and under-estimated D's ability to cope in comparison with D or his keyworker. When this discrepancy was discussed with D and his mother, D tended to go along with his mother's view. It appeared that D was perhaps required to cope in situations where he was on his own or with friends, but depended on his mother when in her company. Mrs M seemed to reinforce this dependency with a sympathetic reaction, however, this in turn, reinforced her beliefs that D was incapable of coping on his own and that his fear may cause him to have a heart attack or run into the road. For these reasons, and because of other fears concerning D being bullied or mugged, Mrs M minimised D's opportunities to walk unaccompanied.

Related to this was Mrs M's rather limited and stereotyped views of people with Down's syndrome generally; views which were found to be reinforced by her GP. Mrs M tended to view D as a child to be protected and looked after. Her identity and lifestyle were largely determined by her role as mother and carer, and D had not been able to separate or develop his independence partly because of her need of him. The prospect of D dying in his 20's had perhaps prevented his mother from ever looking beyond D as a child and making the necessary adaptations in their relationship. D's dog phobia appeared to service Mrs M's need to keep her son close to her given the increasing emphasis the centre was placing on expanding D's horizons.

Treatment Procedures

Butler's (1991) cognitive behaviour therapy for phobias was combined with the treatment methods outlined by Lindsay et al (1988) to tackle D's anxiety concerning interacting with "known" dogs. This involved graded exposure to feared situations, and the toleration of the anxiety produced using relaxation and cognitive techniques, thereby breaking the vicious circle that maintains symptoms and facilitating new learning. Even although it appeared from assessment that D was fairly confident in his ability to deal with dogs in public places, both the hierarchies shown in **Appendix 5.2** were worked through, firstly to give D practice and to increase his confidence in his ability to deal with dogs generally, and secondly to systematically desensitise Mrs M to D dealing with dogs.

Mrs M was employed as "co-therapist" and the rationale for desensitisation was explained to both D and his mother. Treatment progressed as follows:

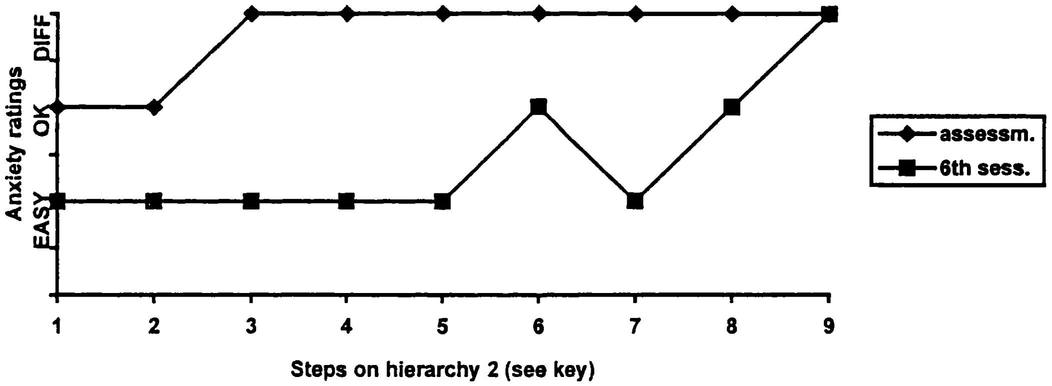
1. Lindsay and Baty's (1986) abbreviated progressive relaxation and controlled breathing exercises (designed for people with learning disabilities) taught and D encouraged to practice at home with mother.
2. D taught to substitute anxious thoughts about being bitten or overpowered by dogs for more positive self statements, e.g. "I can cope with this dog by ignoring it" and "The dog is not interested in me".
3. Exposure to hierarchy 1 (see **Appendix 5.2.1**). Therapist modelled appropriate responses for both D and Mrs M. Relaxation and breathing exercises and positive self statements encouraged *in situ.* D and his mother encouraged to practice steps in between sessions.
4. Exposure to hierarchy 2 (see **Appendix 5.2.2**).Same method used as for hierarchy 1. Generalisation promoted using two different types of dogs (large, docile dog and smaller, lively puppy) and in two different settings (park and living room).

Outcome

1. Zung SAS - After eight treatment sessions D reported the presence of three out of a possible twenty generalised anxiety symptoms which was one less than at assessment. As D had exhibited few generalised anxiety symptoms at assessment, the scope for reduction was limited.
2. Graded hierarchies - Hierarchy 1 - After two sessions D was able to demonstrate to his mother his ability to cope with dogs encountered in public places. As D started off reporting low levels of anxiety, his anxiety ratings showed no change across treatment.

Hierarchy 2 - This was completed in six sessions using an elderly, docile dog in the park. Figure i illustrates D's progress across sessions: after six sessions, D reported finding steps one to five and step seven to be "easy", steps six and eight "okay" and the last step remained "difficult". It was noted, however, that D's physiological symptoms of anxiety did not necessarily decrease in synchrony with the self-report measures: D was observed to continue breathing rapidly, perspiring and trembling when faced with situations he rated as "okay" or "easy". It may have been that D was uncertain of how to use the rating system employed, but a more likely explanation seemed that he wanted to impress his mother and the therapist by his progress. For this reason, and in order to promote generalisation, further practise was planned using a different dog and setting.

Figure i: Anxiety ratings ("easy " - "okay" - "difficult") for hierarchy 2 across 6 treatment sessions



Key:
Step 1: D stroke dog (on lead) for 20 seconds (back, head and face on) - dog sitting.
Step 2: D stroke dog (on lead) for 20 seconds(back, head and face on) - dog standing.
Step 3: Step 1, but dog off lead.
Step 4: Step 2, but dog off lead.
Step 5: D feed dog on lead.
Step 6: D feed dog off lead.
Step 7: D hold lead for 10 seconds with hand over hand support.
Step 8: Step 7 but without hand support.
Step 9: D walk with dog on lead for I minute.

