

**PSYCHOSEXUAL CONSEQUENCES OF TRAUMATIC BRAIN  
INJURY FOR VICTIMS AND THEIR PARTNERS**

and

**RESEARCH PORTFOLIO**

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Submitted in part fulfilment of the degree of  
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**To the memory of Suki and Benji**

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# **Main Research Project Literature Review**

## **Psychosexual Consequences of Traumatic Brain Injury: A Review of the Literature**

**This literature review has been written according to the guidelines of *Brain Injury*. Author's notes and other material relating to the paper may be found in *Appendix One*.**

## **Abstract**

The psychosexual consequences of traumatic brain injury (TBI) are reviewed. The resulting review demonstrates a complicated interaction between psychosocial and emotional factors. Previous studies have focussed on the relatives and carers point of view rather than that of the patient. When patients have been included, the studies have been almost exclusively of male patients. Following from this, future ideas for research are outlined.



## Introduction

Traumatic brain injury (TBI) is one of the most common causes of disability in young adults throughout the westernised world [1]. It is estimated that in the United Kingdom there are 150 people per 100,000 of the population with a major disability resulting from TBI at any one time [2]. This means that there are more than 120,000 people in the United Kingdom suffering from the long term effects of head injury and as life expectancy is not typically reduced, this figure increases each year [3]. Many more males than females experience TBI and people between the ages of 15 and 24 years form the highest group [4]. The most common cause of TBI is road traffic accidents [4].

When researching the different disabilities which can result, studies have shown that physical disability is not usually of major importance. For example, McKinlay *et al* [5] found that 50 out of 55 very severely disabled patients were independently mobile six months after injury. A further three managed with a stick or crutch leaving only two out of 55 confined to a wheelchair.

In contrast to this level of physical disability, cognitive, behavioural, and personality changes have been highlighted as major problems following head injury [5]. These disabilities have been found to persist for up to five years post injury [6] and can be a barrier in returning to work [7].

Many studies have investigated the cognitive, behavioural, and personality changes following head injury [5,6,8, 9, 10]. In particular, in recent years a number of studies have been published on the psychosocial sequelae of head injury [11, 12]. These were reviewed by Morton and Wehman [13] who noted that very little work has been conducted on changes in sexual relationships after head injury. This is in spite of the emphasis on achieving sexual satisfaction in contemporary society and the importance of sexual relationships psychosocially [14].

Within the literature that exists it is noted that complaints of diminished sexual functioning are clinically common in couples where one partner has suffered a TBI. For example, Kosteljanetz *et al* [15] found that 58% of a group of 19 male patients suffering from post-concussion syndrome showed evidence of sexual dysfunction and Boller and Frank [16] reported that three out of four head injury patients had decreased frequency of sexual relations. In a comparison with the general

population, Rosenbaum and Najenson [17] stated that rates of sexual problems were higher following TBI.

The above mentioned studies suggest that despite a lack of research, psychosexual problems following TBI are important. What follows is a review of the literature on psychosexual problems following TBI. The aim of this review is to establish what research has been conducted, the results of this research, and to generate additional research questions.

### **The Nature of Psychosexual Problems**

The term 'sexual dysfunction' refers to the impairments or disturbances in sexual desire, arousal, or orgasm [18]. This includes all types of dysfunction within 'normal' sexuality regardless of whether the cause is organic or psychological. The term 'psychosexual' problems is usually used when referring to the dysfunctions caused and/or maintained by psychological factors.

Sexual satisfaction, and therefore sexual dysfunction, is a very subjective concept, as what is seen as dysfunctional may vary from person to person, couple to couple, and society to society. Non-clinical populations have been found to include groups of people whose sexual functioning may be considered by some as dysfunctional. For example, Frank *et al* [19] reported a study of 100 well-educated, happily married couples. They found 80% of the couples were happy with their sexual and marital relations despite 40% of the men reporting erectile or ejaculatory problems, and 60% of the women reporting problems with arousal and reaching orgasm.

Common male psychosexual problems are low interest and desire, impotence, premature ejaculation, retarded ejaculation, and sexual aversion [18]. Reports in the literature demonstrate that these are the common psychosexual problems reported following TBI. In addition, changes in the frequency of intercourse [14, 20], increased desire [21]. It should be noted that these are reported by the sexual partners TBI patients, not the patients themselves.

Female sexual dysfunction is similar to that of men. The most common psychosexual problems are low interest or desire, absence of responsiveness, anorgasmia, vaginismus, painful intercourse, sexual aversion [18]. Only one study has looked at female equivalents following TBI and similar problems were identified [22].

Human sexuality is extremely complicated and there are many different interacting factors involved. Bancroft [23] describes these interactions as the psychosomatic circle of sex and this is summarised in *Figure One*. The whole body is involved in this complex interaction between psychological and physiological processes. For example, cognitive processes can influence the limbic system and other parts of the brain in an excitatory or inhibitory fashion. The limbic system then affects levels of peripheral and genital arousal via reflex arcs in the spinal cord. The individual's perception and interpretation of these levels of arousal then feedback into the system, changing responses accordingly. The whole system relies on communication and feedback between the different component parts. This means that there are many stages at which things can go wrong.

Physiological and neurological factors are obviously important in normal sexual functioning. They are also important following TBI. Sexual problems arising specifically from damage to the brain are rare and are usually associated with lesions in the medial temporal structures, damage to the hypothalamus, or damage to the medial posterior surface of the cerebral hemispheres [24]. In particular, damage to the hypothalamic-pituitary-gonadal axis, which regulates testosterone release and sex drive, has been documented as a consequence of TBI [25]. However, the research into this area is complex and an in-depth review of the physiological and neurophysiological factors involved in sexual problems is outside the scope of this review: the reader is referred to Bancroft [23]. What will be reviewed here are the psychological factors and associated emotional states involved in the breakdown of sexual function following TBI.

## **Psychosexual Consequences of Traumatic Brain Injury**

### *Anxiety and Depression*

The TBI literature documents a high incidence of anxiety and depression post injury. For example, Brooks and Aughton [26] studied anxiety and depression in a group of 35 patients following TBI by asking relatives to rate changes. They found that 74% of the relatives noted problems with anxiety and 73% with depression. These high rates of affective symptomatology following head injury are supported by McKinlay *et al* [5] who found anxiety and depression to be problematic for all of their 55 patients studied. These problems persisted through 3, 6, and 12 months post-injury. Degrees of anxiety and depression have been found up to five years following injury [6]. Problems in this

area have also been demonstrated in studies of patients who have demonstrated good recovery in other areas [10].

The studies mentioned so far have been concerned with anxiety and depression from a relative's perspective. Tyerman and Humphrey [27] assessed the general anxiety and depression of 25 patients, 2 to 15 months post head injury. 60% of these were classified as clinically depressed and 44% as clinically anxious. In a similar study, Kinsella *et al* [9] found 33% of patients to be depressed and 26% anxious up to two years following the injury.

It is not just the victims of brain injury who experience symptoms of anxiety and depression. Several studies have also demonstrated long term persisting problems in the relatives, carers, and in particular, the partners of patients with TBI [21, 28].

Within the literature on sexual dysfunction, anxiety has been pin-pointed as a major factor associated with the breakdown in sexual relations [23, 29, 30]. Some difficulties are caused by anxiety and some are maintained and perpetuated by it. For example, one instance of failure to maintain an erection may lead to anxiety about possible failure on subsequent occasions. Likewise, an association has been demonstrated between depression and sexual dysfunction, particularly in terms of loss of desire [31]. In addition to the biochemical mechanisms involved [23], mood is important because it effects how people feel about themselves, and how attractive, desirable, worthy of love etc. they feel.

From these studies it would be logical to assume that high levels of anxiety and depression are associated with high levels of sexual dysfunction following TBI. With the exception of one study, this has not been studied empirically. O'Carroll *et al* [22] followed up 36 TBI patients to investigate the nature psychosexual problems. They used the Golombok Rust Inventory of Sexual Satisfaction (GRISS) [32], the General Health Questionnaire (GHQ) [33], and the Hospital Anxiety and Depression Scale (HAD) [34] to investigate the relationship between symptoms of anxiety and depression in patients and their partners and sexual dysfunction. They found positive correlations between overall psychiatric symptomatology (as measured by the GHQ) and depression (from the HAD) with the total amount of psychosexual dysfunction (from the GRISS). For the women only, they found that high levels of anxiety were associated with infrequent intercourse, dissatisfaction with intercourse, and vaginismus. Although this study included measures of anxiety and depression in the patients and their partners, the authors did not draw any

conclusions about the relationship between patient and partner symptomatology and levels of psychosexual dysfunction. This was highlighted as an area requiring further investigation.

### *Relationship Problems*

High rates of marital breakdown following head injury have been documented in the TBI literature [17, 35]. This is an important area to consider as the quality of a relationship is an important factor in psychosexual functioning [36, 37]. Sexual difficulties can develop easily in the context of a poor marital relationship [18]. Jealousy, fears and worries about infidelity, constant conflicts in areas of life other than sex, may all contribute to and be maintained by a sexual problem. A lack of sexual contact is often used as the main battleground for other marital conflicts [38].

The importance of the nature of the relationship becomes even more important following head injury as changes in personality and behaviour are common consequences. For example, Thomsen [39] noted that 84% of families studied complained of personality and behavioural changes following TBI. Brooks *et al* [6] found that these changes continued to be problematic five years after injury.

It is unlikely that changes in behaviour and personality can occur without a consequent change in the rôles of the people involved in the relationship. For example, a previously dominant and independent person who is physically dependent on his or her partner following the injury may find that the new dependent rôle is incompatible with the continuation of a sexual relationship.

Some studies have been conducted to investigate the interaction between personality and behaviour changes and reported relationship changes. Lezak [21] found that significant changes in sexual interest as well as problems with apathy, silliness, lability, inflexibility, and intellectual impairments were considered by patients' partners and relatives to contribute to the family and marital difficulties found. Spouses expressed a degree of frustration at their sexual and affectional needs not being met and Lezak attributed this to poor interpersonal skills and a diminished capacity for empathy by the patient.

Mauss-Clum and Ryan [40] surveyed a group of wives and mothers of male patients with brain injury and found that the majority of patients were dependent, impatient, irritable, and had temper outbursts when it came to sex. Changes in levels of interest

in sex (increases or decreases) were reported by 47% of the mothers and wives. A smaller number of respondents reported that patients were also inflexible, self-centered, had decreased self control, and demonstrated inappropriate public behaviour. Willingness to engage in a mutually satisfying sexual relationship with the patients was clearly affected not only by the changes in the patient, but also by the reactions of the family members to these changes. Emotional distress was commonly reported by wives and many reported that they were "*married but didn't have a husband*".

Another consequence of the behaviour and personality changes on a relationship will be a change in the channels and methods of communication. Communication is an extremely important part of a relationship and once relationship problems arise, ineffective communication not only sustains the problem but often aggravates it [23]. Peters *et al* [12] studied the marital relationships of 55 couples in whom the male partner had suffered a head injury and found that following a severe injury, communication of emotions and agreement between partners about sex was significantly impaired resulting in detrimental changes to the relationship.

The changes mentioned above provide a long-term physical and emotional burden of caring to the partner of a patient with a TBI. Given this it is not surprising that there are adverse changes in some sexual relationships. Spouses are often stressed by the patients' dependency arising from intellectual and physical impairments, including memory dysfunction, impaired learning, communication disorders, and fatigability [10, 28]. This stress can then result in additional anxiety and depression, thereby aggravating existing psychosexual problems, and creating even more problems within the relationship.

Levels of affective symptomatology and the quality of the relationship are obviously important factors in the development and maintenance of psychosexual problems. It is also possible that there is an interaction between the two with levels of anxiety and depression in either partner placing added strain on the relationship. This needs to be investigated in more detail using samples including victims of TBI and their partners.

#### *Other Psychological Factors*

The behavioural and personality changes described earlier are often grouped together under the label of 'frontal lobe syndrome' [41]. Central to this are symptoms of

concrete thinking, poor planning and monitoring of actions, and inflexibility [42]. Sexual disinhibition is frequently seen as a specific deficit of frontal lobe damage but it has been suggested that it is just another behavioural consequence of general disinhibition and poor monitoring [41]. For example, a young man recovering from a TBI may be slightly disinhibited and unable to monitor the effects of his own behaviour as a result of the damage sustained. Coupled with a normal sex drive and absence of a girlfriend, this man may be described by others as sexually inappropriate. This conclusion would be drawn because he may occasionally misinterpret the sexual behaviour of others (for example, reading a friendly comment as a sign of sexual interest), be impulsive and impatient in his actions, and think in very black and white terms (for example, "I like her so she must like me"). Within the literature on psychosocial consequences following traumatic brain injury, many studies have shown a link between the severity of injury, time post injury, and age at injury [43, 44]. One previously mentioned study has attempted a similar profile for the psychosexual consequences of TBI [22]. They found that the severity of the injury was not predictive of later psychosexual problems, that male patients become more dissatisfied as time progresses after the injury, and that older age was associated with more psychosexual problems.

### **Summary and Recommendations**

The literature on psychosexual consequences of traumatic brain injury has been reviewed. The results of this review have been discussed in terms of general psychosocial factors (relationships, personality, and behaviour) and emotional (anxiety and depression) consequences of brain injury.

It is clear that psychosexual problems are complex and that a number of interacting factors are involved. For example, if a female patient feels unattractive because of some physical changes, she may worry that her partner does not find her sexually attractive any more. This worry may result in her withdrawing from her partner and avoiding all sexual contact for fear of rejection. This same fear stops her from talking about it with her partner. Her partner may become frustrated at this lack of communication, the relationship deteriorates, and they both withdraw from each other even more. This confirms her worry that she is not attractive, she becomes depressed, withdraws even more, and the cycle repeats itself until one part of it is broken. This exaggerated example demonstrates the importance of identifying problems early on in order to prevent further breakdown of the relationship. It has been suggested that early assessment and intervention may help prevent this deterioration in

relationships [22]. Treatment programmes focussing on counselling, education, and behavioural sex therapy have been designed and evaluated on non-head-injured populations with good results [45]. However, such treatment programmes have yet to appear in the TBI literature. One factor contributing to this lack of treatment studies will be that there are still questions which need to be answered about the nature of the psychosexual consequences of TBI.

Firstly, anxiety and depression have both been pin-pointed as important factors in the aetiology and maintenance of psychosexual problems in a clinical non-brain-injured population. Some studies have attempted to look at the rôle of these affective factors in psychosexual problems following TBI but the results are not clear. Studies have tended to focus on partners of patients, and when patients are included, the samples tend to be male only. Future research would need to include male and female patients with their partners to investigate the interaction between individual affective symptoms and the overall psychosexual problem.

Secondly, as studies have tended to focus on the views of the partner, little information is available as to the feelings of the patient involved and whether or not the patient and partner agree on the problems present.

Thirdly, although relationship problems have been documented, it has been from the partner or other relative's point of view. The relationship as far as the patient perceives it has not been investigated.

Finally, there is clearly an interaction between all the factors involved and research would need to include measures of psychosexual, psychosocial, and emotional dysfunction to investigate these.

These general areas are important to research as further knowledge on the nature of psychosexual problems is crucial for the development of intervention programmes. An experimental study aimed at targeting these research gaps can be found later in this volume [46].



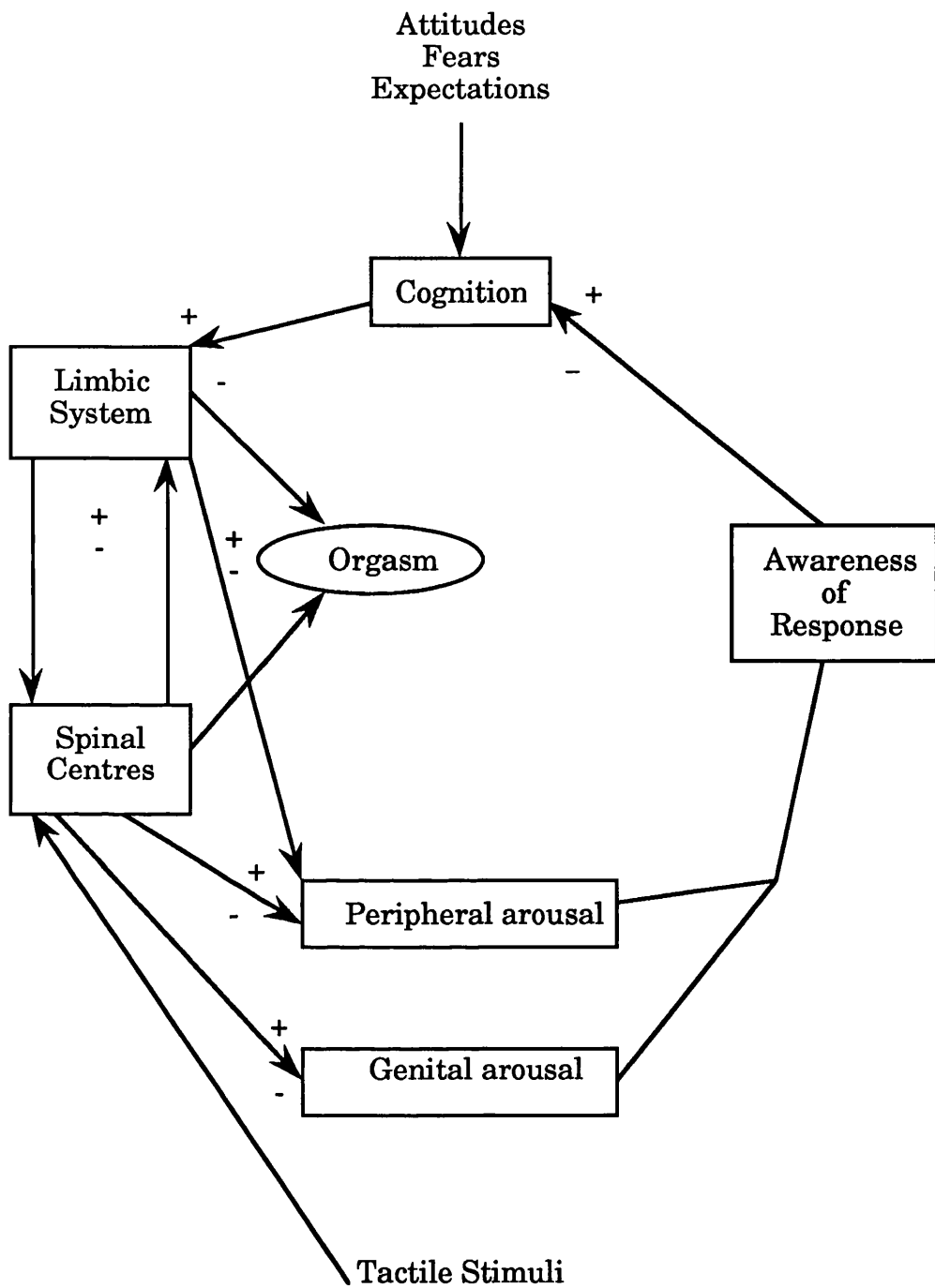


Figure One: The psychosomatic circle of sex (Bancroft, 1989). + = excitation, - = inhibition.

## References

1. RIMEL, R.W. and JANE, J.A.: Characteristics of the head injured patient. In: M. Rosenthal, E.R. Griffith, M.R. Bond and J.D. Miller (editors) *Rehabilitation of the Head Injured Adult* (F.A. Davis Company, Philadelphia), pp. 9-21, 1983.
2. FIELD, J.H.: *Epidemiology of Head Injuries in England and Wales*. (HMSO, London), 1976.
3. POWELL, T.: *Head Injury. A Practical Guide*. (For Headway by Winslow Press, Oxon), 1994.
4. WILLER, B., ABOSCH, S. and DAHMER, E.: Epidemiology of Disability from traumatic brain injury. In: R.L. Wood (editor) *Neuro-behavioural Sequelae of Traumatic Brain Injury* (Taylor & Francis Ltd, London), pp. 18-36, 1990.
5. MCKINLAY, W.W., BROOKS, D.N., BOND, M.R. *et al*: The short-term outcome of severe head injury as reported by relatives of the injured persons. *Journal of Neurology, Neurosurgery, and Psychiatry*, **44**: 527-533, 1981.
6. BROOKS, D.N., CAMPSIE, L., SYMINGTON, C., *et al*: The five year outcome of severe blunt head injury: a relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry*, **49**: 764-770, 1986.
7. THOMSEN, I.V.: Late psychosocial outcome in severe blunt head trauma: a review. *Brain Injury*, **1**: 131-143, 1987.
8. BROOKS, D.N. and MCKINLAY, W.W.: Personality and behavioural change after severe blunt head injury: a relatives view. *Journal of Neurology, Neurosurgery, and Psychiatry*, **46**: 336-344, 1983.
9. KINSELLA, G., MORAN, C., FORD, B. *et al*: Emotional disorder and its assessment within the severe head-injured population. *Psychological Medicine*, **18**: 57-63, 1988.
10. LEVIN, H.S., BENTON, A.L. and GROSSMAN, R.G.: *Neurobehavioural Consequences of Closed Head Injury* (Oxford University Press, New York), 1982.
11. ODDY, M. and HUMPHREY, M.: Social recovery during the year following severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, **43**: 798-802, 1980.
12. PETERS, L., STAMBROOK, M., MOORE, A. *et al*: Psychosocial sequelae of closed head injury: effects on the marital relationship. *Brain Injury*, **4**: 39-47, 1990.

