# Psychosocial Problems After Stroke

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# Declaration

I, Suzanne O'Rourke, hereby certify that this thesis:

(a) has been composed by myself

and

(b) that the work contained herein is my own, excepting in those areas where the help of others is acknowledged.

Signed

Date

# Acknowledgements

I would like to begin by thanking the Scottish Home and Health Department, Chest Heart and Stroke Scotland and the Stroke Association for providing the funding to support this trial. The individuals I must thank are many. They include: Trish Staniforth who courageously allowed herself to be assessed and the many patients and carers who did likewise without whom the trial could not have taken place. The Lothian Stroke Register Team including Marion Livingston and Michael McDowell whose help with randomisation and the trials creation allowed the trial to run smoothly. The department's computing advisors David Perry and Alan Bowie, and statisticians David Signourini and especially Jim Slattery, the expertise of all of whom was indispensable. Siobhan MacHale for her collaboration. Fiona Waddell for her ability to listen and advise. Robert Taylor for his psychological expertise, supervision and guidance. Caspian Woods for his constant emotional support and reassurance. Finally, my supervisor Martin Dennis who has given up much of his time to guide me with great patience, has taught me much and without whom this thesis would not have been written.

I dedicate this thesis to my parents, Sheena and Colm O'Rourke.

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# Abstract

Each year in the UK 80,000 people survive their first stroke. Many of these people will suffer psychosocial difficulties including depression, anxiety and social maladjustment. Such problems are often not identified or treated effectively. It would therefore be useful to establish their nature and frequency, to identify those patients at particular risk and to develop therapeutic interventions.

We attempted to address these issues in the context of a randomised controlled trial of a Stroke Family Care Worker (SFCW), an intervention we hoped would reduce psychosocial difficulties.

We assessed a consecutive series of stroke patients who were referred to a teaching hospital within one month of stroke. Having collected detailed baseline data, patients were then randomised either to receive care from, or avoid contact with, the SFCW. Six months after onset we assessed, blind to treatment allocation, patients' psychosocial and physical outcomes using standardised measures. These included, the Oxford Handicap Scale, the Barthel Index, the Frenchay Activities Index, the General Health Questionnaire-30 item, the Social Adjustment Scale, the Recovery Locus of Control Scale, the Medical Coping Modes Questionnaire, the Mental Adjustment to Stroke Scale, the Hospital Anxiety and Depression Scale, the Patient Satisfaction Scale, and a service and equipment use questionnaire.

In this thesis I describe the psychosocial outcome of 417 patients six months after stroke, and address some of the issues involved in measuring these aspects of outcome. I go on to examine independent factors which may be related to poor outcomes to increase our understanding of their aetiology and to identify those at greatest risk. Finally I compare the outcomes of patients treated by our SFCW and those who were not to establish the effectiveness of this intervention in alleviating psychosocial problems.

# 1. Introduction

Each year in the UK about 100,000 people will suffer their first ever-in-a-lifetime stroke (Bamford et al., 1988) reflecting an incidence of 200 to 290 people per 100,000 (Bamford et al., 1988; The Department of Health, 1994) and a prevalence of 2% (The Department of Health, 1994). Of patients affected, 20% will die within one month and a further 10% within one year (Dennis and Warlow, 1987) accounting for 12% of deaths in the UK, 76,000 people in 1990 (The Department of Health, 1994). Therefore about 80,000 patients survive their first stroke each year in the UK. Since 1972 the mortality from stroke in Scotland has been consistently higher than in any other country in the UK or in any single regional health authority.

Stroke is not solely a disease of the elderly although its incidence does increase with age. Of the 100,000 people in the UK suffering their first stroke each year, 25,000 will be under 65 years and 54,000 under 75 years (Bamford et al., 1988).

Stroke is the second commonest cause of severe disability amongst adults living in private households (Martin et al., 1988) and represents the primary cause of impairment for 4.2% of impaired adults living in private households (Harris et al., 1971). More than 52% of those patients disabled by stroke and living in private households in Great Britain experience either 'very severe' or 'severe handicap' and a further 10% 'appreciable' handicap (Harris et al., 1971).

Estimates suggest that stroke accounts for 4.3% of all Scottish NHS resources, and 5.5% of hospital resources (Isard and Forbes., 1992) and there has been a substantial rise in the number of prescriptions dispensed for the treatment and prevention of stroke (The Department of Health, 1994).

In the last two decades mortality rates from stroke have fallen both in the UK and many other Western nations (The Department of Health, 1994). Whether this reflects a reduction in incidence, perhaps through improved treatment of risk factors, a decline in case fatality or some systematic change in the certification of deaths is debatable (Modan and Wagener, 1992;

Dennis and Warlow, 1987). It would be important for the future planning of services to know whether this reduction in mortality was at the cost of a rise in severe disability. Thirty year projections from 1983 to 2023 suggest that the number of first strokes will increase by 30%, and the associated six month mortality rate by 40%, whilst the number of patients severely handicapped six months after first stroke may increase by only 8% (Malmgren et al., 1989). So although we expect a rise in the number of patients disabled by first strokes, the increased burden may be primarily in the acute management of stroke.

We have known for some time that patients who survive strokes suffer from a variety of poor psychosocial outcomes which may include depression, anxiety, reduced participation in social activities and social maladjustment. The impact that stroke has on social activity and adjustment is a relatively neglected area of research. We have a very limited understanding of the determinants or nature of these aspects of psychosocial outcome. Most research has focused on mood disorders although even in this domain our understanding is incomplete. For example, it is not clear whether stroke patients suffer greater frequency or intensity of mood disorders than groups matched for age and disability which would suggest that mood disorder after stroke was qualitatively different from that in other circumstances. Folstein (1977) found that 45% of stroke patients suffered from depression compared to only 10% of orthopaedic controls and Leegaard (1983) found stroke patients experienced more depression than patients after myocardial infarction. However, Robins (1976) found no significant difference in the frequency of depression experienced by institutionalised stroke patients and institutionalised controls with chronic disability. As all three studies were on small numbers of patients, 30, 84 and 36 (Folstein et al., 1977; Leegaard, 1983; Robins, 1976) previous reviews have concluded that the case is so far unproven (House, 1987*b*; Primeau, 1988).

Psychosocial difficulties may not only be responsible for increased unhappiness amongst patients after stroke, but may also impede recovery or even contribute to deterioration in other aspects of their functioning. Areas of psychosocial functioning are intimately related, with difficulties in one area contributing to those in another. Social maladjustment may lead to symptoms of anxiety and depression. Depression after stroke has been associated with increased mortality (Morris et al., 1993*a*, 1993*b*) and physical impairment (Morris et al., 1992; Parikh et al., 1987, 1990; Sinyor et al., 1986*a*) with the adverse effects sustained after depression has improved (Parikh et al., 1990). In addition, post stroke depression is associated with increased cognitive impairment (Morris et al., 1992; Robinson et al., 1986), perhaps even producing a dementia type picture in its own right (Robinson et al., 1986). Socially, depression may contribute to a failure to resume pre-morbid social activities and a deterioration in social functioning after stroke (Feibel and Springer, 1982; Robinson et al., 1985*a*).

## 1.1 Thesis structure.

This study is an attempt to further elucidate the difficulties of a psychological or social nature experienced by many patients after stroke: their psychosocial outcome. I will first describe the nature and frequency of poor psychosocial outcome after stroke in a cohort of hospital referred stroke patients six months after their strokes to indicate the size of this problem. I will then examine the aetiology of mood disorders, social functioning and patients' satisfaction, before using this information to develop models to predict those patients most at risk of psychosocial difficulties. Finally I will report the results of a randomised trial of a Stroke Family Care Worker (SFCW), a possible therapeutic intervention for psychosocial problems.

Having described why psychosocial outcome after stroke is important I will next describe the present study. In chapter two, I describe my methods, beginning first with case ascertainment and initial assessment, and the reasoning behind my choice of each outcome measure. I will discuss each measure in terms of its previous use, evidence for its reliability and validity and alternatives that might have been used. For some measures I will present additional data from our study relating to their reliability and validity.

In chapter three I will go on to describe our hospital referred cohort's baseline characteristics and the results of their follow up assessment at six months. Chapter four will describe the complex inter-relationship between measures of psychosocial and physical outcomes to provide clues to the possible aetiology of poor psychosocial outcome after stroke before examining its physiological correlates (i.e. the relationship between the site and size of the lesion and mood). Using this information I will then try to develop models which might aid the identification of patients at greatest risk of poor psychosocial outcomes to provide the means to target patients for intervention. The results of a randomised controlled trial of one possible therapeutic intervention, a Stroke Family Support Worker, will then be presented and discussed in chapter five.

Prior to the discussion at the end of each chapter I will present the results of a literature review of previous studies in the relevant area. Therefore the literature reviews are located as follows:

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| Section 3.10 | Studies of social functioning after stroke | page 3-108. |
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| Section 4.2.2. | Previous studies of the physiological correlates of mood disorder after stroke. | page 4-166. |
| Section 4.3.3. | Previous studies of variables that predict psychosocial outcome. | page 4-198. |
| Section 5.6 | Previous studies of social work interventions after stroke. | page 5-255. |

I conducted systematic reviews using a variety of search strategies on both the Medline and Psychlit databases and consulted the bibliographies of relevant articles. Searches were confined to papers published in the English language and journals were not systematically searched by hand. Therefore while the following literature review does not represent an exhaustive review of international findings I am confident that I have identified the majority of English language papers published in prominent journals. To avoid biasing my review further I have included all the relevant published papers which I have identified in tables at the end of each section.

I hope that the present study will elucidate the problem of poor psychosocial outcome after stroke, leading not only to a greater understanding of its frequency and aetiology, but also to a better identification of those at risk and their more effective treatment.

# 2. METHODS

## 2.1 The trial.

This study was conducted in the context of a randomised controlled trial of a Stroke Family Care Worker which was funded by the Scottish Home and Health Department. Therefore, whilst it was always intended to use the data collected to examine other aspects of psychosocial outcome after stroke, the methodology of the study was primarily aimed toward the needs of the trial.

As part of the trial patients' primary carers were asked to complete self assessment questionnaires. The methods used and results of the analyses of these data are not reported in this thesis which focuses on the patients themselves.

## 2.2 The Western General Hospital and referral patterns.

This study was based in the Western General Hospital which is a large teaching hospital. While it has no clearly defined catchment area, it serves a predominantly urban population in the North of the city of Edinburgh. The majority of patients are referred by their General Practitioners. As the hospital does not currently have an accident and emergency department it receives no self referred cases. The Western General Hospital also comprises a number of specialist units each of which serve a larger area, for example, the Department of Clinical Neurosciences' Neurovascular Clinic receives referrals from all of South East Scotland, thus serving a population of 1.2 million. As a result, the three Neurovascular clinics each week see up to 15 new patients suffering from stroke, TIA or illnesses mimicking these. In addition, the hospital has a specialised Stroke Unit and a Department of General Medicine, the latter having an affiliated Care of the Elderly Department to which they may refer.

Patients referred to the Western General Hospital who are suspected of having suffered a stroke are assessed by a stroke physician or neurologist shortly after admission or during their first visit to our Neurovascular clinic. The majority of admitted patients are then cared for by a multi-disciplinary stroke team, often within the specialist stroke rehabilitation unit. The stroke team includes nurses, physical, occupational and speech therapists and a hospital based social worker in addition to a stroke physician and a Stroke Family Care Worker (SFCW).

## 2.3 The Lothian Stroke Register.

Since 1990, the Neurosciences Trials Unit at the Western General Hospital has maintained the Lothian Stroke Register; a record of all strokes assessed within the hospital. Each patient suspected of having had a stroke is assessed by a stroke physician or neurologist, either during the patient's visit to the Neurovascular clinic, (outpatients), or on the first working day after admission, (inpatients). The assessing physician completes a standardised assessment form (Appendix A) which provides the basis for a discussion of each patient at a weekly interdisciplinary meeting where evidence, including computerised tomography (CT) scans, is reviewed and a consensus on whether the presenting event was a stroke (using the World Health Organisation definition) is reached. The assessment form is a detailed record of all personal and admission details, patient history, treatment, general and neurological examination and investigations. All confirmed strokes are entered into the register.

The Lothian Stroke Register now includes more than 1,000 strokes along with the results of either telephone or written follow ups at six months and one, two and three years. Each follow up includes the Barthel Index (BI), the Oxford Handicap Scale (OHS), details of any recurrent strokes, myocardial infarctions, fits or bone fractures since the last assessment, whether the patient remains in the same residence, their new living arrangement if relevant, and whether they are employed, driving or smoking.

## 2.4 Randomisation, eligibility criteria and consent.

For a two year period, from October 1992 until October 1994, all patients entered into the Lothian Stroke Register were considered for randomisation into the trial. The process of randomisation is described in detail in section 5.1. Broad eligibility criteria were adopted both to ensure a representative sample of patients with stroke and because we were uncertain which patients and carers would most benefit from the intervention of the SFCW. All patients with a confirmed stroke within the last 30 days were randomised unless:

a. The patient was unlikely to survive beyond the next week.
b. The patient lived more than 25 miles from the randomising hospital so that regular visits from our SFCW would have been impractical.
c. The patient had another, major illness which was likely to dominate the pattern of their future care.

Patient consent was not a criteria for randomisation as formal consent was not required. However patients were able to refuse contact with our SFCW at any time and their permission was obtained for follow up prior to my assessment visit. This randomisation and consent procedure received ethical approval from the local ethics committee. We adopted this approach since the intervention was considered unlikely to harm and patients could choose not to participate at any time. While we acknowledge that our failure to ask patients for their consent is most unusual, it did serve an important function in that it kept the patient blind to treatment allocation. Had patients been aware of their randomisation into a trial, they would in due course also have been aware of the treatment group to which they had been allocated. The negative effects of such knowledge would have been twofold. Had patients been provided with information about the SFCW service and then randomised to the control group, the possibility existed that they could consequently have suffered psychological ill effects, thus perhaps biasing the control group and risking a false positive result. Secondly, treatment group patients' knowledge that their answers contributed to the assessment of a person with whom they had regular contact and to whom they may have felt some loyalty could have influenced their responses, especially those concerning satisfaction with treatment. Again such a bias might have resulted in a false positive result.

## 2.5 The intervention.

For those randomised the intervention began immediately. The role of the SFCW (Trish Staniforth) was to adapt to meet the needs of each individual patient and their family. The number and length of contacts were not specified in order to reflect the likely actual operation of someone in such a post. Patients who were randomised not to receive her care had no contact with the SFCW but received all care that was available prior to the creation of her post. The intervention is described in greater detail in section 5.3.

## 2.6 Patient follow-up at six months.

Six months after randomisation a member of the Lothian Stroke Register (LSR) team, Marion Livingston (ML) contacted General Practitioners (GP) to confirm the patient's address, telephone number and ascertain whether they were still alive. I then contacted all patients by letter before telephoning to arrange an appointment. I visited all patients in their place of residence to administer the primary patient questionnaire. Patients who had successfully completed this questionnaire were given a secondary questionnaire to complete independently and a stamped addressed envelope (SAE) for ease of return. Patients who were unable to complete the primary questionnaire with my help were judged unlikely to be able to complete the secondary questionnaire alone. We included all questions relating to satisfaction with services and service use in the second, independently completed, questionnaire so that I was not unblinded to the patients' treatment allocation by any discussion of such matters. This also allowed us to ask further questions which might have made the initial interview too long.

### *2.6.1 Summary of assessment visit.*

I tried to standardise my follow up visits as much as possible. They usually followed the pattern summarised below:

⇒ Introductions. I told patients that I worked at the hospital, but was independent of the stroke team that had cared for them, and that the purpose of my visit was simply to see how they were getting on after their strokes. No mention was made of the trial or the SFCW.

⇒ The patient and I completed the Primary Patient Questionnaire together (refer to Appendix B).

⇒ I recorded my opinion of whether the patient was in the treatment or control group (refer to 5.1).

⇒ I asked the patient to complete a further questionnaire, (the secondary patient questionnaire- refer to Appendix C), after my visit and to return it in the SAE provided. Patients were told that the secondary questionnaire enquired about their satisfaction with their treatment *prior to my visit* and that I could not be present in case my presence influenced them.

⇒ Any issues raised during the assessment were discussed and if I thought a referral to the SFCW might be beneficial I discussed this with the patient and, if they agreed, completed a referral form on return to the hospital (refer to 5.3). These referrals did not interfere with the process of randomisation as the assessment follow up had already been completed.

⇒ For 145 consecutive, cognitively intact patients (those who had successfully completed the first patient questionnaire with myself), including the pilot, patients were asked if they would consent to a further visit from Dr. Siobhan MacHale (SM) who would discuss their mood in more depth (refer to 2.6.2).

Those patients who failed to return their secondary questionnaires within one month of my visit were sent a reminder letter thanking them for their help during my visit and requesting the completed forms. If this was not successful a further letter with replacement forms and SAE was sent, followed by a letter from our consultant Dr. Martin Dennis (MSD) with replacement forms and SAE and finally by phone calls from MSD or myself.

### *2.6.2 Psychiatric interview.*

A psychiatric follow up was conducted for a separate study, forming the basis for a MPhil thesis focusing on psychiatric morbidity and its relationship to lesion location following stroke. The results are reported elsewhere (MacHale et al., 1996*a*, 1996*b*).

For 12 months consecutive patients who successfully completed the six month follow up with myself, (n=152), were asked to consent to a further visit by SM. Those who consented (n=145) were telephoned by her personally to arrange a suitable time to visit them at their place of residence. A semi-structured psychiatric interview, the Lifetime version of the Schedule for Affective Disorders and Schizophrenia (SADS) (Endicott and Spitzer, 1978), including additional questions to allow a DSM-IV diagnosis, and a short emotionalism questionnaire (House et al. 1989*b*) was administered to determine psychiatric morbidity. Family psychiatric history, social and demographic details, corroborating evidence from family members and from medical and psychiatric case-notes were also collected. After interview details of the patients' neurological status and CT scan results were obtained from the Lothian Stroke Register.

I took advantage of the psychiatric follow up to further evaluate a number of outcome measures. During the pilot study I administered the Mental Adjustment to Stroke Scale (MAS) as part of the primary patient questionnaire. To test its inter-rater reliability SM also administered it during her interview. During the main study when the MAS was completed independently by patients, its test retest reliability was further examined by SM asking patients to complete the measure a second time after her interview, again returning it by post (refer to 2.7.4.1.). During the pilot study the test-retest reliability of the Patient Satisfaction Scale was also examined with SM asking patients to complete the measure a second time after her interview (refer to 2.7.6.1.). The results of the psychiatric interview were then used as a 'gold standard' against which to compare the General Health Questionnaire and the Hospital Anxiety and Depression Scale and to assess their validity (refer to 2.7.2.3.).

## 2.7 Selecting our outcome measures.

As our primary aim was to measure the effect of the SFCW we tried to predict those domains of outcome that she was likely to influence. Thus our principle domains of outcome were activities of daily living (ADL), mood disorders, social functioning, patient satisfaction and mental adjustment. In addition I wanted to examine possible mechanisms of psychosocial dysfunction including patients' method of coping and locus of control. During the first six months of randomisation prior to patients being due for follow up I searched the literature for instruments designed to measure psychosocial outcomes with a view to choosing those most suitable for identifying any treatment effect.

The choice of outcome measures was difficult due to the large number of measures available, the fact that few had been used in stroke and the fact that the primary measures had also to be applicable for carers. We felt it important to consider whether measures had previously been used in patients with stroke, other physically ill populations or the elderly for a number of reasons. It was important that the practicality, validity and reliability of measures with similar populations had been tested, or at least that the measure had been successfully used in stroke or similar patients. In addition, previous use of measures in stroke aids both communicability, as readers would be familiar with the measures used, and comparison with previous studies. Evidence of construct validity (i.e. that the measure reflects the conditions it purports to measure) and reliability (that repeated testing either by the same researcher [intra-rater reliability] or by different researchers [inter-rater reliability] produces equivalent results) was also noted. Validity was necessary for all measures as, having decided a priori which areas of patient health we wished to measure, we required scales that accurately assessed those areas. Reliability was important not because patients would undergo repeated testing either by one or more researchers but because poor reliability can introduce 'noise' and reduce the power of the study to identify statistically significant differences between treatment groups. Where appropriate, when measures define patients as 'cases' or 'not cases', note was taken of instruments sensitivity, (the probability that a person having a condition will be correctly identified), and specificity, (the probability that a person not having a condition will be correctly identified). In randomised trials where psychological outcomes are important, the power of the study is reduced when outcomes are misclassified, so that an outcome instrument with a high accuracy is important. In the trial both the treatment group and control group will be equally effected by any inaccuracy, however such inaccuracy could obscure statistically significant differences between the groups. Inaccurate measures would affect reported rates of illness or dysfunction, could create spurious or obscure genuine relations between outcomes and lead to inaccurate models of prediction.

Summarised below are the measures I used in the patient follow up and their method of administration. The remainder of this section describes each measure in turn and discusses the reasons for our choice.

**Table 2-1: Patient measures and their method of administration.**

| PATIENT MEASURES | | |
|---|---|---|
| Questionnaire | Completion | Measure |
| Primary Patient Questionnaire | Completed with psychologist | General Health Questionnaire - 30 item<br>Frenchay Activities Index<br>Social Adjustment Scale<br>Medical Coping Modes Questionnaire<br>Recovery Locus of Control Scale |
| | Completed by psychologist | Hodkinson`s Mental Test (where necessary)<br>Barthel Index<br>Oxford Handicap Scale |
| Secondary Patient Questionnaire | Completed by patient independently, returned in SAE | Mental Adjustment to Stroke Scale<br>Patient Satisfaction Scale<br>Service Use Questionnaire<br>Equipment Received Questionnaire<br>Hospital Anxiety and Depression Scale |

Note: The Primary Patient Questionnaire forms Appendix B and the Secondary Patient Questionnaire Appendix C.

### *2.7.1 Measures of physical functioning.*

We wished to measure two aspects of patients' physical functioning after stroke, their level of handicap and their level of disability. Handicap refers to the limitation or inability to perform a given role that an individual percieves as normal for themselves. The definition of handicap therefore varies according to the role that is normal for that individual depending on, for example, their age, sex, social and cultural factors. Handicap therefore represents the lack of agreement between the individual's own, or their associates', expectations of their performance in certain roles and their actual performance due to impairment or disability (World Health Organization, 1980). On the other hand disability is defined in terms of what is considered normal for human beings generally and is therefore independent of an individuals's own perceived roles. Disability refers to a restriction or inability to perform tasks in a manner considered normal for a human being. The concept of disability does not reflect whether the restriction or inability to perform an activity is permanent or temporary and disability itself may arise both from physical impairment or from a person's psychological reaction to impairment.

#### *2.7.1.1 The Oxford Handicap Scale:*

*Origins*

The Oxford Handicap Scale (Bamford et al., 1989) is a modified version of the Rankin Disability Scale (Rankin, 1957). It was designed specifically to measure handicap in stroke patients and has been used in a number of large stroke trials (European Carotid Surgery Trialists' Collaborative Group, 1991; Multicentre Acute Stroke Trial-Italy (MAST-I) Group, 1995).

*Structure and Coding*

The Oxford Handicap Scale is a seven point Scale, scored 0,1,2,3,4,5,6 describing patients' level of physical handicap.

0 = No symptoms.
1 = Minor symptoms that do not interfere with lifestyle.

2 = Minor handicap; symptoms that lead to some restriction of lifestyle but do not interfere with the patient's capacity to look after himself.
3 = Moderate handicap; symptoms that significantly restrict lifestyle and prevent totally independent existence.
4 = Moderately severe handicap; symptoms that clearly prevent independent existence though not needing constant attention.
5 = Severe handicap; totally dependent patient requiring constant attention night and day.
6 = Dead.

The OHS has been used to divide patients into independent and dependent if categorised 0-2 and 3-5 respectively.

*Evidence of Validity / Reliability*

Studies of inter-rater reliability suggests moderate to substantial inter-observer agreement (Bamford et al., 1989). However, the fact that the scale refers to a patient's level of symptoms and that its score is also determined by their level of physical dependency may mean that the scale does not purely reflect the patient's handicap.

*Alternative Measures Considered*

The only alternative measure considered was the original Rankin Disability Scale, however their have been doubts regarding its inter-rater reliability (Wolfe et al., 1991) and the OHS was designed to provide an improved scale for use with stroke patients.

*Justification for Measure Selection*

The Oxford Handicap Scale was chosen because it was both specifically designed for, and is widely used with, stroke patients making it easily communicated. In addition, patients' pre-stroke OHS score was routinely collected by the Lothian Stroke Register whose physician also estimated the patients' OHS score at one year after stroke during their initial neurological assessment. It was therefore useful for the present study to use the same scale for comparative purposes. We did not expect our intervention to affect patients' OHS scores but the measure provided a satisfactory method of describing our patients at follow up.

### *2.7.1.2 The Barthel Index:*

#### *Origins*

The Barthel Index (BI; Appendix B; Mahoney and Barthel., 1965) was developed for clinical use as a simple index of independence in self care activities of patients with neuromuscular or musculoskeletal disorders. It is a primarily a measure of functional disability and does not measure disability in the areas of communication, hearing or cognition.

#### *Structure and Coding*

The Barthel Index is a ten item ordinal scale assessing patient's daily physical functioning, covering grooming, mobility, continence and feeding. We have adopted the modified scoring system where each item is scored either 0,1; 0,1,2 or 0,1,2,3 reflecting such categories as 'independent', 'needs help with some items' and 'unable to do anything without help' (Collin et al., 1988). It therefore has a possible score range of 0 to 20 with a higher score indicating increasing independence.

#### *Evidence of Validity / Reliability*

The Barthel Index has been shown to have very good test-retest (Kappa 0.98) and inter-rater reliability (Kappa 0.88; Wolfe et al., 1991; Roy et al. 1988), is sensitive to clinical change (Wood-Dauphinee et al., 1990) with a difference of 4/20 points likely to reflect a genuine change (Collin et al., 1988), and has satisfactory cross-cultural reliability (Chino, 1990).

#### *Alternative Measures Considered*

Two alternative measures that have been used in stroke were considered; the Nottingham ADL Scale and the Katz ADL Index. The Nottingham ADL scale was designed for use with stroke patients and like the Barthel has ten activities on which patients are rated. However it does not include patients' continence or their ability to climb stairs instead asking if they can drink from a cup or prepare a hot drink. Continence has many social implications and was therefore thought to be an important outcome to record in the present study. The Katz ADL Index is very similar to the Barthel Index but the consensus in both literature review and comparative studies is that the Barthel Index is superior (Gresham et al., 1980; Wade, 1992; Wade and Collin, 1988).

*Justification for Measure Selection*

The Barthel Index is perhaps the most widely used measure of physical disability in stroke and therefore possesses excellent levels of comparability and familiarity. It has also been widely used to compare the results of interventions and to measure change over time (Granger and Hamilton, 1990).

## 2.7.2 Measures of mood.

Many different measures have been used to assess mood disorders after stroke, making the task of choosing which to include in this study difficult. I wanted the measures to be familiar to likely readers and to avoid the use of questions referring to physical symptoms which might be due to the stroke rather than a mood disorder.

A summary of the self rating scales of mood previously used in stroke is presented in Table 2-1 at the end of this section. I did not include interviewer rated scales as I wished to use the same measure in carers (who would be completing the scale alone, refer to 2.1.) as in patients.

As it was a difficult choice between the GHQ and the HAD Scale we decided to use both and take the opportunity to make a much needed comparison of their utility in stroke. Both measures have the extremely important benefit of communicability, that is, having been used widely before, they possess both familiarity and the ability to allow comparison across studies. The HAD Scale is substantially shorter; 14 questions, than the GHQ-30; 30 questions, and provides information on the nature of the patient's mood disorder. It might therefore be superior to the GHQ-30 if both measures had similar accuracy.

### *2.7.2.1 The General Health Questionnaire:*

*Origins*

Perhaps the most widely used standardised measure of mental health available, the General Health Questionnaire (Appendix B; Goldberg, 1972) has often been used in stroke patients (Ebrahim et al., 1987; Johnson et al., 1995; Collin et al., 1987; Robinson and Price, 1982).

Rather than diagnosing specific psychiatric disorders the GHQ identifies patients who are likely to be a psychiatric 'case' allowing further, more detailed, assessment to be undertaken. The original scale contains 60 questions but the authors have produced shorter versions of 30, 28, and 12 questions.

### *Structure and Coding*

The authors recommend that the four response options for each question are scored 0,0,1,1, where any score above zero represents a deterioration in mood from the 'usual state'. This allows the GHQ-30 to give a score of between 0 and 30, with a higher score indicating a greater likelihood of being a psychiatric case. The recommend cut-off for determining a psychiatric case is 4/5 as derived from a General Practitioner sample (Goldberg, 1972) although a higher cut-off of 11/12 has been suggested for a neurology inpatient sample (Bridges and Goldberg, 1984).

### *Evidence of Validity / Reliability*

The GHQ is unique in asking patients to report their present symptoms in comparison with a usual state and has thus been criticised for being insensitive to chronic disorders. However, we asked patients to consider their 'usual state' to be the period immediately prior to their stroke thus allowing us to identify the effect of their strokes on their present mood. The sensitivity and specificity of the GHQ have been shown to be acceptable in stroke patients (Table 2-2).

### *Alternative Measures Considered*

The evaluation of alternative measures is summarised in Table 2-2 at the end of this section.

### *Justification for Measure Selection*

The GHQ-30 proved our main choice of mood measure primarily because its widespread use in previous research gave it a high level of communicability and familiarity. It is also relatively short, specifically adapted for a physically ill population and has high levels of sensitivity and specificity.

We chose the 30 item version as questions referring to physical health are avoided to facilitate its unbiased use in physically ill populations. We chose not to use the GHQ-28 despite its ability to provide scores on four subscales, as it included such questions on physical health and the GHQ-30 has been recommended as more suitable for physically ill patients (Malt et al., 1989).

### *2.7.2.2 The Hospital Anxiety and Depression Scale:*

#### *Origins*

The Hospital Anxiety and Depression Scale (HAD Scale; Appendix B) was designed to screen patients attending non-psychiatric medical outpatient clinics for clinically significant anxiety and depression that may be contributing to their distress. The HAD Scale was devised to improve upon the General Health Questionnaire by being substantially shorter, by avoiding reference to somatic symptoms and by providing information about the nature of the psychiatric disorder rather than simply identifying a case (Zigmond and Snaith, 1983; Snaith, 1990).

#### *Structure and Coding*

The HAD Scale has two subscales, Depression and Anxiety, each of which has seven questions. Questions are in the form of 'I' statements, for example 'I get sudden feelings of panic', and each has four possible responses, for example 'Very often indeed', 'Quite often', 'Not very often', and 'Not at all'. Each question is scored 0,1,2,3, giving a possible score range of 0 to 21 for each subscale, where a higher score indicates a greater level of distress for the subscale in question. The author does not recommend that the subscales are summed (Snaith, 1990, 1991).

#### *Evidence of Validity / Reliability*

The HAD Scale has been shown to possess acceptable levels of sensitivity and reliability in stroke patients (refer to Table 2-2).

#### *Alternative Measures Considered*

The evaluation of alternative measures is summarised in Table 2-2 at the end of this section.

### *Justification for Measure Selection*

The HAD Scale was specifically devised to identify mood disorders in the physically ill, is very short and provides information on the nature of the mood disorder. It has been widely used in many populations, thus possessing communicability, and is suitable for self completion in this study as it was designed to be independently completed by patients.

**Table 2-2: Summary of the self report measures of mood most commonly used after stroke regarding their suitability for the present study.**

| **Measure** | **Designed for use with physically ill?** | **Cut-off tested, gold standard, sensitivity & specificity** | **Comments** |
|---|---|---|---|
| Beck Depression Inventory (BDI)<br>21 questions. | May measure distress, not depression in disabled people (Wade, 1992). | PSE 1 to 12 months after stroke<br>C-O= 4/5: True +ve =0.9-1.0<br>False +ve =0.5-0.59<br>C-O=5/6: True +ve =0.9-1.0<br>False +ve =0.42-0.47<br>C-O=6/7: True +ve =0.9-1.0<br>False +ve =0.32-0.36<br>C-O=7/8: True +ve =0.8-1.0<br>False +ve =0.27-0.32<br>C-O=8/9: True +ve =0.8-1.0<br>False +ve =0.15-0.29<br>C-O=9/10: True +ve =0.7-0.85<br>False +ve =0.09-0.22<br>C-O=10/11: True +ve =0.6-0.78<br>False +ve =0.05-0.19<br>C-O=11/12: True +ve =0.5-0.78<br>False +ve =0.05-0.12<br>(House et al., 1989*a*) | Should be abandoned in research (Kearns et al., 1982) |
| Centre for Epidemiological Studies Depression Scale (CES-D)<br>20 questions. | No | C-O =20-Interview<br>Sens =0.56 /Spec =0.91<br>(Agrell and Dehlin, 1989) | GDS & SDS better than CES-D (Agrell and Dehlin, 1989) |
| The Geriatric Depression Scale (GDS)<br>15 or 30 questions | No | C-O =10-Interview;<br>Sens=0.88 /Spec=0.64 (Agrell and Dehlin, 1989)<br>For depression- PSE<br>C-O = 9/10; Sens=0.84 / Spec=0.50<br>C-O= 10/11; Sens=0.84 / Spec=0.66<br>C-O = 11/12; Sens=0.74 / Spec=0.70<br>For anxiety only-PSE<br>C-O= 13/14; Sens=0.68 / Spec=0.73<br>C-O= 14/15; Sens=0.65 / Spec=0.79<br>C-O= 15/16; Sens=0.61 / Spec=0.83<br>(Johnson et al., 1995) | GDS better than CES-D (Agrell and Dehlin, 1989).<br>GHQ-28 better than GDS and HAD for depression (Johnson et al., 1995). |

Sens= Sensitivity; Spec= Specificity; C-O= Cut-off; +ve = positive.

**Table 2-2. continued.**

| **Measure** | **Designed for use with physically ill?** | **Cut-off tested, gold standard, sensitivity & specificity** | **Comments** |
|---|---|---|---|
| The General Health Questionnaire (GHQ-28)<br>28 questions | Yes | For depression-PSE<br>C-O=4/5; Sens=0.89 / Spec=0.75<br>C-O = 5/6; Sens=0.78 / Spec=0.81<br>C-O=6/7; Sens=0.44 / Spec=0.86<br>For anxiety only-PSE<br>C-O=3/4; Sens=0.79 / Spec=0.46<br>C-O = 4/5; Sens=0.71 / Spec=0.56<br>C-O=5/6; Sens=0.50 / Spec=0.62<br>(Johnson et al., 1995) | GHQ-28 better than GDS and HAD for depression (Johnson et al., 1995). |
| The General Health Questionnaire (GHQ-30) - 30 item | Yes | C-O = 8/9; Sens=0.8 / Spec=0.76<br>(O'Rourke et al. 1996) | |
| The Hospital Anxiety and Depression Scale (HADS)<br>14 questions | Yes | Depression Scale-PSE<br>C-O = 3/4; Sens=0.94 / Spec=0.32<br>C-O = 4/5; Sens=0.83 / Spec=0.44<br>C-O=5/6; Sens=0.61 / Spec=0.50<br>(Johnson et al., 1995)<br>C-O = 6/7; Sens=0.8 / Spec=0.79<br>(O'Rourke et al., 1996)<br>Depression scale<br>C-O = 9/10; Sens=0.73 / Spec=1.00<br>(Sharpe et al., 1990)<br>Anxiety Scale<br>C-O=4/5; Sens = 0.95 / Spec =0.38<br>C-O= 5/6; Sens=0.80 / Spec=0.46<br>C-O=6/7; Sens=0.57 / Spec=0.56<br>(Johnson et al., 1995)<br>C-O=6/7; Sens=0.83 / Spec=0.68<br>(O'Rourke et al., 1996) | GHQ-28 better than GDS and HAD for depression (Johnson et al., 1995).<br>Feasible & reliable for use in stroke (Visser et al., 1995). |
| The Wakefield Depression Inventory (WDI)<br>12 questions | No | | Should be abandoned in research (Kearns et al., 1982) |
| The Zung Self Rating Depression Scale (SDS)<br>20 questions | No | Interview<br>C-O=45; Sens=0.76 / Spec=0.96<br>(Agrell and Dehlin, 1989) | Should be abandoned in research, (Kearns et al., 1982).<br>GDS & SDS better than CES-D (Agrell and Dehlin., 1989) |

Sens= Sensitivity; Spec= Specificity; C-O= Cut-off; +ve = positive.

### *2.7.2.3 A Comparison of the GHQ and the HAD Scale.*

My literature review of self report measures of mood has illustrated how few studies have attempted to compare self report measures of mood in stroke with standardised psychiatric interviews. The results of such studies are important both to help with the informed choice of measures and to indicate the likely level of measures' mis-classification which is important when calculating the statistical power needed when setting up studies. As we were using two self report measures, the GHQ and the HADS, and some of our patients were undergoing a structured psychiatric interview, the SADS, we took the opportunity to calculate the sensitivity and specificity of these two measures.

I will therefore digress from my description of our outcome measures briefly to present the results of this additional study.

**METHODS:**

As described previously I visited patients for a standard follow up visit six months after their randomisation into the trial and administered the GHQ as part of an extensive assessment, leaving a secondary questionnaire including the HAD Scale for independent completion and return. Two weeks later, (Mean 14.2 days), a Psychiatric Registrar, (SM), visited the patient and, unaware of their scores on the GHQ or HADS, administered the SADS to identify those with a current psychiatric diagnosis (refer to 2.6.2.). The SADS was chosen in preference to the comparable Present State Examination, (Wing et al., 1967), as it allows a more detailed assessment of affective disorders and has previously been used to assess psychiatric morbidity in a stroke population (Dam et al., 1989; Eastwood et al., 1989). Supplementary questions were also administered to generate a Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) diagnosis. A possible confounding variable in this physically ill sample, the fatigue rating scale, was excluded. All indications from use in both the present and previous studies suggest that the SADS is both reliable and valid (Endicott and Spitzer, 1978). Diagnoses were grouped as depressive or anxiety disorders for the purposes of analysis as specified in Table 2-3.

I calculated the sensitivity and specificity for each possible threshold of both the GHQ and the HAD scale and plotted a Receiver Operating Characteristics (ROC) curve of sensitivity against 1- specificity. I then compared the areas under different curves, a global measure of predictive power using the non-parametric method of DeLong et al. (1988). Finally, I calculated the optimal cut-offs for each measure for different 'cost ratios' using the method described by Sox (1988).

## RESULTS:

During the period of this particular study we randomised 187 (71.4%) patients referred to our hospital with acute stroke. Of these 16 died, 19 were severely cognitively impaired and 7 refused follow up, leaving 145 patients (77.5%) who were assessed by both the psychiatrist and myself at six months. The 145 subjects had a median age of 68 (range 18-90 years), and 75 (51.7%) subjects were male. One hundred and thirty three (91.7%) patients completed the GHQ and 111 (76.6%) the HADS. Data were complete for both measures in 105 (72.4%) patients. The primary causes of incomplete responses were inability to comprehend questions, refusal to answer specific questions and failure of patients to return the self completion form containing the HADS (42% of those incomplete). We compared the baseline data of those in whom data were complete, (n=105), with the remainder of those randomised (n=82). Patients in whom complete data were not collected were significantly more likely to have suffered a severe stroke with cortical damage and cognitive impairment. In turn those patients who successfully completed all measures had experienced significantly milder strokes and had been less dependant prior to their strokes.

**Table 2-3: Grouped patient diagnoses according to the SADS psychiatric evaluation.**

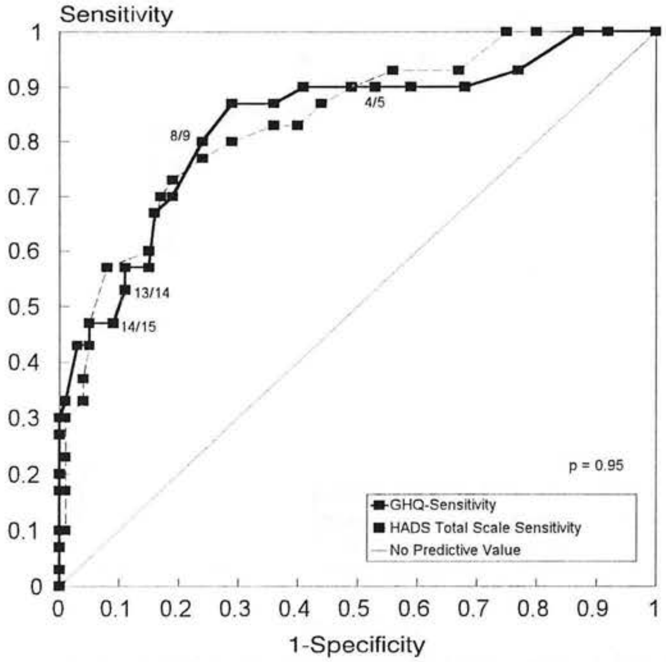
| Diagnosis | n (n=105) | Grouped Diagnoses | n | % |
|---|---|---|---|---|
| Major depressive disorder | 14 | Depression | 19 | 18 |
| Depressive disorder, not otherwise specified | 1 | | | |
| Adjustment disorder with depressed mood | 3 | | | |
| Adjustment disorder with mixed anxiety and depressed mood | 1 | | | |
| Generalised anxiety disorder | 2 | Anxiety | 13 | 12.4 |
| Agoraphobia with or without panic disorder | 8 | | | |
| Adjustment disorder with anxious mood | 1 | | | |
| Adjustment disorder with mixed anxiety and depressed mood | 1 | | | |
| Specific phobia | 1 | | | |
| Alcohol dependence | 6 | Other | 8 | 7.6 |
| Personality disorder | 1 | | | |
| Sedative, hypnotic or anxiolytic dependence | 1 | | | |
| Number of DSM-IV diagnoses = 40<br>Number of patients with any DSM-IV diagnoses = 30 (28.6%)<br>Number of patients with more than one DSM-IV diagnoses = 8<br>Of whom 7 patients have 2 diagnoses and 1 patient has 4 diagnoses. | | | | |

Note: 'n' refers to number of patients rather than number of diagnoses as some patients had multiple diagnoses.

The SADS psychiatric evaluation of those 105 patients in whom data were complete identified 30 patients (28.6%) with 40 psychiatric diagnoses, depressive disorders in 19 patients (18%), anxiety in 13 patients (12.4%), and a variety of other disorders in 8 patients (7.6%), (Table 2-3). The psychiatric evaluation of those 40 patients who failed to complete the study measures identified 14 patients (35%) with 19 psychiatric diagnoses, depressive disorders in 11 patients (27.5%), anxiety in 3 patients (7.5%), and a variety of other disorders in 5 patients (12.5%).

I compared the GHQ and HAD Scale using ROC Curves. I found no significant difference between the GHQ and the HAD Scale total score to identify any DSM IV case (z=0.068, p=0.95, Figure 2-1). Neither was there any significant difference between the ability of the GHQ and the HAD Depression subscale to detect cases of DSM IV depression, (z=0.587, p=0.56, Figure 2-2), or the GHQ and the HAD Anxiety subscale to detect cases of DSM IV anxiety (z=-1.155, p=0.25, Figure 2-3).

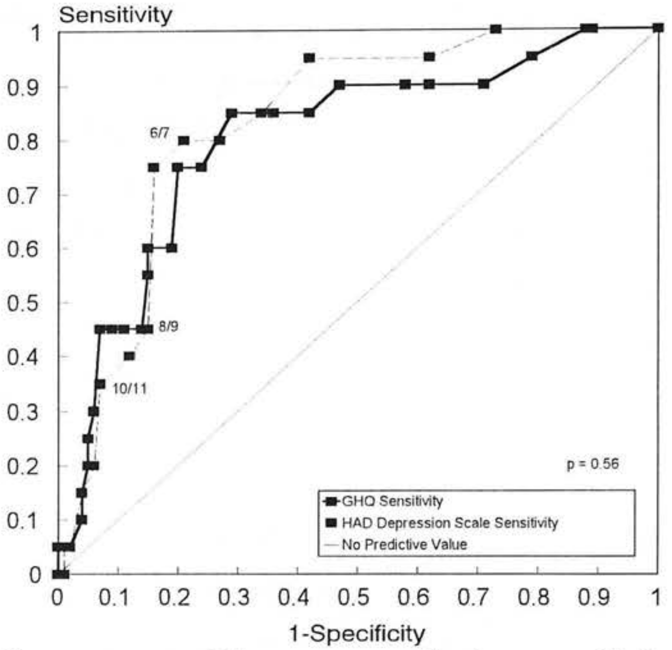
**Figure 2-1: ROC curve illustrating the ability of the GHQ and HAD summed scale to identify any DSM-IV case at various cut-off points.**



Note: A perfect measure would have an area under the curve of 1.0, whereas a measure with no diagnostic value would have an area of 0.5, i.e. the ROC curve would lie on the diagonal. Cut-offs referred to in the text are labelled to illustrate their position on the ROC curve. There was no significant difference between the areas under the ROC curves, z=-0.07, p=0.95.

The sensitivity and specificity rates for all cut-offs and grouped diagnoses for the GHQ are illustrated in Figure 2-1. The recommended cut-off point, derived from a General Practitioner sample, for the GHQ 30 is 4/5 where the probability of being a case, the sensitivity, is 0.5 (Goldberg, 1972). Using this cut-off in the present sample of stroke patients to *identify all diagnoses* produces a sensitivity of 0.9 and a specificity of 0.47. In this study to gain a sensitivity of 0.5, on which the recommended cut-off was based, a cut-off of either 13/14 or 14/15 would be necessary where the sensitivity is 0.53 and 0.47, and specificity is 0.89 and 0.91 respectively. The ROC curves suggest that for both a high sensitivity and specificity the best cut-off is 8/9 in the present population with a sensitivity of 0.8, specificity of 0.76 (Figure 2-1).

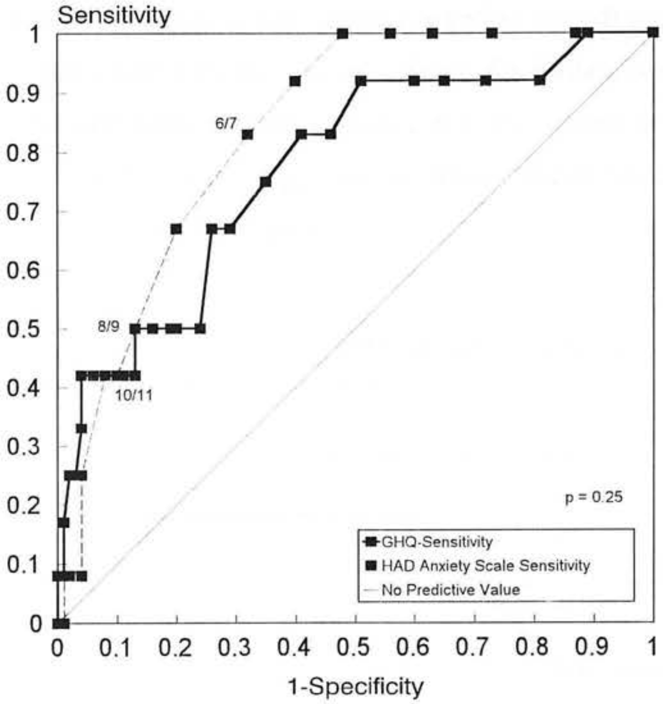
**Figure 2-2: ROC curve illustrating the ability of the GHQ and the HAD Depression Subscale to identify DSM-IV cases of depression at various cut-offs.**



Note: A perfect measure would have an area under the curve of 1.0, whereas a measure with no diagnostic value would have an area of 0.5, i.e. the ROC curve would lie on the diagonal. Cut-offs referred to in the text are labelled to illustrate their position on the ROC curve. There was no significant difference between the areas under the ROC curves, z=-0.59, p=0.56.

The authors of the HAD scale recommend a cut-off point of 8/9 for a high sensitivity and 10/11 for high specificity for both their anxiety and depression subscales (Zigmond and Snaith, 1983). Using the same 8/9 cut-off point in the present study for the depression subscale, *identifying depression only*, produced a rather low sensitivity of 0.45, and a specificity of 0.85. A cut-off of 10/11 produced a sensitivity of 0.35, and a specificity of 0.93. A similar sensitivity and specificity were better achieved in this sample using a cut-off of 6/7, sensitivity 0.8, specificity 0.79 (Figure 2-2).

**Figure 2-3: ROC curve illustrating the ability of the GHQ and the HAD Anxiety Subscale to identify DSM-IV cases of Anxiety at various cut-offs.**



Note: A perfect measure would have an area under the curve of 1.0, whereas a measure with no diagnostic value would have an area of 0.5, i.e. the ROC curve would lie on the diagonal. Cut-offs referred to in the text are labelled to illustrate their position on the ROC curve. There was no significant difference between the areas under the ROC curves, z=-1.6, p=0.25.

For the HAD scale, anxiety subscale, *identifying cases of anxiety only*, a cut-off point of 8/9 produced a sensitivity of 0.5 and specificity of 0.87. A cut-off of 10/11 produced a sensitivity of 0.42 and a specificity of 0.92. Again, as in the depression subscale, a better balance between sensitivity and specificity was achieved using a cut-off of 6/7, sensitivity 0.83, specificity 0.68 (Figure 2-3). As previously mentioned the authors do not recommend the summing of the two subscales and so have not published recommended cut-off points. I have included figures for the summed scale in the present study to facilitate comparison with previous studies (e.g. Lewis and Wessely, 1990; Figure 2-1).

To further facilitate choice of cut-offs I calculated various cost ratios. Cost refers to the relative importance in different situations of a measure possessing either high sensitivity (i.e. very few false negatives) or high specificity (i.e. very few false positives). For example, in some situations it may be far worse to miss a potentially treatable patient by using a measure with a low sensitivity, than it would be to further examine a patient who is actually well by using a measure with a low specificity. The costs of each cut-off have been calculated through a range of a false negative (a patient missed) costing from 0.25 to 4 times the cost of a false positive (a well patient referred for further assessment). For example, it may be considered twice as costly to miss a depressed patient than to refer a well patient for further assessment, corresponding to a ratio of two. The optimum cut-offs for different cost ratios are plotted in Figures 2-4 and 2-5.

**Figure 2-4: The optimum GHQ cut-offs for identifying any DSM-IV case, depression or anxiety for a range of cost ratios.**

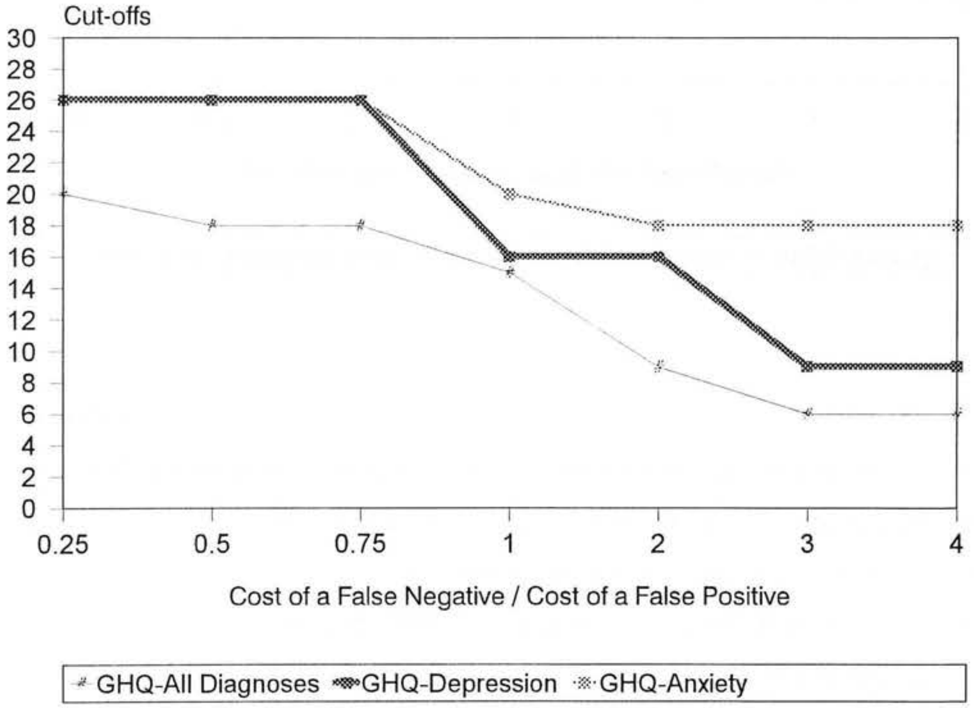
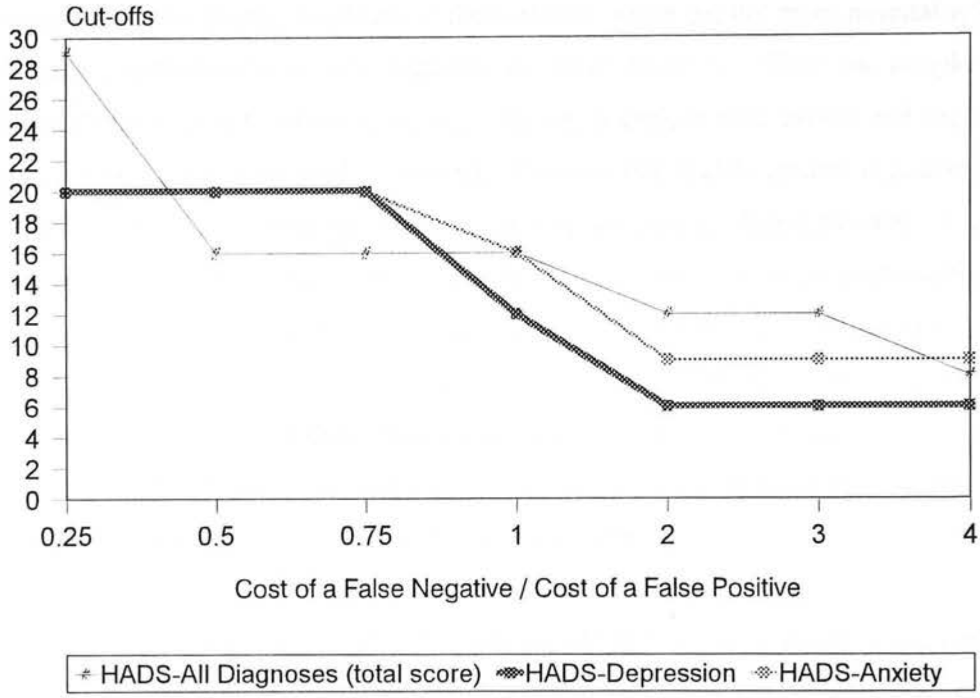


**Figure 2-5: The optimum HAD Scale cut-offs for identifying any DSM-IV case, depression or anxiety for a range of cost ratios.**



## DISCUSSION:

It is increasingly important for both clinicians and researchers to possess a reliable method of identifying mood disorders after stroke. Post stroke depression is a common and debilitating disorder that may slow rehabilitation and produce a permanent negative influence on recovery (Burvill et al. 1995*a*; Ebrahim et al. 1987; Parikh et al. 1987, 1990; Robinson et al. 1984*c*, 1986; Young and Forster. 1991). Early screening and identification of mood disorders may be important if an effective treatment exists. In addition, large randomised controlled trials of treatment which aim to influence psychological outcomes require reliable self report measures; knowledge of both sensitivity and specificity is necessary to compute the power of the study and to facilitate the choice of cut-off.

This part of my study refers to a reasonably representative sample of hospital referred stroke patients comparable on most indices to the total population assessed during this time period. The necessity for patients to be referred to hospital may have resulted in extremely mild and severe strokes being under represented. Patients who suffered severe cognitive impairment or who were unable to communicate effectively were excluded as assessment by self report would have been invalid. While we would acknowledge that due to such impairments these patients might be at greater risk of depression, self report measures are an inappropriate form of assessment in this group. Furthermore those strokes which did not merit hospital referral might have a correspondingly low frequency of mood disorders. Thus our sample may represent a 'middle ground' of stroke severity, failing to capture mild strokes and excluding those whose impairment prevented assessment. However this 'middle ground' is precisely the population in whom such measures would be most appropriate in clinical practice. Patients whose strokes are mild enough to not warrant hospital referral, may be proportionately less likely to experience post stroke mood disorders (refer to 4.1.1.) and little infrastructure exists to screen patients not attending outpatients. Patients suffering severe cognitive or communication impairments will not be suitable subjects for self report measures whether in a clinical or research setting. Hence our patients are representative of those that hospital staff may routinely wish to screen for post stroke mood disorders.

Only one previous comparison of the GHQ and the HAD Scale in stroke has been reported (Johnson et al., 1995). In an indirect comparison using the 28 item version of the GHQ (n=66) Johnson et al. (1995) reported it to be superior to the HAD Scale (n=93) at detecting both anxiety and depression. Similar studies have been conducted in other medically ill populations. Lewis and Wessley (1990) found no difference between the GHQ -12 item and the summed HAD Scale at detecting cases of minor psychiatric disorder in a sample of dermatological patients. Wilkinson and Barczak (1988) found the HAD Scale was generally more sensitive and simpler to complete than the GHQ-28 in a General Practitioner sample. Aylard (1987) undertook a further validation of both the HAD Scale and the anxiety and depression subscales of the GHQ-28 in a hospital outpatient sample, finding both to be suitable for preliminary screening and suggesting the use of a borderline range; a score range where patients are 'bordering' on 'caseness', in the GHQ.

When considering which measure should be recommended for what purpose it is useful to refer to the ROC curves for comparison. Figures 2-1 to 2-3 illustrate that there are no overall differences between the two measures at identifying 'any diagnosis', depression or anxiety and remarkably little difference between the performance of those cut-offs that provide the best balance between sensitivity and specificity for each diagnostic category. For identifying any diagnosis the HAD Scale total score is superior where a high sensitivity is required, producing a higher sensitivity than the GHQ for all specificities below 0.5. However for sensitivities between 0.75 and 0.9 the GHQ has a consistently higher specificity. Figures 2-2 and 2-3 show that the HAD Depression and Anxiety subscales better identify cases of depression and anxiety than the GHQ at almost all levels above a sensitivity of 0.5. The ROC curves provide useful indications of the performance of specific cut-offs but it must be remembered that the areas under the curves taken as a whole were not significantly different.

As the recommended cut-offs for the GHQ and HADS appear sub-optimal in the present sample, a comparison of these results with those of previous studies comparing self-report questionnaires in *identifying depression* with psychiatric interview suggests our results are atypical. In comparison to the Beck Depression Inventory, the Centre for Epidemiological Studies Depression Scale, the Geriatric Depression Scale, the Zung Self Rating Depression Scale, the Hamilton Depression Rating Scale, the Comprehensive Psychopathological Rating Scale-Depression, the Cornell Scale, and the GHQ-28, in our study the GHQ-30 recommended cut-off of 4/5 has a better sensitivity, 0.9, but worse specificity, 0.42 whereas the recommended HAD Scale cut-off of 10/11 has a very poor sensitivity, 0.35, and superior specificity, 0.93 (Agrell and Dehlin, 1989; Shinar et al., 1986; House et al., 1989*a*; Johnson et al., 1995). Thus in the present sample the GHQ-30 appears to possess excellent sensitivity, better than all previously reported measures in stroke, and poor specificity, worse than all previously reported measures in stroke at the recommended cut-off. The HAD Scale conversely has excellent specificity, better than all previously reported measures in stroke, and poor sensitivity, worse than all previously reported figures in stroke at the recommended cut-offs. This observation further suggests that the use of the traditionally recommended 4/5 cut-off for the GHQ-30 and 10/11 cut-off for the HAD Scale are inappropriate in a stroke population.

When considering which cut-off is most appropriate for a given population or use, the comparative cost of a false positive or false negative in those circumstances must be considered. For example in a clinical setting where it is most undesirable to miss cases and resources are not too limited, a false negative may be deemed to cost twice a false positive. Reference to figure 2-4 illustrates that at point 2 on the horizontal axis the optimal cut-off on the GHQ when identifying any diagnosis is 9/10. Reference to Figures 2-4 and 2-5 illustrate the optimum cut-offs for each cost ratio. It is suggested that to facilitate a decision regarding cut-off points, potential users consider the comparative costs within their frame of use and choose the optimum cut-off for their cost ratio as specified in the figures.

The GHQ-30 is more than twice the length of the HADS; and its response format, with reference to the 'usual', and the questions themselves were difficult for many patients to understand. Particularly relevant for a population six months post stroke is the criticism that the GHQ misses chronic cases due to its reference to a 'usual' state (Goldberg et al., 1976). We hoped instructions to regard 'usual' as health status prior to stroke would partially overcome this but found that patients had difficulty remembering pre-stroke health. Although the GHQ-30 was chosen for having few somatic questions those on sleep, chatting and getting out often reflected physical as well as mental health problems. This could in part account for the increased rates of positive responses in our population in comparison to the general practitioner sample previously used for validation.

The two measures were applied in different ways. I administered the GHQ by reading out each question and recording the patients' answers for them. The HAD Scale was left with patients for self completion. This was reflected in the substantially higher completion rate for the GHQ, 92%, compared to the HAD Scale, 77%. Of those in whom the HADS data were incomplete, 14 (42%) had failed to return the questionnaire. Of the returned questionnaires 85% were complete. Incomplete HADS were primarily a result of entire questionnaire pages being missed, odd questions being ignored or two boxes being ticked for each question. These are all problems that could have been avoided if the HADS were completed, like the GHQ, in the presence of the psychologist or other suitable health professional. Incomplete GHQs were the result of deficits in communication, understanding or patients refusal to answer specific questions. We suspect that the performance of the GHQ would have been hindered by the complexity of the questions had patients completed it alone.

The GHQ-30 and HAD Scale appeared to differ little in terms of their sensitivity and specificity, although the HAD Scale was significantly shorter and, we suspect, may have been easier for patients to complete.

### 2.7.3 Measures of social functioning.

#### 2.7.3.1 The Frenchay Activities Index:

*Origins*

The Frenchay Activities Index (FAI; Appendix B; Holbrook and Skilbeck, 1983) was developed specifically on and for stroke patients with the aim of providing an accurate picture of both pre and post morbid functioning. It concerns areas of regular, mainly social activities, which require some degree of decision making and organisation in three areas, domestic chores, leisure/work and outdoor activities. It avoids items relating to basic self care (Holbrook and Skilbeck, 1983).

*Structure and scoring*

The scale has 15 questions with ordinal response choices reflecting either the frequency of participation in an activity during the last three or six months, or the amount of an activity, for example, 'None', 'Light', 'Moderate', or 'All necessary'. Questions are scored 0,1,2,3, producing a total score of between 0 and 45, where a higher number indicates a greater ability to perform daily functions (Wade et al., 1985*b*). No recommended cut-off points to define greater and lesser abilities have been published, the scale is designed to be interpreted as a continuous measure. However, the categorisation of total scores as illustrated below has been used by authors previously in stroke (Kettle and Chamberlain, 1989; Schuling et al., 1993; Wade et al., 1985*a*, 1985*b*).

| | |
|---|---|
| Score of 0 | = No social activity. |
| Score of 1-10 | = Little social activity. |
| Score of 11-30 | = Moderate social activity. |
| Score of 31- 45 | = Major social activity. |

Evidence of validity / reliability

The construct and discriminative validity of the index has been supported by correlation with the Barthel Index, Sickness Impact Profile and Wakefield Depression Inventory. It appears sensitive to the severity of stroke and change over time and appears to have an adequately high ceiling (Holbrook and Skilbeck, 1983; Schuling et al., 1993; Wade et al., 1985*b*). While some questions suffer a sex bias the numbers biased in favour of men and women are equal and appear to balance each other (Wade et al., 1985*b*). The total score has been found to possess reasonable inter-rater reliability although individual items varied considerably in this respect. The authors have since modified the instructions to improve this (Wade et al., 1985*b*).

### *Alternative Measures Considered*

In addition to the Frenchay Activities Index, three other instrumental ADL scales have been designed for use with stroke patients; The Hamrin Activities Index (Hamrin, 1982), The Rivermead ADL Assessment (Whiting and Lincoln, 1980), and The Nottingham Extended ADL Index (Nouri and Lincoln, 1987; Chong, 1995). The Hamrin and Nottingham scales each contain 22 questions making them longer than the FAI and encompass basic ADL activities in their locomotion and mobility subscales thus producing repetition when used in conjunction with the Barthel Index. The consistency of the Nottingham ADL Scale's hierarchical ranking has been questioned when used with depressed patients and by asking whether a patient has or has not performed an activity it does not take into account the frequency or quantity of activity (Nouri and Lincoln, 1987). The Rivermead ADL scale containing 31 items is twice the length of the FAI and the areas covered overlap considerably with those of the Barthel Index.

### *Justification for Measure Selection*

The Frenchay Activities Index was chosen for inclusion in the present study as it measured what was felt to be an important area of outcome, reintegration into social activities, with no repetition of our functional outcome measure, the Barthel Index. The scale was specifically designed for use with stroke patients and had already been used in more than 1,500 stroke patients (Wade et al., 1985*b*) thus making it communicable. It is short and easy to use, it is known to be valid and sensitive, and it has been recommended for research purposes (Wade et al., 1985*b*).

### *2.7.3.2 The Social Adjustment Scale:*

*Origins*

The Social Adjustment Scale (SAS; Appendix B; Weissman and Bothwell, 1976) was developed from the already widely used Structured and Scaled Interview to Assess Maladjustment (SSIAM). It is a measure of role performance in various domains of social interaction during the previous two weeks. The scale was validated in a community sample and psychiatric outpatients and has been used in a wide range of physically ill patients including those recovering from cardiac disease (Weissman et al., 1978).

*Structure and Coding*

The SAS measures functioning in six different areas; work, (as occupation or housework), social and leisure activities, relationship with extended family, marital relationship, parental role and membership of family unit. We decided a priori to remove the parental role and student subscales as we predicted few patients would be students or have children still living in the same home. In addition, questions on the parental subscale were identical to those asked in the extended family subscale (Weissman et al., 1978).

The remaining scales of the SAS contain 42 questions each of which is rated on either a five or six point scale, scored either 1,2,3,4,5 or 1,2,3,4,5,8, where '8' is not applicable (not included in summed score), with a higher score indicating greater dysfunction. The authors specify that scores within each subscale are summed and a mean obtained in addition to an overall mean score for the scale as a whole (Weissman et al., 1978).

*Evidence of Validity / Reliability*

Evidence of validity includes the ability to differentiate between psychiatric patients and controls (Weissman et al., 1978), between depressed patients who had recovered and those in an acute episode (Weissman and Bothwell, 1976) and the existence of high levels of agreement between depressed patients' and relatives' reports (Weissman et al., 1978). In addition the scale has been shown to possess high internal consistency and test-retest reliability (Edwards et al., 1978).

*Alternative Measures Considered*

While many different measures, and measurement criteria of, social functioning have been used in stroke the majority have been specifically designed or adapted for the study in which they were used and have not been used subsequently by different authors. Thus the prospective researcher is left with a choice of many measures, each of which has been used once in stroke but for which little evidence of reliability or validity exists (Angeleri et al., 1993; Astrom et al., 1993; Colantonio et al., 1993; Evans et al., 1988; Evans and Northwood, 1983; Friedland and McColl, 1987, 1992; Glass and Maddox, 1992; Labi et al., 1980; Robinson et al., 1984*b*; Starkstein et al., 1988*b*; Thames and McNeil, 1987; Thompson et al., 1989).

*Justification for Measure Selection*

We chose the Social Adjustment Scale because it has been widely used, has evidence of reliability and validity in a range of populations, is useful for screening and is not affected by socio-demographic variables (Paykel and Weissman, 1973; Weissman and Bothwell, 1976; Weissman et al., 1978; Edwards et al., 1978). It had previously been shown to be sensitive to change in patients recovering from depression (Weissman and Bothwell, 1976) and capable of detecting treatment effects in clinical trials (Weissman et al., 1974).

### 2.7.4 Measure of mental adjustment.

#### 2.7.4.1 The Mental Adjustment to Stroke Scale:

*Origins*

The Mental Adjustment to Cancer Scale (MAC) was developed to assess the cognitive and behavioural responses of patients to their diagnosis. The authors suggest two aspects of mental adjustment: appraisal, the patients' perception of the implications of their diagnosis, and reaction, what the patient thinks and does to reduce the threat posed by the illness (Greer et al., 1989). A primary mental adjustment of fighting spirit or denial, rather than stoic acceptance or helplessness/hopelessness, has been associated with a greater likelihood of being alive and free from recurrence at five and ten year follow ups in cancer patients (Pettingale et al., 1981). A primary mental adjustment of anxious pre-occupation has been associated with depression and anxiety, and a fatalistic or helpless/hopeless response with depression (Greer and Watson, 1987).

### *Structure and Coding*

The MAC has four subscales: Fighting Spirit - Helplessness, a continuum with 22 items, Anxious Preoccupation with nine items, Fatalism with eight items and Denial / Avoidance with one item. Each question has a four point response format of 'Definitely does not apply to me', 'Does not apply to me', 'Applies to me' and 'Definitely does apply to me', scored 1,2,3,4. As the number of questions and the direction of scoring for a positive response in each subscale differs all summed subscale scores undergo a transformation to correct for this. After transformation a higher score reflects more negative mental adjustment (Watson et al., 1989). The definition of each aspect of mental adjustment is as follows;

⇒ *Fighting Spirit:*

Patient fully accepts diagnosis, adopts an optimistic attitude, seeks information and is determined to fight the disease.

⇒ *Helplessness/Hopelessness:*

Patient is engulfed by knowledge of the diagnosis, daily life is disrupted by a pre-occupation with the diagnosis and dying (Greer and Watson, 1987).

⇒ *Anxious Pre-occupation:*

Persistent anxiety which may be accompanied by depression. The patient seeks information but tends to interpret it pessimistically.

⇒ *Denial/Avoidance:*

The patient either rejects the diagnosis or denies / minimises its seriousness.

⇒ *Fatalism:*

Stoic Acceptance, the patient accepts the diagnosis, does not seek further information and adopts a fatalistic attitude (Greer and Watson, 1987; Greer et al., 1989).

### *Evidence of Validity / Reliability*

The face validity of the Mental Adjustment to Cancer scale is impressive and it appears to assess a unique area of patients' well being. As a result we adapted the scale for use with stroke patients. Attempting to alter questions as little as possible we simply substituted the word 'stroke' for the word 'cancer' calling the adapted version The Mental Adjustment to Stroke (MAS) scale (Appendix C). The scale has not previously been used in stroke, but in cancer patients it has been shown to be acceptable to patients, easy to administer, reliable and stable over time (Greer and Watson, 1987).

As we had altered the scale and because it had not previously been used in stroke we tested the inter-rater reliability of the scale during our pilot study and the test-retest reliability over 12 months of the main study.

During the pilot study I administered the MAS as part of the primary patient questionnaire. Patients who had successfully completed the scale were administered it a second time by SM during her psychiatric interview (n = 13; refer to 2.6.2.). One of the thirteen patients who underwent both interviews during the pilot study failed to answer all forty questions. Therefore when each question was analysed individually either 12 or 13 of the 20 pilot patients had completed each question twice.

During the main study the MAS formed part of the independently completed secondary patient questionnaire and was thus given to all patients who had successfully completed the primary patient questionnaire. The method of administration was altered for two reasons: the results of our inter-rater reliability testing suggested that there was some influence of the interviewer on patients' responses (Table 2-4) and patients had no difficulty with the questions suggesting that they would be able to complete it alone. For the first year of the main study patients who successfully completed the primary patient questionnaire also received a further follow up from a psychiatrist (SM) who left patients with a self completion version of the MAS and a SAE for its return. Thus in the test-retest study the MAS was completed on both occasions as a self report measure rather than being interviewer administered as in the pilot.