Concurrent therapy with Mrs M

One of the aims of working though the behavioural hierarchies had been to challenge Mrs M's catastrophic thinking about D's ability to cope with dogs, and from her reports this appeared to have been fairly successful. However, Mrs M also tended to catastrophise when thinking about unexpected situations D might come across when travelling independently, such as being bullied or not knowing what to do if his usual bus service was cancelled, or if he got over-tired. Mrs M appeared not only to over-estimate the likelihood of negative events occurring, but also under-estimated D's available coping strategies. Time was therefore spent exploring some of these underlying concerns within a cognitive behavioural framework.

Although after the first twelve weeks of treatment Mrs M still harboured some concerns, she did not intend to dissuade D from attending college and had agreed to begin encouraging D to travel to his centre, college and clubs either on his own or with friends. Mrs M also began to talk about where D would live in the future.

Discussion

After twelve sessions D appeared to have made considerable progress in his ability to interact with "known dogs" and was able to demonstrate this, and his previously questioned handling of strays, to his mother. In addition, Mrs M's confidence in D's abilities to cope with dogs appeared to have increased, and she had begun to question some of her catastrophic thinking related to D's developing independence in other areas of his life.

It was apparent that what originally presented as a simple phobia of a young man with a learning disability was, in effect, largely driven by the needs of his mother for whom the phobia served to keep her son close. Dossetor and Nicol (1989) have pointed out that the increasing freedom and autonomy which adolescence brings - with its increase in activities and time spent with peers and corresponding decrease in sharing with parents - is frequently absent or reversed for those with a learning disability. This would appear to be the case with D. However, as rapport and trust developed, it was possible to engage Mrs M on her perceptions of D's learning disability and its implications for her life.

Bicknell (1983) provides a useful framework for examining the reactions of parents to the presence of a handicapped person within the family in which a modified bereavement reaction takes place. Parents are thought to go through transitional stages of shock, panic, denial, grief (anger and guilt) towards acceptance. However, Bicknell postulates that certain maladaptive responses may prevent acceptance from ever being truly achieved. One of these maladaptive responses is infantilisation. Given the original prognosis of a much fore-shortened lifespan for D, it appeared that Mrs M may not have progressed beyond accepting D as anything other than "her boy". This was reflected not only in her tendency to be overprotective, but also in her behaviour towards D more generally, e.g. combing his hair in public and joking about female friends being "little girlfriends". As a result, the necessary "letting go" had not followed and was exacerbated due to real or imagined skill deficits in activities of daily living (e.g. cooking, cleaning, handling money) which may have arisen from Mrs M's taking on of all domestic chores as part of her role as wife and mother. Significantly, Mrs D's tendency to infantilise D was potently reinforced by the opinions and prejudice of the GP, whose professional credibility leant great weight to Mrs M's beliefs.

Although Butler (1991) draws attention to the possibility of relationship factors contributing to the maintenance of phobias, this would seem to be particularly relevant when treating people with learning disabilities where issues to do with separation and infantilisation are perhaps more salient. In the case described, the danger of not addressing the needs of the immediate family and attitudes of the wider system of which D was part, was that the "mother-son" dog phobia would recur throughout D's life whenever separation became an issue.

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Chapter 6

Single Case Research Study

(Written for submission to ***Clinical Child Psychology and Psychiatry***.

See **Appendix 6.1** for Notes for Contributors)

Coping with Childhood Cancer: Implications for Siblings

A Case Report

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Coping with Childhood Cancer: Implications for Siblings

Abstract

The case study presented explores the interaction of child, family, and illness factors in the development of separation anxiety in the sibling of a child with leukaemia, and examines how these factors combined to produce more general family dysfunction. Treatment focused on helping the child to express and explore insecure and hostile feelings towards his family. Davis' (1993) framework of family adaption to illness was used to explore how individual members of the family construed the illness and cognitive techniques were used to help challenge dysfunctional schemata. Treatment and outcome are discussed in terms of the need to address issues concerning wider family functioning.

Key words: chronic illness, separation anxiety, maternal anxiety, sibling rivalry

Coping with Childhood Cancer: Implications for Siblings

Introduction

It is now well established that a paediatric condition in a young child has a psychosocial impact not only on the patient, but on other family members (Stoneman and Brody, 1993). Given the lifelong significance of sibling relationships, Lobato et al (1988) commented on the likelihood that 'the substantial changes in the health and functioning of a sibling will affect the other(s) and that these changes may correspond systematically to characteristics of the children, the family, and the disease or disability itself' (p. 390). Empirical research, however, tends not to support the popular belief that siblings of chronically ill children will automatically experience more problems in overall psychological functioning than do siblings of well children (e.g. Spinetta, 1981; Tew and Laurence, 1973). In fact, it appears that some children may even benefit psychologically from this experience: children growing up with an ill or disabled brother or sister have been found to be more sensitive, compassionate and socially competent, more capable of empathy, and more aware of other people's suffering than peers who have not been exposed to illness in their sibling (Havermans and Eiser, 1994; Horowitz and Kazack, 1990). However, other studies have reported the presence of psychological problems including anxiety, depression, aggressive behaviour, poor peer relations and somatic disorders (e.g. Ferrari, 1984; Tew and Laurence, 1973).

Janus and Goldberg(1995) maintained that more emotionally aware children may be more open to both positive and negative aspects of having an ill brother or sister. They found that empathic siblings were more likely to be perceived by their mothers as being resentful towards the ill child and suggested that empathy maybe accompanied by a sharpened perception of other people's behaviour, and thus, perhaps a realisation of differential treatment by others, such as parents.