13. MORTON, M.V. and WEHMAN, P.: Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury*, **9**: 81-92, 1995.
14. KREUTZER, J.S. and ZASLER, N.D.: Psychosexual consequences of traumatic brain injury: methodology and preliminary findings. *Brain Injury*, **3**: 177-186, 1989.
15. KOSTELJANETZ, M., JENSEN, T., NORGDARD, B. *et al*: Sexual and hypothalamic dysfunction in the post-concussional syndrome. *Acta Neurologica Scandinavica*, **63**: 169-180.
16. BOLLER, F. and FRANK, E.: *Sexual Dysfunction in Neurological Disorders: Diagnosis, Management, and Rehabilitation* (Raven Press, New York), 1982.
17. ROSENBAUM, M. and NAJENSON, T.: Changes in life patterns and symptoms of low mood as reported by wives of severely brain-injured soldiers. *Journal of Consulting and Clinical Psychology*, **44**: 881-888, 1976.
18. DE SILVA, P.: Sexual dysfunction. Investigation. In: S.J.E. Lindsay and G.E. Powell (editors) *The Handbook of Clinical Adult Psychology* (Routledge, London), pp. 199-212, 1994.
19. FRANK, E., ANDERSON, C. and RUBINSTEIN, D.: Frequency of sexual dysfunction in normal couples. *New England Journal of Medicine*, **299**: 111-115.
20. ODDY, M., HUMPHREY, M. and UTTLEY, D.: Subjective impairment and social recovery after closed head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, **41**: 611-616.
21. LEZAK, M.D.: Living with the characterologically altered brain injured patient. *Journal of Clinical Psychology*, **39**: 592-598.
22. O'CARROLL, R.E., WOODROW, J. and MAROUN, F.: Psychosexual and psychosocial sequelae of closed head injury. *Brain Injury*, **5**: 303-315, 1991.
23. BANCROFT, J.: *Human Sexuality and its Problems* (Churchill Livingstone, London), 1989.
24. MILLER, B.L., CUMMINGS, J.L., McINTYRE, H. *et al*: Hypersexuality or altered sexual preference following brain injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, **49**: 867-873.
25. FLEISHER, A., RUDMAN, N., PAYNE, G. *et al*: Hypothalamic hypothyroidism and hypogonadism in prolonged traumatic coma. *Journal of Neurosurgery*, **49**: 647-650, 1978.
26. BROOKS, D.N. and AUGHTON, M.E.: Psychological consequences of blunt head injury. *International Rehabilitation Medicine*, **1**: 160-165.

27. TYERMAN, A. and HUMPHREY, M.: Changes in self-concept following severe head injury. *International Journal of Rehabilitation Research*, **7**: 11-23, 1984.
28. BROOKS, D.N., McKINLAY, W.W., SYMINGTON, C. *et al*: Return to work within the first seven years of severe head injury. *Brain Injury*, **1**: 5-19, 1987.
29. LIEF, H.I.: Anxiety, sexual dysfunctions, and therapy. In: W.E. Fann, I. Karacan, A.D. Pokorny, *et al* (editors) *Phenomenology and Treatment of Anxiety* (Spectrum, New York), 1979.
30. MASTERS, W.H. and JOHNSON, V.E.: *Human Sexual Inadequacy* (Little Brown, Boston), 1970.
31. SCHREINER-ENGEL, P. and SCHIAVI, R.: Lifetime psychopathology in individuals with low sexual desire. *Journal of Nervous and Mental Diseases*, **174**: 646-651.
32. RUST, J. and GOLOMBOK, S.: *Manual of the Golombok-Rust Inventory of Sexual Satisfaction* (NFER-Nelson: Windsor), 1986.
33. GOLDBERG, D.: *Manual of the General Health Questionnaire* (NFER-Nelson, Windsor), 1978.
34. ZIGMOND, A. and SNAITH, R.: The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, **67**: 361-370.
35. THOMSEN, I.V.: The patient with severe head injury and his family. *Scandinavian Journal of Rehabilitation Medicine*, **6**: 180-183.
36. CROWE, M.J and RIDLEY, J.: *Therapy with Couples* (Blackwell, Oxford), 1990).
37. WOODY, J.D.: *Treating Sexual Distress: Integrative Systems Therapy* (Sage, Newbury), 1992.
38. HARBIN, H.T. and GAMBLE, B.: Sexual conflicts related to dominance and submission. *Medical Aspects of Human Sexuality*, **11**: 84-89.
39. THOMSEN, I.V.: Late outcome of severe blunt head trauma: a 10-15 year second follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry*, **47**: 260-268.
40. MAUSS-CLUM, N. and RYAN, M. Brain Injury and the Family. *Journal of Neurosurgical Nursing*, **13**: 165-169.
41. EAMES, P.: Organic bases of behaviour disorders after traumatic brain injury. In: R.L. Wood (editor) *Neuro-behavioural Sequelae of Traumatic Brain Injury* (Taylor & Francis Ltd, London), pp. 134-150, 1990.
42. POWELL, G.E. and WILSON, B.A.: Introduction to neuropsychology and neuropsychological assessment. In: S.J.E. Lindsay and G.E. Powell (editors)

*The Handbook of Clinical Adult Psychology* (Routledge, London), pp. 645-687, 1994.

43. LEZAK, M.D.: Brain damage is a family affair. *Journal of Clinical and Experimental Neuropsychology*, **10**: 111-123, 1988.
44. KOZLOFF, R.: Networks of social support and the outcome from severe head injury. *Journal of Head Trauma Rehabilitation*, **2**, 14-23, 1987.
45. DE SILVA, P.: Sexual dysfunction. Treatment. In: S.J.E. Lindsay and G.E. Powell (editors) *The Handbook of Clinical Adult Psychology* (Routledge, London), pp. 213-228, 1994.
46. DAVIS, A.M.: *Psychosexual consequences of traumatic brain injury for victims and their partners* (Unpublished D.Clin.Psy. thesis, University of Glasgow), 1996.

# **Main Research Project Proposal**

## **Psychosexual Consequences of Traumatic Brain Injury for Victims and their Partners**

Additional information relating to this proposal may be found in  
*Appendix Two.*

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## **2. Title**

Psychosexual consequences of traumatic brain injury for victims and their partners.

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<sup>1</sup> Initially it was planned that the project would be conducted at Scotcare National Brain Injury Rehabilitation Unit. This is a post-acute setting concerned with the rehabilitation of individuals with brain damage, primarily as a result of head injury. Following initial perusal of the computer data base of patients, it transpired that it would not be possible to collect the numbers required. The unit is very specialised and the majority of people attending had sustained very severe injuries and many had not been able to return to independent family life. It was considered more appropriate to target people living in the community where psychosexual issues would be more relevant. Contact was therefore made with local West of Scotland branches of *Headway*. *Headway* is a national charity concerned with supporting families, patients, and carers following head injury. The majority of their clients are living in the community in the same psychosocial situation they were in prior to their injury. According to staff, sexual problems were frequently encountered by clients. This was therefore considered a more suitable pool of participants. This alteration to the recruitment procedure does not change the overall methodology of the research study.

### **3. Summary**

Research into psychosexual dysfunction following closed head injury (CHI) is sparse and no such studies have been conducted in Scotland. This contrasts with the large amount of research into psychosocial problems following CHI. This study is concerned with examining the psychosexual problems experienced by CHI victims and their partners. Measures of changes in sexual behaviour, affect and personality, and relationships will be used. Participants will be recruited through a brain injury rehabilitation unit<sup>1</sup> and information will be gathered via postal questionnaires and/or semi-structured interviews. The results will provide empirical data on the nature of psychosexual problems following CHI and how the victim and his or her partner has been affected. At present this area is neglected in the rehabilitation of CHI. Left untreated psychosexual problems can escalate and have a detrimental effect on many areas of the victim's life. Clearer knowledge about the problems encountered in this area can aid in the development of more sophisticated assessment tools and intervention programmes.

### **4. Introduction**

In spite of the emphasis on achieving sexual satisfaction in contemporary society and the large number of studies on psychosocial outcome following head injury (see Morton & Wehman [1995] for a review), very little work has been conducted on changes in sexual relationships after head injury.

Within the literature that exists it is noted that while complaints of diminished sexual functioning are clinically common in couples where one partner has suffered closed head injury, there is relatively little empirical data documenting the extent of the problem (Kreutzer & Zasler, 1989). Where there are studies, they usually relate to single cases (eg. Crenshaw, 1985), or clinical descriptions (rather than empirical findings) of small groups of patients who appeared to suffer from sexual problems post head injury (eg. Miller et al 1986). Kosteljanetz et al (1981) suggested that sexual dysfunction post head injury may be relatively common and Rosenbaum and Najenson (1976) state that it is more common than in the normal population. Boller and Frank (1982) reported that three out of four head injury patients had decreased frequency of sexual relations.

High rates of marital breakdown following head injury have been documented (Rosenbaum & Najenson, 1976; Thomsen, 1974). Peters et al (1990) studied the



marital relationships of 55 couples in whom the male partner had suffered a head injury. They found that dyadic consensus, affectional expression, overall dyadic adjustment, and affectional expression were significantly lower in the severely head injured group. Similarly Oddy, Humphrey, and Uttley (1978) found that half of their married patients reported a decrease in frequency of sexual intercourse six months post injury. Half of their sample reported an increase.

Lezak (1978) reported that many patients suffer from either a completely absent sex drive or increased sexual interest. Significant changes in sexual interest as well as problems with apathy, silliness, lability, inflexibility and intellectual impairments were considered to contribute to the family and marital difficulties found. Frustration of sexual and affectional needs was also found to be a relatively common consequence of brain injury. Lezak attributed spouses' sexual frustration partly to patients' poor interpersonal skills and diminished capacity for empathy. She noted that patients' desires for sexual intimacy may often exceed their actual ability to perform.

Mauss-Clum and Ryan (1981) surveyed a group of wives and mothers of male patients with brain injury to investigate needs and reactions. Forty seven percent of the wives and mothers reported that the patients were either preoccupied with or disinterested in sex. The majority of the respondents indicated that patients were dependent, impatient, irritable, and had temper outbursts when it came to sex. A smaller number of respondents reported that patients were also inflexible, self-centered, had decreased self control, and demonstrated inappropriate public behaviour. Willingness to engage in a mutually satisfying sexual relationship with the patients was clearly affected not only by the changes in the patient, but also by the reactions of the family members to these changes. Emotional distress was commonly reported by wives and many reported that they were *"married but didn't have a husband"*.

These adverse changes in sexual relationships are not a surprise given the long-term physical and emotional burden of caring for a brain-injured spouse. Spouses are often stressed by the patients' dependency arising from intellectual and physical impairments, including memory dysfunction, impaired learning, communication disorders, and fatigability (Brooks *et al*, 1987; Levin, Benton & Grossman, 1982). Extreme personality changes occur including verbal and physical aggression directed at caretakers (Lezak, 1978; Mauss-Clum & Ryan, 1981). Childishness, emotional lability, irritability, and restlessness were common sequelae reported by Thomsen (1984) at 10-15 years after severe head injury. Kreutzer and Zasler (1989)

found that head injury alters sexual functioning as well as desire and that these changes are mostly for the worse. The majority of their respondents reported decreased ability to maintain an erection, decreased sex drive, and diminished frequency of intercourse.

This study is aimed at evaluating, in an empirical way, perceived changes in sexual behaviour, affect, and relationships following traumatic brain injury in victims and their partners. Studies that have been conducted tend to focus on men only or on the uninjured partner. It is important to gather information from both people to hear both sides of the story.

The whole area of psychosexual problems has been neglected in Scotland and in the rehabilitation of CHI in general. Discussions about sex are still considered taboo by many and as a result avoided. However, as described earlier, if such problems are not acknowledged they can have a detrimental effect on the patient's relationships and ability to cope. Thus, more information is required about the nature of psychosexual problems encountered so that intervention programmes can be developed.

## **5. Aims and Hypotheses**

The study is aimed at answering the following questions:

- (i) What psychosexual complaints are the most common following CHI?
- (ii) Is there a relationship between psychosexual dysfunction and anxiety/depression in patients and their partners?
- (iii) Do partners and patients agree on what the psychosexual problems are?
- (iv) How has the relationship been affected by the problems?
- (v) How do patients and partners feel about the changes that have taken place?
- (vi) Have any of the respondents been asked about the problems or offered help in any form?

- (vii) Is the degree of psychosexual dysfunction related to the severity of the head injury and/or time elapsed since injury?
- (viii) Are gender and age important predictors in the development of psychosexual problems following CHI?

## **6. Plan of Investigation**

### **6.1 Participants**

Participants will be recruited through the Scotcare National Brain Injury Rehabilitation Unit in Bonkle, Lanarkshire.<sup>1</sup> This is a post-acute setting concerned with the rehabilitation of individuals with brain damage, primarily as a result of head injury. The unit provides in-patient treatment although some individuals return as out-patients. The unit serves the whole of Scotland and Northern Ireland.

All patients who have been admitted to Scotcare, since it opened, for rehabilitation following a CHI will be targeted.<sup>2</sup> Patients who did not have a partner at the time of the injury will not be included. A recruitment procedure similar to the one adopted by O'Carroll, Woodrow, and Maroun (1991) will be followed. A recruitment letter will be sent to all identified patients stating the aims of the project. This letter will be sent on behalf of the primary investigator by the unit psychologist.<sup>3</sup> A reply slip at the bottom will include the following: (a) a request for the primary investigator to have access to their current address and to medical notes held at the unit, (b) a question of whether they have a current partner and if so would s/he be interested in participating, and (c) a choice as to where they would like to complete the questionnaires (at home alone, with the investigator at home, at the unit, over the telephone). It is anticipated that around 150 patients will be identified initially, of which approximately 30% will agree to participate (estimated from previous studies, eg. Kreutzer & Zasler, 1989; O'Carroll, Woodrow & Maroun, 1991). This will provide a number of about 45. A low response rate is anticipated as reluctance to participate in sexual behaviour research is a well documented phenomenon (Reinish, Sanders & Ziemba-Davis, 1990). Providing a choice of participation methods should increase the compliance rates.

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<sup>2</sup> All clients registered with the local *Headway* branches who had sustained a closed head injury were targeted.

<sup>3</sup> Letters were sent out by local branch managers.

## **6.2 Measures**

- (i) Golombok Rust Inventory of Sexual Satisfaction (GRISS: Rust & Golombok , 1985). This is a 28-item self-report scale that comes in male and female forms and provides a profile of psychosexual dysfunction. This questionnaire is readily available and is intended for use with heterosexual couples or individuals with a current heterosexual relationship. The raw scores are converted to a pseudostanine scale from 1-9 and a score of 5 or more is indicative of a problem. A global score is calculated and subscales are provided for impotence, premature ejaculation, anorgasmia, vaginismus, infrequency, poor communication, dissatisfaction, non-sensuality, and avoidance. This questionnaire has been used with normal populations and people with brain injuries and validity and reliability has been demonstrated (Rust & Golombok, 1985; 1986). Copies of the questionnaire are provided in *Appendix Two*.
- (ii) General Health Questionnaire (GHQ: Goldberg, 1978). This is a widely used 30 item self-report measure of general psychiatric symptomatology which is often used in head injury research (eg. Kinsella et al, 1988). The GHQ has been validated against diagnostic interviews in psychiatric inpatients and outpatients.
- (iii) Hospital Anxiety and Depression Scale (HAD: Zigmond & Snaith, 1983). This is a 14-item self-report scale designed specifically to differentiate between patients who are anxious or depressed on account of their physical condition.
- (iv) Psychosexual Assessment Questionnaire (Kreutzer & Zasler, 1989). This is an 11-item questionnaire with three categories looking at changes in sexual behaviour, affect and self-esteem, and relationship characteristics. A copy of this questionnaire is provided in *Appendix Two*.

## **6.3 Design and Procedure**

As some of the measures involved will contain questions of a very personal and sensitive nature, assessment through the post was chosen as the primary method. However, in order to improve compliance rates a choice of method will be offered. For those participating by post, packages containing the measures will be sent out with pre-paid return envelopes. A time-limit of one month will be set following which a

reminder postcard will be sent. This will be followed by a telephone call if questionnaires have not been returned. Participants will be asked to complete the questionnaires on their own and not to discuss the questions prior to selecting answers. This method was considered reliable following the findings of Kinsella et al (1988). Questionnaires will be administered in the form of a semi-structured interview for participants requesting a telephone call, home visit, or visit to the unit.

A specific separate control group will not be employed as it would not be possible to come up with a suitable control for a head-injured population. The head-injured patient has experienced physical, cognitive, emotional, behavioural, and personality changes that affect the whole dynamics of the situation and this cannot be controlled for. However, different comparisons will be made within the head-injury group sampled. For example, time post injury, type of injury, length of PTA etc. Where partners are involved, comparisons will be made between their results and the patients'. The GRISS has been validated on a normal sample enabling comparisons for levels of psychosexual dysfunction.

It is anticipated that packages will be sent out during January 1996. Following this data collection should be complete by Easter 1996.

#### **6.4 Settings and Equipment**

Additional equipment is not required. Accommodation is available at Scotcare for those requesting a day visit to the unit.<sup>4</sup>

#### **6.5 Data Analysis**

Data from returned questionnaires will be collated by hand and transferred to a database on computer for storage and analysis.

Analysis will be conducted using SPSS for PCs and applied to the questions listed in Section 5 as follows:

- (i) Information concerning the psychosexual complaints following CHI will be obtained using descriptive statistics of the questionnaire results.

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<sup>4</sup>Arrangements were made with the local branches to see people on site if necessary.

- (ii) The relationship between psychosexual dysfunction and anxiety and depression will be investigated using regression analyses.
- (iii) The level of consensus over problems between partners will be examined using paired correlations.
- (iv-v) Changes in the relationship and how the participants feel about the changes as a result of the problems will be determined using qualitative data and descriptive statistics.
- (vi) Descriptive statistics will be used to describe the nature and quantity of help offered to participants.
- (vii) The relationship between severity of injury and time post onset and psychosexual problems will be examined using correlation and regression analysis.
- (viii) The relationship between age and gender and psychosexual problems will be examined using correlation and regression analysis.

In addition, it will be important to assess the interaction between anxiety and depression, age, gender, severity of injury, and time post injury on the level of psychosexual dysfunction. This will be examined using analyses of covariance and stepwise regression.

## **7. Purpose of the Project**

The purpose of this project is to identify the nature of psychosexual problems following closed head injury and how they have affected the victims and their partners. This is an area of research not previously tackled in Scotland and will provide data which will be of benefit in the future development of assessment and intervention packages.

## **8. Timescales**

Recruitment letters sent out by the second week of January 1996.

Data collection completed by Easter 1996.

Data analysis completed by June 1996.

Writing up will take place throughout the whole project.

## **9. Ethical Approval**

The Scotcare National Brain Injury Rehabilitation Unit is a member of the Independent Hospitals Association. Thus there is no local governing ethical committee. All research proposals are reviewed by the clinical psychologists in post, the unit manager, and the company's management team.<sup>5</sup>

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<sup>5</sup> Prior to the change to *Headway* as the recruitment pool, this process had taken place and the research was approved. As part of changing to *Headway*, the proposal went through the same process of “in-house” ethical approval.

## 10. References

- Boller, F. & Frank, E. (1982). *Sexual Dysfunction in Neurological Disorders: Diagnosis, Management, and Rehabilitation*. New York: Raven Press.
- Brooks, N.; Campsie, L.; Symington, C.; Beattie, A. & McKinlay, W. (1987). The effects of severe head injury on patient and relative within 7 years of injury. *Journal of Head Trauma Rehabilitation*, **2**, pp1-13.
- Crenshaw, T. (1985). Head Trauma and Orgasm. *Medical Aspects of Human Sexuality*, **19**, pp115-121.
- Goldberg, D. (1978). *Manual of the General Health Questionnaire*. Windsor-NFER-Nelson.
- Kinsella, G.; Moran, C.; Ford, B. & Ponsford, J. (1988). Emotional disorder and its assessment within the severe head-injured population. *Psychological Medicine*, **18**, pp57-63.
- Kosteljanetz, M; Jensen, T.; Norgard, B.; Lunde, I.; Jensen, P. & Johnsen, S. (1981). Sexual and hypothalamic dysfunction in the post-concussional syndrome. *Acta Neurologica Scandinavica*, **63**, pp169-180.
- Kreutzer, J.S. & Zasler, N.D. (1989). Psychosexual consequences of traumatic brain injury: methodology and preliminary findings. *Brain Injury*, **3**(2), pp177-186.
- Levin, H.S. ; Benton, A.L. & Grossman, R.G. (1982). *Neurobehavioural Consequences of Closed Head Injury*. New York: Oxford University Press.
- Lezak, M.L. (1978). Living with the characterologically altered brain injured patient. *Journal of Clinical Psychiatry*, **39**, pp592-598.
- Mauss-Clum, N. & Ryan, M. (1981). Brain injury and the family. *Journal of Neurosurgical Nursing*, **13**, pp165-169.
- Miller, B.; Cummings, J.; McIntyre, H. & Ebers, G. (1986). Hypersexuality or altered sexual preference following brain injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, **49**, pp867-873.