### The Inter-Rater Reliability of the MAS Scale:

The inter-rater reliability of each question on the MAS Scale was analysed by computing percentage agreement between first and second response and by calculating the Kappa statistic. The results of this analysis are illustrated in Figure 2-4. For the purposes of analysis question responses were coded as 0,0,1,1, that is categorised as 'Does not apply to me' or 'Applies to me'.

Categorising the Kappa values according to the method of Brennan and Silman (1992) eight (21%) questions had very good agreement between each testing (Kappa 0.81-1.0), and a further nine (24%) questions good agreement (Kappa 0.61-0.80). Eight (21%) questions had moderate agreement between testings (Kappa 0.41-0.6), seven (18%) questions fair agreement (Kappa 0.21-0.4) and six (16%) questions poor agreement (Kappa <0.20). It was not possible to calculate Kappa values for the remaining two questions because if on one presentation of a question all patients respond in the same manner an 'empty row' is created which precludes the calculation of the Kappa statistic. For all questions at least 50% of patients responded with the same answer on both testings (Table 2-4).

Consideration of the results of this reliability study must be qualified with due consideration of the extremely small sample size. Rather than being simply a study of the inter-rater reliability of the MAS scale the methodology used combined both an assessment of the inter-rater reliability of the scale and its test-retest reliability. The sample of only 13 patients meant that the study had very limited power but the fact that 35% of the sample were unable to give any answers at all may be a more relevant fact in assessing the utility of the test than any assessment of reliability. Our small exploratory study can only provide a very limited guide to the reliability of this measure.

**Table 2-4: The percentage agreement and Kappa values calculated between first and second completion of the MAS Scale to reflect inter-rater reliability.**

| % | Kappa | Question |
|---|---|---|
| 100.0 | 1 | I worry about the stroke returning or getting worse. |
| 100.0 | 1 | I've had a good life what's left is a bonus. |
| 100.0 | 1 | I think of other people who are worse off. |
| 100.0 | 1 | I feel completely at a loss about what to do. |
| 100.0 | 1 | I count my blessings. |
| 100.0 | 1 | I believe that my that my positive attitude will benefit my health. |
| 100.0 | 1 | I feel that nothing I can do will make any difference. |
| 100.0 | 1 | I feel that life is hopeless. |
| 92.3 | * | I think my state of mind can make a lot of difference to my health. |
| 92.3 | 0.75 | I suffer great anxiety about it. |
| 92.3 | 0.75 | At the moment I take one day at a time. |
| 92.3 | 0.63 | I feel like giving up. |
| 92.3 | 0.63 | I try to have a very positive attitude. |
| 92.3 | 0.75 | I feel fatalistic about it. |
| 92.3 | 0.75 | I firmly believe that I will get better. |
| 84.6 | 0.58 | I feel that there is nothing I can do to help myself. |
| 84.6 | -0.08 | I try to carry on my life as I've always done. |
| 84.6 | 0.41 | I am determined to put it all behind me. |
| 84.6 | 0.41 | I try to keep a sense of humour about it. |
| 84.6 | 0.63 | I try to fight the illness. |
| 83.3 | 0.56 | I have been doing things that I believe will improve my health, e.g., exercised. |
| 83.3 | 0.63 | I've put myself in the hands of God. |
| 83.3 | 0.64 | I've left it all to my doctors. |
| 76.9 | 0.42 | Other people worry about me more than I do. |
| 76.9 | 0.32 | I see my illness as a challenge. |
| 76.9 | 0.52 | I feel very angry about what has happened to me. |
| 76.9 | 0.42 | I don't really believe I had a stroke. |
| 75.0 | 0.31 | Since my stroke I now realise how precious life is and I'm making the most of it. |
| 75.0 | 0.4 | I have plans for the future, e.g. holiday, jobs, housing. |
| 69.2 | 0.41 | I have difficulty believing that this happened to me. |
| 69.2 | 0.16 | I am not very hopeful about the future. |
| 69.2 | * | I avoid finding out more about it. |
| 61.5 | 0.2 | I would like to make contact with others in the same boat. |
| 61.5 | -0.23 | I feel I can't do anything to cheer myself up. |
| 61.5 | 0.24 | I am trying to get as much information as I can about strokes. |
| 61.5 | 0.24 | I feel that problems with my health prevent me from planning ahead. |
| 61.5 | 0.2 | I keep quite busy, so I don't have time to think about it. |
| 61.5 | 0.24 | I don't dwell on my illness. |
| 53.8 | 0.15 | I feel that I can't control what is happening. |
| 50.0 | -0.13 | I have been doing things that I believe will improve my health e.g. changed my diet. |

*Note: No Kappa value is quoted for two questions as on one presentation for each question all patients responded with the same response thus creating an 'empty row' precluding a kappa value from being calculated.

**The Test-Retest Reliability of the MAS Scale:**

The test-retest reliability of the MAS Scale was also analysed using the 0,0,1,1 coding format calculating the percentage agreement and Kappa value between first and second completion (Table 2-5).

The test-retest reliability of the MAS Scale (n=97) was very good in three (7.5%) questions (Kappa 0.81-1.0), good in 13 (32.5%) questions (Kappa 0.61-0.8), moderate in 17 (42.5%) questions (Kappa 0.41-0.6), fair in six (15%) questions (Kappa 0.21-0.4) and poor in only one (2.5%) question (Kappa <0.2). Percentage agreements between first and second responses were consistently high, never falling below 67.7% with 32 (80%) questions achieving more than 80% agreement.

The results of my examination of the MAS's test-retest reliability are much better than those of the measure's inter-rater reliability suggesting that in this context it is preferable to use this measure as a self report scale as it may be susceptible to interviewer influence.

### *Alternative Measures Considered*

The Mental Adjustment to Stroke Scale was included in this study in the hope that it might illustrate the effect of the SFCW as well as for inherent interest.

**Table 2-5: The percentage agreement and Kappa values calculated between first and second completion of the MAS Scale to reflect test-retest reliability.**

| % | Kappa | Questions |
|---|---|---|
| 97.87 | 0.89 | I feel like giving up. |
| 94.62 | 0.52 | I try to have a very positive attitude. |
| 93.62 | 0.63 | I feel that life is hopeless. |
| 93.55 | 0.37 | I count my blessings. |
| 93.48 | 0.84 | At the moment I take one day at a time. |
| 92.78 | 0.59 | I believe that my positive attitude will benefit my health. |
| 92.63 | 0.5 | I think of other people who are worse off. |
| 92.47 | 0.33 | I think my state of mind can make a lot of difference to my health. |
| 91.58 | 0.82 | I've put myself in the hands of God. |
| 91.4 | 0.55 | I am determined to put it all behind me. |
| 91.4 | 0.55 | Since my stroke I now realise how precious life is and I'm making the most of it. |
| 91.3 | 0.59 | I try to fight the illness. |
| 91.2 | 0.62 | I feel completely at a loss about what to do. |
| 90.32 | 0.47 | I try to keep a sense of humour about it. |
| 89.58 | 0.49 | I firmly believe that I will get better. |
| 89.36 | 0.64 | I feel that nothing I can do will make any difference. |
| 89.25 | 0.68 | I feel fatalistic about it. |
| 89.01 | 0.76 | I would like to make contact with others in the same boat. |
| 89.01 | 0.64 | Other people worry about me more than I do. |
| 87.23 | 0.73 | I am trying to get as much information as I can about strokes. |
| 87.23 | 0.65 | I keep quite busy, so I don't have time to think about it. |
| 87.1 | 0.43 | I feel that there is nothing I can do to help myself. |
| 86.81 | 0.65 | I suffer great anxiety about it. |
| 86.17 | 0.46 | I have plans for the future, e.g. holiday, jobs, housing. |
| 86.02 | 0.62 | I've had a good life and what's left is a bonus. |
| 85.87 | 0.65 | I feel very angry about what has happened to me. |
| 85.57 | 0.69 | I feel that problems with my health prevent me from planning ahead. |
| 84.04 | 0.35 | I have been doing things that I believe will improve my health. |
| 82.8 | 0.18 | I try to carry on my life as I've always done. |
| 82.65 | 0.35 | I feel I can't do anything to cheer myself up. |
| 81.91 | 0.59 | I've left it all to my doctors. |
| 81.72 | 0.63 | I worry about the stroke returning or getting worse. |
| 79.35 | 0.56 | I feel that I can't control what is happening. |
| 79.35 | 0.57 | I have difficulty believing that this happened to me. |
| 78.35 | 0.5 | I have been doing things that I believe will improve my health. |
| 77.42 | 0.43 | I am not very hopeful about the future. |
| 77.17 | 0.48 | I see my illness as a challenge. |
| 77.17 | 0.5 | I don't really believe I had a stroke. |
| 74.19 | 0.36 | I avoid finding out more about it. |
| 67.7 | 0.33 | I don't dwell on my illness. |

### *2.7.5 Measures to assess the possible mechanisms of psychosocial outcome.*

The following measures were not included in this study to directly evaluate our SFCW. Rather they were included in the hope that they might shed light on some of the causes of poor psychosocial outcome after stroke.

#### *2.7.5.1 Recovery Locus of Control Scale:*

*Origins*

Recovery locus of control refers to the extent to which individual patients believe that their recovery is determined by themselves (internal control) or factors outwith their influence such as chance or other people (external control). Higher internal locus of control has been associated with higher self esteem and a more positive outcome, whereas higher external locus of control, the perception of having reduced control over events, has been associated with poorer outcomes (Moore and Stambrook, 1992).

The Recovery Locus of Control Scale (RLOC; Appendix B; Partridge and Johnston, 1989) was specifically designed for use with patients currently suffering a physical disability and included stroke patients in its developmental sample. As an internal locus of control is associated with better outcomes, perhaps through increasing adaptive coping or through increased involvement in rehabilitation, the level of internal locus of control may be useful in predicting improved health outcomes in individuals with physical disability. The Recovery Locus of Control Scale has indeed been shown to predict outcome independently of the initial severity of patient disability (Partridge and Johnston, 1989).

*Structure and Coding*

The RLOC scale asks questions regarding a patient's personal belief in the extent to which they think future events are determined by both internal and external factors. It has nine questions, five relating to internal control and four to external control. Questions relating to internal control are scored 5,4,3,2,1, where a response of 'strongly disagree' scores 1. Questions on external control are scored 1,2,3,4,5 where a response of 'strongly disagree' is scored five. This gives a possible score range of 9-45 with a higher number indicating greater belief in internal control.

In addition three further questions under development by the scale's authors at the time were included. These referred to a locus of control in the effect of powerful others (questions 3, 6, 9). During the period of analysis consultation with the scale's authors revealed that development work on these additional questions suggested that they were not reliable and that they should no longer be used. We therefore excluded their results from the analysis using the scale's original nine questions.

*Evidence of Validity / Reliability*

The RLOC scale has been found to have both construct and predictive validity, and to be internally consistent, in patients suffering from stroke or wrist fracture and undergoing physiotherapy (Partridge and Johnston, 1989). No further research has been conducted regarding the scale's reliability.

*Alternative Measures Considered*

No alternative measure exists specifically for patients who already have a disability. The Health Locus of Control Scale and Multidimensional Health Locus of Control Scale primarily focus on control over preventative health behaviours and Rotter's I-E scale, while frequently used, does not specifically address health control (Partridge and Johnston, 1989).

*Justification for Measure Selection*

The Recovery Locus of Control Scale is the only available scale specifically designed to assess perceived control over recovery of an existing disability. Its developmental sample included stroke patients in whom it appears to have both predictive and construct validity.

### *2.7.5.2 Medical Coping Modes Questionnaire:*

*Origins*

The Medical Coping Modes Questionnaire (MCMQ; Appendix B; Feifel et al., 1987) was designed to assess the methods of coping adopted in physically ill populations with either illnesses that are a threat to life or those that are not. It was developed from a sample including patients within three months after a myocardial infarction, patients with chronic illnesses or disabilities that were not a threat to life (e.g. rheumatoid arthritis), and patients with cancer. The methods patients use to cope with their illness are increasingly recognised as having an influence on the recovery process. Thinking of illness as a challenge, something to be confronted, and the endorsement of behavioural action strategies is related to reduced incidence of mood symptoms (O'Rourke et al.,1995; Sinyor et al., 1986*a*; Schussler, 1992). Conversely high levels of avoidance or acceptance/resignation are correlated with an increased risk of negative mood symptoms and less effective coping (O'Rourke et al., 1995; Feifel et al., 1987).

Whilst the MCMQ, MAS and the RLOC describe their overall focus of measurement in different terms, i.e. medical coping mode, mental adjustment and recovery locus of control respectively, it should be noted that some overlap may exist as the descriptions of their constituent dimensions appear similar. For example, confrontation (MCMQ) may be similar to fighting spirit (MAS), avoidance (MCMQ) may be similar to denial / avoidance (MAS) and likewise an internal locus of control (RLOC) may reflect aspects of a confrontational coping mode (MCMQ) or the possession of fighting spirit (MAS).

*Structure and Coding*

The MCMQ has three subscales Confrontation, Avoidance, and Acceptance / Resignation with eight, seven and four items respectively. Each question is scored 1,2,3,4, with the direction of scoring reversed for some questions; a higher score reflects increasing use of the subscales' coping method.

### *Evidence of Validity / Reliability*

The scale has been shown to possess construct validity when compared to the results of personality tests, alternative questions asking patients about their attitudes and coping reactions, and responses of physicians and relatives regarding the patient's attitude and coping reactions. Within scale correlation coefficients were 0.70 for the confrontation scale, 0.66 for the avoidance scale and 0.67 for the acceptance resignation scale (Feifel et al., 1987).

### *Alternative Measures Considered*

A number of scales designed to measure use of coping methods are available including the Ways of Coping Checklist (68 items; Folkman and Lazarus, 1980), the Ways of Coping - Revised Scale (67 items; Folkman and Lazarus, 1985), the Revised Ways of Coping Checklist (42 items; Vitaliano et al., 1989), the Coping Styles Questionnaire (44 items; Roger et al., 1993) and the Jalowiec Coping Scale (40 items; Jalowiec et al., 1984). However, none of these were specifically developed for use in a physically ill sample, none have been used in stroke and all are very long with a minimum of 40 questions (Roger et al., 1993; Vitaliano et al., 1989). The one coping scale that has previously been used in stroke was based on an altered version (COPE; Kaloupek et al., 1984) of a Coping Checklist developed on a healthy community sample (Billings and Moos, 1981) and still required further alteration to make it suitable for use in stroke (Sinyor et al., 1986*a*). These additional changes were not specified by the authors to allow their use in subsequent studies (Sinyor et al., 1986*a*).

### *Justification for Measure Selection*

The MCMQ was chosen as it had the advantage of being short, specifically designed to assess coping responses to a current illness, and was developed on a sample including patients similar to our own in terms of disability and threat to life.

### 2.7.6 Measure of satisfaction with treatment.

#### 2.7.6.1 The Patient Satisfaction Scale:

*Origins*

Our Patient Satisfaction Scale (PSS; Appendix C) was an amalgamation of the Hospsat and Homesat questionnaires (Pound et al., 1994) plus seven additional questions. The Hospsat and Homesat patient satisfaction questionnaires were developed as a disease specific measure of patient satisfaction with both inpatient and outpatient care after stroke. Questions were derived from in-depth interviews with stroke survivors, the views of consultants and literature review and were tested on 149 patients six months after stroke. In addition we developed a further seven questions which addressed areas of satisfaction that our Stroke Family Care Worker might be expected to influence.

*Structure and Coding*

Each question takes the form of a positive statement about the patient's treatment and care with the response options, 'Strongly agree', 'Agree', 'Disagree', and 'Strongly disagree' (Pound et al., 1994). Our additional seven questions utilised the same question and response format. The resulting questionnaire (The Patient Satisfaction Scale, PSS) contained 20 questions each of which was scored 0,0,1,1, giving a score range of 0 to 20 where a higher score indicated greater dissatisfaction.

*Evidence of Validity / Reliability*

The Hospsat and Homesat scales have been shown to have both convergent validity and some degree of discriminative validity, with internal consistency and test-retest reliability being good for 11 of the questions (Pound et al., 1994). These results are especially applicable to the present sample as both the test and present study sample were patients six months after stroke. The seven additional questions possessed good face validity.

**Study of test -retest reliability:**

During the pilot study we examined the test-retest reliability of the Patient Satisfaction Scale (PSS) inclusive of our additional seven questions which had undergone no previous testing. As in the main study pilot study patients completed the PSS as part of the secondary independently completed questionnaire. During the subsequent psychiatric interview (refer to 2.6.2) patients were left with a second copy of the PSS again for independent completion and return.

The test-retest reliability of the scale was analysed using percentage agreement categorising responses as satisfied or dissatisfied, thus questions were coded 0,0,1,1. The small number of patients completing measures led to empty rows or columns when scores were cross-tabulated which meant that it was not possible to use the Kappa statistic on the majority of questions. The results of this analysis are illustrated in Table 2-6 at the end of this section.

**Table 2-6: The test-retest reliability of the patient satisfaction scale with percentage agreement between first and second completion.**

| % | n | Questions |
|---|---|---|
| 100 | 11 | I have been treated with kindness and respect by the staff at the hospital. |
| 100 | 10 | The staff attended well to my personal needs while I was in hospital. |
| 100 | 11 | I was able to talk to the staff about any problems I might have had. |
| 100 | 11 | I have received all the information I want about the causes and nature of my stroke. |
| 100 | 11 | The doctors have done everything they can to make me well again. |
| 100 | 7 | I am satisfied with the type of treatment the therapists have given me. |
| 100 | 5 | Things were well prepared for my return home (i.e. aids had been organised if necessary). |
| 100 | 4 | I get all the support I need from services such as meals on wheels, home helps etc. |
| 100 | 6 | I am satisfied with the outpatient services provided by the hospital. |
| 100 | 7 | I think the ambulance service is reliable. |
| 100 | 5 | *I am satisfied with the practical help I have received since I left hospital* |
| 100 | 7 | *I have received enough information about recovery and rehabilitation after stroke* |
| 100 | 6 | *Somebody has really listened and understood my needs and problems since I left hospital.* |
| 100 | 8 | *I have not felt neglected since I left hospital.* |
| 100 | 6 | *I have had enough emotional support since I left hospital.* |
| 100 | 5 | *I have received enough special equipment (e.g. rails, wheelchairs, commode etc.).* |
| 100 | 9 | *I know who to contact if I have a problem relating to my stroke.* |
| 90.9 | 11 | I am happy with the amount of recovery I have made. |
| 83.3 | 6 | I have had enough therapy. |
| 83.3 | 6 | I was given all the information I needed about allowances and services after leaving hospital. |

Note: Due to limitations of space some questions have been truncated, please refer to Appendix C for questions in their original form. Questions in italics are those added for the purposes of the present study.

Test-retest results were very encouraging with 85% of questions achieving perfect agreement between the responses on the first and second completion. However our sample size of between four and 11 patients is extremely small and our results therefore provide only a possible indication of the reliability of the measure. A much larger study would be neccessary before any confident assertion could be made that the PSS had satisfactory test-retest reliability.

*Alternative Measures Considered*

There were no alternative disease specific measures of patient satisfaction available.

*Justification for Measure Selection*

We chose to include the Hospsat and Homesat scales in the present study because they represented the only patient satisfaction scales specifically developed on and for stroke patients and because they were applicable both to pre and post discharge. Furthermore the scale appeared to have been developed using good methodology, and had some evidence of validity and reliability.

## 2.7.7 Measures of services used and equipment received.

### 2.7.7.1 Service Use & Equipment Received Questionnaires:

*Origins*

We wished to find out if our SFCW affected the number of services or amount of equipment received. To this end we devised two questionnaires, one enquiring after service use and one about equipment received (Appendix C), with the intention of allowing a cost comparison between treatment and control groups.

*Structure and Coding*

The service use questionnaire asked patients whether, since discharge, they had received any physical, occupational or speech therapy, visited or been visited by their General Practitioner, been visited by a District Nurse, Social Worker, Home Help or the Meals on Wheels Service, or received chiropody or respite care. Questions concerning therapy or district nursing also asked where the service was received, how often (once, occasionally or regularly), and if regularly, how many times each week for how many weeks. The remaining questions asked if the service had been received and if it had then on how many occasions.

The Equipment Received Questionnaire simply listed items of equipment in seven categories, Kitchen, Bath, Seating, Walking, Toilet, Stair and Wheelchair Aids, and asked patients to tick in either the box marked 'yes' or the box marked 'no' to indicate whether they had received the equipment.

### *Evidence of Validity / Reliability*

A pilot test comparing patients' records to their responses on the service and equipment use questionnaires was considered desirable but was not conducted due to time constraints. The measures underwent no development work.

### *Alternative Measures Considered*

We were not aware of any suitable alternatives.

### *Justification for Measure Selection*

While throughout the follow up we endeavoured to use measures that had been previously used in outcome studies, preferably in stroke, the lack of any alternative measure of service and equipment use led us by necessity to design our own.

# 3. A Description of Our Patients At Baseline and Six Months

In this chapter I will describe the patients included in this study, their follow up at six months and their psychosocial outcome.

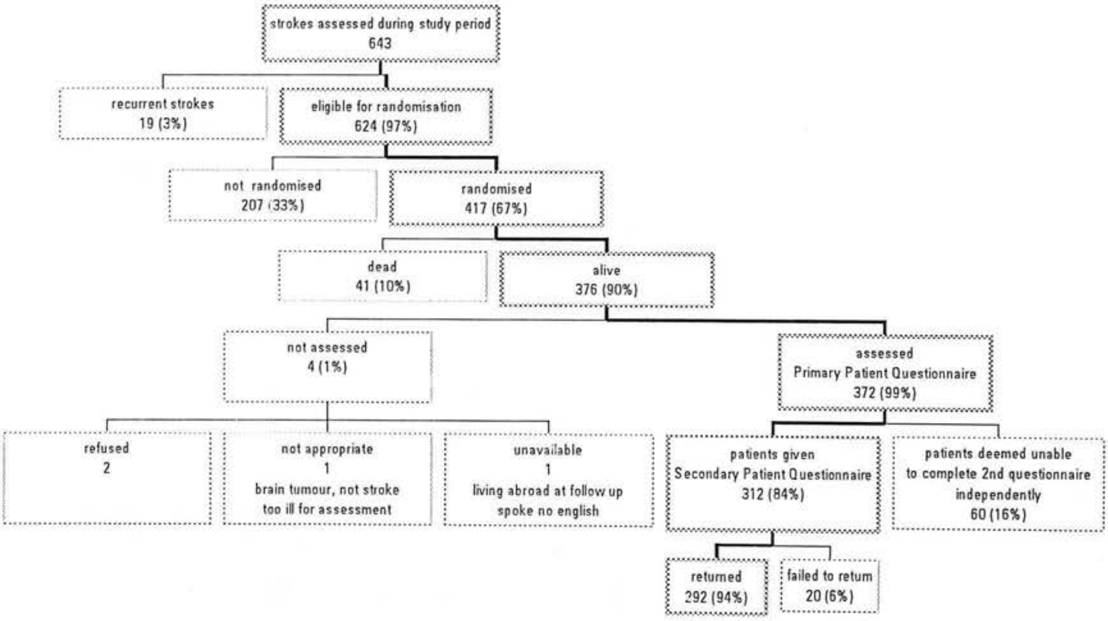
I will first compare the baseline characteristics of those randomised in our trial with those patients who were assessed at the study hospital but not randomised. The baseline characteristics of randomised patients, including their demographic data, their medical history and the history of the present event, will then be described before detailing the completion rates for outcome measures in the six month follow up.

## 3.1 Patients

### *3.1.1 Numbers referred, randomised, and assessed at six months.*

During the two year randomisation period, 643 cases of stroke were assessed, 19 (3%) of these were referred twice having had both a first and a recurrent stroke during the study period and were not eligible for randomisation a second time. Of the remaining 624 patients, 417 (67%) were randomised in the trial. At six months post stroke, 372 (89%) of the 417 patients randomised were followed up, 41 (10%) patients had died and four (1%) were not interviewed; two who refused, one whose diagnosis had been altered to brain tumour and one who was no longer resident in UK (Figure 3-1).

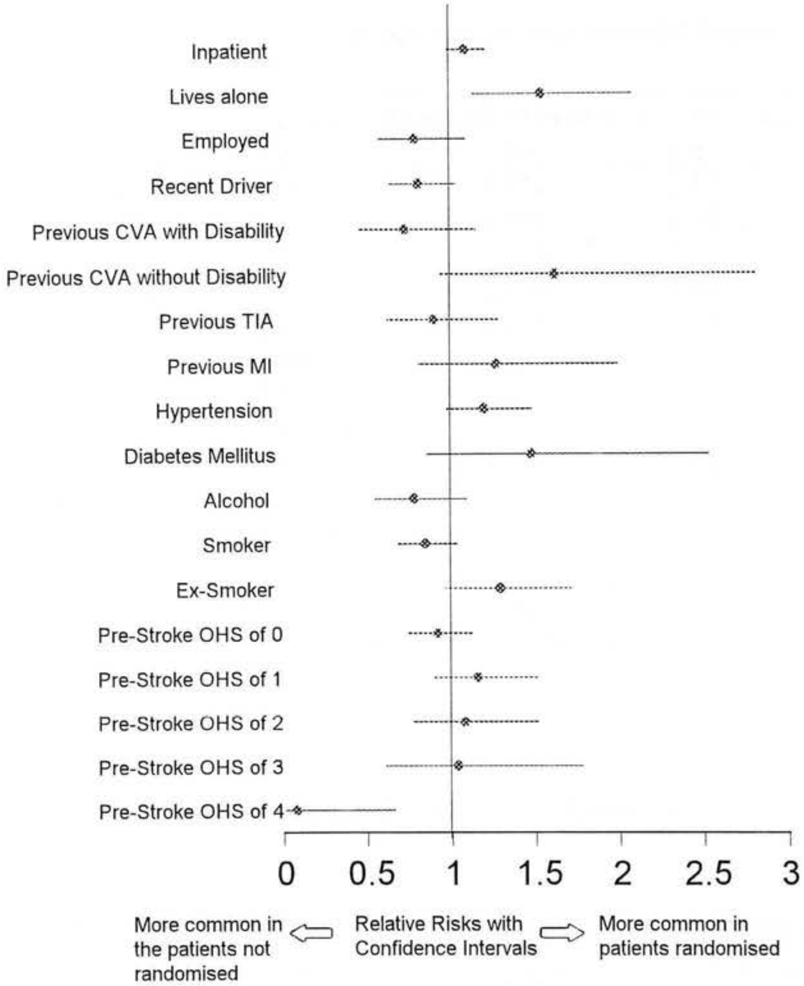
**Figure 3-1: Patients referred, randomised and assessed during study period.**



### 3.1.2 How representative of all patients referred were the patients randomised to the study?

Patients who were randomised (n=417) were compared to those who were excluded by our eligibility criteria (n= 207) (refer to 2.4).

**Figure 3-2: Comparison of baseline variables in patients referred to the study hospital with stroke who were randomised and those who were not.**



Note: TIA= Transient Ischemic Attack; MI= Myocardial Infarction; OHS= Oxford Handicap Scale.

The trial sample (n=417) was reasonably representative of stroke patients assessed during the trial period with only four significant differences between the groups on baseline variables

(Figure 3-2 and Table 3-1). Randomised patients were significantly older (p=0.006) and more likely to live alone (p=0.003) reflecting a tendency to select patients most likely to benefit from the influence of our SFCW. This difference in ages is reflected in the tendency of patients not randomised to be more likely to be employed. Of patients not randomised 45.4% were 65 years or under whereas in the randomised group only 37.5% were in this age range. The randomised group were significantly less likely to have a pre-stroke Oxford Handicap Scale score of four, (p= 0.003), showing that patients unlikely to survive were not randomised.

**Table 3-1: Comparison of the age distribution amongst patients who were randomised and those who were not.**

| Age Group | Patients Randomised (n=416*) | | Patients Not Randomised (n=207) | |
|---|---|---|---|---|
| | n | % | n | % |
| < 41 years | 16 | 3.8% | 12 | 5.8% |
| 41 - 50 years | 19 | 4.6% | 20 | 9.7% |
| 51 - 60 years | 71 | 17.1% | 37 | 17.9% |
| 61 - 70 years | 120 | 28.8% | 65 | 31.4% |
| 71 - 80 years | 121 | 29.1% | 48 | 23.2% |
| 81 - 90 years | 68 | 16.3% | 23 | 11.1% |
| > 90 years | 1 | 0.2% | 2 | 1% |
| Range | 18 - 92 | | 20 - 95 | |
| Mean | 67.8 | | 64.6 | |
| Median | 69 | | 67 | |
| T- Test of difference between means | p value = 0.006 | | | |

*The age for one randomised patient is missing.
Percentages are rounded and therefore may not add up to 100.

### *3.1.3 Characteristics of patients randomised*

Baseline patient assessment included demographic data and abilities prior to the event (Table 3-2), relevant medical history (Table 3-3) and a history of the stroke itself (Table 3-4). Baseline assessments were a median of 51 hours after stroke onset (range 2 - 576 hours, mean 103 hours). One hundred and thirty five patients (32%) were seen within 24 hours of stroke onset, 200 (48%) within 48 hours, 257 (62%) within 72 hours and 337 (81%) within one week.

The majority of patients were between 50 and 90 years old (n = 380, 91%), with, as previously stated, only 37.5% (n=156) 65 years or under reflected in low employment figures immediately prior to the event (n = 78, 19%). One third of patients lived alone (n = 135, 32%).

**Table 3-2: Patients' demographic data and abilities prior to event.**

| Patient Characteristic | | Number for whom data is available | Patients with characteristic n | % |
|---|---|---|---|---|
| Male | | 417 | 208 | 50% |
| Age | < 40 years | 416 | 16 | 4% |
| | 41 - 50 years | | 19 | 5% |
| | 51 - 60 years | | 71 | 17% |
| | 61 - 70 years | | 120 | 29% |
| | 71 - 80 years | | 121 | 29% |
| | 81 - 90 years | | 68 | 16% |
| | > 90 years | | 1 | 0% |
| Mean Age | 67.8 | | | |
| Median Age | 69 | | | |
| Lives alone | | 417 | 135 | 32% |
| Employed until this event | | 416 | 78 | 19% |
| Car driver in last 3 months | | 411 | 125 | 30% |
| Oxford Handicap Scale before stroke | OHS = 0 | 417 | 158 | 38% |
| | OHS = 1 | 417 | 132 | 32% |
| | OHS = 2 | 417 | 87 | 21% |
| | OHS = 3 | 417 | 39 | 9% |
| | OHS = 4 | 417 | 1 | 0% |
| | OHS = 5 | 417 | 0 | 0% |

The patients' medical history revealed that 22% (n=92) had suffered a previous stroke and that the most prevalent risk factor was hypertension affecting nearly half the sample (n = 193, 47%) (Table 3-3). The majority of patients were inpatients (n = 324, 78%) (Table 3-4), many experienced a motor deficit (n=300, 72%) (Table 3-4), and almost half were unable to walk at time of assessment (n = 185, 44%) (Table 3-4).

**Table 3-3: Patients' medical history.**

| Patient Characteristic | Number for whom data is available | Patients with characteristic | |
|---|---|---|---|
| | | n | % |
| Previous stroke with residual disability | 417 | 41 | 10% |
| Previous stroke without residual disability | 417 | 51 | 12% |
| Current smoker | 416 | 158 | 38% |
| Ex smoker > 12 months | 415 | 134 | 32% |
| Alcohol > 2 units daily | 411 | 70 | 17% |
| Hypertension - history or treatment at any time | 415 | 193 | 47% |
| Diabetes mellitus known before stroke | 417 | 50 | 12% |
| Previous myocardial infarction | 417 | 62 | 15% |
| Atrial fibrillation known before stroke | 416 | 46 | 11% |
| Angina pectoris known before stroke | 416 | 77 | 19% |
| Breathless walking on an incline | 411 | 75 | 18% |
| Intermittent claudication | 413 | 52 | 13% |
| Cardiac surgery | 417 | 17 | 4% |
| Peripheral vascular surgery | 417 | 13 | 3% |
| Previous carotid endarterectomy | 417 | 3 | 1% |
| Known prior malignancy | 416 | 33 | 8% |
| Epilepsy known before stroke | 417 | 13 | 3% |

**Table 3-4: History of patients' strokes.**

| Patient Characteristic | | Number for whom data is available | Patients with characteristic | |
|---|---|---|---|---|
| | | | n | % |
| Side of brain lesion | Right | 417 | 169 | 41% |
| | Left | | 182 | 44% |
| | Brainstem / cerebellum | | 61 | 15% |
| | uncertain | | 5 | 1% |
| | bilateral | | 0 | 0% |
| Clinical classification* | | 417 | 64 | 15% |
| Total Anterior Circulation Stroke (TACS) | | | 161 | 39% |
| Partial Anterior Circulation Stroke (PACS) | | | 107 | 26% |
| Lacunar Circulation Stroke (LACS) | | | 67 | 16% |
| Posterior Circulation Stroke (POCS) | | | 18 | 4% |
| Admitted to hospital | | 417 | 324 | 78% |
| Hodkinson mental test score < 10 | | 332 | 179 | 54% |
| Glasgow coma scale score < 15 | | 417 | 92 | 22% |

* For an explanation of clinical classifications used see Table 4-7.

**Table 3-4 continued.**

| Patient Characteristic | | Number for whom data is available | Patients with characteristic n | % |
|---|---|---|---|---|
| Right handed | | 412 | 389 | 94% |
| Dysphasia | | 412 | 103 | 25% |
| Dysarthria | | 391 | 119 | 30% |
| Other cortical signs, e.g. neglect or visuospatial dysfunction | | 377 | 87 | 23% |
| Right hemianopia | | 390 | 40 | 10% |
| Left hemianopia | | 390 | 37 | 9% |
| Motor deficit | | 414 | 300 | 72% |
| Sensory deficit | | 361 | 105 | 29% |
| Cerebellar deficit | | 382 | 41 | 11% |
| Definite brainstem signs | | 417 | 37 | 9% |
| Unable to sit independently | | 417 | 89 | 21% |
| Unable to stand independently | | 417 | 146 | 35% |
| Unable to walk independently | | 417 | 185 | 44% |
| Incontinence of urine since stroke | | 416 | 82 | 20% |
| Seizure since symptom onset | | 417 | 10 | 2% |
| Clinical prediction of outcome at one year- Oxford Handicap Scale (OHS) | OHS = 0 | 417 | 35 | 8% |
| | OHS = 1 | | 146 | 35% |
| | OHS = 2 | | 91 | 22% |
| | OHS = 3 | | 88 | 21% |
| | OHS = 4 | | 27 | 6% |
| | OHS = 5 | | 3 | 1% |
| | OHS = 6 | | 27 | 6% |

### *3.1.4 Completion of patient measures.*

All 372 patients who underwent a follow-up interview were administered the primary patient questionnaire. However it was not possible to complete a full assessment in all patients primarily due to cognitive or communication difficulties. Tables 3-5 and 3-6 show the number of patients who attempted each measure, the number who successfully completed each and the reasons for non-completion.

The secondary patient questionnaire was designed for independent completion and so was not left with patients who were unable to successfully complete the primary patient questionnaire with my help. The secondary questionnaire was completed and returned independently so there was no opportunity to ask patients to complete any missed questions. Many questionnaires were therefore returned with either individual questions or entire pages missed. The Primary Patient Questionnaire is reproduced in Appendix B, and the Secondary Patient Questionnaire in Appendix C.

Patients referred to as 'unassessable' are those whose cognitive impairment or communication deficits meant that a complete assessment was not possible. Where patients are referred to as 'incomplete or missed' it means that they either refused to answer odd questions, refused to continue the assessment or returned questionnaires without completing every question.

**Table 3-5: Completion of primary patient measures.**

| **Measure** | **Unassessable** | **Incomplete or missed** | **Complete** | |
|---|---|---|---|---|
| Oxford Handicap Scale | 0 | 1 | 371 | 99.7% |
| Barthel Index | 0 | 3 | 369 | 99.2% |
| General Health Questionnaire | 41 | 21 | 310 | 83.3% |
| Frenchay Activities Index | 28 | 3 | 341 | 88.2% |
| Social Adjustment Scale | 48 | 0 | 324 | 87.1% |
| Recovery Locus of Control Scale | 62 | 4 | 306 | 82.3% |
| Medical Coping Modes Questionnaire | 65 | 8 | 299 | 80.4% |
| *Measures attempted in all 372 patients assessed at six months - completed with assessor* | | | | |

**Table 3-6: Completion of secondary patient measures.**

| **Measure** | **Incomplete or missed** | **Complete** | |
|---|---|---|---|
| Mental Adjustment to Stroke Scale | 59 | 233 | 79.8% |
| Patient Satisfaction Scale | 94 | 198 | 67.8% |
| Individual Service Use Questions | 12 - 32 | 260 - 280 | 89-96% |
| Categorised Equipment Received Questions | 14 - 32 | 260 - 278 | 89-95% |
| Hospital Anxiety and Depression Scale | 40 | 252 | 86.3% |
| *Secondary Questionnaire returned by 292 patients after independent completion.* | | | |

In order to assess the extent of psychosocial difficulties after stroke I first analysed the data to describe patients' outcome at six months. Each of our primary areas of outcome; patients' physical functioning, mood, social functioning including both activities and adjustment, and patients' mental adjustment are addressed in turn. The distribution of patients' scores on each measure are shown and, where possible, cutting points are used to allow the actual frequency of patients experiencing problems to be determined.

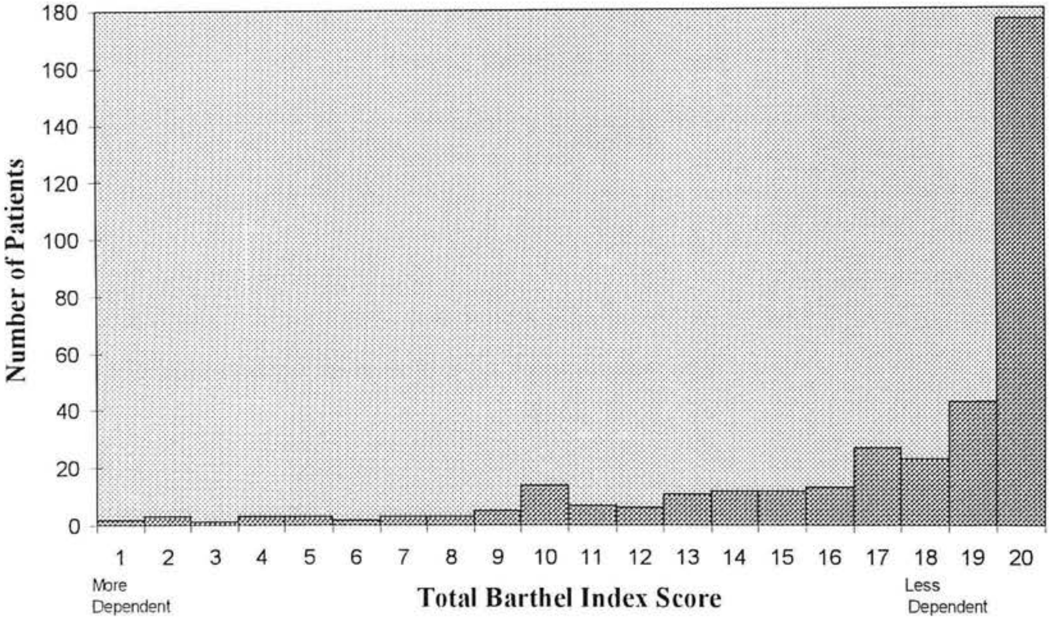
## 3.2 Patients' physical outcome.

Patients' scores on the Barthel Index (BI) and Oxford Handicap Scale (OHS) were recorded at their six month follow up.

### *3.2.1 The Barthel Index:*

On the Barthel Index, nearly half the patients 48% were rated as independent with a score of 20, 76% scored over 15 and only 7% scored less than 10 suggesting severely limited abilities.

**Figure 3-3: Distribution of patients' Barthel Index Scores with descriptive statistics.**

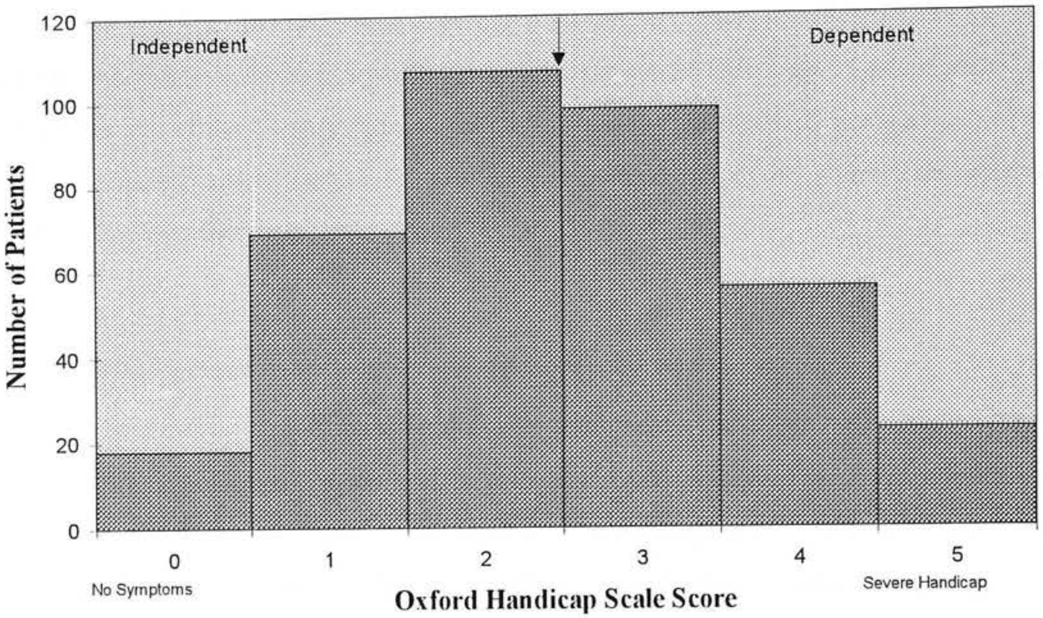


| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 369 | 17.2 | 19 | 1 - 20 |

### *3.2.2 The Oxford Handicap Scale:*

Similarly according to their OHS scores almost equal numbers of surviving patients were independent and dependent (52% scoring 0 - 2 indicating independence, 48% scoring 3-5 indicating dependence) (Figure 3-4).

**Figure 3-4: Distribution of patients' Oxford Handicap Scale scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 371 | 2.5 | 2 | 0 - 5 |

Therefore both of our measures show that approximately half of our sample were independent in the basic activities of daily living at their six month follow up.

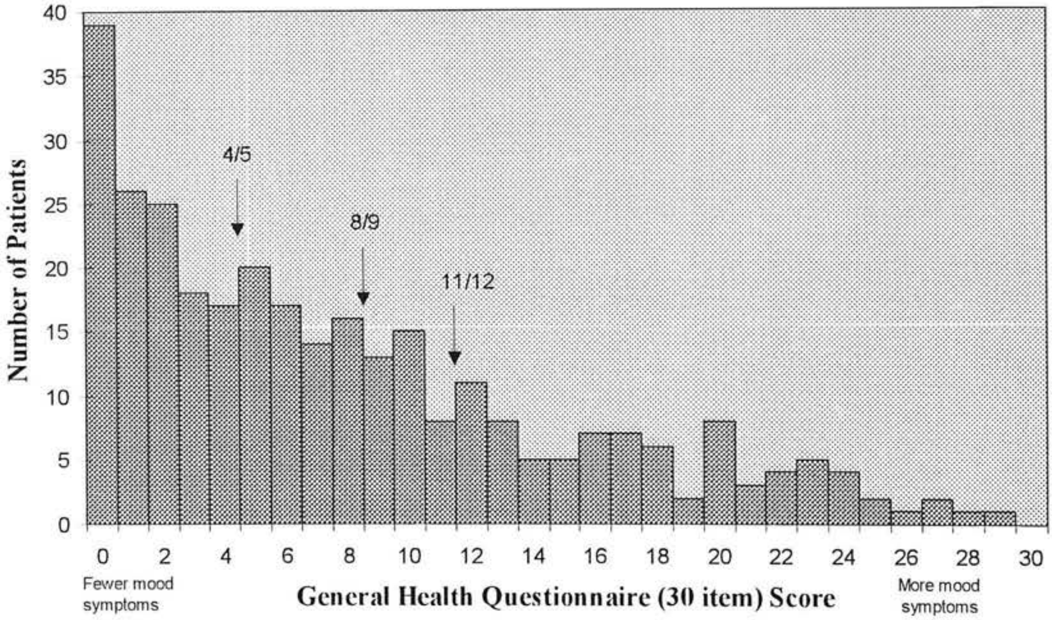
## 3.3 Patients' mood.

Patients' mood was measured in two ways at their six month follow up. I administered the GHQ-30 as part of the Primary Patient Questionnaire and I left the HAD Scale as part of the Secondary Patient Questionnaire for independent completion, to be returned as soon as possible after the assessment visit.

### 3.3.1 *The General Health Questionnaire - 30 item:*

To assess the prevalence of psychiatric illness we used three alternative GHQ cut-offs. These were 4/5, as recommended by the scale's authors but only validated on a GP sample, 8/9 which we found in our own study to be optimum in this sample (refer to 2.7.2.3) and 11/12 which has been recommended by the scale's authors for a neurology inpatient sample.

**Figure 3-5: Distribution of patients' General Health Questionnaire scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 310 | 7.9 | 6 | 0 - 29 |

The GHQ suggests that as many as 60% of patients were likely to be a psychiatric case when a low cut-off, 4/5, with high sensitivity was used. Even using a high cut-off, 11/12, and therefore a high specificity, the GHQ classified more than a quarter of patients as likely cases (Figure 3-5, Table 3-7).

**Table 3-7: Percentage of patients likely to be a psychiatric case using various cut-offs.**

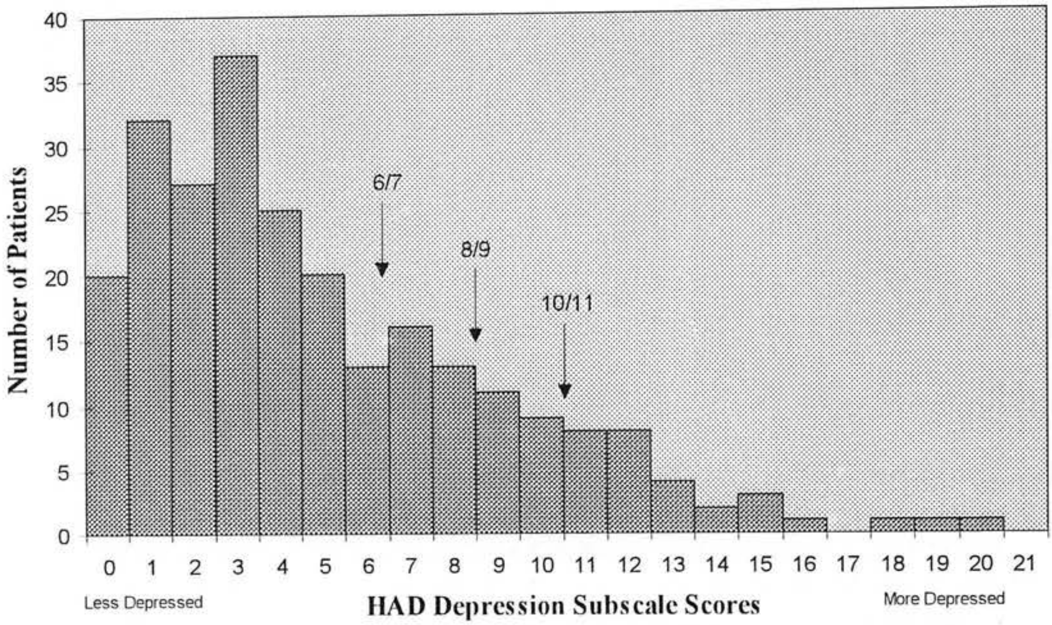
| | **Cut - off** | **Patients unlikely to be a psychiatric case** | | **Patients likely to be a psychiatric case** | |
|---|---|---|---|---|---|
| n = 310 | | **Number** | **%** | **Number** | **%** |
| | 4 / 5 | 125 | 40.3% | 185 | 59.7% |
| | 8 / 9 | 192 | 61.9% | 118 | 38.1% |
| | 11 / 12 | 228 | 73.5% | 82 | 26.5% |

### *3.3.2 The Hospital Anxiety and Depression Scale:*

The HAD Scale differs from the GHQ in having two subscales, depression and anxiety. It can therefore specify whether a patient's psychiatric state is likely to be a depressive or anxiety disorder. I analysed both HAD subscales using three cut-offs; 8/9 for a high sensitivity and 10/11 for a high specificity as recommended by the scale's authors and 6/7 as found to be optimum cut-off in our sample (refer to 2.7.2.3).

### The Depression Subscale

**Figure 3-6: Distribution of patients' Hospital Anxiety and Depression Scale, Depression Subscale scores with descriptive statistics**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 252 | 5.0 | 4 | 0 - 20 |

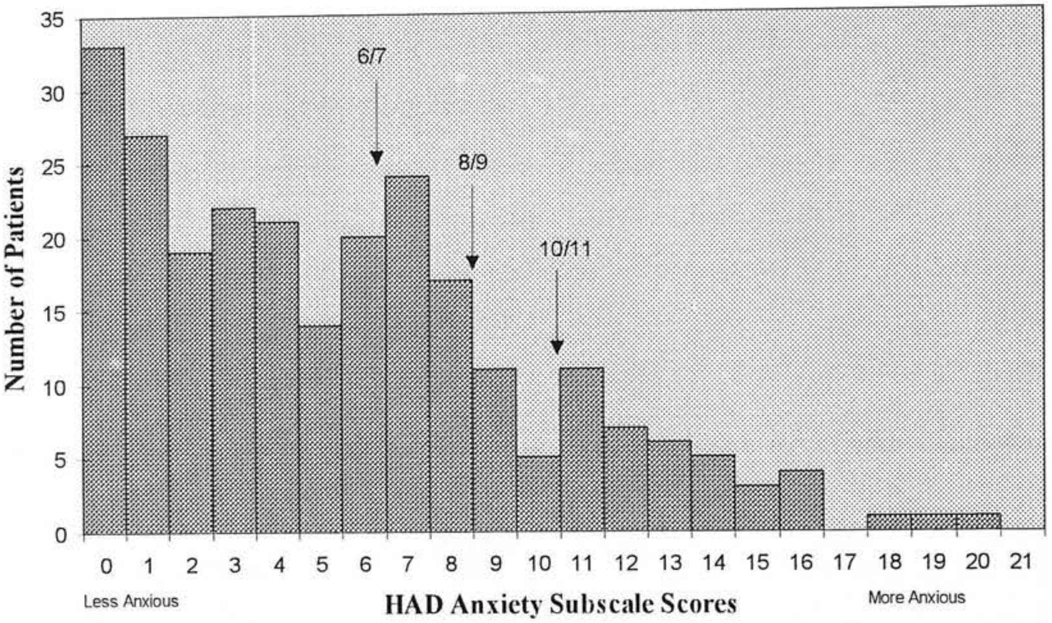
**Table 3-8: Percentage of patients likely to have a depressive disorder at various cut-offs.**

| | Cut - off | Patients unlikely to be a 'Depressed' | | Patients likely to be defined 'Depressed' | |
|---|---|---|---|---|---|
| n = 252 | | Number | % | Number | % |
| | 6 / 7 | 174 | 69% | 78 | 31% |
| | 8 / 9 | 203 | 80.6% | 49 | 19.4% |
| | 10 / 11 | 223 | 88.5% | 29 | 11.5% |

The HAD Depression Subscale classed between 11% and 31% of patients as depressed (Figure 3-6, Table 3-8).

## The Anxiety Subscale

**Figure 3-7: Distribution of Patients' Hospital Anxiety and Depression Scale, Anxiety Subscale scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 252 | 5.5 | 5 | 0 - 20 |

**Table 3-9: Percentages of patients likely to have an anxiety disorder at various cut-offs.**

| | Cut - off | Patients unlikely to be 'Anxious' | | Patients likely to be defined 'Anxious' | |
|---|---|---|---|---|---|
| n = 252 | | Number | % | Number | % |
| | 6 / 7 | 156 | 61.9% | 96 | 38.1% |
| | 8 / 9 | 197 | 78.2% | 55 | 21.8% |
| | 10 / 11 | 213 | 84.5% | 39 | 15.5% |

The HAD Anxiety Subscale suggests that patients were more likely to be experiencing heightened anxiety than depression with a range of between 15% and 38% of patients classified as anxious (Figure 3-7, Table 3-9).

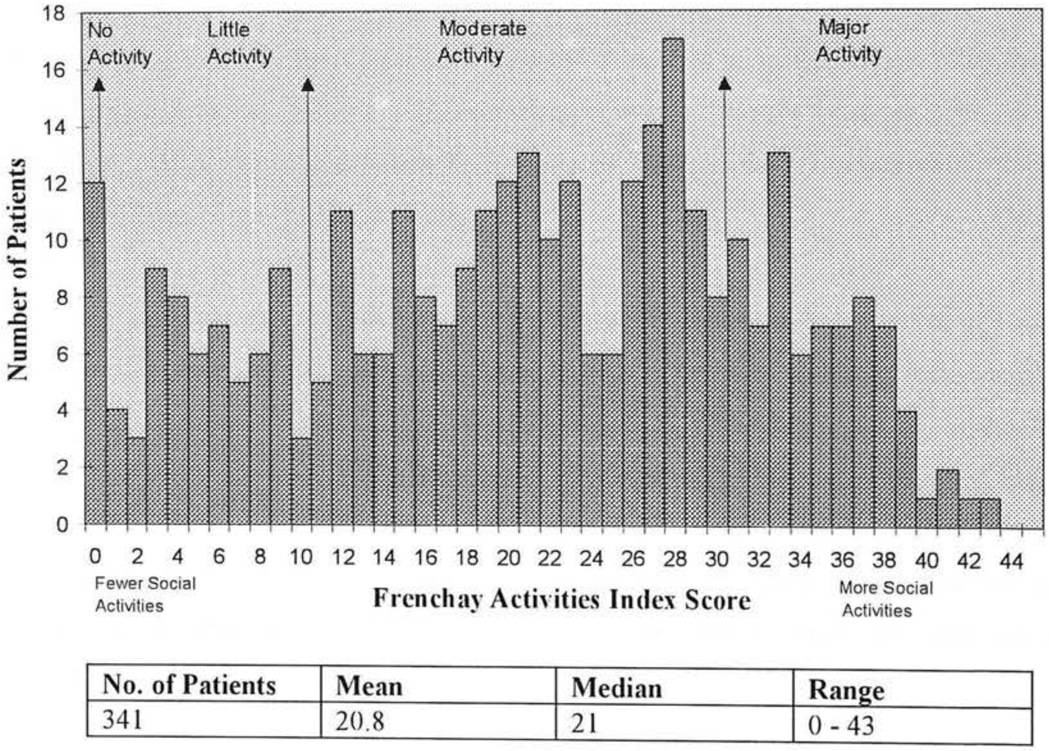
## 3.4 Patients' social functioning.

I administered two measures of patients' social functioning during their primary interview; one concerning their social activities, the Frenchay Activities Index (FAI), and one their social adjustment, the Social Adjustment Scale (SAS).

### 3.4.1 The Frenchay Activities Index:

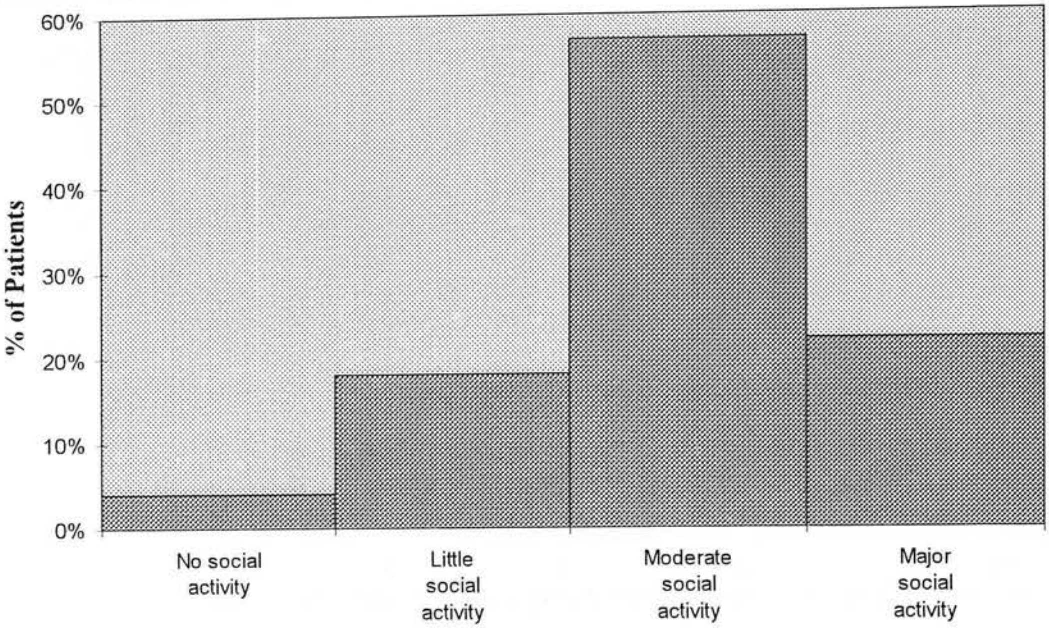
Many patients had attained reasonable levels of social functioning at their six month assessment with 21.7% (n = 74) reporting major activity (scores >30), 57.2% (n = 195) moderate activity (scored 11-30), 17.6% (n = 60) little activity (scored 1- 10) and 3.5% (n = 12) no activity (scored 0) (Figures 3-8 and 3-9).

**Figure 3-8: Distribution of Patients' Frenchay Activities Index scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 341 | 20.8 | 21 | 0 - 43 |

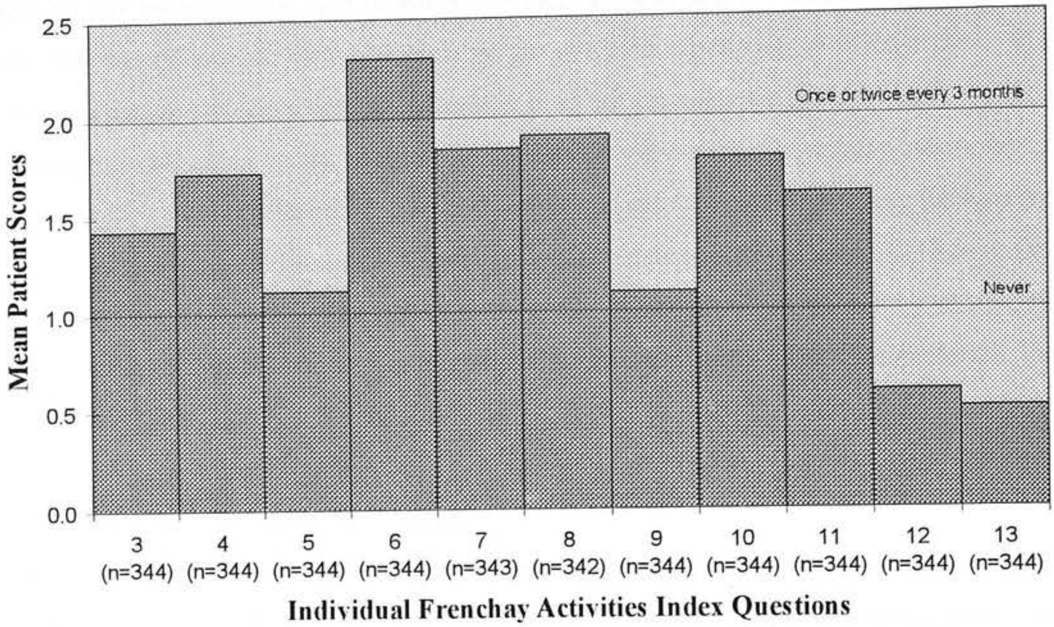
**Figure 3-9: Distribution of the percentage of patients in each category of social activities.**



Ten of the FAI's 14 questions use the same response categories in answer to how often they perform an activity this is 'Never', 'Less than once per week', 'Once or twice per week', and 'Most days'. This allows some limited comparisons between the frequency with which patients participate in various activities (Figure 3-10).

Figure 3-10 illustrates that few patients ever participate in gardening or household and car maintenance (questions 12 and 13). More often patients report local shopping (question 6), social activities (question 7) and walking outside for up to 15 minutes (question 8). It should be noted that mean scores, although very crude measures, never reached a score of three (which would indicate that the activity was undertaken between three and twelve times every three months), reflecting that the 'average' patient would undertake each activity either never or only once or twice every three months. However, this average score may obscure a bimodal distribution.

Figure 3-10: Mean patient scores on the ten individual Frenchay Activities Index questions which use the same response options.



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**Key to Figure 3-10.**

| In the last 3 months how often have you been:- | Patients' mean score |
|---|---|
| 3. Washing clothes? | 1.43 |
| 4. Doing light housework? | 1.73 |
| 5. Doing heavy housework? | 1.12 |
| 6. Local shopping? | 2.3 |
| 7. On social outings? | 1.84 |
| 8. Walking outside for up to 15 minutes? | 1.9 |
| 9. Actively pursuing a hobby? | 1.1 |
| 10. Driving a car or travelling on a bus? | 1.79 |
| 11. On any outings / car rides? | 1.6 |
| 12. Gardening? | 0.6 |
| 13. Doing household or car maintenance? | 0.5 |

Note: The number of patients answering each question alters as some patients did not answer all questions.

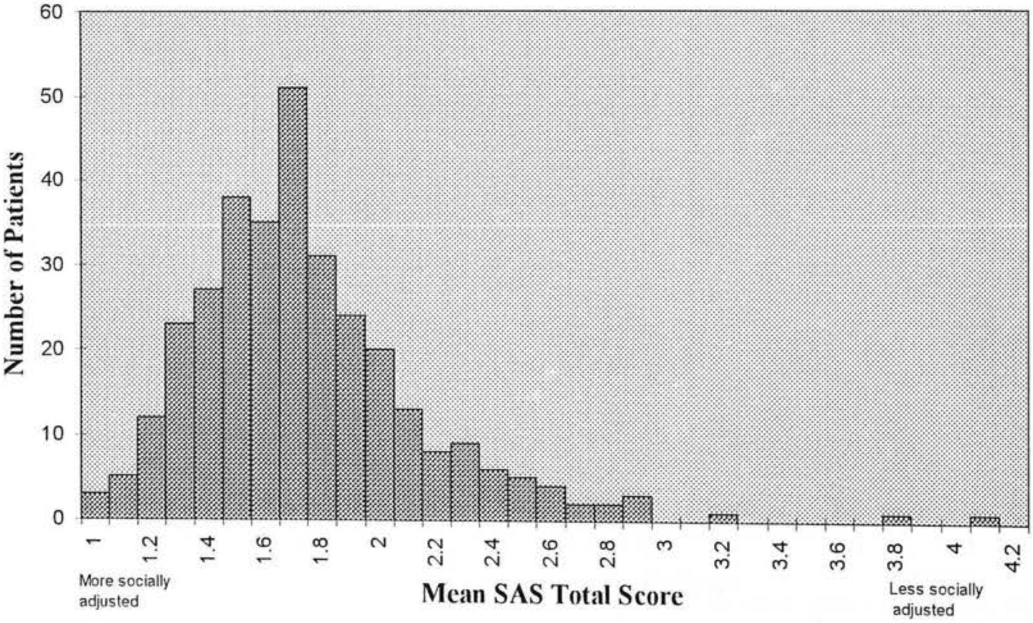
### *3.4.2 The Social Adjustment Scale:*

The SAS has six subscales each of which produces a mean score. Patients do not answer scales that do not apply to them and therefore the numbers completing each scale vary. For example, a patient who does not have a partner does not complete the partner subscale. The total score is calculated as the mean score of those questions that have been answered as directed by the authors (refer to 2.7.3.2.). No cut-offs or categories for describing SAS scores have been developed. Unfortunately no normative data exists that would allow us to comment on the severity or otherwise of our patients' reported symptoms. We hope that by presenting the distribution of patients' scores in this study we will provide a point of comparison for others in the future.

#### The Total Social Adjustment Scale Score

Patients' total social adjustment scores were positively skewed but 12% of patients scored more than one standard deviation above the mean, of whom 4% scored more than two standard deviations above the mean (Figure 3-11).

**Figure 3-11: Distribution of Patients' Social Adjustment Scale Total score with descriptive statistics.**

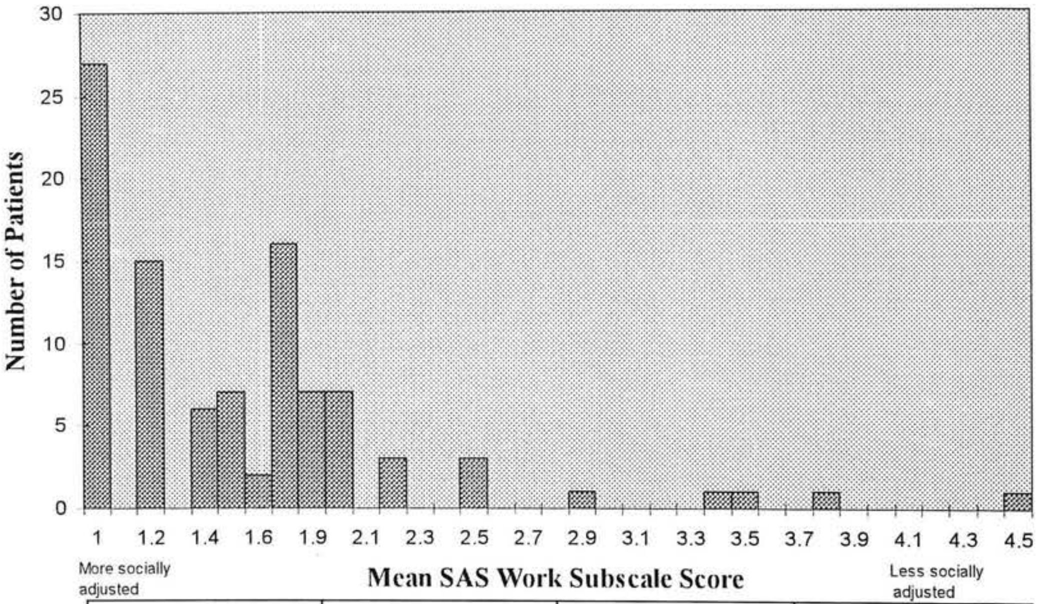


| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 324 | 1.7 | 1.6 | 1 - 4.1 |

### The Work Subscale

The work subscale is applicable both to patients in employment and those that considered themselves employed as housekeepers. Many patients see themselves as fulfilling neither category with many men and those that received home help not considering themselves housekeepers. Thus the scale was only completed by 98 patients, of whom 8% (n=8) scored more than one standard deviation above the mean and 4% (n=4) more than two standard deviations above the mean (Figure 3-12). A comparison with patients' responses on the 'gainful work' question in the FAI suggests that many of the 98 responses above did not apply to those in paid employment. In response to the FAI work question, 285 (87%) patients said they were not in gainful work, 4 (1%) said that they worked up to ten hours each week, 10 (3%) that they worked between 10 and 30 hours per week and 29 (9%) said that they worked more than 30 hours each week. These figures reveal that six months after their strokes only 55% (n=43) of patients who were working prior to their strokes (n=78) had returned to work. The number of hours patients worked per week prior to their strokes was not recorded so it is not possible to comment on whether some of these patients had returned to employment but were working shorter hours.

**Figure 3-12: Distribution of Patients' Social Adjustment Scale Work Subscale scores with descriptive statistics.**

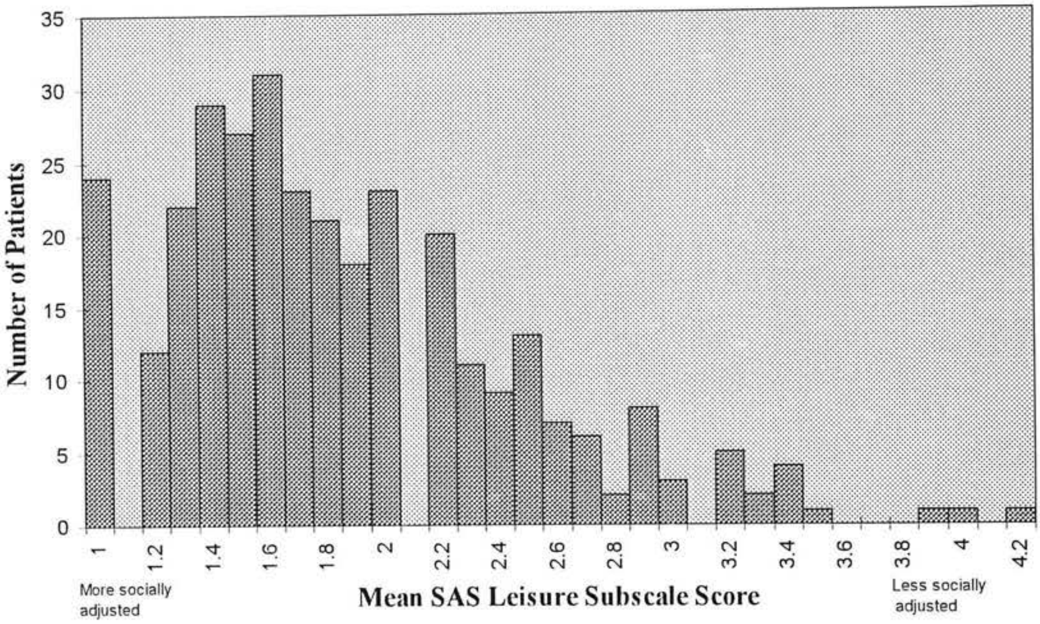


| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 98 | 1.6 | 1.5 | 1 - 4.5 |

### The Leisure Subscale

Patients report greater maladjustment regarding their leisure activities (Figure 3-13).

**Figure 3-13: Distribution of Patients' Social Adjustment Scale Leisure Subscale scores with descriptive statistics.**

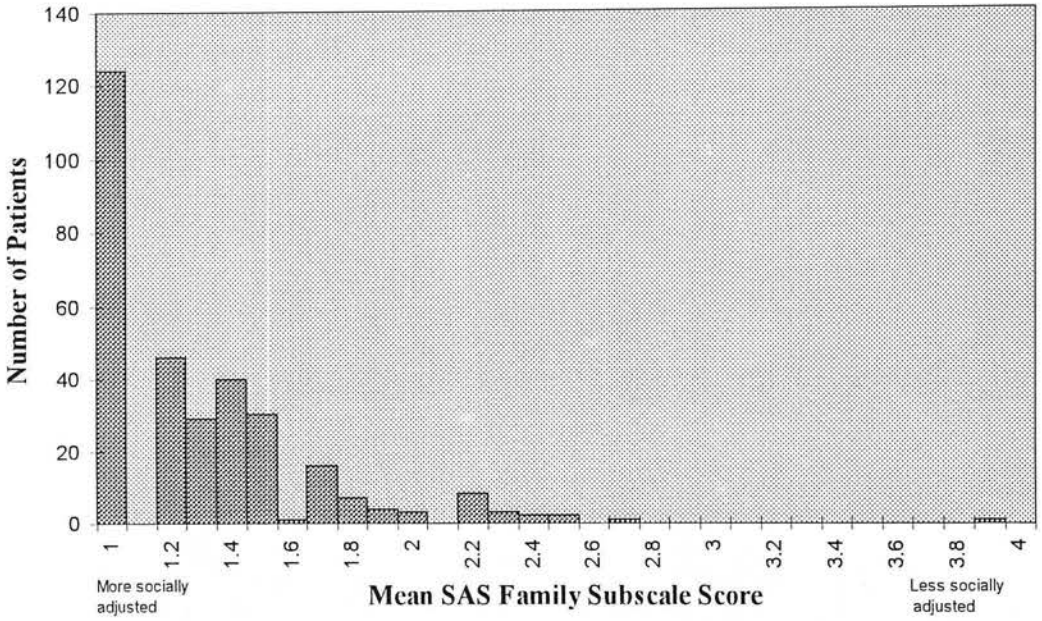


| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 324 | 1.8 | 1.7 | 1 - 4.1 |

### The Family Subscale

Patients report fewer difficulties regarding extended family relationships (Figure 3-14).