Lobato et al (1988) reviewed predictors of psychological distress in siblings of chronically ill children and found links between adverse effects and sibling constellation variables such as sibling sex, birth order and age spacing and with more general family variables such as socio-economic status, maternal social support and parental reaction and coping. Breslau et al (1981,1982) found that older sisters and younger brothers (in relation to a disabled child) show higher rates of behavioural problems with younger brothers tending to exhibit aggressive or delinquent behaviours and older sisters tending more towards depression and anxiety. They speculate that the added stress of having an ill sibling may foster greater differentiation of roles and responsibilities within the family.

Bank and Kahn (1982) have highlighted the effect of age spacing. They proposed that close spacing fosters sibling identification and shared interests probably as a result of increased contact and interaction. The increased contact of closely spaced siblings is likely, however, to be associated with more intense competition, conflict, and ambivalence, especially within same-sex pairs. Thus, it would appear that age spacing, in so far as it reflects the normal process of sibling identification and deidentification, may be an important consideration.

Other factors which have been thought to be related to the development of psychopathology in siblings include disease characteristics such as time of onset, aetiology, course and prognosis. For example, the behavioural and psychological adaptability needed by the sibling who has to contend with an illness which frequently or unpredictability recurs and results in repeated bouts of family disruption, may be quite different than for siblings dealing with diseases of different courses (Lobato et al, 1988).

The psychosocial adjustment of parents has been investigated as a protective factor for their children's adjustment (e.g. Kong et al, 1986; Thomson et al, 1994) with the general finding that maternal functioning is often predictive of the psychosocial adjustment of both the ill child and the healthy sibling. Townes and Wold (1977) reported that adjustment in the siblings of children with leukaemia was positively related to level of communication between parents and siblings. Such findings emphasise the need to consider sibling relationships within the context of other family relationships, resources, beliefs and values, and that the family, in turn, needs to be viewed within the wider socio-cultural context. Thus, dynamic family models of adaption to illness or disability (e.g. Crnic et al, 1983) would suggest that many of the effects of disease or disability on siblings are indirect or secondary, rather than primary and are a reflection of interactional or systems relationships.

The case study presented explores the interaction of child, family, and illness factors in the development of separation anxiety in the sibling of a child with leukaemia and examines how these factors combined to produce more general family dysfunction. A complete formulation of the problems required an investigation into the structure and dynamics of the extended family, allowing intervention to be targeted most effectively.

Presenting Problem

SM was an eight year old boy who experienced difficulty separating from his mother. His parents were also concerned about difficulties he experienced at school including poor hand writing and a general problem with motor co-ordination skills. His concentration and motivation were also poor and although he was receiving learning support, his parents were concerned that S would have to repeat a year at school.

Relevant Family History

S lived at home with his brother, A (nine years), his mother (a housewife), father (an architect), and his maternal grandfather. They lived in the maternal grandparents' house following the grandmother's death of cancer two and a half years previously. A was diagnosed as having acute lymphoblastic leukaemia when he was two years old (S was eight months). A was hospitalised for extended periods, but finished the main bulk of treatment five years ago. During A's hospitalisations, Mrs M did not stay in the hospital with A, but she and her husband split their time between A and S with the help of child minders. Mrs M described feeling guilty about constantly having to leave one child to be with the other. About a year and a half previously, A had complained of headaches and there was some question of a secondary tumour. After a period of four months of uncertainty, A was once again given the all clear.

S's grandfather had apparently experienced great difficulty accepting his wife's death and only six months after this had been diagnosed as having prostate cancer. This was subsequently dealt with surgically restoring him to full health. Mrs M had nursed her father through his cancer and, following pressure exerted by both her husband and father, they had sold their home and bought over her father's house. Mrs M talked tearfully of her mother's death and of the emotional implications of moving into what she still regarded as her mother's domain. Mrs M expressed feelings that her home was not her own and reported an absence of clear boundaries with her father, and difficulties asserting herself with him.

Developmental History

Pregnancy was planned and uncomplicated and there were no neonatal problems. S was generally a 'good' baby, sleeping and feeding well. Developmental milestones were normal, although toilet training did not begin until S was three and a half years because of the pressures of A's illness at this time. Bladder and bowel control were, however, quickly achieved.

Mrs M reported recurrent separation problems when S had attended play group, and his previous and current schools. The problem had come to a head five months after starting his new school (and only a few months after A's most recent 'health scare'), when S would refuse to get out of the car and would stand screaming and refusing to enter the playground. This problem only seemed to occur when Mrs M took the boys to school and S would go without fuss when his father or grandfather dropped him off.

Mrs M described S as an otherwise undemanding and even tempered child who tended to be dominated by his older brother, and although they often played well together, there was some sibling rivalry. S was believed to be particularly envious of A's regular hospital visits and was apparently 'delighted' to have his own attendance card and clinic to attend.

In addition to concerns about S's poor motor skills, Mrs M reported also worrying about his tendency to retreat into a fantasy world with pre-occupations about 'Power Rangers' and karate.

Assessment Measures

Assessment was carried out over sessions with S and both his parents, S and his mother, individual sessions with S and with his mother, and a telephone conversation with S's teacher. From this, and the information obtained from a behavioural diary kept across treatment, it appeared that, although S's tantrums had markedly reduced in frequency over the several months they had waited for an appointment, a degree of separation anxiety was still present. Mrs M, however, avoided taking S to school but dreaded the odd occasion when she might have to take them, anticipating the likely distressing scene. It also became apparent that S sometimes threw tantrums if his parents went out in the evenings.

S's teacher reported difficulties with writing and art, and concentration and motivation problems. She described S as 'very lazy' and 'immature' requiring constant prompting and usually having to take unfinished work home with him. His reading and work requiring verbal responses were good and she reported no particular behavioural problems.