Morton, M.V. & Wehman, P. (1995). Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury*, **9**(1), pp81-92.

O'Carroll, R.E.; Woodrow, J. & Maroun, F. (1991). Psychosexual and psychosocial sequelae of closed head injury. *Brain Injury*, **5**(3), pp303-315.

Oddy, M.; Humphrey, M. & Uttley, D. (1978). Subjective impairment and social recovery after closed head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, **41**, pp611-616.

Peters, L.; Stambrook, M.; Moore, M. & Esses, L. (1990). Psychosocial sequelae of closed head injury: effects on the marital relationship. *Brain Injury*, **4**, pp39-47.

Reinish, J.; Sanders, S. & Ziemba-Davis, M. (1990). The study of sexual behaviour in relation to the transmission of Human Immunodeficiency Virus. *American Psychologist*, **43**, pp921-927.

Rosenbaum, M. & Najenson, T. (1976). Changes in life patterns and symptoms of low mood as reported by wives of severely brain-injured soldiers. *Journal of Consulting and Clinical Psychology*, **44**, pp881-888.

Rust, J. & Golombok, S. (1985). The Golombok-Rust Inventory of Sexual Satisfaction (GRISS). *British Journal of Clinical Psychology*, **24**, pp63-64.

Rust, J. & Golombok, S. (1986). *Manual of the Golombok-Rust Inventory of Sexual Satisfaction*. Windsor: NFER-Nelson.

Thomsen, I.V. (1974). The patient with severe head injury and his family. *Scandinavian Journal of Rehabilitation Medicine*, **6**, pp180-183.

Thomsen, I.V. (1984). Late outcome of severe blunt head trauma: a 10-15 year second follow-up. *Journal of Neurology, Neurosurgery, and Psychiatry*, **47**, pp260-268.

Zigmond, A. & Snaith, R. (1983). The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, **67**, pp361-370.

# **Main Research Project Paper**

## **Psychosexual Consequences of Traumatic Brain Injury for Victims and their Partners**

This paper has been prepared according to the guidelines of *Brain Injury*. Author's notes and additional information relating to this paper may be found in *Appendix Three*.

## **Abstract**

In contrast to the extensive literature on psychosocial outcomes of traumatic brain injury (TBI), psychosexual consequences have been neglected. This study is aimed at providing some information on psychosexual consequences of TBI and other factors involved. The results of a questionnaire study of 32 TBI victims and their partners are presented. The participants completed measures of psychosexual functioning and affective symptomatology. High levels of general psychosexual dysfunction were found with associated anxiety and depression. The results are discussed in terms of a complex interaction between all factors concerned.

## Introduction

Traumatic brain injury (TBI) is one of the most common causes of disability in young adults throughout the westernised world [1]. It is estimated that in the United Kingdom there are 150 people per 100,000 of the population with a major disability resulting from TBI at any one time [2]. This means that there are more than 120,000 people in the United Kingdom suffering from the long term effects of head injury and as life expectancy is not typically reduced, this figure increases each year [3]. Many more males than females experience TBI and people between the ages of 15 and 24 years form the highest group [4]. The most common cause of TBI is road traffic accidents [4].

Many studies have investigated the cognitive, behavioural, and personality changes following head injury [5,6,7, 8, 9]. In particular, in recent years a number of studies have been published on the psychosocial sequelae of head injury [10, 11]. These were reviewed by Morton and Wehman [12] who noted that very little work has been conducted on changes in sexual relationships after head injury. This is in spite of the emphasis on achieving sexual satisfaction in contemporary society and the importance of sexual relationships psychosocially [13].

The literature on psychosexual consequences of traumatic brain injury has been reviewed in a paper earlier in this volume [14]. This review focussed on the discussion of psychosexual problems in terms of emotional and psychosocial factors. The literature to date has focussed mainly on the perceptions of partners of victims of TBI rather than the patients. It was also noted that when patients have been included, they are almost exclusively male.

The whole area of psychosexual problems following TBI has been neglected in Scotland and in the rehabilitation of TBI in general. Discussions about sex are still considered taboo by many and as a result avoided. However, as described by Davis [14], if problems are not acknowledged they can have a detrimental effect on the patient's relationships.

Following the review of the literature, this study was designed to complete some of the gaps identified in the research and to provide a start to investigations in Scotland. More specifically, the study was designed to help answer the following questions:

1. What psychosexual complaints are the most common following TBI?

2. Is there a relationship between psychosexual dysfunction and anxiety and/or depression in patients and their partners?
3. Do partners and patients agree on what the psychosexual problems are?
4. How has the relationship been affected by the problem?
5. How do patients and their partners feel about the changes that have taken place?
6. Have any of the respondents been asked about the problems or offered help in any form?
7. Is the degree of psychosexual dysfunction related to the severity of head injury and/or time elapsed since injury?
8. Are gender and age important predictors in the development of psychosexual problems following TBI?

## **Method**

### *Participants*

Participants were recruited through local West of Scotland branches of *Headway*. *Headway* is a national charity concerned with the provision of support for victims of head injury and their carers and families. All TBI victims registered with the charity within the West of Scotland were targeted. A recruitment procedure similar to the one adopted by O'Carroll, Woodrow, and Maroun [15] was developed. 163 clients were initially identified. At the first stage 51 were excluded because they were not in a relationship at the time they sustained their injury.

A recruitment letter was sent on behalf of the author to all the remaining 112. This letter stated briefly the aims of the project and included a statement that participation in the project would not affect any treatment or rehabilitation s/he was currently receiving. A reply slip at the bottom included the following: (a) a request for a current address should s/he wish to participate, (b) a request for the author to have access to his/her *Headway* records, (c) a question of whether s/he has a current partner and if so whether s/he would be interested in participating, and (d) a choice as to where s/he would like to complete the questionnaires used (at home alone, with the author at home, at a local *Headway* branch, or over the telephone). A low response rate was anticipated as reluctance to participate in sexual behaviour research is a well documented phenomenon [16].

## Measures

The following measures were used for the participants:

- (i) Golombok Rust Inventory of Sexual Satisfaction (GRISS) [17]. This is a 28-item self-report scale that comes in male and female forms and provides a profile of psychosexual dysfunction. This questionnaire is readily available and is intended for use with heterosexual couples or individuals with a current heterosexual relationship. The raw scores are converted to a scale from 1-9 and a score of 5 or more is indicative of a problem. A global score is calculated and subscales are provided for impotence, premature ejaculation, anorgasmia, vaginismus, infrequency, poor communication, dissatisfaction, non-sensuality, and avoidance. This questionnaire has been used with normal populations and people with brain injuries [15] and validity and reliability has been demonstrated [17, 18]. A copy of the male and female versions of the scale can be found in *Appendix Two* of this volume.
- (ii) General Health Questionnaire (GHQ) [19]. This is a widely used 30 item self-report measure of general psychiatric symptomatology which is often used in head injury research [20]. The GHQ has been validated against diagnostic interviews in psychiatric inpatients and outpatients. A cut-off score of 6 to indicate psychiatric 'caseness' was adopted as this is the most commonly used one for the 30-item GHQ [21].
- (iii) Hospital Anxiety and Depression Scale (HAD) [22]. This is a 14-item self-report scale designed specifically to differentiate between patients who are anxious or depressed on account of their physical condition. Separate scores for levels of anxiety and depression are obtained (7 items for each). Clear cut-off points are provided regarding normal (0-7), borderline (8-10), and clinical scores (11+).
- (iv) Psychosexual Assessment Questionnaire (PAQ) [13]. This is an 11-item questionnaire with three categories looking at changes in sexual behaviour, affect and self-esteem, and relationship characteristics. This was included to provide a measure of *change* in psychosexual functioning in addition to the measures of current functioning obtained by the GRISS. The questionnaire was designed for use with men following TBI so it was sent to the male TBI victims

only. A copy of this questionnaire can be found in *Appendix Two* of this volume.

### *Procedure*

Following the initial recruitment letter, those requesting assessment by post received a questionnaire pack. This included a pre-paid reply envelope. After one month a reminder postcard for return of the questionnaire pack was sent. This was followed by a telephone call if the questionnaires were still not returned. Participants were asked to complete the questionnaires on their own and not to discuss the questions prior to selecting answers. For those requesting assessment in person, questionnaires were administered in the form of a semi-structured interview.

The recruitment procedure resulted in 32 pairs of TBI victims and their partners participating in the study. (A full breakdown of the recruitment process can be seen in *Appendix Three*).

### **Results**

#### *Demographics and Descriptive Data*

32 pairs of TBI victims and their partners were recruited. This constitutes a 52% response rate. This is considerably higher than in previous studies [13, 15] and is probably a reflection of the provision of a choice of assessment settings and the use of reminder post cards and telephone calls.

The demographics and results of the questionnaires are shown in *Table 1*. The results from the PAQ are not included in this table as the authors have not yet developed a scoring system. In addition, it was not possible to include a measure of the severity of the victims injury as this information was not available consistently.

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Insert *Table 1* about here

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In terms of the representativeness of the sample, there is a predominance of men in the TBI group and the sample as a whole is a young one. This is consistent with epidemiological studies mentioned in the introduction [2, 4].

Using the recommended cut-off scores for the GRISS Total score, 57% of the TBI victims fell into the dysfunctional range and only 42% of their partners did. The GHQ demonstrated psychiatric caseness in 59% of the victims and 40% of their partners. In terms of specific affective symptoms, 31% of victims and 22% of partners fell in the borderline range for anxiety on the HAD. 11% of victims and 3% of partners had clinical scores for anxiety. For HAD depression scores, 16% of victims and 9% of partners were borderline, whereas 6% of victims and 1% of partners were in the clinical range.

The remainder of the results section will focus on answering the questions listed at the end of the introduction.

### *Psychosexual Complaints Following TBI*

#### *Common psychosexual complaints*

Results for this section were obtained from the GRISS subscale scores. For the male TBI victims, infrequency and avoidance were the most commonly reported problems reaching dysfunctional levels in 68% and 57% of cases respectively. For their partners, non-communication was regarded as the biggest problem (dysfunctional in 62% of cases). For the female TBI victims, dissatisfaction and infrequency were the most common (dysfunctional in 52% and 47% of cases respectively). The partners of the female victims reported the same problems, i.e. dissatisfaction and infrequency (42% and 40% of cases respectively).

#### *Agreement between partners*

The degree of consensus over problems between partners was examined using paired correlations. Based on the results reported in the previous section, it seemed prudent to conduct the correlations for males and females separately as male TBI victims were not reporting the same problems as their partners but female TBI victims were. The correlations were calculated using the GRISS total scores as the male subscales are not the same as the female ones. The result of these analyses suggested that male TBI victims do not agree with the partners ( $r= 0.261$ , n.s.) as there was no discernible correlation between the GRISS total scores. In contrast, there appeared to be agreement between the female TBI victims and their partners. This correlation was not significant ( $r= 0.69$ , critical  $r= 0.707$  at  $p\leq 0.05$ ) but given that the numbers were small ( $n=6$ ), this may be interpreted as a trend towards consensus.



*The relationship between anxiety and depression and psychosexual problems*

From the literature reviewed by Davis [14], it was predicted that high levels of anxiety and depression would result in high levels of psychosexual dysfunction. Initially, it was anticipated that this could be tested using regression analysis. However, it has been pointed out that if a sample does not include at least 20 times more cases than independent variables, use of regression analysis is inappropriate [23]. Even using the more lenient criteria of a minimum of 5 cases to each independent variable, this technique could not be considered appropriate because there are only 6 female TBI victims. Consequently, correlational analyses were conducted to look at the degree of association between anxiety and depression in individuals and their reported psychosexual problems.

It has already been mentioned that the subscales of the male and female forms of the GRISS are not directly comparable statistically. In addition, it has been demonstrated that partners may not always agree on the nature of their psychosexual problem. Each group of participants (i.e. male and female TBI victims and partners) will therefore be considered separately in this section. The GHQ, and HAD anxiety and depression scores were correlated with the overall level of psychosexual dysfunction (GRISS total score) for each group. In addition, the affective questionnaires were correlated with the GRISS subscales which reached dysfunctional levels for each group. These have already been discussed as the most common psychosexual problems reported. A summary of the significant correlations at  $p \leq 0.01$  is provided in *Table 2*.

Firstly, for the male TBI victims, GRISS total was positively correlated with GHQ and HAD anxiety and depression ( $r=0.586$ ;  $r=0.487$ ;  $r=0.639$  respectively). In terms of the male avoidance score, there was a positive correlation with GHQ ( $r=0.532$ ) and HAD depression ( $r=0.713$ ). The reported problem with infrequency was positively associated with GHQ ( $r=0.496$ ), HAD depression ( $r=0.512$ ), and HAD anxiety ( $r=0.480$ ). The partners of the male TBI victims reported poor communication as the main problem. This was associated with high GHQ scores ( $r=0.634$ ) and HAD depression ( $r=0.563$ ). The overall psychosexual dysfunction in these women was associated with high GHQ scores ( $r=0.547$ ), HAD depression ( $r=0.481$ ), and HAD anxiety ( $r=0.613$ ).

Secondly, the female TBI victims reported dissatisfaction and infrequency as the most common psychosexual problems. These did not correlate with any of the three measures but overall levels of psychosexual dysfunction was associated with GHQ

( $r=0.880$ ) and HAD anxiety ( $r=0.896$ ). For the partners of these victims level of psychiatric symptomatology as measured by the GHQ was associated with the overall level of psychosexual dysfunction ( $r=0.921$ ) and infrequency ( $r=0.894$ ).

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Insert *Table 2* about here

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#### *The rôle of severity of injury and time elapsed since injury*

As previously mentioned, measures of the severity of the injury sustained were not readily available so the importance of severity could not be determined in this study.

In terms of time elapsed since injury, some interesting results were obtained. For the male TBI victims, time was found to be positively correlated with general psychosexual dysfunction (GRISS total,  $r=0.823$ ) but negatively correlated with the problem of avoidance ( $r=-0.674$ ). This suggests that in general, psychosexual dysfunction worsens with time but male victims' avoidance of sexual contact actually decreases. Time elapsed since injury was also associated with increased psychosexual dysfunction in female TBI victims ( $r=0.885$ ), male partners ( $r=0.914$ ), and female partners ( $r=0.629$ ).

#### *The rôle of age and gender*

Age was found to correlate with general psychosexual dysfunction ( $r=0.613$ ), avoidance ( $r=0.597$ ), and infrequency ( $r=0.817$ ) for the male TBI victims. For their partners, increased age was associated with poor communication ( $r=0.625$ ). In contrast, age was not found to be associated with the problems reported by the female TBI victims but their partners reported infrequency problems with increasing age ( $r=0.894$ ).

Due to the design of the study, it was not possible to conduct any statistical tests focussing on the rôle of gender in psychosexual problems as the group sizes were too unequal.

#### *Changes in the Relationship Following TBI*

So far, the results have focussed on current levels of psychosexual dysfunction following TBI for victims and their partners. This information does not provide information on whether a *change* has taken place in the relationship.

Changes in the relationship as a result of the injury were examined using the results of the PAQ. The authors of the PAQ have not developed a numerical scoring system for the results. Therefore, for the sexual behaviour items, participants were grouped according to whether they reported a decrease, no change, or an increase. As mentioned in the introduction, the results are from the male TBI victims only (n=26).

A summary of the results for changes in sexual behaviour is shown in *Figure 1*. 53% of the male victims reported a decrease in their sex drive following the injury. 30% indicated that there was no change and 17% reported an increase in drive. The majority of the men indicated a decrease in their ability to maintain an erection (61%), 3% actually said their ability had improved, while 36% did not report any change. The amount of time spent on foreplay activities remained unchanged for 64%, decreased for 22%, and was increased in 14%. The ability to reach orgasm had either decreased (41%) or not changed (48%) in the majority of cases. 11% reported an increase in ability to reach orgasm. The actual frequency of sexual intercourse was reduced in the majority of cases (69%). 2% reported an increase in frequency while 29% reported no change.

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Insert *Figure 1* about here

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In terms of affect and self esteem, the majority of the male TBI victims reported a decline in self-confidence (59%) and sex appeal (63%). In addition, it was noted that depression was considered more of a problem after the injury than before: 76% reported an increase in depressive symptoms.

The PAQ also enabled evaluation of changes in the relationship. 36% of the men reported no change in communications with their partner, while 53% reported a decrease, and 11% stated that communications had actually improved. The status of the relationship was considered unchanged in only 12% of the cases. 59% reported poorer relationships and 29% stated that things had improved since the injury.

These results are for the male TBI victims only. However, as a small handful of the couples were interviewed in person, some comments on the psychosexual changes which have taken place since the injury have been gleaned from partners. These have been listed verbatim in *Appendix Three* and include comments on participants feelings about the changes as well.

### *Support for Psychosexual Problems*

The final part of this results section concerns the nature of support TBI victims and their partners have received for psychosexual problems. Only 13% of the couples could recall anyone talking to them about possible sexual problems when the victim was in hospital. This small figure does reflect the need of couples as 47% stated that they would have liked some information in the early stages. 6% reported that they had expressed concerns over some sexual difficulty but were not given the opportunity to discuss things further. 43% stated that they would have been too embarrassed to discuss the difficulties with anyone other than their partner. Only one couple had actually received treatment, in the form of counselling, for their psychosexual problems.

### **Discussion**

This study was aimed at describing the psychosexual problems which may arise as a result of TBI and identifying additional factors involved in the presentation. A set of questions was posed at the end of the introduction and the results obtained go some way to answering them.

High rates of anxiety and depression following head injury have been noted in previous studies as reviewed by Davis [14]. The level of affective symptomatology was slightly lower in this study but evident nonetheless. In terms of the level of psychosexual dysfunction reported, 57% of the TBI victims and 42% of their partners fell into the dysfunctional range with their GRISS total scores. This is consistent with the results of previous studies [15].

The most common problems reported by men after TBI were infrequency and avoidance while their partners stated that inadequate communication about sex was more of a problem. When it is the woman who has sustained the injury, dissatisfaction with sex and infrequency of intercourse were recorded as the biggest problem. This was the case for their partners as well. This suggests that partners are more likely to agree on their psychosexual problems if it is the women who has been injured. One possible explanation of this is that the relative rôles of each person in the relationship change much more when it is the man who has been injured. The change in rôles may result in altered patterns of communication so that the couple

find it harder to discuss their problems. The result is a lack of consensus as to what the problem is.

The rôle of anxiety and depression and general psychiatric disturbance was examined in relation to psychosexual dysfunction. High rates of general psychiatric disturbance as measured by the GHQ were associated with high rates of general psychosexual dysfunction for all groups concerned. More specifically, the results pointed to anxiety as an important factor in the presentation of psychosexual dysfunction. In relation to depression, it was demonstrated that the amount of male avoidance reported by male victims increased with rising levels of depression. This is probably the result of depression decreasing the person's libido so that s/he does not feel like participating in any sexual contact. Infrequent sexual intercourse was also associated with high levels of depression and anxiety.

Another interesting finding was the association between time since injury and psychosexual disturbance. For the male TBI victims, the results suggested that although psychosexual problems in general worsen with time, one specific problem, that of male avoidance, actually improves. It is possible that when sexual contact is less frequent, many problems are not apparent to the parties involved. As the amount of sexual contact is increased, there is more opportunity for problems to develop and so the level of psychosexual dysfunction increases.

The findings relating to age and psychosexual dysfunction can be explained in terms of social and cultural expectations. There exists a long-standing belief within our culture that as people get older there is no longer a need for sex [24]. This attitude can be reflected in the results demonstrating high levels of male avoidance and infrequency of intercourse with increasing age.

In addition to the current levels of psychosexual dysfunction detected, the study demonstrated that there is a change in behaviour and relationships as a result of TBI. As expected, the majority of the changes reported were for the worse: inability to maintain an erection, decreased sex drive, diminished frequency of intercourse. Some people reported improvements in their behaviour, for example, increased sex drive. However, it transpired from informal discussions with partners, that although the victim perceives the change as positive, the partner receiving the change does not. Negative changes in the quality of the relationship were also noted by the majority of victims and these were associated with poor psychosexual functioning.

The results of this study provide some information as to why psychosexual problems exist after TBI . Anxiety and depression are obviously important factors, not just in the victims, but in the partners too. However, it is not clear whether these are causative or maintaining factors. It is likely that they are important in both stages [14]. In addition to the rôle of affective symptomatology, it is important to consider the rôle of behaviour and personality. Changes in these are common consequences of TBI and can have a powerful effect on the relationship of a couple [15]. Changes in personal rôles within the relationship can also occur, and these in turn can affect other psychosexual and psychosocial factors. There is obviously a very complex interaction between all the factors involved and it will be important for future research to investigate this.