**Figure 3-14: Distribution of Patients' Social Adjustment Scale Family Subscale scores with descriptive statistics.**

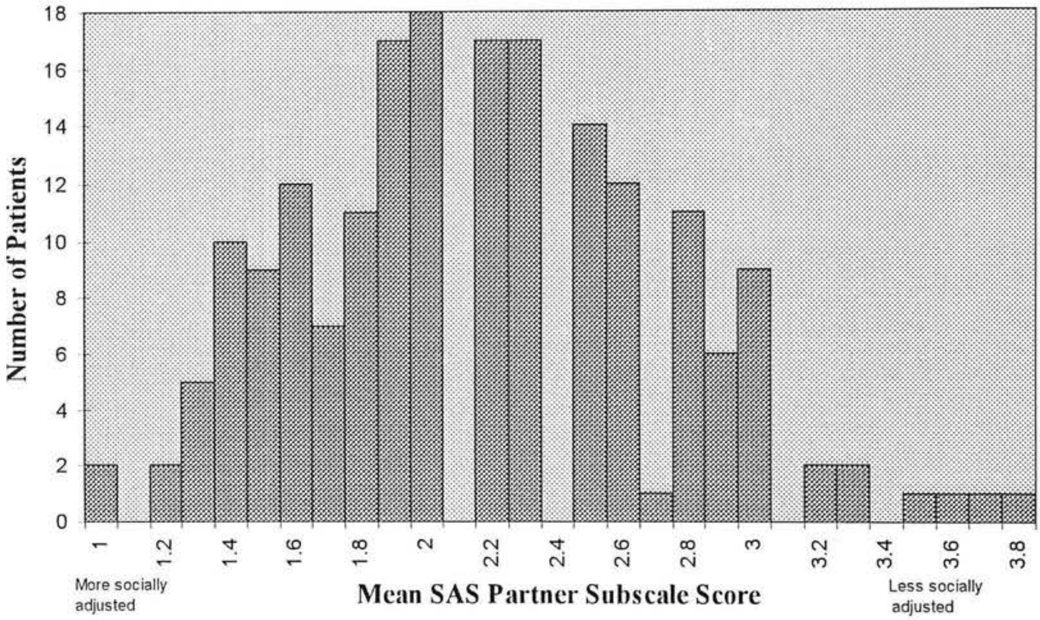


| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 317 | 1.3 | 1.1 | 1 - 3.9 |

### The Partner Subscale

Unlike the other SAS subscales where patient scores are positively skewed their scores on the Partner subscale conform to a normal distribution with the majority of patients reporting some difficulties (Figure 3-15).

**Figure 3-15: Distribution of Patients' Social Adjustment Scale Partner Subscale scores with descriptive statistics.**

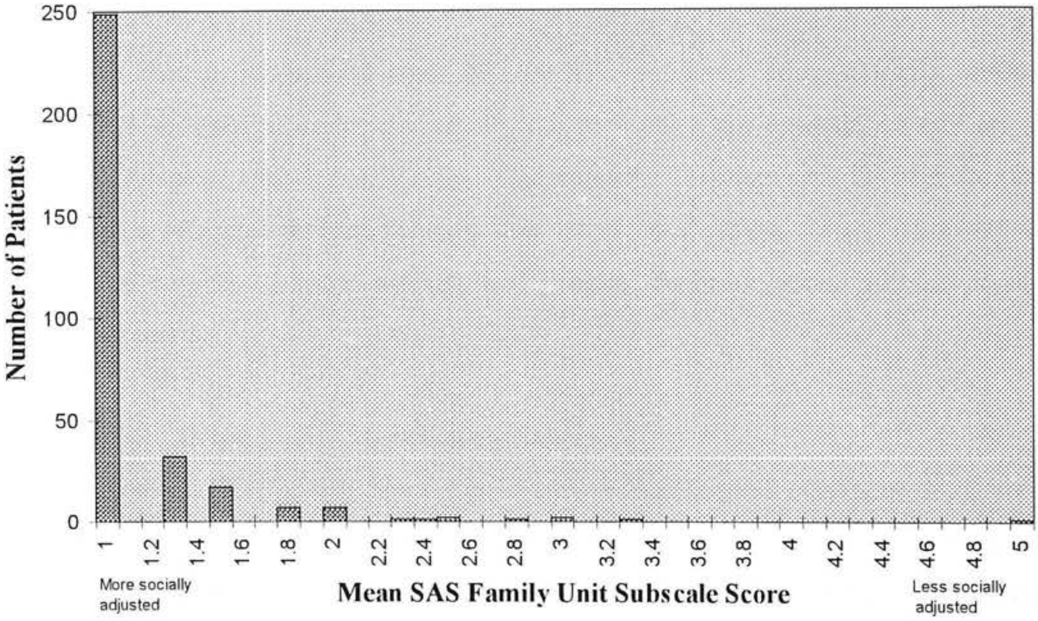


| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 188 | 2.1 | 2.1 | 1 - 3.7 |

### The Family Unit Subscale

The Family Unit Subscale appeared to have little utility when it was actually being administered as all four of its questions were similar to those in the previous Family Subscale and patients questioned their 'repeated' asking thus leading to repetition of previous answers. Three of the questions were exactly those that had appeared earlier in the scale but this time referred to partners or children rather than extended family. The distinction was far from clear to most patients who had limited contacts with any family members outwith their own home and despite instructions often had referred to those family members regarded as family unit by the SAS in the previous subscale referring to extended family.

**Figure 3-16: Distribution of Patients' Social Adjustment Scale Family Unit Subscale scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 321 | 1.7 | 1.6 | 1 - 4.1 |

## 3.5 Patients' mental adjustment

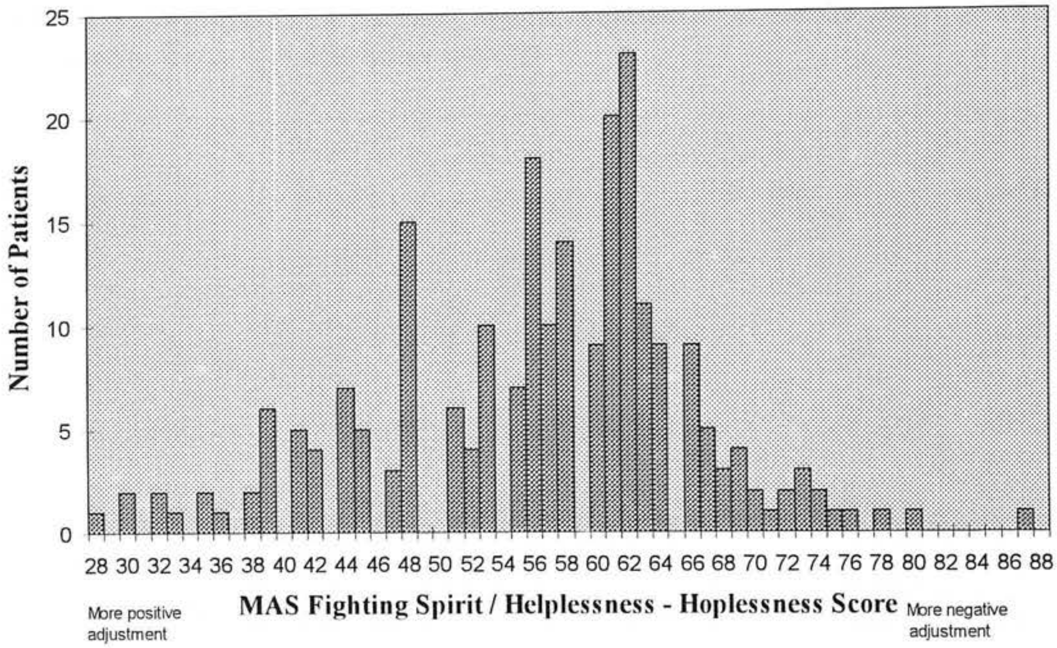
I measured patients' adjustment to stroke, that is the extent to which they adopt certain coping responses in their adjustment to their diagnosis, using the Mental Adjustment to Stroke Scale. The scale has four subscales: Fighting Spirit - Helplessness/Hopelessness, Anxious Preoccupation, Fatalism and Avoidance / Denial. No recommended ranges or cutting points for these scores exist for stroke patients so, for the present purposes, I have developed cut-offs for our sample using the methods described by the original MAC scale's authors in the scale manual (Watson et al. 1989). The authors recommend that the cutting point be defined as one standard deviation above the mean score and that all patients who score above this on any subscale should be defined as suffering from negative mental adjustment in that area. However for the Fighting Spirit subscale this alters as it reflects a positive adjustment and the cut-off is defined as one standard deviation below the mean score.

The authors further recommend that all patients' scores on each subscale undergo transformation to make subscales compatible with each other, for example, so that for all subscales a high score indicates more negative adjustment. Therefore each figure illustrating the distribution of scores on each subscale uses transformed patient scores. However the calculation of cut-offs to define caseness and patients' dominant mental adjustment uses patients' raw scores.

**Fighting Spirit - Helplessness / Hopelessness Subscale**

Patients' scores on the Fighting Spirit / Helplessness Hopelessness continuum illustrate a normal distribution with the majority of patients occupying the middle ground in the continuum, that is having a balance between fighting spirit and helplessness/ hopelessness (Figure 3-17). The combined score is calculated by subtracting the patient's hopelessness score from their fighting spirit score before the score undergoes the previously discussed transformation. Therefore the two cut-offs developed for each scale cannot be marked on Figure 3-17. Seven percent of patients were defined as cases lacking in fighting spirit and 9% of patients as cases of helplessness and hopelessness (Table 3-10). Note that cases on the Fighting Spirit subscale are defined as lacking in fighting spirit if they fall below the cut-off as fighting spirit is a positive adjustment and the other subscales indicate areas of negative adjustment.

**Figure 3-17: Distribution of patients' Mental Adjustment to Stroke Scale, Fighting Spirit - Helplessness / Hopelessness scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 233 | 56.5 | 58 | 28 - 87 |

**Table 3-10: The number of patients classified as cases on the Fighting Spirit and Helplessness/ Hopelessness subscales of the Mental Adjustment to Stroke Scale.**

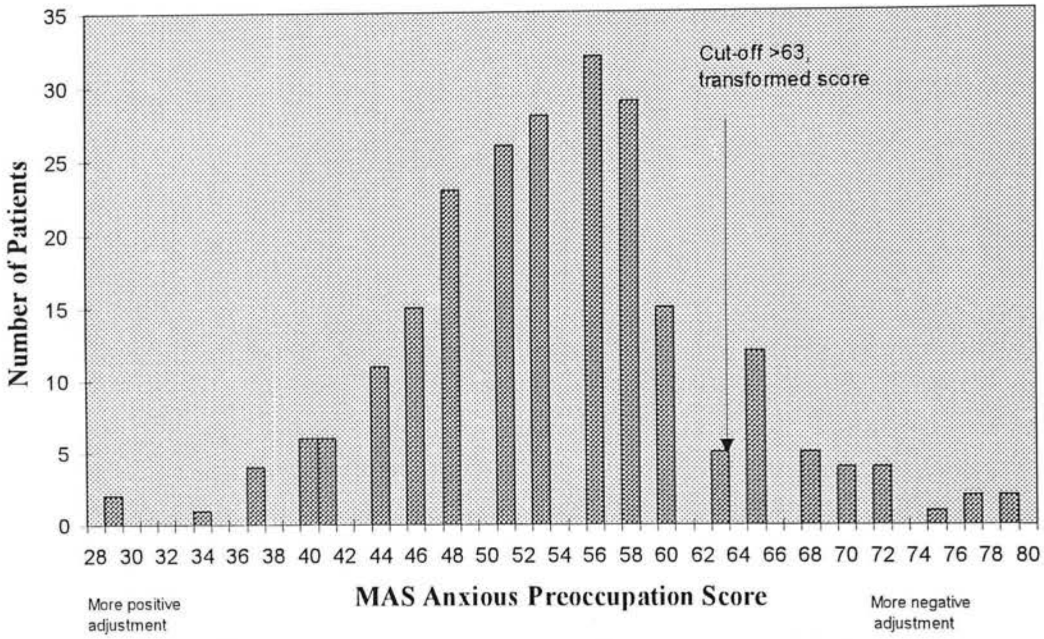
| MAS Subscale | Cut-off | Cases | |
|---|---|---|---|
| | | n | % |
| Fighting Spirit | <44 | 23 | 7.1% |
| Helplessness / Hopelessness | >14 | 22 | 9.4% |

Note: Cut-offs refer to patients' raw scores before the scales are combined and transformed.

### The Anxious Preoccupation Subscale

Again patients' scores were normally distributed suggesting that the majority of patients experienced a moderate level of anxious preoccupation with their diagnosis. Thirteen percent of patients were defined as cases of anxious preoccupation (Figure 3-19, Table 3-11).

**Figure 3-18: Distribution of patients' Mental Adjustment to Stroke Scale, Anxious Preoccupation scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 233 | 54 | 53 | 29 - 79 |

**Table 3-11: The number of patients classified as cases on the Anxious Preoccupation subscale of the Mental Adjustment to Stroke Scale.**

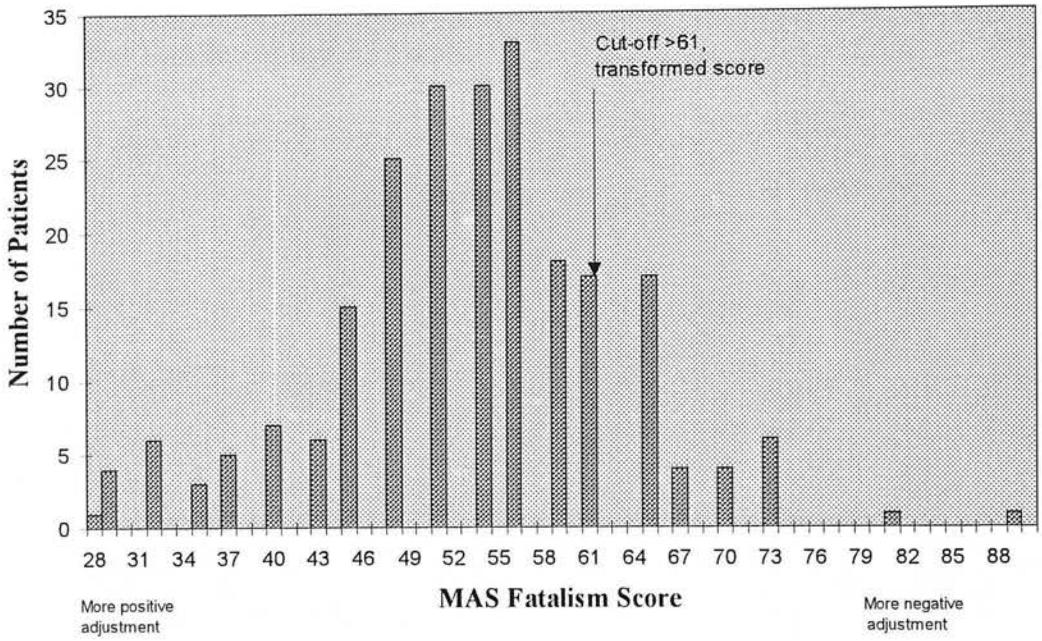
| MAS Subscale | Cut-off | Cases | |
|---|---|---|---|
| | | n | % |
| Anxious Preoccupation | >63 | 30 | 12.9% |

Note: The cut-off refers to patients' transformed scores, the cut-off for raw scores is > 26.

### The Fatalism Subscale

Fifteen percent of patients were defined as having poor mental adjustment in terms of a fatalistic attitude toward their diagnosis (Figure 3-19, Table 3-12).

**Figure 3-19: Distribution of patients' Mental Adjustment to Stroke Scale Fatalism scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 233 | 53.2 | 54 | 26 - 89 |

**Table 3-12: The number of patients classified as cases on the Fatalism subscale of the Mental Adjustment to Stroke Scale.**

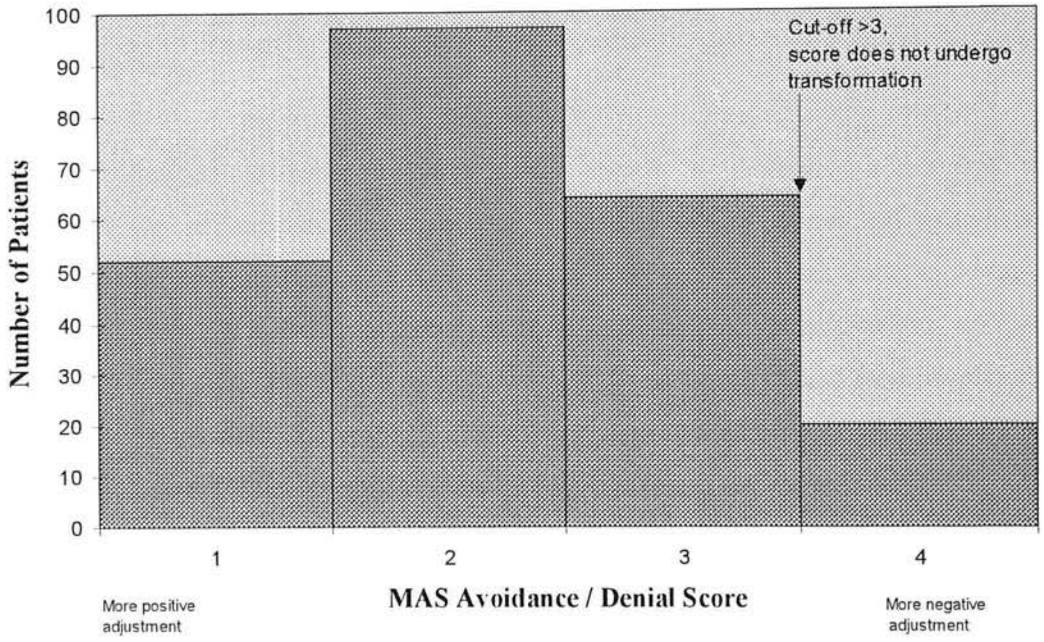
| MAS Subscale | Cut-off | Cases | |
|---|---|---|---|
| | | n | % |
| Fatalism | >61 | 33 | 15.2% |

Note: The cut-off refers to patients' transformed scores, the cut-off for raw scores is > 22.

**The Avoidance / Denial Subscale**

To be defined as a case on the Avoidance / Denial Subscale patients had to score four on the scale's one question. On this question 'I don't really believe I have had a stroke' 8.6% of patients were classified as cases for answering 'Definitely applies to me' (Figure 3-20, Table 3-13).

**Figure 3-20: Distribution of patients' Mental Adjustment to Stroke Scale Avoidance / Denial scores with descriptive statistics.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 233 | 2.2 | 2 | 1 - 4 |

**Table 3-13: The number of patients classified as cases on the Avoidance / Denial subscale of the Mental Adjustment to Stroke Scale.**

| MAS Subscale | Cut-off | Cases | |
|---|---|---|---|
| | | n | % |
| Avoidance / Denial | >3 | 20 | 8.6% |

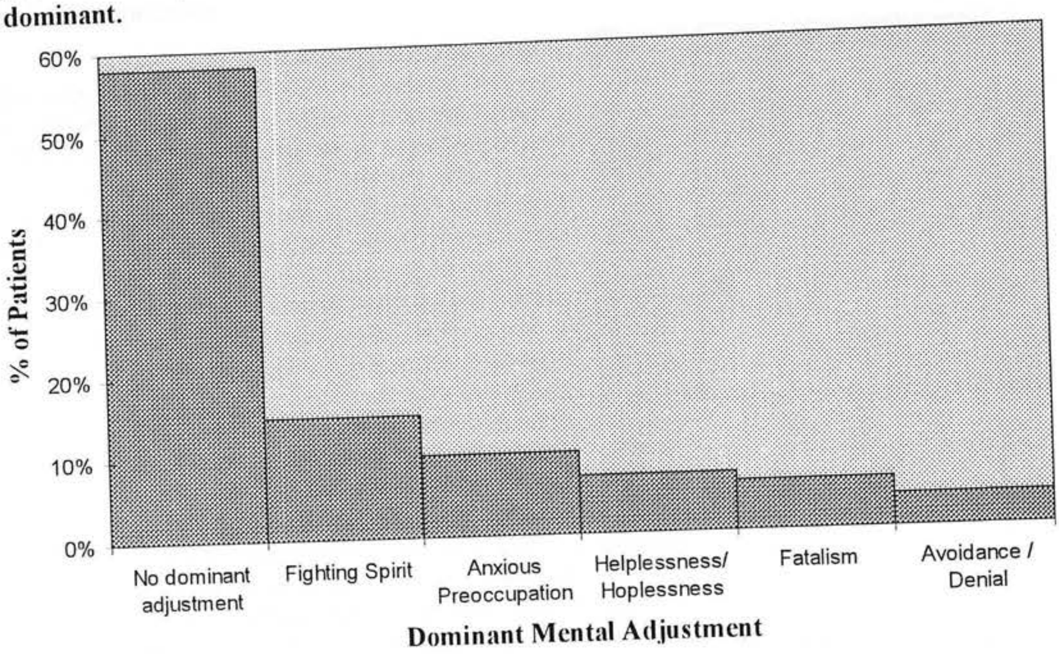
Note: Patients' scores on the avoidance / Denial subscale do not undergo transformation.

### 3.5.1 *Patients' Dominant Mental Adjustment*

Patients' dominant mental adjustment was calculated using the method suggested by the MAC scale's authors (Watson et al. 1989). For each patient and each subscale the mean score for the subscale was subtracted from the patients' score before the remainder was divided by the subscales' standard deviation. A patient's dominant mental adjustment was that on which they scored more than one (i.e. one standard deviation above the mean). If patients scored above one standard deviation above the mean on more than one subscale, the subscale on which they scored highest was defined as their dominant subscale. Patients who scored less than one standard deviation above the mean on all subscales were defined as having no dominant subscale.

Comparison between subscales is difficult with regards to discussing which was the predominant type of mental adjustment amongst patients as 58% of patients had no dominant mental adjustment. That is, 58% of patients did not score more than one standard deviation above the mean on any subscale (or below the mean on the fighting spirit subscale). Of those patients that were defined as having a dominant mental adjustment 15% of those displayed a positive adjustment, fighting spirit, and 27% a negative mental adjustment with their mental adjustment being one of the remaining subscales (Figure 3-21).

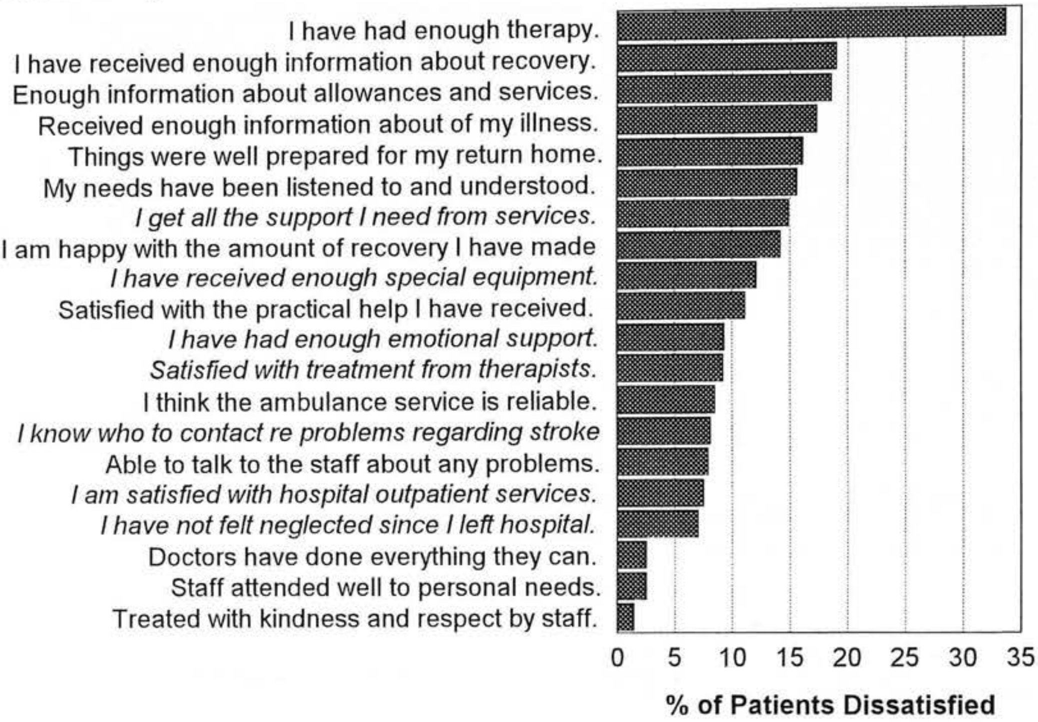
**Figure 3-21: The percentage of patients defined as having each area of mental adjustment as dominant.**



## 3.6 Patients' satisfaction with treatment.

Patients' satisfaction scores were analysed both at the level of individual questions and as total scores. For each satisfaction question the percentage of patients who responded that they were dissatisfied with that aspect of their care was calculated with the percentage dissatisfied ranging from 1.4% to 33.6%. The statement with which the most patients were dissatisfied was 'I have had enough therapy' to which with 33.6% of patients responded that they were dissatisfied. This was more than double the number who expressed dissatisfaction on any other question where the maximum was 15% (Figure 3-22).

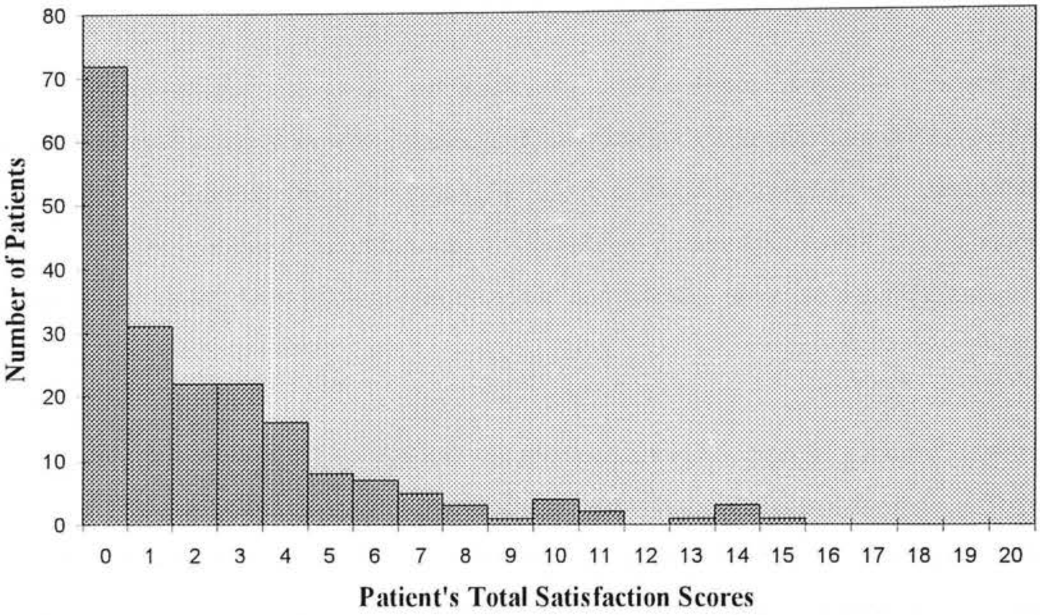
**Figure 3-22: The percentage of patients dissatisfied with their care for each patient satisfaction question.**



Note: Questions in italics are the seven additional questions designed specifically for this study. Questions have been truncated, for questions in their original form please refer to Appendix C.

Patients' satisfaction scores were also analysed as a total score with the number of questions on which patients responded that they were dissatisfied being recorded. Sixty four percent (n=126) of patients were dissatisfied with at least one aspect of their care although the median number of questions on which patients were dissatisfied was one.

**Figure 3-23: Distribution of patients' total satisfaction scores.**



| No. of Patients | Mean | Median | Range |
|---|---|---|---|
| 198 | 2.5 | 1 | 0 - 15 |

## 3.7 The critical assessment of studies of stroke outcome.

Any review of articles concerning prognosis after stroke should critically examine the methodology used to aid an informed decision of the confidence with which the data should be viewed. Four particularly important criteria by which to judge methodology are whether the study has a clearly defined inception cohort, the referral pattern of patients to this cohort, whether follow up of study patients was complete and whether objective outcome measures were used (Sackett et al., 1991).

The inception cohort from which patients are obtained should consist of patients identified early after stroke to avoid the bias associated with patients being filtered through different channels according to their needs. For instance a sample of patients who have been discharged from acute care into a rehabilitation hospital will include only patients who have survived with some disability and have potential for improvement; it will exclude patients with very severe strokes and those with no residual disability. The inception cohort should also consist of patients identified at a uniform time post stroke. The course of psychosocial outcome after strokes changes over time so grouping patients assessed during the acute phase with those assessed many months or years after stroke is unhelpful both in terms of comparison with other studies and for informing clinical practice. Ideally study patients should represent a consecutive series drawn from an unbiased inception cohort. That is, all patients recorded in a community stroke register or, as a second best, all those referred to a study hospital during a given time period. Alternatively, patients may be randomly selected from such an inception cohort. Many studies set detailed inclusion criteria, such as that the stroke is the patient's first or that the patient has undergone CT, which makes their results difficult to generalise and compare with others.

Studies should clearly explain the source of referrals to the initial study cohort, that is, if the cohort is of hospital inpatients the criteria for referral to that hospital should be clear to inform the reader of possible referral bias. For example, hospitals with specialist units or reputations of excellence or interest in a particular area may suffer centripetal bias, where they are more likely to be referred difficult cases, or popularity bias, where they choose to preferentially keep track of interesting or unusual cases (Sackett et al., 1991). If patients have undergone a number of referrals before reaching the study cohort they may suffer referral filter bias whereby each referral has 'filtered' only certain types of patients through to the next stage resulting in the end sample having been selected on a number of criteria. Finally initial study cohorts may suffer diagnostic access bias if factors such as geography or finance exert an influence on whether a patient receives the diagnosis necessary for entry to the study (Sackett et al., 1991). In stroke this is most likely to affect studies where patients require a CT scan, access to which differs greatly between hospitals.

The majority of studies examining post stroke mood disorders have drawn patients either from patients referred to hospital, or hospital or rehabilitation unit inpatients. However, since in the UK many patients are not admitted to hospital (Bamford et al., 1986), hospital samples will be unrepresentative and perhaps skewed toward those with more severe strokes. A truly representative view can therefore only be gained from community based studies which include all new cases of stroke occurring in a well defined population. I identified only four community based studies of post stroke mood disorders (Table 3-14).

At the time of patients' follow up assessment, studies should be able to account for all patients initially entered into the study. Failure to assess all study patients may lead to biased results as the outcome of those patients not assessed is not known. Patients may be lost to follow up for a reason and those reasons should be specified to allow the reader to assess for themselves the extent to which the patients lost to follow up may have biased results. For example, in a study of depression after stroke a number of patients refusing to be assessed may reflect a greater frequency of the apathy associated with depression amongst these patients indicating that the result found in assessed patients may be an underestimate. However, in the study of stroke the collection of complete data in all patients will rarely be possible. Many of the neurological syndromes associated with stroke will impede the assessment of mood disorders. The most obvious of these are communication deficits such as aphasia and dysphasia but others such as anosognosia may also make it difficult to complete some assessments satisfactorily. While the loss of patients with severe communication deficits to a study is unfortunate it is difficult to avoid so that most studies refer only to those who were assessable and therefore studies remain comparable. It is more of a problem if patients are lost to follow up, refuse to participate or move away for example, as it is difficult to determine how representative the remaining sample is. Finally if the proportion of patients in the remaining sample is very small we must question the samples' representativeness and in any case any estimate of the frequency of an outcome will be very imprecise.

The diagnostic criteria for an outcome event or the method of describing outcomes should be unambiguous and should be applied consistently. Measures of psychosocial outcome fall into two main groups: structured interviews and self report measures. A structured psychiatric interview is considered the best means of identifying mood disorders (House, 1987*a*; Ramasubbu and Kennedy, 1994). However, there are a number of different psychiatric interviews such as the Present State Examination (PSE) and the Psychiatric Assessment Scale (PAS), in addition to a number of criteria by which to categorise their results, such as the Diagnostic and Statistical Manual of Mental Disorders (DSM) and Research Diagnostic Criteria (RDC). With self report measures of mood disorders the situation is even more difficult due to the enormous number of measures available and the fact that the criteria for 'caseness' is normally whether a score falls above or below a given cut-off. Cut-offs for defining caseness are normally defined by the authors during the development of the measure and by subsequent studies in different populations. However, the appropriate cut-off may differ in different patient populations. For instance in stroke, where patients have many somatic symptoms a higher cut-off may be appropriate.

### *3.7.1 Sources of selection bias within our study.*

The sample of patients included in this study have undergone a number of selection processes each of which will affect both its generalizability and validity as a frequency study of psychosocial outcome.

The methodology of this study is not ideal for a study of the frequencies of poor post stroke psychosocial outcome. Ideally a study would assess a consecutive sample of unselected community stroke patients and be confident of having detected all stroke patients within their defined population. Our study included only those patients who were referred to the study hospital for assessment. Patients referred to the study hospital were unlikely to be representative of all strokes occurring in the community served. No patients were self referred or were referred through an accident and emergency department. The majority were referred by their GPs, many of whom were from the immediate locality. In addition, specialist units within the hospital received cases of stroke referred from district hospitals leading to an increased number of unusual stroke cases.

Our patients were further selected through our exclusion criteria. We chose not to randomise patients who lived further than 25 miles from the study hospital as we felt that it was impractical to deliver the intervention and that these patients might not therefore gain enough treatment from our SFCW. We also excluded patients who had their strokes in the context of another serious illness that was likely to dominate the pattern of their future care, again because they might fail to benefit from the full impact of our SFCW. Finally we excluded patients who were unlikely to survive beyond the following week again for fear of diluting any treatment effect. The geographical exclusion criteria would hopefully not have biased the sample as we believe there is no difference in the nature of the strokes or socio-economic background of the near and far resident groups. However, more unusual cases may have been referred from a greater distance to our specialist neurovascular clinic. Therefore our geographical exclusion criteria may actually have made our series more representative of strokes in general since we excluded the more unusual cases referred from district hospitals. This exclusion criteria may also partially explain why patients randomised to the trial were older as younger patients may have been more likely to warrant specialist referral to our hospital but be unlikely to be randomised as they would mainly live outwith the 25 mile limit we set for patient inclusion. The exclusion of patients unlikely to survive and those with another dominating illness is likely to have influenced the figures for our sample's physical outcome at six months particularly in terms of mortality. This is illustrated in the description of physical outcomes of our sample with only a 10% case fatality rate in comparison to a 20% 30 day case fatality rate in a UK community sample (Dennis and Warlow, 1987). However, whilst our case fatality rates are low the proportion of our patients who were independent, between 48% and 52%, is similar to those amongst survivors of community samples where 47% and 53% were independent in ADL at six months (Wade et al., 1985*a*, 1987). Our exclusion of patients unlikely to survive is also illustrated by the fact that patients with a pre-stroke OHS of 4 were significantly less likely to be randomised into the trial. In addition there are many non-significant differences between the groups reflecting the degree of patient selection present.

Eleven percent of patients were not assessed at six months. Ten percent of these had died prior to follow up and one percent were not assessed due to refusal, relocation or misdiagnosis. In addition, questionnaires were not fully completed by all patients due to cognitive or communication deficits or refusal to answer individual questions.

I will now move on to describe the previous studies of psychosocial outcome keeping these methodological points in mind.

## 3.8 Studies of depression after stroke.

Studies of depression after stroke primarily fall into two categories, those whose inception cohort was a community sample defined by GP age/sex register or geographical area, and those whose inception cohort were hospital referred. As the patients identified by each are likely to differ I have chosen to discuss the frequency of mood disorder in each of these types of study in turn.

### *3.8.1 Community studies.*

Of the four community studies of depression after stroke two, those of Burvill (with Johnson reporting on same cohort) and Wade, took their inception cohort from a defined geographical area (Burvill et al. 1995*a*; Johnson et al. 1995; Wade et al. 1985a, 1987) and two, House and Sharpe, using the same inception cohort, from the referrals of selected GP practices (House et al., 1991; Sharpe et al., 1990; Table 3-14). Burvill and Wade included all referred strokes whilst House and Sharpe included only patients experiencing their first ever strokes. All four studies used the World Health Organisation definition of stroke. None of the studies suffered referral biases because they identified all strokes occurring within their defined population.

The study by House (1991) achieved the most complete follow up with fewer than 1% of patients living at the time of assessment being lost to follow up. Sharpe's study (1990) took patients from the same cohort as House but was not a true cohort study as it included only patients who were living and had a single classifiable lesion visible on CT scan. It therefore lost no patients to follow up as patient selection took place immediately prior to assessment. Burvill (1995*a*, 1995*b*) assessed 74% of patients living at time of follow up, losing 13% due to cognitive deficits, 6.5% due to delayed notification, 4% due to patient refusal, 2% to patient emigration and 1% due to patient aphasia. Wade (1985*a*; 1987) assessed between 61% and 71% of patients alive at each follow up. Between 9% and 13% were lost to follow up due to delayed notification and between 17% and 30% due to cognitive or communication deficits.

All four studies illustrate the different frequencies found when using different diagnostic criteria, a problem that the authors of all four studies acknowledged by using more than one measure or diagnostic criteria, thus allowing further opportunities for comparisons across studies. Both Burvill (1995*a*, 1995*b*) and House (1991) endeavoured to validate their self report measures through comparison with a structured psychiatric interview. Sharpe et al. (1990) used the Present State Examination (PSE) and the traditionally recommended HAD cut-off for a high sensitivity which has been validated in physically ill populations but not in stroke. House (1990) and Wade (1985, 1987) quoted many different cut-offs so that the reader could make their own choice. Despite these efforts any attempt at a comparison illustrates the difficulties which arise when studies use different measures. Of the eight measures used in the four studies only two, the HAD and the PSE have been used in more than one study, and comparisons remain difficult because the patients were assessed at markedly different times post stroke. Thus, comparing across measures during the first month post onset, the frequency of depression varies from 12% to 34%. At four months post onset within one study the estimated frequency varied from 20% to 31% and at 6 months the estimates varied from 6% to 32%, with these two extreme values quoted coming from a single study. Estimates of frequency at 12 months varied between 1% and 31% and in the one community study dealing with long term survivors of three to five years the frequency was 14% to 18% depending on the measure used.

If we focus on structured psychiatric interviews using DSM III criteria only (as used in three of the studies) the studies do not all use the same interview method and patients were assessed at different times after stroke. Thus at one month 25% of patients appeared depressed (House et al., 1991), at four months 23% (Burvill et al., 1995*a*), 6 months 21% (House et al., 1991), 12 months 15% (House et al., 1991) and 3-5 years 18% (Sharpe et al., 1990). While this appears to demonstrate a smooth reduction in frequency over time different assessment measures were used, and four of the figures are based on samples of less than 120 patients with two of those on less than 90. Such small samples may have led to imprecise estimates of the frequency of depression after stroke. All four community studies were on consecutive series of patients, had acceptable rates of follow-up and no unreasonable exclusion criteria although Burvill et al. (1995*a*, 1995*b*) do not explain why the numbers receiving each self report measure differ from each other and from the number undergoing psychiatric interview.

### 3.8.2 Hospital or rehabilitation based studies.

Of the 19 studies remaining which did not use community samples, five took patients from an inception cohort of consecutive hospital admissions (Astrom et al., 1992, 1993; Collin et al., 1987; Ebrahim et al., 1987; Greveson et al., 1991; Starkstein et al., 1988), three from consecutive entries into the same stroke data bank (Herrmann et al., 1995; Robinson et al., 1983; Shinar et al., 1986) and seven from consecutive admissions to rehabilitation hospitals (Eastwood et al., 1989; Folstein et al., 1977; Gordon et al., 1991; Kettle and Chamberlain, 1989; Morris et al., 1992; Schwartz et al., 1993; Sinyor et al., 1986*a;* Tables 3-15, 3-16). Studies by Finklestein et al. (1982) and Robinson (1982) specified that patients were randomly selected hospital inpatients, the former being rehabilitation hospital patients, but failed to explain the method of random selection. Schubert et al. (1992) reported that patients were rehabilitation centre inpatients but did not state that they were consecutive admissions. The remaining study by Dam et al. (1989) reported that patients were hospital assessed but gives no information on how they were selected. Studies by Folstein et al. (1977), Robinson et al. (1983; 1987), Starkstein et al. (1988*a*), Robinson and Price (1982) and Shinar et al. (1986) were all based at the John Hopkins University School of Medicine in Baltimore. Papers referring to the same patients have been grouped in a single line in each of the literature review tables but it is not possible from reading the papers to be sure that none of the remaining studies do not have some patients in common.

Few studies specified the referral pattern to their study hospitals. Amongst all studies of general hospital admissions only one, that by Astrom et al. (1992) gave referral criteria stating that theirs was the only hospital serving the area and that their sample was therefore unselected. By definition, patients being admitted to rehabilitation hospitals will have undergone referral selection as being both in need of, and likely to benefit from, rehabilitation.

Exclusion criteria were similar for most studies, almost all specifying that patients should not have another severe or neurological illness (Folstein et al., 1977; Gordon et al., 1991; Herrmann et al., 1995; Morris et al., 1992; Sinyor et al., 1986*a*), that patients should not have a psychiatric history (Gordon et al., 1991; Herrmann et al., 1995; Sinyor et al., 1986*a*) or be taking psychotropic medicines (Gordon et al., 1991; Sinyor et al., 1986*a*) and sometimes that this be the patient's first stroke (Herrmann et al., 1995; Sinyor et al., 1986*a*). Studies concerned with lesion location selected only those patients with a single unilateral lesion visible on CT scan (Dam et al., 1989; Herrmann et al., 1995; Schwartz et al., 1993; Starkstein et al., 1988*a*) one excluding those with brainstem infarctions (Folstein et al. 1977). Some exclusion criteria were more unusual; Ebrahim et al. (1987) excluded patients who were still inpatients at the time of follow up as they could not be assessed in similar circumstances to the remainder. Such a criterion risks omitting patients whose strokes were more severe necessitating their longer hospitalisation, a possible source of bias. Others specified arbitrary age limits (Gordon et al., 1991; Sinyor et al., 1986*a*) or included only patients still under the care of the study hospital (Robinson et al., 1984*c*), for instance those returning to outpatients, excluding those receiving care elsewhere without detailing the factors influencing place of treatment (Robinson et al., 1984*c*). Unusually, Starkstein (1988*a*) from the same team excluded patients who did not score within ten points on their test-retest administration of the Zung Self Rating Depression Scale and failed to specify the time between testings. Schwartz et al. (1993) excluded females as their sample was predominantly male.

Exclusion criteria were not the only major source of 'selection' within samples. One study was unable to trace 15% of patients (Collin et al., 1987), whilst others listed 7% lost due to administrative errors (Ebrahim et al. 1987), 29% either untraced or unwilling to participate (Kettle and Chamberlain, 1989), or 9% simply lost to follow up (Robinson et al., 1987).

In some cases exclusion criteria have dramatically reduced the sample size suitable for assessment, with studies assessing only 16%, 39%, 51%, 54%, 63% respectively (Gordon et al., 1991; Sinyor et al., 1986*a*; Starkstein et al., 1988*a*; Collin et al., 1987; Ebrahim et al., 1987) of the original patient series. Thus final patient samples were often very small ranging in the 18 studies from 20 to 187 patients, with 12 studies having fewer than 100 patients and five studies fewer than 50 patients meaning that we must question the precision of their estimates.

Of the 18 studies, 11 used interviewer assessment (Table 3-15) while the remaining seven used self report questionnaires (Table 3-16). Of those who used interviews, Astrom (1992) and Dam (1989) specified that these were by a psychiatrist, Finklestein (1982) and Schwartz (1993) stated that interviewer consensus was obtained using parts of the Hamilton Depression Rating Scale, while Herrman (1995) used a structured interview 'when possible' and the remaining six specified the use of a named structured interview (Eastwood et al., 1989;

Folstein et al., 1977; Gordon et al., 1991; Morris et al., 1992; Robinson et al., 1983; Starkstein et al., 1988*a*). Of these, Folstein (1977), Robinson (1983) and Starkstein (1988*a*), all based at the John Hopkins University School of Medicine, used a modified version of the PSE. The reason for modifying either the PSE or DSM III criteria typically centre on the time scales required for diagnosis. The PSE assesses patients' functioning in the previous month and the DSM III criteria for dysthymia requires symptoms for a two year period. Depending on the time of assessment such time frames may not be suitable for the assessment of a post stroke population.

The difficulty of producing a figure for the frequency of depression after stroke from such data is that patients have been assessed at many different time points after stroke and many samples specify merely a post stroke sample with a broad time range post onset within the one sample (Dam et al., 1989; Collin et al., 1987; Finklestein et al., 1982; Kettle and Chamberlain, 1989; Robinson and Price, 1982; Schwartz et al., 1993).

Amongst those studies using an assessment interview, depression was found to affect between 25% and 68% of patients within three months of stroke, 16% to 32% of patients at one year and 19% to 42% of patients at specified assessment periods of over two years after stroke (Table 3-15).

For those studies using self report measures, depression was found to affect between 22% and 47% of patients in the acute post stroke period and between 19% and 29% for specified periods of more than two years post stroke. Comparison of frequencies is especially difficult amongst this sample as most time intervals in months post stroke are specified as a range with no two studies specifying the same ranges (Table 3-16).

For both interviewer and self report assessments the frequencies quoted are over so broad a range and such diverse time periods that no real comparison between rates specified by interviewer assessment versus self report are possible except to say that both methods produce the diverse results summarised above. Amongst those studies using both methods (Burvill et al., 1995*a*; House et al., 1991; Johnson et al., 1995; Sharpe et al., 1990) the figures for self report and interviewer assessment seem comparable, with the frequencies given by various possible cut-offs ranging between the frequencies estimated by the different diagnostic systems used to classify the results of psychiatric interviews (House et al., 1991).

## 3.9 Studies of anxiety after stroke.

After a major illness one would expect patients to suffer heightened levels of anxiety especially if that illness had long lasting symptoms and posed the threat of recurrence. Despite evidence that Generalised Anxiety Disorder is both common and interferes substantially with patients' social lives and functional recovery after stroke it has been studied far less frequently than depression (Astrom, 1996).

My literature review identified ten studies of anxiety after stroke, five with inception cohorts from consecutive hospital admissions, (Astrom, 1996; Castillo et al., 1993; Malec et al., 1990; Morris et al., 1993*b*; Starkstein et al., 1990) three from community stroke registers (Burvill et al. 1995*b*; House et al. 1991; Johnson et al. 1995; Sharpe et al. 1990), one from consecutive patients presenting with hemiplegia (source of patients not stated) (Seitz and Edwardson, 1987) and one where inpatients were selected to provide a range of physical and mental disability (Gibson et al., 1991; Table 3-17). However there are significant problems in interpreting the results of four of these studies. Magni and Schifano (1984) assess their patients at two different time points and yet combine their results. Gibson (1991) refers to brain injury, including both head injury and stroke patients, so the amount it can tell us about stroke alone is limited. Malec et al. (1990) while appearing to use many of the same exclusion criteria as other studies of post stroke mood disorder may have adhered to these more rigorously than others or had a particularly ill sample. Thirty-three percent of their original sample were lost due to a history of prior neurological disease or other injury in addition to stroke and their criteria that patients should be over 55 years excluded another 13%. In all, Malec's final assessed sample represents only 13% of the original patient series. Again as in studies of depression many of the sample sizes are very small ranging from 20 to 294 with four having 60 or fewer patients meaning their estimates of the frequency of anxiety may be imprecise.

The remaining studies do not give a consistent picture of the frequency of anxiety disorders after stroke. Four studies quote the frequencies of grouped anxiety disorders; Burvill, Sharpe, Morris and Starkstein, the first two using community and the latter hospital samples. They estimate the frequency of post stroke anxiety disorders to be anything from 4% to 24% (Burvill et al., 1995*b*; Johnson et al., 1995; Sharpe et al., 1990; Morris et al., 1993*b*; Starkstein et al., 1990). The studies of House and Castillo quote the frequencies of Generalised Anxiety Disorder, finding widely disparate figures of 1% in House's community sample and 27% in Castillo's hospital inpatient sample (1991, 1993). The difference may be due to the different source of samples as both authors used versions of the PSE.

## 3.10 Studies of social functioning after stroke.

Defining social functioning after stroke is rather more difficult than defining depression or anxiety both of which have well recognised internationally defined classification criteria. Social functioning, whether as regards to social adjustment or to social activities, instead appears to be defined in the literature by the measures used to assess it. Therefore, we can only describe the social outcomes of stroke patients specifically with regard to the assessment measures used so that comparison between studies is often not possible, as all may be measuring very different aspects of what is called social functioning.

The majority of studies of social functioning after stroke have adopted a descriptive rather than frequency orientated approach and have found widespread difficulties in this area after stroke. Stroke survivors often report long term reduction in their social activities (Angeleri et al., 1993; Astrom et al., 1992; Labi et al., 1980; Sjogren, 1982) both within and outside the home in comparison either to their own pre-stroke functioning (Feibel and Springer, 1982; Schuling et al., 1993; Sjogren, 1982) or that of control groups (Angeleri et al., 1993; Astrom et al., 1992; Kettle and Chamberlain, 1989; Schuling et al., 1993). Relationships with children are maintained whilst those with friends and neighbours lessen early after stroke and have not recovered to match that of the general elderly population even three years after onset (Astrom et al., 1992). Difficulties in social functioning also extend to spousal and family relationships (Holbrook, 1982; Thames and McNeil, 1987; Sjogren, 1982) which may be especially important as better functioning families have been reported as having better compliance with treatment (Friedland and McColl, 1987). Social functioning difficulties have been associated with reduced life satisfaction (Astrom et al., 1992) and are evident even in those patients who have made a complete physical recovery (Labi et al., 1980).

Perhaps due to the difficulty in defining aspects of social functioning and the lack of suitable categories or cut-offs for use with measures of social functioning, studies quoting frequencies of maladjustment are rare (Table 3-18). Of the six such studies that I have identified four use community samples (Labi et al., 1980; Schuling et al., 1993; Wade et al., 1985*a*, 1985*b*), two sharing the same inception cohort (Wade et al., 1985*a*, 1985*b*), and two use rehabilitation samples and will therefore include only patients with some level of residual disability, one actually specifying that patients should be hemiplegic (Kettle and Chamberlain, 1989; Santus et al., 1990). Table 3-18 illustrates that in common with others studies of stroke patients, studies of their social functioning use different measures to assess different aspects of outcome at different time periods. Four of the six studies use the FAI, both suggesting that the majority of patients are somewhere in the middle, moderate social activity category (Kettle and Chamberlain, 1989; Wade et al., 1985*a*, 1985*b*; Schuling et al., 1993). The patients included in the sample of Kettle and Chamberlain (1989) appeared to be involved in fewer social activities probably reflecting the fact that they were rehabilitation admissions and therefore all had some functional impairment in comparison to Wade's community sample. In comparison to control patients those who have had a stroke have lower levels of social activity both after their stroke (Schuling et al., 1993; Kettle and Chamberlain, 1989) and before (Schuling et al., 1993).

## 3.11 Our patient outcomes: discussion.

Our outcome measures, using the cut-off points determined as best for our sample (refer to 3.3), suggest a psychiatric case rate of 38%, depression 19% and anxiety 22%. Comparisons with the three British studies which conducted follow-ups at six months (Tables 3-14, 3-15, and 3-16) (Ebrahim et al., 1987; House et al., 1991; Wade et al., 1985*a*, 1987;) which quoted rates of depression between 10% and 32% (community samples 10% to 32%, inpatients

23%), suggest that our results occupy 'the middle ground' regarding our HAD Scale rate of depression. Our measure of psychiatric case rate, the GHQ, defined 38% of patients as likely to be psychiatric cases which appears high but does include cases of all psychiatric illness rather than just depression. The remaining study of outcome at six months is American by Robinson et al. (1984*c*) used the modified PSE with DSM III criteria and found depression affected 60% of their small sample of 50 patients. The one study of post stroke anxiety at six months which was in a British community sample identified between 1% and 3% of patients as having a specific anxiety diagnosis (House et al., 1991). Our measure of anxiety, the HAD Anxiety subscale, refers to all anxiety related diagnoses rather than the individual diagnoses referred to in House's study. It diagnosed 22% of our sample as having an anxiety disorder. Even taking into account that our figure refers to all anxiety disorders there is still a remarkable discrepancy between the frequency of anxiety in our sample and that in House's. It may be that as our sample was entirely hospital referred (rather than partially hospital referred as in a community sample) they experienced more anxiety either due to being referred to hospital or to the nature of their illness that prompted the referral.

The HAD Scale identifies a much lower frequency of depression (19%) and anxiety (22%) than the case rate defined by the GHQ (38%). If the percentages of patients defined as depressed and anxious by the HAD Scale are summed to equal 41%, and the number of patients with both a diagnosis of depression and anxiety subtracted (n=30, 12%) the HAD gives a case rate of 29%. This is somewhat lower than the case rate defined by the GHQ but these differing frequencies are almost certainly due to the conditions these measures are designed to detect. Each HAD subscale specifically identifies either depression or anxiety whereas the GHQ identifies any case including both those with depression or anxiety and those with other disorders. An additional explanation for any difference in the number of patients diagnosed with mood disorders would be provided if the scales differed in their sensitivity and specificity. However, our own analysis found that using these cut-offs the GHQ and both HAD subscales had a sensitivity of 0.8, and a specificity of 0.68-0.79. Finally, far fewer patients completed the HAD Scale than the GHQ. The GHQ was completed with the help of an interviewer and was successfully completed by 310 patients. The HAD Scale was left with patients for independent completion and was returned complete by 252 patients. Those patients who were depressed and succeeded in completing the GHQ may have been more likely to fail to return the secondary questionnaire, or to have only partially completed it. There may therefore be a bias towards patients suffering from mood disorders failing to complete the HADS.

Our sample exhibits high levels of social activity with 82% reporting either moderate or major activity on the FAI. This compares very favourably with an equivalent figure of only 49% in a British community sample of stroke patients at six months (Wade et al., 1985*a*) and that of stroke rehabilitation patients at a median of 21 months, 53% (Kettle and Chamberlain, 1989). However, the high level of social activity observed may be a product of the influence of selection biases on our sample (refer to 3.7.1.). The categories into which patients' scores on the FAI have been grouped have been used previously in stroke (Kettle and Chamberlain, 1989; Wade et al., 1985*a*), but their validity has not been tested.

The Social Adjustment Scale reveals that patients reported most maladjustment in their relationships with their partners and least in their relationships with their extended families. This is a similar trend to that found in a geographically defined community control sample where relationships with extended family were also rated the area of least maladjustment and relationships with partners an area of high maladjustment, second only to the leisure subscale in the number of difficulties reported (Weissman et al., 1978). In comparison to this sample our patients' mean total score of 1.7 was similar to their 1.6, but marginally higher in the areas of work (mean stroke patients 1.6 vs. mean controls 1.4), relationship with partner (2.1 vs. 1.8), and family unit (1.7 vs. 1.5) (Weissman et al., 1978). Our sample's mean total score and mean scores for individual subscales were better than those of a sample of acute depressives (Weissman et al., 1978). Unfortunately a lack of normative data did not allow us to develop cut-offs which would facilitate the identification of cases of maladjustment which would have been very useful. The scale has not previously been used in stroke patients, in whom social functioning has rarely been studied in a systematic way. The scale assesses patients' social relationships within various spheres and therefore measures a very different area of functioning to that of the FAI. In interviews the questions of the SAS prompted discussion of difficulties that had not surfaced with either the FAI or GHQ. It therefore appeared to be uniquely relevant in accessing problems that would otherwise not have come to light. Conversely, it was perhaps the most difficult of the measures to administer being personally intrusive and sometimes distressing to patients.

We also decided to measure patients' mental adjustment to their illness, another unique area of functioning which is often neglected. The majority of patients showed no dominant mode of mental adjustment, suggesting that the method of identifying patients' dominant adjustment may not be effective. Of those that did show a dominant mode, the majority had a negative dominant mental adjustment of either helplessness/hopelessness, anxious preoccupation, fatalism or avoidance/denial. Whilst it is difficult to quantify any impact these forms of adjustment may have on patients, they may well provide a useful focus for therapeutic intervention.

Almost two thirds of patients were dissatisfied with at least one aspect of their care with one third responding that they disagreed with the statement 'I have had enough therapy'. This suggests that there is a gap between patients' expectation of care and their actual care. In the case of the question 'I have had enough therapy', on which patients expressed more dissatisfaction than any other question, a gap may exist between the therapist's appraisal of whether a patient will benefit from further treatment and the patient's own opinion. This gap may provide a fruitful focus for intervention. Encouraging more realistic expectations in patients may increase their satisfaction and this may in turn facilitate positive outcome in other areas.

This description of patients' physical, social and psychological functioning after stroke provides a picture only of their functioning six months after their stroke. Unfortunately we do not have information on our patients' pre-morbid functioning to allow us to judge whether patients' psychosocial functioning has remained stable, improved or declined. Further, we cannot comment on whether the functioning of our stroke patients is better or worse than those of age matched community controls. Future studies might attempt to gain information on patients' pre-morbid functioning, perhaps through a standardised measure completed with patients or carers during the acute phase, and have a control group matched for age, sex and whether participants live alone.

When we were planning our trial there was little information regarding the use of some of these measures in stroke to tell us whether they were relevant, practical or reliable. We have attempted to remedy some of these deficiencies by examining the utility and reliability of some of our measures including the HADS, GHQ, MAS and PSS. Prior to the start of our trial we were also unable to estimate the sample size we might need to show a difference between our treatment and control groups. The data presented in this study would potentially allow others to calculate how many patients they would need to randomise to, for example, identify a 10% absolute improvement in the proportion of patients with poor involvement in social activities on the FAI.

**Table 3-14: Studies of post stroke depression using community samples.**

| Author & Year | Patients | Time of Assessment | Diagnostic Measure | Criteria | Any Depression |
|---|---|---|---|---|---|
| Burvill et al. (1995*a*) | n = 294<br>Community register. | 4 Months | PAS | DSM III<br>PSE | 23%<br>20% |
| Johnson et al. (1995) | n = 120 | | GDS | >10 | 31% |
| | n = 66 | | GHQ -28 | >5 | 29% |
| | n = 92 | | HAD | >4 | 20% |
| House et al. (1991) | n = 128<br>Community register.<br>First strokes only. | | | | |
| | n = 89 | 1 month | PSE | DSM III<br>ICD-9 | 25%<br>12% |
| | n = 119 | 6 months | | DSM III<br>ICD-9 | 21%<br>13% |
| | n = 112 | 12 months | | DSM III<br>ICD-9 | 15%<br>5% |
| | n = 76 | 1 month | BDI | > 9<br>>12<br>>16 | 32%<br>20%<br>8% |
| | n = 107 | 6 months | | > 9<br>>12<br>>16 | 32%<br>15%<br>6% |
| | n = 88 | 12 months | | > 9<br>>12<br>>16 | 16%<br>8%<br>1% |
| | n = 111 (controls)<br>GP sample stratified by age and sex | | PSE | DSM III<br>ICD-9 | 9%<br>9% |
| | | | BDI | > 9<br>>12<br>>16 | 20%<br>10%<br>5% |
| Sharpe et al. (1990) | n = 60<br>Community stroke register.<br>First strokes only. | 3 - 5 years | PSE<br>HAD-Depression | DSM III<br>>9 | 18%<br>14% |

PAS= Psychiatric Assessment Schedule; GDS= Geriatric Depression Scale; GHQ= General Health Questionnaire; HAD= Hospital Anxiety and Depression Scale; DSM= Diagnostic and Statistical Manual of Mental Disorders; PSE= Present State Examination; ICD= International Classification of Diseases. BDI= Beck Depression Inventory.

**Table 3-14. continued.**

| Author & Year | Patients | Time of Assessment | Diagnostic Measure | Criteria | Any Depression |
|---|---|---|---|---|---|
| Wade et al. (1985*a*) | n = 334<br>Community stroke register | 6 months | WDI | >15<br>>19 | 31%<br>20% |
| Wade et al. (1987) | n = 379 | 3 weeks | | >15<br>>19 | 34%<br>22% |
| | n = 377 | 6 months | | >15<br>>19 | 32%<br>20% |
| | n = 348 | 12 months | | >15<br>>19 | 31%<br>18% |

WDI= Wakefield Depression Inventory.

**Table 3-15: Studies of the post stroke frequency of depressive disorders in hospital or rehabilitation samples using structured psychiatric interviews.**

| Author & Year | Patients | Time of Assessment | Diagnostic Measure | Criteria | Any Depression |
|---|---|---|---|---|---|
| Astrom et al. (1992, 1993) | n = 98<br>Consecutive hospital admissions | | Interview by psychiatrist. | DSM-III Major depression excluding organic factor criterion | |
| | n = 76 | Discharge | | | 25% |
| | n = 73 | 3 months | | | 31% |
| | n = 68 | 1 Year | | | 16% |
| | n = 57 | 2 Years | | | 19% |
| | n = 49 | 3 Years | | | 29% |
| Dam et al. (1989) | n = 92<br>Hospital assessed | 0-43 months | Psychiatrist using psychiatric rating scales | RDC | 30.4% |
| | n = 30 (controls)<br>Prolapsed intervertebral disc. | | | | 10% |
| Eastwood et al. (1989) | n = 187<br>Consecutive rehabilitation hospital admissions. | Study entry -mean 82 days | SADS | RDC | 54% |
| | | 4 months post entry or at discharge | | | 52.9% |
| Folstein et al. (1977) | n = 20<br>Consecutive rehabilitation hospital admissions. | > 30 days | Modified PSE | Total score | 45% |
| | n=10 controls (orthopaedic) matched for physical disability | | | | 10%<br>(no P value quoted) |
| Finklestein et al. (1982) | n = 25<br>randomly selected hospital inpatients | 11 to 111 days | Interviewed by 3 experienced observers using parts of HDRS | Interviewer rated | 48% |
| | n = 13 controls<br>non-stroke disabled patients. | | | | 0%<br>P=< 0.01 |

DSM= Diagnostic and Statistical Manual of Mental Disorders; RDC= Research Diagnostic Criteria; SADS= Schedule for Affective Disorders and Schizophrenia; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale;

**Table 3-15. continued.**

| Author & Year | Patients | Time of Assessment | Diagnostic Measure | Criteria | Any Depression |
|---|---|---|---|---|---|
| Gordon et al. (1991) | n = 116 Consecutive rehabilitation hospital admissions | 2 months | SADBD | DSM III | |
| | n = 80 RHL | | | | 68% |
| | n = 36 LHL | | | | 56% |
| Herrmann et al. (1995) | n = 47 Consecutive series from stroke data bank, = first event | 2 months | Where possible- a structured clinical interview | DSM III | 36% |
| Morris et al. (1992) | n = 49 Consecutive rehabilitation hospital admissions | 2 months | CIDI | DSM III | 41% |
| Robinson et al. (1983) | n = 103 Consecutive series from stroke data bank | 2 weeks post stroke | Modified PSE | DSM III | 47% |
| Robinson et al. (1987) | n = 65 | In hospital | | | 32% |
| | n = 37 | 12 months | | | 32% |
| | n = 48(20 Patients seen on both occasions) | 24 months | | | 42% |
| Robinson et al. (1984*c*) | n = 61 (from 103) | | | | |
| | n = 40 | 3 months | | | 45% |
| | n = 50 | 6 months | | | 60% |
| Schwartz et al. (1993) | n = 91 Male consecutive rehabilitation hospital admissions | 1-103 months | Interviewer consensus using psychiatric history & HDRS | DSM Major depression | 40% |
| Starkstein et al. (1988*a*) | n = 79 consecutive hospital admissions (excluded if >10 point variance on SDS retest). | < 2 months | Modified PSE | DSM III | |
| | n = 37 Posterior circulation infarct | | | | 27% |
| | n = 42 MCA infarct | | | | 48% |

DSM= Diagnostic and Statistical Manual of Mental Disorders; CIDI= Composite International Diagnostic Interview; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale; SDS= Zung Self Rating Depression Scale; SADBD= Structured Assessment of Depression in Brain Damaged Individuals; RHL= Right Hemisphere Lesion; LHL= Left Hemisphere Lesion; MCA= Middle Cerebral Artery.

**Table 3-16: Studies of the post stroke frequency of depressive disorders in hospital or rehabilitation samples using self report measures**

| Author & Year | Patients | Time of Assessment | Diagnostic Measure | Criteria | Any Depression |
|---|---|---|---|---|---|
| Collin et al. (1987) | n = 111 Consecutive hospital admissions | 1-2 years | WDI | >14 | 56% |
| | | | | >18 | 34% |
| | | | GHQ-28 item | >5 | 50% |
| | | | | >10 | 31% |
| Ebrahim et al. (1987) | n = 149 Consecutive hospital admissions | 6 months | GHQ -28 | >11 | 23% |
| Greveson et al. (1991) | n = 67 Consecutive hospital admissions. | 3 years | WDI | >18 | 28% |
| Kettle & Chamberlain (1989) | n = 70 Rehabilitation unit admissions. | Median 21 months | WDI | >14 | 44% |
| | | | | >18 | 31% |
| | n = 25 (controls) From Age Concern classes. | | | >14 | 0% |
| Robinson & Price (1982) | n = 103 randomly selected from hospital stroke clinic. Categorised by time post stroke | 6 - 15 years At initial interview | GHQ-28 | = 5 | 29% |
| | | | | = 6 | 23% |
| | | | | = 8 | 17% |
| | n = 15 | 0-5 months | | = 5 | 13% |
| | n=33 | 6-12 months | | | 45% |
| | n = 9 | 3-4 years | | | 22% |
| | n = 11 | 5-6 years | | | 27% |
| | n = 16 | 7-9 years | | | 19% |
| | n = 19 | =>10 years | | | 26% |
| Schubert et al. (1992) | n =15 rehabilitation centre inpatients | | | DSM | 68% |
| | | | BDI | >11 | 50% |
| Shinar et al. (1986) | n = 27 Consecutive series from stroke data bank | 7 - 10 days | CES-D | >16 | 41% |
| Sinyor et al. (1986) | n = 64 Consecutive hospital admissions- first strokes | 'within weeks' | SDS | >60 | 22% |
| | | | | >50 | 47% |

WDI= Wakefield Depression Inventory; GHQ= General Health Questionnaire; BDI= Beck Depression Inventory; CES-D= Centre for Epidemiological Studies - Depression; DSM= Diagnostic and Statistical Manual of Mental Disorders; SDS= Zung Self Rating Depression Scale.

**Table 3-17: Studies of the post stroke frequency of anxiety disorders**

| Author & Year | Patients | Time of Follow up | Diagnostic Measure | Criteria | Any Anxiety |
|---|---|---|---|---|---|
| Astrom, (1996) | n = 80 | In hospital | Interview by Psychiatrist | DSM III R GAD | 28% |
| | Consecutive hospital admissions | 3 months | | | 31% |
| | | 1 year | | | 24% |
| | | 2 years | | | 25% |
| | | 3 years | | | 19% |
| Burvill et al. (1995*b*) | n = 294 Community stroke register. | 4 months | PAS | DSM III | 11% |
| | | 1 Year | | | 21% |
| | n = 106 (controls) | 4 months | | | 7% |
| Johnson et al. (1995) | n = 120 | 4 months | GDS | >14 | 24% |
| | n = 66 | | GHQ -28 | >4 | 19% |
| | n = 93 | | HAD | >5 | 23% |
| Castillo et al. (1993) | n = 309 Consecutive hospital admissions | In hospital | Modified PSE & HDRS | DSM III R GAD | 27% |
| Gibson et al. (1991) | n = 50 With cerebral damage. 44 due to stroke. 6 due to trauma | No details quoted | | | |
| | n = 39 | | HAD Anxiety | >10 | 13% |
| House et al. (1991) | n = 128 Community stroke register. First strokes only. | | PSE | DSM III | |
| | n = 89 | 1 month | | GAD | 1% |
| | n = 119 | 6 months | | | 1% |
| | n = 112 | 12 months | | | 1% |
| | n = 109 controls | | | | 1% |
| | n = 89 | 1 month | | Adjustment disorder - anxious | 4% |
| | n = 119 | 6 months | | | 3% |
| | n = 112 | 12 months | | | 4% |
| | n = 109 controls | | | | 1% |
| | n = 89 | 1 month | | ICD-9 Anxiety neurosis | 3.5% |
| | n = 119 | 6 months | | | 2.5% |
| | n = 112 | 12 months | | | 3% |
| | n = 109 controls | | | | 1.5% |

DSM= Diagnostic and Statistical Manual of Mental Disorders; GAD= Generalised Anxiety Disorder; PAS= Psychiatric Assessment Schedule; GDS= Geriatric Depression Scale; GHQ= General Health Questionnaire; . HAD= Hospital Anxiety and Depression Scale; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale; ICD= International Classification of Diseases.

**Table 3-17. continued.**

| **Author & Year** | **Patients** | **Time of Follow up** | **Diagnostic Measure** | **Criteria** | **Any Anxiety** |
|---|---|---|---|---|---|
| Magni & Schifano, (1984) | n = 30 Consecutive patients | n=17 assessed within 45 days.<br>n=13, assessed 8-12 months after onset. | Symptom Distress Checklist | >2 | 23% |
| | n=30 (controls) Matched for age, sex, marital status, socio-economic variables & type of illness. | | | >2 | 6.6% |
| Malec et al. (1990) | n = 20 Hospital admissions, > 55 years | within 6 weeks | HDRS | >7 | 35% |
| | | | | RDC | 30% |
| Morris et al. (1993*b*) | n = 84 | 2 months | CIDI | DSM III | 4% |
| Sharpe et al. (1990) | n = 60 Community stroke register | 3 - 5 years | PSE | DSM III | 20% |
| | | | HAD-Anxiety | >8 | 14% |
| Starkstein et al. (1990) | n=225 Consecutive hospital admissions | In hospital | Modified PSE | DSM III | 13% |

HDRS= Hamilton Depression Rating Scale; RDC= Research Diagnostic Criteria. CIDI= Composite International Diagnostic Interview; DSM= Diagnostic and Statistical Manual of Mental Disorders; PSE= Present State Examination; HAD= Hospital Anxiety and Depression Scale.