Assessment of S's anxieties was carried out using projective techniques which elicited a number of important themes for further investigation:

1. Drawings - Di Leo (1973) describes how drawings can be used as diagnostic aids and, in particular, that a child's drawing of his family can provide important information on how he sees himself in relation to those most important in his life. S drew many pictures across treatment sessions, but his picture of his family (see **Appendix 6.2**) was particularly revealing: it showed his father spraying a hose at his crying brother, while S and his mother looked on smiling. Di Leo points out that hostility may be expressed by the use of weapons directed at the adversary.
2. Open sentences - Herbert (1991) recommends this technique for uncovering important clues to the source of a child's anxieties. The endings S provided indicated aggressive feelings towards his brother, and in addition, a dislike of school and his teacher.
3. 'Five faces' - This technique described by Jewett (1991) involves the child drawing faces which reflect specified feelings and then to add any of their own. This is intended as a diagnostic aid and as a means to begin talking about feelings with a child. S added 'mad', 'silly' and 'idiot' faces and again described feeling very angry about various incidents involving his brother.

S was co-operative and talked fairly easily during sessions, although he had been initially reluctant for his mum to leave. Mrs M responded in a 'roundabout' way by telling him she was slipping out to go to the toilet. Although generally able to attend to the task at hand, S would often go off at a tangent and frequently fantasised about cartoon and film characters.

Formulation

The repeated separation of S and his mother which inevitably resulted from A's frequent and prolonged hospitalisations, came at a particularly sensitive time in S's emotional development. There exists extensive evidence (e.g. Bowlby, 1973) that around seven months, infants begin to show marked distress when their mother departs leaving them alone. Separation anxiety typically reaches a peak at around 18 months and then gradually diminishes. S experienced repeated separation from his mother from the age of eight months, and it is notable that S's anxiety came to a head most recently around the time of a recurrence of A's health problems, which inevitably would have involved A and his mother attending hospital, often excluding S. At assessment S reported worries about his mum not returning to him and also appeared upset at the thought of her picking up her career or developing interests or commitments which did not involve him.

Mrs M had considerable anxiety about S having missed out as a result of the distress and upheaval in the family when A's leukaemia was diagnosed. She felt responsible for S's anxiety and also worried that she might now be to blame for S's apparent motor co-ordination problems. Her anxiety appeared to be contributing to her lack of confidence in dealing with S's distress. She was also putting herself under considerable pressure to try to make up for 'lost time' and was pre-occupied with trying to maintain equality. For Mrs M this meant treating both sons the same.

However, as S tried to assert his independence, he appeared to feel 'overshadowed' by his older, 'special' brother who seemed to be more confident and more able academically. As they did the same things, and did them together, this provided plenty of opportunity for comparisons to be made, and resulted in S feeling resentful and hostile towards his brother.

This formulation of the problem was borne out by the projective techniques employed with S. S's retreat into aggressive fantasy enabled him to cope with, and express, these feelings. An example of this arose on our sixth session when S's mother described how S had rudely told his swimming teacher that he did not want to continue with the private weekly lessons which S and his brother received together. As a 'punishment' for this, S had been made to practice his handwriting with his mother in the gallery while A had a double swimming lesson. During the second half of this session, while Mrs M was out of the room, S told me that his swimming teacher 'had been watching

"Terminator" films and had become cruel'. He said she was trying to trip him up and that he had done karate kicks and somersaults in order to fight her. S told how the teacher had held his head under the water, although he thought it would have looked to his mum from the gallery as if she was actually trying to help him.

Treatment

Part of four sessions were spent with S helping him to express and explore his feelings towards his family. Assessment merged into treatment as the projective techniques outlined above facilitated the ventilation of S's feelings of insecurity in relation to his mother, and hostility and aggression towards his brother.

Three sessions were spent with S's mother discussing her lack of confidence in dealing with S and her poor self-esteem in general. Mrs M expressed feelings of inadequacy concerning her role as a mother and of guilt at not being able to be there for both her sons during A's illness and hospitalisations. Davis (1993) outlined a framework for understanding the psychological processes by which parents experience and adapt to serious illness in their children. Drawing on Kelly's (1955) Personal Construct Theory, Davis maintains that family adaption to disease or illness is dependent on how individual members of the family construe or interpret the illness and how it impacts on their internal 'models' of the world. Thus Davis maintains that 'the process of helping parents is one of exploring with them the hypotheses they have about their world so as to clarify and, if necessary, change them. The ways of doing this are primarily through discussion and listening... ' (p.15). This framework provided a useful means of exploring Mrs M's self-constructions, and her constructions of both S and A. Mrs M appeared to benefit from ventilating her feelings of guilt and anger and cognitive therapeutic techniques were used to challenge her thoughts about being an inadequate mother.

Over these sessions it became apparent that Mrs M harboured considerable resentment towards her father: he had apparently always favoured her elder brother and had shown him preferential treatment. She felt that the ultimate expression of this had been his use of 'emotional blackmail' to get her to move into his house to look after him, whilst making no such demands on her brother. This sense of inequality and injustice stemming from her own childhood, coupled with A's illness and a feeling that S had 'lost out' in some way, perhaps prompted Mrs M to overcompensate in the handling of her own sons. The result was that both boys had exactly the same toys and clothes, both went to the same clubs and had the same interests. Mrs M seemed very anxious about diverging from this and also experienced great difficulty being assertive with S when he threw tantrums or made unreasonable demands.

Cognitive therapy was therefore used to challenge Mrs M's thinking concerning the consequences of treating her sons separately, i.e. that it was possible to treat them differently without showing preferences. Mrs M was encouraged to help S develop some separate interests and to help her sons foster their independence and individuality.