Finally, it was apparent from this study that psychosexual issues are still not discussed following TBI. It has been demonstrated that problems can worsen with time and that this can result in breakdowns in relationships. It is important that this taboo is broken so that victims and their partners are given the opportunity to discuss problems and seek treatment.

#### **Acknowledgements**

The author would like to thank all the staff and clients at *Headway* who contributed to and participated in the project.

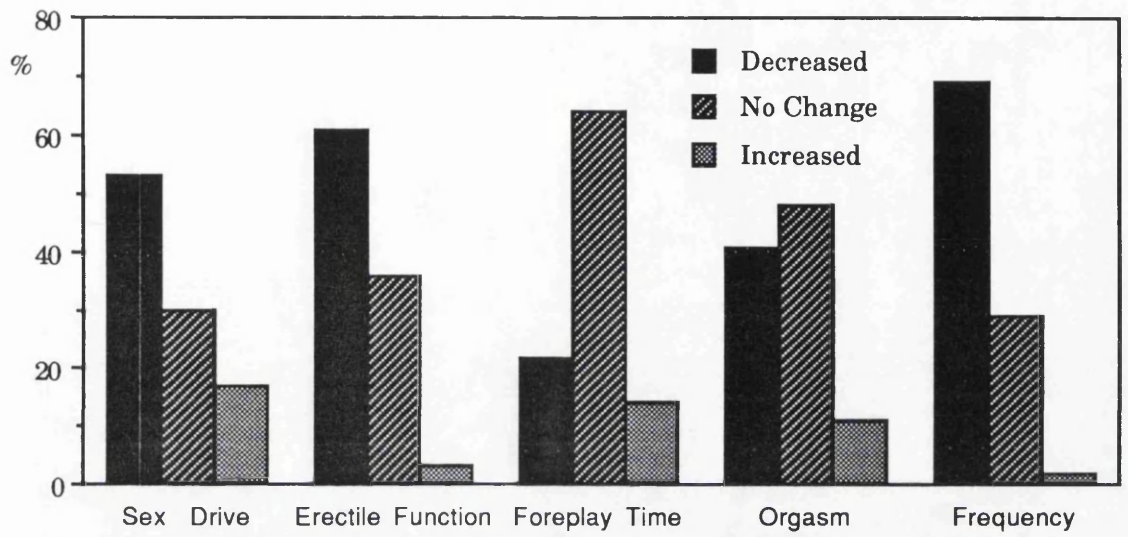
	TBI DATA (n=32) Mean ( $\pm$ SD)	PARTNER DATA (n=32) Mean ( $\pm$ SD)
AGE	38.24 (12.06)	41.35 (13.24)
YEARS SINCE INJURY	5.11 (3.29)	N/A
GENDER	26 MEN, 6 WOMEN	26 WOMEN, 6 MEN
GHQ	8.95 (6.23)	4.01 (3.21)
HAD Anxiety	7.25 (4.11)	6.39 (2.98)
HAD Depression	5.92 (3.24)	2.95 (1.62)
GRISS Total	5.79 (2.51)	3.29 (2.68)

*Table 1: Demographic data and scores from the questionnaires for the TBI victims and their partners.*

	<b>GHQ</b>	<b>HAD Anxiety</b>	<b>HAD Depression</b>
<b>TBI Males</b>	<b>GRISS total Avoidance Infrequency</b>	<b>GRISS total Infrequency</b>	<b>GRISS total Avoidance Infrequency</b>
<b>TBI Females</b>	<b>GRISS total</b>	<b>GRISS total</b>	<b>-</b>
<b>Male Partners</b>	<b>GRISS total Infrequency</b>	<b>-</b>	<b>-</b>
<b>Female Partners</b>	<b>GRISS total Communication</b>	<b>GRISS total</b>	<b>GRISS total Communication</b>

*Table 2: Table showing a summary of the significant correlations between general psychiatric disturbance (GHQ) and anxiety and depression with general psychosexual dysfunction (GRISS total) and the most common specific problems reported.*





*Figure 1: The reported post-injury changes in sexual behaviour by male victims of TBI.*

## References

1. RIMEL, R.W. and JANE, J.A.: Characteristics of the head injured patient. In: M. Rosenthal, E.R. Griffith, M.R. Bond and J.D. Miller (editors) *Rehabilitation of the Head Injured Adult* (F.A. Davis Company, Philadelphia), pp. 9-21, 1983.
2. FIELD, J.H.: *Epidemiology of Head Injuries in England and Wales*. (HMSO, London), 1976.
3. POWELL, T.: *Head Injury. A Practical Guide*. (For Headway by Winslow Press, Oxon), 1994.
4. WILLER, B., ABOSCH, S. and DAHMER, E.: Epidemiology of Disability from traumatic brain injury. In: R.L. Wood (editor) *Neuro-behavioural Sequelae of Traumatic Brain Injury* (Taylor & Francis Ltd, London), pp. 18-36, 1990.
5. MCKINLAY, W.W., BROOKS, D.N., BOND, M.R. *et al*: The short-term outcome of severe head injury as reported by relatives of the injured persons. *Journal of Neurology, Neurosurgery, and Psychiatry*, **44**: 527-533, 1981.
6. BROOKS, D.N., CAMPSIE, L., SYMINGTON, C., *et al*: The five year outcome of severe blunt head injury: a relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry*, **49**: 764-770, 1986.
7. BROOKS, D.N. and MCKINLAY, W.W.: Personality and behavioural change after severe blunt head injury: a relatives view. *Journal of Neurology, Neurosurgery, and Psychiatry*, **46**: 336-344, 1983.
8. KINSELLA, G., MORAN, C., FORD, B. *et al*: Emotional disorder and its assessment within the severe head-injured population. *Psychological Medicine*, **18**: 57-63, 1988.
9. LEVIN, H.S., BENTON, A.L. and GROSSMAN, R.G.: *Neurobehavioural Consequences of Closed Head Injury* (Oxford University Press, New York), 1982.
10. ODDY, M. and HUMPHREY, M.: Social recovery during the year following severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, **43**: 798-802, 1980.
11. PETERS, L., STAMBROOK, M., MOORE, A. *et al*: Psychosocial sequelae of closed head injury: effects on the marital relationship. *Brain Injury*, **4**: 39-47, 1990.
12. MORTON, M.V. and WEHMAN, P.: Psychosocial and emotional sequelae of individuals with traumatic brain injury: a literature review and recommendations. *Brain Injury*, **9**: 81-92, 1995.

13. KREUTZER, J.S. and ZASLER, N.D.: Psychosexual consequences of traumatic brain injury: methodology and preliminary findings. *Brain Injury*, **3**: 177-186, 1989.
14. DAVIS, A.M.: *Psychosexual Consequences of Traumatic Brain Injury: A Review of the Literature* (Unpublished D.Clin.Psy. thesis, University of Glasgow), 1996.
15. O'CARROLL, R.E., WOODROW, J. and MAROUN, F.: Psychosexual and psychosocial sequelae of closed head injury. *Brain Injury*, **5**: 303-315, 1991.
16. REINISH, J., SANDERS, S. and ZIEMBA-DAVIS, M.: The study of sexual behaviour in relation to the transmission of Human Immunodeficiency Virus. *American Psychologist*, **43**: 921-927, 1990.
17. RUST, J. and GOLOMBOK, S.: *Manual of the Golombok-Rust Inventory of Sexual Satisfaction* (NFER-Nelson, Windsor), 1986.
18. RUST, J. and GOLOMBOK, S.: The Golombok-Rust Inventory of Sexual Satisfaction (GRISS). *British Journal of Clinical Psychology*, **24**: 63-64, 1985.
19. GOLDBERG, D.: *Manual of the General Health Questionnaire* (NFER-Nelson, Windsor), 1978.
20. KINSELLA, G., MORAN, C., FORD, B. *et al*: Emotional disorder and its assessment within the severe head-injured population. *Psychological Medicine*, **18**: 57-63, 1988.
21. GOLDBERG, D. and WILLIAMS, P.: *A User's Guide to the General Health Questionnaire* (NFER-Nelson, Windsor), 1988.
22. ZIGMOND, A. and SNAITH, R.: The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica*, **67**: 361-370, 1983.
23. TABACHNICK, B.G. and FIDELL, L.S.: *Using Multivariate Statistics* (Harper Collins Publishers, Inc., New York), 1989.
24. BANCROFT, J.: *Human Sexuality and its Problems* (Churchill Livingstone, London), 1989.

## **Small Scale Service Evaluation Project**

### **Do They Still Have to Dance? A Survey of Bereavement Policies Held by Establishments for People with Learning Disabilities**

This service evaluation has been written according to the guidelines of *Clinical Psychology Forum*. Author's notes and other material relating to the paper may be found in *Appendix Four*.

## Introduction

### *History*

There is a history within society and the health care professions for "*double standards*" when dealing with people with learning disabilities who have been bereaved. In her 1992 article "Don't Ask Us to Dance" (Clinical Psychology Forum, No.44), Oswin describes these "*double standards*" as operating according to whether the bereaved person is bright or "*intellectually disadvantaged*". She cites two poignant examples. The first of these is of a man who was trying not to show too much emotion in front of others following the death of his father. This was interpreted by staff as suggesting that he had not really cared about his father when the opposite was in fact the case. She states that had the man in question been working in an office, his colleagues would probably have been supportive of his attempt at being brave and carrying on as usual. The second example is of a young man who was being encouraged to dance soon after his mother died. To quote:

*"My mum had just died. I went into hospital the same day. They said I needed looking after. I was very sad. They kept wanting me to dance."* (Oswin, p16).

Again, Oswin states that had this taken place outside the realm of learning disabilities, attending a dance and laughing and joking would probably have been accepted in a more negative light.

Up until recently, this approach was seen as standard. Staff would *protect* clients by not telling them about a death. Rather than allowing residents the chance to grieve, the death of a fellow resident would be minimised by discreet and prompt removal of the body and personal possessions (Cathcart, 1995). Clients who had been cared for at home by a relative who had just died, would be moved immediately to a different setting. This would result in a change in routine, new demands, new people, long and unexplained assessments etc. (Oswin, 1992).

In addition to serving as a protective factor, clients were not told because they "would not understand" and there may be a fear that a client will become difficult to manage following such news. These beliefs are considered to have arisen primarily from the lack of knowledge about bereavement and learning disabilities (Oswin, 1981). The notion that clients would not understand the concept of death has been contested in recent years (Bihm & Elliott, 1982; Lipe-Goodson & Goebel, 1983). Behaviour

problems have been documented in clients who have been bereaved but these are considered to arise when the client has not been fully informed and the behaviour is his/her way of communicating that s/he is confused about something (Emerson, 1977; McLoughlin, 1986; Ray, 1978).

This approach of keeping deaths as quiet as possible is inconsistent with approaches to death in the general population. People are now encouraged to talk about their bereavement and are given time and privacy to grieve. From the literature reviewed, it would appear that adults with learning disabilities have been denied the opportunity to grieve. This picture is incongruent with the recent trends within the health service towards normalisation as outlined by O'Brien (1980). In support of this, there is extensive literature on dying and bereavement in general (eg. Kubler Ross, 1969; Stroebe & Stroebe, 1987; Worden, 1991), but very little that applies to learning disabilities.

#### *The Need for Policies on Bereavement*

Worden(1991) suggests that if people are supported during bereavement, they will be more able to cope with the loss of family and friends in the future. This applies to people with learning disabilities as well (Cathcart, 1995). Cathcart states that helping people to understand what happens when someone dies will make it easier for them to cope with the current situation and prepare for the inevitable happening again. Adults attending services will be faced with bereavement following the death of fellow clients and carers, as well as that of friends and family. If they are in a residency, then the death of another client is likely to have an impact similar to losing a family member (Cathcart, 1994). Professional carers in day and residential services need the opportunity to grieve too. After a client dies, they may experience the same strong emotions as the person's family and close friends.

Oswin (1992) states that organisations have a responsibility to their clients and staff to produce flexible and sensitive guidelines for dealing with a bereavement. She goes on to say that guidelines such as these will help ensure that clients are informed and given the chance to grieve. Managers should also ensure that staff are supported when their work brings them into close contact with people who are dying or who have been bereaved.

The introduction of principles of normalisation has resulted in many changes to learning disabilities services. Clients are becoming increasingly involved in

planning their future and the focus is more on integrated community care rather than institutions. In the last five years, the literature on bereavement and learning disabilities has increased. There are now several studies which suggest ways of supporting bereaved clients with learning disabilities. For example: individual support work (Cathcart, 1991; Kitching, 1987), cognitive therapy (Lindsay, Howells and Pitcaithly, 1993), group support (Turner and Graffam, 1987). A few resources are also available: the resource packs *When Dad Died* and *When Mum Died* ( Hollins and Sireling, 1989), *Understanding Death and Dying* (Cathcart, 1994); *The Last Taboo Video* (Hollins and Sireling, 1991). In addition to these resources there are training courses organised by health and social services as well as voluntary agencies such as CRUSE. The British Institute of Learning Disabilities (BILD) also offers help in setting up inservice training courses for staff.

This study was aimed at assessing how learning disabilities establishments are progressing in providing an appropriate yet normalised bereavement service for their clients. This was achieved by use of a questionnaire looking at different aspects of bereavement care and policies. Based upon principles of normalisation and Cathcart's (1994) guidelines, a normalised approach to bereavement care would incorporate the following points:

- (i) Preparation for loss through:
  - developing a basic understanding of loss
  - developing a basic knowledge about death and dying
  - exploring the client's preferences for death, eg. choice of music, burial or cremation etc.
  
- (ii) Explanation and management of death by:
  - explaining that a death has occurred and what it means
  - allowing viewing of the body if appropriate
  - enabling the client to attend the funeral
  - enabling the client to remember the person, eg. through flowers or music, or making a picture memory book
  - enabling the client to participate in social mourning, eg. receiving cards
  - informing other carers, eg. day centres
  - supporting relatives, clients, and carers through the period of mourning.

## **Method**

### *Sample*

Learning disabilities establishments within the region of Ayrshire in Scotland were targeted (excluding the Isle of Arran). The resulting list comprised a wide mix of services, both residential and non-residential: health service, social work (adult training centres, hostels, and group training tenancies), Enable, Salvation Army, Red Cross, Key Housing, and private nursing homes. Where applicable, head offices of establishments were contacted too. This study was conducted as a part requirement for training in clinical psychology and the author had conducted a core learning disabilities placement within Ayrshire and was therefore familiar with the majority of the establishments contacted.

### *Procedure*

A questionnaire was developed concerning approaches to bereavement in learning disabilities establishments (see *Appendix Four*). The questionnaire comprised four sections: general approach to bereavement (5 items), staff training (5 items), dealing with clients who are bereaved (12 items), and dealing with the death of a client (10 items). The items within the questionnaire were open-ended questions allowing for descriptive responses as well as yes/no answers. The questionnaire took 10 to 15 minutes to complete, depending on the length of answers provided.

Initially, the questionnaire was sent out to all targeted establishments along with a covering letter. The response rate, however, was minimal at 5% so an alternative methodology was adopted. The same list of establishments was used but they were approached by telephone instead. A brief explanation of the project was provided over the telephone and they were asked whether they would be interested in participating. A choice between a telephone interview or personal visit was provided. The questionnaire developed previously formed the basis of the interviews and was expanded or contracted depending on the nature of the establishment. In the end, 17 establishments participated in the study. This figure was 71% of those initially targeted. Eleven (65%) places requested personal visits while the remaining six (35%) conducted the interview over the telephone. Ten (59%) were residential and seven (41%) day services. Six head offices were contacted of which four agreed to participate. These interviews were all conducted over the telephone.



## **Results**

### *General approaches to bereavement*

All head offices contacted stated that they held specific policies on bereavement for their clients, although two of them were still in the process of finalising their documents. One provided a policy for viewing. At the time of doing the survey, 50% of the managers were aware of the policy held or being drafted by head office. One residential establishment had drawn up a document specific to their needs in addition to the policy held by head office.

65% of the managers requested information on how they could improve the service provided.

### *Staff training*

One establishment was found to provide additional staff training specifically in the area of bereavement. This had been developed independently of the overall organisation. The manager's decision for this had ensued difficulties with a couple of residents with a complicated bereavement reaction. Clinical psychology had been involved in both cases and the manager had sought advice as to how such situations might be prevented in the future. Staff training had been organised as a result. 44% of the remainder were interested in the possibility of staff training but were unsure how to obtain it and requested information.

### *Dealing with the bereaved client*

Residential services were found to be more involved in this than day services. 47% of services stated that there had been a change in their approach towards bereaved clients and that they considered these to be the result of changes within the service in general. Four (24%) residential services were actively involved in preparing clients for an imminent death. The preparations described included the following:

- developing a basic understanding about loss
- developing a basic knowledge about death and dying
- discussions about death at appropriate times
- exploring the client's preferences for death, eg. choice of music, burial or cremation etc.

These four establishments had obtained their ideas from leaflets by Cathcart (1994) and discussion with a psychologist and their approach was adopted regardless of whether it was a relative or a fellow client who was dying.

The results demonstrated that services become more involved once a death has occurred with 62% providing support at this stage. With some establishments, the level of involvement varied with perceived ability of the individual client. Four residencies described their management of a death in detail. One example is:

- explaining that death had occurred and what it means
- viewing the body (if appropriate)
- attending the funeral and arranging time off from day placements
- sharing in remembering the person, eg. through flowers or music
- enabling participation in social mourning, eg. receiving cards

The other six residential establishments would consider asking the client if s/he would like to attend the funeral and a member of staff would accompany if necessary. The day services stated that they consider each case individually, usually under the coordination of the key worker and in conjunction with residential services and/or family.

Four residencies described provision of continuing support for clients as required. This incorporated providing time to mourn (in private), arranging time off placements if necessary, and enabling remembering by use of momentos etc. If clients wished to carry on as normal this was accepted too. They reported a need to treat each client individually, as what may suit one person will not be appropriate for another.

The day services reported that they would enable clients to take time off placements to mourn and the majority (71%) stated that it would be beneficial for clients to keep a daily routine going.

#### *Dealing with the death of a client*

There were two sections to this part of the questionnaire: (i) how a client who is dying is prepared, and (ii) how fellow clients and staff are informed and supported. This section applies more to residential services than day services.

All 10 residential places stated that they would inform the family as soon as possible and involve them in the final stages of care if requested. Discussion of this with the client is determined on an individual basis. Day services stated that this would be left to the family or staff at residencies.

80% of the residential services stated that other residents would be informed about the death of a fellow client. Staff and residents are given time to mourn and in one place an external counsellor is brought in to run a support group for staff and clients. This unit described their approach in detail and stated that the introduction of a new resident is planned in advance and discussed with the other clients. Two other residential settings stated that their priority was to keep things running as smoothly as possible so as not to upset the daily routine.

## **Discussion**

In general, the findings from this survey demonstrate that there has been a change in the approach of services to bereavement and clients with learning disabilities and that this is consistent with general principles of normalisation and integrated community care. Bereavement reactions are being acknowledged and clients are provided with the opportunity to prepare for death. Organisations stated that the management of bereavement has been facilitated by increased availability of literature and tools. Bereavement policies are being developed by organisations and the results demonstrated that provision was made for tailoring support to individual needs.

The survey demonstrated some differences in the approach of residential and day services to bereavement. These differences are to be expected as the service provided by the establishments is different. Traditionally, residential services were expected to be the main providers of bereavement care but, in line with normalisation and community care, day services are becoming increasingly involved. This enables consistency for the client across different settings and integration and communication between the services.

Conducting the survey initiated some indepth discussion with two residencies. They reported that bereavement care had been facilitated with the growth of resources but that these were suitable for use with clients with mild disabilities only. Supporting the client with profound and multiple handicaps was considered more problematic, particularly if a complicated bereavement reaction ensues. Further development of

materials would need to focus on this area. The discussion also highlighted the need for clarifying the rôle of clinical psychologists in bereavement care. At present, psychologists are often utilised once the bereavement has become complicated and a problem behaviour has resulted. Should the psychologist be involved at the stage of policy planning and staff training to help prevent such complications or should this be the rôle of specialist agencies such as BILD?

This study sampled just a small area of Scotland but the results are likely to reflect a general trend across the country as head offices were included in the survey and their policies and beliefs will be national. However, it would be interesting to target other areas for comparison.

## **Conclusion**

In the last decade there has been an increase in the amount of research conducted within the area of bereavement and learning disabilities. This has resulted in the development of new materials available for enabling the provision of bereavement care. This information is widely available to learning disability establishments and has been utilised by many. This survey demonstrated that services have changed their approach to bereavement care and that these changes are consistent with principles of normalisation. Establishments highlighted the need for more resources for working with clients with profound and multiple handicaps.