**Table 3-18: Studies of post stroke social functioning.**

| Author & Year | Patients | Time of Follow up | Diagnostic Measure | % Poor Social Adjustment |
|---|---|---|---|---|
| Kettle & Chamberlain (1989) | n = 70<br>Rehabilitation unit admissions. | median 21 months | FAI | |
| | | | 0-10 = little/ no activity | 47% |
| | | | 11-30 = moderate activity | 49% |
| | | | 31-45 = major activity | 4% |
| | n = 25 (controls)<br>drawn from Age Concern classes. | | 0-10 = little/ no activity | 0% |
| | | | 11-30 = moderate activity | 16% |
| | | | 31-45 = major activity | 84% |
| Labi et al. (1980) | n = 121<br>Consecutive community series, who scored >19 on Kenny Self Care Evaluation form. | Long term | -Decreased socialisation outside the home | 50% |
| | | | -Decreased socialisation in the home | 37% |
| | | | -Decrease in hobbies / other interests | 38% |
| | n = 141 Controls<br>Matched for age and sex, scored 19 on Kenny Self Care Evaluation form. | | -Decreased socialisation outside the home | 26%<br>P = < 0.0001 |
| | | | -Decreased socialisation in the home | 26%<br>P = < 0.05 |
| | | | -Decrease in hobbies / other interests | 19%<br>P = < 0.001 |
| Santus et al. (1990) | n = 76<br>Hemiplegic physiotherapy patients | 1 year | SFE - problems with social and family integration | 58% |
| Schuling et al. (1993) | n = 122<br>GP sample | 6 months | FAI | |
| | n = 92 pre-stroke | | 0-10 = little/ no activity | 16% |
| | | | 11-30 = moderate activity | 69% |
| | | | 31-45 = major activity | 15% |
| | n=96 post-stroke | | 0-10 = little/ no activity | 41% |
| | | | 11-30 = moderate activity | 48% |
| | | | 31-45 = major activity | 12% |
| | n=216 controls | | 0-10 = little/ no activity | 8% |
| | | | 11-30 = moderate activity | 54% |
| | | | 31-45 = major activity | 38% |
| Wade et al. (1985*a*) | n = 429<br>Community stroke register | 6 months | FAI* | |
| | | | 15 = no activity | 20% |
| | | | 16-25 = little activity | 31% |
| | | | 26-45 = moderate activity | 40% |
| | | | 46-60 = major activity | 9% |

FAI= Frenchay Activities Index; SFE= Social Functioning Exam;

*Subtract 15 from all scores to compare with new FAI scoring.

Table 3-18. continued.

| Author & Year | Patients | Time of Follow up | Diagnostic Measure | % Poor Social Adjustment |
|---|---|---|---|---|
| Wade et al. (1985*b*) | n=976<br>Community stroke register | | FAI<br>Scored 0 = no activity. | |
| | n = 581 | Pre-stroke | | 8% |
| | n=491 | 6 months | | 21% |
| | n=444 | 1 year | | 9% |

FAI= Frenchay Activities Index.

# 4. Understanding the Causes of Poor Psychosocial Outcome After Stroke

In this chapter I shall examine the inter-relationships between the different domains of patients' psychosocial outcomes before examining the physiological correlates of mood and attempting to predict which patients are most at risk of poor psychosocial outcome using baseline variables.

If we want to identify patients at risk of poor psychosocial outcomes and develop interventions to alleviate their difficulties, we need first to gain an understanding of the mechanisms involved. By mechanisms I mean an examination of factors which may cause or exacerbate poor psychosocial outcome; variables which explain a significant proportion of the variance in psychosocial outcome. The various aspects of patients' psychosocial outcomes, their reported mood symptoms, participation in social activities and their level of social adjustment are all likely to be associated with and perhaps have a causal relationship with one another. In the first part of the chapter I shall examine these inter-relationships and discuss any possible causal relationships between them.

### Statistical methods used in this chapter

I examined the inter-relationships between outcome measures and between baseline variables and outcome to give us a better understanding of poor psychosocial outcome, using similar statistical methods in both of these sections.

In attempting to understand the causation of each aspect of psychosocial outcome after stroke a number of criteria should be considered and it is with these in mind that I undertook the following analysis. If the association had been examined previously were our results consistent with these findings and did such an association make clinical sense? Was the temporal sequence of exposure and outcome in the right order and did that too make clinical sense in trying to explain the cause of poor psychosocial outcome? Did a dose response gradient exist, i.e. as exposure to the independent variable increased did the value of the dependent variable rise or fall accordingly (Sackett et al. 1991)? Finally, had a randomised controlled trial been conducted where a possible causal factor was manipulated and a reduction in the proportion of poor outcome shown? Only if these criteria are satisfied can an assumption of causality be made.

In order to examine aetiology and produce predictive models I have used a variety of regression analyses. These attempt to determine the contribution of one or more independent variables to the explanation of variance in a dependent variable. They have the advantage of not only stating whether a relationship exists in terms of whether variables are more related than would be assumed by chance but also of describing that relationship in terms of the percentage of variance explained which allows us to observe the relative importance or strength of relationships.

Below are explanations of the types of regression analysis used in this chapter.

**Single variable regression:**

A single variable regression is when a single dependent variable (outcome) is entered into a regression with one other independent variable. The *R squared* value tells us how much variance in the dependent variable is explained by or shared with the independent variable. For example, if the GHQ score is the dependent variable and it is entered into a regression with the Barthel Index, the independent variable, the R square is 13.97%, telling us that patients' Barthel Index explains 14% of the variance in GHQ score.

**Multiple regression:**

A multiple regression still has one dependent variable but has several independent variables. This has the advantage of allowing the combination of independent variables to explain variance in the dependent variable. For example, in a multiple regression with the GHQ score as the dependent variable and BI and FAI scores as independent variables one can assess whether adding a third independent variable, i.e. patients' SAS score, contributes anything extra to the explanation of variance in a patient's GHQ score.

Multiple regression analyses are only possible for those patients for whom data relating to each variable are complete. Therefore, the more variables included in the regression the fewer patients are likely to be available for the analysis.

### Backward stepwise multiple regression:

A backward stepwise multiple regression begins by entering all variables specified as they would be in a normal multiple regression. A backward regression then removes the variable contributing least to the explanation of variance and recalculates the regression using the remaining variables. It continues to remove variables in this stepwise fashion until all variables meet some pre-defined criterion. This allows the development of models which, while steadily decreasing the number of variables used for their calculation, still explain as much variance as possible.

It is important to note that only patients with complete data for all starting variables are eligible for inclusion. Therefore even once a variable has been removed during the backwards regression the original patient sample remains. For example, a patient whose data were complete for all variables except the Barthel Index would be excluded from the start of any regression in which the Barthel Index was a variable. Should the backward regression process then remove the Barthel Index from the regression resulting in the patient now having complete data for all included variables this patient would still not be added. Therefore once a model has been selected it may be worth reassessing by entering only those variables to be included and thus using all patients for whom relevant data is complete.

### Forward stepwise multiple regression:

A forward stepwise multiple regression is similar to its backward counterpart but instead starts with a single variable and adds the next best variable, of those specified in the regression command, which coupled with the first will explain the maximum amount of variance. At each step the regression adds another variable and calculates the regression before finishing when no additional variable will add significantly to the model.

### Interpreting regression analyses:

### Beta:

Beta is the coefficient that the variable value must be multiplied by to estimate the predicted value of the dependent variable. In multiple regressions each variable should be multiplied by its own beta value before being added to the intercept value to calculate the predicted value of the dependent variable.

**Standard error:**

The standard error is the standard deviation of the estimated value of a parameter.

**Signif F or P value:**

The p value reflects whether the variance explained is significant, in other words, is unlikely to be a chance effect.

**R squared:**

The value of R squared represents the amount of variance in the dependent variable which is explained by the independent variable or variables. To aid comparison with other studies the correlations between variables (the square root of the R squared value) have also been listed.

**Dose response gradients:**

During my examination of the inter-relationships of my outcome measures those variables that explained the most variance on each outcome were plotted to illustrate a dose response gradient. Patients' mean scores on the dependent variable were calculated for each score on the independent variable and a linear trend line inserted. I recognise that this method may not be optimum, as the means of ordinal scales may not be meaningful, but it does help illustrate the relationships between key variables.

## 4.1 The Inter-Relationship of Psychosocial Outcomes

### *4.1.1 The Inter-Relationship of Mood Disorders With Other Outcome Variables*

To investigate mood disorders I chose the GHQ score as the dependent variable because 310 patients completed it whilst only 252 completed the HADS. It also had the additional advantage of representing a ‘total mood score’ rather than simply anxiety or depression on different subscales.

I performed individual regressions on each outcome variable; the independent variables, with the GHQ score, the dependent variable, to determine how much variance in GHQ score each independent variable explained. These results are illustrated in Table 4-1 in descending order of the amount of variance explained.

**Table 4-1: Regression of individual outcome variables on General Health Questionnaire score as the dependent variable.**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| Social Adjustment: Total | 9.5137 | 0.8739 | <0.0001 | 307 | 0.52 | 27.99% |
| Oxford Handicap Scale Score | 2.9627 | 0.3024 | <0.0001 | 309 | 0.49 | 23.82% |
| Social Adjustment: Leisure | 5.2752 | 0.6226 | <0.0001 | 307 | 0.44 | 19.05% |
| Social Adjustment: Family | 7.9517 | 0.9734 | <0.0001 | 301 | 0.43 | 18.28% |
| Medical Coping Mode: Accept-Resignation | 1.3184 | 0.1795 | <0.0001 | 286 | 0.4 | 15.96% |
| Social Adjustment: Partner | 4.8676 | 0.8525 | <0.0001 | 179 | 0.39 | 15.56% |
| S6-I'm happy with amount of recovery | 3.8679 | 0.5581 | <0.0001 | 268 | 0.39 | 15.3% |
| Frenchay Activities Index Score | -0.2534 | 0.0358 | <0.0001 | 299 | 0.38 | 14.46% |
| Barthel Index Score | -0.8219 | 0.1168 | <0.0001 | 307 | 0.37 | 13.97% |
| S8-I have had enough therapy | 3.3028 | 0.5306 | <0.0001 | 250 | 0.37 | 13.51% |
| Mental Adjustment: Anxious Preoccupation | 0.2925 | 0.0501 | <0.0001 | 226 | 0.36 | 13.23% |
| Mental Adjustment: Fighting S-Hopeless | 0.2398 | 0.0433 | <0.0001 | 226 | 0.35 | 12.06% |
| Social Adjustment: Family Unit | 7.3228 | 1.1442 | <0.0001 | 305 | 0.34 | 11.91% |
| Social Adjustment: Work | 3.7005 | 1.0957 | <0.0011 | 93 | 0.33 | 11.14% |
| Medical Coping Mode: Avoidance | 0.5724 | 0.1021 | <0.0001 | 286 | 0.32 | 9.97% |
| S15-Enough information re. recovery/rehab | 2.8029 | 0.6789 | 0.0001 | 250 | 0.25 | 6.43% |
| Mental Adjustment: Fatalism | 0.1694 | 0.045 | 0.0002 | 226 | 0.24 | 5.95% |
| S4-Enough information re. causes of illness | 2.1852 | 0.5854 | 0.0002 | 263 | 0.23 | 5.07% |

**Table 4-1. continued**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| S18-Enough emotional support since I left | 2.6201 | 0.7096 | 0.0003 | 259 | 0.22 | 5.04% |
| S14-Satisfied with practical help since I left | 2.5285 | 0.7313 | 0.0006 | 239 | 0.22 | 4.80% |
| S7-Satisfied with therapists' treatment | 2.375 | 0.7022 | 0.0008 | 249 | 0.21 | 4.43% |
| S16-Needs/problems listened to/understood | 2.0884 | 0.6668 | 0.0020 | 245 | 0.2 | 3.88% |
| S3-Able to talk to staff about problems | 2.0868 | 0.6456 | 0.0014 | 264 | 0.19 | 3.84% |
| S17-I have not felt neglected since discharge | 2.3422 | 0.7369 | 0.0017 | 261 | 0.19 | 3.75% |
| S12-Satisfied re hospital outpatient services | 1.9277 | 0.7602 | 0.0119 | 240 | 0.16 | 2.63% |
| S2-Staff attended well to my personal needs | 1.7696 | 0.7396 | 0.0174 | 262 | 0.15 | 2.15% |
| S1-Staff treated me with kindness & respect | 1.7901 | 0.7790 | 0.0224 | 264 | 0.14 | 1.98% |
| S19-I've received enough special equipment | 1.4387 | 0.7608 | 0.0599 | 224 | 0.13 | 1.58% |
| S9-Enough information about services etc. | 1.2653 | 0.6445 | 0.0507 | 248 | 0.12 | 1.54% |
| S5-Dr.'s did all they can to make me well | 1.443 | 0.7354 | 0.0507 | 264 | 0.12 | 1.45% |
| S13-I think the ambulance service reliable | 1.3036 | 0.7688 | 0.0913 | 234 | 0.11 | 1.22% |
| S11-Receive all help needed from services | 1.1252 | 0.7106 | 0.1147 | 230 | 0.1 | 1.09% |
| Medical Coping Mode: Confrontational | 0.0173 | 0.1127 | 0.1251 | 286 | 0.09 | 0.83% |
| S20-Know who to contact re stroke problem | 1.0194 | 0.7264 | 0.1617 | 261 | 0.09 | 0.76% |
| Recovery Locus of Control Scale | -0.0861 | 0.1227 | 0.4834 | 292 | 0.04 | 0.17% |
| Mental Adjustment: Denial / Avoidance | 0.3981 | 0.5147 | 0.4401 | 226 | 0.05 | 0.27% |
| S10-Things were well prepared re discharge | 0.5151 | 0.7502 | 0.4930 | 237 | 0.04 | 0.20% |

Note: For all variables except the FAI a higher score indicates a more negative outcome. Variables prefixed 'S' refer to individual patient satisfaction questions. These questions have been truncated, for the complete versions please refer to Appendix C. SE = Standard Error.

When interpreting the data shown in Table 4-1 it should be remembered that each of these regressions was univariate, that is, we cannot say the amount of variance shared or explained by any one variable is independent of that shared by other variables. The table is useful as a guide to the relative strength of relationships between variables. The reader should pay particular attention to the amount of variance explained (the higher this number the stronger the association between variables), the P value (which illustrates how statistically significant this relationship is) and the Beta value (the sign of which, positive or negative, illustrates the direction of the relationship).

The independent variables which explained most variance in GHQ score were a patient's Total SAS Score, 28% of variance, and their OHS Score, 24% of variance. These results were highly significant ($p<0.001$).

To determine if a dose response relationship existed between either OHS or SAS total scores and the GHQ the mean GHQ score for each value of the OHS and SAS total score was plotted and a linear regression trendline inserted (Figures 4-1 and 4-2). The figures suggest that as the severity of physical disability (OHS) or the amount of social maladjustment reported (SAS total) rose so did the number of mood symptoms reported.

**Figure 4-1: The dose response relationship between patients' mean General Health Questionnaire scores and level of dependence defined by the Oxford Handicap Scale.**

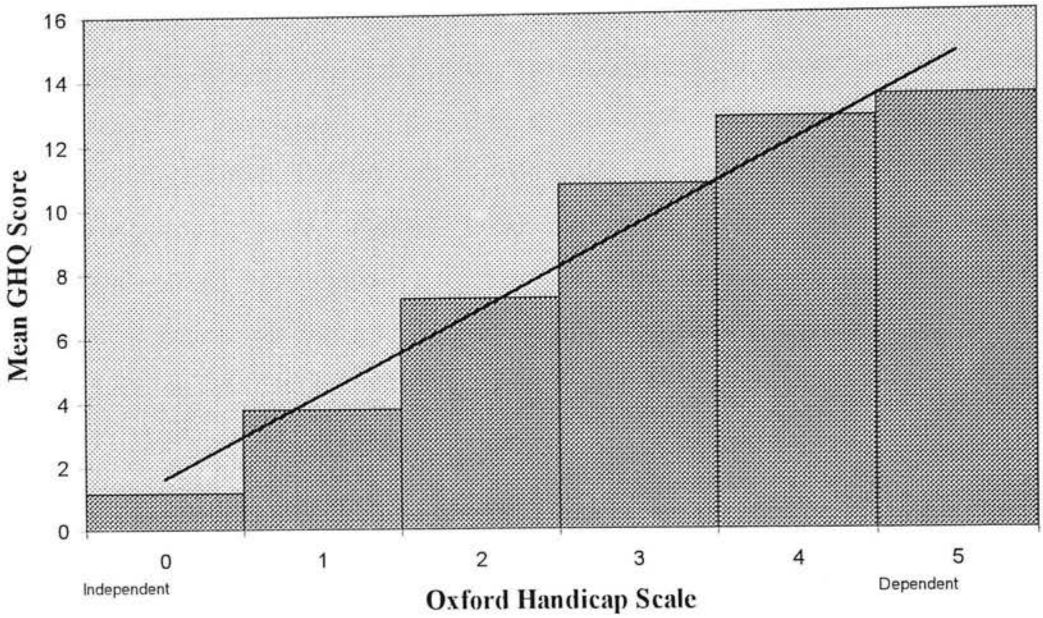
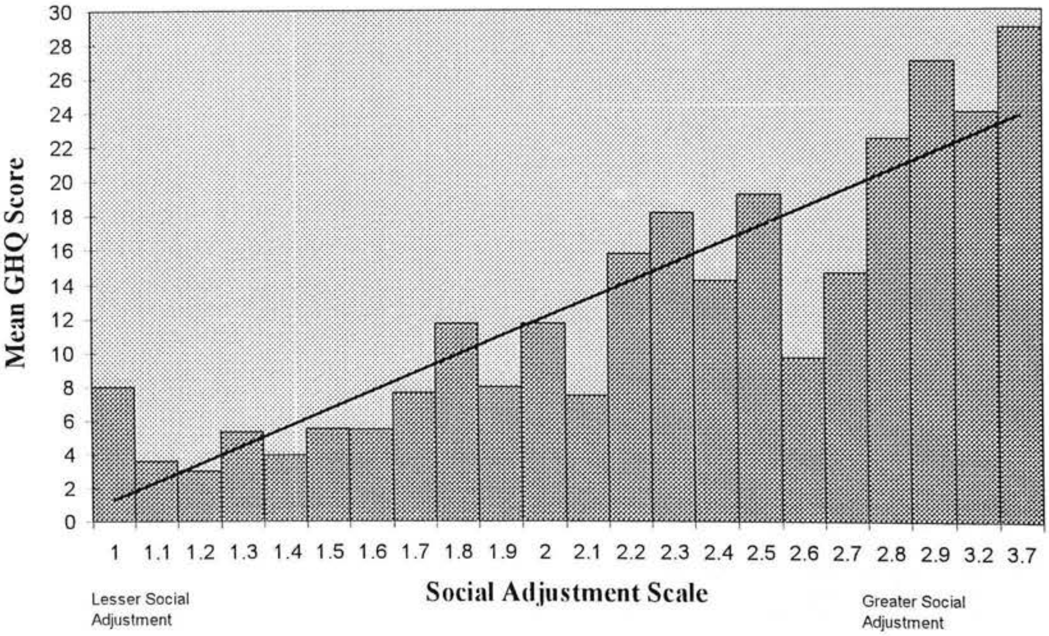


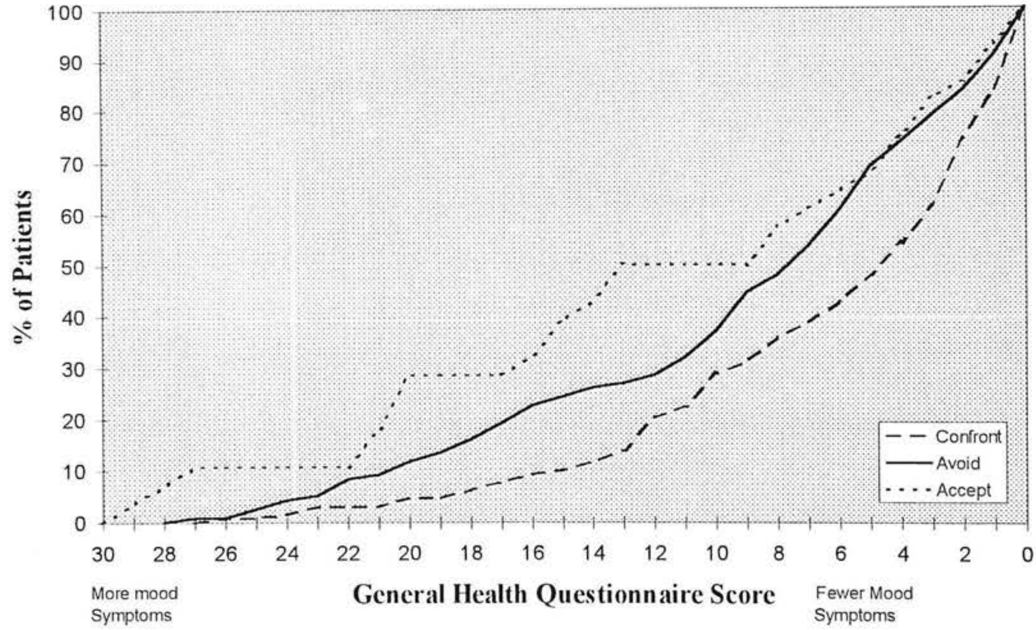
**Figure 4-2: The dose response relationship between patients' mean General Health Questionnaire scores and their level of social adjustment on the Social Adjustment Scale.**



Little research has been conducted on the impact a patient's manner of coping with their illness has on their outcome. Research in other illnesses has suggested a relationship between confrontative, action based strategies and lower levels of mood symptoms and between avoidant strategies and higher levels of mood disorder (Feifel et al., 1987; Sinyor et al., 1986*a*; Schussler, 1992).

To further explore this area I conducted a separate analysis to identify any inter-relationship between medical coping mode and the GHQ. For each patient a dominant method of coping was determined by calculating a patient's score on each subscale as a percentage of the maximum score possible. The subscale for which this percentage was highest was deemed their dominant coping mode. Patients' GHQ scores were initially treated as continuous variables and patients' scores plotted according to their dominant coping mode (Figure 4-3). Again dividing patients according to their dominant coping mode their relative risk of being defined a 'case' on the GHQ was calculated using three cut-offs, 4/5 (Figure 4-4), 8/9 (Figure 4-5) and 11/12 (Figure 4-6) as used previously.

**Figure 4-3: Cumulative distribution of General Health Questionnaire scores by dominant coping mode.**



| Dominant coping mode | n | Mean | Median | Range | P Value |
|---|---|---|---|---|---|
| Confrontational | 129 | 6.2 | 4 | 0 - 26 | 0.0003 |
| Avoidant | 119 | 8.9 | 7 | 0 - 27 | 0.024 |
| Accepting | 28 | 11.6 | 10.5 | 0 - 29 | 0.028 |

Mood disorders were significantly more common in patients whose dominant coping modes were avoidance, (p=0.024), or acceptance, (p=0.028), and significantly less common in those who were confrontational (p=0.0003) (Figure 4-3). Likewise for all cut-offs patients were at significantly less risk of mood disorders if their dominant coping mode was confrontational (Figures 4-4, 4-5 and 4-6). Patients whose dominant coping mode was avoidant were at significantly greater risk of mood disorders at a low cut-off of 4/5 but not at higher cut-offs. Patients who were dominantly Accepting were at significantly more risk for the highest cut-off of 11/12 but not at lower cut-offs (Figures 4-4, 4-5 and 4-6).

**Figure 4-4: The relative risk of mood disorder for each coping mode for a General Health Questionnaire cut-off of 4/5.**

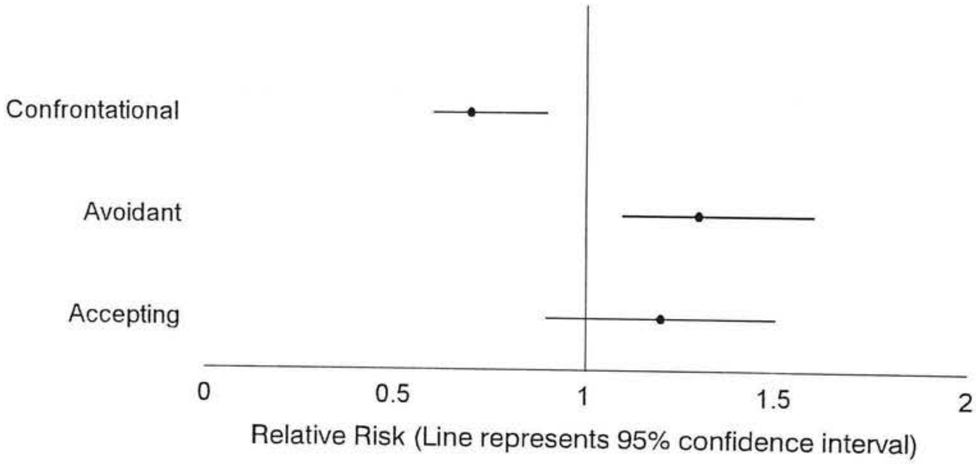


Figure 4-5: The relative risk of mood disorder for each coping mode for a General Health Questionnaire cut-off of 8/9.

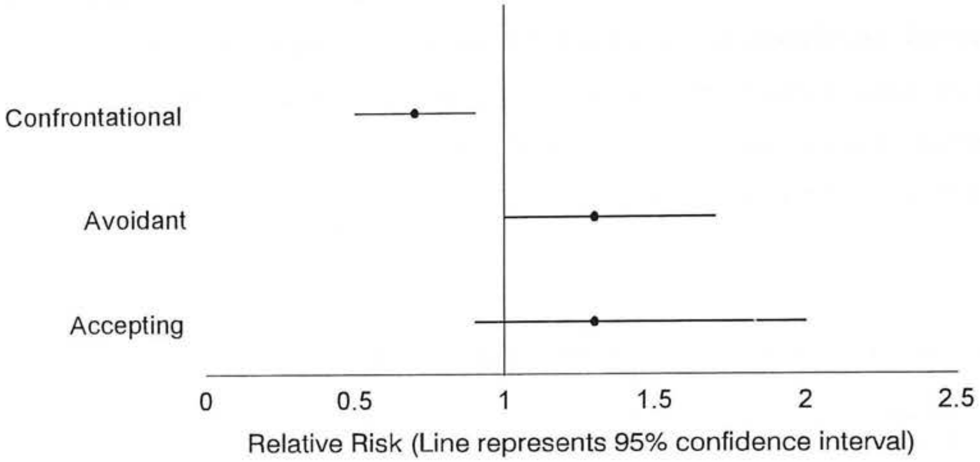
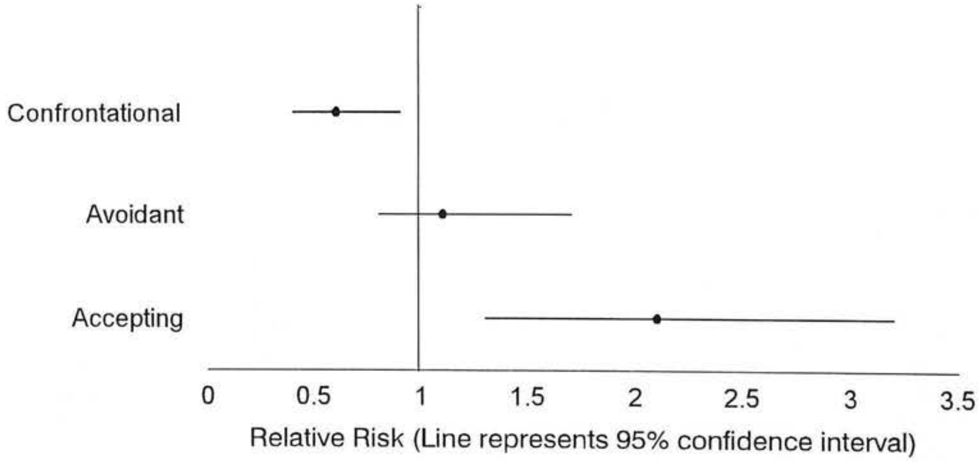


Figure 4-6: The relative risk of mood disorder for each coping mode for a General Health Questionnaire cut-off of 11/12.



### *4.1.2 The Inter-Relationship of Level of Participation in Social Activities With Other Outcome Variables*

The Frenchay Activities Index (FAI) was our measure of social activities and I therefore used its total score as the dependent variable for analyses of the associations between social activities and other variables. Patients' social activities score mainly reflected the patient's physical functioning as measured by their OHS, 54% of variance, and their Barthel score, 48% of variance. A somewhat lower but still highly significant proportion of the variance was explained by the HAD Depression Subscale, 25%.

**Table 4-2: Regression of individual outcome variables on Frenchay Activities Index score as the dependent variable.**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| Oxford Handicap Scale Score | -6.7914 | 0.3454 | <0.0001 | 326 | 0.73 | 54.41% |
| Barthel Index Score | 2.3032 | 0.1334 | <0.0001 | 323 | 0.69 | 48.14% |
| HADS: Depression Subscale | -1.2972 | 0.1404 | <0.0001 | 254 | 0.50 | 25.32% |
| Mental Adjustment: Fatalism | -0.4369 | 0.0667 | <0.0001 | 229 | 0.4 | 15.9% |
| Mental Adjustment: Fighting S-Hopeless | -0.4085 | 0.0659 | <0.0001 | 229 | 0.38 | 14.48% |
| General Health Questionnaire - Total Score | -0.5704 | 0.0805 | <0.0001 | 299 | 0.38 | 14.46% |
| S8-I have had enough therapy | -4.4043 | 0.8018 | <0.0001 | 258 | 0.32 | 10.54% |
| Social Adjustment: Total | -8.5443 | 1.4971 | <0.0001 | 312 | 0.31 | 9.51% |
| S6-I'm happy with amount of recovery | -4.4672 | 0.8545 | <0.0001 | 277 | 0.3 | 9.04% |
| Social Adjustment: Leisure | -5.2739 | 0.9666 | <0.0001 | 312 | 0.3 | 8.76% |
| Social Adjustment: Partner | -4.8296 | 1.3495 | 0.0004 | 182 | 0.26 | 6.64% |
| S12-Satisfied re hospital outpatient services | -4.4001 | 1.0626 | <0.0001 | 251 | 0.25 | 6.44% |
| Medical Coping Mode: Accept-Resignation | -1.2357 | 0.2836 | <0.0001 | 293 | 0.25 | 6.12% |
| Medical Coping Mode: Avoidance | -0.6672 | 0.1547 | <0.0001 | 293 | 0.24 | 6.01% |
| Social Adjustment: Family | -6.0216 | 1.6248 | 0.0003 | 307 | 0.23 | 4.31% |
| S3-Able to talk to staff about problems | -1.9739 | 0.9573 | 0.0402 | 273 | 0.21 | 4.02% |
| Mental Adjustment: Anxious Preoccupation | -0.2411 | 0.0808 | 0.0032 | 229 | 0.2 | 3.77% |
| Recovery Locus of Control Scale | 0.5837 | 0.1769 | 0.0011 | 299 | 0.19 | 3.54% |
| S17-I have not felt neglected since discharge | -3.2792 | 1.059 | 0.0022 | 269 | 0.19 | 3.47% |
| S5-Dr.'s did all they can to make me well | -3.2016 | 1.1062 | 0.0041 | 273 | 0.19 | 3% |
| S14-Satisfied with practical help since I left | -2.8974 | 1.086 | 0.0081 | 249 | 0.17 | 2.80% |
| S4-Enough information re. causes of illness | -2.3139 | 0.8627 | 0.0078 | 272 | 0.17 | 2.6% |
| S15-Enough information re. recovery/rehab | -2.3033 | 0.9782 | 0.0193 | 260 | 0.16 | 2.10% |
| S7-Satisfied with therapists' treatment | -2.3534 | 1.0416 | 0.0247 | 257 | 0.14 | 1.96% |
| S2-Staff attended well to my personal needs | -2.5266 | 1.0935 | 0.0216 | 271 | 0.14 | 1.95% |
| S1-Staff treated me with kindness & respect | -2.7571 | 1.1097 | 0.0220 | 273 | 0.14 | 1.92% |
| S16-Needs/problems listened to/understood | -2.1313 | 0.9683 | 0.0286 | 254 | 0.14 | 1.89% |
| Medical Coping Mode: Confrontational | 0.3422 | 0.1646 | 0.385 | 293 | 0.14 | 1.46% |
| Social Adjustment: Family Unit | -3.711 | 1.8012 | 0.0402 | 309 | 0.12 | 1.36% |
| S18-Enough emotional support since I left | -1.7362 | 1.0611 | 0.1030 | 267 | 0.12 | 1.00% |

**Table 4-2. continued.**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| Social Adjustment: Work | -1.6612 | 1.7114 | 0.3341 | 98 | 0.03 | 0.97% |
| S13-I think the ambulance service reliable | -1.3355 | 1.0741 | 0.2150 | 244 | 0.03 | 0.64% |
| S11-Receive all help needed from services | -1.1659 | 1.0689 | 0.2765 | 239 | 0.02 | 0.50% |
| Mental Adjustment: Denial / Avoidance | -0.7401 | 0.8011 | 0.3566 | 229 | 0.02 | 0.38% |
| S20-Know who to contact re stroke problem | 0.0032 | 10.607 | 0.3528 | 270 | 0.02 | 0.32% |
| HADS: Anxiety Subscale | -0.542 | 0.1468 | 0.0003 | 250 | 0.02 | 5.21% |
| S10-Things were well prepared re discharge | 0.0260 | 1.103 | 0.8136 | 245 | 0 | 0.02% |
| S19-I've received enough special equipment | 0.0162 | 1.1256 | 0.8852 | 233 | 0 | 0.01% |
| S9-Enough information about services etc. | 0.0839 | 0.9624 | 0.9306 | 255 | 0 | 0.00% |

Note: For all variables in Table 4-2 a higher score indicates more negative outcome. Variables prefixed 'S' refer to individual patient satisfaction questions. These questions have been truncated, for the complete versions please refer to Appendix C.

In order to examine the dose response relationship between patients' FAI scores and their level of disability and depression patients' mean FAI score was plotted for each score of the OHS and HAD Depression subscale. Patients' levels of social activity decreased with either an increase in disability or in symptoms of depression.

**Figure 4-7: The dose response relationship between patients' mean Frenchay Activities Index scores and their level of dependence on the Oxford Handicap Scale.**

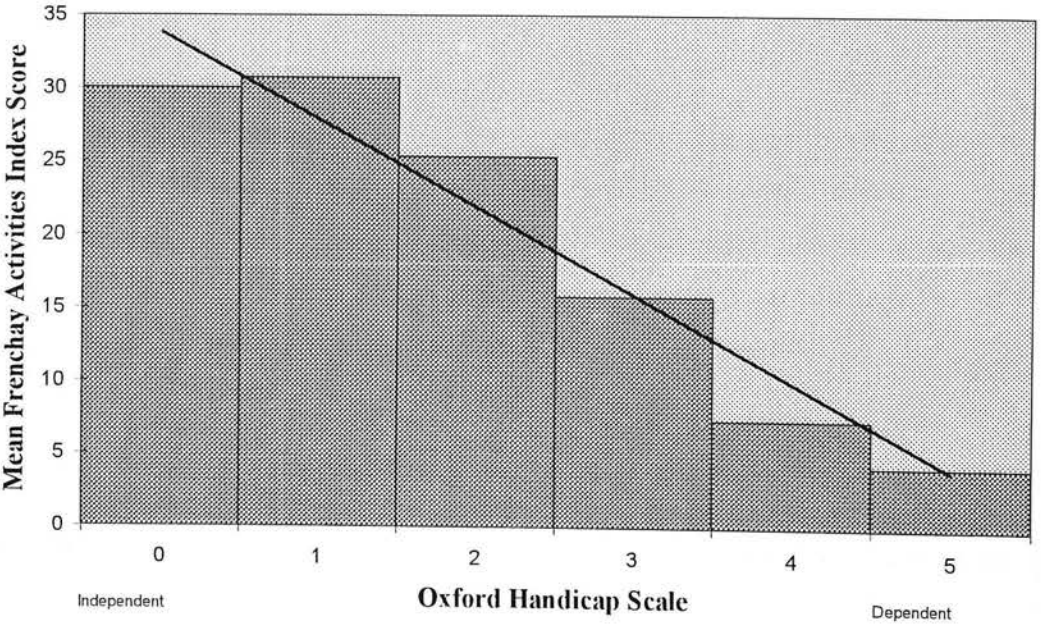
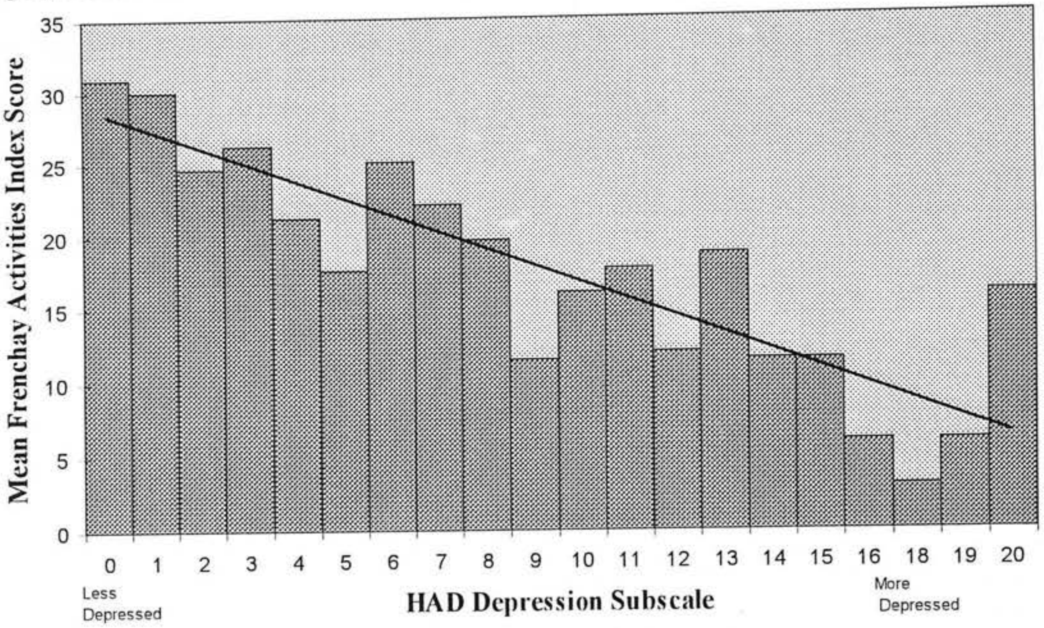


**Figure 4-8: The dose response relationship between patients' mean Frenchay Activities Index scores and their level of depression on the Hospital Anxiety and Depression Scale Depression Subscale.**



### 4.1.3 *The Inter-Relationship of Social Adjustment With Other Outcome Variables*

Patients' total SAS scores were used as the dependent variable when examining the inter-relationships between social adjustment and other variables. Individual regression analyses found that patients' social adjustment reflected their physical functioning and mood symptoms. The OHS explained 33% of variance with patients' social adjustment scores, the GHQ 28%, and the HAD Depression and Anxiety Subscales 20% each.

**Table 4-3: Regression of individual outcome variables on Social Adjustment Scale total score as the dependent variable.**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| Oxford Handicap Scale Score | 0.1186 | 0.0189 | <0.0001 | 323 | 0.57 | 32.98% |
| General Health Questionnaire - Total Score | 0.0294 | 0.0027 | <0.0001 | 307 | 0.53 | 27.99% |
| HADS: Depression Subscale | 0.0417 | 0.0052 | <0.0001 | 256 | 0.45 | 20.15% |
| HADS: Anxiety Subscale | 0.0382 | 0.0049 | <0.0001 | 253 | 0.44 | 19.8% |
| Medical Coping Mode: Accept-Resignation | 0.0692 | 0.0099 | <0.0001 | 299 | 0.38 | 14.11% |

**Table 4-3. continued.**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| Frenchay Activities Index: Total Score | -0.0111 | 0.002 | <0.0001 | 312 | 0.97 | 9.51% |
| S11-Receive all help needed from services | 0.0034 | 0.0384 | 0.9301 | 241 | 0.3 | 9.3% |
| Medical Coping Mode: Avoidance | 0.0291 | 0.0055 | <0.0001 | 299 | 0.29 | 8.48% |
| Mental Adjustment: Anxious Preoccupation | 0.0124 | 0.0029 | <0.0001 | 233 | 0.28 | 7.55% |
| S3-Able to talk to staff about problems | 0.1499 | 0.0336 | <0.0001 | 277 | 0.26 | 6.75% |
| Mental Adjustment: Fighting S-Hopeless | 0.0098 | 0.0025 | 0.0001 | 233 | 0.25 | 6.31% |
| Barthel Index Score | -0.0314 | 0.007 | 0.0001 | 321 | 0.24 | 5.98% |
| Mental Adjustment: Fatalism | 0.0091 | 0.0025 | 0.0004 | 233 | 0.23 | 5.30% |
| S6-I'm happy with amount of recovery | 0.108 | 0.0314 | 0.0007 | 280 | 0.2 | 4.08% |
| S4-Enough information re. causes of illness | 0.0973 | 0.0311 | 0.0019 | 276 | 0.19 | 3.46% |
| S18-Enough emotional support since I left | 0.1156 | 0.0375 | 0.0023 | 269 | 0.18 | 3.43% |
| S14-Satisfied with practical help since I left | 0.1119 | 0.0389 | 0.0043 | 251 | 0.17 | 3.22% |
| S2-Staff attended well to my personal needs | 0.112 | 0.0390 | 0.0044 | 275 | 0.17 | 2.93% |
| S8-I have had enough therapy | 0.0839 | 0.0304 | 0.0063 | 261 | 0.17 | 2.85% |
| S15-Enough information re. recovery/rehab | 0.0804 | 0.0358 | 0.0256 | 262 | 0.14 | 1.905% |
| S1-Staff treated me with kindness & respect | 0.0939 | 0.0428 | 0.0290 | 277 | 0.13 | 1.72% |
| S13-I think the ambulance service reliable | 0.0801 | 0.0394 | 0.0432 | 246 | 0.13 | 1.67% |
| S5-Dr.'s did all they can to make me well | 0.0782 | 0.04 | 0.0515 | 277 | 0.12 | 1.37% |
| S17-I have not felt neglected since discharge | 0.0666 | 0.0387 | 0.0862 | 271 | 0.1 | 1.09% |
| S12-Satisfied re hospital outpatient services | 0.0634 | 0.0394 | 0.1092 | 253 | 0.1 | 1.01% |
| Mental Adjustment: Denial / Avoidance | 0.0423 | 0.0285 | 0.1394 | 233 | 0.09 | 0.94% |
| S9-Enough information about services etc. | 0.0402 | 0.0344 | 0.2433 | 257 | 0.07 | 0.53% |
| Recovery Locus of Control Scale | -0.0078 | 0.0066 | 0.2351 | 306 | 0.07 | 0.46% |
| S7-Satisfied with therapists' treatment | 0.0366 | 0.0377 | 0.3324 | 260 | 0.06 | 0.36% |
| S16-Needs/problems listened to/understood | 0.0322 | 0.353 | 0.3623 | 256 | 0.05 | 0.33% |
| S20-Know who to contact re stroke problem | 0.0314 | 0.0379 | 0.4090 | 272 | 0.05 | 0.25% |
| S19-I've received enough special equipment | -0.0127 | 0.0407 | 0.7546 | 235 | 0 | 0.04% |
| S10-Things were well prepared re discharge | 0.0069 | 0.0387 | 0.8580 | 247 | 0 | 0.01% |
| Medical Coping Mode: Confrontational | -6.363 | 0.0061 | 0.9172 | 399 | 0 | 0.00% |

Note: For all variables except the Frenchay Activities Index a higher score indicates a more negative outcome. Variables prefixed 'S' refer to individual patient satisfaction questions. These questions have been truncated, for the complete versions please refer to Appendix C. SE = Standard Error.

To determine if a dose response relationship existed patients' mean scores on the SAS total scale were plotted for each OHS and GHQ score. Patients' social maladjustment increased with both severity of disability and the number of mood symptoms reported (Figures 4-9 and 4-10).

Figure 4-9: The dose response relationship between patients' mean total Social Adjustment Scale scores and their level of dependence on the Oxford Handicap Scale.

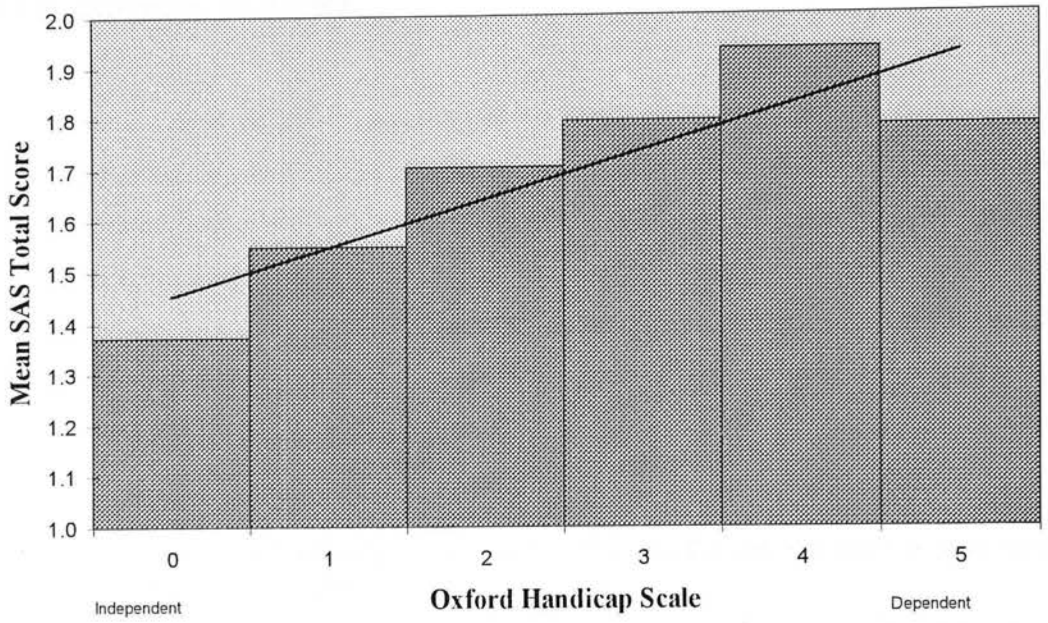
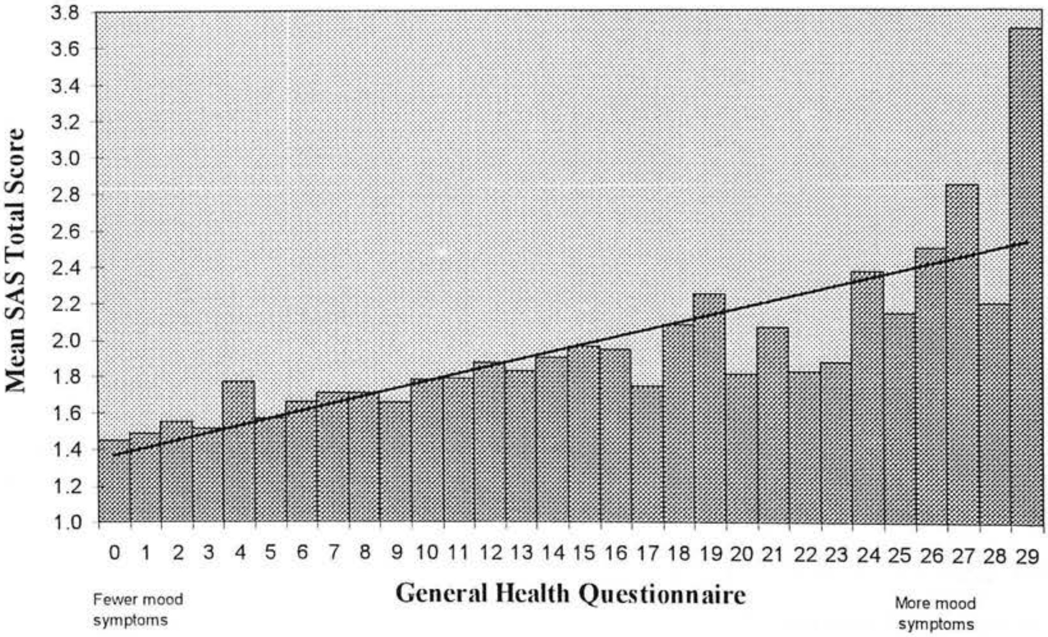


Figure 4-10: The dose response relationship between patients' mean Social Adjustment Scale scores and their reported mood symptoms on the General Health Questionnaire.



### 4.1.4 The Inter-Relationship of Patients' Reported Satisfaction With Other Outcome Variables

Patients' total scores on the Patient Satisfaction Scale (PSS) were used as the dependent variable for examining the variables associated with patients' satisfaction. Patient satisfaction was significantly associated with fewer outcome variables than the other areas of outcome whose inter-relationships we have examined. The outcome variables that individually shared or explained most variance in patients' satisfaction scores were those associated with mood. Of these the HAD Anxiety Subscale accounted for most variance, 24%, the HAD Depression Subscale 17% and the GHQ 11%.

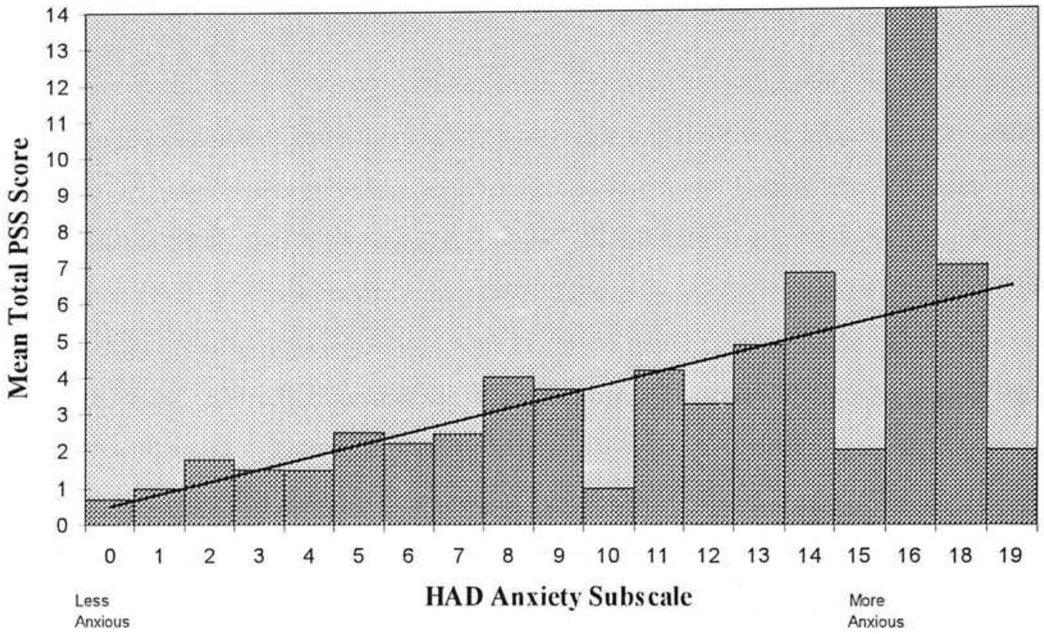
**Table 4-4: Regression of individual outcome variables on Patient Satisfaction Scale total score as the dependent variable.**

| Variable | Beta | SE | P Value | n | Correlation | Amount of Variance |
|---|---|---|---|---|---|---|
| HADS: Anxiety Subscale | 0.3388 | 0.0458 | <0.0001 | 180 | 0.48 | 23.50% |
| HADS: Depression Subscale | 0.3289 | 0.5421 | <0.0001 | 180 | 0.41 | 17.14% |
| General Health Questionnaire - Total Score | 0.1357 | 0.0288 | <0.0001 | 189 | 0.33 | 10.59% |
| Mental Adjustment: Anxious Preoccupation | 0.0875 | 0.0285 | 0.0025 | 171 | 0.23 | 5.28% |
| Mental Adjustment: Fighting S-Hopeless | 0.0669 | 0.0247 | 0.0075 | 171 | 0.2 | 4.16% |
| Social Adjustment: Leisure | 1.0687 | 0.3909 | 0.0068 | 197 | 0.19 | 3.69% |
| Social Adjustment: Partner | 1.0197 | 0.5526 | 0.0678 | 108 | 0.18 | 3.11% |
| Social Adjustment: Total | 1.1829 | 0.572 | 0.0400 | 197 | 0.15 | 2.15% |
| Oxford Handicap Scale Score | 0.3913 | 0.198 | 0.0495 | 197 | 0.14 | 1.96% |
| Frenchay Activities Index | -0.0503 | 0.0212 | 0.0190 | 195 | 0.14 | 1.90% |
| Social Adjustment: Family Unit | 1.2387 | 0.6448 | 0.0562 | 196 | 0.14 | 1.87% |
| Recovery Locus of Control Scale | 0.1045 | 0.0654 | 0.1119 | 190 | 0.12 | 1.4% |
| Social Adjustment: Work | 0.4938 | 0.6629 | 0.4593 | 60 | 0.1 | 0.95% |
| Medical Coping Mode: Avoidance | 0.0763 | 0.0577 | 0.1879 | 190 | 0.09 | 0.92% |
| Barthel Index Score | -0.0932 | 0.0743 | 0.2115 | 196 | 0.09 | 0.80% |
| Mental Adjustment: Denial / Avoidance | -0.2302 | 0.2853 | 0.4209 | 171 | 0.06 | 0.38% |
| Social Adjustment: Family | 0.4526 | 0.5656 | 0.4246 | 193 | 0.05 | 0.33% |
| Mental Adjustment: Fatalism | 0.0116 | 0.0258 | 0.6545 | 171 | 0.03 | 0.12% |
| Medical Coping Mode: Accept-Resignation | 0.0470 | 0.1092 | 0.6671 | 190 | 0 | 0.01% |
| Medical Coping Mode: Confrontational | -0.0016 | 0.0665 | 0.9807 | 190 | 0 | 0% |

SE = Standard Error.

Patients' mean Patient Satisfaction Scale scores were plotted for HAD Anxiety Subscale score to determine if a dose response relationship existed. Figure 4-11 illustrates that as patients reported anxiety symptoms increased so did their dissatisfaction with care.

**Figure 4-11: The dose response relationship between patients' mean total Patient Satisfaction Scale score and their level of anxiety on the Hospital Anxiety and Depression Scale, Anxiety Subscale.**



### 4.1.5 Previous Studies of the Inter-Relationships Between Outcome Variables

Most previous studies have reported the results of single variable correlations focusing on those that were significant. Of the 14 studies listed in Table 4-5, eight have used correlations only, two the Chi Squared statistic only, and one the T Test only. The remainder have used correlation and analysis of variance, correlation and multiple regression, and analysis of variance and multiple regression. Eleven studies selected samples from hospital inpatients or rehabilitation patients; whilst only two were community samples.

The use of correlations to examine the inter-relationships between variables is not ideal. Correlations do not give an indication of how useful one variable is at explaining another, telling you only that a relationship exists. Methodologically preferable is the use of regression analysis because this states not only the significance of any relationship but also the amount of variance that one variable explains in another. However if one variable co-varies with another variable it cannot be stated that the variable that occurs first caused the second. For example, the two variables may share a common cause and it is only through their relationship with the same cause that their values appear to co-vary.

The outcome variables most strongly related to an increase in mood symptoms are increasing dependence in activities of daily living (ADL) or motor impairment or loss, with a consistent relationship from two weeks to two years after stroke (Agrell and Dehlin, 1989; Astrom et al., 1993; Eastwood et al., 1989; Ebrahim et al., 1987; Finklestein et al., 1982; Robinson et al., 1983; Santus et al., 1990; Schwartz et al., 1993; Thompson et al., 1989; Wade et al., 1987). Cognitive impairment is also associated with increased mood symptoms throughout the first year (House et al., 1990; Robinson et al., 1983; Santus et al. 1990; Thompson et al., 1989). Associated with mood symptoms in the longer term, from the first weeks to up to three years post stroke, is a reduction in social contacts and functioning (Astrom et al., 1993; Robinson et al., 1983; Santus et al., 1990; Wade et al., 1987) and social support (Friedland and McColl, 1987; Morris et al., 1991) (Table 4-5). However, from these studies it is impossible to be certain whether increased mood symptoms result from or cause dependency in ADL, cognitive impairment or decreased social functioning. Indeed they may all reflect a common aetiological element such as the volume of brain damage (refer to 4.2.1.).

Only two studies have reported the results of multiple regression analysis (Friedland and McColl, 1987; Santus et al. 1990). The first of these used measures of satisfaction with social support, return to work, social support and functional status and explained 14% of the variance in mood symptoms (Friedland and McColl, 1987). The second used social functioning, cognitive state, ADL and a measure of depression severity (The Hamilton Depression Rating Scale) and states that these were significantly correlated quoting their regression coefficient but not the amount of variance they share (Santus et al., 1990).

I identified only four studies specifically examining the relationship between social functioning and other outcome variables after stroke (Feibel and Springer, 1982; Santus et al., 1990; Schuling et al., 1993; Thames and McNeil, 1987). However, six of the aforementioned studies describing variables related to mood outcome examined the relationship between social variables and mood outcome after stroke.

In all, ten studies report significant associations between patients' social outcome and other outcome variables (Table 4-6). Only two of these studies (Wade et al., 1987; Robinson et al., 1983) began with sample sizes of more than 100 patients and all but one (Friedland and McColl, 1987) used univariate analysis. Despite the variety of measures used, three studies used the Social Functioning Exam (SFE), two the FAI and three of the remainder used their own scale; their results were consistent. Seven of the studies, all of those that examined the relationship, found a significant relationship between mood and social outcome (Astrom et al., 1993; Feibel and Springer, 1982; Friedland and McColl, 1987; Morris et al., 1991; Robinson et al., 1983, 1984*b*, 1985*a*; Santus et al., 1990; Wade et al., 1987). Studies by Santus et al. (1990) and Schuling et al. (1993) also found a significant association with patients' Barthel Index.

I was unable to identify any studies specifically examining the relationship of patient satisfaction with treatment and other outcome variables. However, Friedland et al. (1987) used the Social Support Inventory for Stroke Survivors which includes a measure of satisfaction with social support. Friedland et al. (1987) found that satisfaction with social support was significantly associated with patients' GHQ score (Table 4-5).

### 4.1.6 Discussion.

**Outcomes associated with patients' mood.**

All areas of social functioning, including both social activities and all areas of adjustment, are significantly associated with patients' GHQ scores. The Social Adjustment Scale (SAS) total score shares or explains 28% of the variance in GHQ scores and each of its five individual subscales explain at least 11% individually. The SAS mainly assesses social relationships and how the patients feels about others and themselves in various social domains. For example, do they feel that they have let others down, do they feel others have let them down, have they been able to talk about their feelings to people, or felt ashamed or lonely? The Family Unit subscale provides an example: the four questions ask about unwarranted anxiety, feelings of being 'let down', 'letting others down', and financial worries. The first two questions are likely to reflect a patient's depressed mood while the latter two may represent causal or exacerbating factors to patient's mood. Therefore many of these questions possess face validity as measures of depression rather than simply measures of social adjustment; indeed, this scale has been found to reliably discriminate between depressed and non-depressed patients (Weissman et al., 1974). We must therefore question whether the significant proportion of variance explained by our social adjustment measure simply reflects similarities between the questions in the GHQ and those in the SAS. Perhaps the SAS is to some extent a measure of mood. Many previous studies using a variety of measures have also concluded aspects of social functioning are significantly associated with post stroke mood disorders (Astrom et al., 1993; Friedland and McColl, 1987; Morris et al., 1991; Robinson et al., 1983, 1984*b*, 1985*a*; Santus et al., 1990; Wade et al., 1987). However, none of these studies used the SAS and, as in our study, it is difficult to judge whether the associations they found were due to their measures of social functioning also measuring mood or due to a specific inter-relationship between mood and social adjustment.

Whether people become depressed as a result of this poor social adjustment, because of feelings of social isolation or inability to communicate, or whether this social maladjustment is the result of depression is difficult to determine. This is especially so as a lack of interest in normally enjoyable activities, which would encompass social functioning, is part of the DSM IV definition of major depression. Thus part of the definition of mood disorder is that social functioning will be reduced. It is therefore not surprising if they appear to be associated. The concept of social adjustment, at least as it is defined by the SAS, therefore overlaps with the concept of mood disorder. The validity of the SAS as a measure of a distinct concept of social adjustment needs to be questioned.

Interestingly, while limited social activities (FAI) are associated with our measure of mood, explaining 14% of the variance in GHQ score this is much lower than the proportion of GHQ score variance explained by the feelings that patients have about their social relationships measured by the SAS. This suggests that a group of patients exist that are limited in their social activities but have not become depressed. The implication of this for therapeutic interventions is that the traditional social work approach of increasing patients' participation in activities, whilst valuable, may be less important that aiding their adjustment to their new social situation and altered social relationships. This social adjustment may in turn also be related to the other types of adjustment we have measured including mental adjustment (MAS) and medical coping mode (MCMQ). The four question Acceptance - Resignation subscale of the Medical Coping modes Scale explains 16% of the variance in GHQ scores. These questions address whether a patient has accepted or is resigned to their illness in a negative sense: whether they have given up the pursuit of increased recovery. They assess feelings of loss of control, hopelessness and caring little about oneself. Two of these questions, regarding no hope of recovery and 'nothing that you can do about your illness' could equally be either the cause or the result of mood disturbance. The other two regarding 'not caring what happens to you' and 'feeling like just giving in' to the illness appear far more likely to be the result of depression.

The results of our analysis of the relationship between patients' methods of coping and their risk of mood disorder are difficult to interpret because the direction of the relationship is not clear. Mood disorders could be, at least partially, the result of the coping mode adopted. Alternatively, the choice of an avoidant or accepting coping mode may reflect a patient's mood. If the former is true these results could provide a valuable guide for the focus of therapeutic interventions providing a patient's method of coping is not a long standing personality trait but rather a reaction to circumstances and therefore more amenable to change. Patients may benefit from therapeutic interventions which attempt to influence their use of coping modes in a positive direction, that is toward being more confrontational and less avoidant or accepting. The relationship between coping strategies and mood disorders has been examined only once in the post stroke literature. Sinyor et al. found that reduced use of both behavioural action and rational cognition strategies were associated with increased depression (Sinyor et al., 1986*a*). If the Confrontational Subscale of the MCMQ is interpreted as similar to the behavioural action subscale of the COPE scale used by Sinyor our results are in agreement.

The OHS explains 24% of the variance in mood scores at six months after stroke. It is noteworthy that the OHS measures dependence in ADL encompassing lifestyle in a subjective sense, rather than patients' abilities to perform individual ADL tasks as in the Barthel Index which accounted for only 14% of variance. This may reflect that it is the extent to which lifestyle is restricted rather than the ability to perform certain tasks that is mainly associated with patients' mood. Alternatively, it may be more a product of the ceiling effect that the Barthel Index suffers from (Wellwood et al., 1995). The Barthel Index assesses quite basic abilities meaning that many patients gain the maximum 20 points which may reduce its utility in analyses of this sort. These results are in agreement with the consistently reported association between physical ability and mood disorders in the literature using many measures of both physical functioning and mood symptoms (Astrom et al., 1993; Ebrahim et al., 1987; Eastwood et al., 1989; Robinson et al., 1983, 1984*b*; Santus et al., 1990; Schwartz et al., 1993; Thompson et al., 1989; Wade et al., 1987).

The strong relationship between mood disorders and physical functioning could suggest that post stroke mood disorders are simply a reaction either to disability or its sudden onset. Some studies have found that control patients matched for physical disability are less depressed than stroke patients (Folstein et al., 1977; Finklestein et al., 1982). Perhaps stroke differs from other disabling conditions due to its sudden onset. Closer inspection of the disabled control groups used reveals that Folstein's (1977) sample had either severe arthritis or had suffered hip fractures. More than half of Finklestein's (1982) control sample had also suffered fractures (type unspecified) and the remainder suffered from a variety of conditions including amputation, hip replacement, arthritis and paraplegia. Therefore the disabled control subjects included both those with the sudden onset of disability and those with a slow onset of disability. Such a mixed group in both studies does not aid this discussion. For example, if all control subjects had suffered a sudden onset of disability and still exhibited a lower incidence of mood disorder than the stroke patients this would suggest that it was not the rapidity of onset that caused an increased incidence of mood symptoms amongst stroke patients. In addition as many of the disabled control subjects were suffering from fractures it is reasonable to assume that the majority expected to make a good recovery. It may be that it is this factor that contributes most to the reduced rate of mood symptoms in the control groups studied.

Ideally, to say with confidence that one variable causes another to occur we should not only be able to say that the relationship has been found previously but that the temporal contiguity of the two makes clinical sense (that which you expect to come first does so), and that there is a dose response relationship. As we did not assess patients' psychosocial functioning during our initial assessment it is not possible to comment whether the independent, i.e. OHS or SAS, or dependent, i.e. GHQ, variable in our equation came first. For example, if at baseline patients with severe disability reported a similar number of mood symptoms to those with mild disabilities but at six months patients with severe disabilities reported a far greater number of mood symptoms this would suggest that a patient's level of disability may have caused their level of mood symptoms. We were able to assess whether a dose response relationship existed between our independent and dependent variables. As patients' level of physical disability according to the OHS increased so did the number of mood symptoms they reported. Likewise as patients reported greater social maladjustment on the SAS so they reported a greater number of mood symptoms on the GHQ. We cannot comment on whether greater severity of physical disability causes mood disorder or whether mood disorder significantly reduces a patient's physical recovery or whether social maladjustment causes mood disorder or vice versa. We can however say that the severity of a patient's disability and their social adjustment are significantly associated with their mood scores in a dose response relationship. However, all such analysis of causal relationships should be viewed with a note of warning. Whilst two variables may appear strongly related and vary with one another this may be the result of their sharing a common cause rather than influencing each other directly. To be more confident of a causal relationship one must illustrate a change in the dependent variable as a result of manipulation of the independent variable. For example, if one demonstrated an anti-depressant lifted mood in a randomised controlled trial but also resulted in an improvement in social adjustment or physical functioning this would be good evidence that poor mood causes poor social or physical functioning. Unfortunately a converse example based on the effects of, for example, physiotherapy might not provide the same strength of evidence since physiotherapy may improve mood as well as physical and hence social functioning.

A number of the individual patient satisfaction questions were significantly associated with patients' GHQ scores. This relationship was particularly strong for two questions, whether patients were happy with the amount of recovery they had made and whether they had had sufficient therapy. Patients who answer negatively to these questions are in fact saying 'I'm not happy with the amount of recovery I have made and I need more therapy'. Patients who are depressed may be saying that they have not reached their full potential for recovery, that they are dissatisfied with their present recovery and would like to achieve more. The explanation may be simpler however; a question that asks if patients are happy with anything may reflect mood. Depressed patients may respond to a question asking if they are happy with something referring more to their mood generally than the specific reference of the question. Patient satisfaction has previously been associated with mood disorder after stroke but the satisfaction concerned was with social support rather than with treatment (Friedland and McColl, 1987). Patient satisfaction may not only be important with regards to contentment with treatment received; a feeling of dissatisfaction may increase mood symptoms. Indeed, it makes clinical sense that a patient who feels that they have potential for recovery that is not being exploited by their health care team would become depressed. It is to be hoped that patients who are no longer receiving therapy are not doing so because an experienced therapist is of the opinion that they will no longer gain from such therapy. Therefore patients who feel that they need more therapy have not understood (or not been told) that they will no longer benefit from therapy and so have feelings of lost potential recovery that is associated with an increase in mood symptoms. Such a gap between reality and expectation would therefore be a suitable focus for intervention. If patients are in fact correct that they have further potential for recovery but are not continuing to receive therapy because of a lack of resources or cost their depression would be understandable. However, the focus for intervention in such circumstances is much harder to identify.

### Outcomes associated with participation in social activities.

Patients' levels of social activities, FAI, at six months mainly reflect their level of physical functioning as reflected in their OHS and Barthel scores. This is not very surprising when we examine the questions in the FAI used to assess social activities. Almost all activities specified, such as household or car maintenance, housework, washing dishes, or walking for fifteen minutes, are directly dependent on patients' physical abilities. The only question that is not refers to reading in the last three months, but many stroke patients report increased difficulties with their eyesight and reduced levels of concentration, both of which would affect reading. Our results agree with those of previous studies that have also found a significant relationship between patients' Barthel Index and measures of social activity (Santus et al., 1990; Schuling et al., 1993). It seems likely that this relationship reflects an overlap in the concepts the measures aim to assess as all social activities assessed by the FAI are dependent on patients' physical abilities.

Perhaps more interesting is the fact that the HAD Depression Subscale score which individually could account for 25% of all variance in FAI score when entered into a multiple regression with our physical measures (OHS and BI) added only 2% to the amount of variance accounted for by our physical measures alone. This is consistent with our previous finding that physical outcome and level of depression are closely related.

### Outcomes associated with patients' social adjustment.

Our results suggest that the measurement of social adjustment we used is tapping a unique area of outcome, or at least one that is not associated with any of our other outcome measures. I say this because a backward stepwise multiple regression was unable to create a model that could explain more than 50% of the variance even if all other outcome variables were combined. This means that a proportion of the variance in the social adjustment measure was reflecting or measuring something that was otherwise unmeasured by any of our other assessment instruments.

The largest proportion of variance in patients' SAS score could be explained by patients' mood (GHQ score) and physical functioning (OHS score) both of which had a positive dose response relationship with patients' SAS score. The Acceptance subscale of the MCMQ also correlated significantly with patients' social adjustment perhaps further reflecting the association between mood and this Acceptance/Resignation subscale already found. Further, despite both measures of mood and physical functioning contributing significantly to variance in social adjustment outcome, when the two areas of outcome were combined they added little to each other. This further supports our previous findings that patients' physical functioning and mood are to some extent inter-dependent.

### Outcomes associated with patients' satisfaction.

Patient satisfaction is not simply a product of either patients' physical outcome or mood symptoms although mood symptoms are a major contributor. If these analyses tell us anything it is that patients' satisfaction reflects patients' level of anxiety as both patients' HAD anxiety scores and their MAS Anxious Preoccupation score accounted for a significant amount of variance. This makes sense as for the three patient satisfaction scale questions referring to 'enough information' patient anxiety would increase the likelihood of a negative response or a negative response would reflect a possible cause of patient anxiety.

**Conclusions.**

Every primary outcome measure: the OHS, GHQ, FAI, SAS and PSS shared or explained a significant proportion of the variance with every other primary outcome measure illustrating a striking inter-relationship between the different areas of psychosocial outcome. I have discussed possible causal relationships between outcomes in terms of previous research findings, temporal relationship, dose response relationship and the experimental manipulation of independent variables. An alternative explanation for the inter-relationship of our psychosocial outcomes may be that rather than certain outcomes causing others, that they instead share a common cause. For example, large stroke lesions may be more likely to cause mood symptoms, (refer to 4.2.) causing an increase in GHQ and SAS score, and increased physical disability, which would cause an increase in patients' OHS and a reduction in their FAI scores. Patient satisfaction is also significantly associated with mood and disability but the association is much weaker than that between the other outcome variables. Alternatively patients' psychosocial outcome may be the result of their level of physical disability. Patients' OHS score was the strongest predictor of patients' social activity or social adjustment scores and the second strongest predictor of patients' mood scores. It makes clinical sense that a patient with more severe physical disability is likely to be more depressed, be less able to participate in normal social activity and have an altered body image that may hinder their social adjustment.

If the fundamental cause of poor psychosocial functioning is a larger lesion volume then medical therapies such as thrombolysis during the acute phase may reduce both. Conventional treatment plans after the acute phase aim to improve patients' physical functioning so that if psychosocial outcome is dependent on physical ability then this is already a focus for intervention. In addition it may be advantageous, whatever the cause of poor psychosocial outcome, to target patients' mood because after disability this accounts for the greatest amount of variance in other psychosocial outcomes. Improving a patient's mood, perhaps through focusing on the gap between expectation and reality regarding potential for further recovery, may in turn aid their recovery in other areas of psychosocial functioning.