As Mrs M's self-esteem improved she became more confident in dealing with S's tantrums and this enabled us to tackle Mrs M's avoidance of taking S to school with a graded programme of exposure emphasising a calm, firm approach and the use of relaxation methods. S and his mother were taught Lewis' (1988) progressive muscular relaxation and breathing exercises and were encouraged to use them when S became anxious or upset.

Outcome

By the end of nine treatment sessions, the behavioural diary showed that Mrs M was able to take S to school without any upsets or tantrums. S had been allowed to stop swimming lessons and to join drama and karate clubs, whilst A continued with swimming and football. Mrs M reported that S seemed to enjoy telling the rest of the family about his new hobbies and his progress. Mrs M had decided to go into partnership with her friend in a catering business, something which she had wanted to do for some time, but had felt unable to make a commitment to.

Although S and his mother appeared happier and more relaxed, S still disliked school and both his parents remained concerned about difficulties he had with handwriting. A cognitive assessment was therefore completed with the aim of clarifying any specific difficulties S may have had. **Appendix 6.3** contains the full report on the assessment. To summarise, the results suggested that in comparison with age-related norms, S was of average intelligence with relative strengths in language and comprehension and weaknesses in grapho-motor co-ordination. Depressed scores on performance subtests, however, may have been affected by S's very apparent sensitivity to being timed on tests and consequent test anxiety. Both S's parents and teacher appeared to have been exerting some pressure on S to practice his writing and to 'keep up' with his class and it appeared that this may have been counter-productive.

These findings were fed back to his parents and teacher, and a referral was made to the specialist teacher in the Assessment Unit of the hospital for a more formal assessment of writing and for specific recommendations to be made.

Discussion

This case explores the practical and emotional sequelae of paediatric illness for all family members. Many of the risk factors highlighted in the literature converged to explain the presenting difficulties: relevant illness characteristics included the time of onset, which occurred when S was 8 months and entailed repeated separations from his mother until he was around three years. This coincided with a sensitive period of emotional development and may have contributed to an insecure attachment being formed with his mother, rendering S vulnerable to separation anxieties. The unpredictable course of A's illness with its later recurrence of symptoms (although they were benign) was likely to have thrown the family into disarray once again and re-emphasised for S the exclusive time and attention A received from his mother on their recent hospital visits.

As Bank and Kahn (1982) have suggested, the small age gap between the two brothers fostered close contact and shared interests. However, issues concerning identification and individuality became relevant particularly as Mrs M endeavoured to treat both sons the same in order to avoid preferential treatment. This tendency of Mrs M's could be traced back to her own childhood, but had recently become particularly relevant given the new pressures her father was placing on her. As both boys did the same things and did them together, S felt 'overshadowed' by his older, 'special' brother who seemed more confident and able than he, resulting in hostility, resentment and loss of self-esteem, which S tried to deal with by retreating into aggressive fantasy.

Maternal depression, anxiety (Treiber et al, 1987) adjustment and feelings (Thompson et al, 1994) have been related to psychosocial adjustment of children with an ill sibling, and it is likely that Mrs M's anxiety and poor self-esteem also contributed to S's difficulties.

Thus, the presentation of separation anxieties in a sibling of a child with leukaemia were construed in terms of illness, child and family factors. This multi-dimensional analysis illustrates how these factors combined to produce the presenting problem and contributed to more general levels of family dysfunction, therefore allowing treatment to be targeted optimally.

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Chapter 7

Single Case Research Study

*(Written for submission to **The British Journal of Medical Psychology.***

*See **Appendix 7.1** for Notes for Contributors.)*

Finding the Meaning in Eating Distress: A Psychotherapeutic Approach to the Treatment of an Elderly Man with an Atypical Eating Disorder

A Case Report

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Finding the Meaning in Eating Distress: A Psychotherapeutic Approach to the Treatment of an Elderly Man with an Atypical Eating Disorder

Summary

The case presented is of an elderly man with an atypical eating disorder who met the criteria specified by Bell (1996) for a psychotherapeutic approach to treatment. It reinforces the importance of assessing the motivational status of a person presenting with an eating disorder and the need to flexibly adapt treatment to fit the individual. The process of assessment is described and the rationale for adopting different levels of treatment reported. Treatment is discussed in terms of the need to consider the underlying function of eating for the individual.

Finding the Meaning in Eating Distress: A Psychotherapeutic Approach to the Treatment of an Elderly Man with an Atypical Eating Disorder

Introduction

Although cognitive-behaviour therapy (CBT) is generally considered to be the treatment of choice for eating disorders such as bulimia nervosa (Agras, 1987; Wilson, 1987), Bell (1996) recently highlighted that CBT fails to take sufficient account of, or adequately explore, the extent and source of feelings of worthlessness and the function of the behaviour in managing or dissociating from problems. Fairburn et al (1993) compared the efficacy of Interpersonal Psychotherapy (IPT), a brief psychotherapy originally used in the treatment of depression (Klerman et al, 1984), with CBT in the treatment of bulimia nervosa and found them to be equivalent at one year and six years follow-up (Fairburn et al, in press). Given this, Bell suggests that brief, focal psychotherapy may have similar benefits to CBT in the treatment of bulimia nervosa, but have the advantage of being relevant to a wider client group (i.e. those with "personality disorders").

Prochaska and Di Clemente (1984) proposed a transtheoretical model of treatment whereby therapeutic change is sought firstly at a symptomatic or situational level. However, if this proves to be ineffective, therapy shifts to focus on the maladaptive cognitions supporting the symptoms, and if this is ineffective, change is pursued at the levels of interpersonal conflict, then family systems, through to the least conscious level of intrapersonal conflict. In the context of eating disorders, Bell proposes a similar stepped-care approach which involves offering most clients, in the first instance, a supervised self-help programme using CBT techniques (Treasure et al, 1994). She suggests that more intensive (and therefore more costly) brief focal therapies, such as IPT or Cognitive Analytic Therapy (CAT) (Ryle, 1982, 1985, 1990), could then be offered to clients who fail to engage in, or respond to, CBT.