## **Acknowledgements**

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## References

- BIHM, E. and ELLIOTT, I. (1982) Conception of death in mentally retarded persons. **Journal of Psychology, 3**, 205-210.
- CATHCART, F. (1991) Bereavement and mental handicap. **Bereavement Care, 10**, 9-11.
- CATHCART, F. (1994) **Understanding Death and Dying**. A series of three booklets for the client, relative, and professional carer. Kidderminster: British Institute of Learning Disabilities.
- CATHCART, F. (1995) Death and people with learning disabilities: Interventions to support clients and carers. **British Journal of Clinical Psychology, 34**, 165-175.
- EMERSON, E. (1993) What is normalisation? In H. Brown and H. Smith (Eds) **Normalisation: A Reader for the Nineties**. London: Routledge.
- EMERSON, P. (1977) Covert grief reactions in mentally retarded clients. **Mental Retardation, 15**, 44-45.
- HOLLINS, S. and SIRELING, L. (1989) **When Dad Died and When Mum Died**. Swavesey, Cambridge: Silent Books.
- HOLLINS, S. and SIRELING, L. (1991) **The Last Taboo**. London: St. George's Hospital Medical School.
- KITCHING, N. (1987) Helping people with mental handicaps cope with bereavement. **Mental Handicap, 15**, 60-63.
- KUBLER ROSS, E. (1969) **On Death and Dying**. London: Tavistock.
- LINDSAY, W.; HOWELLS, L. and PITCAITHLY, D. (1993) Cognitive therapy for depression with individuals with intellectual disabilities. **British Journal of Medical Psychology, 66**, 135-141.
- LIPE-GOODSON, P. and GOEBEL, B. (1983) Perception of age and death in mentally retarded adults. **Mental Retardation, 21**, 68-75.

McLOUGHLIN, I.J. (1986) Bereavement in the mentally handicapped. **British Journal of Hospital Medicine**, October, 256-260.

OSWIN, M. (1981) **Bereavement and Mentally Handicapped People**. London: King's Fund document.

OSWIN, M. (1985) Bereavement. In A. Craft, J. Bicknell and S. Hollins (Eds) **A Multidisciplinary Approach to Mental Handicap**. London: Baillière Tindall.

OSWIN, M. (1992) Don't ask us to dance: some aspects of bereavement for people who have learning difficulties. **Clinical Psychology Forum**, No.44, 16-21.

RAY, R. (1978) The mentally handicapped child's reaction to bereavement. **Health Visitor**, 51, 333-334.

STROEBE, W., and STROEBE, M. (1987) **Bereavement and Health**. Cambridge: Cambridge University Press.

TURNER, J. and GRAFFAM, J. (1987) Deceased loved ones in the dreams of mentally retarded adults. **American Journal of Retardation**, 92, 282-289.

WORDEN, J.W. (1991) **Grief Counselling and Grief Therapy. A Handbook for the Mental Health Practitioner**. London: Routledge. Second edition.

# **Single Clinical Case Research Study**

## **A Single Case Example of the Application of Cognitive Behaviour Therapy to Hypochondriasis**

This paper has been written according to the guidelines of the *British Journal of Health Psychology*. Author's notes and other material relating to the paper may be found in *Appendix Five*.

## **Abstract**

The cognitive behavioural treatment of hypochondriasis is described with a single case study. A summary of the assessment is provided followed by details of the treatment approach used. The focus was on the factors involved in maintaining the hypochondriasis. Improvement was made in all targets set and these were maintained at a six week follow-up session. A reduction in symptoms of depression was also achieved. The outcome of the treatment suggests that a cognitive-behavioural approach can be effective in the treatment of hypochondriasis.



## Introduction

Health psychology is a rapidly expanding area of research and practice concerned with the psychological aspects of health problems and clinical issues outside the psychiatric domain (Wardle & Steptoe, 1996). Clinical psychologists working within the area of health psychology have a wide remit, primarily centred on looking at the psychological aspects of chronic illnesses, such as diabetes, renal failure, and chronic fatigue syndrome. The majority of referrals are from physicians who feel that the patient concerned requires psychological support for adjusting to the illness. In addition to this core group of referrals, there will be referrals for patients who are presenting to physicians and general practitioners with fears about a wide variety of physical problems for which no underlying medical cause can be found. It has been estimated that these patients form 30-80% of those who consult physicians and that the majority of these can be described as suffering from the psychiatric disorder Hypochondriasis (Barsky & Klerman, 1983). This percentage is on the increase, as is the number of referrals of these patients to psychology services (Barsky, 1996).

Hypochondriasis is defined as a "*preoccupation with fears of having, or the idea that one has, a serious disease based on the person's misinterpretation of bodily symptoms*" (American Psychiatric Association, 1994). Actual diagnosis of hypochondriasis by physicians is rare (Noyes, Kathol, Fisher, Philips, Suelzer, Holt, 1993) but referrals will often be written in a way which suggests that somatisation is part of the problem. Clear diagnostic criteria are provided by the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV: American Psychiatric Association, 1994 - see *Appendix Five*).

Consistent with the poor diagnosis of hypochondriasis, treatment programmes have been considered unsatisfactory up until recently (Warwick & Salkovskis, 1989). Consequently, the prognosis of the disorder was also poor (Nemiah, 1985; Warwick, 1989). This meant that the sufferer was under prolonged distress and causing considerable cost to physicians because of repeated consultations and investigations (Ford, 1995). This was the case up until the work of Warwick and Salkovskis in the 1980s who suggested a cognitive-behavioural approach to the disorder (Salkovskis & Warwick, 1986; Warwick & Salkovskis, 1985).

The cognitive-behavioural model suggested by Salkovskis and Warwick addresses factors involved both in the aetiology and in the maintenance of hypochondriasis. Incorporated into the model is the notion of a three systems approach (Warwick &

Salkovskis, 1990). This encompasses cognitions, behaviour, and physiology. Normal physiological responses are cognitively appraised and interpreted as both personally relevant and indicative of the presence of a serious disease (Warwick, 1989). This cognitive style of health anxiety is influenced by a number of factors, such as previous experience of related illnesses, misinterpretation of medical information, and selective attention with a confirmatory bias (Salkovskis & Warwick, 1986). The behavioural aspects present are usually avoidance, checking, and reassurance seeking and these are important in maintaining the beliefs (i.e. the misinterpretations).

There are similarities between hypochondriasis and other anxiety disorders, such as panic disorder, and cognitive-behavioural approaches have been shown to be effective in the treatment of panic attacks (for example, Clark, 1986). However, there are important differences between hypochondriasis and other anxiety disorders. For example, in hypochondriasis the fear is constantly present, but in panic disorder the fear subsides between panic attacks. Another difference is that reassurance seeking behaviour is a major part of hypochondriasis and this is not seen in panic disorder. Warwick (1992) suggests that it is important to focus on this behaviour as reassurance can lead to a temporary allaying of anxiety which is then followed by a rapid increase. An exact replication of the cognitive-behavioural treatment approach to panic is therefore not appropriate for hypochondriasis: the treatment requires some tailoring.

Reports of cognitive-behavioural treatment have been largely single case designs but group treatment studies are beginning to appear in the literature (Barsky, 1996; Avia, Ruiz, Olivares, Crespo, Guisado, Sanchez & Varela, 1996). Case studies looking at this approach are still useful in demonstrating specific instances of tailoring the cognitive-behavioural model to a particular presentation. This case study is an example of the application of the cognitive-behavioural techniques suggested by Salkovskis and Warwick in the formulation and treatment of hypochondriasis. This will be of particular interest to clinicians working within the field of health psychology as the patient presented with a physical disorder in addition to the hypochondriasis.

## Case History

### *Case description*

PH is a 48 year old married woman with two sons (ages 22 and 19) living at home. She described a healthy and uneventful childhood and stated that the marriage was good, affectionate, and supportive in all areas. She was employed as a clerical assistant at a local health centre. There was no family history of psychological or psychiatric disturbance. PH had been in hospital on six occasions including two visits for the births of her sons. These visits were for scarlet fever, a tonsillectomy, a haemorrhoid operation, and a hysterectomy. The first two admissions were recalled as traumatic because of the separation from her family. She was receiving hormone replacement therapy and this had proceeded without complications. She took paracetamol about once a week for headaches.

### *Assessment of the development of the problem*

The onset of the current problem was dated to 1978 when her father died from Alzheimer's Disease. He had been ill for three years prior to his death, and PH was very involved in his care. The death of her father resulted in a terrible fear of death, for herself, and close friends and family. This fear was exacerbated when her mother died from Alzheimer's Disease in 1982. She developed severe headaches and was convinced that they were indicative of some terminal illness and that she was going to die. The fear of death lessened slightly until five years ago when she found out that a close friend had cancer. After a year of intense treatment her friend died and since then PH has had a fear that she has, or will develop, cancer.

PH started making frequent visits to the doctor, approximately three times a month over the previous 9 months leading up to the appointment. She found reassurance effective in allaying her health anxiety in the short term only. Once reassured that a particular ache or pain was not a sign of cancer, it would subside and be replaced by a different pain. At one point she developed a pain in her bowel which was diagnosed as Irritable Bowel Syndrome (IBS). She accepted this diagnosis and made successful appropriate changes in her diet and lifestyle under the guidance of her doctor. The pain in her bowel was controlled as a result but the fear of cancer was still present as she believed that IBS carried with it an increased risk of the development of organic pathology. Unlike the previous occasions, reassurance from her doctor had not helped in alleviating the pain although by the time she came for treatment, the pain had moved to being a "dull ache" in her left side.

This "dull ache" in her side was the focus of PH's health anxieties at the time of assessment. In addition, any ache or pain resulted in her thinking that she had cancer or was going to develop cancer. This belief in turn exaggerated the pain and produced additional symptoms of anxiety such as muscle tension, sweating, hyperventilation, pins and needles, and light headedness. She felt well at work where she hardly ever noticed the ache which would come on in the car on the way home. This always made her feel very anxious of which her main symptoms were muscle tension, pins and needles, sweating, and light headedness. She would find herself rubbing the spot where she felt the ache was and the sensation would increase until at home when something would distract her for the short term. Her main thoughts were that she had been misdiagnosed and had cancer of the bowel and the ache in her side was a secondary cancer from this. This thought resulted in her checking for traces of blood every time she emptied her bowels. Sometimes she was able to rationalise the ache as part of the IBS and this reduced her symptoms of anxiety and frequency of checking behaviour. This was usually occurred when in company and when at work. Reading about cancer and IBS made the symptoms worse and she would become hypervigilant, scanning her body for the minutest changes and symptoms listed in articles just in case she had missed any.

PH also reported symptoms of depression. The impact on her life was minimal as she was still able to go to work and go out with friends, although she stated that her quality of life was affected as a result of the problem.

The assessment conducted indicated that PH fulfilled the DSM-IV criteria for Hypochondriasis with secondary depression. A full breakdown of the diagnoses made can be seen in *Appendix Five*.

#### *The cognitive-behavioural treatment approach*

PH described the problem as a psychological one and expressed a great willingness to work towards change. At her initial assessment interview, she was administered the Beck Depression Inventory (BDI: Beck, 1978), the Beck Anxiety Inventory (BAI: Beck, 1978), and the Hospital Anxiety and Depression Scale (HAD: Zigmond & Snaith, 1983). Her initial scores on these are shown in *Table One*. Questionnaires for somatic problems were not used as they have not been found to be useful in clinical practice (Bradley and Prokop, 1982).

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Insert *Table One* about here

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The first stage of treatment involved the introduction of the cognitive-behavioural model of hypochondriasis. Using the procedure outlined by Warwick and Salkovskis (1989) the case of a typical 'cardiac phobic' was presented. Following from this, PH's hypochondriasis was conceptualised within the same framework. This was achieved in the form of a flow chart (based on Warwick & Salkovskis, 1989) and the result is shown in *Figure One*.

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Insert *Figure One* about here

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From *Figure One* it can be seen that PH's previous experience of her parents dying resulted in the development of the dysfunctional assumption that a pain suggests that something is seriously wrong. When combined with the critical incidents of her friend's death from cancer and her development of IBS, the dysfunctional assumption was activated and developed into negative thoughts about the presence of cancer. The result was hypochondriasis with behavioural, cognitive, and physiological symptoms and secondary affective symptoms.

PH stated that she felt some immediate relief at seeing a clear picture of the development of the problem. The next stage was therefore to focus on the maintaining factors involved. The model outlined by Salkovskis (1989) was used and another flow diagram was completed with PH. This can be seen in *Figure Two*. This figure demonstrates that PH experienced anxiety as the result of medical information, the IBS, and the onset of aches and pains. This anxiety was manifest in checking and reassurance behaviour, selective attention on her body, and physiological arousal. Taken together, these symptoms resulted in the misinterpretation of body sensations/signs as indicative of cancer. This misinterpretation was maintained by repeated self checking of her body, physical tests, and information seeking from books and magazines. Engagement in the discussion of this cognitive-behavioural model was not a problem contrary to expectations in the literature (Salkovskis, 1989, Salkovskis & Warwick, 1986) and again, PH reported a lessening in her symptoms of anxiety.

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Insert *Figure Two* about here

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The following treatment was cognitive and behavioural as described by Warwick & Salkovskis (1989). PH was encouraged to keep a diary listing her feelings, thoughts, and the situations involved. Her entries on this confirmed information from the assessment interview that she was much worse at home when alone and that her somatic symptoms of anxiety were important in the maintenance of the problem. This was discussed in detail and resulted in the generation of a set of target problems. These focussed on the factors involved in the maintenance of her hypochondriasis:

1. Behavioural: this category included reassurance seeking from the doctor, checking bodily states (in particular her faeces), and the effects of rubbing and irritating the affected areas.
2. Cognitive: this category included the deliberate focusing of attention on bodily responses which was resulting in a misinterpretation of bodily sensations and signs.
3. Physiological: this comprised the somatic symptoms of anxiety in the form of increased muscle tension, hyperventilation (resulting in pins and needles), and light headedness.

It was agreed with PH that the focus of treatment would be on reducing the symptoms of anxiety in order to provide her with some immediate relief and thus an increased sense of control over the problem. It was hypothesised that a reduction in these symptoms would result in a reduction of the behavioural and physiological maintaining factors and that this in turn would help alleviate the symptoms of depression and low self esteem. The first step in active treatment therefore involved teaching PH applied relaxation and respiratory control (Ost, 1987, Clark, Salkovskis & Chalkley, 1985). In addition, targets were set for the behavioural factors, i.e. reducing her self checking behaviour and reassurance seeking.

After six sessions, PH had achieved her targets for the behavioural factors and had found the controlled breathing and relaxation training to be of benefit. At this stage, the cognitive part of treatment was introduced. This focused on the detection of

negative automatic thoughts and dysfunctional assumptions and was presented to PH in the manner described by Warwick & Salkovskis (1989).

By session eight PH had experienced a great deal of success with the cognitive techniques and was pleased with the progress she had made. This progress was reflected in her BDI, BAI, and HAD scores (see *Table Two*). She reported that thoughts about cancer were no longer the first thoughts which she had in the morning, but she was still preoccupied with the fear that she might get cancer. It transpired that she believed that the diagnosis of IBS brought with it an increased risk of development of organic pathology, in particular cancer.

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Insert *Table Two* about here

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At session nine PH produced a good example of her tendency to misinterpret bodily signs as an indication of cancer. She had experienced severe abdominal pains accompanied by diarrhoea and had been unable to resist checking for traces of blood when she emptied her bowels. There was a lot of red colouration and she interpreted this as a sign of bleeding and became very anxious believing that she had bowel cancer. She visited her doctor who was able to trace the cause of diarrhoea to excessive consumption of red fruit (for example, strawberries, raspberries, nectarines). PH described this event as an important turning point for her as it gave her a tangible example of how the model applied to her own situation.

The final stage of treatment was devoted to the fine tuning of the cognitive and behavioural techniques. By this stage, PH had become quite skilled at exploring and evaluating alternative explanations of her physical symptoms. She was still checking her bowel movements for traces of blood but kept this to a maximum of once a week. Since visiting her doctor between sessions eight and nine, she had not felt the need to engage in any additional reassurance seeking behaviour.

In the final treatment session (session twelve) relapse prevention was discussed with PH. There was a further reduction in her BDI, BAI, and HAD scores and these were maintained at a six week follow up session (see *Table Two*).

### *Outcome of treatment*

Treatment had been aimed at the maintaining factors in PH's hypochondriasis. In very general terms she stated that she felt considerably less anxious and had experienced a reduction in her somatic symptoms of anxiety. In addition to this she felt less depressed and stated that she was beginning to enjoy life again. This was supported by the scores on the questionnaires used as shown in *Table Two*.

Thus it is clear that PH had improved dramatically in terms of overall psychological well being, her scores reducing from high moderate severities to mild/normal levels. Improvements was also achieved with the behavioural maintaining factors. PH had reduced her checking behaviour from twice a day to once a week, she no longer manipulated the aching spot in her side, and had sought reassurance from her doctor only once during treatment. Improvement was apparent in the cognitive domain as well as she was no longer waking up with thoughts about cancer or scanning her body for changes. Physiological arousal had been reduced as a result of the treatment of the somatic symptoms of anxiety. This progress was also maintained at a six week follow -up session.

The treatment was considered a success by PH as she felt "less burdened by the weight of worry" that she had been carrying around with her. Her score on the Global Assessment of Functioning scale (GAF from the DSM-IV diagnosis: see *Appendix Five*) had improved from 68 to 80 and further improvement was expected by her. She was still concerned about developing cancer, mainly as a result of the IBS diagnosis, but was considerably less preoccupied with it. This was discussed with her by considering hypochondriasis on a continuum with normal health anxiety (Barsky, Wyshak & Klerman, 1986). This was helpful to her as it enabled her to set more realistic goals for herself: i.e. not aiming for a completely anxiety free existence.

### **Discussion**

This case history suggests that a cognitive-behavioural approach to the treatment of hypochondriasis can be useful. PH experienced improvement in all of the areas targeted and was able to maintain the improvement. In addition to the reduction in her health anxiety, she also experienced an improvement in her symptoms of depression. PH stated that she had found the treatment to be of benefit and that the use of diagrams had been particularly useful in helping her understand the development and maintenance of her problem.



A single case description of a specific treatment approach like this is useful in providing an example how treatment can be tailored to meet individual needs. Such case descriptions are particularly important in discussing hypochondriasis as large scale controlled studies have yet to be conducted. Large scale studies are required in the future so that the effectiveness of cognitive behaviour therapy can be evaluated against other treatments. This clinical research will be of benefit to clinical psychologists and physicians alike as effective treatment will result in a better prognosis for this complex and expensive disorder.

### **Acknowledgements**

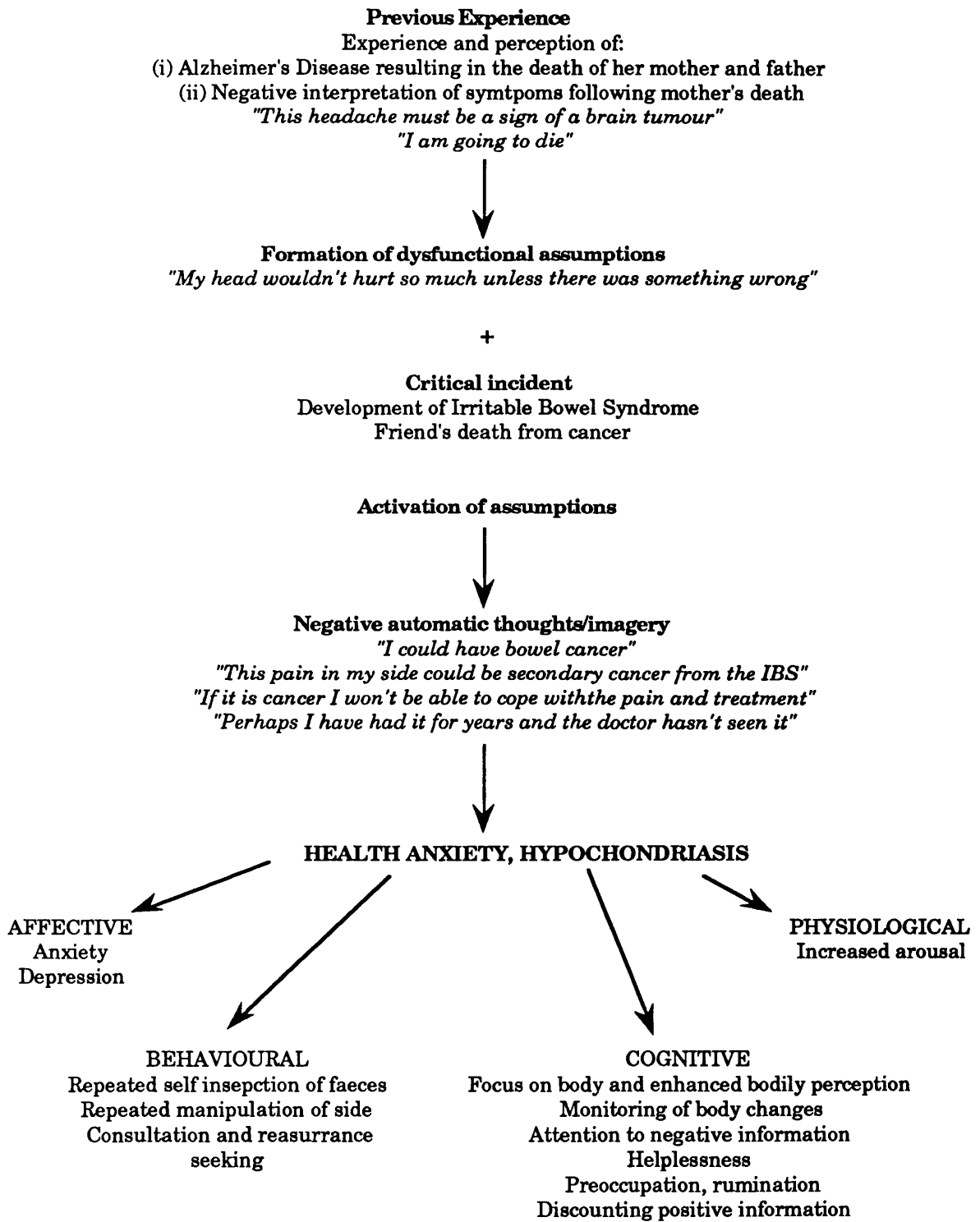
The author would like to thank Mary Keenan Ross for her supervision of this case study.