Finally, it is reasonable to consider whether the observed relationship between measures is simply a product of the measures used, either because the questions in some measures repeat those in others or because the concepts that they are designed to measure are not distinct from one another. For example, we have discussed how questions in the SAS, the Acceptance / Resignation subscale of the MCMQ and patient satisfaction questions possess face validity as measures of mood. Is this because the measures inappropriately contain questions more relevant to another outcome or because the concept they are attempting to measure is not completely distinct from the concept of mood? We must question whether a concept of social adjustment which focuses on our ability to discuss feelings, whether we are happy with our ability to do our work, whether we feel let down by others, ashamed etc. can ever really be judged distinct from mood disorders. Depression is by nature accompanied by feelings of guilt and withdrawal.

To clarify the nature of any causal relationship between variables future research should concentrate on the experimental manipulation of possible causal factors and observe the effect on the dependent variable. To return to a previous example, if anti-depressants reduce mood symptoms and this is followed by a rise in social adjustment we can infer that poor mood reduces social adjustment. However the implications of this finding would be limited if the concept of social adjustment is really another aspect of mood and is therefore being directly influenced by the anti-depressants themselves.

**Table 4-5: Previous studies of the mechanisms of post stroke mood disorder.**

| **Author & Year** | **Patients** | **Time of Follow up** | **Outcome variable related to poor mood outcome** | **Measure of mood and Significance** |
|---|---|---|---|---|
| Agrell & Dehlin, (1989) | n = 40 volunteers-day hospital, rehabilitation clinic or nursing home | 4 months - 2 years. Mean = 14 months | BI <51 | Cornell Scale<br>Correlation<br>p < 0.005 |
| Astrom et al. (1993) | n =73 Stroke unit admissions | | | Interview -DSM III<br>Correlations |
| | | 3 Months | -Dependence in ADL (vs. independent) | p=0.020 |
| | | | -Dysphasia | P=0.001 |
| | | | -Few social contacts outside immediate family | p=0.012 |
| | n = 68 | 1 Year | -Few social contacts -as above | p=0.017 |
| | n = 57 | 2 Years | -Few social contacts -as above | p=0.016 |
| | n = 49 | 3 Years | -Few social contacts -as above | p=0.001 |
| | | | -Fewer meetings with friends or relatives in last week. | p=0.001 |
| | | | -Significantly fewer social meetings than pre-stroke | p=0.005 |
| Ebrahim et al. (1987) | n = 149 Hospital inpatients | | | ANOVA<br>Correlations |
| | | 1 month | -Mean ADL score | p=0.001 |
| | | 6 months | (10 item ranked ordinal scale) | p=0.002 |
| | | | -Mean motor impairment score | p=0.002 |
| Eastwood et al. (1989) | n = 187 Hospital inpatients | Inpatients - mean 82 days | Barthel Index | Correlations<br>HDRS: p=< 0.05<br>SDS: p=< 0.01<br>GDS: p=< 0.01 |
| | | 4 months post entry /discharge | Barthel Index<br>Length of stay | GDS: p=< 0.05<br>HDRS: p=< 0.05 |

DSM= Diagnostic and Statistical Manual of Mental Disorders; ADL= Activities of Daily Living; ANOVA= Analysis of Variance; HDRS= Hamilton Depression Rating Scale; SDS= Zung Self Rating Depression Scale; GDS= Geriatric Depression Scale.

**Table 4-5. continued**

| **Author & Year** | **Patients** | **Time of Follow up** | **Outcome variable related to poor mood outcome** | **Measure of mood and Significance** |
|---|---|---|---|---|
| Finklestein et al. (1982) | n = 25 randomly selected rehabilitation inpatients | 11 to 111 days | | Moderate to severe mood disturbance- Interviewer rated using parts of HDRS |
| | Left hemisphere lesions | n = 13 | Severe degrees of sensorimotor disability | Chi Square<br>$p < 0.05$ |
| Friedland & McColl, (1987) | n = 85 Selected for high no. of stressful life events in recent past-rehabilitation inpatients | 2 - 24 months post discharge | SSISS | GHQ -28<br>ANOVA |
| | | | -Satisfaction with social support | $p = <0.05$ |
| | | | -Support of a single significant personal relationship | $p = <0.05$ |
| | | | -Support of close friends | $p = <0.05$ |
| | | | -Support of individuals' in one's community | $p = <0.05$ |
| | | | Satisfaction<br>Functional Status<br>Return to pre-morbid occupation<br>Personal - social support<br>Friend - social support<br>Community - social support<br>Quality - social support | Multiple Regression<br>$p=0.001$<br>Adjusted $R^2=0.14$ |
| House et al. (1990) | n = 128 Consecutive series from community stroke register. | | | Correlations |
| | n= 76 | 1 month | MMS | BDI: $p= 0.001$ |
| | n=89 | | | PSE: $p= 0.002$ |
| | n=107 | 6 months | | BDI: $p= 0.006$ |
| | n=119 | | | PSE: $p=0.02$ |

HDRS= Hamilton Depression Rating Scale; SSISS= Social Support Inventory for Stroke Survivors; GHQ= General Health Questionnaire; ANOVA= Analysis of Variance; MMS= Mini Mental State; BDI= Beck Depression Inventory; PSE= Present State Examination.

**Table 4-5. continued**

| **Author & Year** | **Patients** | **Time of Follow up** | **Outcome variable related to poor mood outcome** | **Measure of mood and Significance** |
|---|---|---|---|---|
| Morris et al. (1991) | n = 76 rehabilitation inpatients | | ISSI | T-Test<br>> severe symptoms MADRS: $p=0.002$ |
| | n = 18 | 2 months | -Perceived low social support | > depressed cases using CIDI $p=0.045$ |
| | n = 38 | 14 months | -Perceived low social support | > severe symptoms MADRS: $p=0.001$ |
| Robinson et al. (1983) | n = 103 Consecutive series from stroke data bank | 2 weeks post stroke | -SFE | Correlations<br>SDS: $p< 0.02$<br>HDRS: $p< 0.02$<br>PSE: $p< 0.02$ |
| | | | -JHFI | SDS: $p< 0.001$<br>HDRS: $p< 0.001$<br>PSE: $p< 0.001$ |
| | | | -MMS | SDS: $p< 0.02$<br>HDRS: $p< 0.02$<br>PSE: $p< 0.02$ |
| | | | -Age (younger more depressed) | SDS: $p< 0.02$<br>HDRS: $p< 0.02$<br>PSE: $p< 0.001$ |
| | | | -Socioeconomic status | SDS: $p< 0.02$ |
| Robinson et al. (1984*b*) | Same sample | | | HDRS/SDS/PSE |
| | n=61 | 2 weeks | -JHFI | $p< 0.01$ |
| | n=40 | 3 months | | $p< 0.01$ |
| | n=50 | 6 months | | $p<0.001$ |
| | n=61 | 2 weeks | -MMS | $p< 0.05$ |
| | n=50 | 6 months | | $p< 0.01$ |
| | n =61 | 2 weeks | -SFE | $p< 0.05$ |
| | n =50 | 6 months | | $p< 0.001$ |
| | n=61 | 2 weeks | -Age (younger more depressed) | $p< 0.05$ |

ISSI= Interview Schedule for Social Interaction; MADRS= Montgomery Asberg Depression Rating Scale; CIDI= Composite International Diagnostic Interview; SFE= Social Functioning Exam; JHFI= John Hopkins Functioning Inventory; MMS= Mini Mental State; PSE= Present State Examination; SDS= Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale.

**Table 4-5. continued**

| Author & Year | Patients | Time of Follow up | Outcome variable related to poor mood outcome | Measure of mood and Significance |
|---|---|---|---|---|
| Robinson et al. (1985*a*) | n = 30<br>Randomly selected from stroke clinic and data bank<br>3 days - 10 years<br>mean 2 years post stroke | 6 months | SFE | Correlation with mean for PSE/SDS/HDRS<br>$p<0.01$ |
| Santus et al. (1990) | n = 76<br>Hemiplegic physiotherapy patients | 1 year | <br>Urinary incontinence<br>MMS<br>BI<br>SFE<br><br><br>SFE<br>MMS<br>BI<br>HDRS | Correlation<br>DSM: $p<0.0149$<br>HDRS: $p<0.01$<br>HDRS: $p<0.001$<br>HDRS: $p<0.001$<br><br>Multiple<br>Regression<br>$p< 0.05$<br>regression<br>coefficient = 0.15 |
| Schwartz et al. (1993) | n = 91 male rehabilitation patients | 1-103 months, median 2 months | CDS | HDRS =>18:<br>$p<0.001$ |
| Thompson et al. (1989) | n = 40 outpatients receiving therapy that 'volunteered'. | 1 - 60 months, mean 9 months. | <br><br>-Months since stroke<br>All measures for items below were specially constructed<br>-Lower physical functioning<br>-Lower cognitive functioning<br>-Less meaningfulness<br>-Less hope<br>-Lower perceived control over social life | Chi Square<br>GDS<br>$p<0.01$<br><br><br>$p<0.05$<br>$p<0.01$<br>$p<0.01$<br>$p<0.01$<br>$p<0.01$ |

SFE= Social Functioning Exam; PSE= Present State Examination; SDS= Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale; DSM= Diagnostic and Statistical Manual of Mental Disorders; . MMS= Mini-Mental State; BI= Barthel Index; CDS= Crichton Disability Scale; GDS= Geriatric Depression Scale;

**Table 4-5. continued.**

| **Author & Year** | **Patients** | **Time of Follow up** | **Outcome variable related to poor mood outcome** | **Measure of mood and Significance** |
|---|---|---|---|---|
| Wade et al. (1987) | n = 976<br>Community stroke register | | | Correlations<br>WDI score |
| | n = 379 | 3 weeks | BI | $p<0.01$ |
| | n = 331 | | IQ (Raven's matrices) | $p<0.01$ |
| | n = 342 | | Motor loss (Motricity Index) | $p<0.01$ |
| | n = 377 | 6 months | BI | $p<0.01$ |
| | n = 345 | | Current social activities -FAI | $p<0.01$ |
| | n = 357 | | Reduction in social activities-FAI | $p<0.01$ |
| | n = 348 | 12 months | BI | $p<0.01$ |
| | n = 330 | | IQ (Raven's matrices) | $p<0.01$ |
| | n = 348 | | Current social activities- FAI | $p<0.01$ |

BI= Barthel Index; FAI= Frenchay Activities Index; WDI= Wakefield Depression Inventory; IQ= Intelligence Quotient.

**Table 4-6: Previous studies of the mechanisms of social outcome.**

| Author & Year | Patients | Time of Follow up | Outcome Variable Related to Poor Social Outcome | Description & Significance |
|---|---|---|---|---|
| Astrom et al.<br>(1993) | n =73<br>Stroke unit admissions<br><br>n = 68<br>n = 57<br>n = 49 | 3 Months<br>1 Year<br>2 Years<br>3 Years | Depression Interview using DSM III criteria | Correlation<br>-Few social contacts outside immediate family<br>p=0.012<br>p=0.017<br>p=0.016<br>p=0.001<br>-Fewer meetings with friends or relatives in last week.<br>p=0.001<br>-Significantly fewer social meetings than pre-stroke<br>p=0.005 |
| Feibel & Springer.<br>(1982) | n = 91<br>Hospital inpatients | 6 months | Depression status (nurse observation of) | Chi Square<br>Reduction in social activities from pre-morbid to 6 months<br><br>p=< 0.01 |
| Friedland & McColl.<br>(1987) | n = 85<br>Selected for high no. of stressful life events in recent past-rehabilitation inpatients | 2 - 24 months post discharge | GHQ-28 | ANOVA<br>SSISS<br><br>-Satisfaction with social support p<0.05<br>-Support of a single significant personal relationship p<0.05<br><br>-Support of close friends p<0.05<br>-Support of individuals' in one's community p<0.05 |

DSM= Diagnostic and Statistical Manual of Mental Disorders; SSISS= Social Support Inventory for Stroke Survivors; GHQ= General Health Questionnaire; ANOVA= Analysis of Variance;

**Table 4-6. continued**

| Author & Year | Patients | Time of Follow up | Outcome Variable Related to Poor Social Outcome | Description & Significance |
|---|---|---|---|---|
| Morris et al. (1991) | n = 76<br>rehabilitation inpatients | 14 months | MADRS | T-Test<br>ISSI -Perceived low social support<br>p=0.002 |
| | n = 38<br>For patients with spousal attachment figure | | CIDI | p = 0.045 |
| | | | MADRS | -Perceived low social support<br>p=0.001 |
| Robinson et al. (1983*a*) | n = 103<br>Consecutive series from stroke data bank | 2 weeks post stroke | SDS | Correlation- SFE<br>p< 0.02 |
| | | | HDRS | p< 0.02 |
| | | | PSE | p< 0.02 |
| Robinson et al. (1984*b*) | Same sample<br>n =61<br>n =50 | 2 weeks<br>6 months | Mean HDRS, SDS, PSE | P< 0.05<br>P< 0.001 |
| Robinson et al. (1985) | n = 30<br>Randomly selected from stroke clinic and data bank<br>3 days - 10 years mean 2 years post stroke | 6 months | Mean HDRS, SDS, PSE | Correlation- SFE<br>p<0.01 |
| Santus et al. (1990) | n = 76<br>Hemiplegic physiotherapy patients | 1 year | MMS | Correlations<br>SFE: p<0.001 |
| | | | Age | SFE: p<0.019 |
| | | | BI | SFE: p<0.001 |
| | | | HDRS | SFE: p<0.001 |
| | | | Low socio-economic class | SFE =<0.15*<br>p <0.05 |
| | | | Poor health | SFE =<0.15*<br>p<0.05<br>* cut-off below which = socially integrated. |

MADRS= Montgomery Asberg Depression Rating Scale; CIDI= Composite International Diagnostic Interview; ISSI= Interview Schedule for Social Interaction; SDS= Zung Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale; PSE= Present State Examination; SFE= Social Functioning Exam; MMS= Mini Mental State; BI= Barthel Index; FAI= Frenchay Activities Index.

**Table 4-6. continued**

| Author & Year | Patients | Time of Follow up | Outcome Variable Related to Poor Social Outcome | Description & Significance |
|---|---|---|---|---|
| Schuling et al. (1993) | n = 94<br>GP referrals | 6 months | BI | FAI<br>Correlation = 0.66<br>No p value |
| Thames & McNeil (1987) | n = 52<br>From rehabilitation clinic, inpatients > 10 days.<br>n = 10 living alone<br>n = 42 Living with family member | Not quoted | Living with family members (is worse than those living alone). | T Test<br>Social adjustment using their own scale.<br>$p<0.02$ |
| Wade et al. (1987) | n = 976<br>Community stroke register | | WDI | Correlations |
| | n = 345 | 6 months | | Current social activities -FAI $p<0.01$ |
| | n = 357 | | | Reduction in social activities- FAI $p<0.01$ |
| | n = 348 | 12 months | | Current social activities- FAI $p<0.01$ |

BI= Barthel Index; WDI= Wakefield Depression Inventory; FAI= Frenchay Activities Index.

## 4.2 The Physiological Correlates of Mood

Stroke is a physiological illness that involves damage to the brain of the affected patient. Such damage provides an obvious focus for any discussion of a physiological cause of post stroke mood disorder. Since the early 1980's when a team from the John Hopkins University School of Medicine in Baltimore first suggested a specific relationship between the occurrence of depression and lesions in the anterior left hemisphere, the debate has continued and provided a focus for subsequent research (Robinson et al., 1983; Robinson and Price, 1982). This debate has concentrated on four aspects of lesion location; anterior versus posterior lesions, the side of lesion, the distance of the lesion from the frontal pole and lesion size.

### *4.2.1 An examination of the Physiological Correlates of Mood*

I wished to examine the issues raised in the lesion location literature in our cohort but was unable to do so directly as analysis using available CT scans was outwith the remit of this study in terms of expertise and time. Results on a limited sample are reported elsewhere (MacHale, 1996*a*). However, I do have relevant data on most patients including a physician's clinical classification of the hemispheric side of the lesion and the vascular territory of the lesion. The former is directly comparable to much of the previous literature and the Bamford stroke classification system which defines the vascular territory of the lesion, also reflects the lesion size (Table 4-7; Bamford, 1991). These classifications have been used previously in stroke and have been shown to be reliable and valid (Lindley et al., 1993).

**Table 4-7: Bamford's classification of subtypes of cerebral infarction based on clinical findings at the time of maximal deficit from a single stroke.**

Total Anterior Circulation Syndrome (TACS)
- motor and sensory deficit.
- ipsilateral hemianopia.
- new disturbance of higher cerebral function.

Partial Anterior Circulation Syndrome (PACS)
- any two of the above
- or isolated disturbance of higher cerebral function.

Posterior Circulation Syndrome (POCS)
- unequivocal signs of brainstem disturbance.
- or isolated hemianopia.

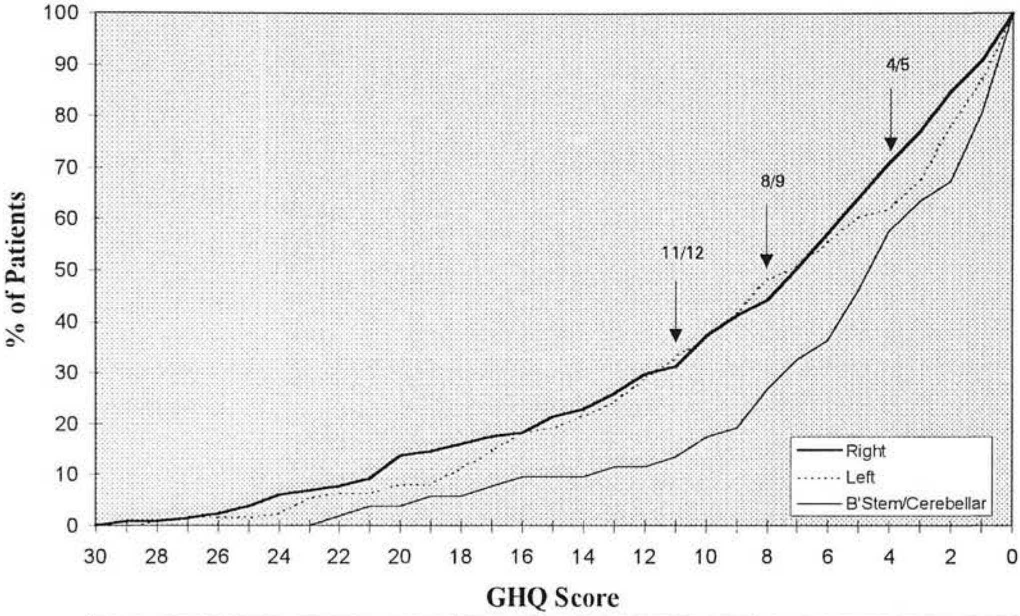
Lacunar Syndrome (LACS)
- pure motor stroke.
- or pure sensory stroke.
- or pure sensorimotor stroke.
- or ataxic hemiparesis.

From (Bamford, 1991)

I first examined the relationship between patients' GHQ score as a continuous variable and their site of lesion (left hemisphere, right hemisphere, brainstem / cerebellum) to see if we could replicate previous findings of increased mood symptoms in left hemisphere stroke patients (Figure 4-12). Therefore treating patients' GHQ scores as continuous variables I divided patients according to the site of their lesion and plotted their GHQ scores as cumulative percentages. This method allows the reader to examine the percentage of patients defined as cases for any given cut-off. The cut-offs we have used in the present study are marked on Figure 4-12. To establish whether differences between different sites of lesion were significant I conducted a Mann Whitney U analysis for non-parametric data, the results of which are shown in the table to Figure 4-12.

Patients with stroke lesions in the brainstem or cerebellum reported significantly fewer mood symptoms that those with lesions elsewhere. There was little difference in the number of mood symptoms reported by patients with left and right hemisphere lesions.

**Figure 4-12: Cumulative distribution of patients' General Health Questionnaire scores categorised by site of lesion.**



| Site of Lesion | n | Median GHQ score | P value- Each site vs. all others |
|---|---|---|---|
| Right Hemisphere | 131 | 7 | 0.08 |
| Left Hemisphere | 124 | 7 | 0.75 |
| Brainstem / Cerebellar | 52 | 4 | 0.005 |

Note: Significance was calculated using the Mann Whitney U statistic.

The GHQ is mainly used as a case finding instrument, classifying patients as likely to be psychiatric cases according to whether they fall above or below certain cut-offs. The cut-offs used were those used throughout this study, 4/5 as originally recommended by the scale's authors, 8/9 which we have found optimum in our study (refer to 2.7.2.3) of the GHQ and 11/12 which was found suitable for neurology inpatients. The relative risks of patients with each site of lesion for each of these cut-offs in illustrated in three forest plots (Figures 4-13, 4-14 and 4-15).

Again for all three cut-offs the original finding that patients with brainstem or cerebellar strokes were significantly less likely to develop mood disorders remained. Interestingly for the lowest cut-off of 4/5 an increased likelihood of patients with right hemisphere lesions having a mood disorder reaches statistical significance. However as on the two higher cut-offs patients with left and right hemisphere strokes are at almost identical risk of mood disorders this finding is unlikely to be of clinical relevance.

**Figure 4-13: The relative risk of mood disorder for each site of stroke lesion using a General Health Questionnaire cut-off of 4/5.**

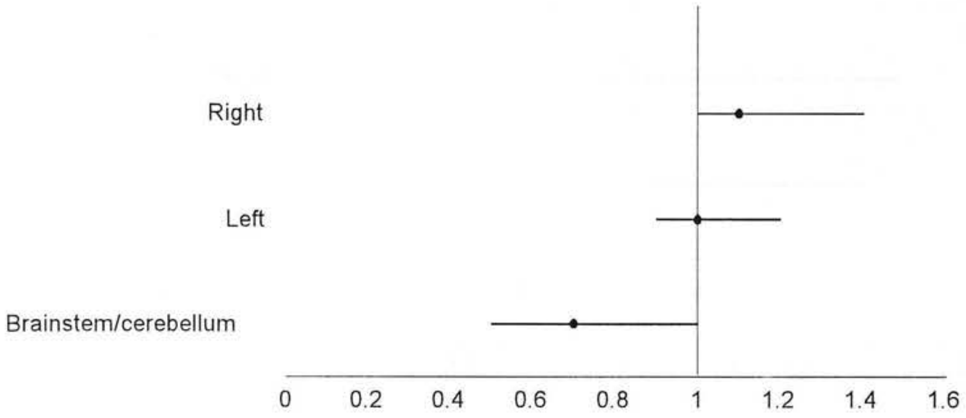


**Figure 4-14: The relative risk of mood disorder for each site of stroke lesion using a General Health Questionnaire cut-off of 8/9.**

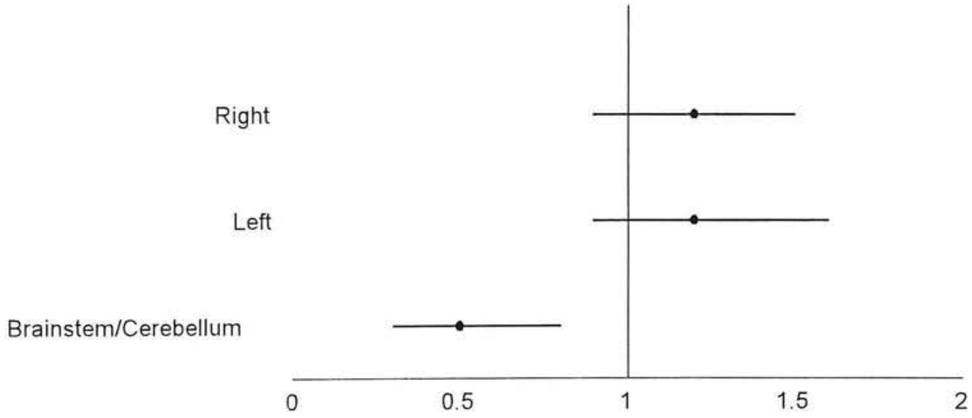
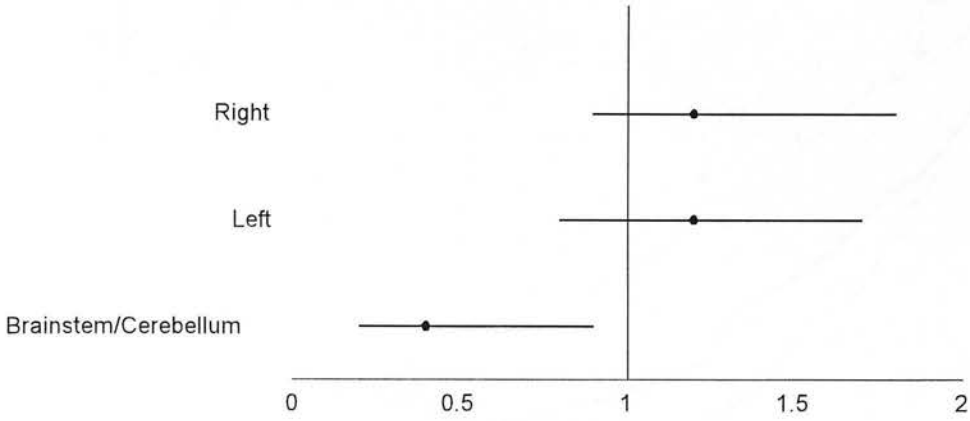
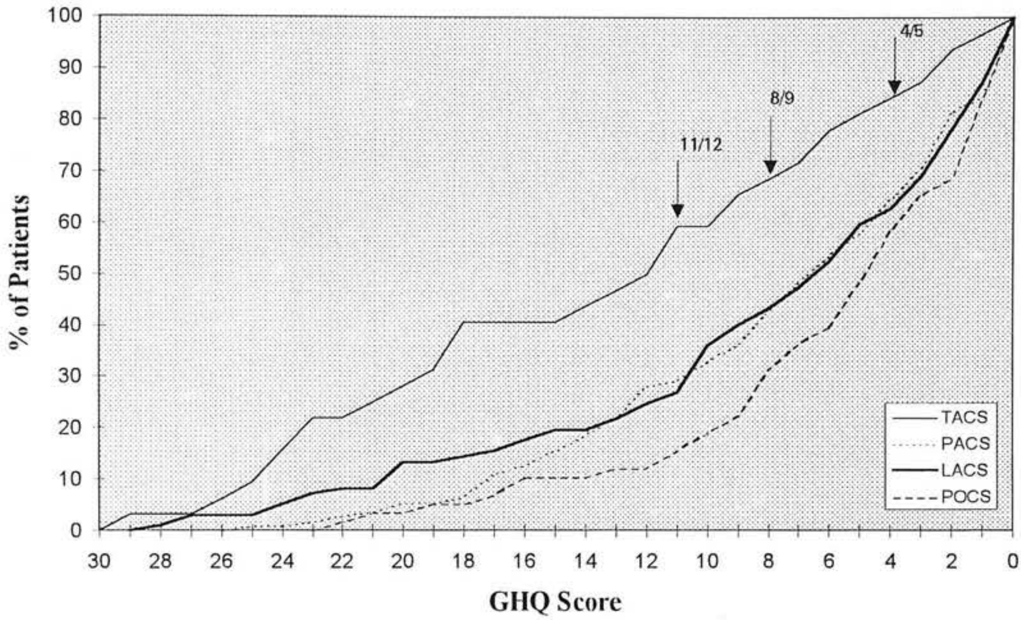


**Figure 4-15: The relative risk of mood disorder for each site of stroke lesion using a General Health Questionnaire cut-off of 11/12**



All of the patients in our cohort had been classified according to Bamford's criteria. I therefore further examined the relationship between mood and lesion location by examining the area of vascular territory affected by the lesion and patients' mood outcome. Patients' GHQ scores were analysed as continuous variables plotting a cumulative percentage distribution of each of Bamford's four clinical classifications (Figure 4-16).

**Figure 4-16: Cumulative distribution of patients scores on the General Health Questionnaire with patients categorised according to clinical classification of lesion.**



| Clinical Classification | n | Median GHQ score | P Value- Each classification vs. all others |
|---|---|---|---|
| Total Anterior Circulation Stroke | 32 | 11.5 | 0.0001 |
| Partial Anterior Circulation Stroke | 110 | 6 | 0.63 |
| Lacunar Stroke | 97 | 6 | 0.98 |
| Posterior Circulation Stroke | 58 | 4 | 0.01 |

Note: Significance was calculated using the Mann Whitney U statistic.

The results indicate that patients who have total anterior circulation syndrome are significantly more likely to develop a mood disorder and that those who have posterior circulation syndrome are significantly less likely to do so. These results are illustrated both in the distribution of scores illustrated and the median scores and Mann Whitney U analysis (Figure 4-16). This result is most relevant to the debate on whether it is lesion volume which affects mood outcome as TACS are associated with large brain lesions (Wardlaw et al., 1996).

In addition I calculated the relative risk of patients developing a mood disorder according to their clinical classification using the same three GHQ cut-offs as used previously in this study, 4/5, 8/9 and 11/12 (Figures 4-17, 4-18, and 4-19).

**Figure 4-17: The relative risk of mood disorder for each classification of stroke lesion using a General Health Questionnaire cut-off of 4/5.**

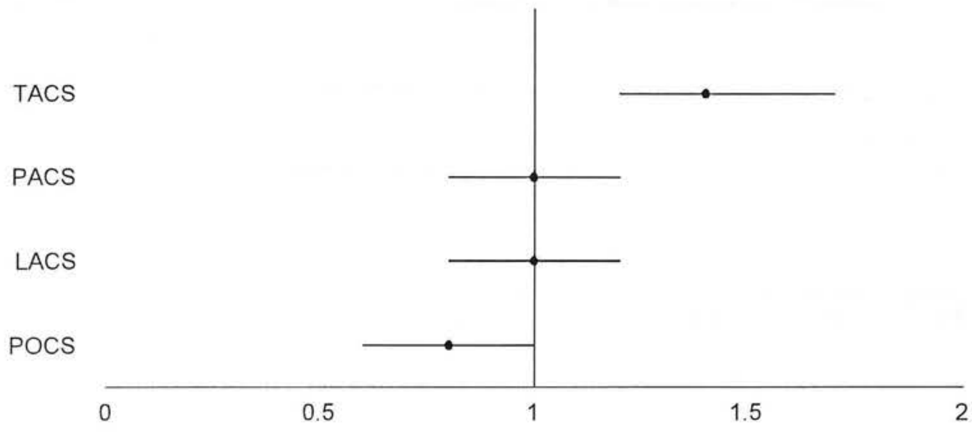


**Figure 4-18: The relative risk of mood disorder for each classification of stroke lesion using a General Health Questionnaire cut-off of 8/9.**

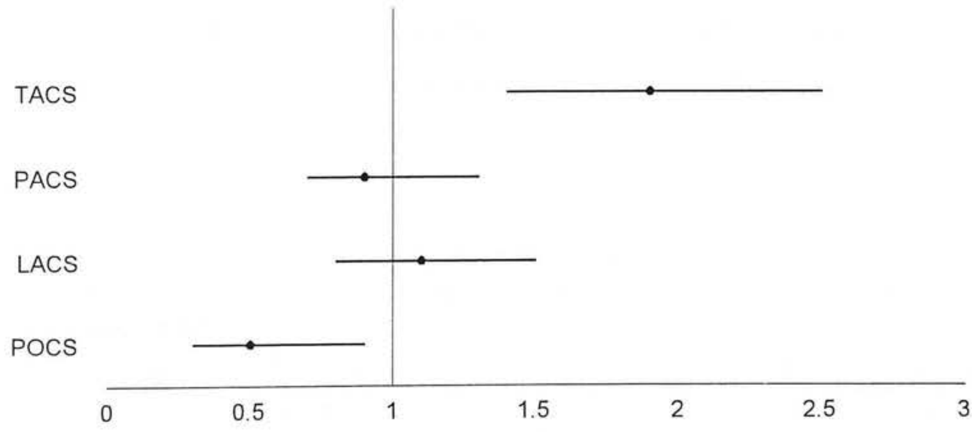
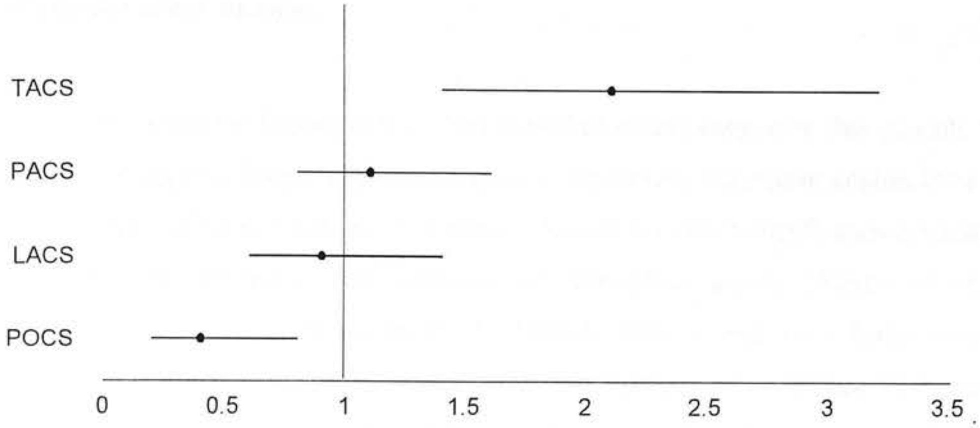


**Figure 4-19: The relative risk of mood disorder for each classification of stroke lesion using a General Health Questionnaire cut-off of 11/12.**



For all three GHQ cut-offs the results remained the same as those for our original analysis. Patients who had total anterior circulation syndrome were significantly more likely to be defined as a case and patients who had a posterior circulation syndrome were significantly less likely to be defined a case. To determine if the association of TACS lesions with mood disorder differed according to hemisphere affected I also analysed the relative risk, for each cutting point, of patients with left hemisphere TACS developing a mood disorder in comparison to those with right hemisphere TACS (Table 4-8). There was no significant difference in the relative risk of mood disorder between patients who had a right hemisphere TACS and a left hemisphere TACS.

**Table 4-8: The relative risk of patients with left hemisphere Total Anterior Circulation Syndrome (TACS) developing mood disorder in comparison to patients with right hemisphere TACS.**

| GHQ Cut-off | Relative Risk | Confidence Intervals | P Value |
|---|---|---|---|
| 4 / 5 | 0.85 | 0.57 - 1.27 | 0.37 |
| 8 / 9 | 0.76 | 0.42 - 1.4 | 0.34 |
| 11 / 12 | 0.64 | 0.27 - 1.51 | 0.26 |

### *4.2.2 Previous studies of the physiological correlates of mood disorder after stroke.*

Since 1983, when the Baltimore team first published results suggesting that patients with left anterior hemisphere lesions experienced greater depression, subsequent studies have focused on this aspect of lesion location. Left anterior lesions have been significantly associated with depression in comparison with posterior left hemisphere lesions (Astrom et al., 1993; Herrmann et al., 1995; Robinson et al., 1984*a*), with anterior right hemisphere lesions (Robinson et al., 1984*a*; Starkstein et al., 1987) or with any other location (Robinson et al., 1983; Starkstein et al., 1987). Two British studies have refuted these findings, identifying no increase in depression amongst patients with left anterior lesions compared to any other location (House et al., 1990*b*; Sharpe et al., 1990). A further two studies have found the opposite, i.e. that posterior or non-frontal lesions are associated with increased depression (Schwartz et al., 1993; Stern and Bachman, 1991). Thus there are six studies supporting the hypothesis that left anterior lesions are associated with increased depression and four disputing this hypothesis. It is noteworthy that four of the six positive studies are from the same team at the John Hopkins University School of Medicine (Robinson et al., 1983; Robinson et al., 1984*a*; Starkstein et al., 1988*a*; Starkstein et al., 1987) and two of the four negative studies also share authors, this time from the Warneford Hospital in Oxford (Sharpe et al., 1990; House et al., 1990*b*). Therefore the ten studies in table 4-9 should not be viewed as completely independent of each other.

When discussing lesion location it is important that all studies for comparison have used the same definitions when specifying these locations. The Baltimore team who first examined this area have used the same definitions in all four of their studies in Table 4-9. They specified that anterior lesions were those whose mean anterior border was less than 40% of the anterior-posterior distance. Posterior lesions are those whose mean anterior border was posterior to 40% of the anterior-posterior distance. Fortunately, for purposes of comparison, all but one of the remaining six studies continued to use the definitions of the Baltimore group (Astrom et al., 1993; Herrmann et al., 1995; House et al., 1990*b*; Sharpe et al., 1990; Schwartz et al., 1993). Stern and Bachman (1991), instead defined lesions as either dorsal or ventral, and frontal if the lesion was predominantly in the two frontal regions. Importantly it should be noted that all such studies are dependent on a single appropriate lesion visible on CT scan and that patients without such a lesion were excluded from analysis. Therefore all such studies are by necessity on a small percentage of patients which may reduce the applicability of their findings to stroke patients in general.

Reliably diagnosing depression after stroke is more difficult than in elderly patients without stroke due to the specific neurological deficits stroke can induce. Patients may have communication deficits including dysphasia, aphasia and aprosody which may hinder their ability to either understand questions or express their thoughts and feelings. In addition, they may suffer emotional lability or many physical symptoms such as apathy or sleep disturbance which may mimic signs of depression. It would also be preferable if criteria for the diagnosis of depression were standardised across studies. Of our ten studies, five used the PSE with DSM III criteria (House et al., 1990*b*; Robinson et al., 1984*a*; Sharpe et al., 1990; Starkstein et al., 1987, 1988*a*), although three of these used a modified PSE (Robinson et al., 1984*a*; Starkstein et al., 1987, 1988*a*), and a further three conducted clinical interviews again using DSM III criteria (Astrom et al., 1993; Herrmann et al., 1995; Schwartz et al., 1993). The remaining two studies were by Stern and Bachman (1991) who used the Visual Analogue Dysphoria Scale on which little has been published and Robinson et al. (1983) who used the Zung Self Rating Depression Scale and Hamilton Depression Rating Scale, both of which have been used previously in stroke. Using only those studies using clinical interviews and DSM III criteria to discuss the evidence for an association between mood and left anterior lesions does not influence our conclusions because of the two omitted studies one supported the hypothesis (Robinson et al., 1983) and one did not (Stern and Bachman, 1991).

Of critical importance is the blinding of either the radiologist reading the CT scans to the result of the psychiatric interview or the blinding of the psychiatric interviewer to the results of the CT scan. Of the 19 studies in the following literature review 12 specified that one of these assessments was undertaken blind to the results of the other (Astrom et al., 1993; Eastwood et al., 1989; House et al., 1990*b*; Parikh et al., 1987; Robinson et al. 1983, 1984*b*, 1985*c*; Robinson and Price, 1982; Schwartz et al., 1993; Sharpe et al., 1990; Starkstein et al., 1987, 1988*a*;) but in a further six studies no mention of blinding is made (Finklestein et al., 1982; Gordon et al., 1991; Herrmann et al., 1995; Nelson et al., 1994; Robinson et al., 1984*a*; Sinyor et al., 1986*b*) and in the remaining study we are told only that CT scans were rated independently (Stern and Bachman, 1991).

A final important consideration when referring to these studies is sample size. As only patients for whom both CT data is available and a single visible lesion exists on CT scanning can be included numbers tend to be very small. The number of patients with left anterior lesions in the studies quoted range between eight and 16, with two studies failing to report this figure (Schwartz et al., 1993; Stern and Bachman., 1991). Such sample sizes are much smaller than those that would normally be acceptable and the perils of making statistical inferences from such samples must be borne in mind.

### *The Side of Lesion*

The Baltimore group's original results suggested that the association between left anterior hemisphere strokes and depression remained when lesions were simply divided according to which hemisphere they affected (Robinson and Price, 1982). I have identified 12 studies which specifically analysed the frequency of depression in left versus right hemisphere lesions (Table 4-10). Of these, five (Astrom et al., 1993; Nelson et al., 1994; Robinson and Price, 1982; Starkstein et al., 1987, 1988*a*) supported Robinson's assertion that depression was more common in patients with left hemisphere lesions, six found no significant differences between hemispheres (Agrell and Dehlin, 1989; Eastwood et al., 1989; Gordon et al., 1991; Herrmann et al., 1995; House et al., 1990*b*; Sharpe et al., 1990) and one found depression to be more common in patients with right hemisphere lesions (Schwartz et al., 1993).

Five of these studies included analysis of whether left anterior hemisphere lesions were associated with depression. It is interesting to compare their findings to see whether any association of depression with left hemisphere lesions is really only reflecting a stronger association with left anterior hemisphere lesions. Of these studies, two found that depression was significantly more common in patients with either left hemisphere or left anterior hemisphere lesions (Astrom et al., 1993; Starkstein et al., 1987) and two found that there were no significant differences when lesions in either area were compared to all other lesions (House et al., 1990*b*; Sharpe et al., 1990). Thus the two former studies may be reporting a genuine association between anterior left hemisphere lesions and merely a secondary association between left hemisphere lesions and depression as the second association may be a product of the first. Starkstein's results suggest that this may be the case as the significance of association between left anterior hemisphere lesions vs. all other lesions is more significant than that for left hemisphere lesion vs. right hemisphere (Starkstein et al., 1987). This is supported by the fifth study in which Herrman (1995) found that patients with left anterior hemisphere stroke were significantly more depressed but that this relationship was no longer significant if lesion location was dichotomised into simply left or right hemisphere. Such a comparison cannot be made for Astrom's study as she compared left anterior hemisphere lesions with left posterior lesions rather than all other locations (Astrom et al., 1993).

### *The Distance of the Lesion from the Frontal Pole*

In addition to their finding that left anterior lesions may be associated with post stroke depression the Baltimore team suggested that the nearer a left hemisphere lesion was to the frontal pole the greater the patient's likelihood of developing depression. My literature review identified nine studies which have addressed this issue (Table 4-11).

The distance between a lesion and the frontal pole of the ipsilateral hemisphere (called ANTPER); House et al., 1990*b*) was found to be significantly related to depression in left hemisphere lesions (Eastwood et al., 1989; Parikh et al., 1987; Robinson et al., 1984*a*, 1984*b*; Starkstein et al., 1987), right hemisphere lesions (Herrmann et al., 1995; Robinson et al., 1984*a*, 1984*b*) and the lesions of both hemispheres combined (House et al., 1990*b*; Sinyor et al., 1986*b*). Therefore, of our nine studies, eight found that the ANTPER distance was related to depression for at least some lesions. Only one study, that by Sharpe (1990), found no relationship between ANTPER distance and any lesion location. However as most studies examined the relationship between a number of lesion locations and ANTPER distance this summary is very simplified and each location has to be considered in turn.

Considering only the ANTPER distance of left hemisphere lesions with the left frontal pole, while five studies find a significant association (Eastwood et al., 1989; Parikh et al., 1987; Robinson et al., 1984*a*, 1984*b*; Starkstein et al., 1987) two do not (Herrmann et al., 1995; Sharpe et al., 1990). Of the five positive studies four are from the Baltimore team and therefore may not be independent of each other and one reports that while the association existed six months after stroke it was weak at one year and was no longer evident at two years.

Only two studies have looked specifically at lesions in the left anterior hemisphere, their ANTPER distance and depression. The first of these was part of the original Robinson et al. (1984*a*) study which initially found the relationship; the second was by Sharpe et al. (1990) who was unable to replicate Robinson's findings.

Six studies have examined the relationship between ANTPER distance and depression in right hemisphere lesions. A study by Herrman et al. (1995) and two by Robinson et al. (1984*a*, 1984*b*) discovered a positive association although in one of Robinson's studies the direction of this relationship reversed between the acute period and six months. Whereas two weeks after stroke a greater ANTPER distance was associated with increased depression, at six months patients with lesions nearer the frontal pole were more depressed. Three further studies by Eastwood, Parikh and Sharpe (1989, 1987, 1990) were unable to consistently replicate this relationship although Parikh (1987) found one of three measures of depression significantly associated with ANTPER distance during the acute period.

As in the studies of lesion location it is important to examine the definitions used to define the distance from the lesion to frontal pole. Robinson et al. (1985*c*) determined the distance of the lesion from the ipsilateral frontal pole by measuring the distance from the anterior edge of the lesion to the frontal pole and dividing by the overall anteroposterior distance in that brain slice. This means that the distance is calculated in proportion to the 'length' of brain on the slice of CT scan in question. Eight of the nine studies have used this method with the ninth, Eastwood et al. (1989), merely stating that the distance was measured and providing no further details.

As we have found in most aspects of stroke research, criteria for defining depression vary considerably. The majority of the studies in Table 4-11 use more than one measure; unfortunately the three studies using only one measure have all used self report measures, two of which were not used in any of the other studies (Eastwood et al., 1989; Herrmann et al., 1995; Sinyor et al., 1986*a*). Considering only the six studies which have used the PSE, (as structured psychiatric interviews are considered best), five found a significant relationship between ANTPER distance and depression (House et al., 1990*b*; Parikh et al., 1987; Robinson et al., 1984*a*, 1984*b*; Sharpe et al., 1990; Starkstein et al., 1987).

### *The Size of the Lesion*

A further hypothesis regarding the relationship of lesions to likelihood of depression is that it is the size of lesion that is important and that larger lesions will be associated with greater depression.

I identified nine studies which had examined the relationship between lesion volume and depression (Table 4-12). Of these, four found a significant positive relationship between size of lesion and depression (Eastwood et al., 1989; Schwartz et al., 1993; Sharpe et al., 1990; Sinyor et al., 1986*b*) and two found no significant associations (Astrom et al., 1993; Herrmann et al., 1995). Of the remaining three studies, one found an association for left hemisphere lesions only (Finklestein et al., 1982); one found no associations when dichotomising between hemispheres two weeks after stroke but did find an association between the volume of all lesions and mood disorder at 6 months (Robinson et al., 1984*b*) and the third study found no relationship at one or six months but one of two measures did show a small significant relationship at one year (House et al., 1990*b*). Therefore the majority of studies did find at least some relationship between lesion volume and depression although sometimes not on all measures of depression used or at all follow up intervals.

Three of the studies analysed their data separately for patients with left and right hemisphere lesions (Finklestein et al., 1982; Robinson et al., 1984*b*; Sharpe et al., 1990). Robinson et al. (1984*b*) found no relationship between either right or left hemisphere lesion volume and any of their three measures of depression. Finklestein (1982) found an association between the volume of left, but not right, hemisphere lesions and depression. Sharpe et al. (1990) found an association between the volume of left hemisphere lesions and depression using the HADS but not the PSE, and conversely found a relationship between the volume of right hemisphere lesions and depression using the PSE but not the HADS. Therefore there is little evidence to suggest that the relationship between the volume of left hemisphere lesions and depression may be stronger than that of right hemisphere lesions and depression.

Unfortunately these studies appear to have differed in their methods of measuring lesion volume. Three studies specified that they calculated lesion volume as a proportion of total brain volume (Astrom et al., 1993; Eastwood et al., 1989; Sinyor et al., 1986*b*) and one that lesion size was calculated as a proportion of forebrain volume (Herrmann et al., 1995). Two further studies used the same method to categorise the actual size of lesion into three ranges of millilitres (House et al., 1990*b*; Sharpe et al., 1990). Two further studies specified that they used a specialised computer programme to determine lesion volume, but did not say whether this was adjusted to allow for total brain volume (Robinson et al., 1884*b*, 1985*c*; Schwartz et al., 1993). The remaining study stated only that the volume was measured (Finklestein et al., 1982). Grouping studies according to their method of measurement did not produce any conformity of interpretation, with results being mixed for all methods.

Of course larger lesions are likely to cause greater disability and therefore any increased levels of depression may have more to do with this mediating variable than any physiological aspect of their brain damage. An alternative explanation suggested by House (1990*b*) is that as larger lesions are more likely to involve the anterior area of the brain so any association between lesion size and depression may reflect any relationship between left hemisphere anterior lesions and depression.

### 4.2.3 Discussion

As our measures were not directly comparable to those using CT scans in previous studies our results cannot be used to directly comment on the findings of other studies. They do however offer some pointers.

We were able to compare patients who had suffered left hemisphere strokes with those who had suffered right. We found no difference in the relative risk of mood disorders for patients in these two groups but did find that patients who fell into neither group, having lesions in the brainstem or cerebellum, were significantly less likely to be depressed. This result agrees with five of the 11 previous studies (Eastwood et al., 1989; Gordon et al., 1991; Herrmann et al., 1995; House et al., 1990*b*; Sharpe et al., 1990). None of those studies compared patients with brainstem/cerebellar lesion to all others, but one, Starkstein et al. (1988*a*) reported that patients with middle cerebral artery territory lesions were significantly more likely to experience a mood disorder than those with brainstem/cerebellar lesions. Any CT scan study of cerebellar/brainstem strokes is likely to have very few patients since most strokes in this area are not visible on CT. Our large sample size means our study is probably more powerful than CT studies to comment on right vs. left hemisphere vs. posterior strokes since the clinical accuracy of this tripartite classification is very high.

Our analysis of patients' clinical classification and mood is of some relevance to both the debate concerning anterior left hemisphere lesions and that concerning lesion size. Both the TACS and PACS classifications refer to lesions in the anterior circulation with TACS referring to a larger legion in this territory. Therefore it is likely that if a lesion is described as a TACS that some of its mass will be in the anterior hemisphere as it is defined by Robinson et al. (1984*a*). Therefore our finding that patients with TACS were significantly more likely to have a mood disorder could add some limited weight to the argument that anterior hemisphere strokes are related to increased mood symptoms. There is good evidence that TACS lesions are larger (Wardlaw et al., 1996) and our results therefore lend weight to those studies suggesting that the greater the volume of a lesion the greater the likelihood of mood disorder (Eastwood et al., 1989; Schwartz et al., 1993; Sharpe et al., 1990; Sinyor et al,. 1986*b*). Again, we find no evidence of an increased risk of mood disorders associated with lesions in either hemisphere when patients with TACS are dichotomised by hemispheric side of lesion. These classifications also allow us to comment on any association between cortical versus subcortical lesions and mood disorder as the clinical classifications TACS and PACS refer to cortical lesions and the clinical classifications LACS and POCS refer to subcortical lesions. Our results suggest that cortical lesions (TACS) are associated with more reported mood symptoms than subcortical (POCS) (Figure 4-17, 4-18 and 4-19). There was no difference in the relative risk of mood disorder in patients with PACS or LACS. The two previous studies comparing cortical with subcortical lesions (Astrom et al., 1993; Starkstein et al., 1987) (Table 4-9) found no significant difference in the frequency of mood disorders.

My review has illustrated that it is not possible to gain clear evidence either for or against a relationship between stroke lesion location and mood outcome from the literature as it now stands. What is required is a more systematic review of the literature in conjunction with a meta-analysis. Future studies would be advised to use magnetic resonance imaging rather than CT due to the latter's limited ability to show all lesions and its lack of accuracy in indicating the size of lesions. In addition they should adhere to the methodological criteria used by the majority of studies previously (regarding definition of lesion site), use standard diagnostic criteria and outcome measures, achieve complete follow up at a sensible time after stroke and ensure a large enough sample.

**Table 4-9: Previous studies relating mood to the lesion's vascular territory.**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Astrom et al. (1993) | n = 76<br>Consecutive admissions to hospital stroke unit | Hospital Discharge | ANT LHL vs. POST LHL | Major depression<br>Psychiatric interview<br>p=0.017 |
| | | | Subcortical vs. cortical lesions | p = NS |
| | n = 16 ANT LHL<br>n = 8 POST LHL | | Cerebral atrophy | p = NS |
| Castillo et al. (1993) | n = 309<br>Consecutive inpatients | In hospital | Lesion location | Modified PSE<br>Depressed vs. not depressed p=NS |
| | n=102 symptom free<br>n=28 depressed only<br>n=36 anxious only | | Cortical LHL | Depressed cortical LHL patients more likely to be anxious than non-depressed cortical LHL patients p<0.003 |
| | | | Cortical RHL | Frequency of depression/anxiety p=NS |
| Herrmann et al. (1995) | n = 47<br>From consecutive series from stroke data bank, = first event. | 2 months | ANT LHL vs. POST LHL | CDS:<br>p< 0.05<br>MADRS: p< 0.05 |
| | n=15 RHL<br>n = 32 LHL<br>n = 9 ANT LHL | | LHL in basal ganglia, lenticulo-striate or anterior choroidal artery area of vascular supply vs. remainder. | Major depression: p<0.01<br>CDS: p<0.001<br>MADRS: p<0.01 |
| House et al. (1990*b*) | n = 73<br>consecutive series from community register | 1 month | ANT vs. intermediate or POST | PSE & BDI<br>p = NS |
| | | 6 months | | p = NS |
| | | 1 year | | p = NS |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; PSE= Present State Examination; CDS= Cornell Depression Scale; MADRS= Montgomery Åsberg Depression Rating Scale; BDI= Beck Depression Inventory.

**Table 4-9. continued.**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Robinson et al. (1983) | n = 103<br>Consecutive series from stroke data bank<br>n=8 ANT LHL<br>n=12 Parietal/ occipital LHL<br>n=10 ANT RHL | 2 weeks post stroke | ANT LHL vs. left parietal/ occipital<br>ANT LHL vs. ANT RHL | SDS: p< 0.02<br>HDRS: p< 0.02<br>SDS: p< 0.02 |
| Robinson et al. (1984*a*) | Consecutive series of right handed inpatients<br>n = 14 RHL<br>n = 22 LHL<br>n = 10 ANT LHL<br>n = 8 POST LHL<br>n = 6 ANT RHL<br>n = 6 POST RHL | mean 10-12 days post stroke | ANT LHL<br>vs. ANT RHL<br>vs. POST LHL<br>vs. POST RHL | SDS/HDRS/PSE<br>p<0.05<br>p<0.05<br>p<0.02 |
| Robinson et al. (1985*b*) | n=30<br>Left handed patients-consecutive hospital admissions<br>n=8 ANT LHL<br>n=7 POST LHL | In hospital | ANT LHL >POST LHL | Modified PSE<br>p<0.025 |
| Schwartz et al. (1993) | n = 91<br>Male rehabilitation patients<br>n = ANT LHL not quoted | 1-103 months, median 2 months | Posterior lesions<br>Occipital lesions<br>LHL in internal capsule | Interview & HDRS: p<0.01<br>HDRS: p=0.03<br>HDRS: p=0.015 |
| Sharpe et al. (1990) | n = 60<br>Community stroke register<br>n = 13 ANT LHL | 3 - 5 years | ANT LHL vs. remainder | PSE & HADS<br>p = NS |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; SDS= Zung Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale; PSE= Present State Examination.

**Table 4-9. continued**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Starkstein et al. (1988*a*) | 79 consecutive hospital admissions.<br>n = 37 POST<br>n = 42 MCA<br>MCA LHL = 23<br>MCA RHL = 19 | 6 months<br>1-2 years | MCA vs. brainstem/ cerebellar | All depression<br>$p < 0.05$<br>$p = 0.05$ |
| Starkstein et al. (1987) | n = 45<br>from consecutive series of hospital admissions,.<br>n=16 CORT LHL<br>n=9 CORT RHL<br>n=13 S-CORT LHL<br>n = 7 S-CORT RHL<br>n=11 ANT LHL | < 2 months post stroke | ANT LHL vs. remainder | Higher mean depression scores<br>PSE: $p<0.003$<br>HDRS: $p< 0.023$<br>SDS: $p<0.003$ |
| | | | ANT LHL vs. ANT RHL | $p < 0.01$ |
| | | | ANT CORT vs. POST CORT | PSE diagnosis: $p< 0.01$ |
| | | | ANT S-CORT LHL vs. POST S-CORT LHL | p = NS |
| | | | CORT LHL vs. S-CORT LHL | All measures<br>p = NS |
| | | | CORT RHL vs. S-CORT RHL | All measures<br>p = NS |
| Stern & Bachman, (1991) | n = 52<br>Consecutive hospital referrals<br>n=11 Ventral RHL<br>n = ANT LHL not quoted.<br>n=26 Dorsal LHL | 1 month - 4 years | -Non-frontal lesions vs. remainder | Note: MANOVA Visual Analogue Dysphoria Scale.<br>$p< 0.01$ |
| | | | -Non-frontal lesions vs. remainder | $p< 0.05$ |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions. NS = Not significant; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale; SDS= Zung Self Rating Depression Scale.

**Table 4-10: Previous studies examining the association between depression and hemispheric side of lesion.**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Agrell & Dehlin, (1989) | n = 40<br>Volunteers from day hospital, rehabilitation clinic or nursing home. | 4-2.5 years<br>Mean = 14 months | LHL vs. RHL | GDS, SDS, CES-D, HDRS, CPRS-D or CDS.<br>p=NS |
| Astrom et al. (1993) | n = 76<br>Consecutive hospital admissions<br>n=24 LHL<br>n=23 RHL | Hospital Discharge | LHL > RHL | Interview, DSM III-Major depression<br>p=0.001 |
| Astrom, (1996) | n=80<br>Hospital inpatients during one year | In hospital | LHL vs. RHL<br>RHL > LHL<br>LHL > RHL | Interview DSM III All GAD<br>p=NS<br>GAD only<br>p<0.04<br>GAD & Depression<br>p<0.04 |
| Castillo et al. (1993) | n = 309<br>Consecutive inpatients<br>n=102 symptom free<br>n=28 depressed only<br>n=36 anxious only | In hospital | LHL<br>RHL | Modified PSE<br>Depressed & anxious patients > LHL than anxious only patients<br>p<0.04<br>Anxious only patients > RHL than depressed & anxious patients<br>p<0.04 |
| Eastwood et al. (1989) | n = 187<br>Hospital inpatients<br>n = 11 LHL | 4 months post entry or at discharge | LHL > RHL | SADS: p = NS |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; GAD= Generalised Anxiety Disorder; GDS= Geriatric Depression Scale; SDS= Zung Self Rating Depression Scale; CES-D= Centre for Epidemiologic Studies Depression Scale; HDRS= Hamilton Depression Rating Scale; CPRS-D= Comprehensive Psychopathological Rating Scale -Depression; CDS= Cornell Depression Scale; DSM= Diagnostic and Statistical Manual of Mental Disorders; PSE= Present State Examination; SADS= Schedule for Affective Disorders and Schizophrenia.

**Table 4-10. continued.**

| **Author & Year** | **Patients** | **Time of Follow up** | **Lesions tested for association with depression** | **Measure of mood and Significance** |
|---|---|---|---|---|
| Gordon et al. (1991) | n = 116<br>Consecutive admissions to rehabilitation hospital<br>n = 80 RHL<br>n = 36 LHL | 2 months | LHL > RHL | The Structured Assessment of Depression in Brain Damaged Individuals incorporating BDI MAACL & HDRS<br>p=NS |
| Herrmann et al. (1995) | n = 47<br>Consecutive series from stroke data bank.<br>n=15 RHL<br>n = 32 LHL | 2 months | LHL > RHL | CDS<br>p=NS |
| House et al. (1990*b*) | n = 73<br>consecutive series from community register | 1 month<br>6 months<br>1 year | LHL > RHL | PSE: p=NS<br>BDI: p=NS<br>PSE: p=NS<br>BDI: p=NS<br>PSE: p=NS<br>BDI: p=NS |
| Nelson et al. (1994) | n = 70<br>inpatients<br>n = 29 RHL<br>n = 27 LHL | 2 weeks post stroke | LHL > RHL | Neuropsychology Behaviour and Affect Profile, depression score<br>p = <0.01 |
| Robinson & Price. (1982) | n = 103<br>randomly selected from hospital stroke clinic. | 6 - 15 years at initial interview | LHL > RHL | mean GHQ-28 score<br>p=<0.002 |
| Robinson et al. (1985*b*) | n=30 Left handed patients- consecutive hospital admissions<br>n=18 LHL<br>n=12 RHL | In hospital | LHL > RHL | Modified PSE p<0.01<br>SDS= p<0.05<br>HDRS= p=NS |
| Schwartz et al. (1993) | n = 91 male rehabilitation patients<br>n=27 RHL<br>n=26 LHL | 1-103 months, median 2 months | RHL > LHL | p< 0.03 |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; BDI= Beck Depression Inventory; MAACL= Multiple Affect Adjective Checklist; CDS= Cornell Depression Scale; PSE= Present State Examination; BDI= Beck Depression Inventory; GHQ= General Health Questionnaire; SDS= Zung Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale.

**Table 4-10. continued.**

| **Author & Year** | **Patients** | **Time of Follow up** | **Lesions tested for association with depression** | **Measure of mood and Significance** |
|---|---|---|---|---|
| Sharpe et al. (1990) | $n = 60$<br>Community stroke register<br>$n = 27$ LHL<br>$n = 28$ RHL | 3 - 5 years | LHL > RHL | $p = \text{NS}$ |
| Thompson et al. (1989) | $n = 40$<br>Volunteer therapy outpatients | 1-60 months<br>mean = 9 months | LHL > all other lesions | $p < 0.05$ |
| Starkstein et al. (1988*a*) | 79 consecutive hospital admissions.<br>$n = 37$ POST<br>$n = 42$ MCA<br>PC LHL = 6<br>PC RHL = 3 | 6 months<br>1-2 years | POST LHL > POST RHL & brainstem | modified PSE:<br>$p = 0.002$<br>$p = 0.017$ |
| | MCA LHL = 23<br>MCA RHL = 19 | Time not clear | MCA LHL > RHL | Major depression<br>$p < 0.03$ |
| | | | MCA RHL > LHL | Minor depression<br>$p = 0.077$ |
| Starkstein et al. (1987) | $n = 45$<br>from consecutive series of hospital admissions..<br>$n = 16$ LHL<br>$n = 9$ RHL | < 2 months post stroke | LHL > RHL | PSE diagnosis: $p < 0.05$ |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; PSE= Present State Examination.

**Table 4-11: Previous studies examining the relationship between the distance of the lesion from the frontal pole of the ipsilateral hemisphere and depression.**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Eastwood et al. (1989) | n = 187<br>Hospital inpatients<br>n = 47 depressed cases (RDC)<br>n=32 non depressed stroke controls | 4 months post entry or at discharge | LHL Distance from frontal pole<br>Closer > depressed | GDS: $p =< 0.01$ |
| | | | LHL Distance from frontal pole in cases vs. controls<br>Closer > depressed. | SADS: $p < 0.05$ |
| | n=4 LHL cases<br>n=7 LHL controls<br>n=18 RHL cases<br>n=9 RHL controls | | RHL Distance from frontal pole in cases vs. controls | SADS: p = NS |
| Herrmann et al. (1995) | n = 47<br>Consecutive series from stroke data bank<br>n=15 RHL<br>n = 32 LHL<br>n = 9 ANT LHL | 2 months | RHL Distance to frontal pole.<br>Closer > depressed. | CDS: $p < 0.05$ |
| | | | LHL distance to frontal pole | CDS: p = NS |
| | | | Lateral ventricle to brain ratio | CDS: p = NS |
| House et al. (1990*b*) | n = 73<br>consecutive series from community register | 1 month<br>6 months | Lesion distance to frontal pole - includes RHL & LHL<br>Closer > depressed | PSE: $p = 0.05$<br>PSE: $p =0.01$<br>BDI: $p =0.01$ |

RHL = Right hemisphere lesions. LHL = Left hemisphere lesions. POST = Posterior lesions. ANT = Anterior lesions. NS = Not significant; GDS= Geriatric Depression Scale; SADS= Schedule for Affective Disorders and Schizophrenia; CDS= Cornell Depression Scale; PSE= Present State Examination; BDI= Beck Depression Inventory.

**Table 4-11. continued**

| Author & Year | Patients | Time of Follow up | Lesions tested for an association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Parikh et al. (1987) | $n = 94$<br>inpatients included in stroke data bank | | | |
| | $n = 28$ LHL | In hospital | LHL distance to frontal pole<br>Closer > depressed | $p < 0.05$ |
| | $n = 9$ LHL | 6 months | | PSE: $p < 0.05$<br>HDRS: $p < 0.05$<br>SDS: $p < 0.05$ |
| | $n = 6$ LHL | 1 year | | PSE: $p < 0.05$<br>HDRS: $p = NS$<br>SDS: $p = NS$ |
| | $n = 7$ LHL | 2 years | | PSE: $p = NS$<br>HDRS: $p = NS$<br>SDS: $p = NS$ |
| | $n = 10$ RHL | 3 and 6 months | RHL distance to frontal pole<br>Closer > depressed | PSE: $p = NS$<br>HDRS: $p < 0.05$<br>SDS: $p = NS$ |
| | $n = 5$ RHL | 1 year | | PSE: $p = NS$<br>HDRS: $p = NS$<br>SDS: $p = NS$ |
| | $n = 7$ RHL | 2 years | | PSE: $p = NS$<br>HDRS: $p = NS$<br>SDS: $p = NS$ |
| Robinson et al. (1984*b*) | LHL | | Distance of lesion to frontal pole<br>Closer > depressed | HDRS/SDS/PSE |
| | $n = 17$ | 2 weeks | | $p < 0.001$ |
| | $n = 9$ | 3 months | | $p < 0.001$* |
| | $n = 9$ ANT lesions | 6 months | | $p < 0.001$ |
| | $n = 10$ RHL | 2 weeks | Distance of lesion to frontal pole<br>Closer < depressed | HDRS: $p < 0.01$ |
| | | 6 months | Closer > depressed | HDRS: $p < 0.05$ |
| Robinson et al. (1985*c*) | $n = 9$ LHL | 3 months | ANTPER | Mean PSE/SDS/HDRS<br>$p < 0.05$* |
| | $n = 15$ LHL | 6 months | | $p < 0.01$<br>* Appear to be same patients but different p values quoted. |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale; SDS= Zung Self Rating Depression Scale.

**Table 4-11. continued.**

| Author & Year | Patients | Time of Follow up | Lesions tested for an association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Robinson et al. (1984*a*) | Consecutive series of right handed inpatients<br>n = 14 RHL<br>n = 22 LHL<br>n = 10 ANT LHL<br>n = 8 POST LHL<br>n = 6 ANT RHL<br>n = 6 POST RHL | mean 10-12 days post stroke | LHL distance to frontal pole Closer>depression<br>ANT LHL distance to frontal pole Closer>depression<br>RHL to frontal pole Closer < depressed | SDS/HDRS/PSE $p<0.05$<br>$p<0.001$<br>$p<0.01$ |
| Robinson et al. (1985*b*) | n=30<br>Consecutive series of left handed inpatients<br>n=8 ANT LHL | In hospital | ANT LHL distance to frontal pole Closer > depressed | $p<0.01$ |
| Sharpe et al. (1990) | n = 60<br>Community stroke register<br>n =27 LHL<br>n = 13 ANT LHL<br>n = 28 RHL | 3 - 5 years | ANTPER positions<br>ANTPER RHL<br>ANTPER position LHL<br>ANTPER ANT LHL | PSE & HADS<br>p = NS<br>p = NS<br>p = NS<br>p = NS |
| Sinyor et al. (1986*b*) | n = 35<br>Consecutive rehabilitation hospital admissions<br>n = 16 RHL<br>n = 19 LHL | 'within weeks' | ANTPER<br>Closer > depressed | SDS: $p<0.05$ |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions, NS = Not significant; SDS= Zung Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale; PSE= Present State Examination; HADS= Hospital Anxiety and Depression Scale.

**Table 4-11. continued**

| Author & Year | Patients | Time of Follow up | Lesions tested for an association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Starkstein et al. (1987) | n = 45 from consecutive series of hospital admissions..<br>n=16 CORT LHL<br>n=9 CORT RHL<br>n=13 S-CORT LHL<br>n=7 S-CORT RHL | < 2 months post stroke | LHL distance to frontal pole | PSE: $p < 0.01$ |
| | | | CORT LHL ANTPER | PSE: $p < 0.05$<br>HDRS: p = NS<br>SDS: $p < 0.05$ |
| | | | CORT RHL ANTPER | PSE: $p < 0.05$<br>HDRS: p = NS<br>SDS: p = NS |
| | | | S-CORT LHL ANTPER | PSE: $p < 0.01$<br>HDRS: $p < 0.05$<br>SDS: p = NS |
| | | | S-CORT RHL ANTPER | All measures p = NS |

RHL = Right hemisphere lesions, LHL = Left hemisphere lesions, POST = Posterior lesions, ANT = Anterior lesions. NS = Not significant; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale; SDS= Zung Self Rating Depression Scale.

**Table 4-12: Previous studies examining the relationship between size of lesion and depression.**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Astrom et al. (1993) | n = 76<br>Consecutive hospital admissions | Hospital Discharge | Lesion volume | p = NS |
| Eastwood et al. (1989) | n = 187<br>Hospital inpatients | 4 months post entry or at discharge | Total fraction of brain infarcted:<br><20%<br>20-40%<br>>41%<br>mean % of brain volume infarcted<br>LHL<br>RHL | SADS: p=NS<br>SADS: p=NS<br>SADS: p=NS<br>SADS: p<0.05<br>HDRS: p<0.05 |
| Finklestein et al. (1982) | n = 25<br>randomly selected inpatients in rehabilitation Hospital | 11 to 111 days | Medium to large LHL<br>RHL | Interview using parts of HDRS<br>p = < 0.05<br>p = NS |
| Herrmann et al. (1995) | n = 47<br>Consecutive series from stroke data bank. | 2 months | Lesion volume<br>Lateral ventricle to brain ratio | CDS: p=NS<br>CDS: p=NS |
| House et al. (1990) | n = 73<br>consecutive series from community register | 1 month<br>6 months<br>1 year | Lesion volume | BDI: p=NS<br>PSE: p=NS<br>BDI: p=NS<br>PSE: p=NS<br>BDI: p=NS<br>PSE: p=0.05 |

RHL = Right hemisphere lesions; LHL = Left hemisphere lesions; NS = Not significant; SADS= Schedule for Affective Disorders and Schizophrenia; HDRS= Hamilton Depression Rating Scale; PSE= Present State Examination; BDI= Beck Depression Inventory.

**Table 4-12. continued.**

| Author & Year | Patients | Time of Follow up | Lesions tested for association with depression | Measure of mood and Significance |
|---|---|---|---|---|
| Robinson et al. (1984*b*) | n = 103 Consecutive patients from stroke data bank | 2 weeks | Lesion volume | |
| | | | LHL | PSE: $p=NS$<br>HDRS: $p=NS$<br>SDS: $p=NS$ |
| | | | RHL | PSE: $p=NS$<br>HDRS: $p=NS$<br>SDS: $p=NS$ |
| | | | Lesion volume | Mean PSE/SDS/HDRS |
| Robinson et al. (1985*c*) | | 3 months | | $p=NS$ |
| | | 6 months | | $p<0.01$ |
| Schwartz et al. (1993) | n = 91 male rehabilitation patients | 1-103 months, median 2 months | Lesion volume | $p<0.01$ |
| Sharpe et al. (1990) | n = 60 Community stroke register | 3 - 5 years | Lesion volume | |
| | n = 27 | | LHL | HADS: $p<0.01$ |
| | n=27 | | | HAD-D :$p<0.01$ |
| | n=27 | | | HAD-A: $p<0.05$ |
| | n=26 | | | PSE: $p=NS$ |
| | n=28 | | RHL | HADS: $p=NS$ |
| | n=28 | | | HAD-D: $p=NS$ |
| | n=28 | | | HAD-A: $p=NS$ |
| | n=28 | | | PSE: $p<0.05$ |
| | n=55 | | All lesions | HADS: $p<0.01$ |
| | n=55 | | | HAD-D: $p<0.05$ |
| | n=55 | | | HAD-A: $p<0.01$ |
| | n=54 | | | PSE: $p<0.01$ |
| Sinyor et al. (1986*b*) | n = 35 Consecutive hospital admissions | 'within weeks' | Lesion volume | HSCL-D: $p<0.05$ |

RHL = Right hemisphere lesions; LHL = Left hemisphere lesions; NS = Not significant; BDI= Beck Depression Inventory; PSE= Present State Examination; HDRS= Hamilton Depression Rating Scale; SDS= Zung Self Rating Depression Scale; HADS= Hospital Anxiety and Depression Scale; HAD-D= HAD Depression Subscale; HAD-A= HAD Anxiety Subscale; HSCL-D= Hopkins Symptom Checklist- Depression.