Moreover, Bell recommends offering brief psychotherapy as the treatment of choice for clients where:

1. it is apparent that there are unresolved emotional conflicts or relationship problems, particularly arising from child abuse;
2. there are borderline or other personality dysfunctions which limit clients' capacity to consistently manage behavioural change (as is required for CBT);
3. the client specifically requests a broader focused treatment.

As Prochaska and Di Clemente (1984) have also highlighted, patients presenting for treatment are not always ready for change. They categorised patients as falling into the stages of precontemplation, contemplation, action, or maintenance and hypothesised that treatment strategies should be tailored to fit accordingly. Bell (1996) suggests that psychotherapeutic approaches such as CAT are particularly helpful in working with patients with eating disorders who are ambivalent about change as it seeks to describe and explain the function and origins of the problems in the context of wider needs and difficulties and helps patients to find their own ways of tackling these underlying problems, which may or may not begin with addressing disordered eating.

The case presented is of an elderly man with an atypical eating disorder who met the criteria specified by Bell for a psychotherapeutic approach to treatment. His ambivalent motivation to tackle his eating problems was explored using a process of motivational interviewing (Miller and Rollnick, 1991) and treatment was adapted to fit the stage of change he was at.

Presenting Problem

Mr RT was a 61 year old man with a 40 year history of gastric problems. He vomited after almost everything he ate and reported that this had been the case, to a greater or lesser extent, for most of his adult life in spite of numerous gastric investigations and operations. No medical explanation could be found for his recurrent vomiting, although R reported that he was in the habit of making himself sick in order to regulate indigestion or "make room" for more food. R had always been slightly underweight (around 8 stone, 5 foot 6 inches tall), but he had recently lost five pounds, putting him at his lowest weight.

History

R first experienced stomach pains when he was 15 years of age, and developed a stomach ulcer not long after. He also started drinking alcohol around this time and by his twenties, he had a severe alcohol problem: he would binge drink at weekends and induce vomiting in order to continue to drink more. He had a number of gastric operations throughout his 30's and 40's and at age 60 he had a partial gastrectomy. Neither the operations nor anti-emetic medication helped his vomiting.

R suffered a heart attack at age 55 and underwent bypass surgery four years later. He continued to smoke 20 cigarettes a day.

R had a number of psychiatric admissions throughout his life, beginning with a three month admission when he was 18 years with anxiety problems. In his thirties he was regularly hospitalised with a variety of problems considered to be linked to alcoholism, including depression, an overdose and marital difficulties. R stopped drinking twelve years previously with the help of AA. He had attended psychiatry briefly in the previous year for help with depression and was treated with anti-depressant medication. He remained on fluoxitine (20mg).

Family Background

R was the second oldest of eight children. His father was an alcoholic who undermined him and beat him regularly. R described a warm, loving relationship with his mother, whom he appeared to idolise. His parents both died of heart attacks; his father twelve years previously and his mother four years after that.

R married his first wife at 19 and had three children. He reported having beaten his first wife over a period of ten years when he was drunk, before she left him and had an affair with a neighbour. R reported feeling devastated at being “cuckolded”, and that he had gone to sea for several months to escape what he felt to be “public humiliation”. Although they had got back together again for several years, his continual distrust of her led to their divorce in 1971. He married for a second time in 1977, but this marriage ended eight years later. R met his present wife, F, in 1986 and they married in 1990. He reported longstanding marital difficulties which he believed were rooted in "paranoia" about his wife's fidelity.

R worked as a plumber until he was made redundant at age 53.

Assessment

Henck and van Bilsen (1991) proposed that people will be motivated to change their lifestyles when they know what problems are caused by their behaviour and are concerned about these problems, but at the same time, they feel positive about themselves and competent to make the necessary changes. Assessment was therefore directed at knowledge/awareness, concern, self-esteem and self-efficacy.

1. *Awareness / knowledge* - Assessment of R's eating and vomiting indicated that the DSM IV (1994) criteria for a diagnosis of bulimia nervosa were not met: daily food diaries showed that although R "snacked" fairly constantly throughout the day, this was not in the form of "binges". He felt out of control of his eating and felt compelled to induce vomiting after almost everything he ate (eight to nine times per day). However, vomiting was not a response to concerns about body shape or putting on weight (R thought he was too thin and would have preferred to have weighed about 10 stone); rather it was a way of relieving uncomfortable feelings of fullness which were exacerbated by the reduced size of his stomach, thus allowing him to continue his constant stream of eating. He was also aware that he tended to eat more and consequently vomit more when bored or upset.

During the assessment period, it became clear that R had insight into the extent of his eating problem and was repulsed and embarrassed by it. Initially he was reluctant to keep or discuss his food diaries as he felt humiliated in much the same way as when his wife commented on his eating and vomiting. Miller and Rollnick (1991) suggest that this kind of resistance should be understood as a sign that the strategies being used are inappropriate at the client's present stage of change. Therefore, having established base-line information about the frequency of eating and vomiting, the focus shifted to explore issues to do with concern.

2. *Concern* - Although R reported being worried about his eating/vomiting pattern and his recent drop in weight, he also appeared to be somewhat resigned to it. He described himself as a "fatalist" and made comments such as "every day is a bonus" and "by rights I should be dead". He had a general air of apathy and flat affect. The Beck Depression Inventory (BDI) (Beck et al, 1961) was used to assess the severity of depression and gave a score of 20 indicating moderate levels of depression.