		Score	Classification
<b>BDI</b>		22	Moderate depression
<b>BAI</b>		26	Moderate anxiety
<b>HAD</b>	Anxiety	15	Definite caseness
	Depression	13	Definite caseness

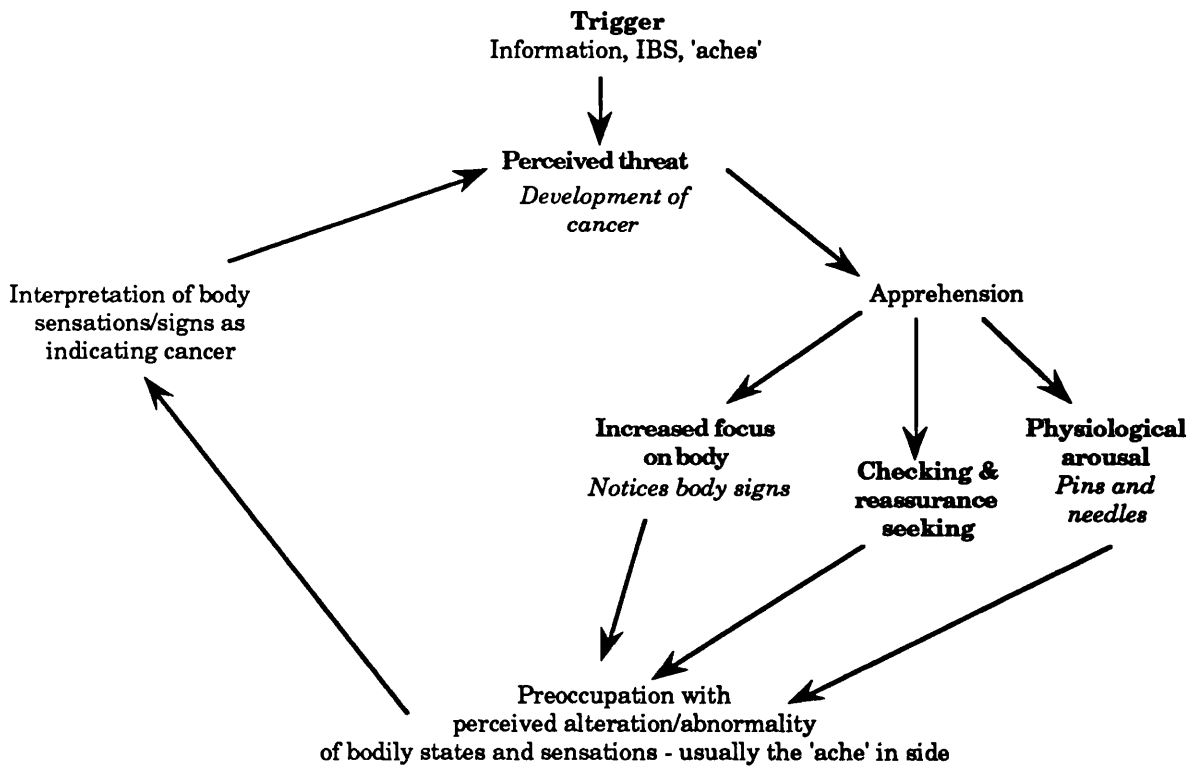
*Table 1: PH's scores at initial interview on the BDI, BAI, and HAD.*

		Session Eight		Session Eight		Six Week Follow-up	
		Score	Range	Score	Range	Score	Range
<b>BDI</b>		19	Mild	13	Borderline	13	Borderline
<b>BAI</b>		18	Mild	13	Mild	13	Mild
<b>HAD</b>	Anxiety	15	Caseness	9	Borderline	6	Borderline
	Depression	11	Caseness	5	Normal	5	Normal

*Table Two: PH's scores at sessions eight and twelve and at six week follow-up on the BDI, BAI, and HAD questionnaires. Scores demonstrate an improvement in all areas which is maintained after six weeks.*



*Figure One: Cognitive-behavioural analysis of the development of PH's hypochondriasis. Based on Warwick & Salkovskis (1989).*



*Figure Two: Cognitive-behavioural analysis of the maintenance of PH's hypochondriasis. Based on Salkovskis (1989).*

## References

- American Psychiatric Association (1994). *Diagnostic and Statistical Manual of Mental Disorders*. Fourth edition. Washington DC: American Psychiatric Association.
- Avia, M.D., Ruiz, M.A., Olivares, M.E., Crespo, M., Guisado, A.B., Sanchez, A., Varela, A. (1996). The meaning of psychological symptoms: effectiveness of a group intervention with hypochondriacal patients. *Behaviour Research and Therapy*, **34**(1), 23-31.
- Barsky, A.J. (1996). Hypochondriasis. Medical management and psychiatric treatment. *Psychosomatics*, **37**(1), 48-56.
- Barsky, A.J. & Klerman, G. (1983). Overview: hypochondriasis, bodily complaints and somatic styles. *American Journal of Psychiatry*, **140**, 273-281.
- Barsky, A.J., Wyshak, G. & Klerman, G. (1986). Hypochondriasis: an evaluation of DSM-III-R criteria in medical outpatients. *Archives of General Psychiatry*, **43**, 493-500.
- Beck, A.T. (1978). *Beck Depression Inventory*. The Psychological Corporation.
- Beck, A.T. (1978). *Beck Anxiety Inventory*. The Psychological Corporation.
- Bradley, L.A. & Prokop, C.K. (1982). Research methods in contemporary medical psychology. In P.C. Kendall & J.N. Butcher (Eds), *Handbook of Research Methods in Clinical Psychology*. New York: John Wiley and Sons.
- Clark, D. (1986). A cognitive approach to panic. *Behaviour Research and Therapy*, **24**(4), 461-470.
- Clark, D.M., Salkovskis, P.M. & Chalkley, A.J. (1985). Respiratory control as a treatment for panic attacks. *Journal of Behaviour Therapy and Experimental Psychiatry*, **16**, 23-30.
- Ford, C.V. (1995). Dimensions of somatization and hypochondriasis. *Neurology Clinics*, **13**(2), 241-253.

- Nemiah, J.C. (1985). Hypochondriasis. In H.I. Caplan & B.J. Saddock (Eds), *Comprehensive Textbook of Psychiatry*, pp. 1538-1543. Volume 4. Baltimore: Williams & Wilkins.
- Noyes, R., Kathol, R.G., Fisher, M.M., Phillips, B.M., Suelzer, M.T. & Holt, C.S. (1993). The validity of DSM-III-R hypochondriasis. *Archives of General Psychiatry*, 50(12), 961-970.
- Ost, L.G. (1987). Applied relaxation: description of a coping technique and review of controlled studies. *Behaviour Research and Therapy*, 25, 397-410.
- Salkovskis, P.M. (1989). Somatic problems. In K.Hawton, P.M. Salkovskis, J. Kirk, & D.M. Clark (Eds), *Cognitive Behaviour Therapy for Psychiatric Problems*, pp. 235-276. *A Practical Guide*. Oxford: Oxford University Press.
- Salkovskis, P.M. & Warwick, H.M.C. (1986). Morbid preoccupations, health anxiety and reassurance: a cognitive behavioural approach to hypochondriasis. *Behaviour Research and Therapy*, 24(5), 597-602.
- Wardle, J. & Steptoe, A. (1996). Editorial. *British Journal of Health Psychology*, 1, 1.
- Warwick, H.M.C. (1989). A cognitive-behavioural approach to hypochondriasis and health anxiety. *Journal of Psychosomatic Research*, 33(6), 705-711.
- Warwick, H.M.C. (1992). Provision of appropriate and effective reassurance. *International Review of Psychiatry*, 4(1), 76-80.
- Warwick, H.M.C. & Salkovskis, P.M. (1985). Reassurance. *British Medical Journal*, 290, 1028.
- Warwick, H.M.C. & Salkovskis, P.M. (1989). Hypochondriasis. In J. Scott, J.M.G. Williams & A.T. Beck (Eds), *Cognitive Therapy in Clinical Practice. An Illustrative Casebook*, pp. 78-102. London: Routledge.
- Warwick, H.M.C. & Salkovskis, P.M. (1990). Hypochondriasis. *Behaviour Research and Therapy*, 20(2), 105-117.

Zigmond, A.S. & Snaith, R.P. (1983). The hospital anxiety and depression scale. *Acta Psychiatrica Scandinavica*, **67**, 361-370.

# **Single Clinical Case Research Study**

## **An Illustration of the Use of Music as a Clinical Tool when Working with Client with Severe Learning Disabilities**

This paper has been written according to the guidelines of *Journal of Intellectual Disability Research*. Author's notes and other material relating to the paper may be found in *Appendix Six*.



## **Abstract**

The use of musical interaction in improving communication and social interaction with a client with severe learning disabilities is described. The design is a simple AB one with outcome measured in terms of frequency counts of basic communication skills, such as eye contact and turn-taking. The intervention is shown to be successful improving social interaction and communication within sessions. Difficulties encountered with the treatment are described.

## **Key terms**

Musical interaction, social interaction, communication, autism.

## **Introduction**

Musical interaction is a variation on traditional music therapy, pioneered at Sutherland House School in Nottingham. This is a school for children with autism and musical interaction was designed specifically to meet the needs of these children. The main aim is to facilitate the building of a relationship between clients and those working with them on a day to day basis. The rôle of the therapist is to support and facilitate the interaction, interpreting and reacting to every contribution with voice and musical instruments (Prevezer, 1991). Music is used because it has more flexibility than spoken language. Music can emphasise a verbal or gestural invitation, it can draw out a response, wait for the child, repeat a phrase, reflect a pensive or an exultant mood. It can also imitate a series of vocal or breathy sounds, mark a significant moment, and give the child a model of prosody and inflection of phrase (Bunt, 1994).

The rationale of this approach is based on what is known about normal child development and the importance of early communication (Christie, Newson, Newson & Prevezer, 1994):

- (i) Young babies have an in-built ability to use actions like eye contact, head and body movements, and smiling to facilitate communication with adults. These aspects of communication are known as pragmatics and are an important feature in developing social interaction between people and develop long before the use of actual words.
- (ii) The use of pragmatics enables babies to respond to adults and invites a response from the adult. For example, if a baby is given a toy which s/he likes this will be demonstrated by increased and prolonged eye contact and a movement of the body towards the adult. Alternatively, anger will be communicated by reduced eye contact and moving away with overall tensing of muscles.
- (iii) Another aspect of pragmatics is social timing. This is the use of nodding, vocalisations, interaction/pitch, and turn-taking to facilitate communication. Babies have an in-built sense of social timing and this facilitates their development of any form of language.

At Sutherland House three main strategies are used during musical interaction. The least structured of these involves joining in with, imitating, and later extending the child's spontaneous movements and sounds and treating them as if they were intentional attempts at communication, even when they are clearly not. Most children were found to respond by giving more eye contact, and eventually by using a wider range of sounds in a much more positive and intentional way, incorporating some of the therapists' extensions of their original sounds (Prevezer, 1991). The other two strategies are closely related to each other. The "running commentary" involves using words in a simple song to fit in with whatever the child is doing at the time, whether it is jumping, rocking, or looking out of the window. The third strategy provides a more structured framework using a song with short verses, which are flexible enough to accommodate anything the child might do or suggest.

Children and adults with autism appear to lack the basic building blocks of communication (i.e. social timing and pragmatics) and as a result have problems with social interactions (Newson, 1978). The case to be described is an adult client with severe learning disabilities who demonstrated 'autistic tendencies' in the area of communication and social interaction. The application of a modified form of musical interaction to enable the client to develop some of the basic building blocks to communication will be described. This is relevant to all disciplines working with clients with learning disabilities as its application is not restricted to one area of expertise.

## **Case report**

EG is a 45 year old woman resident in a private nursing home. At the time of referral she had been resident there for four months. Prior to that she had been in respite care for six months. This had been the result of a gradual deterioration in her behaviour to the point that her parents were no longer able to cope with her at home. Her brother was resident at the same home.

It transpired from discussion with the manager of the home, that EG's initial development was normal in all aspects until she was about three years old. At this time she started to deteriorate and this rapidly continued until she was at a level similar to her current functioning. Over the following years there had been no significant change until the deterioration in behaviour which resulted in her having to leave home.

At the initial assessment it was clear that EG had severe learning disabilities. Her behaviour exhibited clear autistic type features with impairment in social interaction and communication and some stereotypies. When introduced to EG, she made very fleeting eye contact only. At approximately two minute intervals she would rise very suddenly and start to leave the room. This was always prevented by her key worker. A one to one key worker had been assigned to EG as she had a tendency to wander off. The manager and EG's key worker stated that the main difficulty they were experiencing with EG was the lack of any social interaction. When she first arrived at the home she showed no recognition of her brother, nor he of her. Since being assigned a one to one worker she had started to show signs of recognition, in that she would hold out her hand when she first saw her key worker and non-verbally requested hugs. Staff had not seen her smile at anything and any eye contact had been extremely minimal and fleeting.

As a result of EG's problems with social interaction and communication, staff were finding it difficult to implement an effective programme of care and EG's quality of care was considered to be suffering as a result.

EG had basic daily living skills but did not do anything spontaneously. She was totally continent and completely mobile. She was physically able to dress herself but had never demonstrated this at the home. She would eat independently but very slowly. She occasionally went to the toilet on her own. When left to her own devices she would pace the corridors or sit with a book and turn the pages continually. The only discovered motivators for her were cups of tea and different aromas. One member of staff had also mentioned that EG **seemed** to like music. This was supported during a second meeting with EG. On arrival a normal greeting to EG elicited no response at all. Five minutes later, the greeting was repeated but sung instead of said. EG immediately turned and held eye contact for a couple of seconds. Following this response various things such as morning tea break were sung to her. She responded by orienting towards the sound each time. This pointed to the possible therapeutic use of music in initiating interaction with EG. An approach using musical interaction was considered doubly appropriate for EG as (a) it would provide immediate reinforcers for any attempts at interaction and communication through music and song, and (b) it was designed with autistic disorder in mind so it would suit EG's autistic tendencies.

## Treatment

The overall target for EG was to improve social interaction and communication. To achieve this EG needed to develop the basic building blocks of communication, such as eye contact and turn-taking. Definitive targets were not set but treatment was centred around improving EG's basic communication skills and focussed on eye contact, imitation, turn-taking, vocalisation, and basic attempts at communication, such as nodding and pointing.

A basic AB design was adopted: i.e. a period of baseline recording followed by the implementation of treatment. Baseline recordings were completed over two weeks, six half hour sessions in total. The purpose of the baseline was to assess EG's basic communication skills. Frequency counts for eye contact, imitation, turn-taking, vocalisation, and basic attempts at communication were made. This was done by the author and EG's key worker simultaneously. The frequency counts for each observer were correlated to obtain a measure of inter-rater reliability. All correlation coefficients were in the positive direction and significant at  $p \leq 0.01$  with 5 degrees of freedom (the minimum  $R=0.874$ ) suggesting good inter-rater reliability.

For the first three weeks following baseline recordings, treatment sessions were conducted twice weekly. After this, four sessions took place at fortnightly intervals. Instead of describing each session in turn, the general process of treatment will be described.

This first six sessions lasted approximately 45 minutes to an hour. At the beginning of each session 15 to 20 minutes was spent with the key worker planning the structure of the session. The next 15 minutes were spent working with EG with the key worker observing and recording data. The final part of the session was spent in discussion with the key worker. The time spent with the key worker was critical as it was anticipated that she would be able to take over the sessions at a later date and also start incorporating the techniques into EG's daily schedule.

The sessions with EG were organised so that they provided EG with a setting in which she could experience and later enjoy some degree of social interaction and develop the basic skills required. The techniques used were modified slightly from the musical interaction used at Sutherland House. The main reason for this was that none of the staff had any musical training so the focus was on demonstrating how to use song, which is available to all. Two main techniques were used:

(i) Imitation

This involved imitating or joining in with EG's spontaneous sounds and movements and treating them as if they were intentional attempts to communicate. Any response at all (even fleeting eye contact) was rewarded immediately with sung verbal praise. In later sessions this technique was expanded to turn-taking by leaving time for EG to respond after she had been imitated and then imitating if she produced another response.

(ii) Activity songs

EG was found to respond more readily to sung words than plain spoken words. The use of songs while engaging in activities was therefore hypothesised to be more appealing to her. Action songs were made up for any activities, no matter how basic. If EG was simply pacing around the room then a song was sung about it. The style and rhythm adopted would match EG's movements. This was extended to activities of daily living, for example, dressing songs.

EG was always given a choice of objects to use during the sessions. Initially the choice was between two and this was increased to three after four sessions. A variety of choices was provided from session to session. Household objects were used as interesting alternatives to musical instruments, for example, maracas made out of some rice and a plastic jar. Each new object was demonstrated physically and visually and EG was then given time to respond. Activity songs and imitation were used all the time to help her and reward any response.

Different styles of music were adopted for the activity songs, such as Scottish, rock and roll, and classical. Once EG developed imitation and turn-taking in the sessions different activities were introduced. For example, copying games involving rhythms, clapping, tapping; copying movements in time to tunes; sound recognition games; body naming songs and games.

To make eye contact easier, all activity (when possible) took place at EG's level and opposite to her. Sung verbal prompts such as "I can't see you" or "look at me" were used to encourage EG to make eye contact. Objects which she wanted were held up to the face to increase the chances of her making eye contact when searching.

The pace of working was slow so that EG had time to respond and to provide time for observation. When possible, sessions were terminated before EG got bored with the session so that she was not left with negative feelings about the sessions.

The first six sessions were video recorded for staff members to watch. The final four sessions were structured in the same way but with the key worker leading and the author observing. Following this, the key worker felt confident enough to incorporate the sessions into EG's daily routine. Two, 10 to 15 minute sessions were planned for each day. The sessions were before morning tea and afternoon coffee so that EG had immediate reinforcement additional to that provided during the session. This allowed for follow-up observations to be conducted after three months.

## Results

The frequency of imitation, eye contact, turn-taking, verbalisations, and general attempts at communication (eg, pointing, touching) was recorded in each session. The results of this is shown in *Figures One (a) to (e)*. From these figures it can be seen that EG improved on all measures taken. In addition, EG was still improving after three months of continued input by her key worker.

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Insert *Figures One (a) to (e)* about here

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These results suggest that EG was learning the basic skills required in social interaction and communication. This was supported by feedback from staff who felt that EG had become more involved in the sessions and seemed to be enjoying the interaction with others. Her key worker had found EG to be more relaxed throughout the day and everyday activities had become easier as EG was participating more. In contrast to the sessions, she remained very withdrawn around the home and did not initiate any interaction with other residents. However, she had begun to avoid her brother by leaving the room if he entered by turning her back on him.

## Discussion

EG presented as a client with severe learning disabilities and autistic tendencies. Her main problems were in the area of social interaction and communication. The approach adopted was musical interaction aimed at reinforcing the basic building blocks of communication and interaction. EG showed improvements in all areas measured.

The technique of using musical interaction was successful in improving social interaction with EG. Staff had continued to use the techniques and additional improvement was made over three months. However, this improvement was still limited to the structured sessions and EG remained very withdrawn outside the structured time. For EG to continue to improve the twice daily sessions would need to be continued, modified, and expanded. Staff had already been provided with a video which demonstrated the initial sessions with EG. At discharge a detailed handout was given to them as well. This described musical interaction in detail, went through the process of how to do it, and provided lots of different examples and alternative ideas. Staff were encouraged to continue with the programme (including the recording) and to expand it as EG improved. The expansion would involve different activities for sensory and social stimulation. For example, exploring different tastes, smells, and sounds. Detailed examples of how this could be achieved in a musical way were documented. In addition to this, EG was referred for one to one music therapy.