## 4.3 Predicting Poor Psychosocial Outcomes

We have established that many patients experience poor psychosocial functioning after stroke and have gained some understanding of the possible mechanisms involved. It would now make sense to see if, armed with this knowledge, we can predict shortly after stroke onset which patients are most at risk of poor psychosocial outcomes. Such an ability would greatly aid the targeting of interventions to prevent or alleviate psychosocial difficulties. This information may also help us to better understand the aetiology of poor psychosocial outcome and provide information to allow the better adjustment of casemix between cohorts in which psychosocial outcome is examined.

### *4.3.1 Predicting patients' mood*

Using the data from our initial neurological assessment taken either on the first working day after admission or during patients' first outpatient appointments I identified variables which were associated with patients' mood at six months as measured by their GHQ score. I first conducted a univariate regression using each baseline variable in turn as my independent variable and the GHQ as my dependent variable (Table 4-13).

**Table 4-13: Univariate regression of baseline variables and General Health Questionnaire score at six months in descending order of amount of variance explained.**

| Variable | Beta | Standard Error | P Value | n | Amount of Variance |
|---|---|---|---|---|---|
| TACS | 5.8997 | 1.2814 | <0.0001 | 310 | 6.44% |
| Left hemianopia | 6.4004 | 1.4693 | <0.0001 | 300 | 5.99% |
| Any motor deficit | 3.7030 | 0.8426 | <0.0001 | 309 | 5.92% |
| Unable to stand independently | 3.639 | 0.89 | 0.0001 | 310 | 5.15% |
| Unable to walk independently | 2.8779 | 0.8212 | 0.0005 | 310 | 3.84% |
| Cortical signs other than dysphasia/dysarthria | 3.1663 | 1.0256 | 0.0022 | 296 | 3.14% |
| Sensory deficit | 2.6730 | 0.9003 | 0.0032 | 289 | 2.98% |
| POCS | -2.6939 | 1.0220 | 0.0088 | 310 | 2.21% |
| Mental test score* | -0.8467 | 0.3696 | 0.0228 | 268 | 1.94% |
| Incontinent of urine since stroke | 2.5996 | 1.2493 | 0.0383 | 310 | 1.39% |
| Age* | -0.0657 | 0.3222 | 0.0424 | 310 | 1.33% |

**Table 4-13. continued.**

| **Variable** | **Beta** | **Standard Error** | **P Value** | **n** | **Amount of Variance** |
|---|---|---|---|---|---|
| Clinical prediction of outcome at one year- Oxford Handicap Scale Score* | 1.1458 | 0.3206 | 0.0004 | 310 | 3.98% |
| Oxford Handicap Scale score before stroke* | 0.9236 | 0.4526 | 0.0421 | 310 | 1.33% |
| Right hemisphere stroke | 1.3686 | 0.8122 | 0.0930 | 310 | 0.91% |
| Eye opening - Glasgow Coma Scale* | -2.0719 | 1.2522 | 0.0990 | 310 | 0.88% |
| Sex (1= male, 2= female) | 1.0367 | 0.8053 | 0.1990 | 310 | 0.54% |
| Atrial fibrillation known before stroke | -1.7670 | 1.5346 | 0.2504 | 310 | 0.43% |
| PACS | -0.8123 | 0.8411 | 0.3349 | 310 | 0.30% |
| Lives alone | -0.7033 | 0.8548 | 0.4113 | 310 | 0.22% |
| Previous stroke with residual disability | 1.2042 | 1.4524 | 0.4077 | 310 | 0.22% |
| Best verbal - Glasgow Coma Scale* | -0.3055 | 0.4269 | 0.4747 | 310 | 0.17% |
| Breathless walking on an incline | 0.7383 | 1.1010 | 0.5030 | 306 | 0.15% |
| Dysphasia | 0.3031 | 1.0547 | 0.7740 | 303 | 0.03% |
| Left hemisphere stroke | 0.2392 | 0.8226 | 0.7714 | 310 | 0.03% |
| LACS | 0.1952 | 0.8692 | 0.8224 | 310 | 0.02% |
| Right hemianopia | 0.2995 | 1.5476 | 0.8467 | 301 | 0.01% |
| Alcohol > 2 units daily | -0.0182 | 1.0358 | 0.9860 | 308 | 0.00% |
| Best motor - Glasgow Coma Scale* | 0.0256 | 2.1552 | 0.9905 | 310 | 0.00% |
| Hypertension - history/treatment at any time | -0.0156 | 0.8107 | 0.9847 | 309 | 0.00% |

Note: All variables, except those marked *, are coded '1' if the variable is true for a patient, and '0' if the variable is not true for that patient. Variables marked * are coded as whole numbers. For example Age is coded as the number of years and Oxford Handicap Scale score as 0-6.

Variables thought to be relevant were then entered into a backward stepwise linear multiple regression. The models suggested by the continuing backward regression were judged as to whether they represented an acceptable balance between the amount of information required and the variance predicted. They were then further analysed in two ways. For each model the variables used were again entered into a regression equation which this time would include more patients as patients only needed complete data on those variables to be included. Then the GHQ was recoded using the cut-off 8/9 to categorise patients as likely or unlikely to be a case. The predicted GHQ score for each patient using each model was then calculated to construct a two by two table to illustrate the concurrence between patients' predicted and actual categorisation as a case.

Two models were developed in this way, one which required six pieces of baseline information and one which required two pieces.

### Predicting patients' mood: Model 1 with six variables

The initial backward regression using 258 patients suggested that this model explained 15% of variance in patients' GHQ scores at six months. When the variables for this model only were entered into a regression it used 303 patients, as it required patients only be complete in the variables used, but the amount of variance explained rose to 15% (Table 4-14).

When model 1 was further analysed as a 'case finder' it was found to have reasonable specificity (0.74) and poorer sensitivity (0.49) correctly classifying 64% of patients (Table 4-16). A worked example is illustrated in Table 4-15 to illustrate how our predictive models would be used in practice.

**Table 4-14: Predicting patients' mood; Results of linear regression analysis of Model 1 with six variables.**

R Square 0.14968
Standard Error 6.62761

Analysis of Variance

| | DF | Sum of Squares | Mean Square |
|---|---|---|---|
| Regression | 6 | 2288.62591 | 381.43765 |
| Residual | 296 | 13001.85594 | 43.92519 |

F = 8.68380 Signif F < 0.0001

| Variable | Beta | SE B | Variable | Beta | SE B |
|---|---|---|---|---|---|
| TACS | 4.5262 | 1.5018 | OHS prior to stroke | 1.0236 | 0.4585 |
| Age | -0.0944 | 0.0325 | Unable to stand | 1.4604 | 1.0397 |
| Dysphasia | -0.6573 | 1.0067 | (Constant) | 10.7898 | 2.1999 |
| Any motor deficit | 2.5434 | 0.8611 | | | |

**Table 4-15: A worked example of how to use a predictive model in practice.**

| Variable | Value of variable in Patient 001 | Beta | Variable value multiplied by Beta |
|---|---|---|---|
| TACS | 0 | 4.5262 | 0 |
| Age | 76 | -0.0944 | -7.1744 |
| Dysphasia | 1 | -0.6573 | -0.6573 |
| Any motor deficit | 0 | 2.5434 | 0 |
| OHS prior to stroke | 0 | 1.0236 | 0 |
| Unable to stand | 0 | 1.4604 | 0 |
| | | Total = | -7.8317 |
| (Constant) | | Add constant's Beta value to total | 10.7898 |
| | | Patients' predicted GHQ score at 6 months | *3* |
| | | Patients' actual GHQ score at 6 months | *1* |

**Table 4-16: Predicting patients' mood outcome, the predictive value of model 1, predicting patients' mood with six variables.**

| | | **General Health Questionnaire - 30** | |
|---|---|---|---|
| | | **Mood disorder** | **No mood disorder** |
| **Model 1's Prediction** | **Mood disorder** | 56 | 49 |
| | **No mood disorder** | 59 | 139 |

**Sensitivity of Model 1 = 0.49**

The proportion of people who will develop a mood disorder who are predicted to do so.

**Specificity of Model 1 = 0.74**

The proportion of people who will not develop mood disorder who are predicted not to do so.

**Positive Predictive Value of Model 1 = 0.53**

The proportion of people predicted to develop a mood disorder who do so.

**Negative Predictive Value of Model 1 = 0.70**

The proportion of people predicted not to develop mood disorder who do not.

### Predicting patients' mood: Model 2 with two variables

I chose the second model because of the small amount of data needed on each patient. While the two variable model predicted only two thirds the amount of variance of the five variable model, 10% (Table 4-18), it correctly categorised a higher percentage of patients, 65% (Table 4-19). However this was at the cost of a very low sensitivity (0.18), the clinical implications of which are considered later (refer to 4.3.4.).

**Table 4-17: Predicting patients' mood; Results of linear regression analysis of Model 2 with two variables.**

| | | | |
|---|---|---|---|
| R Square | 0.10023 | | |
| Standard Error | 6.75153 | | |
| Analysis of Variance | | | |
| | DF | Sum of Squares | Mean Square |
| Regression | 2 | 1553.84757 | 776.92378 |
| Residual | 306 | 13948.43075 | 45.58311 |
| F = 17.04412 | | Signif F < 0.0001 | |

| Variable | B | SE B | Variable | B | SE B |
|---|---|---|---|---|---|
| TACS | 4.8411 | 1.2958 | (Constant) | 5.3776 | 0.6820 |
| Any motor deficit | 2.9688 | .8484 | | | |

**Table 4-18: The predictive value of model 2, predicting patients' mood with two variables.**

| | | General Health Questionnaire - 30 | |
|---|---|---|---|
| | | **Mood disorder** | **No mood disorder** |
| **Model 2's Prediction** | **Mood disorder** | 21 | 11 |
| | **No mood disorder** | 97 | 180 |

**Sensitivity of Model 1 = 0.18**

The proportion of people who will develop a mood disorder who are predicted to do so.

**Specificity of Model 1 = 0.94**

The proportion of people who will not develop mood disorder who are predicted not to do so.

**Positive Predictive Value of Model 1 = 0.66**

The proportion of people predicted to develop a mood disorder who do so.

**Negative Predictive Value of Model 1 = 0.65**

The proportion of people predicted not to develop mood disorder who do not.

### 4.3.2 *Predicting patients' social functioning.*

As with mood disorder, it would also be useful to identify at an early stage those patients who are likely to experience difficulties with their social functioning. For this purpose we divided social functioning into social activities, measured by the Frenchay Activities Index (FAI) and social adjustment measured by the SAS. I first examined the contribution of individual variables to each outcome and then attempted to develop models that could be used during the acute phase of stroke to predict those patients who were likely to experience difficulties.

#### *4.3.2.1 Social activities.*

Using patients' FAI scores as the dependent variable, each item of information collected at stroke onset underwent univariate linear regression to determine the percentage of variance in the patients' FAI scores it could explain. These are arranged in descending order of amount of variance explained in Table 4-19.

**Table 4-19: Univariate regression of baseline variables and Frenchay Activities Index at six months in descending order of amount of variance explained.**

| Variable | Beta | SE | P Value | n | Amount of Variance |
|---|---|---|---|---|---|
| Clinical prediction of outcome at one year- Oxford Handicap Scale score* | -4.3024 | 0.447 | <0.0001 | 328 | 22.13% |
| Unable to stand independently | -11.2719 | 1.2126 | <0.0001 | 328 | 20.95% |
| Unable to walk independently | -9.8296 | 1.1073 | <0.0001 | 327 | 19.51% |
| Cortical signs other than dysphasia/dysarthria | -9.7363 | 1.4408 | <0.0001 | 315 | 12.73% |
| TACS | -11.7915 | 1.9014 | <0.0001 | 328 | 10.55% |
| Incontinent of urine since stroke | -10.9802 | 1.8582 | <0.0001 | 328 | 9.68% |
| Oxford Handicap Scale score before stroke* | -3.6225 | 0.6186 | <0.0001 | 328 | 9.52% |
| Mental test score* | 2.3154 | 0.4332 | <0.0001 | 283 | 9.23% |
| Left hemianopia | -11.731 | 2.2197 | <0.0001 | 317 | 8.15% |
| Any motor deficit | -6.3437 | 1.2261 | <0.0001 | 327 | 7.61% |
| Employed until this event | 7.0044 | 1.361 | <0.0001 | 327 | 7.54% |
| Previous stroke with residual disability | -8.4200 | 2.0525 | 0.0001 | 328 | 4.91% |
| Age* | -0.1841 | 0.0463 | 0.0001 | 328 | 4.63% |
| Sensory deficit | -4.9579 | 1.3459 | 0.0003 | 306 | 4.27% |
| POCS | 4.9678 | 1.5063 | 0.0011 | 328 | 3.23% |
| Cerebellar deficit | 5.5806 | 1.8494 | 0.0028 | 315 | 2.83% |
| Eye opening - Glasgow Coma Scale* | 4.7440 | 1.8946 | 0.0128 | 328 | 1.89% |
| Breathless walking on an incline | -3.5113 | 1.5405 | 0.0233 | 325 | 1.58% |
| Diabetes mellitus known before stroke | -4.2199 | 1.867 | 0.0245 | 328 | 1.54% |
| Right hemisphere stroke | -1.9975 | 1.1942 | 0.0954 | 328 | 0.85% |
| Definite brainstem signs | 2.8338 | 2.0657 | 0.1711 | 328 | 0.57% |
| Best verbal - Glasgow Coma Scale* | 0.8131 | 0.6333 | 02001 | 328 | 0.5% |
| Right hemianopia | -2.6636 | 2.1481 | 0.2159 | 318 | 0.48% |
| LACS | 1.4656 | 1.275 | 0.2512 | 328 | 0.4% |
| Lives alone | 1.1081 | 1.245 | 0.3760 | 328 | 0.24% |
| Dysphasia | -1.0434 | 1.4686 | 0.4779 | 321 | 0.16% |
| Angina pectoris known before stroke | 0.7714 | 1.541 | 0.6170 | 328 | 0.08% |
| PACS | 0.5582 | 1.2125 | 0.6456 | 328 | 0.07% |
| Best motor - Glasgow Coma Scale* | 1.3115 | 4.3657 | 0.7641 | 328 | 0.03% |
| Left hemisphere stroke | 0.2969 | 1.1912 | 0.8034 | 328 | 0.02% |
| Alcohol > 2 units daily | 0.4451 | 1.5175 | 0.7695 | 326 | 0.02% |
| Sex (1= male, 2= female) | -0.0347 | 1.1774 | 0.9765 | 328 | 0% |

Note: All variables, except those marked *, are coded '1' if the variable is true for a patient, and '0' if the variable is not true for that patient. Variables marked * are coded as whole numbers. For example Age is coded as the number of years and Oxford Handicap Scale score as 0-6.

All variables were then entered into a backwards linear regression. The maximum variance explained by the regression was 51.35% using 53 variables on 261 patients. From this I developed a model which required six variables for completion.

## Predicting social activity; Model 1 with five variables

Thus the our five variable model predicting participation in social activities explained 36% of the variance in patients' social activities scores at six months, developed from a model using 315 patients (Table 4-20).

**Table 4-20: Results of linear regression analysis of a five variable model predicting patients' participation in social activities.**

| | |
|---|---|
| R Square | 0.35652 |
| Standard Error | 8.67807 |

Analysis of Variance

| | DF | Sum of Squares | Mean Square |
|---|---|---|---|
| Regression | 5 | 12892.98988 | 2578.59798 |
| Residual | 309 | 23270.42599 | 75.30882 |

F = 34.24032 Signif F < 0.0001

| Variable | B | SE B | Variable | B | SE B |
|---|---|---|---|---|---|
| Unable to stand | -8.1691 | 1.3005 | OHS prior to stroke | -2.3786 | .5698 |
| Employed prior to stroke | 4.2917 | 1.2390 | Visuospatial dysfunction | -4.4907 | 1.3715 |
| Any motor deficit | -3.2153 | 1.1027 | (Constant) | 27.5749 | 1.0596 |

The FAI is not designed as a case finding instrument and has no recommended cut-off point. However, a system used by many authors previously (Kettle and Chamberlain, 1989; Schuling et al., 1993; Wade et al., 1985*a*, 1985*b*) divides patients according to no activity (score 0), little activity (score 1-10), moderate activity (score 11-30), major activity (score 31- 45). In terms of identifying patients who might be in need of therapeutic intervention it seemed useful to divided the FAI in a practical way to enable health professionals to group patient should they wish. I chose to group patients with little or no activity as in need of further help and those with moderate or major activity as not in need of further help. Therefore the FAI score was dichotomised using a cut-off of 10/11 to test the case finding ability of our model. Using this cut-off our six variable model correctly categorised 85% of all cases (Table 4-21).

**Table 4-21: The predictive value of a five variable model predicting patients' participation in social activities.**

| | | **Frenchay Activities Index** | |
|---|---|---|---|
| | | **Few social Activities** | **Moderate / Major Activities** |
| **Model 2's Prediction** | **Few social Activities** | 19 | 6 |
| | **Moderate / Major Activities** | 40 | 250 |

**Sensitivity of Model 1 = 0.32**

The proportion of people who will participate in few social activities who are predicted to do so.

**Specificity of Model 1 = 0.98**

The proportion of people who will participate in moderate or major social activity who are predicted to do so.

**Positive Predictive Value of Model 1 = 0.76**

The proportion of people predicted to participate in few social activities who do so.

**Negative Predictive Value of Model 1 = 0.86**

The proportion of people predicted to participate in moderate or major activities who do so.

### *4.3.2.2 Social adjustment.*

As before, each baseline variable underwent a univariate regression with the SAS total score as the dependent variable to determine the amount of variance in patients' social adjustment individual variables could explain (Table 4-22).

**Table 4-22: Univariate regression of baseline variables and Social Adjustment Scale total score at six months in descending order of amount of variance explained.**

| Variable | Beta | Standard Error | P Value | n | Amount of Variance |
|---|---|---|---|---|---|
| Driver in last three months | -0.2069 | 0.0476 | <0.0001 | 320 | 5.61% |
| Current smoker | 0.169 | 0.0455 | 0.0002 | 324 | 4.10% |
| Cerebellar deficit | -0.254 | 0.0706 | 0.0004 | 308 | 4.06% |
| Oxford Handicap Scale score before stroke* | 0.088 | 0.0252 | 0.0006 | 324 | 3.64% |
| Left hemianopia | 0.2771 | 0.0881 | 0.0018 | 313 | 3.08% |
| TACS | 0.229 | 0.0761 | 0.0028 | 324 | 2.74% |
| Breathless walking on an incline | 0.1764 | 0.0600 | 0.0035 | 320 | 2.65% |
| Right hemisphere stroke | 0.1352 | 0.0461 | 0.0036 | 324 | 2.61% |
| Unable to stand independently | 0.1498 | 0.0518 | 0.0041 | 324 | 2.53% |
| Cortical signs other than dysphasia/dysarthria | 0.1667 | 0.0599 | 0.0057 | 309 | 2.46% |
| Clinical prediction of outcome at one year- Oxford Handicap Scale Score* | 0.0478 | 0.0186 | 0.0107 | 324 | 2.01% |
| Any motor deficit | 0.1219 | 0.0492 | 0.0136 | 323 | 1.88% |
| Previous stroke with residual disability | 0.1775 | 0.0813 | 0.0297 | 324 | 1.46% |
| POCS | -0.1239 | 0.0588 | 0.0360 | 324 | 1.36% |
| Diabetes mellitus known before stroke | 0.1458 | 0.0728 | 0.0459 | 324 | 1.23% |
| Age* | -0.0035 | 0.0018 | 0.0538 | 324 | 1.15% |
| Sex (1= male, 2= female) | 0.086 | 0.0458 | 0.0614 | 324 | 1.08% |
| Sensory deficit | 0.0921 | 0.0518 | 0.0764 | 301 | 1.05% |
| Unable to walk independently | 0.0833 | 0.0476 | 0.0813 | 323 | 0.94% |
| Definite brainstem signs | -0.1276 | 0.0803 | 0.1130 | 324 | 0.78% |
| Lives alone | 0.0759 | 0.0485 | 0.1186 | 324 | 0.76% |
| Mental test score* | -0.0258 | 0.0180 | 0.1537 | 280 | 0.73% |
| Incontinent of urine since stroke | 0.1081 | 0.0739 | 0.1442 | 324 | 0.66% |
| Left hemisphere stroke | -0.5912 | 0.0468 | 0.2071 | 324 | 0.49% |
| PACS | -0.492 | 0.0477 | 0.3029 | 324 | 0.33% |
| Alcohol > 2 units daily | 0.0589 | 0.0596 | 0.3238 | 322 | 0.3% |
| LACS | 0.0463 | 0.0499 | 0.3540 | 324 | 0.27% |
| Hypertension - history/treatment at any time | -0.0431 | 0.0463 | 0.3534 | 322 | 0.27% |
| Eye opening - Glasgow Coma Scale* | -0.0645 | 0.0754 | 0.3928 | 324 | 0.23% |
| Dysphasia | -0.0487 | 0.5913 | 0.4110 | 316 | 0.22% |
| Right hemianopia | -0.0579 | 0.0885 | 0.5134 | 314 | 0.14% |
| Angina pectoris known before stroke | -0.0176 | 0.0604 | 0.7707 | 324 | 0.03% |
| Atrial fibrillation known before stroke | 0.0125 | 0.0879 | 0.8869 | 324 | 0.01% |
| Best verbal- Glasgow Coma Scale* | -0.0027 | 0.024 | 0.9118 | 324 | 0% |
| Best motor- Glasgow Coma Scale* | -0.0125 | 0.1257 | 0.9211 | 324 | 0% |

Note: All variables, except those marked *, are coded '1' if the variable is true for a patient, and '0' if the variable is not true for that patient. Variables marked * are coded as whole numbers. For example Age is coded as the number of years and Oxford Handicap Scale score as 0-6.

All variables were then entered into a backward regression analysis which at its optimum, using all variables, explained only 29.16% of variance. The SAS is not a case finding instrument and therefore does not have any published cut-offs with which to categorise patients. However, as the need in clinical settings may be to identify patients at whom therapeutic interventions may be targeted, I thought it useful to attempt to identify patients at risk of more severe social maladjustment. I defined maladjustment as a score higher than one standard deviation above the mean, i.e. 2.2 or above. My attempts at creating a short practical model which would explain much of the variance in patients' SAS total score were not fruitful, reflecting the finding that even including all variables little of the variance could be explained. All models that were developed and appeared to explain some of the variance in patients' SAS scores on closer inspection were simply categorising all patients as not being cases of maladjustment, that is not scoring more than one standard deviation above the mean. As such models are of no clinical or descriptive use they are not reported here.

### 4.3.3 Previous studies of variables that predict psychosocial outcome.

Studies attempting to predict outcome after stroke continue to use a broad range of variables, measures of mood outcome and statistical methods, making comparison difficult (Table 4-23). Four of these studies have conducted univariate analyses, either non-parametric tests or univariate correlations. (Astrom et al., 1993; Robinson et al., 1985*a*; Schwartz et al., 1993; Wade and Hewer, 1986), thus only finding that a relationship exists rather than attempting to define this relationship. Some definition of the relationships was gained in the remaining two studies which used multivariate analyses (Eastwood et al., 1989; Thompson et al., 1989).

A previous psychiatric history is the variable most often examined with two studies reporting it to be a significant predictive variable, one using univariate and one multivariate analysis (Eastwood et al., 1989; Schwartz et al., 1993) and one finding no association using univariate analyses (Astrom et al., 1993). ADL at the time of assessment (but this was three days to ten years after stroke) was found to be a significant predictor by Robinson et al. (1985*a*) using univariate analysis, but only for patients with right hemisphere lesions by Eastwood (1989) using multivariate analysis, and not to be significant at all by Astrom (1993) using univariate analysis. Similarly, Eastwood (1989) found a previous stroke to be a significant predictor of depression in right hemisphere lesion patients only, using multivariate analysis and this was also reported by Thompson (1989) using both univariate and multivariate analysis. Eastwood's (1989) preponderance of findings applicable only to right hemisphere lesions may be a result of the much larger proportion of right hemisphere strokes in his sample (n=27 right hemisphere strokes, n=11 left hemisphere strokes). Both living alone prior to stroke and mini mental state score were found to be significant predictors in single studies using univariate analyses (Astrom et al., 1993; Robinson et al., 1985*a*) and age was found not to be a significant predictor in three studies also using univariate analyses (Thompson et al., 1989; Astrom et al., 1993; Wade and Hewer, 1986).

These studies all profess to be examining factors which predict mood outcome. In stroke it would be most useful to be able to use variables available at onset or during acute hospitalisation to predict future outcome. It is therefore surprising that four of these studies (Robinson et al., 1985*a*; Schwartz et al., 1993; Thompson et al., 1989; Wade and Hewer,

1986) have not adopted a methodology whereby patient data is collected at the acute stage and patients followed up at a set time post stroke. Robinson et al. (1985) did conduct follow ups at a specific time after an initial assessment, but their initial assessments were not at the acute stage of patients' strokes. They were between three days and ten years post onset. It is therefore difficult to apply Robinson's findings to the prediction of acute stroke patients' later outcome. Schwartz (1993), Thompson (1989) and Wade (1986) only did one assessment of patients but collected information that would have been available to the examining physician at onset. However, again these assessments (combined baseline and follow up) did not occur at a specific time post stroke but up to six months which appears reasonable (Wade and Hewer, 1986), 60 months (Thompson et al., 1989) or 103 months (Schwartz et al., 1993) which appear less reasonable. These are better than the Robinson's (1985*a*) study because the results are still relevant to the prediction of how acute stroke patients will fare, but it is just not clear at what stage post stroke the predictive variable is related to outcome. Alternatively one might conclude that their results are generalisable over a long period post stroke.

My literature search identified only two studies which specifically attempted to predict social functioning of any definition after stroke (Table 4-24). The first by Robinson et al. (1985*a*) was part of the study just discussed and therefore suffers from the same difficulties associated with baseline measures taken at a broad range of time post stroke. Robinson et al. (1985*a*) found that patients' level of depression, mini mental state score and their physical functioning at time of initial assessment predicted their level of depression six months later. For some of these patients who were many years post stroke these results may simply reflect patient stagnation, that they were experiencing very little change over time.

Wade and Hewer (1986) again assessed their patients only once, and found age to be significantly associated with social activity participation in a univariate analysis. Their study is included in this section because age is a variable known at onset.

### 4.3.4 Discussion

We have developed three models, two to predict which patients are likely to suffer mood disorders and one that predicts which patients are likely to participate in few social activities at six months after stroke. Each model was developed on a well described inception cohort, using all clinically relevant data that is easily available in the period immediately after stroke onset. The use of arbitrary thresholds in predictive data was avoided, each item of data was defined clearly to aid generality of use and the internal structures of the model made clear. Our first model predicting mood with six variables had moderate specificity and low sensitivity, suggesting that it would both fail to identify many patients in need of further assessment and incorrectly identify some patients as in need of further assessment when they were not. Our two remaining models possess high specificity, that is the patients they identify as likely to be in need of a therapeutic intervention are highly likely to be genuine cases of need. However, this is at the cost of a low sensitivity, that is, both models are likely to fail to identify a proportion of patients who will be in need of further assistance. These two models would therefore not be useful in a 'catch all' screening situation but might be more suited to a clinical setting where resources for further intervention were limited and health professionals would wish patients identified to be highly likely of needing further assessment or intervention even if this were at the cost of missing some patients in difficulty (refer to 2.7.2.3.).

The clinical utility of our models is far from proved. For our models to be useful their predictive accuracy would have to be greater than the predictions of the health professionals that may wish to use them. In addition, models should be easy to calculate. The ease with which our models could be calculated would be increased if the number of decimal places used were reduced but the formulae are unlikely to be committed to memory and would at least require paper and pencil. Finally by testing the models on the same sample from which they were developed we have risked a 'self fulfilling prophecy'. These models should now be tested on an independent sample to further examine their ability as case finders. As little previous research had been conducted in the field, we possessed no clear starting point from which to work, but we hope that our results may provide such a starting point for others.

Our results are also useful in providing us with further clues to the aetiology of mood disturbance and social limitations after stroke. Our two models predicting mood included variables indicating stroke severity (any motor deficit, unable to stand, and TACS), and lesion location (TACS), the latter supporting further the results of our examination of the physiological correlates of mood. Our model predicting participation in social activities also includes variables indicating the stroke's severity (any motor deficit and unable to stand) in addition to the patients pre-stroke functioning (pre-stroke OHS and employment status).

Our attempt at creating prognostic models of psychosocial outcome may be more successfully used for a different purpose. They might provide clues that will allow the successful adjustment for casemix in cohorts whose psychosocial outcomes are being compared. The increasingly competitive nature of the National Health Service means that the comparison of patient outcomes across different centres is becoming more common and the attention of purchasers and providers is beginning to turn to patients' psychosocial outcome. Little research has previously been conducted on factors which contribute to patients' psychosocial outcome but if the outcomes of different cohorts of patients are to be compared an increasing knowledge of this area will be necessary to allow the successful statistical adjustment for casemix. That is to allow the difference in relevant baseline factors between groups to be taken into account when their eventual outcomes are being compared. Our results may provide a starting point for those wishing to establish precisely which baseline factors are relevant.

**Table 4-23: Previous studies of variables predicting mood outcome after stroke.**

| Author & Year | Patients | Time of Follow up | Baseline Predictor of Mood | Description & Significance |
|---|---|---|---|---|
| Astrom et al. (1993) | n = 76<br>Consecutive admissions to hospital stroke unit | Hospital Discharge | | Non-parametric test<br>Interview DSM III<br>-Major depression |
| | | | Lived alone pre-stroke | p=0.028 |
| | | | Dysphasic | p =0.001 |
| | | | Social network variables | p = NS |
| | | | Psychiatric history | p = NS |
| | | | Age | p = NS |
| | | | Sex | p = NS |
| | | | ADL | p = NS |
| Eastwood et al. (1989) | n = 187<br>Hospital inpatients | 4 months post entry or at discharge | | ANOVA |
| | | | Psychiatric History | HDRS: p= 0.035 |
| | | | Interaction between side of lesion & history of CVA | GDS: p=0.035 |
| | n = 27 RHL | | RHL- History of CVA | GDS: p=0.009 |
| | n = 11 LHL | | LHL -Interaction between functional disability & psychiatric history | p=0.001 |
| | n = 25 No reported psychiatric history | | If no psychiatric history then Functional disability significant | p=0.045 |
| | | | Controlling for time since stroke- on functional disability, previous CVA. | ANOVA<br>Excluding above for all p = NS. |

DSM= Diagnostic and Statistical Manual of Mental Disorders; HDRS= Hamilton Depression Rating Scale; GDS= Geriatric Depression Scale; ANOVA= Analysis of Variance; CVA= Cerebrovascular Accident; LHL= Left Hemisphere Lesion; RHL= Right Hemisphere Lesion; NS= Not significant; ADL= Activities of Daily Living.

**Table 4-23. continued**

| **Author & Year** | **Patients** | **Time of Follow up** | **Baseline Predictor of Mood** | **Description & Significance** |
|---|---|---|---|---|
| Robinson et al. (1985*a*) | n = 30<br>Randomly selected from stroke clinic and data bank<br>3 days - 10 years.<br>Mean 2 years post stroke | 6 months | | Univariate correlations Mean PSE/SDS/HDRS |
| | | | Intellectual functioning (MMS) | p<0.01 |
| | | | Physical functioning (JHFI) | p< 0.01 |
| | | | Depression - mean PSE/SDS/HDRS | p<0.01 |
| | | | Social Functioning | p = NS |
| Schwartz et al. (1993) | n = 91 male rehabilitation patients | 1-103 months, median 2 months | | Chi Square |
| | | | History of depression | HDRS =>18: p<0.005 |
| Thompson et al. (1989) | n = 40 volunteers - therapy outpatients | 1 - 60 months, mean 9 months. | | Univariate correlation |
| | | | Previous stroke | p<0.05 |
| | | | Age | p = NS |
| | | | | Multiple regression |
| | | | Months since stroke | p < 0.01 |
| | | | 1st or 2nd stroke | p < 0.03 |
| | | | Age | p = NS |
| | | | Site of stroke | p = NS |
| | | | Physical functioning | p = NS |
| | | | Cognitive functioning | p = NS |
| | | | Financial stress | p = NS |
| Wade & Hewer, (1986) | n = 544 | Within 6 months | | Univariate correlation |
| | | | Age | WDI: p = NS |

MMS= Mini Mental State; NS= Not significant; PSE= Present State Examination; SDS= Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale; JHFI= John Hopkins Functional Inventory; WDI= Wakefield Depression Inventory.

**Table 4-24: Previous studies predicting social functioning after stroke.**

| **Author & Year** | **Patients** | **Time of Follow up** | **Baseline Predictor of Social Functioning** | **Description & Significance** |
|---|---|---|---|---|
| Robinson et al. (1985*a*) | n = 30<br>Randomly selected from stroke clinic and data bank<br>3 days - 10 years mean 2 years post stroke | 6 months | Depression (mean value for PSE, SDS, HDRS) | p<0.01 |
| | | | Intellectual functioning (MMS) | p< 0.01 |
| | | | Physical functioning (JHFI) | p<0.05 |
| Wade & Hewer, (1986) | n = 544 | Within 6 months | Age | Univariate correlation<br>FAI: p<0.01 |

PSE= Present State Examination; SDS= SDS Self Rating Depression Scale; HDRS= Hamilton Depression Rating Scale; MMS= Mini Mental State; JHFI= John Hopkins Functional Inventory; FAI= Frenchay Activities Index.

# 5. A randomised trial of a Stroke Family Care Worker

Identifying which patients are likely to experience poor psychosocial outcome will serve little purpose if no effective preventative or alleviating therapeutic interventions exist to improve their outcome. We attempted to assess the efficacy of one such intervention that has recently been increasing in popularity, a Stroke Family Care Worker (SFCW).

The design chosen for the study was that of a randomised controlled trial to be analysed on an intention-to-treat basis. Randomised trials randomly allocate individual patients to intervention and control groups, and look for quantitative differences between groups rather than qualitative differences between individuals. Analysing between group differences reduces the need for individual patients to be similar, instead relying on large numbers and strict randomisation to ensure *groups* are comparable at baseline. Randomisation allows variables that a priori are thought to influence outcome to be evenly distributed between treatment and control groups, using either stratification or minimisation, so that any difference between groups at follow up should be due to the intervention. Analysis on an intention-to-treat basis measures the result of being allocated to an intervention despite the fact that any treatment effect may be diluted by patients choosing to withdraw from the intervention group; i.e. treatment group patients who 'cross over', that is refuse the intervention, remain in the treatment group for the purpose of analysis. The purpose of intention-to-treat analysis is to prevent the 'cross over' of patients from one group to another disturbing the randomisation and perhaps creating dissimilar groups which are no longer comparable. This appeared particularly relevant in the present study where we were attempting to assess the impact of the SFCW in a normal working environment. In normal circumstances some patients would choose not to receive her service and it was important that this be taken into account when assessing her effectiveness. In order to reduce chance between-group differences trials rely on the randomisation of large numbers of patients and thus require the broad eligibility criteria which we adopted. This maximises the generalisability of results but risks obscuring effects in subgroups. It is therefore necessary to collect baseline data to allow subgroup analysis. Randomised trials have been described as 'the gold standard for effectiveness studies on group interventions by protocol' (Raphael, 1977).

This was an exploratory study using a broad range of outcomes to examine the effect of one SFCW in one centre. Its results are therefore of limited generalizability. We aimed to randomise a large number of patients using broad eligibility criteria because the type of patient most likely to benefit was unknown and we did not wish to exclude more patients than necessary.

## 5.1 Randomisation.

Patients who met the eligibility criteria (refer to 2.4) were randomised using a specialised computer program in blocks of six. Randomisation was stratified according to age, sex, whether living alone prior to stroke and stroke severity, all collected routinely as part of the Lothian Stroke Register. Our measure of stroke severity was whether patients were predicted by the physician at their initial assessment to have, at one year after stroke, an Oxford Handicap Scale of less than, or equal to or greater than, three. This was a crude but unbiased measure which proved to have good sensitivity (0.6) and specificity (0.9) (Table 5-1). This somewhat unconventional measure of severity was adopted as all other measures of severity available at baseline were dependent on the time of assessment and because there is no widely accepted method of measuring global 'severity' of stroke. The initial assessment took place a median of 51 hours (range 2 to 576 hours) after the initial onset of symptoms, so that a uniform collection of an alternative baseline measure of severity was not possible.

**Table 5-1: Cross-tabulation of predicted and actual Oxford Handicap Scale score at one year after stroke.**

| | | **Outcome at one year** | |
|---|---|---|---|
| | | *Independent* | *Dependent* |
| **Clinical Prediction** | *Independent* | 184 | 78 |
| | *Dependent* | 23 | 116 |

Sensitivity = 0.6
Specificity = 0.9
Accuracy = 0.7
Note: Data at one year was missing for 16 patients.

These stratification criteria were chosen to achieve a balance between treatment and control groups for important variables. Increased age has been associated with reduced potential for recovery of both physical and psychological functioning (Wade and Hewer, 1986; Alexander, 1994; Ahlsio et al., 1984) and gender may be associated with survival and gains from rehabilitation (Wood Dauphinee et al., 1984). Living alone versus not was a criterion as we wished to have a similar number of carers in the treatment and control groups and the presence of other persons in the home might have a therapeutic effect in its own right or dilute any possible treatment effect. An equal distribution of patients living alone was needed in each group should the SFCW's effect be mediated by the presence of others in the home. Stroke severity has a direct effect on functional recovery, in turn affecting patients' ability to resume social activities and increasing their risk of depression (O'Rourke and Dennis, 1995; Ahlsio et al. 1984).

A member of the Lothian Stroke Register (LSR) team, Marion Livingston (ML), was responsible for the collection of 'new' stroke assessment forms on a weekly basis and co-ordinated their entry into a computerised database. A table with random patient allocation was stored on a PC so that persons involved in randomising patients could not find out to which intervention the next patient would be allocated. ML then ran the randomisation programme, recorded treatment allocation and gave copies of the initial assessment forms of patients allocated to the treatment group to the SFCW and all those entered into the trial to myself. Copies of the initial assessment forms contained a box to be ticked if the patient was suitable for randomisation; they contained no further reference to the SFCW and no indication to which group the patient had been allocated.

### Assessor Blinding

The omission of treatment allocation on assessment forms was part of a policy to keep me blind to the treatment allocation of patients. To this end departmental staff were made aware of the need to avoid discussion of randomised patients in my presence and the SFCW and myself did not discuss the trial or patients we had seen. At no time did I have any part in, or access to, the randomisation process. In order to prevent me being unblinded during the assessment of patients, a very structured interview was devised, using standardised measures to help prevent undirected conversation. Questions on satisfaction with treatment and services received were left for patients to complete independently as discussion of such areas was thought highly likely to lead to unbinding.

Despite such efforts some unblinding did take place. On at least three occasions I was unblinded by departmental staff either unwittingly or because they thought it necessary and unavoidable. On a number of further occasions patients unblinded me to their treatment allocation in various ways, including asking if the SFCW and I would like to combine our visits, recalling the SFCW's contact with them, or having her contact card on display. Approximately three months into the study it was decided I should record a 'forced choice' at the end of each assessment and record whether I thought the patient was in the treatment or control group. Analysis of these data, on 312 patients, shows that I guessed correctly in 59% (p=0.002) of cases, significantly more than predicted by chance. Such results may have been avoidable if patients had been asked to avoid mentioning the SFCW, however this would only have been possible if patients were aware of the trial, a situation which may have led to a false positive trial result (refer to 2.4.). While such a result is not perfect it reflects the difficulties of conducting a blinded, randomised trial of an intervention that may have a very pervasive effect of the life of a patient and that must be assessed by a long and in-depth interview which of necessity must discuss areas the intervention may have influenced.

## 5.2 Comparison of baseline variables in treatment vs control groups.

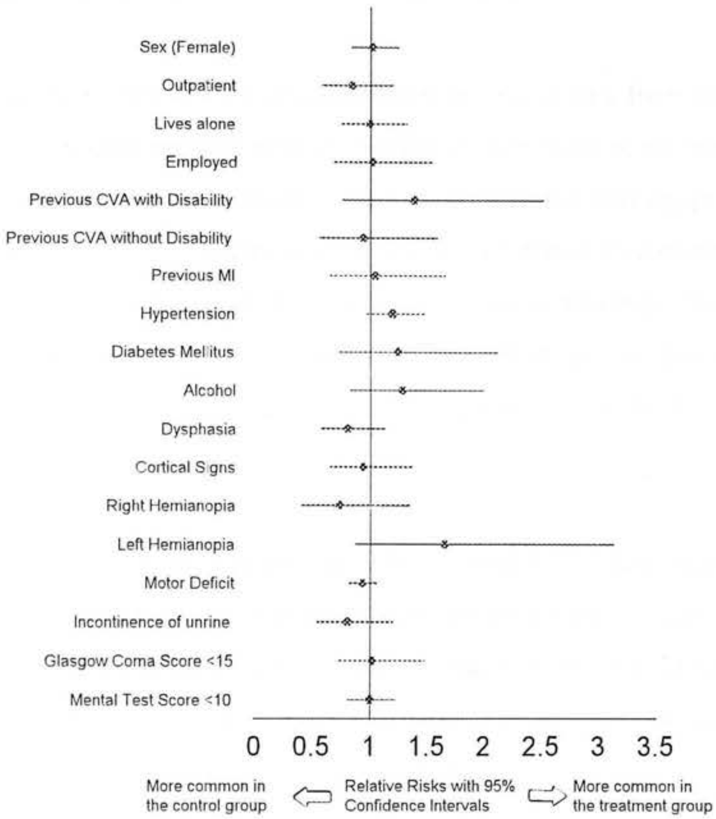
Of the 417 patients randomised, 210 were randomised to receive treatment from the SFCW and 207 to avoid contact. At baseline there were no significant differences between treatment and control groups with regard to many social, medical history or neurological examination variables (Table 5-2, Figure 5-1). We observed a non-significant trend for treatment group patients to be more likely to have had a previous stroke with disability or to have a left hemianopia (Figure 5-1).

**Table 5-2: Comparison of baseline data in treatment and control groups.**

| **Baseline Variables** | | **Number of Patients With Variable** | | **Relative Risk** | **Confidence Intervals** | **P Value** |
|---|---|---|---|---|---|---|
| | | **Treatment (n=210)** | **Control (n=207)** | | | |
| Site of Lesion | Right hemisphere | 84 | 85 | 0.97 | 0.77 - 1.23 | 0.83 |
| | Left hemisphere | 90 | 92 | 0.96 | 0.78 - 1.2 | 0.74 |
| | Brainstem / Cerebellum | 33 | 28 | 1.16 | 0.73 - 1.85 | 0.53 |
| | Uncertain | 3 | 2 | 1.48 | 0.25 - 8.76 | 0.66 |
| Stroke Classification | | | | | | |
| Total Anterior Circulation Infarct | | 34 | 30 | 1.12 | 0.71 - 1.76 | 0.63 |
| Partial Anterior Circulation Infarct | | 78 | 83 | 0.93 | 0.73 - 1.18 | 0.54 |
| Lacunar Infarct | | 54 | 53 | 1.00 | 0.72 - 1.39 | 0.98 |
| Posterior Circulation Infarct | | 39 | 28 | 1.37 | 0.88 - 2.14 | 0.16 |
| Uncertain | | 5 | 13 | 0.38 | 0.14 - 1.04 | 0.05 |
| Oxford Handicap Scale (OHS) Score at Initial Assessment | OHS of 0 | 77 | 81 | 0.94 | 0.73 - 1.2 | 0.60 |
| | OHS of 1 | 68 | 64 | 1.05 | 0.79 - 1.39 | 0.75 |
| | OHS of 2 | 44 | 43 | 1.01 | 0.69 - 1.47 | 0.96 |
| | OHS of 3 | 21 | 18 | 1.15 | 0.63 - 2.09 | 0.65 |
| | OHS of 4 | 0 | 1 | 0 | 0 - 6.26 | 0.31 |
| Clinical Prediction of OHS at 1 Year | OHS of 0 | 19 | 16 | 1.17 | 0.62 - 2.21 | 0.63 |
| | OHS of 1 | 75 | 71 | 1.04 | 0.8 - 1.35 | 0.76 |
| | OHS of 2 | 46 | 45 | 1.15 | 0.8 - 1.66 | 0.97 |
| | OHS of 3 | 42 | 46 | 0.9 | 0.62 - 1.31 | 0.58 |
| | OHS of 4 | 12 | 15 | 0.79 | 0.38 - 1.64 | 0.52 |
| | OHS of 5 | 1 | 2 | 0.49 | 0.05 - 5.39 | 0.55 |
| | OHS of 6 | 15 | 12 | 1.23 | 0.59 - 2.57 | 0.58 |
| | **Group** | **Mean** | **Median** | **Range** | **P Value** | |
| Age | Treatment | 67.1 | 69.4 | 18 - 90 | 0.33 | |
| | Control | 68.4 | 69.8 | 29 - 92 | | |

Relative Risks of more than 1 indicate a greater likelihood of the variable occurring in the treatment group.

**Figure 5-1: Comparison of baseline variables in treatment and control group patients.**



Note: An almost equal relative risk between treatment and control groups for the variables; sex and lives alone are to be expected because these were variables on which patients were stratified. CVA= Cerebrovascular Accident; MI= Myocardial Infarction.

## 5.3 The intervention.

The role of the SFCW was to adapt to meet the needs of each individual patient and their family. The number and length of contacts were not specified in order to reflect the real working of such a post.

The SFCW gave information and counselling about a wide variety of topics including home care, aids and adaptations, housing, diet, benefits, support groups and the like. Our SFCW came from a social work background and had considerable experience working for voluntary agencies for the disabled. In her previous work in Edinburgh she had accumulated extensive knowledge concerning local resources in the community. Patients who were randomised to our intervention were contacted by our SFCW within one week of randomisation. She would access health services, social services and voluntary agencies as well as offering some counselling herself.

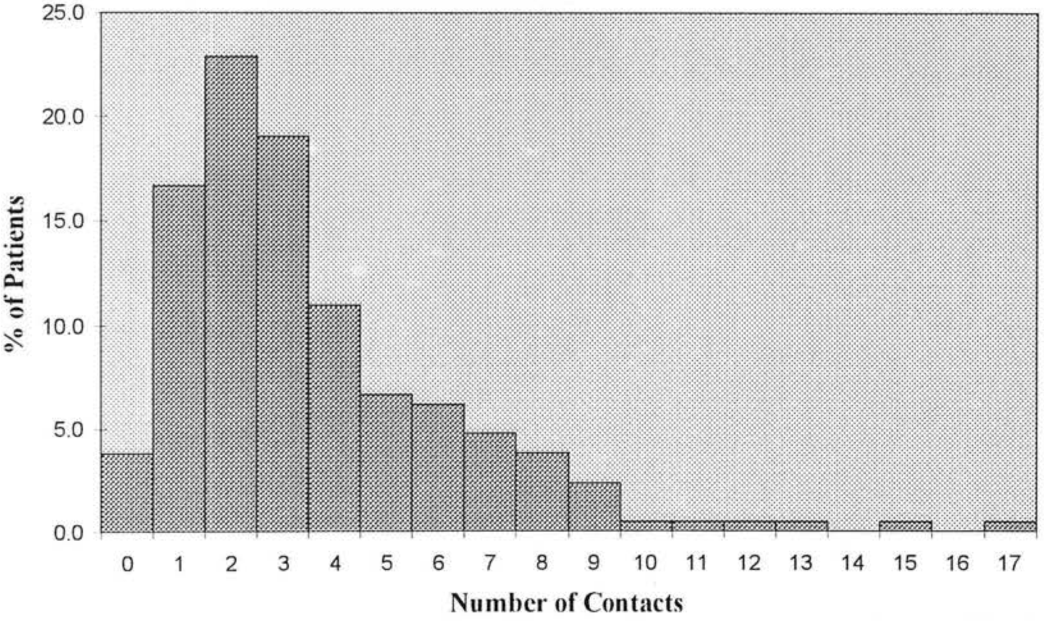
Those patients who were not randomised to receive care from the SFCW were not contacted and she endeavoured to have no interaction with them on the wards, which she reported she managed, albeit with difficulty. After the six month follow up, patients I thought were in need of her services were referred to the SFCW. I referred 56 patients to the SFCW at 6 months, 52 from the control group and four from the treatment group. The small number of treatment group patients referred to the SFCW in part reflects the fact that many patients, when referral was suggested, acknowledged that they already knew the SFCW and would contact her themselves.

Our SFCW kept detailed records of her intervention. Three databases were designed for this purpose, in the first of which she recorded all patient contacts, the method of contact, for example letter or home visit, and the time taken. In the second she recorded the content of the contact which included the topics discussed (e.g. day-care) and the actions taken (e.g. referral for day-care). The third database included records of all patient referrals including the agency to which referrals had been made. The purpose of this data collection was to allow detailed description of the intervention to facilitate discussion of its effect. The following description is the result of analyses of these databases. A note of caution should be sounded however. Our SFCW endeavoured to record her actions as accurately as possible but the daily practicality of such a post meant that she did not take notes taken during patient contacts and data recording was not always a priority, sometimes being completed some days after the contact had taken place. Thus the following description of our SFCW's intervention provides a guide to, rather than an exact record, of her work.

### *5.3.1 Number of contacts.*

Our SFCW contacted 202 of the 210 patients who were randomised to receive her input. Six of the eight patients with whom she did not make contact were suffering extreme ill health and died in hospital a mean of 27 days after their strokes. Two patients were found to be suffering brain tumours, rather than strokes, one of whom died prior to the six month assessment, and one shortly afterwards being too ill for assessment at time of follow-up. Patients who received no contact from the SFCW remained in the treatment group during our analysis due to our adoption of an intention-to-treat method (refer to 5.0.). The number of SFCW contacts for each patient is illustrated in Figure 5-2.

**Figure 5-2: The number of Stroke Family Care Worker contacts per patient with descriptive statistics.**

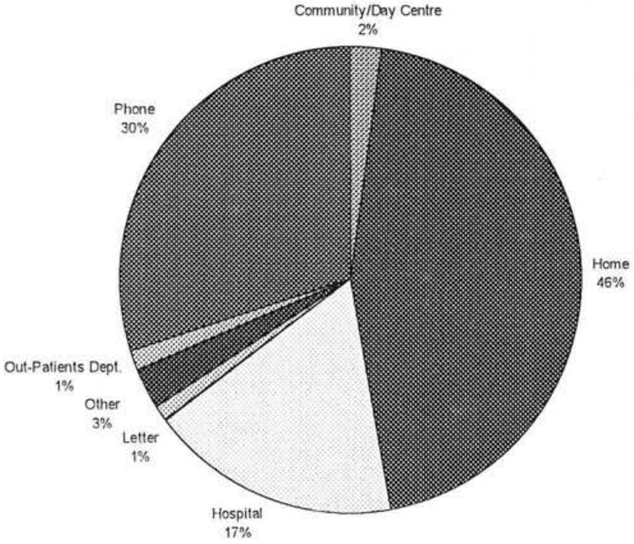


| No. of Patients | No. of Contacts | Mean | Median | Range |
|---|---|---|---|---|
| 210 | 748 | 3.6 | 3 | 0 - 17 |

### *5.3.2 Type of contact.*

The majority of contacts involved the SFCW visiting, (46%), or telephoning, (30%), the patient and family at their home or visiting patients on the ward prior to discharge, (17%) (Figure 5-3).

**Figure 5-3: Stroke Family Care Worker method or place of contact with treatment group families.**



However, it is likely that the number of hospital contacts recorded is an underestimate as accurate recording of contact in the ward was impractical.

### *5.3.3 Content of contact; counselling and information given.*

Our SFCW endeavoured to complete a checklist of topics discussed during each patient contact. Table 5-3 represents a summary of this record illustrating the large number and diversity of patients' and carers' concerns and the relative frequency with which these occurred.

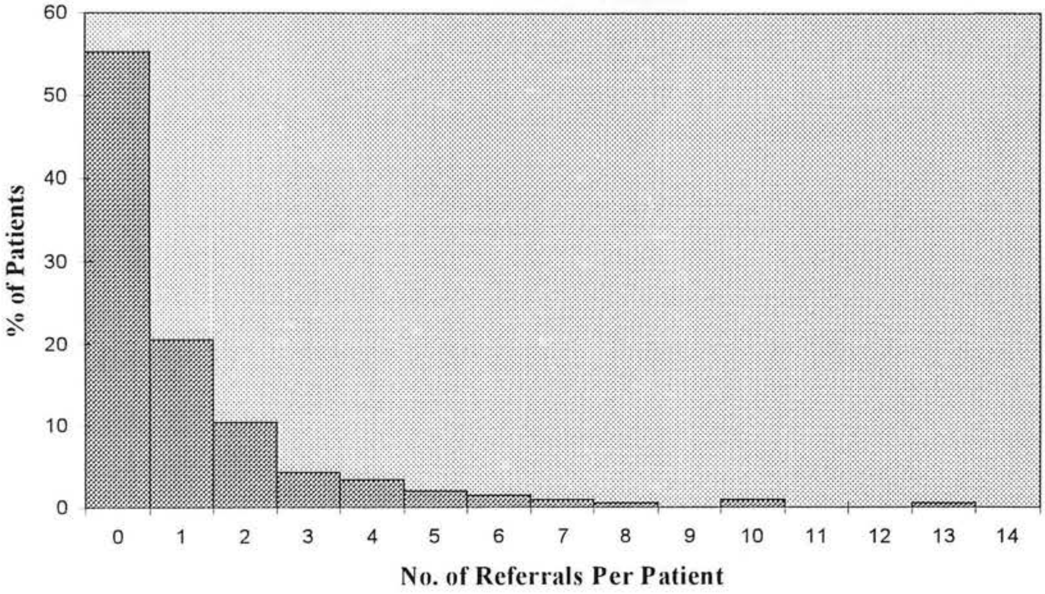
**Table 5-3: Topics of information and counselling given and proportion of time spent on each.**

| Topic Discussed by SFCW with Patient | No. of Times Discussed | % of Topics Discussed | Average no. of Times Discussed with Patient |
|---|---|---|---|
| Health | 659 | 15.5 | 3.3 |
| Information | 559 | 13.1 | 2.8 |
| Activity | 410 | 9.6 | 2.0 |
| Home care | 325 | 7.6 | 1.6 |
| Therapy | 301 | 7.1 | 1.5 |
| Day-care | 246 | 5.8 | 1.2 |
| Counselling | 231 | 5.4 | 1.1 |
| Benefits | 208 | 4.9 | 1.0 |
| Housing | 166 | 3.9 | 0.8 |
| Equipment | 156 | 3.7 | 0.8 |
| Transport | 140 | 3.3 | 0.7 |
| Voluntary organisations | 105 | 2.5 | 0.5 |
| Diet | 75 | 1.8 | 0.4 |
| Respite | 66 | 1.5 | 0.3 |
| Support groups | 46 | 1.1 | 0.2 |
| Carer-discussion with | 567 | 13.3 | 2.8 |

### 5.3.4 Referrals.

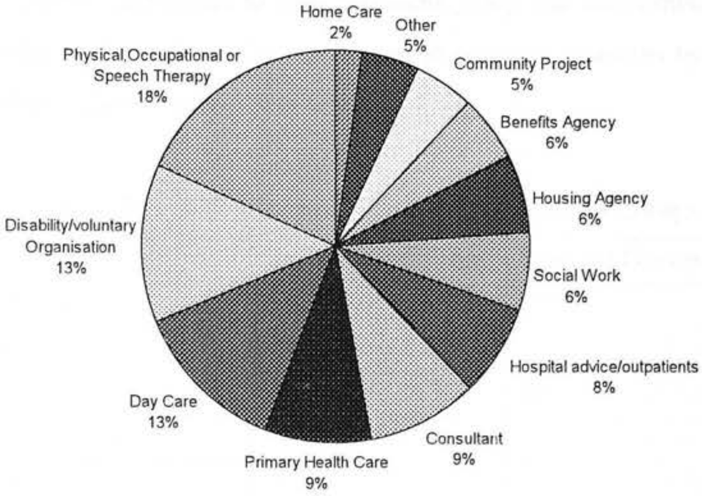
Our SFCW referred almost one half of patients to specialist outside agencies, (Figure 5-4), including a variety of professional, medical and voluntary organisations (Figure 5-5).

**Figure 5-4: The number of referrals to other agencies per patient instigated by the Stroke Family Care Worker with descriptive statistics.**



| No. of Patients | No. of Referrals | Mean | Median | Range |
|---|---|---|---|---|
| 210 | 235 | 1.1 | 0 | 0 - 13 |

**Figure 5-5: Agencies to which patients were referred by the Stroke Family Care Worker.**



| n | No. of Referrals | Mean no. of Referrals | Median no. of referrals | Range |
|---|---|---|---|---|
| 94 | 235 | 2.5 | 2 | 1 - 13 |

## 5.4 Follow up.

The number of patients randomised to each treatment group and the number assessed at six months is illustrated in Table 5-4. The completion of outcome measures by patients in each treatment allocation is illustrated in Table 5-5.

**Table 5-4: Distribution of patients between treatment and control groups.**

| | Treatment Group | | Control Group | | Total | |
|---|---|---|---|---|---|---|
| **Originally randomised** | 210 | | 207 | | 417 | |
| **Patients dead at six months** | 19 | (9%) | 22 | (11%) | 41 | (10%) |
| **Patients alive at six months** | 191 | (91%) | 185 | (89%) | 376 | (90%) |
| **Patients lost to follow up** | 4 | (2%) | 0 | (0%) | 4 | (1%) |
| **Assessed at six months (Primary Patient Questionnaire)** | 187 | (89%) | 185 | (89%) | 372 | (89%) |
| **Secondary Patient Questionnaire** | 145 | (69%) | 147 | (71%) | 292 | (70%) |

**Table 5-5: Numbers of patients completing each measure, treatment vs. control.**

| **Measure** | **Treatment Group** | | | | |
|---|---|---|---|---|---|
| | **Attempted** | **Not Assessable** | **Incomplete or missed** | **Complete n** | **%** |
| Frenchay Activities Index | 187 | 16 | 7 | 164 | 88 |
| General Health Questionnaire | 187 | 20 | 11 | 156 | 83 |
| Social Adjustment Scale | 187 | 23 | 0 | 164 | 88 |
| Barthel Index | 187 | 0 | 0 | 187 | 100 |
| Oxford Handicap Scale | 187 | 0 | 3 | 184 | 99 |
| Mental Adjustment to Cancer Scale | 145 | 0 | 32 | 113 | 78 |
| Hospital Anxiety and Depression Scale | 145 | 0 | 17 | 128 | 88 |
| Patient Satisfaction Scale | 145 | 0 | 42 | 103 | 71 |
| Services Received Questionnaire | 145 | 0 | 10-18 | 129-137 | 89-95 |
| Equipment Received Questionnaire | 145 | 0 | 11-23 | 124-136 | 86-95 |
| **Measure** | **Control Group** | | | | |
| | **Attempted** | **Not Assessable** | **Incomplete or missed** | **Complete n** | **%** |
| Frenchay Activities Index | 185 | 17 | 4 | 164 | 89 |
| General Health Questionnaire | 185 | 21 | 10 | 154 | 83 |
| Social Adjustment Scale | 185 | 25 | 0 | 160 | 86 |
| Barthel Index | 185 | 0 | 3 | 182 | 99 |
| Oxford Handicap Scale | 185 | 0 | 1 | 184 | 99 |
| Mental Adjustment to Cancer Scale | 147 | 0 | 27 | 120 | 82 |
| Hospital Anxiety and Depression Scale | 147 | 0 | 23 | 124 | 84 |
| Patient Satisfaction Scale | 147 | 0 | 52 | 95 | 65 |
| Services Received Questionnaire | 147 | 0 | 4-16 | 131-143 | 89-97 |
| Equipment Received Questionnaire | 147 | 0 | 5-11 | 136-142 | 93-97 |

## 5.5 Results of outcome measures.

### *5.5.1 Survival and physical functioning.*

The relative risk of patients being either 'dead' or 'dead or dependent' at six months in either the treatment or control groups was calculated (Table 5-6).

**Table 5-6: The relative risk of patients being dead, or dead or dependent, at six months according to treatment allocation.**

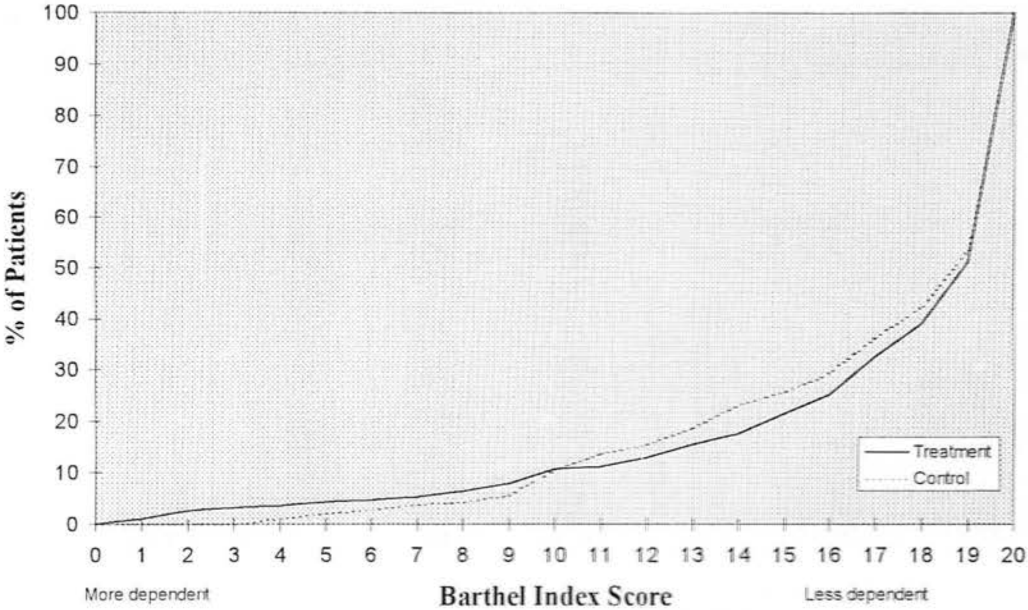
| | | n | % | Relative Risk | 95% Confidence Intervals |
|---|---|---|---|---|---|
| **Dead (n=417)** | **Treatment** | 19 | 9% | 0.85 | 0.48 - 1.53 |
| | **Control** | 22 | 10.6% | | |
| **Dead or dependent (n=412)** | **Treatment** | 108 | 26.2% | 0.98 | 0.81 - 1.19 |
| | **Control** | 110 | 26.7% | | |

Two measures of patients' physical functioning were taken during the six month follow up using the Barthel Index and the Oxford Handicap Scale.

### The Barthel Index

Patients' Barthel scores were treated as a continuous variable (i.e. no cut-off was used) and analysed using the Mann-Whitney U statistic, a distribution free, non-parametric, statistic analysing differences in central tendencies. Treatment and control groups possessed identical medians and there was no statistically significant difference between groups (p=0.50; Figure 5-6).

Figure 5-6: Comparative cumulative distribution of treatment and control group Barthel Index at six months with descriptive statistics.



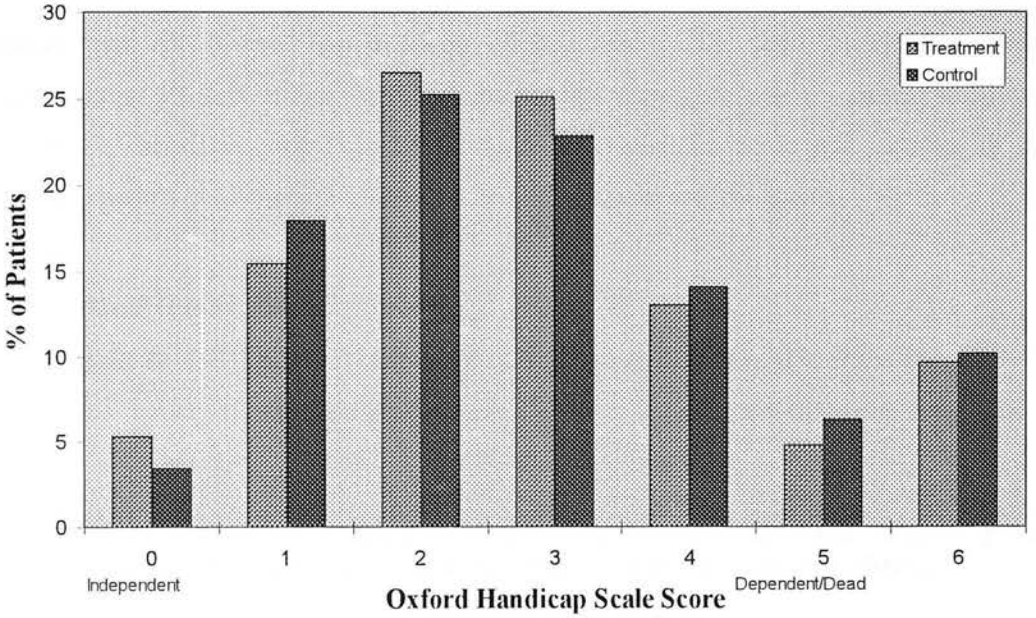
| P value = 0.56 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 187 | 17.2 | 19.0 | 1 - 20 |
| Control Group | 182 | 17.1 | 19.0 | 4 - 20 |

Note: P value attained using Mann-Whitney U analysis.

### The Oxford Handicap Scale

Patients' Oxford Handicap Scale illustrated a similar distribution between treatment and control group patients, with almost identical descriptive statistics and no significant difference when analysed as a continuous variable (Figure 5-7). Patients classified as 'six' on the OHS were deceased at time of follow up.

**Figure 5-7: Comparative distribution of treatment and control group patients' Oxford Handicap Scale at six months with descriptive statistics.**



| **P value = 0.71** | **No. of Patients** | **Mean** | **Median** | **Range** |
|---|---|---|---|---|
| Treatment Group | 207 | 2.8 | 3 | 0 - 6 |
| Control Group | 206 | 2.9 | 3 | 0 - 6 |

Note: P value attained using Mann-Whitney U analysis. For a listing of OHS categories refer to 2.7.1.1.

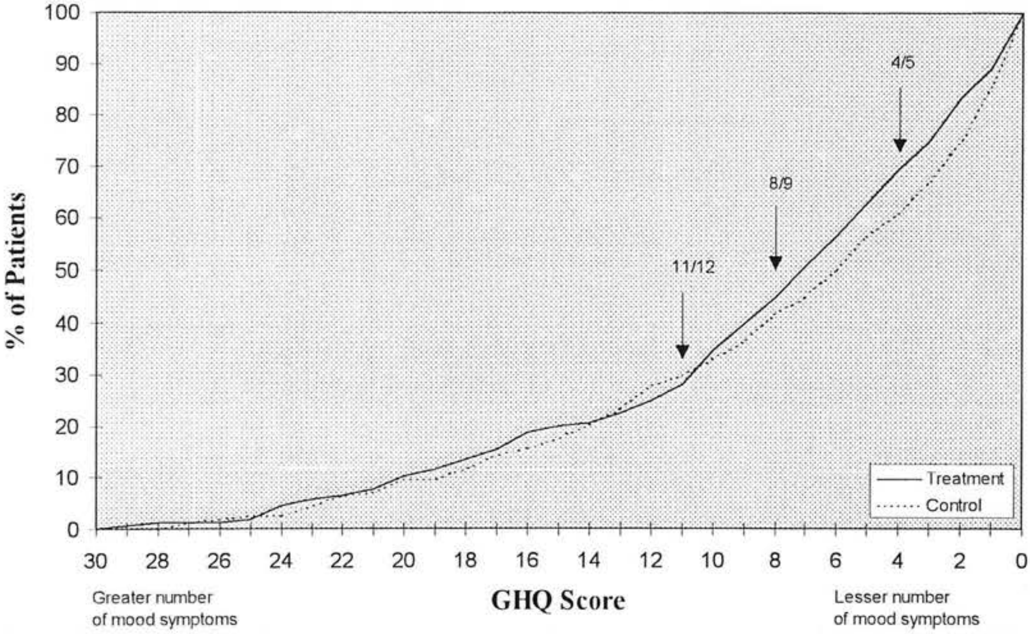
### *5.5.2 Mood.*

Patients were administered two measures of their mood. The first, the General Health Questionnaire, 30 item version; which I administered during the primary patient follow up interview. The second, the Hospital Anxiety and Depression Scale was included in the secondary patient questionnaire which I left with patients for self completion.

#### The General Health Questionnaire:

Initially, patients' GHQ scores were treated as continuous variables for analysis (Figure 5-8). There was a non-significant trend for the control group to experience fewer mood symptoms.

**Figure 5-8: Comparative cumulative distribution of treatment and control group patients' scores on the General Health Questionnaire with descriptive statistics.**

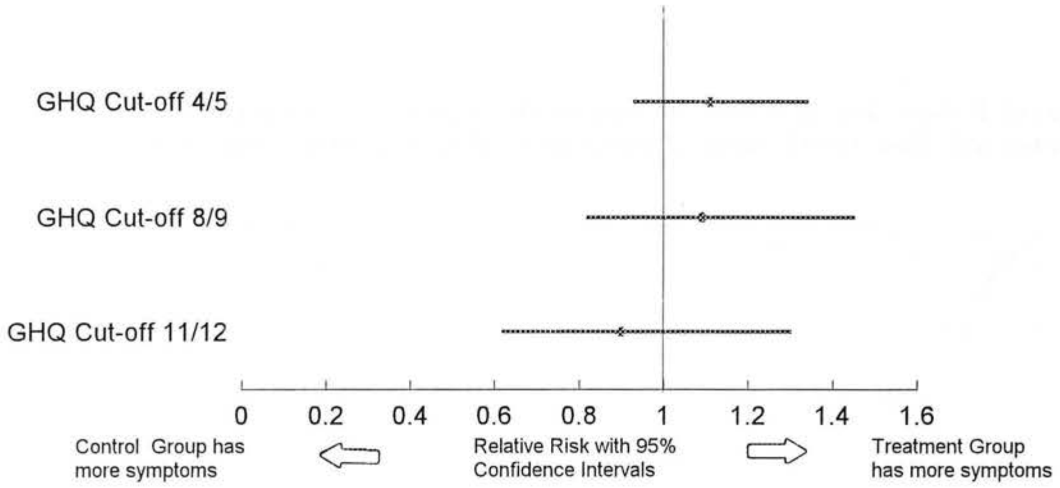


| **P value = 0.27** | **No. of Patients** | **Mean** | **Median** | **Range** |
|---|---|---|---|---|
| Treatment Group | 156 | 8.2 | 7 | 0 - 29 |
| Control Group | 154 | 7.6 | 5.5 | 0 - 27 |

Note: P values were calculated using the Mann-Whitney U statistic.