Although R seemed to have a fairly high level of awareness about his eating, his concern was ambivalent and reflected a more pervasive ambivalence about life.

3. *Self-esteem* - R reported never having thought much of himself and that as early as he could remember, his father had beaten him and put him down. R also reported several sexually abusive experiences by a male neighbour when he was young, memories of which had always made him feel insecure about his masculinity. Discussion focused on how alcohol had been one way of proving himself to be a man and also a means of standing up to his father.

Memories of how he had treated his first wife and family throughout his drinking career plagued him with guilt and remorse. He regarded himself as "a typical, utterly selfish alcoholic". His first wife's infidelity and suspicions about the faithfulness of his current wife made him feel useless as a husband and lover. Thus, for R, his lack of control over eating was just another in a long line of things he had failed at. R seemed to lack concern about his eating and about his life generally, as he felt he did not deserve to live.

4. *Self-efficacy* - Given the long history attached to his eating problems and the range of medical treatments tried, R seemed to think there was little that could be done to change the situation. More generally, he tended to underplay his past achievements, most notably attributing his stopping drinking to the help of AA and to God's grace.

Formulation

From an early age, R learnt to cope with difficulties by shutting them out through alcohol. It was significant that his eating and vomiting became more of a problem 8 years ago, coinciding with a particularly stressful time when his second marriage had just finished, he had lost his job and his home, and his mother had died. R was not drinking at this time, and it would appear that eating had served to distract and comfort him through this. Eating had become substituted for alcohol as a way of avoiding experiencing difficult feelings such as loss, remorse, anger, insecurity and disappointment. It was important for R to "keep a lid" on these feelings, fearing that if they surfaced they would overcome him and he would resort to alcohol, which he believed would kill him this time. As his eating and vomiting protected him from this, the prospect of giving it up was terrifying in the absence of other coping strategies.

R's low self-esteem and feelings of inadequacy appeared to be longstanding and could be traced back to physical, emotional and sexual abuse he had experienced as a child. His idolism of his mother had extended to his first wife who, driven away by his alcoholism, had made him distrustful of women in general and wary of making himself vulnerable in subsequent relationships. Thus he held back emotionally and sexually from his current wife, leaving her feeling "shut out" and dissatisfied and him feeling selfish and useless. It seemed to be a "damage limitation exercise": the less he gave, the less he would eventually lose. However, this was proving to be self-fulfilling and was actually serving to drive F away.

Treatment

Motivation

Table i summarises the interventions used across different stages of treatment. As R had initially resisted a more symptoms-orientated, cognitive behavioural approach to treatment, the focus of therapy shifted (session three) to explore the important, literally life-sustaining function his eating seemed to serve in protecting him from painful emotions. As the therapeutic alliance developed, R was able to experience these emotions in a safe environment without being overwhelmed or resorting to alcohol. Connections were made between past experiences and his current ambivalence about life and low self-esteem. Over these sessions, R's self-esteem grew through a process of re-attribution in which he began to acknowledge his part in overcoming difficulties, and his strengths as well as his weaknesses. For example, he had only ever regarded himself as taking from AA, and had overlooked the help and encouragement he gave others through his ongoing contribution to their programme. Thus, R began to revise his ineffectual and somewhat helpless self-image.

In this way the motivational areas which had been lacking were developed, i.e. R's concern, self-esteem and self-efficacy. In addition, the rapport and trust that developed between patient and therapist allowed R the corrective experience of being open and vulnerable with a woman who would not betray or abandon him. Perrin (1996) maintained that therapy is successful when the client is not only able to begin to give up the symptoms, but also uses the experience of the therapeutic relationship to engage in more open and honest relationships with other people. After ten sessions, R reported feeling motivated to tackle his eating problems more directly, and ready to begin concurrent marital therapy with the aim of generalising from his positive experience of open, trusting communication within the therapeutic situation to his relationship with his wife. In this way R would be developing alternative coping mechanisms and thus decreasing his need to continually eat.

Table i: Summary of interventions used across treatment

Session	Intervention
1 - 2	Assessment - information gathered on presenting problem, background, & family history; BDI administered; food diaries started & baseline information obtained.
3 - 6	Motivation assessed (concern, self-esteem, self-efficacy) & developed; connections made between past experiences & current feelings and difficulties.
7 - 10	Continued work on self-esteem; use of therapeutic relationship for cathartic expression of "taboo" feelings. Functional significance of eating & drinking explored. Alternative coping mechanisms considered.
11 - 17	Half of each of 5 sessions targeted eating/vomiting: diary recommenced, stimulus control techniques employed, written guidelines given (see **Appendix 7.2**), activity scheduling, exercise programme started -distraction, improve mood, desensitise to leaving house; BDI re-administered (15th session with R). Concurrent marital work: half of 5 sessions with R & F, & 2 sessions with F on her own. Themes of idolism, & infidelity explored; cognitive techniques used to identify cognitive distortions; negative automatic thoughts identified & challenged.

Direct work on eating

Part of five sessions were spent directly focusing on establishing routine and control over R's eating habits: R was given a set of "eating guidelines" (see **Appendix 7.2**) in order to achieve some stimulus control and kept a diary of eating and vomiting. It became apparent from these recordings that R's eating was more controlled and that he vomited less in the morning, but once started, he would continue to vomit after almost everything he ate. R was therefore encouraged to progressively delay vomiting each day and also to eat the foods that made him feel most nauseous later on.