### Problems encountered with treatment

This type of therapy is usually confined to individual sessions between a music therapist and the client. Music therapy as a therapy for people with learning disabilities is now well established (eg. Nordoff & Robbins, 1985). It is considered effective in the treatment of autistic disorder as well (eg. Alvin & Warwick, 1991; Brown, 1994). However, it is only in recent years that professionals other than music therapists have adopted techniques like these (eg. Prevezer, 1991). Care staff are therefore relatively unfamiliar with such techniques and as a result can be very wary of them. When working with EG it was important that the approach adopted became as universal as possible throughout the nursing home for maximum effect. Thus a lot of time was spent demonstrating the basic techniques to staff and allowing them to explore new ideas with it. Not all staff were open to the new ideas but this was not pressed as the key staff members involved had been very cooperative and open to suggestions.

The whole process was time consuming but in this case it was considered to be time well spent as staff were able to interact and communicate better with EG and they felt that the quality of care that EG was receiving had improved as a result.

In summary: this case report has demonstrated the successful use of musical interaction in improving interaction with a client with severe learning disabilities.



Outcome was assessed using measures of basic communication, such as eye contact and turn-taking. EG improved in all areas after 10 treatment sessions and continued to show improvement after an additional three months. Generalisation of the skills learned had been minimal but strategies to improve this were discussed with staff. Use of this technique is not limited to psychologists or music therapists but can be applied by a wide variety of health professionals working in this area.

### **Acknowledgements**

The author would like to thank Dorothy Murray for her supervision of this case study. In addition, thanks go to all the staff involved at the nursing home for their support in using this technique.

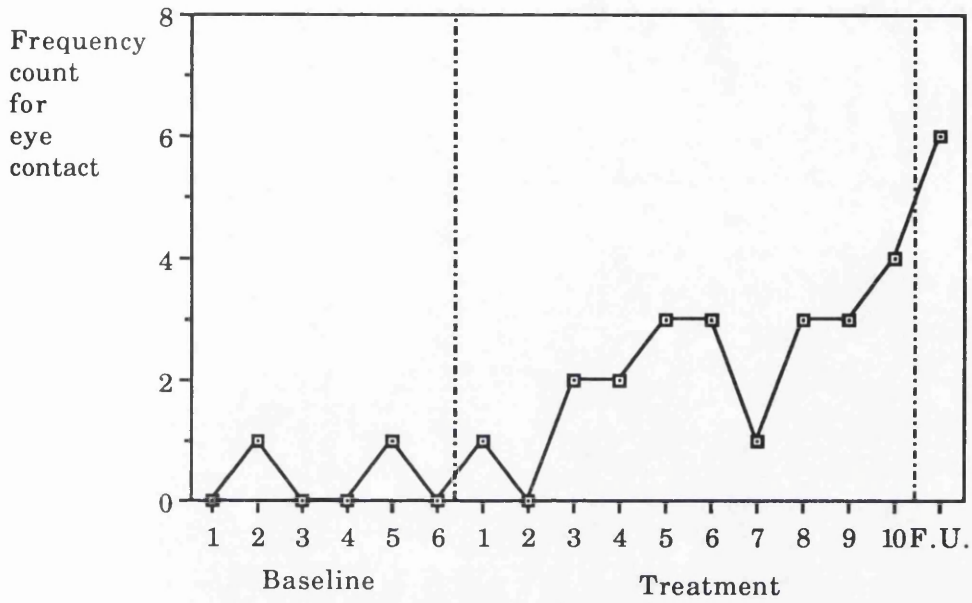


Figure One (a): Graph showing the frequency counts for eye contact made by EG during each session. F.U. = three month follow-up session.

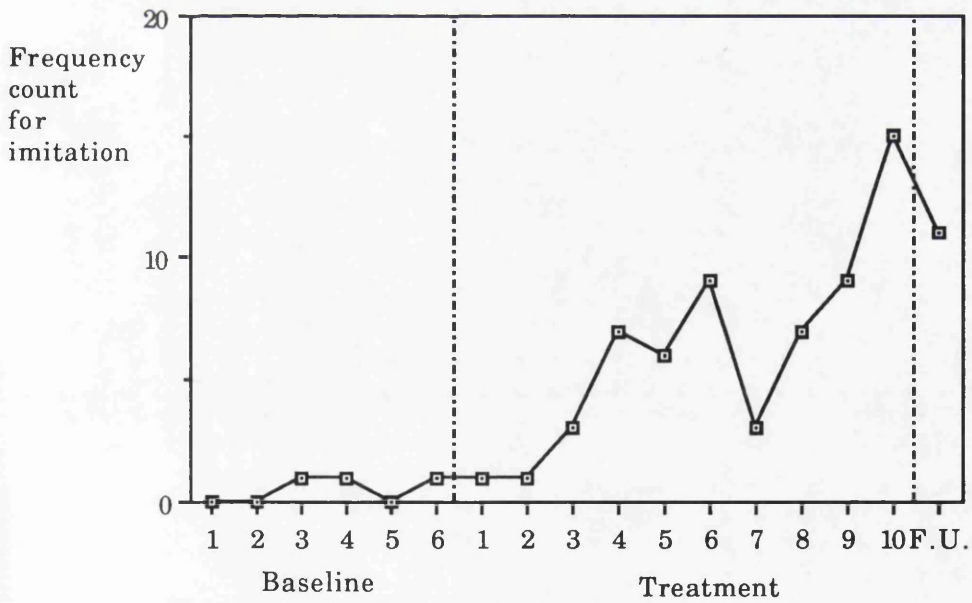


Figure One (b): Graph showing the frequency counts for imitation by EG during each session. F.U. = three month follow-up session.

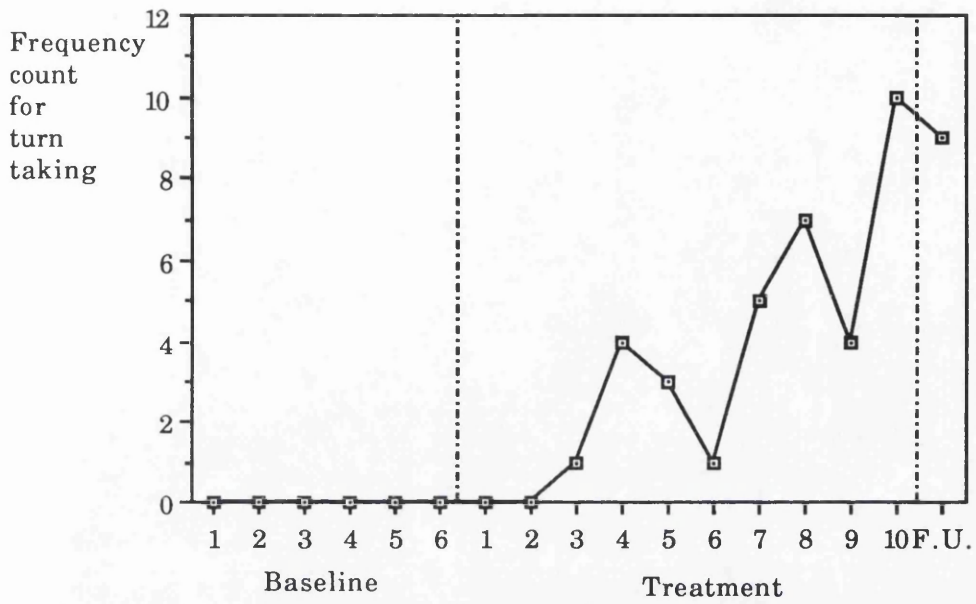


Figure One (c): Graph showing the frequency counts for turn-taking by EG during each session. F.U. = three month follow-up session.

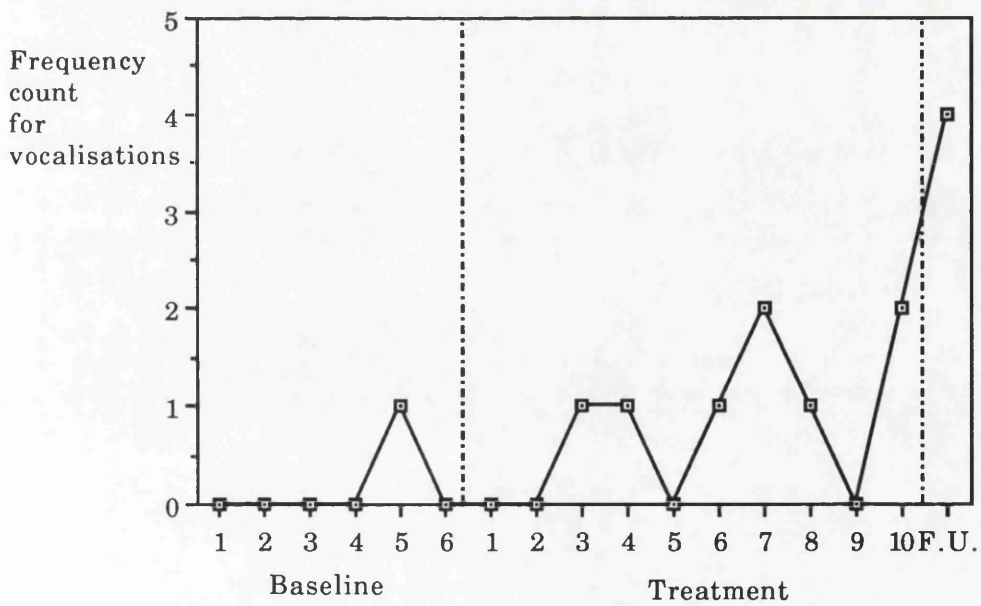
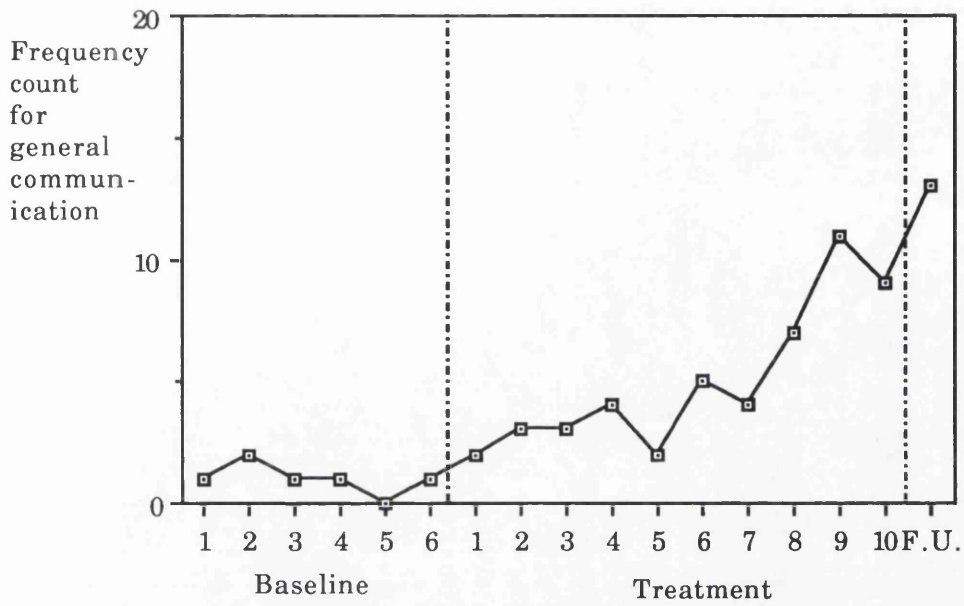


Figure One (d): Graph showing the frequency counts for vocalisations made by EG during each session. F.U. = three month follow-up session.



*Figure One (e): Graph showing the frequency counts for attempts at general communication made by EG during each session. F.U. = three month follow-up session.*

## References

- Alvin, J. & Warwick, A. (1991). *Music Therapy for the Autistic Child*. Open University Press.
- Brown, S.M.K. (1994). Autism and music therapy - is change possible, and why music? *British Journal of Music Therapy*, 8(1).
- Bunt, L. (1994). *Music Therapy: An Art Beyond Words*. London: Routledge.
- Christie, P; Newson, E.; Newson, J. & Prevezer, W. (1994). An interactive approach to language and communication for non-speaking children: practical guidelines from a developmental stand-point. *Handbook of Child and Adolescent Therapy in Britain*. Open University Press.
- Newson, E. (1978). *Making Sense of Autism*. Inge Wakehurst Papers: National Autistic Society.
- Nordoff, P. & Robbins, C. (1985). *Therapy in Music for Handicapped Children*. London: Gollancz.
- Prevezer, W. (1991). Strategies for tuning into autism. *Therapy Weekly*, October 18, pp4.

# **Single Clinical Case Research Study**

## **Memory Retraining Following Closed Head Injury: A Single Case Study**

**This paper has been written according to the guidelines of *Neuropsychological Rehabilitation*. Author's notes and other material relating to it may be found in *Appendix Seven*.**

## **ABSTRACT**

Memory problems are common after head injury and can be a major barrier to returning to work. Well controlled group studies focussing on the efficacy of memory rehabilitation programmes are sparse because of the problems involved in designing them within a clinical setting. Single case studies provide a suitable alternative. This paper describes the implementation of three different memory retraining programmes tailored to the rehabilitation needs of a young man following a closed head injury. The techniques were a reality orientation programme, use of a daily activity schedule, and PQRST. The results suggest that new techniques can be easily learned and understood but actual everyday use of the techniques is harder to achieve.

## INTRODUCTION

Memory problems are very common after head injury (for example, Oddy, Humphrey & Uttley, 1978; Oddy, Coughlan, Tyerman & Jenkins, 1985; van Zomeren & van den Burgh, 1985) and have been found to be a barrier to the resumption of employment (Brooks, McKinlay, Symington, Beattie & Campsie, 1987). McKinlay, Brooks, Bond, Martinage, and Marshall (1986) examined memory difficulties in a group of patients with severe head injuries and found that 73% were still experiencing problems three months post injury and at 12 months, 69% had continuing problems with memory. A five year follow up of this group found that 67% were still suffering from problems with their memory (Brooks, Campsie, Symington, Beattie, McKinlay, 1986). Thomsen (1987) reported on another long term follow-up of patients with severe injuries and found memory problems in 80% of the cases at two and a half years post injury and in 75% 10 to 15 years post injury.

The nature of the memory deficit experienced by patients following head injury has been reviewed in a number of papers (see for example, Schacter & Crovitz, 1977; Brooks, 1984). The pattern of deficits is generally considered to reflect impaired long-term memory. The impact of this on everyday life is absent-mindedness, a poor ability to recall recent events, and a poor prospective memory (Sunderland, Harris & Gleave, 1984).

Reports on memory rehabilitation have looked at methods of reinstating memory processes and also the teaching of memory compensation strategies. The results of the most recently published studies suggest that while patients with memory disorders can profit from instruction in the use of external memory aids, cognitive-behavioural interventions designed to "remediate" their memory deficits are ineffective (Cermak, 1976; Cermak & O'Connor, 1983; Crovitz, 1979; Ryan & Ruff, 1988; Wilson, 1987). Despite these negative findings, the number of treatment programmes and computer software systems designed for "memory retraining" continues to grow (Benedict, Brandt & Bergey, 1993).

Review papers of the memory rehabilitation literature have demonstrated a lack of valid, between-group studies that address the efficacy of memory retraining (Benedict, 1989; Franzen & Haut, 1991; O'Connor & Cermak, 1987). This lack of controlled research is unlikely to change in the near future as there are many obstacles to conducting group intervention studies in the clinical setting. For example, group studies require large pools of patients, with similar processing



deficits, who can be assigned randomly to treated and non-treated conditions (discussed by Gordon, 1987).

An alternative to group research is the single case study approach (Barlow & Hersen, 1984). Using this approach, clinicians can evaluate the significance of an intervention in individual patients, while tailoring the treatment to meet the individual patient's needs. As patients serve as their own controls, the researcher can determine whether a patient's performance changes following a specific intervention while avoiding the problem of withholding treatment. In addition, single case studies can be useful in providing hypotheses for further examination with group research (Canavan, 1994).

The work presented in this paper is a single case example of memory retraining conducted within a clinical neurological rehabilitation setting. The focus was on meeting the patient's everyday memory needs in order for him to achieve his rehabilitation goals and the methods adopted utilised different single case designs.

## **METHOD**

### **Patient**

KH is a 20 year old man studying science at university. At 18 years old he sustained a closed head injury when involved in a go-karting crash. He was in a coma for one month following the accident during which time he had a laparostomy and a tracheostomy and developed tension pneumothorax, acute pancreatitis, a chest infection, and a urinary tract infection. In addition, he required naso-gastric feeding. At this stage post-trauma he was noted to have cognitive impairments, severe dysarthria, and variable levels of concentration and awareness.

Seven months after the accident, KH was admitted to a specialist in-patient brain injury rehabilitation unit for assessment with a view to rehabilitation. At his initial assessment, he was unable to verbalise but was competent in the use of a QWERTY chart. His responses suggested that he had a retrograde amnesia of about one month. He was oriented to year and place, but not to time, month or day. It was not possible to accurately assess the length of post traumatic amnesia as he reported that his first memory since the accident was "now". He had no recall of what he had had for lunch and thought that he had been in the unit since his accident. When asked about specific

cognitive problems, he reported difficulty with his memory. When discussing this, he reported that he was more concerned with remembering what happened during and immediately after the accident, than his current everyday memory. His main aim from rehabilitation was to return back to university and pursue a career in biological research.

## **Neuropsychological Assessment**

The initial neuropsychological assessment included a large battery of commonly used, standardised tests. The following is a summary of this assessment.

A brief screen of language function indicated no gross problems of comprehension as he was able to follow a three part spoken command and a single part written command. He was able to write his name but had difficulty copying a simple geometric design.

From his educational background, it was estimated that KH was functioning in the "high average" range of intelligence prior to his accident. His performance on selected verbal subtests of the Wechsler Adult Intelligence Scale-revised (WAIS-R: Wechsler, 1981) indicated that current intellectual function was significantly impaired by comparison. Nevertheless, he achieved scores in the average range on tests of verbal reasoning and abstract conceptual thinking: his age scaled scores achieved IQ equivalents of 95 and 110 in the Comprehension and Similarities subtests respectively. Relative to this, he demonstrated poor attention and concentration and slowed thinking on the Arithmetic subtest. It was not possible to complete any of the performance subtests from the WAIS-R.

In terms of memory function, KH was assessed using selected subtests from the Wechsler Memory Scale-Revised (WMS-R: Wechsler, 1987). On the Logical Memory subtest he scored 5 on immediate recall and 0 on the delayed recall. These scores both fall at the first percentile. His ability to learn new associations in visual non-verbal material was likewise limited: he learned only two of six associations by the third trial of the Visual Paired Associates Task and was unable to learn any more over a further three trials.

As far as attention was concerned, KH's attention span for non-verbal information was in the average range as he scored 7 on the tapping forwards subtest from the WMS-R and 8 on the backwards version.

To summarise: KH's cognitive difficulties were characterised by severe impairment of memory as well as some impairment of attention/concentration and of general intellectual functioning.

Following his neuropsychological assessment, it was recommended that KH was trained in reality orientation and in the use of memory aids to help him with his everyday memory.

## **Memory Retraining**

The memory retraining work to be described formed just a small part of KH's overall rehabilitation. He was a full-time patient at the unit and received physiotherapy, occupational therapy, and speech therapy on a daily basis. Following his assessment he had been provided with a *Lightwriter* communication aid. This aid requires the patient to type in what he wishes to say and the machine then produces the words. This improved communication with KH as it was considerably faster than using a QWERTY chart.

The memory retraining procedure will be described by looking at each technique used in turn.

*Reality Orientation.* At KH's assessment, it was noted that he was orientated to year and place but not to time, month, or day. Implementation of a Reality Orientation (RO) programme for KH was therefore considered important. This took the form of an ABAB (reversal) design; i.e. baseline followed by formal RO training followed by removal of the training to see if the improvements made were maintained. The baseline phase took place in the first week following assessment. Each morning following breakfast, KH was asked a set of 10 orientation questions. The questions were as follows:

What day is it?

What time is it?

What date is it?

What month is it?

What year is it?

What season is it?

Where are you?

Where is that near?

Why are you here?

What are your aims?

If KH did not know the answer to a question he was encouraged to guess but not actually provided with the correct answer.

During the formal RO treatment stage, the questions were asked every hour from 9am to 5pm. When an answer was not known, KH was taught the correct response. This stage lasted for five weeks. After this, formal RO training was withdrawn and KH was asked the set of questions at the beginning of the day only as in the initial baseline stage. Treatment was then re-introduced after 9 days and continued for another 13 weeks. The final stage was a withdrawal of the formal training programme again.

*Daily Activity Scheduling (DAS).* A second problem highlighted at KH's assessment was his difficulty in recalling what events had taken place earlier in the day. Three weeks into his rehabilitation, he was therefore introduced to a Daily Activity Schedule (DAS). DAS is a simplified diary developed by psychologists working at the unit where KH was being rehabilitated. The most common use of DAS within the unit is to provide a written record of the days events. This record is then used to help recall of what has happened. The DAS sheets can take many forms and the one used for KH can be seen in *Appendix Seven*.

The design of this stage of treatment was a simple AB one. The three weeks following assessment before commencing DAS counted as the baseline stage. During these weeks, KH was asked during his psychology sessions what recall he had of the day's events. Results were recorded as a percentage of the different sessions recalled.