Secondly, data were analysed using the same three cutting points we have used previously; 4/5, 8/9 and 11/12 (refer to 2.7.2.3. and 3.3.1.). The relative risk of patients in either the treatment or control group being defined as a case, that is having a score above that indicated by the cut-off point, was calculated and plotted with 95% confidence intervals on forest plots (Figure 5-9). We calculated significance using the chi square statistic as the variables were dichotomous. No significant differences existed between treatment and control groups for any of the cut-offs.

**Figure 5-9: Relative risk of patients in the treatment and control groups being defined a 'psychiatric case' using three alternative cut-offs on the General Health Questionnaire with descriptive statistics.**



| GHQ Cut-off | Number and % of Patients Defined a 'Case' | | P Value |
|---|---|---|---|
| | **Treatment Group (n=156)** | **Control Group (n=154)** | |
| 4/5 | 98 ( 63%) | 87 (56%) | 0.26 |
| 8/9 | 62 (40%) | 56 (36%) | 0.54 |
| 11/12 | 39 (25%) | 43 (28%) | 0.56 |

Note: P values were calculated using the Chi Square statistic.

Some patients had only partially completed the scale (treatment group n=11, control group n=10) and were therefore not included in the above analysis. To determine if these patients would have altered our results these patients were included in an additional analysis if either they had already scored over the given cut-off on the questions they had answered, or if they were so far below the given cut-off that even if they had answered positively to all omitted questions they would still not reach the cut-off of 'caseness'. This procedure was completed for all three of the above cut-offs and the difference between treatment and control groups analysed. The results of our analysis after including the partially completed data did not differ from those above.

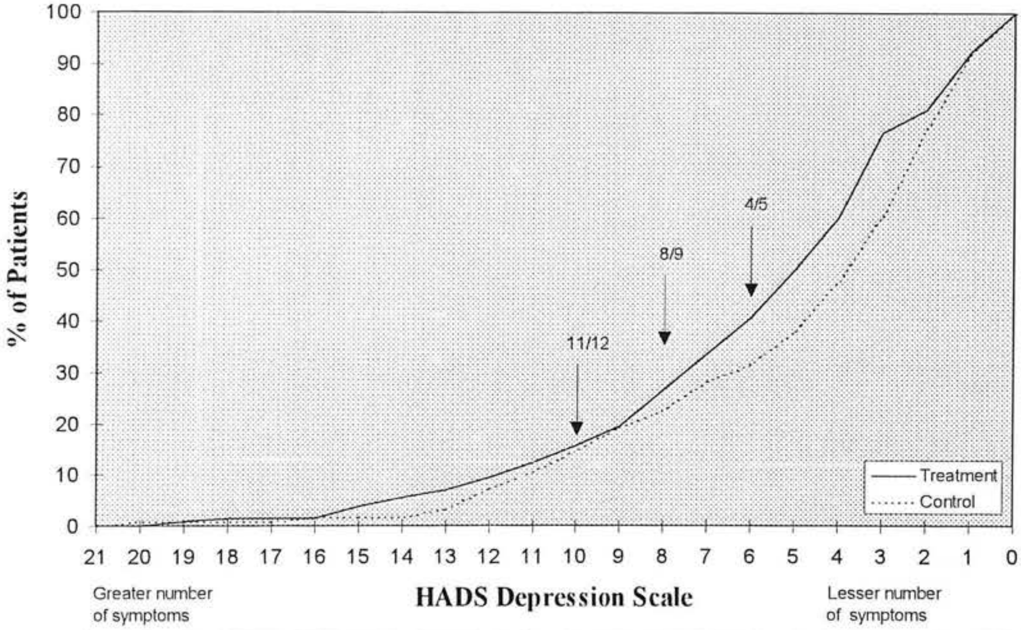
## The Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale consists of two subscales, anxiety and depression (refer to 2.7.2.2.). Analysis of each subscale was undertaken separately.

### The Depression Subscale

Initial analyses of the HAD Depression Subscale as a continuous variable produced a non-significant trend suggesting the control group experienced fewer symptoms of depression (Figure 5-10).

**Figure 5-10: Comparative cumulative distribution of treatment and control group Hospital Anxiety and Depression Scale Depression Subscale Scores with descriptive statistics.**

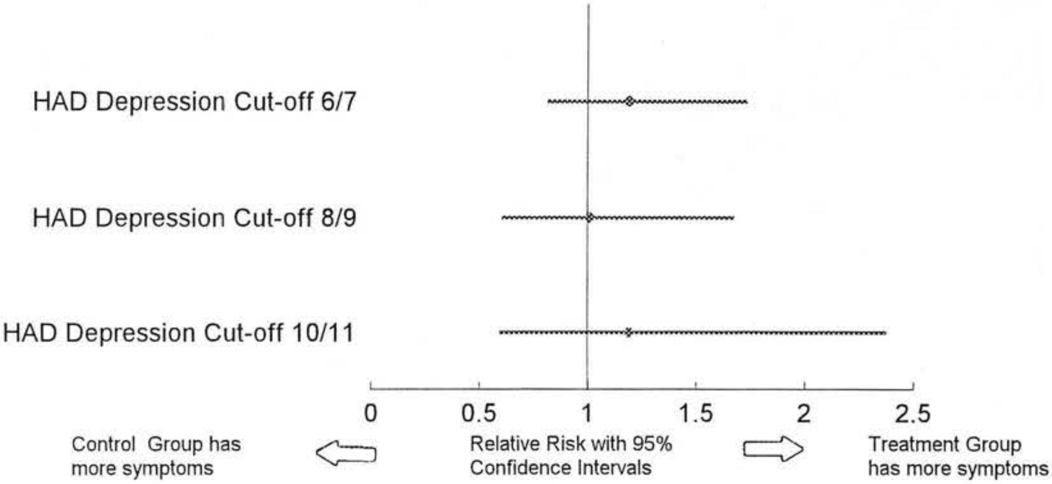


| P value = 0.07 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 128 | 5.4 | 4.5 | 0 - 19 |
| Control Group | 124 | 4.6 | 3 | 0 - 20 |

Note: P values were calculated using the Mann-Whitney U statistic.

The relative risk of a patient in either the treatment or control groups being defined as depressed, that is having a score above that dictated by the cutting point for any of our three cut-offs, with 95% confidence intervals, was plotted on a forest plot (Figure 5-11). Significance was calculated using the Chi Square statistic for dichotomous variables. Results suggested an almost identical risk (Relative risk = 1.01) of being defined as depressed in the treatment or control groups using the 8/9 cutting point and a non-significant increased risk in the treatment group using the 6/7 and 10/11 cutting points (Figure 5-11).

**Figure 5-11: The relative risk of patients in the treatment and control groups being defined 'depressed' by the Hospital Anxiety and Depression Scale Depression Subscale at three alternative cut-off points with descriptive statistics.**



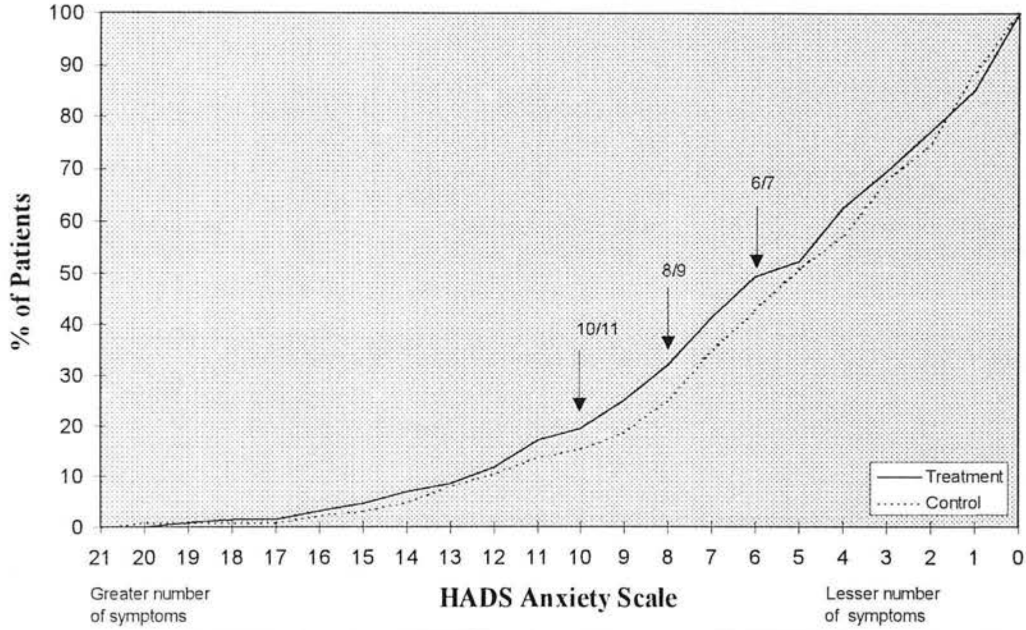
| HAD Depression Subscale Cut-off | Number and % of Patients Defined 'Depressed' | | P Value |
|---|---|---|---|
| | **Treatment Group (n=128)** | **Control Group (n=124)** | |
| 6/7 | 43 (34%) | 35 (28%) | 0.36 |
| 8/9 | 25 ( 20%) | 24 (19%) | 0.62 |
| 10/11 | 16 (13%) | 13 (10%) | 0.97 |

Note: P values were calculated using the Chi Square statistic.

### The Anxiety Subscale

We first analysed the HAD Anxiety Subscale as a continuous variable, computing descriptive statistics and analysing significance using the Mann-Whitney statistic. No significant differences were evident between treatment and control groups (Figure 5-12).

**Figure 5-12: Comparative cumulative distribution of treatment and control group Hospital Anxiety and Depression Scale Anxiety Subscale scores with descriptive statistics.**

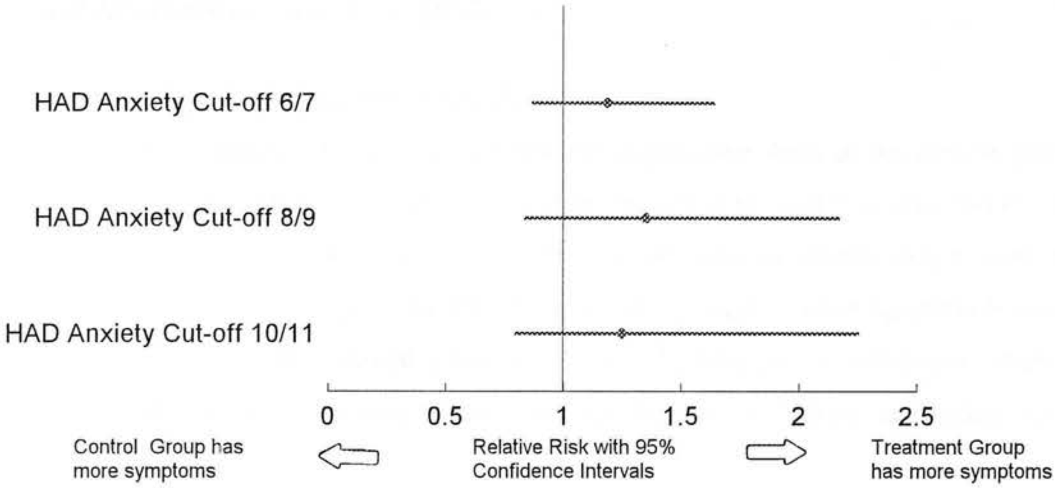


| **P value = 0.44** | **No. of Patients** | **Mean** | **Median** | **Range** |
|---|---|---|---|---|
| Treatment Group | 128 | 5.7 | 5 | 0 - 19 |
| Control Group | 124 | 5.2 | 5 | 0 - 20 |

Note: P values were calculated using the Mann-Whitney U statistic.

The HAD Anxiety Subscale was also analysed using the three recommended cutting points, 6/7, 8/9 and 10/11. The relative risk of patients in either the treatment or control groups being defined as anxious, that is having a score above the cut-off, was calculated and plotted with 95% confidence intervals on a Forest plot (Figure 5-13). Results suggested a non-significant trend for patients in the treatment group to be at greater risk of anxiety at each of our three cutting points.

**Figure 5-13: Relative risk of patients in the treatment and control groups being defined an 'Anxious' Case by the Hospital Anxiety and Depression Scale Anxiety Subscale at three alternative cut-offs with descriptive statistics.**



| HAD Anxiety Subscale Cut-off | Number and % of Patients Defined 'Anxious' | | P Value |
|---|---|---|---|
| | **Treatment Group (n=128)** | **Control Group (n=124)** | |
| 6/7 | 53 (41%) | 43 (35%) | 0.27 |
| 8/9 | 32 (25%) | 23 (19%) | 0.22 |
| 10/11 | 22 (17%) | 17 (14%) | 0.45 |

Note: P values were calculated using the Chi Square statistic.

Again, for both subscales, we conducted further analysis of patients who had only partially completed the scales who were included when their scores gave a clear indication of whether they were a case or not for any given cut-off. Analysis including these patients indicated no significant differences between treatment and control groups for any of the above cut-offs for either scale.

### *5.5.3 Mental adjustment.*

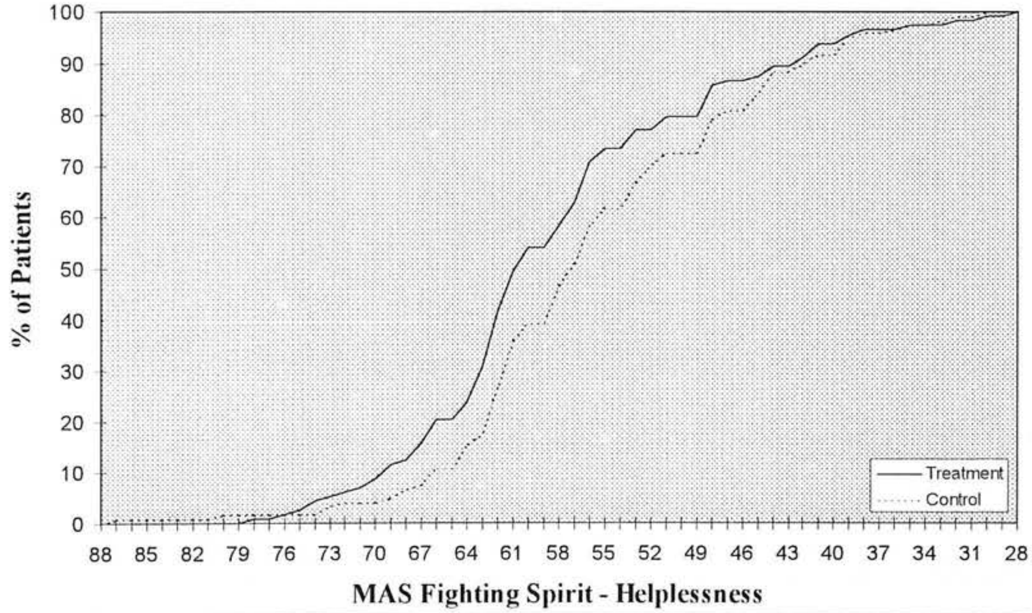
### The Mental Adjustment to Stroke Scale

Please refer to section 2.7.4.1. for an explanation of the subscales and scoring system of the Mental Adjustment to Stroke Scale (MAS).

### The Fighting Spirit - Helplessness Subscale

Treatment group patients' scores were significantly higher than those of the control group indicating increased helplessness / hopelessness in this group (p=0.017) (Figure 5-14). In addition, when patients' scores were categorised to indicate whether patients were a 'case' of negative mental adjustment, (refer to 3.9.) treatment group patients were significantly more likely to be a case of poor mental adjustment on the helplessness / hopelessness subscale (p=0.05) and there was a non-significant trend for them to be lacking in fighting spirit (p=0.21) (Table 5-7).

**Figure 5-14: Comparative cumulative distribution of treatment and control group patients' Mental Adjustment to Stroke Scale, Fighting Spirit/Helplessness scores with descriptive statistics.**



| P value = 0.02 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 113 | 57.8 | 60 | 28 - 78 |
| Control Group | 120 | 55.3 | 57 | 30 - 87 |

Note: P values were calculated using the Mann-Whitney U statistic.

**Table 5-7: The number of patients in the treatment and control groups defined as cases of negative mental adjustment for either Fighting Spirit or Helplessness / Hopelessness on the Mental Adjustment to Stroke Scale.**

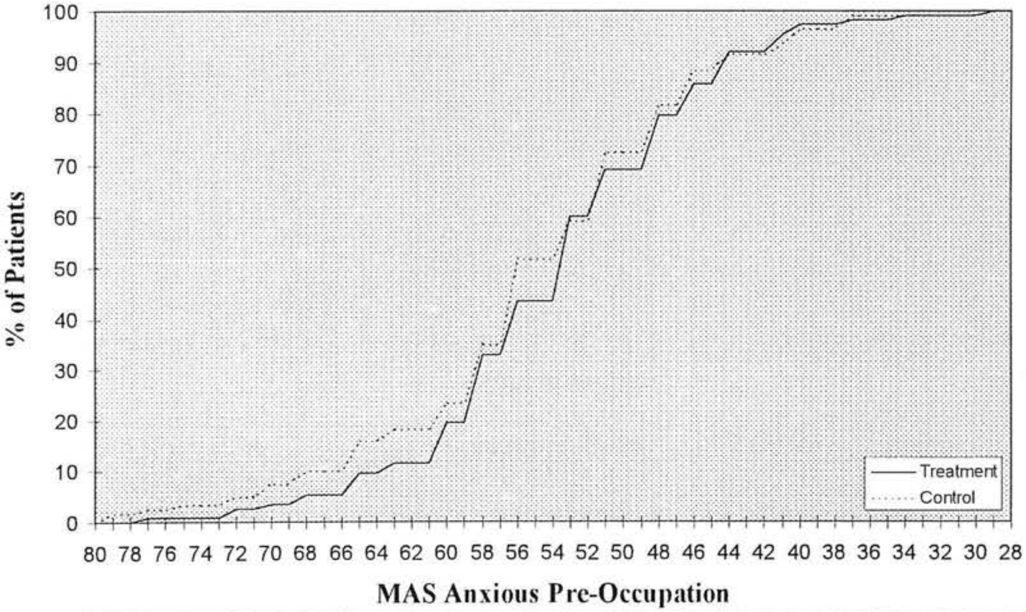
| | Cut-off | Treatment Group | | Control Group | | P Value |
|---|---|---|---|---|---|---|
| Fighting Spirit | < 44 | 14 | 12.3% | 9 | 7.5% | 0.21 |
| Helplessness/ Hopelessness | > 14 | 15 | 13.3% | 7 | 5.8% | 0.05 |

Note: Cut-offs refer to raw scores as only combined Fighting Spirit, Helplessness / Hopelessness scores undergo transformation. Accordingly cut-offs could not be marked on Figure 5-14 as the figure plots transformed scores. P value was calculated using the Chi Square statistic.

### The Anxious Pre-occupation Subscale

There were no significant differences between treatment and control group patients in terms of their anxious pre-occupation either when treating their scores as continuous variables (Figure 5-15) or when categorising patients as cases (Table 5-8). However, there was a non-significant trend for control group patients to suffer more anxious pre-occupation than those in the treatment group

**Figure 5-15: Comparative cumulative distribution of treatment and control Group Patients' Mental Adjustment to Stroke Scale Anxious Pre-occupation Scores with descriptive statistics.**



| P value = 0.42 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 113 | 53.3 | 53 | 29 - 77 |
| Control Group | 120 | 54.6 | 56 | 29 - 79 |

Note: P values were calculated using the Mann-Whitney U statistic.

**Table 5-8: The number of patients in the treatment and control groups defined as cases of negative mental adjustment on the Anxious Pre-occupation Subscale of the Mental Adjustment to Stroke Scale.**

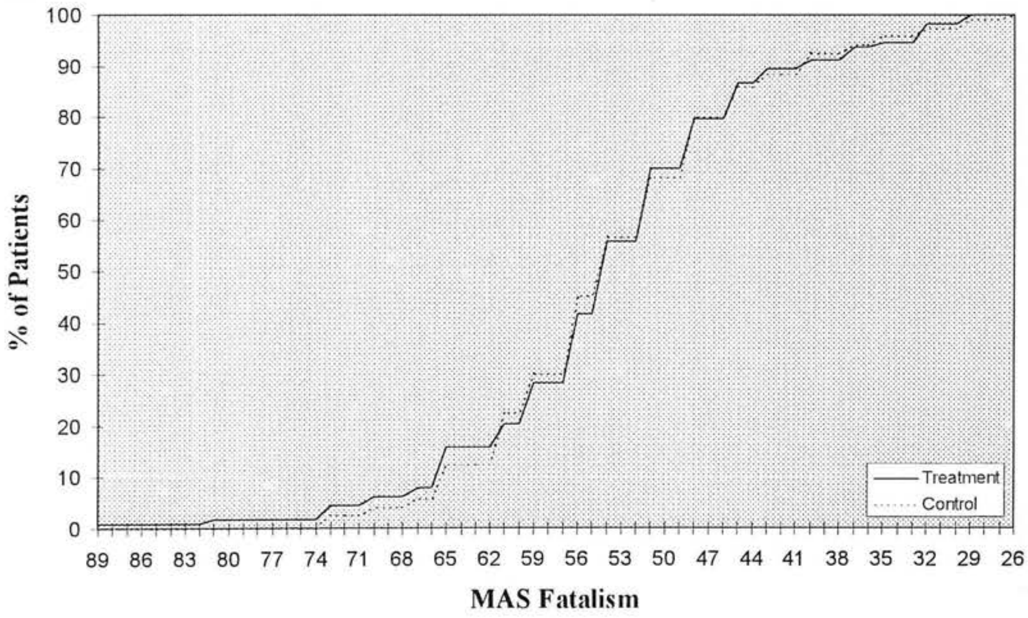
| | Cut-off | Treatment Group | | Control Group | | P Value |
|---|---|---|---|---|---|---|
| Anxious Preoccupation | >63 | 11 | 9.7% | 19 | 15.8% | 0.16 |

Note: Cut-off refers to transformed scores. P value was calculated using the Chi quare statistic.

### The Fatalism Subscale

Figure 5-16 illustrates the almost identical distribution of treatment and control group scores on the Fatalism subscale with equal means and medians and a P value of 0.94.

**Figure 5-16: Comparative cumulative distribution of treatment and control group patients' Mental Adjustment to Stroke Scale Fatalism scores with descriptive statistics.**



| P value= 0.94 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 113 | 53.4 | 54 | 29 - 89 |
| Control Group | 120 | 53.0 | 54 | 26 - 73 |

Note: P values were calculated using the Mann-Whitney U statistic.

**Table 5-9: The number of patients in the treatment and control groups defined as cases of negative mental adjustment on the Fatalism Subscale of the Mental Adjustment to Stroke Scale.**

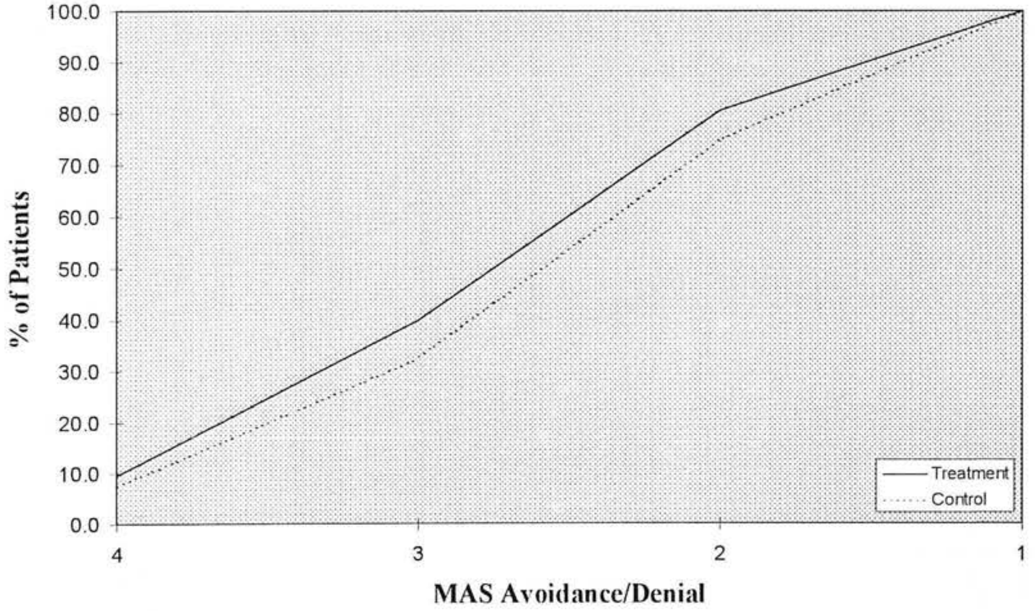
| | Cut-off | Treatment Group | | Control Group | | P Value |
|---|---|---|---|---|---|---|
| Fatalism | >61 | 18 | 15.9% | 15 | 12.2% | 0.45 |

Note: Cut-off refers to transformed scores. P value was calculated using the Chi Square statistic.

### The Avoidance / Denial Subscale

The relationship between treatment and control group patients scores illustrated in Figure 5-17 shows a persistent trend in favour of the control group exhibiting less of the negative adjustment of avoidance / denial. This trend did not reach statistical significance either when scores were treated as continuous or when they were categorised (Figure 5-17 and Table 5-10).

**Figure 5-17: Comparative cumulative distribution of treatment and control group patients' Mental Adjustment to Stroke Scale Avoidance / Denial Scores with descriptive statistics.**



| P value = 0.19 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 113 | 2.3 | 2 | 1 - 4 |
| Control Group | 120 | 2.2 | 2 | 1 - 4 |

Note: P values were calculated using the Mann-Whitney U statistic.

**Table 5-10: The number of patients in the treatment and control groups defined as cases of negative mental adjustment on the Avoidance / Denial Subscale of the Mental Adjustment to Stroke Scale.**

| | Cut-off | Treatment Group | | Control Group | | P Value |
|---|---|---|---|---|---|---|
| Avoidance / Denial | >3 | 11 | 9.7% | 9 | 7.5% | 0.54 |

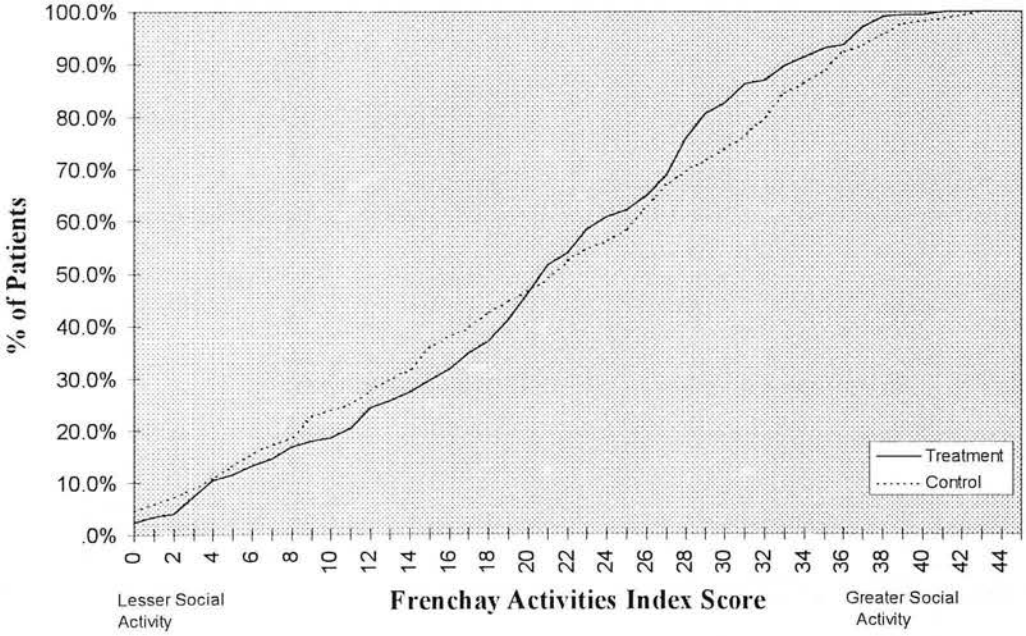
Note: Cut-off refers to raw scores as the Avoidance / Denial subscale does not undergo transformation. P value was calculated using the Chi Square statistic.

### *5.5.4 Social functioning.*

**The Frenchay Activities Index**

Patients social and daily activities were measured using the Frenchay Activities Index (FAI; refer to 2.7.3.1.). There are no recommended cut-offs for the scale which we therefore analysed treating scores as a continuous variable (Figure 5-18).

**Figure 5-18: Comparative cumulative distribution of treatment and control group Frenchay Social Activities Index scores with descriptive statistics.**

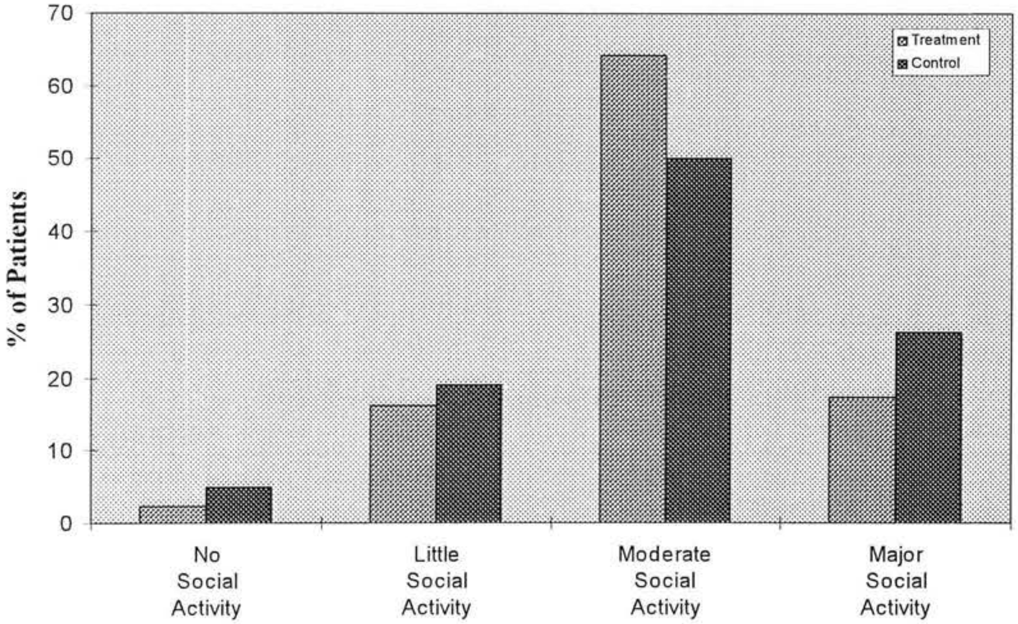


| P value 0.86 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 173 | 20.7 | 21 | 0 - 41 |
| Control Group | 168 | 20.9 | 22 | 0 - 43 |

Note: P value attained using Mann-Whitney U analysis.

In addition, patients' scores were categorised as indicating no, little, moderate or major social activity (Figure 5-19). Treatment group patients were significantly more likely to participate in moderate social activities (p=0.0082) whilst the control group were significantly more likely to participate in major social activities (p=0.0475). Taking into account that these categories, although widely used, have not been validated and that the differences are in the opposite direction to each other and at the same end of the scale, no firm inferences can be drawn from these results. They may simply be a product of the cut-offs chosen.

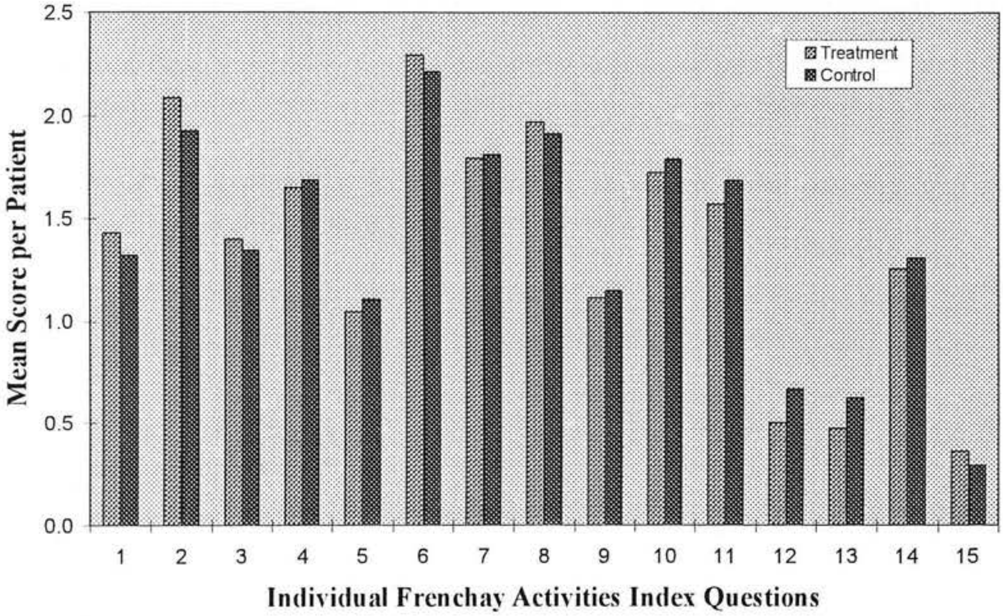
**Figure 5-19: Comparative distribution of treatment vs. control groups for categorised Frenchay Activity Index scores.**



| Category | Treatment Group (n=173) | | Control Group (n=168) | | P Value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| No social activity<br>FAI = 0 | 4 | 2.3% | 8 | 4.8% | 0.2197 |
| Little social activity<br>FAI = 1-10 | 28 | 16.2% | 32 | 19.0% | 0.4877 |
| Moderate social activity<br>FAI = 11-30 | 111 | 64.2% | 84 | 50% | 0.0082 |
| Major social activity<br>FAI = 31-45 | 30 | 17.3% | 44 | 26.2% | 0.0475 |

Additional analysis was undertaken of treatment vs. control groups for each question to ascertain if groups differed in any specific domain. For illustrative purposes we calculated the average score for each question for all patients in the treatment and all patients in the control groups (Figure 5-20). To see if treatment and control group patients' scores for each question differed we computed a Mann-Whitney U analysis and revealed no significant differences between groups (key to Figure 5-20).

**Figure 5-20: Comparative distribution of average treatment and control group scores on individual Frenchay Activities Index scores.**



**Key to Figure 5-20.**

| In the last 3 months how often have you been:- | P Value | Mean Score Treatment | Mean Score Control |
|---|---|---|---|
| 1. Preparing the main meal? | 0.41 | 1.43 | 1.32 |
| 2. Washing up? | 0.10 | 2.09 | 1.93 |
| 3. Washing clothes? | 0.51 | 1.40 | 1.35 |
| 4. Doing light housework? | 0.86 | 1.65 | 1.69 |
| 5. Doing heavy housework? | 0.88 | 1.05 | 1.11 |
| 6. Local shopping? | 0.34 | 2.29 | 2.21 |
| 7. On social outings? | 0.93 | 1.80 | 1.82 |
| 8. Walking outside for up to 15 minutes? | 0.26 | 1.98 | 1.92 |
| 9. Actively pursuing a hobby? | 0.89 | 1.12 | 1.15 |
| 10. Driving a car or travelling on a bus? | 0.92 | 1.73 | 1.79 |
| 11. On any outings / car rides? | 0.4 | 1.57 | 1.69 |
| 12. Gardening? | 0.35 | 0.50 | 0.67 |
| 13. Doing household or car maintenance? | 0.18 | 0.47 | 0.63 |
| 14. Reading books? | 0.69 | 1.25 | 1.31 |
| 15. Gainful work? | 0.42 | 0.36 | 0.29 |

n = 173 Treatment group; n = 168 control group

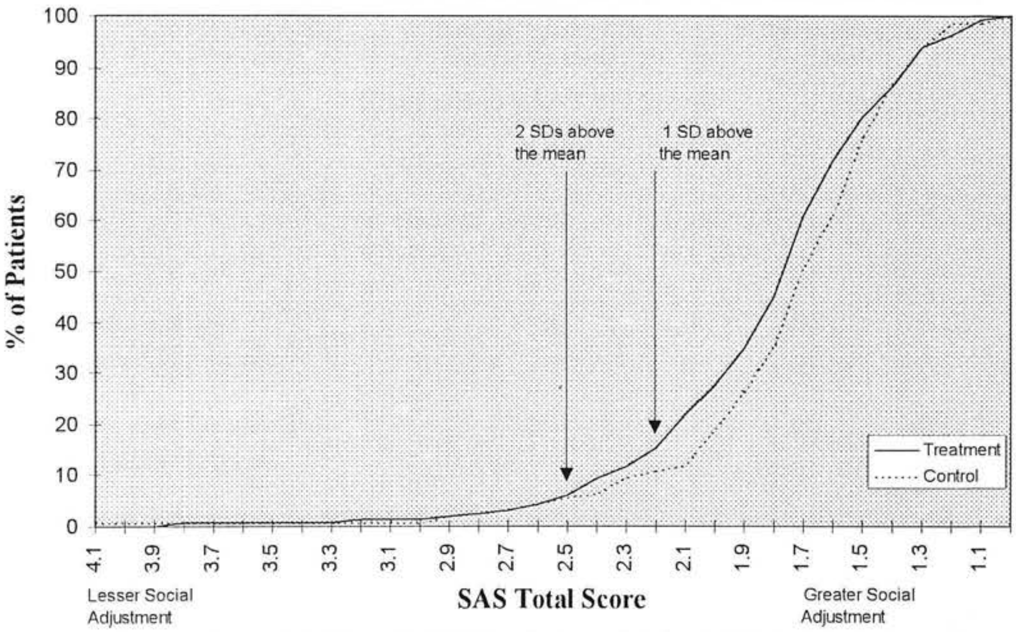
### The Social Adjustment Scale

For an explanation of the subscales and scoring of the Social Adjustment Scale (SAS) please refer to section 2.7.3.2. Mean scores for each subscale and the mean total were analysed as continuous data and described in terms of the number of patients scoring above one and two standard deviations above the mean of the sample's combined distribution.

### The Social Adjustment Scale Total Score

Analysis of patients' mean total scores illustrated a non-significant trend towards treatment group patients being more likely to experience social maladjustment (Figures 5-21 and 5-22).

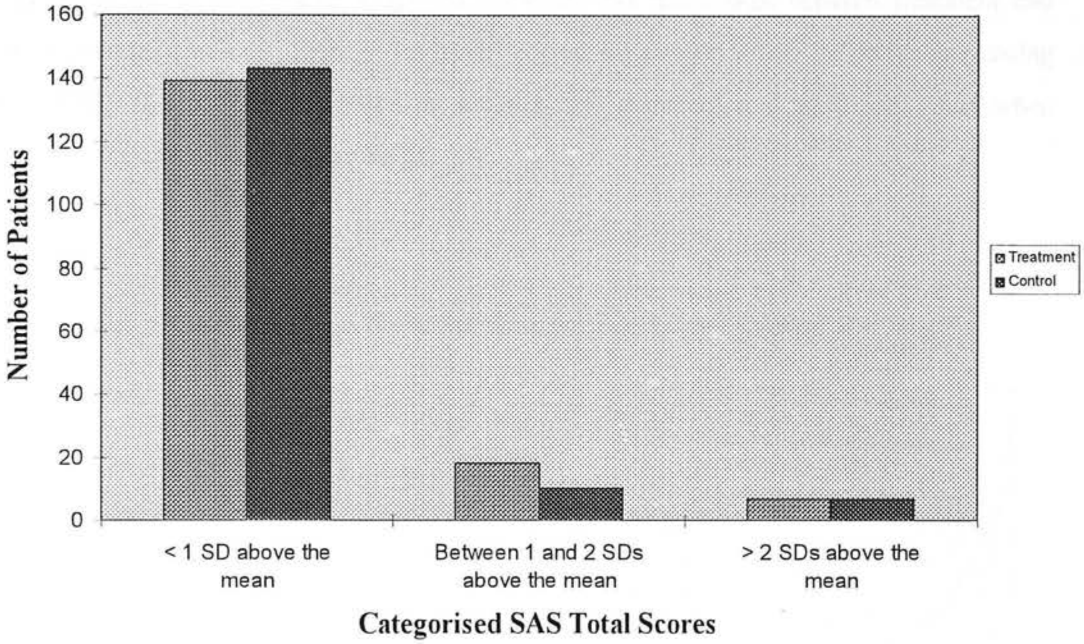
**Figure 5-21: Comparative cumulative distribution of treatment and control group scores for the Social Adjustment Scale total score with descriptive statistics.**



| P value = 0.061 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 164 | 1.7 | 1.7 | 1 - 3.7 |
| Control Group | 160 | 1.7 | 1.6 | 2 - 4.1 |

Note: P values were computed using the Mann-Whitney U statistic.

**Figure 5-22: Categorised Social Adjustment Scale total scores, treatment vs. control groups.**



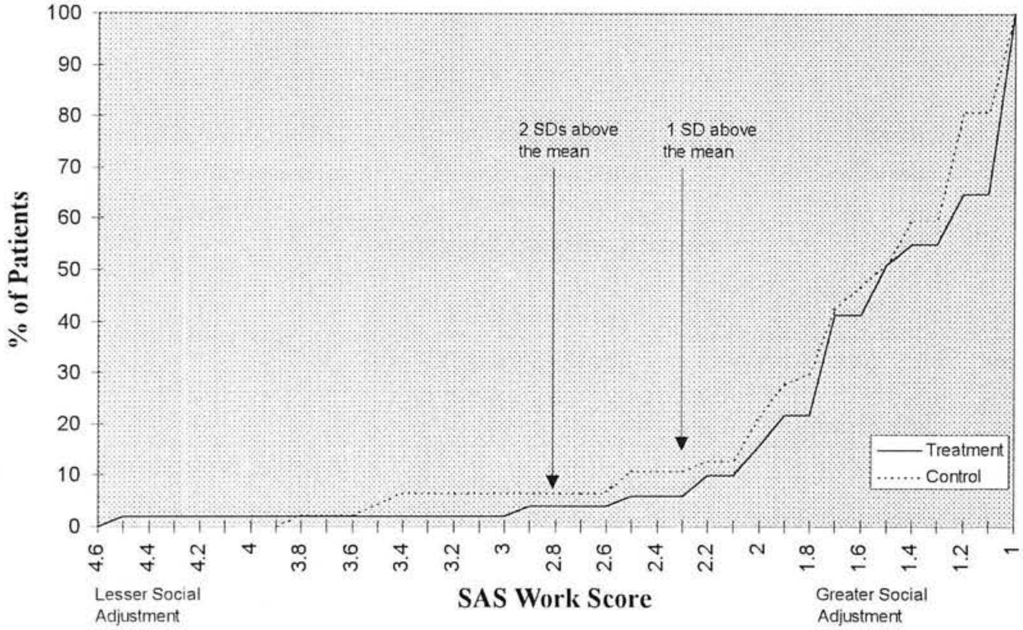
| Category | Treatment Group n = 164 | | Control Group n = 160 | | P Value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| Less than one standard deviation above the mean: < 2.2 | 140 | 85% | 144 | 90% | 0.20 |
| Between one and two standard deviations above the mean: 2.2 - 2.5 | 17 | 10% | 9 | 6% | 0.12 |
| More than two standard deviations above the mean: > 2.5 | 7 | 4% | 7 | 4% | 0.96 |
| Equal to or more than one standard deviation above the mean: >2.1 | 24 | 15% | 16 | 10% | 0.20 |

Note: P values were calculated using the Chi Square statistic. Percentages may not add up to 100% due to rounding. SD= Standard Deviation.

### The Work Subscale

Analysis of the work subscale suggested no significant differences between treatment and control groups. However, there was a trend towards the control group patients experiencing more difficulties both when plotted as a cumulative distribution (Figure 5-23) and when patients were categorised (Figure 5-24).

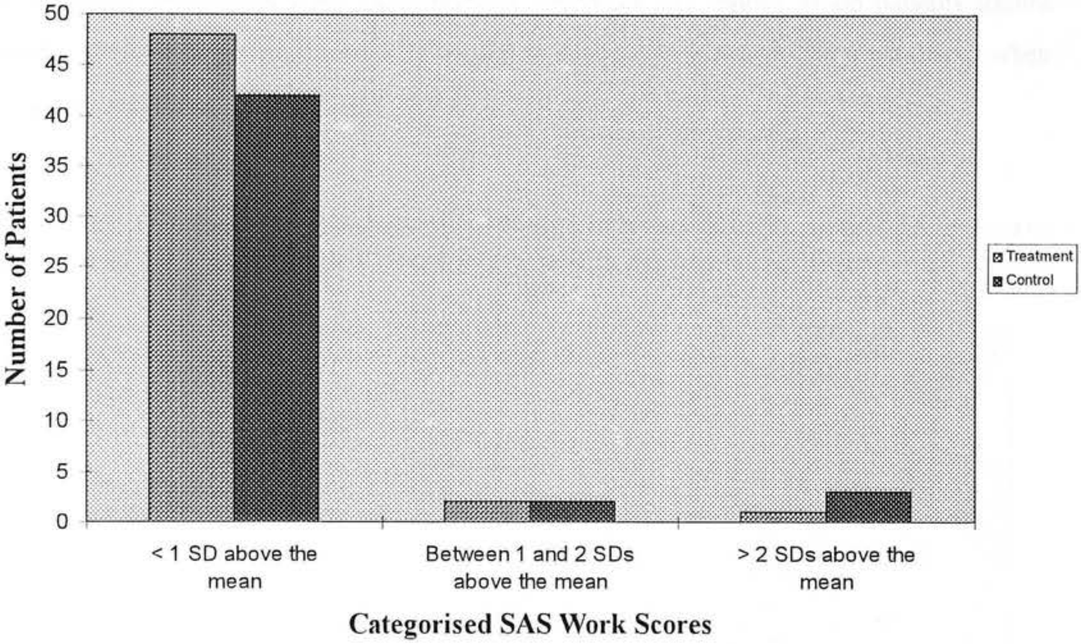
**Figure 5-23: Comparative cumulative distribution of treatment and control group scores on the Social Adjustment Scale Work Subscale with descriptive statistics.**



| P value = 0.299 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 51 | 1.5 | 1.5 | 1 - 4.5 |
| Control Group | 47 | 1.6 | 1.5 | 1 - 3.8 |

Note: P values were computed using the Mann-Whitney U statistic.

**Figure 5-24: Categorised Social Adjustment Scale Work Subscale scores, treatment vs. control groups.**



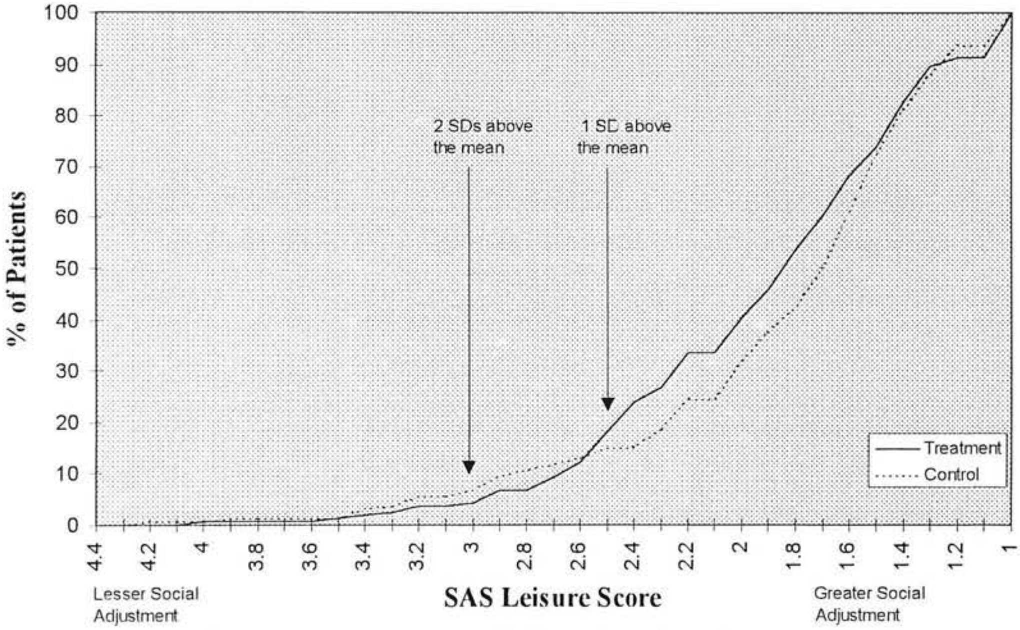
| Category | Treatment Group n = 51 | | Control Group n = 47 | | P Value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| Less than one standard deviation above the mean: < 2.5 | 48 | 94% | 42 | 89% | 0.39 |
| Between one and two standard deviations above the mean: 2.5 - 3.0 | 2 | 4% | 2 | 4% | 0.93 |
| More than two standard deviations above the mean: > 3.0 | 1 | 2% | 3 | 6% | 0.27 |
| Equal to or more than one standard deviation above the mean: >2.4 | 3 | 6% | 5 | 11% | 0.39 |

Note: P values were calculated using the Chi Square statistic. Percentages may not add up to 100% due to rounding. SD= Standard Deviation.

### The Leisure Subscale

No significant differences were found between treatment and control group patients leisure subscale scores either when scores were treated as continuous variables (Figure 5-25) or when they were categorised (Figure 5-26).

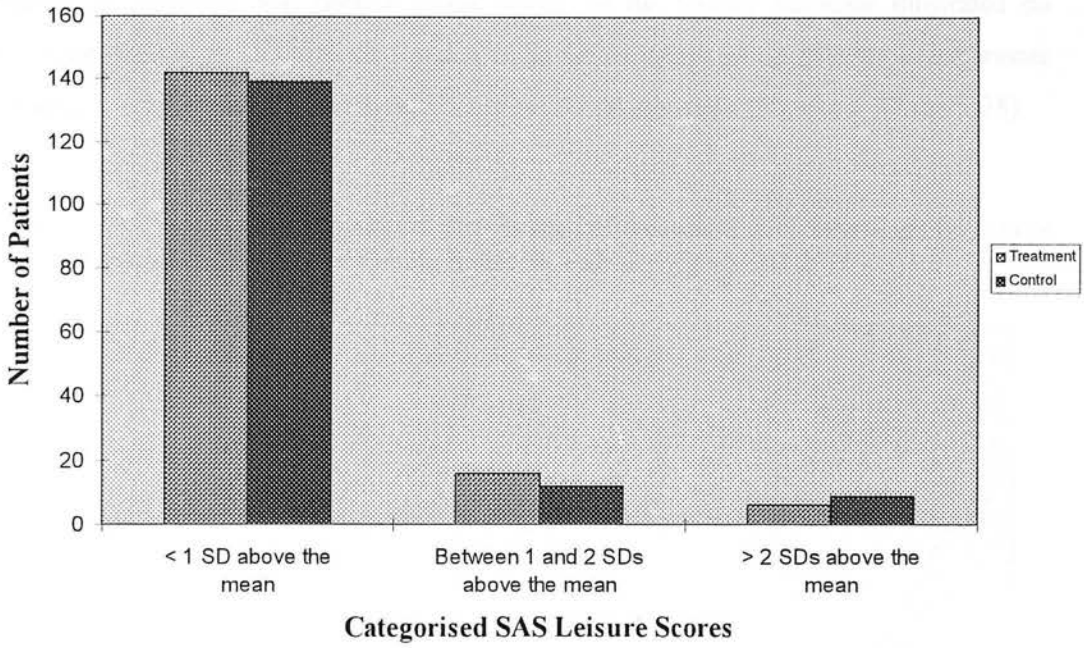
**Figure 5-25: Comparative cumulative distribution of treatment and control group scores on the Social Adjustment Scale Leisure Subscale with descriptive statistics.**



| **P value = 0.148** | **No. of Patients** | **Mean** | **Median** | **Range** |
|---|---|---|---|---|
| Treatment Group | 164 | 1.85 | 1.78 | 1 - 4 |
| Control Group | 160 | 1.78 | 1.61 | 1 - 4.1 |

Note: P values were computed using the Mann-Whitney U statistic.

**Figure 5-26: Categorised Social Adjustment Scale Leisure scores, treatment vs. control groups.**



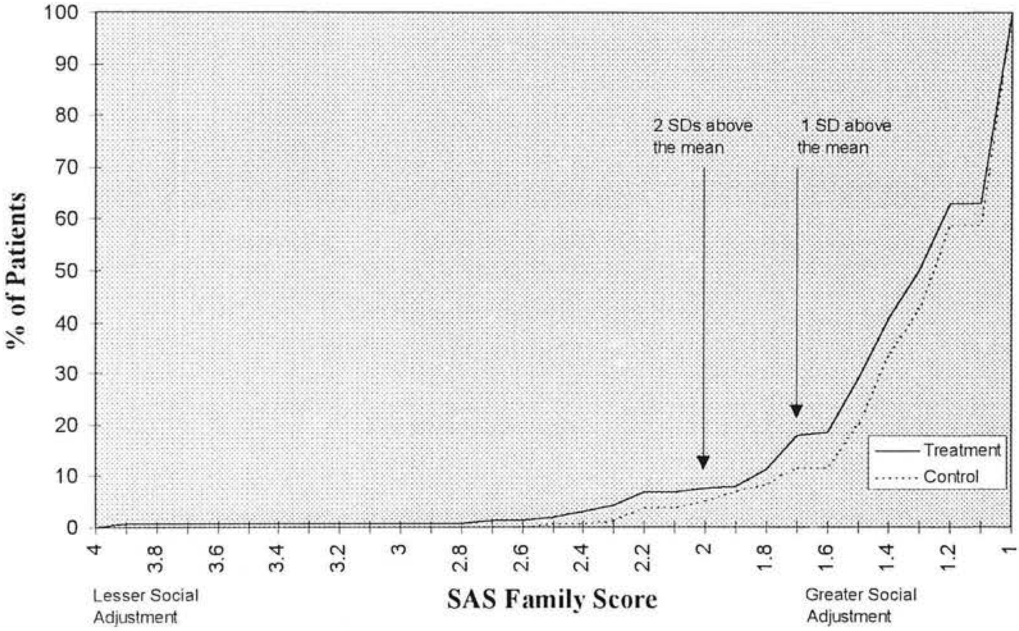
| Category | Treatment Group<br>n = 164 | | Control Group<br>n = 160 | | P Value |
|---|---|---|---|---|---|
| | **n** | **%** | **n** | **%** | |
| Less than one standard deviation above the mean: < 2.5 | 142 | 87% | 139 | 87% | 0.94 |
| Between one and two standard deviations above the mean: 2.5 - 3.0 | 16 | 10% | 12 | 8% | 0.47 |
| More than two standard deviations above the mean: > 3.0 | 6 | 4% | 9 | 6% | 0.4 |
| Equal to or more than one standard deviation above the mean: >2.4 | 24 | 15% | 21 | 13% | 0.94 |

Note: P values were calculated using the Chi Square statistic. Percentages may not add up to 100% due to rounding. SD= Standard Deviation.

### The Family Subscale

Analysis of treatment and control group scores on the Family Subscale illustrated no significant differences although there was a trend for treatment group patients to experience more social adjustment problems in the area of family relationships (Figures 5-27 and 5-28).

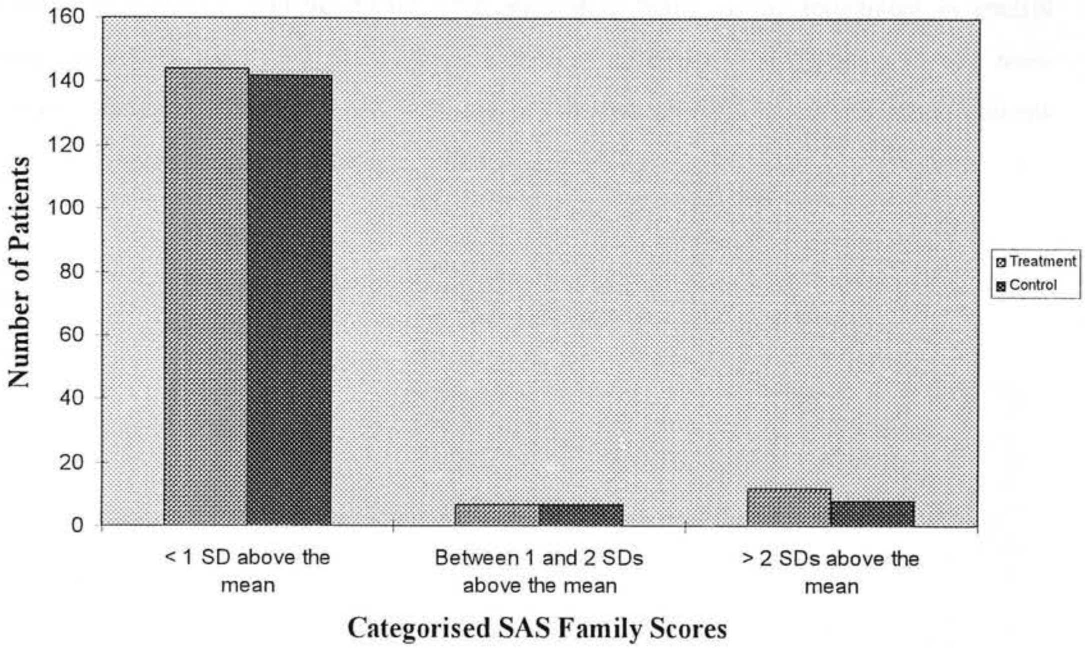
**Figure 5-27: Comparative cumulative distribution of treatment and control group scores on the Social Adjustment Scale Family Subscale with descriptive statistics.**



| P value = 0.15 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 162 | 1.3 | 1.2 | 1 - 3.9 |
| Control Group | 155 | 1.2 | 1.1 | 1 - 2.5 |

Note: P values were computed using the Mann-Whitney U statistic.

**Figure 5-28: Categorised Social Adjustment Scale Family Subscale scores, treatment vs. control groups.**



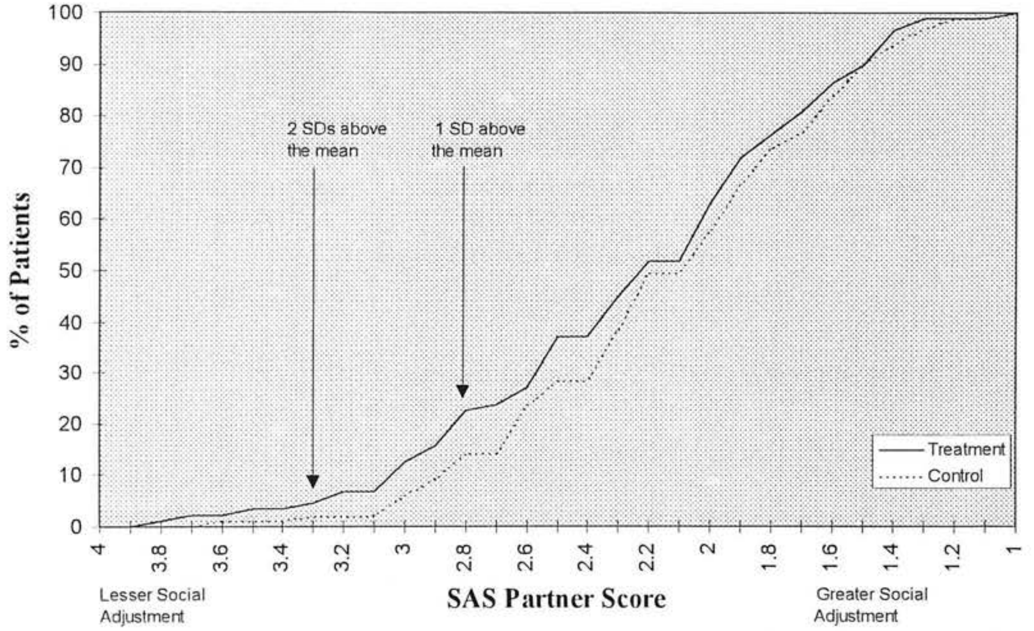
| Category | Treatment Group n = 162 | | Control Group n = 155 | | P Value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| Less than one standard deviation above the mean: < 1.7 | 144 | 89% | 142 | 92% | 0.41 |
| Between one and two standard deviations above the mean: 1.7 - 2.0 | 7 | 4% | 7 | 5% | 0.93 |
| More than two standard deviations above the mean: > 2.0 | 11 | 7% | 6 | 4% | 0.41 |
| Equal to or more than one standard deviation above the mean: >1.6 | 18 | 11% | 13 | 8% | 0.41 |

Note: P values were calculated using the Chi Square statistic. Percentages may not add up to 100% due to rounding. SD= Standard Deviation.

## The Partner Subscale

Analysis illustrated a non-significant trend suggesting better social adjustment in control group patients on the Partner Subscale with 16% of treatment group patients scoring more than one standard deviation above the mean in this area and 9% of control group patients doing so (Figures 5-29 and 5-30).

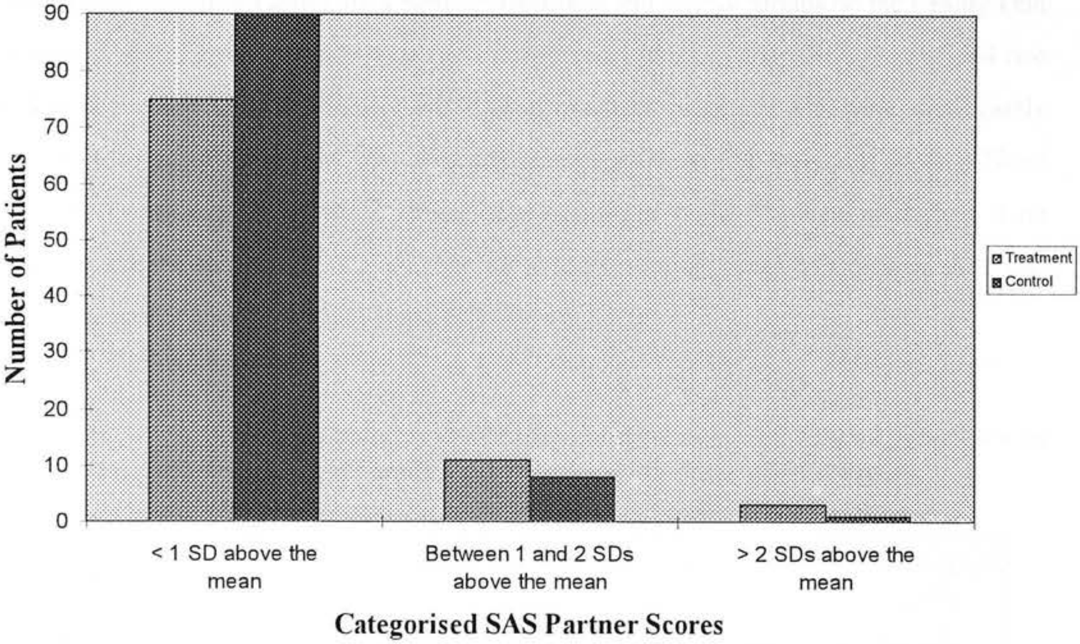
**Figure 5-29: Comparative cumulative distribution of treatment and control group scores on the Social Adjustment Scale Partner Subscale with descriptive statistics.**



| **P value = 0.287** | **No. of Patients** | **Mean** | **Median** | **Range** |
|---|---|---|---|---|
| Treatment Group | 89 | 2.2 | 2.1 | 1 - 3.7 |
| Control Group | 99 | 2.1 | 2.0 | 1 - 3.6 |

Note: P values were computed using the Mann-Whitney U statistic.

**Figure 5-30: Categorised Social Adjustment Scale Partner Subscale scores, treatment vs. control groups.**



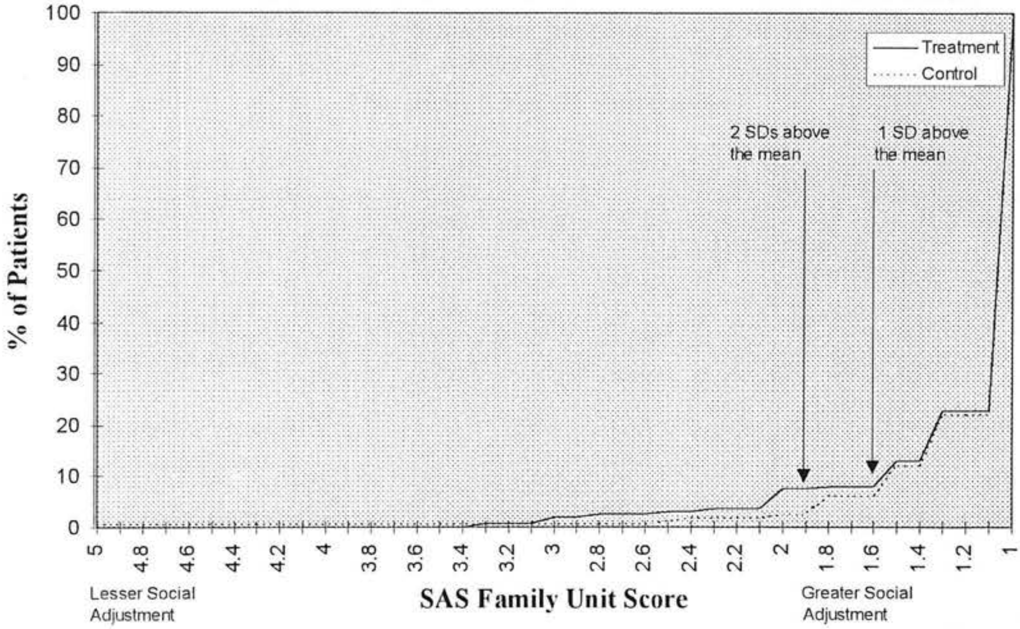
| Category | Treatment Group n = 89 | | Control Group n = 99 | | P Value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| Less than one standard deviation above the mean: < 2.8 | 75 | 84% | 90 | 91% | 0.17 |
| Between one and two standard deviations above the mean: 2.8 - 3.3 | 11 | 12% | 8 | 8% | 0.33 |
| More than two standard deviations above the mean: > 3.3 | 3 | 3% | 1 | 1% | 0.26 |
| Equal to or more than one standard deviation above the mean: >2.7 | 14 | 16% | 9 | 9% | 0.17 |

Note: P values were calculated using the Chi Square statistic. Percentages may not add up to 100% due to rounding. SD= Standard Deviation.

### The Family Unit Subscale

We found two significant differences between treatment and control groups on the Family Unit Subscale. Control group patients were significantly more likely to score between one and two standard deviations above the mean (p=0.05) and treatment group patients were significantly more likely to score more than two standard deviations above the mean (p=0.04). These results are in opposite directions, both are only significant at the 5% level, and there is no significant difference between the number of patients scoring equal to or more than one standard deviation above the mean (Figures 5-31 and 5-32).

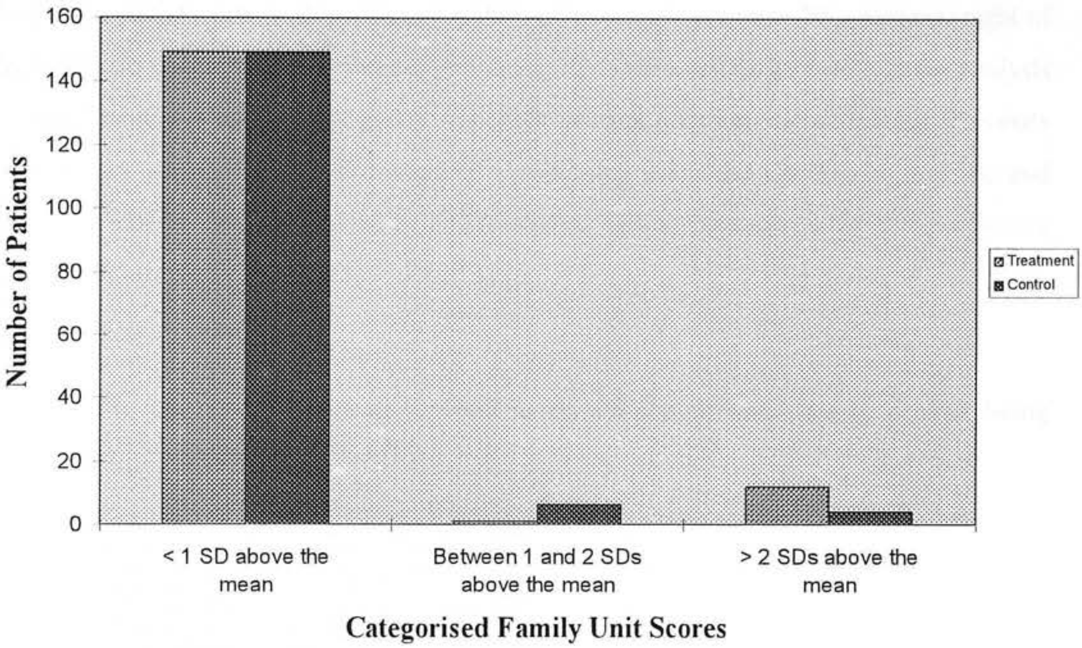
**Figure 5-31: Comparative cumulative distribution of treatment and control group scores on the Social Adjustment Scale Family Unit Subscale with descriptive statistics.**



| P value = 0.779 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 162 | 1.2 | 1.0 | 1 - 3.3 |
| Control Group | 159 | 1.1 | 1.0 | 2 - 5.0 |

Note: P values were computed using the Mann-Whitney U statistic.

**Figure 5-32: Categorised Social Adjustment Scale Family Unit Subscale scores, treatment vs. control groups.**



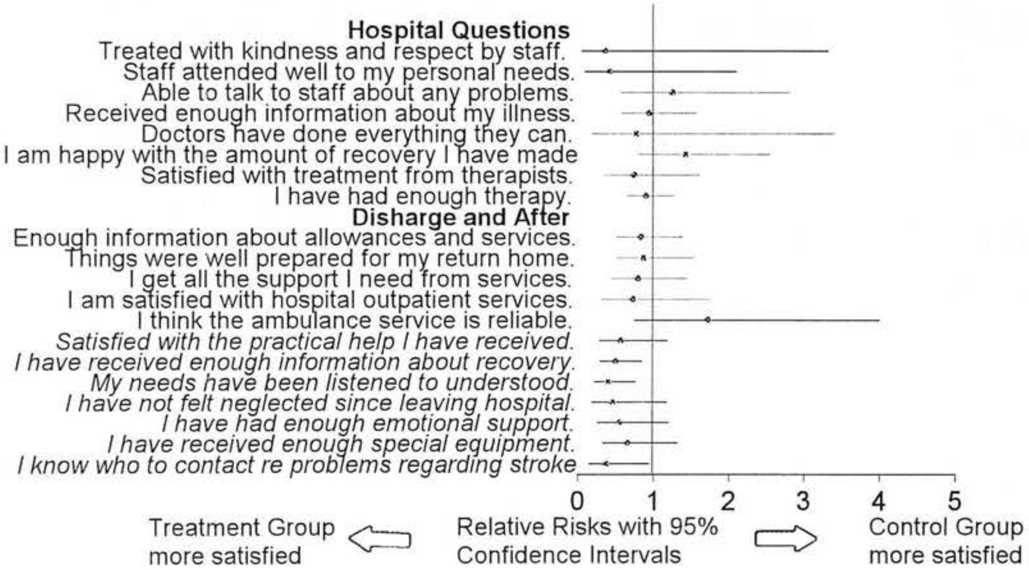
| Category | Treatment Group<br>n = 162 | | Control Group<br>n = 159 | | P Value |
|---|---|---|---|---|---|
| | n | % | n | % | |
| Less than one standard deviation above the mean: < 1.6 | 149 | 92% | 149 | 94% | 0.55 |
| Between one and two standard deviations above the mean: 1.6 - 1.9 | 1 | 1% | 6 | 4% | 0.05 |
| More than two standard deviations above the mean: > 1.9 | 12 | 7% | 4 | 3% | 0.04 |
| Equal to or more than one standard deviation above the mean: >1.5 | 13 | 8% | 10 | 6% | 0.55 |

Note: P values were calculated using the Chi Square statistic. Percentages may not add up to 100% due to rounding. SD= Standard Deviation.