R's general activity levels were low probably as a result of low mood, but it became clear that he was also reluctant to leave his home because of the lack of availability of food and of somewhere private to vomit. R's food diaries also showed that he ate and vomited more when bored or unoccupied. R was therefore encouraged to activity schedule and, after consulting with his GP, an exercise programme specifically designed for people over 60 (Mutrie and Blamey, 1994) was introduced. The aims of the exercise programme were threefold: firstly, given the widely documented psychological benefits of aerobic exercise (e.g. McCann and Homes, 1984; Pierce and Pate, 1994), to help alleviate his low mood. Secondly, as it involved walking for progressively longer periods over several weeks, it gradually exposed him to leaving his home, and thirdly, it served to distract him from overeating and vomiting in the afternoons when the desire to do so was its strongest.

Concurrent marital work

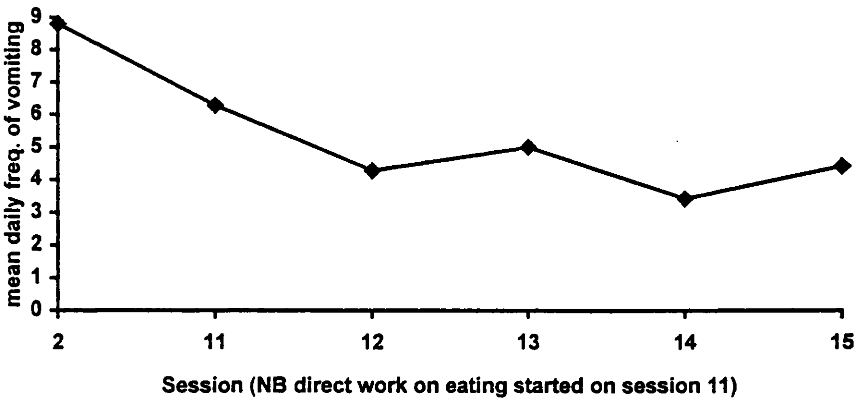
Two sessions were spent with F on her own and part of five sessions with R and F together. Both R and F believed their difficulties to be rooted in his "paranoia" about F's fidelity. F was 10 years R's junior and enjoyed socialising, but as R was reluctant to socialise, she would sometimes go out without him. However, R would "interrogate" her afterwards about where she had been and with whom, and would often ruminate about the details for days. He described several incidents where her "story" had been inconsistent and he suspected she was having an affair. R described F as a "good, kind woman" who was unlikely to be unfaithful, but as he had thought this of his first wife who had then (as he saw it), gone on to betray him, this offered no consolation.

Cognitive strategies were employed to help R identify negative automatic thoughts about his wife's fidelity and to begin to systematically challenge them. Certain cognitive distortions (Beck, 1976) were identified, including overgeneralisation, dichotomous reasoning, selective abstraction and arbitrary inference. Joint sessions also focused on R's tendency to idolise women and how this had resulted in disappointment and feelings of betrayal in the past. This led to an exploration of the source of his fears of infidelity and how R employed a "damage limitation" exercise within their relationship in order to protect himself from being hurt. The implications for both of them were discussed.

Outcome

Having spent ten sessions addressing motivational issues and exploring the function of R's eating and vomiting, R engaged enthusiastically in the more structured treatment of his disordered eating and vomiting. After a further five sessions of more direct work on R's eating/ vomiting and concurrent marital work, he reported improved mood, reflected in a decrease from 20 (moderate depression) to 12 (mild depression) on the BDI and feeling for the first time in years that there might be "light at the end of the tunnel" concerning his eating problems. R was also walking for 30 minutes three to four times per week, had resumed one of his hobbies (DIY) and had returned to his AA meetings. As figure 1 shows, vomiting decreased from approximately eight to nine times per day (at session 2) to an average of three to four times (session 15), and he was able to delay starting vomiting until mid afternoon. His weight had stabilised at 7 stone 11 (increase of 2 lbs) and he reported feeling physically fitter as a result of exercising.

Figure 1: Mean daily frequency of vomiting across treatment



Although R and F reported feeling more able to openly discuss their difficulties and that R's paranoid thinking was less frequent and intense, it remained an ongoing struggle for them with F considering a separation.

Discussion

The case described highlights the importance of assessing a person's motivation to change and the need to structure intervention accordingly. As Prochaska and Di Clemente (1982) have noted, unless a client is at the point on the motivational cycle where they are ready to change, then no amount of psychotherapy of any kind will be effective. It does not follow that a person will be ready to change their eating behaviour simply because they have been referred by another professional for help with an eating disorder. Thus, the therapist must be sensitive to, and paced by, the client's presenting motivational status, flexibly adapting the type and level of therapeutic input accordingly.

Rather than viewing resistance as the client's problem, this case illustrates how resistance can provide vital information for gauging the appropriateness of intervention, thus allowing treatment to be targeted most effectively. Indeed, it is likely that failure to consider such issues would have resulted in RT dropping out of treatment, feeling more helpless and hopeless than ever, thus exacerbating his eating problems.

This case also emphasises the need sometimes to go beyond the presenting symptoms and to engage in what Perrin (1996) called "the search for meaning in eating distress". During treatment, both RT and the therapist were able to come to an understanding of the function of his eating and vomiting as the only apparent solution available to him for coping with his more deep-rooted emotional problems (Bell, 1996). It was only when the functional significance of the eating behaviour was uncovered that R was able to begin exploring alternative coping strategies and was therefore able to assume some control over his eating and vomiting. The implications of persevering with a more symptoms-focused approach in the case of RT would have been to ask him to do the impossible; to give up something which he believed kept him alive. This case therefore endorses Bell's (1996) claim for the use of a stepped care approach to eating disorders whereby clients are first of all offered a supervised cognitive behavioural self-help programme, but that more intensive focal psychotherapy should be offered to those who fail to engage in, or respond to, this initial approach. The onus is therefore on the therapist to promptly identify, and sensitively respond to, those who require more.

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