Following the baseline stage, KH was instructed to make short entries for everything which he did throughout the day - even if it entailed sitting doing nothing. At the start of treatment, he used a typewriter to make the entries as he still had difficulty writing. Once his handwriting improved, he decided to write his entries instead. KH was encouraged to record entries in his DAS after each activity, usually every hour. After a couple of days it became apparent that KH was unable to remember that he had to complete his DAS. Staff were asked to provide him with a verbal prompt after each session. After this, a digital watch with an alarm was acquired for him and the alarm set to go off every hour on the hour. He was then prompted to fill in his DAS each time the alarm went off. This prompt was gradually withdrawn as KH learnt to use the alarm as a reminder. Other patients were quick to remind him that he had to complete his DAS when his alarm went off.

KH's recall of events was assessed during his individual psychology sessions and was recorded as a percentage of the number of sessions and activities correctly recalled. In addition to this, a record was kept of the number of verbal prompts provided.

In addition to being used as a retrospective memory aid, DAS can be used as an aid to prospective memory (i.e. remembering what needs to be done in the future). This was attempted with KH but as he was initially reliant on a typewriter, he was unable to provide an immediate visual distinction between what he had done and what he had to do and he ended up confusing the two. DAS was therefore restricted to what he had done.

*PQRST*. PQRST is an acronym for "Preview, Read, Question, State, and Test". The notion comes from the field of study techniques and is taught as an aid to recalling written information (Robinson, 1970). The procedure is as follows:

1. Preview: preview the material to be remembered by skim reading it briefly.
2. Question: ask important questions about the text. For example, "What is the main point the author is trying to portray? Who is it about? Where does it take place?"
3. Read: Read the material thoroughly in order to answer the questions set.
4. State: state the answers. If the answers to the questions are not clear then read through the article again, until they are clear.
5. Test: test at frequent intervals for the retention of the information.

PQRST is a commonly taught memory strategy in brain injury rehabilitation. Few studies, however, have actually looked at the effectiveness of PQRST as such a strategy. Glasgow, Zeiss, Barrera, and Lewinsohn (1977) and Wilson (1987) have demonstrated it to be more effective than simple rehearsal of material (i.e. rote learning). This strategy was considered appropriate for KH as he had expressed a desire to return to his university studies.

PQRST was introduced six weeks into KH's rehabilitation. In the week prior to commencing PQRST, KH was given a short newspaper article to read each day. He was asked to read it very carefully and to remember as much as possible as he would be asked questions on it immediately afterwards and then after a 30 minute delay. His performance was scored in terms of the number of questions answered correctly. The results of this stage were considered to act as a pre-treatment baseline. Following this, KH was allocated one individual session per day to learn the PQRST method. After one week he was able to recall what the letters stood for and explain

each stage of the process. After this, he was given a short newspaper article to read and apply the PQRST method. Immediately after completing the process, his recall of the paragraph was tested using the questions which he had devised. To gain some consistency he was asked to devise six questions for each paragraph. This was repeated after a filled interval of 30 minutes. These sessions were planned every weekday for the first month and then twice a week for the next two months. In addition to these daily individual sessions, KH began attending the PQRST group once a week.

## RESULTS

The results to each part of KH's memory retraining will be described separately.

*R.O.* The results of KH's RO training programme can be seen in *Figure 1*. This graph demonstrates that KH's orientation improved with the implementation of the formal RO training. When this training was withdrawn after five weeks, his performance dropped suggesting that further training was required. Training was therefore continued for another 13 weeks until his performance reached ceiling level (i.e. 100%). Formal training was then withdrawn and KH's performance remained at ceiling level thus demonstrating maintenance of his orientation.

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Insert *Figure 1* about here

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*DAS.* Results of this part of KH's memory retraining are shown in *Figures 2(a)* and *2(b)*. *Figure 2(a)* shows the number of prompts required to complete his DAS and the number of entries made. As he was prompted after each session on the hour, this allowed for a maximum of 8 prompts throughout the working day. The figures reported are frequency counts of prompts and entries and have been averaged over each week of treatment. For the first three days when he received no prompts at all, KH did not make any entries in his DAS. When he was prompted after each session, the frequency of entries began to improve. After four weeks, the verbal prompts were faded and his watch alarm acted as the prompt. Following this, the number of entries made was variable with no obvious pattern.

*Figure 2(b)* shows the progress made by KH in recalling his DAS entries. The scores are the percentage of activities and sessions correctly recalled. During the first stage of this treatment, KH's progress was slow. There was a drop in his recall when he

started writing the entries rather than typing them. This was followed by an improvement in his recall which continued to rise as the treatment progressed.

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Insert *Figures 2(a)* and *(b)* about here

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It was important to see whether the use of a DAS actually improved KH's recall of events. This was achieved by correlating the results for the number of entries made with his recall of events. A significant positive correlation would suggest that completion of his DAS was aiding KH's recall. The result ( $r=0.142$ ,  $df=14$ ) was not statistically significant .

*PQRST*. Results of this part of KH's memory retraining are shown in *Figure 3*. Results for the individual *PQRST* sessions only are recorded as the structure of the *PQRST* group was too varied. For the treatment stage, the results shown are averaged over the week and recall is reported in terms of the percentage of questions correctly answered. From *Figure 3* it can be seen that KH made good progress in using *PQRST* as a memory strategy for the recall of newspaper articles. His immediate recall was better than his delayed recall, which never exceeded 41%. The dip in the graph at week seven was when KH was unwell with a cold and his performance was reported as poor in all sessions.

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Insert *Figure 3* about here

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## DISCUSSION

This single case study has demonstrated the use of three different memory retraining programmes. The results of each technique will be discussed in turn.

*Reality Orientation*. The results of KH's R.O. programme were good. From the design used, it was clear that his improvement was the result of the intensive training received and once his performance reached ceiling level, he was able to maintain his orientation without additional training.

*Daily Activity Schedule.* KH learnt this technique quickly and was able to describe, un-aided, its function two days after being introduced to it. In contrast to being able to remember what the technique was for, he required considerable prompting in implementing its use. An attempt was made to fade out the amount of verbal prompts provided and introduce an alarm system. This part of the treatment was not successful as KH would often ignore the alarm and fail to make an entry in his DAS. However, when asked what the alarm was for, he was always able to say that it was a reminder for him to complete his DAS. He was unable to say why he still did not do so.

KH's recall of activities did improve throughout the DAS programme but it is not clear whether this was a direct result of using the DAS. The correlation between DAS entries made and DAS recall was not significant suggesting that use of the DAS was not responsible for the improvements noted. This is an important question to answer and may be addressed by using an ABAB (reversal) design so that use of the DAS can be withdrawn and recall still monitored. In addition to this question, it would be interesting to research whether recall changes as a function of time. The expectation would be that recall for recent events would be better than recall for events which took place several hours earlier.

*PQRST.* As with the DAS, KH learnt this technique very quickly and was able to work independently once set up with a task. He did demonstrate an improvement in his recall of newspaper articles but his rate of forgetting was rapid and recall was poor after a 30 minute delay. In addition, throughout the PQRST treatment stage, it was apparent that KH required prompting to implement the technique, as he did with the DAS.

Taken together, these results are interesting in that they demonstrated that compensatory memory strategies can be learned following head injury. In contrast to learning the new techniques, it has been demonstrated that everyday implementation of them is much harder to achieve. This is consistent with the literature mentioned in the introduction: external memory aids can be of use but attempts at actual memory remediation are ineffective. In this instance, KH was able to learn how to use external memory aids but his memory remained impaired to the point that he was unable to remember to use them. This points to the need for more intensive retraining programmes with additional external cues to make the use of memory aids more habitual.



## **ACKNOWLEDGEMENTS**

The author would like to thank Florrie Gullion and William McKinlay for their supervision of this case study.

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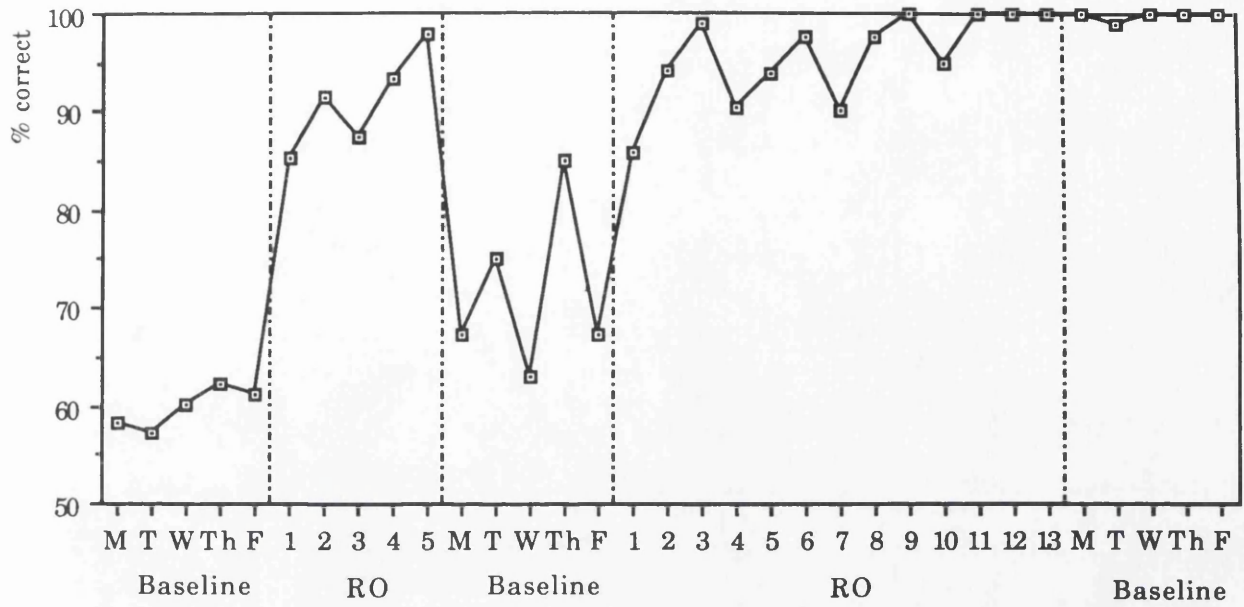
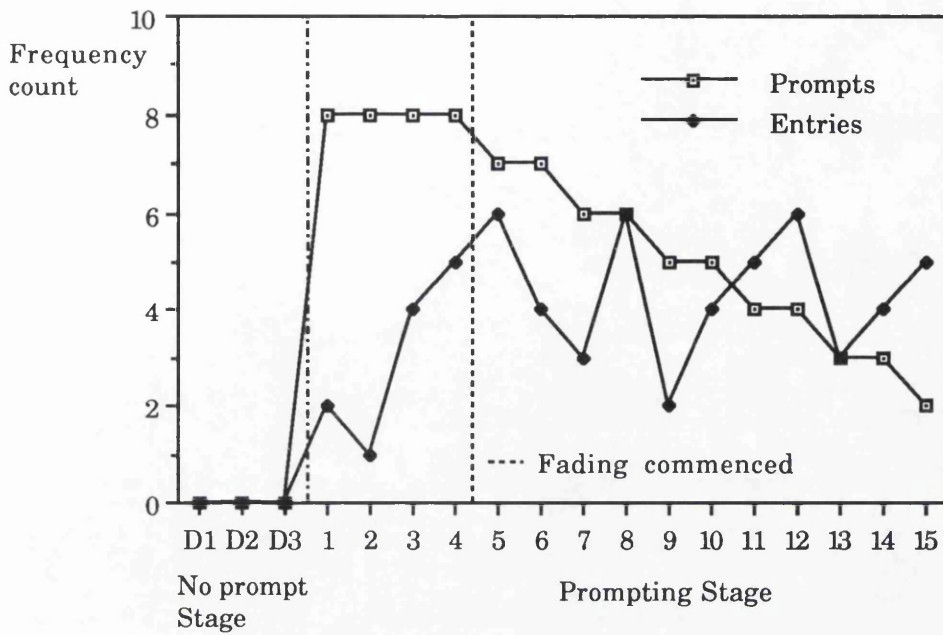
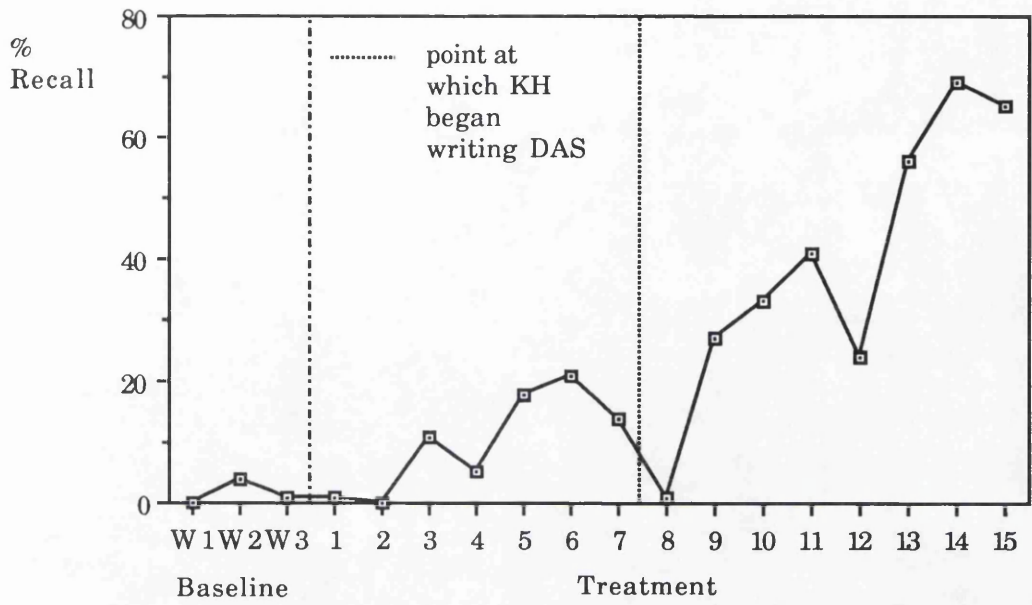


Figure 1: Graph showing KH's progress through his Reality Orientation (RO) programme. The results are in terms of the percentage of questions answered correctly. For the baseline stages this is given for each day. For the RO treatment stages, the percentages have been averaged over the week.



*Figure 2(a): Graph showing the number of verbal prompts provided and the number of entries made by KH in his DAS. D1 to D3 refer to the first three days when no prompts were provided. The remaining scores have been averaged over each week.*



*Figure 2(b): Graph showing KH's recall of DAS entries during the three week baseline and 15 week treatment stage. For both stages, scores have been averaged across each week.*

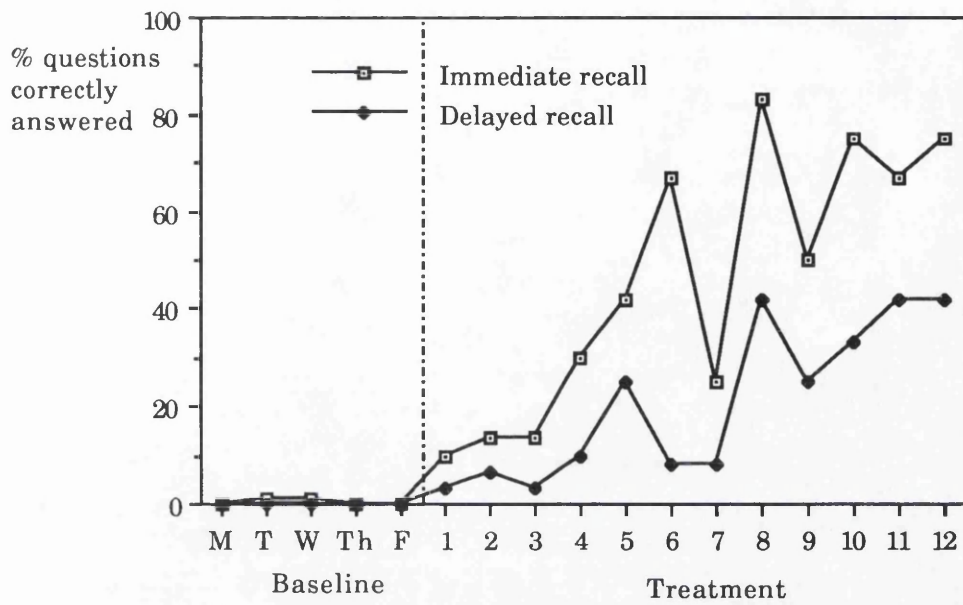


Figure 3: Graph showing the percentage of questions answered correctly by KH on immediate and delayed recall of PQRST passages.

## REFERENCES

Barlow, D.H. & Hersen, M. (1984). *Single Case Experimental Designs: Strategies for Studying Behaviour Change*. New York: Pergamon Press.

Benedict, R.H.B., Brandt, J. & Bergey, G. (1993). An attempt at memory retraining in severe amnesia: an experimental single-case study. *Neuropsychological Rehabilitation*, 3(1), 37-51.

Benedict, R.H.B. (1989). The effectiveness of cognitive remediation strategies for victims of traumatic head-injury: a review of the literature. *Clinical Psychology Review*, 9, 605-626.

Brooks, D.N. (1984). Cognitive deficits after head injury. In D.N. Brooks (Ed.), *Closed Head Injury*. Oxford: Oxford University Press.

Brooks, N., Campsie, L., Symington, C., Beattie, A., McKinlay, W. (1986). The five year outcome of severe blunt head injury: a relative's view. *Journal of Neurology, Neurosurgery, and Psychiatry*, 49, 764-770.

Brooks, N., McKinlay, W., Symington, C., Beattie, A., Campsie, L. (1987). Return to work within the first seven years of severe head injury. *Brain Injury*, 1, 5-19.

Canavan, A.G.M. (1994). Single-case methodology in clinical neuropsychology. In S.J.E. Lindsay & G.E. Powell (Eds.), *The Handbook of Clinical Adult Psychology*. London: Routledge.

Cermak, L.S. (1976). The encoding capacity of a patient with amnesia due to encephalitis. *Neuropsychologia*, 14, 311-326.

Cermak, L.S. & O'Connor, M. (1983). The anterograde and retrograde retrieval ability of a patient with amnesia due to encephalitis. *Neuropsychologia*, 21, 213-234.

Crovitz, H.F. (1979). Memory retraining in brain-damaged patients: the airplane list. *Cortex*, 15, 131-134.

Franzen, M.D. & Haut, M.W. (1991). The psychological treatment of memory impairment: a review of empirical studies. *Neuropsychology Review*, 2, 29-63.

Glasgow, R.E., Zeiss, R.A., Barrera, M. & Lewinsohn, P. (1977). Case studies on remediating memory deficits in brain damaged individuals. *Journal of Clinical Psychology, 33*, 1049-1054.

Gordon, W.A. (1987). Methodological considerations in cognitive remediation. In M.J. Meier, A.L. Benton & L. Diller (Eds.), *Neuropsychological Rehabilitation*. New York: Guilford Press.

McKinlay, W.W., Brooks, D.N., Bond, M.R., Martinage, D.P., Marshall, M.M. (1981). The short term outcome of severe head injury as reported by relatives of the injured persons. *Journal of Neurology, Neurosurgery, and Psychiatry, 44*, 527-533.

O'Connor, M. & Cermak, L.S. (1987). Rehabilitation of organic memory disorders. In M.J. Meier, A.L. Benton & L. Diller (Eds.), *Neuropsychological Rehabilitation*. New York: Guilford Press.

Oddy, M., Humphrey, M. & Uttley, D. (1978). Subjective impairment and social recovery after closed head injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 41*, 611-626.

Oddy, M., Coughlan, T., Tyerman, A. & Jenkins, D. (1985). Social adjustment after closed head injury: a further follow-up seven years after injury. *Journal of Neurology, Neurosurgery, and Psychiatry, 48*, 564-568.

Robinson, F.P. (1970). *Effective Study*. New York: Harper.

Ryan, T.V. & Ruff, R.M. (1988). The efficacy of memory retraining in a group comparison of head trauma patients. *Archives of Clinical Neuropsychology, 3*, 165-179.

Schacter, D.L. & Crovitz, H.F. (1977). Memory function after closed head injury: a review of the quantitative research. *Cortex, 13*, 150-176.

Sunderland, A., Harris, J.E. & Gleave, J. (1984). Memory failures in everyday life following severe head injury. *Journal of Clinical Neuropsychology, 6*, 127-142.

Thomsen, I.V. (1987). Late psychosocial outcome in severe blunt head trauma: a review. *Brain Injury, 1*, 131-143.

Van Zomeren, A.H. & van den Burg, W. (1985). Residual complaints of patients two years after severe head injury. *Journal of Neurology, Neurosurgery, and Psychiatry*, 48, 21-8.

Wechsler, D. (1981). *Wechsler Adult Intelligence Scale-revised. Manual*. New York: Psychological Corporation.

Wechsler, D. (1987). *Wechsler Memory Scale-Revised. Manual*. San Antonio, TX: The Psychological Corporation.

Wilson, B.A. (1987). *Rehabilitation of Memory*. London: The Guilford Press.