### *5.5.5 Satisfaction with treatment*

The Patient Satisfaction Scale, with our additional questions, contains 20 questions, eight of which refer to in hospital care and the remaining 12 to post discharge care. Initial analysis compared treatment and control group responses to each question, dichotomising responses into satisfied or dissatisfied. We assessed significance using the Chi Square statistic and plotted the relative risk of a patient being dissatisfied for each question with 95% confidence intervals (Figure 5-33).

**Figure 5-33: The relative risk of patients in the treatment and control groups being dissatisfied with aspects of their care.**



Note: Due to the confines of space all questions have been truncated. Please refer to Table 5-11 following for questions in their original format. Question in italics are additional questions added for the present study.

Figure 5-33 illustrates that, of the 20 questions, 17 had a relative risk of less than 1.0 indicating greater satisfaction in the treatment group. There was a significant difference between patients' responses in the treatment and control groups for three of these questions; those referring to receipt of adequate information, (p=0.009), having one's needs listened to and understood, (p=0.004) and knowing who to contact regarding problems with stroke, (p=0.03). None of the questions where patient responses indicated a trend toward the control group being more satisfied reached statistical significance.

To provide a clearer indication of levels of dissatisfaction between groups we calculated the percentage of dissatisfied patients in each group. Table 5-11 lists the number of patients in each group who answered each question, the percentage dissatisfied and whether there was a significant difference in responses between the treatment and control groups.

**Table 5-11: The percentage of patients in the treatment and control group who were dissatisfied with each aspect of their care.**

| Question | Treatment | | Control | | P Value |
|---|---|---|---|---|---|
| | n= | % Dissatisfied | n = | % Dissatisfied | |
| -I have been treated with kindness and respect by the staff at the hospital. | 136 | 0.7 | 142 | 2.1 | 0.34 |
| -Staff attended well to personal needs while I was in hospital | 136 | 1.5 | 140 | 3.6 | 0.27 |
| -I was able to talk to the staff about any problems I might have had. | 136 | 8.8 | 142 | 7.0 | 0.58 |
| -I have received all the information I want about the causes and nature of my illness. | 137 | 16.8 | 140 | 17.9 | 0.81 |
| -The doctors have done everything they can to make me well again. | 137 | 2.2 | 141 | 2.8 | 0.73 |
| -I am happy with the amount of recovery I have made. | 137 | 16.8 | 144 | 11.8 | 0.23 |
| -I am satisfied with the type of treatment the therapists have given me. | 128 | 7.8 | 133 | 10.5 | 0.45 |
| -I have had enough therapy. | 129 | 31.8 | 133 | 35.3 | 0.54 |
| -I was given all the information I needed about the allowances or services I might need after leaving hospital. | 125 | 16.8 | 133 | 20.3 | 0.47 |
| -Things were well prepared for my return home. | 120 | 15.0 | 128 | 17.2 | 0.64 |
| -I get all the support I need from services such as meals on wheels, home helps, district nursing etc. | 122 | 13.1 | 120 | 16.7 | 0.44 |
| -I am satisfied with the outpatient services provided by the hospital. | 127 | 6.3 | 127 | 8.7 | 0.47 |
| -I think the ambulance service is reliable. | 120 | 10.8 | 127 | 6.3 | 0.20 |
| -I am satisfied with the practical help I have received since I left hospital. | 124 | 8.1 | 128 | 14.1 | 0.13 |

**Table 5-11 continued.**

| Question | Treatment | | Control | | P Value |
|---|---|---|---|---|---|
| | n= | % Dissatisfied | n = | % Dissatisfied | |
| -I have received enough information about recovery and rehabilitation after stroke. | 128 | 12.5 | 135 | 25.2 | 0.009* |
| -Somebody has really listened and understood my needs and problems since I left hospital. | 125 | 8.8 | 132 | 22.0 | 0.004* |
| -I have not felt neglected since I left hospital. | 136 | 4.4 | 136 | 9.6 | 0.1 |
| -I have had enough emotional support since I left hospital. | 136 | 6.6 | 134 | 11.9 | 0.13 |
| -I have received enough special equipment. | 122 | 9.8 | 114 | 14.9 | 0.24 |
| -I know who to contact if I have problems relating to my stroke. | 135 | 4.4 | 138 | 11.6 | 0.03* |

*Statistically significant

Note: P values were calculated using the Chi Square statistic. This table lists questions in their original format.

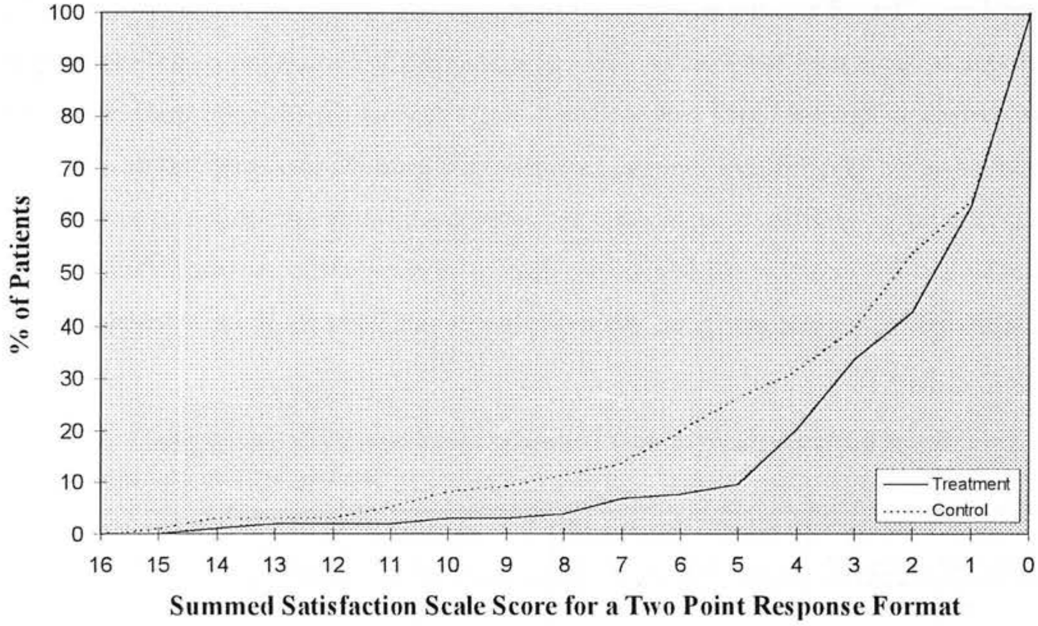
The number of patients answering each question differs because as patients completed the measure independently a 100% response rate was not obtained. Therefore all patients who have answered the question are included in the analysis even if they did not complete all 20 satisfaction scale questions.

### Summed Patient Satisfaction Scale using a two point response format

To gain an overall view of whether patients were satisfied with a greater number of aspects of their care in either the treatment or control group we summed answers to give a total score with each question being scored 0,0,1,1. This gives a possible score range of 0-20 with higher numbers indicating greater dissatisfaction. We analysed data using an independent T test to assess the difference between group means.

Treatment group patients were consistently and significantly more satisfied with their standard of care as reflected both in Figure 5-34 and mean (p=0.039) and median scores.

Figure 5-34: Comparative cumulative distribution of treatment and control group summed Patient Satisfaction Scale scores using a two point response format with descriptive statistics.



| P value = 0.039 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 103 | 2.0 | 1 | 0 - 14 |
| Control Group | 95 | 2.9 | 2 | 0 - 15 |

Note: P values were calculated using the T Test.

### *5.5.6 Service and Equipment Use*

I left our questionnaires on services and equipment received with patients for self completion. The questionnaire on services asked them not only which services had been received but also the provider, how often the service was received and for how long. Incomplete answers on forms returned and anecdotal evidence suggested that patients had difficulty with the latter parts of these questions and that data collected in these areas is unlikely to be accurate. Therefore further analysis of the provider of each service and the frequency of each contact was not undertaken due to the small numbers of accurately completed questions of this nature.

**Table 5-12: Comparison of services and equipment (categorised) received by patients in the treatment and control groups.**

| Services & Equipment | No. of Patients to Answer Question | | Treatment Group Received Service | | Control Group Received Service | | P Value |
|---|---|---|---|---|---|---|---|
| | Treatment Group | Control Group | No. | % | No. | % | |
| Physiotherapy | 133 | 134 | 43 | 32.3 | 51 | 38.1 | 0.33 |
| Occupational Therapy | 129 | 131 | 33 | 25.6 | 34 | 26 | 0.95 |
| Speech Therapy | 137 | 140 | 21 | 15.3 | 21 | 15 | 0.94 |
| Visited GP. | 136 | 139 | 100 | 73.5 | 102 | 73.9 | 0.91 |
| GP Home Visit | 136 | 142 | 74 | 54.4 | 71 | 50.4 | 0.54 |
| District Nurse | 136 | 143 | 53 | 39 | 46 | 32.4 | 0.24 |
| Home Help | 135 | 141 | 37 | 20.3 | 27 | 19.1 | 0.10 |
| Social Worker | 136 | 140 | 60 | 44.1 | 21 | 15.2 | <0.01* |
| Chiropodist | 135 | 140 | 47 | 34.8 | 45 | 32.4 | 0.73 |
| Meals on Wheels | 137 | 140 | 5 | 3.6 | 3 | 2.2 | 0.45 |
| Respite Care | 134 | 139 | 1 | 0.7 | 0 | 0 | 0.31 |
| Kitchen Aids | 134 | 142 | 16 | 11.9 | 27 | 19 | 0.12 |
| Bathing Aids | 136 | 142 | 51 | 37.5 | 50 | 35.2 | 0.69 |
| Seating Aids | 134 | 139 | 31 | 23.1 | 33 | 23.7 | 0.91 |
| Walking Aids | 135 | 139 | 43 | 31.9 | 35 | 25.2 | 0.22 |
| Lavatory Aids | 135 | 140 | 30 | 22.2 | 33 | 23.6 | 0.79 |
| Stair Aids | 124 | 130 | 18 | 14.5 | 19 | 14.6 | 0.98 |
| Wheelchair | 128 | 130 | 14 | 10.9 | 21 | 16.2 | 0.22 |

Note: Grouped equipment results are based on patients who answered one or more of the questions referring to equipment within each group.

Table 5-12 shows the services and equipment received by patients in the treatment and control groups reflecting answers to such questions as 'Have you seen a physiotherapist since leaving hospital? Yes or No'. A significant difference between treatment and control groups was evident only in the question regarding having seen a social worker, ($p<0.01$). In Table 5-12 questions concerning equipment received are categorised into areas. That is, patients are classed as having received a piece of bathroom equipment if they had received one or more of the items in that category. Individual items of equipment in each category and the number of patients in receipt are listed in Table 5-13.

**Table 5-13: Individual items of equipment received by patients in the treatment and control groups.**

| Equipment | | No. of Patients to Answer Question | | Treatment Group Received Service | | Control Group Received Service | | P Value |
|---|---|---|---|---|---|---|---|---|
| | | Treatment Group | Control Group | No. | % | No. | % | |
| Kitchen | Cup | 131 | 132 | 2 | 1.5 | 5 | 3.8 | 0.25 |
| | Cutlery | 133 | 137 | 11 | 8.3 | 20 | 14.6 | 0.1 |
| | Other | 127 | 132 | 9 | 7.1 | 13 | 9.8 | 0.43 |
| Bathing | Rail | 127 | 131 | 23 | 18.1 | 20 | 15.3 | 0.54 |
| | Seat | 132 | 139 | 39 | 29.6 | 42 | 30.2 | 0.9 |
| | Hoist | 120 | 127 | 2 | 1.7 | 3 | 2.4 | 0.7 |
| | Other | 115 | 124 | 5 | 4.3 | 10 | 8.1 | 0.24 |
| Seating | Chair | 131 | 136 | 25 | 19.1 | 21 | 15.4 | 0.43 |
| | Stool | 124 | 129 | 4 | 3.2 | 10 | 7.6 | 0.12 |
| | Other | 117 | 126 | 4 | 3.4 | 7 | 5.6 | 0.42 |
| Walking | Frame | 125 | 132 | 8 | 6.4 | 7 | 5.3 | 0.7 |
| | Stick | 132 | 136 | 33 | 25 | 27 | 19.9 | 0.31 |
| | Rail | 125 | 134 | 15 | 12 | 16 | 11.9 | 0.99 |
| | Other | 114 | 127 | 1 | 0.9 | 2 | 1.6 | 0.63 |
| Lavatory | Rail | 127 | 134 | 16 | 12.6 | 15 | 11.2 | 0.73 |
| | Raised Seat | 125 | 138 | 15 | 12 | 24 | 17.4 | 0.22 |
| | Commode | 127 | 134 | 12 | 9.4 | 10 | 7.5 | 0.56 |
| Stair | Rail | 122 | 127 | 16 | 13.1 | 18 | 14.2 | 0.81 |
| | Ramp | 122 | 125 | 4 | 3.3 | 0 | 0 | 0.04 |
| | Lift | 122 | 125 | 1 | 0.8 | 1 | 0.8 | 0.99 |
| | Other | 113 | 122 | 0 | 0 | 2 | 1.6 | 0.17 |
| Wheelchair | | 128 | 130 | 14 | 10.9 | 21 | 16.2 | 0.22 |

### 5.5.7 Subgroup analyses.

At the outset of the study we decided to adopt broad eligibility criteria, as it was unclear who, if anyone, would benefit from the SFCW. The resulting broad sample of patients could therefore be divided into subgroups in an attempt to identify any particular populations that gained benefit from the intervention. Subgroup analysis was undertaken only after a priori discussion of which subgroups would be clinically expected to gain from the intervention and analysis was only undertaken in these areas. With such large amounts of data, extensive subgroup analysis would be likely to suggest significant gains for some treatment group patients, and equally for some control group patients, but such results are likely to be spurious (Counsell et al., 1994). It should also be noted that significant effects from hypotheses that were not generated a priori can only be regarded as hypothesis generating.

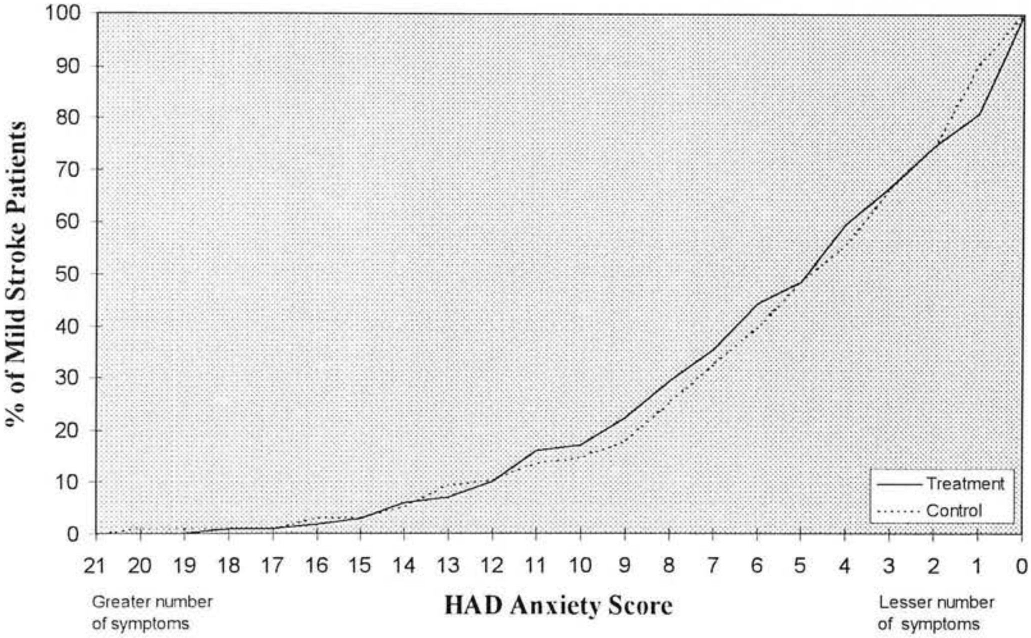
It has been suggested that anxiety is a reaction to a 'threat' whilst depression is a reaction to a feeling of loss. We therefore hypothesised that patients with mild strokes would be particularly susceptible to anxiety related disorders and those with more severe strokes to depression. The former case would be the result of anxiety about future health and the latter the realisation that a major medical event had occurred and recovery may be limited.

We therefore examined patients with mild strokes (defined as having a clinical prediction of Oxford Handicap Scale 0-2 at one year), and severe strokes (a clinical prediction of 3-6 at one year), for anxiety and depressive disorders in turn to determine if there was a treatment effect in either of these subgroups.

#### *5.5.7.1 Was there a reduction in anxiety amongst mild stroke patients?*

For those patients who had suffered a mild stroke (n=194). I compared the HAD Anxiety Subscale scores of those in the treatment and control groups using a Mann Whitney U analysis. Results indicated no significant difference in the levels of anxiety experienced by patients in the treatment and control groups (Figure 5-35).

**Figure 5-35: Comparative cumulative distribution of treatment vs. control group mild stroke patients Hospital Anxiety and Depression Scale Anxiety Subscale score with descriptive statistics.**



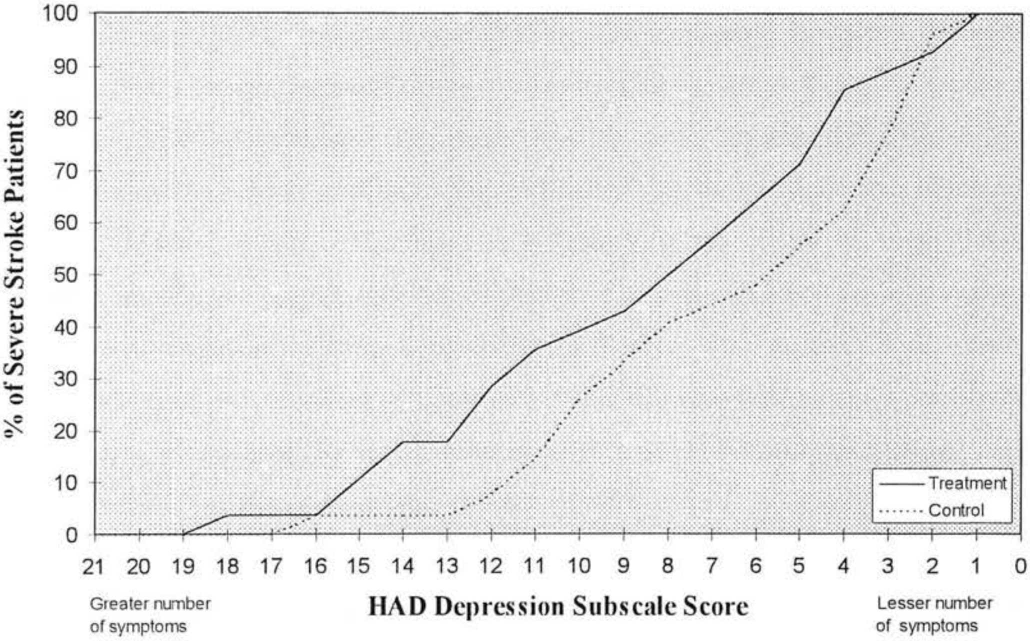
| P value = 0.95 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 99 | 5.3 | 4 | 0 - 18 |
| Control Group | 95 | 5.2 | 4 | 0 - 20 |

Note: P value was derived from Mann-Whitney U analysis.

### *5.5.7.2 Was there a reduction in depression amongst severe stroke patients?*

I compared the HAD Depression Scale scores of patients randomised after having a severe stroke (n=55). No significant differences were found between the treatment and control groups although there was a non-significant trend in favour of the control group (Figure 5-36).

**Figure 5-36: Comparative cumulative distribution of treatment and control group severe stroke patients Hospital Anxiety and Depression Scale Depression Subscale scores with descriptive statistics.**



| P value = 0.11 | No. of Patients | Mean | Median | Range |
|---|---|---|---|---|
| Treatment Group | 28 | 8.1 | 7.5 | 0 - 18 |
| Control Group | 27 | 6.2 | 5 | 0 - 16 |

Note: P value was derived from Mann-Whitney U analysis.

## 5.6 Previous studies of social work interventions after stroke.

In agreement with anecdotal and intuitive evidence, research has long suggested that social support exerts a positive effect on both mental and physical health (Friedland and McColl, 1987; Glass and Maddox, 1992; Weinert, 1987). In the field of stroke, the perception of social support and size of social network has been significantly associated with physical and psychosocial functioning, motivation, and with the presence, severity and duration of post stroke depression (Colantonio et al., 1993; Friedland and McColl, 1987; Glass and Maddox, 1992; Morris et al., 1991; Thompson et al., 1989). The mechanism for such a therapeutic effect is unclear, although two models have come to the fore, the Stress Buffering Hypothesis and the Main Effects Hypothesis. The stress buffering model suggests that social support works by intervening between, and protecting the patient from, the harmful effects of stressful life events (Minkler, 1990). This may be by mediating the effects of stress through reappraisal, an adaptive counter response, inhibition of maladaptive responses or dampening the body's neuroendocrine response (Broadhead and Kaplan, 1991). The alternative main effects model argues that social support promotes health in its own right regardless of the level of stress being experienced, for example members of a social network encouraging health promoting behaviours among one another (Minkler, 1990).

If access to social support can indeed exert such a positive effect, is it possible to enhance a persons' social environment to replicate this beneficial effect? There is evidence that social support can reduce psychiatric morbidity, especially in those who perceive their social networks to be non-supportive (Raphael, 1977). However, whilst acknowledging the protective effects of social support generally there is evidence that professional sources of social support may not provide such a positive effect (Friedland and McColl, 1987).

In an attempt to artificially create a supportive environment to mimic this protective effect the Chest, Heart and Stroke Association and individual health boards are presently funding four Stroke Family Carer Worker Posts and 25 assorted similar posts in Scotland. Similarly, in England and Wales NHS purchasing authorities may purchase such services from the Stroke Association. Currently in post are three full time and 39 part time, (25 hours), Stroke Family Care Workers or equivalent positions employed at a cost of approximately £13,000 per part time post. Thus considerable resources are invested in the creation and maintenance of specialist stroke social workers or community nurses. In addition, the existence of such posts may increase resource use by patients in their care who are referred for further treatment, care or equipment. We wished to evaluate the effect on patients of one such post.

Literature review reveals only four previously reported randomised controlled trials of social work intervention after stroke, three of which targeted stroke patients and one their carers (Christie and Weigall, 1984; Friedland and McColl, 1992; Towle et al., 1989*a*, 1989*b*; Evans et al., 1988; Table 5-14). Two of these patient orientated interventions found no measurable effect on patient outcome; the first in areas of depression, life satisfaction, ADL, service provision or functional independence, the second on social support and psychosocial outcome measures (Towle et al., 1989*a*, 1989*b*; Friedland and McColl, 1992). However, the numbers of subjects involved were extremely small (44 and 88) risking a type II error and included only patients more than one year after stroke.

The third, and somewhat larger (213 subjects) study targeting patients, also failed to identify any significant differences between patients on measures of 'activity-independence', or their use of health or community resources. However a non-significant difference was found in mortality between groups with treatment group patients appearing to gain some form of 'therapeutic' effect from their social work intervention (Christie and Weigall, 1984). The authors suggest this provides further evidence for the protective effect of social relationships which have been shown to reduce medium term mortality in community samples even when other risk factors are controlled for (Berkman and Syme, 1979; House et al., 1982).

A more marked effect of social work intervention after stroke has been found when the intervention was targeted at caregivers (Evans et al., 1988). Targeting carers in the period immediately after stroke with either an educational intervention or a combination of education and counselling appeared to improve caregiver knowledge and family stability at both six months and one year post stroke and was particularly marked in the latter combination condition.

**Table 5-14: Randomised trials of social work intervention after stroke.**

| Study Authors | Targeted Sample and Intervention | Assessment Measures | Treatment Effects Noted |
|---|---|---|---|
| Christie & Weigall, (1984) | Treatment n =110<br>Control n =103 | Death during study period | Trend toward lower mortality in treatment group (p=0.07). |
| | Stroke patients<br>> 2 years post stroke | Composite activity / independence score | No effect |
| | 7 contacts over 12 months; advice, counselling, therapy, crisis intervention, plus a stroke club. | Reported use of health and community resources | No effect |
| Evans et al. (1988) | Education group n=64<br>Counselling group n=61<br>Control group n=63 | Stroke Care Information Test | Both conditions better than control, 6 & 12 months*. |
| | Carers of stroke patients<br>Assessed 6 & 12 months after stroke.<br>Education group received 2 x 1 hour classes.<br>Counselling group received 2 1 hour classes and 7 hours of social worker counselling. | Family Assessment Device | Both conditions better than control on problem solving*, communication* and global family function* at 6 & 12 months and affective involvement* at 12 months. |
| | | The ESCROW Profile (social resources) | Counselling condition better than control for behaviour control* at 12 months. |
| | | Personal Adjustment & Role Skills Profile | No effect |

* Counselling condition improved patient adjustment.

**Table 5-14. continued.**

| Study Authors | Targeted Sample and Intervention | Assessment Measures | Treatment Effects Noted |
|---|---|---|---|
| Friedland & McColl, (1992) | Treatment n=48<br>Control n=40 | The Social Support Inventory for Stroke Survivors | No effect |
| | Stroke patients- mean 11.4 months post stroke | The Interpersonal Support Evaluation List | No overall effect, 3 significant questions noted. |
| | Assessed 3 & 6 months later | General Health Questionnaire - 28 item | No effect |
| | 6-12 sessions with patients &/or carers, psycho-educational approach to social support mapping | The Barthel Functional Index | No effect |
| | | The Sickness Impact Profile | No effect |
| Towle et al. (1989*a*, 1989*b*) | Treatment n = 21<br>Control n = 23 | Wakefield Depression Inventory | No effect |
| | Depressed stroke patients | General Health Questionnaire | No effect |
| | 16-39 months post stroke | Nottingham Health Profile | No effect |
| | 4 months of regular contacts with counselling and information | Life Satisfaction Index | No effect |
| | | Frenchay Activities Index | No effect |
| | | Services Questionnaire | No effect |
| | | Aids/Adaptations Checklist | No effect |
| | | Financial Benefits Questionnaire | No effect |
| | | Extended Activities of Daily Living Questionnaire | No effect |

However, social work has been shown to be more effective when used as a crisis intervention technique, that is, after a major life event, perhaps explaining why the one positive result involved immediate intervention (Evans et al., 1988). It may also be significant that the successful intervention was targeted at caregivers as it has been suggested that, as caregiver problems have a collective effect on rehabilitation outcome, treatment should reduce caregiver depression, minimise family dysfunction, and increase the families' knowledge about stroke care (Evans et al., 1991).

## 5.7 Discussion of the randomised trial of a Stroke Family Care Worker

The present study has established that our SFCW had a measurable effect on the levels of satisfaction with care felt by stroke patients. Little evidence has been found of an effect on patients in the areas of physical abilities, social activities, mood, social functioning, mental adjustment and service and equipment use.

Our results are remarkably similar to those of the three previous randomised trials of specialised stroke community workers who targeted patients (Christie and Weigall, 1984; Friedland and McColl, 1992; Towle et al., 1989*a*, 1989*b*) In agreement with these studies we found no significant treatment effect on patients' mood (Friedland and McColl, 1992; Towle et al. 1989*a*, 1989*b*), their physical functioning or participation in social activities (Christie and Weigall, 1984; Evans et al., 1988; Friedland and McColl, 1992; Towle et al. 1989*a*, 1989*b*), their social adjustment (Friedland and McColl, 1992) or their service and equipment use (Christie and Weigall, 1984; Towle et al., 1989*a*, 1989*b*). Thus the findings of the present trial appear to reflect those of previous patient targeted trials and in addition include a significant effect in a previously unmeasured area, patient satisfaction with care.

Patients in the treatment and control groups exhibited no differences in their physical functioning on either their BI or OHS scores. Any effect that the SFCW might have had on physical ability would necessarily have been indirect, as her role was not to undertake physical or occupational therapy. It could be hypothesised that an SFCW would increase patients' use of such services as physical and occupational therapy, through encouraging attendance and referral, leading to greater physical gains in the treatment group. However, a greater uptake of services amongst the treatment group was not recorded. Similarly, the SFCW may increase the provision of specialised equipment to the treatment group, the use of which may increase the physical functioning and independence of patients. Again, however, no increase in equipment provision was noted in the treatment group (see 5.5.6.).

Alternatively, it could be hypothesised that our SFCW would have a positive affect on patients' physical functioning by reducing their level of depression. Evidence exists that higher levels of depression are associated with increased physical disability perhaps through impeding gains from physical therapy (Morris et al., 1992, 1993a, 1993b; Parikh et al. 1987, 1990; Sinyor et al. 1986*a*), so a more depressed control group might be expected to have greater disability. However, a greater number of mood symptoms were not evident in the control group. If depressed mood is in reality inversely related to gains in physical therapy the direction of causality of this relationship would be debatable. Equal levels of mood disorder amongst treatment and control group patients may have helped to create equal levels of physical ability, or similar physical abilities may be reflected in similar frequency of mood disorder and levels of social functioning.

Trends on both the HADS subscales and the GHQ suggest that patients in the treatment group experienced more mood symptoms than those in the control group, although this trend is not statistically significant either when measures were treated as continuous variables or when recommended cutting points were used. We had anticipated that treatment group patients would experience fewer mood symptoms as a result of increased information, advice, counselling, services and support.

It could alternatively be hypothesised that a 'practice' effect might occur, whereby treatment group patients may display a greater ability and willingness to voice their mood symptoms as a result of already having been encouraged to do so by the SFCW. Such an effect may explain the slight trend in favour of the control group or indeed, if large enough, cloud a treatment effect. Alternatively, it may be considered that the greater discussion of difficulties amongst the treatment group may have increased the awareness of the mood symptoms themselves.

The treatment group patients were significantly more helpless / hopeless than those in the control group. This suggests that treatment group patients may have considered that the role of confronting or fighting their illness was performed more effectively by the SFCW who would have appeared capable and knowledgeable. This is supported by the non-significant trend of treatment group patients to have less fighting spirit than control group patients. The giving up of this role may have led subsequently to a rise in feelings of helplessness / hopelessness.

There was a non-significant trend for control group patients to report more anxious preoccupation than those in the treatment group. Such a trend might reflect, as we would expect, that treatment group patients may have been provided with more information, have more opportunities to discuss their concerns and be more aware of whom they could turn to for help.

The FAI reflected remarkably little difference between patients in the treatment and control groups. This was true both for the total score and for the analysis of individual questions where the difference between groups never reached a significance level of more than 10%. The FAI included at least four items we hypothesised our SFCW could influence. These included whether the patient had been on any social outings or outings/car rides, or was pursuing a hobby or reading books. Her ability to affect the remaining items may have been more tenuous, as these were more reliant on physical capabilities, including such activities as gardening, washing dishes, household or car maintenance, housework and employment.

We hypothesised that our SFCW would encourage and aid the maintenance of normal social functioning, not only through the direct means of increasing attendance at stroke clubs and day hospitals but more subtly by smoothing family relations through this difficult period of adjustment and increasing patients' confidence with their new body image. However, such an effect was not evident in patients' social adjustment scores where there was little difference between treatment and control groups.

A trend suggesting greater well being in the control group was observed for the Family and Partner subscales and for the total score which almost reached statistical significance ($p=0.06$). A possible explanation for such a trend is that treatment group patients chose to confide their feelings in the SFCW although this would not register on this scale. In contrast control group patients may have confided in friends and family members and would therefore gain higher social functioning scores.

Treatment group patients were significantly more satisfied with three aspects of their care; that they had received enough information about recovery and rehabilitation after stroke, that somebody had really listened and understood their needs and problems, and that they knew who to contact if they had any problems relating to their strokes. It is interesting to note that the three questions for which there was a significant difference between treatment and control groups were all additional questions added for the purpose of the present study and that two of the three had perfect test-retest reliability (Kappa of 1.0) (refer to 2.7.5.1.). The additional questions were designed to specifically assess those areas we thought that the SFCW would target and where she would be most likely to make a difference. Thus the areas in which she had a significant effect, information provision, empathic listening and 'being available', are precisely those in which an effect was predicted.

Trends suggested greater satisfaction in the treatment group for 85% of the questions asked. These results suggest that the SFCW made a tangible difference to patients' perceptions of their professional care and that they valued her input. However, it could be questioned whether satisfaction is a legitimate outcome measure, as it is a relatively intangible concept that lacks the simple appeal of outcomes reflecting patients' independence, functional ability or mood symptoms reported. Satisfaction traditionally refers to the satisfaction of a desire or the gratification of a feeling, but in terms of satisfaction with treatment and care it may refer more accurately to the gap between reality and expectation. That is, patients have an expectation of the care and treatment that they *should* receive and it is the shortfall between this expectation and the reality of the treatment and care that they *do* receive that determines satisfaction or lack of it.

There are two possible explanations for why the treatment group expressed greater satisfaction with their level of care. Patients may have valued the input of the SFCW and answered many of the questions with her intervention in mind, for instance those concerning emotional support, being listened to and understood, and the provision of adequate information. The fact that those individual questions on which a significant difference between treatment and control groups was noted reflect precisely those areas that could have been answered with reference to the SFCW's intervention, as they were designed to do, support this idea. A second explanation for greater satisfaction in the treatment group is that our SFCW may have reduced the gap between reality and expectation. For example, helping patients and their families to realise that they are unlikely to regain any more physical ability and that further therapy will not be of benefit, may reduce the dissatisfaction voiced in response to the 'They have had enough therapy' question.

No differences were evident between treatment and control groups for either their use of services or in the quantity of equipment they had received. The one significant difference was that treatment group patients reported having seen a social worker more often since their discharge from hospital. Our SFCW was perceived by patients as a social worker and no question specifically referred to her input; it is therefore reasonable to presume that the responses of patients in the treatment group merely reflected the trial intervention. The fact that no differences were evident also suggests that the SFCW did not result in a rise in the indirect costs that would be associated with any rise in service or equipment use.

While our trial illustrated greater treatment satisfaction amongst treatment group patients it is perhaps surprising that no significant differences were found in patients' physical functioning, mood symptoms, social activities or social adjustment. Such domains represent areas in which it could have been predicted that our SFCW could have contributed to improvement by such means as increasing referrals to therapy, increasing outpatient attendance, counselling, information provision or equipment provision. A number of possible explanations exist for such an effect not being found.

a) Perhaps the most relevant of these is the context in which our intervention took place, i.e. within a well organised stroke service. Specialist stroke social worker posts have been created in addition to the traditional medical /therapy model of care and function in parallel with those services normally available to patients after stroke. Likewise our service existed in conjunction with normal hospital discharge planning and the hospital social worker who traditionally was responsible for stroke patients. For ethical reasons, and also to reflect normal hospital functioning, control group patients received all normal, that is pre-SFCW, care, including contact with the hospital social worker where appropriate. During the study period the study hospital provided a specialised stroke unit with a multi-disciplinary rehabilitation team providing a very cohesive, well organised service with excellent social work support. Thus the trial was attempting to identify a significant treatment effect of our SFCW over and above that already available. While the results of the present study are valid in similar hospital settings it may be that a significant treatment effect would have been observed in more domains had the intervention been in the context of a poorer initial service.

b) The responses of treatment group patients may have been influenced by a practice effect. That is, extensive discussion of difficulties and negative emotions, both experienced and to be expected, may have resulted in treatment group patients being more aware, less reticent, and better able to voice symptoms than those in the control group. Such an effect could result in the clouding of any treatment effect as the responses of control group patients may represent an underestimate of their real symptoms, that is the responses of those in the treatment and control groups may not be comparable.

c) Our treatment and control groups may not have been adequately balanced by our randomisation process. For those baseline factors that we collected our groups were well balanced at baseline suggesting our randomisation was effective. However, we did not collect information on patients' medical coping modes, their mental adjustment or their locus of control at baseline. For example, our finding that treatment group patients are more helpless / hopeless may be the result of an unbalanced randomisation. Further analysis of treatment and control group patients on those measures which were considered to have a bearing on the mechanisms of psychosocial outcome, the MAS Scale and the MCMQ, illustrated some interesting differences between the groups. On the MAS Scale's continuum of Fighting Spirit to Helplessness treatment group patients appeared significantly more helpless, an adjustment associated with increased risk of mood disorder. On the MCMQ treatment group patients were significantly less likely to possess a predominantly Confrontational coping mode, associated with reduced risk of mood disorder, and significantly more likely to possess an Avoidant or Accepting/Resigned coping mode, associated with greater risk of mood disorder. Thus it appears that both in terms of mental adjustment and coping modes treatment group patients were at significantly more risk of mood disorder. It is important to consider the extent to which one's coping mode and type of mental adjustment are stable personality traits as opposed to responses to the circumstances with which patients are faced. If these traits are stable personality characteristics they could have obscured any treatment effects. Patients with a pre-disposition to unhelpful coping and adjustment strategies associated with greater risk of mood disorder may have been more often randomised to the treatment group. Alternatively if these traits are considered adaptive responses to life events then it must be considered whether the obtained result constituted a negative treatment effect. That is, did the existence of the intervention lead patients to entrust the role of confronting or fighting the illness to the SFCW, in turn not allowing themselves to benefit from the positive role of confronting or fighting the illness themselves? If such a transaction did take place, making patients more susceptible to mood symptoms through their predominantly avoidant or resigned coping mode or more 'helpless/hopeless' mental adjustment, treatment group patients should appear to suffer from more mood symptoms than those in the control group. We found no evidence that this was the case. This reflects either that for this sample a more 'helpless/hopeless' mental adjustment and avoidant or resigned coping mode was not associated with an increase in mood symptoms (although this was not the case taking the sample as a whole, see 4.1.1.); or that treatment group patients, while suffering an increase in mood symptoms via this mechanism, also benefited from a decrease in mood symptoms through the intervention by some alternative mechanism and that the interplay between the two resulted in comparable levels of mood symptoms in both treatment and control groups. A final explanation is that the significant differences between treatment and control groups' mental adjustment and medical coping modes may be the result of chance in the context of a large collection of measures.

d) With our large battery of tests it seems unlikely that we failed to measure a domain over which our SFCW had a significant effect, although this must remain a possibility. We attempted a priori to consider all areas in which a treatment effect may have occurred and designed our follow up interview specifically to measure these. If a further domain exists which we failed to measure and in which our SFCW would have had an effect the relevance in terms of patients' well-being must be questioned.

A more likely possibility is that one or more of our outcome measures lacked either validity or sensitivity. It may have failed to measure the domain it purported to measure as accurately as was necessary, or failed to identify a large enough proportion of genuine cases, (i.e. low sensitivity, a high false negative rate). We gave careful consideration to the choice of measures, and while the resulting test battery often represented a compromise of the best of those that were available and practical, we carefully assessed all in terms of their reliability, validity, sensitivity, specificity, communicability and previous use in stroke. Thus while we acknowledge that our measures may have been inadequate they represent the most suitable of those available.

e) We suspect that our choice to conduct our follow up interviews six months after randomisation, within seven months of stroke, may have been too early. At six months many traditional support services such as continuing therapy and outpatient clinic follow up appointments are still ongoing providing patients with continuing care and attention and, through these, hope that their recovery process is still ongoing. It may be that it is at one year after stroke, when traditional hospital input has ceased and patients realise that their recovery may have come to an end, that they are most vulnerable to psychosocial difficulties. Unfortunately, whilst this factor was recognised during the trial's initial planning, funding constrained the duration of follow up.

f) Treatment group patients may not have received an adequate 'dose' of our SFCW to produce a significant impact, with 20% of patients receiving one or no contacts, and only 57% of patients receiving three or more contacts. Our choice not to specify the number of contacts per patient was deliberate. This enabled our intervention to mimic, and therefore provide information on, the real workings of someone in such a post who we felt would respond to needs as and when they arose. Further, had we specified the number of contacts per patient, patient consent would have been neccessary, which for a number of reasons we felt was not ideal (refer to 2.4.).

g) We may have randomised too few patients for the study to gain enough power to show a treatment effect. However, this is unlikely as we did not find a consistent trend in favour of the treatment group.

h) It is possible our broad eligibility criteria meant that the effect of our SFCW on a particular subgroup was diluted by the rest of our patients. Before embarking on our subgroup analysis we were careful to consider those subgroups in which it would make clinical sense for the intervention to produce a benefit. With such a large number of outcome measures the risk existed that we could find a subgroup in which the treatment group's benefit was statistically significant by chance alone (Counsell et al., 1994). To avoid this risk, and that of sample numbers becoming too small, we limited our analysis to only two patient subgroups. Therefore the possibility remains that by taking care to avoid indiscriminate analysis and the accompanying risk of spurious significant results we failed to identify a subgroup of patients or carers that genuinely benefited from the intervention.

We assessed the outcome of one further group, the primary carers of patients randomised to the trial. Whilst carers do not form the focus of this thesis they were assessed (n=231) using a battery of tests similar to those for the patients, again completing a primary measure during my assessment visit and a secondary measure that was completed and returned independently. Carers completed the Frenchay Activities Index, the General Health Questionnaire - 30, the Social Adjustment Scale, the Caregiving Hassles Scale, the Hospital Anxiety and Depression Scale and a Carer Satisfaction Scale. Only one significant difference was found between carers who (matched with their care-recipient) were randomised to the treatment and control groups: treatment group carers were significantly more satisfied with their treatment than those in the control group.

Therefore we have identified a positive effect of our SFCW on both patient and carer outcome: both experience improved satisfaction with treatment. The issue is what value we place on their satisfaction. Satisfied patients are more likely to comply with medical advice but patients may be satisfied even when they have received inappropriate investigations or incorrect diagnoses (Hopkins, 1990). Is the cost of the salary of an SFCW a reasonable price to pay for the increase in satisfaction amongst the families that they contact?

Our trial was of only one SFCW in one centre where we were attempting to show a treatment effect over and above that of an already well organised stroke service. The question remains whether significant effects on other domains of outcome would be evident in different settings. Future trials need to be conducted in other centres; indeed two are already underway in Oxford (Wade, 1996) and Newcastle (Barer, 1996). In addition, future treatments may wish to adopt a more focused approach to this sort of intervention. For example, an ongoing trial in Leeds is examining the effect of psychiatric nurses specifically attempting to influence the way in which patients view and approach their illness, teaching them 'empowerment' (House, 1996). We look forward with interest to their results.

# 6. Summary

Six months after their strokes, our sample of hospital referred patients reported many psychosocial difficulties. Half of all patients were dependent on others for basic activities of daily living, a quarter were classed as having a mood disorder and a negative mental adjustment and almost a fifth reported social adjustment difficulties and little or no social activity. Thus, even six months after the onset of their strokes when 87% of patients had returned home to attempt to resume their pre-morbid lifestyle, many were experiencing a significant impact on their quality of life from poor psychosocial recovery.

This description of psychosocial outcomes after stroke cannot be said with certainty to be typical either of all stroke patients or even of all hospital referred stroke patients. Our patients underwent a number of selection processes before entry into the trial and any other hospital referred sample to whom we may wish to apply our results will have undergone similar selection biases unique to that hospital. An ideal study of psychosocial outcome after stroke would include all cases of stroke occurring in a well defined population thus avoiding selection bias. Within the confines of our study some further improvements could have been made in its evaluation of the frequency of psychosocial outcomes. It would have been interesting to have collected information on patients' pre-morbid functioning through an interview with either the patient or their carer soon after onset. Whilst these data would have been vulnerable to the various biases associated with retrospectively collected data they might have provided a valuable insight into whether patients' functioning remained stable, improved or declined over the follow up period. Similarly, a control group would have allowed us to identify if stroke patients experience more difficulties than, for example, age matched controls or whether their psychosocial functioning is different to that of patients with disability from another source. It may also have been interesting to observe change in patients over time if our primary outcome measures had been administered at a uniform point soon after onset as well as at six months. This study has illustrated the relevance and practicality of a range of, hitherto little used, measures of psychosocial outcomes for use in stroke. We also examined the reliability and validity of some of these. Our reported frequencies might also aid future researchers in estimating the sample sizes they would need to show a treatment effect between groups. For example, our description of the distribution of GHQ scores in our sample would allow the calculation of the number of patients who would have to be randomised to illustrate a 10% improvement in patients' GHQ scores.

All domains of psychosocial outcome were inter-related. Each area; disability, mood, social functioning and satisfaction with treatment were all significantly associated with one another. This relationship could be the result of a genuine relationship between these domains of outcome. Alternatively it could reflect either that the measures lack validity or that the concepts they are purporting to measure overlap with one another. I have noted that some of our measures contain questions that possess face validity as questions of domains of outcome other than that which they profess to measure. For example, many questions on the Social Adjustment Scale or Patient Satisfaction Scale appear also to measure mood. This could mean that these measures lack internal consistency (not all questions measure the same outcome), discriminative validity (the extent a measure does not correlate with measures of different entities) or that it is the definitions of the concepts themselves that overlap. Unlike the internationally defined concepts of specific mental disorders through classification systems such as the Diagnostic and Statistical Manual of Mental Disorders or Research Diagnostic Criteria, domains of outcome such as social adjustment, patient satisfaction and mental adjustment have no definitive criteria. Often they are simply defined as the outcome assessed by a certain measure. In turn studies adopting different measurement scales may also be adopting different definitions of the domain they wish to assess. Before we can be confident of conclusions regarding whether a genuine relationship exists between variables further research needs first to examine the nature of the domains of outcome themselves and attempt to gain a consensus definition between health specialities.

The area that consistently explained most of the variance in patients' psychosocial outcome measures was their severity of disability. It was therefore factors at baseline that predicted severity of physical disability that proved the best predictors of which patients were likely to experience psychosocial difficulties. Both our models predicting patients' mood and their participation in social activities at six months included whether patients' had suffered a motor deficit, whilst the six variable model predicting mood and that predicting social activity both included whether the patient could stand at time of assessment. The two models of mood both included whether the patient had suffered a TACS, reflecting both site and size of lesion and the likely severity of disability. Our second model predicting mood used only two variables, whether the patient had suffered a TACS or any motor deficit and classified a higher percentage of patients correctly than its counterpart requiring more information. Thus all of our models attempting to predict patients' psychosocial outcome at six months from variables available soon after onset indicate the importance of severity of disability in understanding patients' psychosocial outcome. Our models now need to be examined for their biological plausibility and their practicality for use in a clinical setting. Even if our models do fulfil these requirements our assessment of their accuracy using the data set from which they were developed represents a 'self fulfilling prophecy'. Before we can confidently suggest that our models would be useful in clinical practice they would have to be tested in an independent cohort.

The clues to the predictors of psychosocial outcome that our models provide might be useful in the context of the increasing interest in comparing the performance of different providers of stroke services. The government are very keen to use patient outcomes to reflect these differences in performance. However, several factors determine patient outcome including casemix, treatment received, method of measurement and chance. Davenport et al. (1996) have demonstrated how important adjustment for casemix is in interpreting the difference in patient outcomes after stroke. Factors which predict outcome may be useful for adjusting for differences in casemix but little is known about the factors which predict psychosocial outcome. Purchasers and providers of health services are interested in using psychosocial outcomes (e.g. patient satisfaction and mood) to reflect the care patients have received so that a greater knowledge of those factors that predict psychosocial outcomes will be necessary to allow successful comparison between cohorts in this domain.

The ability to predict which patients are likely to experience poor psychosocial outcome is of little use if such knowledge does not facilitate efforts to prevent or improve their outcome. Without effective therapeutic interventions, knowledge of the existence or causes of problems, and the ability to identify patients at risk is of little benefit. Our attempt to evaluate an increasingly popular intervention, an SFCW working at one centre, did not demonstrate a significant affect on patients' psychosocial outcome although patients were significantly more satisfied with their care. However, we learnt much which could help future researchers in this field. In this study we have demonstrated that satisfaction with treatment, a previously neglected outcome, may be influenced by a therapeutic intervention and is significantly associated with other areas of psychosocial outcome. We have illustrated that it is possible to conduct methodologically sound randomised trials on a psychosocial intervention and that it is possible to keep patients blind as regards allocation to intervention. An additional aspect of patients that researchers may wish to use in randomisation, their mental adjustment, was discussed and a possible focus for intervention, namely encouraging realistic expectations for recovery, was suggested.

Our randomised controlled trial was methodologically sound but was limited in its generalisability through its focus on one person at one centre. Now that we have demonstrated the feasibility of such a trial an obvious next step would be to conduct a multicentre randomised trial, or several single centre trials using similar methodology to allow a prospective meta-analysis, the results of which would reflect the influence of different occupants of such a post at different centres. In addition, as we have highlighted at least one area where a possible personality trait, mental adjustment, may influence patient outcome, it may be useful to assess such traits and psychological functioning soon after onset to ensure that treatment and control groups are equal at baseline.

I hope that this study has further elucidated the problem of poor psychosocial outcome after stroke to allow its more effective identification and treatment and therefore contribute in some small way to the alleviation of patients' suffering.

# Appendix A

## Neurological Assessment Form:
## For collection of patients' baseline data.

# *LOTHIAN STROKE REGISTER*

## Personal details

*Please PRINT all details in **BLACK** ink*
*Use reverse for details or narrative*

| | | | | | | |
|---|---|---|---|---|---|---|
| **Study No.** | | | | | | |

**WGH Hospital No.** WG0 ____________ **NHS no.** ____________

| | | | | | | | | |
|---|---|---|---|---|---|---|---|---|
| **DCN X-ray no.** | | | / | | | | | |

**Surname** ____________ Title ____________

Forenames ____________

Address ____________

____________

Postcode ____________ Tel. No. ____________

Date of birth / / Sex **M** / **F** *(circle)*

**Next of kin / Contact person** ____________

Address ____________

____________

Postcode ____________ Tel. No. ____________

**General Practitioner** ____________

Address ____________

____________

Postcode ____________ Tel. No. ____________

**Patient of interest ?** **Y** / **N** Reasons :
*(circle)*

*(continue overleaf)*

## Admission details

Name : ____________ No. : ☐☐☐☐☐☐

Inpatient : **Y / N** *(circle)* Time ___:___ Date ___/___/___ of admission

*Time is by 24 hour clock, dates are dd/mm/yy* *(if known)* Date ___/___/___ of discharge

**Consultant** *(circle)* JLA / REC / MSD / RG / LK / CL / CMcK / JDM / PLP / WHP / TR / PAGS / RS / PFXS / AJS / CPW / DW / IW / RW / other :

Time ___:___ Date ___/___/___ of examination

Examined by *(circle)* RJD / MSD / PD / PAGS / CPW / other :

---

## Summary of this event

Focus of event : **Brain / Eye** *(circle)* Abnormal neurological signs on examination : **Y / N** *(circle)*

| | | | |
|---|---|---|---|
| **Final diagnosis** Stroke ( > 24 h ) | ☐ | *Code 1 = possible* | *(NOT permitted for RAO)* |
| Transient Ischaemic Attack ( < 24 h ) | ☐ | *2 = probable* | *(NOT permitted for RAO)* |
| Retinal Artery Occlusion *(RAO)* | ☐ | *3 = definite* | |
| Other *(specify):* | ☐ | *9 = not applicable* | |

*Include events within the last 6 months only. Leave no blanks.*

---

## Patient history

*Code boxes 1 = Yes, 2 = No, 9 = unassessable, Blank = may be completed later.*

| | | | |
|---|---|---|---|
| Patient able to give adequate history | ☐ | | |
| Previous Myocardial Infarction | ☐ | Year *(if known)* | ☐☐☐☐ |
| Previous stroke with residual disability | ☐ | Year *(if known)* | ☐☐☐☐ |
| Previous stroke without residual disability | ☐ | Year *(if known)* | ☐☐☐☐ |
| Previous TIA *(specify territories in narrative)* | ☐ | | |
| Previous carotid endarterectomy | ☐ | Year *(if known)* | ☐☐☐☐ |
| *(Code side of CEA 1 = R, 2 = L, 3 = both, 9 = not known)* | | Side *(if known)* | ☐ |

| | | | |
|---|---|---|---|
| Hypertension *(history or treatment at any time)* | ☐ | Non-caucasian *(specify):* | ☐ |
| Angina pectoris known before stroke | ☐ | Alcohol > 2 units daily | ☐ |
| Atrial fibrillation known before stroke | ☐ | Current smoker | ☐ |
| Breathless walking on an incline | ☐ | Ex-smoker > 12 months | ☐ |
| Cardiac surgery *(specify):* | ☐ | Employed until this event | ☐ |
| Intermittent claudication | ☐ | Car driver in past 3 months | ☐ |
| Peripheral vascular surgery | ☐ | Lives alone | ☐ |
| Diabetes mellitus known before stroke | ☐ | Known prior malignancy | ☐ |
| Epilepsy known before stroke | ☐ | | |
| History of migraine with aura | ☐ | | |
| Oxford Handicap Scale before stroke *(Modified Rankin Scale)* | ☐ | | |

*Oxford Handicap Scale:*
*0 = no symptoms*
*1 = minor symptoms which do not interfere with lifestyle*
*2 = some restriction to lifestyle, but look after themselves*
*3 = significant restriction to lifestyle, preventing total independence*
*4 = severe handicap preventing independent existence but not requiring constant attention*
*5 = severe handicap, totally dependent, requiring attention night and day*

## Treatment

*Code boxes 1 = Yes, 2 = No, 9 = unassessable, Blank = may be completed later.*

| | At time of event | Started since event |
|---|---|---|
| Antiplatelet | ☐ | ☐ |
| Anticoagulant | ☐ | ☐ |
| Antihypertensive | ☐ | ☐ |
| Anticonvulsants *(if history of epilepsy)* | ☐ | |
| Antifailure | ☐ | |
| Contra-indications to antithrombotics | ☐ | |

*List all drugs in use at examination (in narrative) :*

## General Examination

Blood pressure

*(admission)* ________ / ________

*(examination)* ________ / ________

| | R | L |
|---|---|---|
| Cervical Bruits *(specify)* | | |
| Noted by referring doctor | ☐ | ☐ |
| Seen at examination | ☐ | ☐ |

| | |
|---|---|
| Clinical heart failure *(ie signs of LVF / RVF, not just on Rx, specify)* | ☐ |
| Clinical valvular heart disease *(not simple flow murmur < 2/6, specify)* | ☐ |
| Peripheral vascular disease *(both foot pulses absent or femoral bruits)* | ☐ |
| Irregular pulse | ☐ |
| Right handed | ☐ |
| Left handed | ☐ |

## Brain Symptoms > 24 hours

*Skip for patients NOT exhibiting brain symptoms longer than 24h*

**History of ictus** Time ____:____ Date ____/____/____ symptoms first noticed

*Time is by 24 hour clock, dates are dd/mm/yy* Time ____:____ Date ____/____/____ of maximum deficit

| | |
|---|---|
| Symptoms present on waking | ☐ |
| Headache within 2 hours of onset | ☐ |
| Vomited since symptom onset | ☐ |
| Loss of consciousness at onset | ☐ |
| Drowsiness since symptom onset | ☐ |

Seizure(s) since symptom onset ☐

- date ____/____/____ of first

- confirmed ☐ seizure ?

- type ☐ *(1=General, 2=Partial, 9=uncertain)*

- number ☐ *(Use 9 for 9 or more)*

## Mental Test Score *(Hodkinson, tick below, score 0-10)*

| | |
|---|---|
| Age | ☐ |
| Time | ☐ |
| 42 West St. *(ask patient to recall at end)* | ☐ |
| Name of Hospital | ☐ |
| Year | ☐ |
| Recognise 2 people *(eg. Dr. and Nurse)* | ☐ |
| Date of birth | ☐ |
| Dates of World War I or II | ☐ |
| Present Monarch | ☐ |
| Count down from 20 to 1 | ☐ |
| **Total** | ☐ |

*(Code '88' if clinically unassessable)*

## Stroke diagnosis

Side of brain lesion *(one only)* ☐

*1 = right*
*2 = left*
*3 = brainstem / cerebellum*
*4 = uncertain*
*5 = bilateral*

Clinical classification *(one only)* ☐

*1 = TACS*
*2 = PACS*
*3 = LACS*
*4 = POCS*
*5 = uncertain*

Clinical prediction of outcome at 1 year ☐ *(0 - 6 on Rankin Scale)*

## Persistent Neurological Signs

*Skip this page for patients NOT exhibiting neurological signs at examination and skip for patients NOT exhibiting brain symptoms longer than 24h*

### Glasgow Coma Scale *(circle below, score 3-15)*

| | | |
|---|---|---|
| **Eye Opening -** | Never | 1 |
| | To pain | 2 |
| | To sound | 3 |
| | Spontaneously | 4 |
| **Best Motor -** | None | 1 |
| | Extend to pain | 2 |
| | Abn flex to pain | 3 |
| | Flex to pain | 4 |
| | Localises pain | 5 |
| | Normal | 6 |
| **Best verbal -** | None | 1 |
| | Noises only | 2 |
| | Inappropriate | 3 |
| | Confused | 4 |
| | Normal | 5 |
| **Total** | | ☐ |

Dysphasia ☐ *(circle)*
Fluent /
Non-fluent /
Other *(specify)* :

Dysarthria ☐

Other cortical signs ☐ *(circle)*
Dyspraxia /
Neglect /
Sensory inattention /
Visuospatial dysfunction

*Code boxes 1 = Yes, 2 = No, 9 = unassessable, Blank = may be completed later.*

| | **R** | **L** |
|---|---|---|
| Hemianopia | ☐ | ☐ |
| Visual inattention | ☐ | ☐ |
| Gaze palsy to this side | ☐ | ☐ |

Abnormal swallowing ☐

Motor deficit *(if yes, code next column)* ☐ If 1 → Motor deficit code

Sensory deficit *(if yes, code next column)* ☐ If 1 → Sensory and cerebellar abnormalities code

Cerebellar deficit *(if yes, code next column)* ☐ If 1 → Cerebellar function and co-ordination

Truncal ataxia ☐
Unable to sit independently ☐
Unable to stand independently ☐
Unable to walk independently ☐
Incontinence since stroke ☐
Bilateral extensor plantars ☐
Neck stiffness ☐
Definite brainstem signs ☐

### Deficit Severity Codes

| | **R** | **L** |
|---|---|---|
| **Motor deficit code:** | | |
| *1 = no deficit, 2 = mild, 3 = moderate, 4 = severe* | | |
| Face | ☐ | ☐ |
| Arm | ☐ | ☐ |
| Drift | ☐ | ☐ |
| Hand | ☐ | ☐ |
| Fine finger movements | ☐ | ☐ |
| Leg | ☐ | ☐ |
| **Sensory and cerebellar abnormalities code:** | | |
| *1 = normal, 2 = reduced, 3 = severely impaired / absent* | | |
| Sensation - proprioception | | |
| Arm / hand | ☐ | ☐ |
| Leg | ☐ | ☐ |
| Sensation - spinothalamic (pain and touch) | | |
| Face | ☐ | ☐ |
| Arm / hand | ☐ | ☐ |
| Leg | ☐ | ☐ |
| **Cerebellar function and co-ordination** | | |
| Arm | ☐ | ☐ |
| Leg | ☐ | ☐ |

## Eye Symptoms / Brain Symptoms lasting < 24h

*Skip this page for patients ONLY exhibiting brain symptoms lasting longer than 24 hours*

*Code sides : 2 = Probable, 3 = Definite, 9 = none. Probable is NOT accepted for RAO.*

| Type | | | Date of first | Date of last | Duration of longest (hh:mm) | Total number |
|---|---|---|---|---|---|---|
| RAO | **R** | ☐ | ___/___/___ | ___/___/___ | n/a | n/a |
| | **L** | ☐ | ___/___/___ | ___/___/___ | n/a | n/a |
| A Fx | **R** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| | **L** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| Cortical | **R** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| | **L** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| LACS | **R** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| | **L** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| POCS | **R** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| | **L** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |
| | **M** | ☐ | ___/___/___ | ___/___/___ | : | ☐ |

## Registration

*Code boxes 1 = Yes, 2 = No, Blank = may be completed later.*

Enter patient into Register ☐

Enter patient into Follow up ☐

**Trials**

| | Eligible | Randomised |
|---|---|---|
| IST | ☐ | ☐ |
| IST 2 | ☐ | ☐ |
| CAPRIE | ☐ | ☐ |
| MAST | ☐ | ☐ |
| NASCET | ☐ | ☐ |
| SFCW | ☐ | ☐ |

**Studies**

| | |
|---|---|
| MRS | ☐ |
| ULTRASOUND | ☐ |
| SECONDARY INSULTS | ☐ |
| PICH | ☐ |
| Other CRI imaging | ☐ |

## Investigations

| Test | Ordered | Date done | Results | |
|---|---|---|---|---|
| Haemoglobin | ☐ | ___/___/___ | ☐☐ ● ☐ | g/dl |
| Haematocrit | ☐ | ___/___/___ | ☐☐ ● ☐ | % |
| Platelets | ☐ | ___/___/___ | ☐☐☐☐ | x $10^9$/l |
| ESR | ☐ | ___/___/___ | ☐☐☐ | mm/hr |
| Urea | ☐ | ___/___/___ | ☐☐ ● ☐ | mmol/l |
| Glucose | ☐ | ___/___/___ | ☐☐ ● ☐ | mmol/l |
| Cholesterol | ☐ | ___/___/___ | ☐☐ ● ☐☐ | mmol/l |
| ECG | ☐ | ___/___/___ | If 1 → | |
| Doppler *(but not in study)* | ☐ | ___/___/___ | | |
| Trans-thoracic echocardiogram | ☐ | ___/___/___ | | |
| Trans-oesophageal echocardiogram | ☐ | ___/___/___ | | |
| CT | ☐ | ___/___/___ | | |

| | |
|---|---|
| Atrial fibrillation | ☐ |
| Bundle branch block | ☐ |
| ST segment change | ☐ |
| LVH | ☐ |
| Acute MI | ☐ |
| Old MI | ☐ |
| Normal | ☐ |

# Appendix B

## The Primary Patient Questionnaire

## *PATIENT*

Patient Name:..............................................................................................

Patient Number:..........................................................................................

Date of Birth:..............................................................................................

Date & Time of Interview:.........................................................................

Address:.....................................................................................................

..................................................................................................................

Tel. No:.......................................................................................................

Carer: YES/NO

P1) Is the patient alive? Yes ☐ No ☐

P2) Do you require help from another person for everyday activities ?

Yes ☐ No ☐

P3) Do you think you have made a complete recovery from your stroke?

Yes ☐ No ☐

P4) __________ Age of Patient

__________ Time, to nearest hour

__________ Address given, for recall at end of test: 42 West St.

__________ Name of area of town, (or hospital).

__________ Year

__________ Date of birth of patient

__________ Month

__________ Years of first world war

__________ Name of monarch

__________ Count backwards from 20-1, (no errors, but may correct self).

**Total** ☐

**In the last 3 months how often have you been :-**

PF1) **Preparing the main meal?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Less than once p/wk | ☐ Once or twice p/wk | ☐ Most days |

PF2) **Washing up?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Less than once p/wk | ☐ Once or twice p/wk | ☐ Most days |

PF3) **Washing clothes?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Once or twice every 3 months | ☐ Between 3 & 12 times every 3 months | ☐ At least weekly |

PF4) **Doing light housework?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Once or twice every 3 months | ☐ Between 3 & 12 times every 3 months | ☐ At least weekly |

PF5) **Doing heavy housework?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Once or twice every 3 months | ☐ Between 3 & 12 times every 3 months | ☐ At least weekly |

**In the last 3 months how often have you been :-**

PF6) **Local shopping?**

☐ Never ☐ Once or twice every 3 months ☐ Between 3 & 12 times every 3 months ☐ At least weekly

PF7) **On social outings?**

☐ Never ☐ Once or twice every 3 months ☐ Between 3 & 12 times every 3 months ☐ At least weekly

PF8) **Walking outside for up to 15 minutes?**

☐ Never ☐ Once or twice every 3 months ☐ Between 3 & 12 times every 3 months ☐ At least weekly

PF9) **Actively pursuing a hobby?**

☐ Never ☐ Once or twice every 3 months ☐ Between 3 & 12 times every 3 months ☐ At least weekly

PF10) **Driving a car or travelling on a bus?**

☐ Never ☐ Once or twice every 3 months ☐ Between 3 & 12 times every 3 months ☐ At least weekly

**In the last 6 months have you been :-**

PF11) **On any outings / car rides?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Once or twice every 3 months | ☐ Between 3 & 12 times every 3 months | ☐ At least weekly |

---

PF12) **Gardening?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Light | ☐ Moderate | ☐ All that is necessary |

---

PF13) **Doing household or car maintenance?**

| | | | |
|---|---|---|---|
| ☐ Never | ☐ Light | ☐ Moderate | ☐ All that is necessary |

---

PF14) **Reading books?**

| | | | |
|---|---|---|---|
| ☐ None | ☐ 1 every 6 months | ☐ Less than 1 every 2 wks | ☐ More than 1 every 2 weeks |

---

PF15) **Gainful work?**

| | | | |
|---|---|---|---|
| ☐ None | ☐ Up to 10 hours per week | ☐ Between 10 & 30 hours per week | ☐ Over 30 hours per week |

---

We should like to know if you have had any medical complaints and how your health has been in general over the past few weeks. Please answer ALL the questions on the page, simply by ticking the answer which you think most nearly applies to you. Remember that we want to know about present and recent complaints, not those that you had in the past.

---

## HAVE YOU RECENTLY:

PG1) **Been able to concentrate on whatever you are doing?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Better than usual | Same as usual | Less than than usual | Much less than usual |

---

PG2) **Lost much sleep over worry?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG3) **Been having restless, disturbed nights?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG4) **Been managing to keep yourself busy and occupied?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| More so than usual | Same as usual | Rather less than usual | Much less less |

---

PG5) **Been getting out of the house as much as usual?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| More than usual | Same as usual | Less than than usual | Much less than usual |

---

PG6) **Been managing as well as most people would in your shoes?**

| | | | |
|---|---|---|---|
| ☐ Better than most | ☐ About the same | ☐ Rather less well | ☐ Much less well |

---

PG7) **Felt on the whole you were doing well?**

| | | | |
|---|---|---|---|
| ☐ Better than usual | ☐ About same as usual | ☐ Less well than usual | ☐ Much less well |

---

PG8) **Been satisfied with the way you have carried out your task?**

| | | | |
|---|---|---|---|
| ☐ More satisfied | ☐ About same as usual | ☐ Less satisfied than usual | ☐ Much less satisfied |

---

PG9) **Been able to feel warmth and affection for those near you?**

| | | | |
|---|---|---|---|
| ☐ Better than most | ☐ About the same | ☐ Less well than usual | ☐ Much less well |

---

PG10) **Been finding it easy to get on with other people?**

| | | | |
|---|---|---|---|
| ☐ Better than most | ☐ About the same | ☐ Less well than usual | ☐ Much less well |

---

PG11) **Spent much time chatting with people?**

| | | | |
|---|---|---|---|
| ☐ More time than usual | ☐ About same as usual | ☐ Less than usual | ☐ Much less than usual |

---

PG12) **Felt that you are playing a useful part in things?**

| | | | |
|---|---|---|---|
| ☐ More so than usual | ☐ Same as usual | ☐ Less useful than usual | ☐ Much less useful |

PG13) **Felt capable of making decisions about things?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| More so than usual | Same as usual | Less so than usual | Much less capable |

---

PG14) **Felt constantly under strain?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG15) **Felt you couldn't overcome your difficulties?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG16) **Been finding life a struggle all the time?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG17) **Been able to enjoy your normal day-to-day activities?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| More so than usual | Same as usual | Less so than usual | Much less than usual |

---

PG18) **Been taking things hard?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG19) **Been getting scared and panicky for no good reason?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG20) **Been able to face up to your problems?**

☐ More so than usual
☐ Same as usual
☐ Less able than usual
☐ Much less able

---

PG21) **Found everything getting on top of you?**

☐ Not at all
☐ No more than usual
☐ Rather more than usual
☐ Much more than usual

---

PG22) **Been feeling unhappy and depressed?**

☐ Not at all
☐ No more than usual
☐ Rather more than usual
☐ Much more than usual

---

PG23) **Been losing confidence in yourself?**

☐ Not at all
☐ No more than usual
☐ Rather more than usual
☐ Much more than usual

---

PG24) **Been thinking of yourself as a worthless person?**

☐ Not at all
☐ No more than usual
☐ Rather more than usual
☐ Much more than usual

---

PG25) **Felt that life is entirely hopeless?**

☐ Not at all
☐ No more than usual
☐ Rather more than usual
☐ Much more than usual

---

PG26) **Been feeling hopeful about your own future?**

☐ More so than usual
☐ About same as usual
☐ Less so than usual
☐ Much less hopeful

---

PG27) **Been feeling reasonably happy, all things considered?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| More so than usual | About same as usual | Less so than usual | Much less than usual |

---

PG28) **Been feeling nervous and strung up all the time?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG29) **Felt that life isn't worth living?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

PG30) **Found at times you couldn't do things because your nerves were too bad?**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Not at all | No more than usual | Rather more than usual | Much more than usual |

---

**We are interested in finding out how you have been doing in the last two weeks. We would like you to answer some questions about your work, spare time and your family life. There are no right or wrong answers to these questions. Check the answers that best describe how you have been in the last two weeks.**

---

## WORK OUTSIDE THE HOME:

*Please check the situation that best describes you:*

PS01) **I am -**

☐ a worker for pay
☐ a housewife
☐ a student
☐ retired
☐ unemployed

---

PS02) **Do you usually work for pay more than 15 hours per week?**

☐ Yes
☐ No

---

PS03) **Did you work any hours for pay in the last two weeks?**

☐ Yes
☐ No

---

*Check the answer that best describes how you have been in the last two weeks:*

PS1) **1. How many days did you miss from work in the last two weeks?**

☐ No days missed
☐ One day
☐ I missed about half the time
☐ Missed more than half the time but did make at least one day
☐ I did not work any days
☐ On vacation all of the last two weeks

---

*If you have not worked any days in the last two weeks, go on to Question 7.*

PS2) **2. Have you been able to do your work in the last 2 weeks?**

☐ I did my work well
☐ I did my work well but had some minor problems
☐ I needed help with my work and did not do it well about half the time
☐ I did my work poorly most of the time
☐ I did my work poorly all the time

---

PS3) **3. Have you been ashamed of how you do your work in the last 2 weeks?**

☐ I never felt ashamed
☐ Once or twice I felt ashamed
☐ About half the time I felt ashamed
☐ I felt ashamed most of the time
☐ I felt ashamed all the time

---

PS4) **4. Have you had any arguments with people at work in the last 2 weeks?**

☐ I had no arguments and got along very well
☐ I usually got along well but had minor arguments
☐ I had more than one argument
☐ I had many arguments
☐ I was constantly in arguments

---

PS5) **5. Have you felt upset, worried or uncomfortable while doing your work in during the last 2 weeks?**

☐ I never felt upset
☐ Once or twice I felt upset
☐ Half the time I felt upset
☐ I felt upset most of the time
☐ I felt upset all of the time

---

PS6) **6. Have you found your work interesting these last 2 weeks?**
☐ My work was almost always interesting
☐ Once or twice my work was not interesting
☐ Half the time my work was uninteresting
☐ Most of the time my work was uninteresting
☐ My work was always uninteresting

---

## WORK AT HOME - HOUSEWIVES ANSWER QUESTIONS 7-12

PS7) **7. How many days did you do some housework during the last 2 weeks?**

☐ Every day
☐ I did the housework almost every day
☐ I did the housework about half the time
☐ I usually did not do the housework
☐ I was completely unable to do the housework
☐ I was away from home all of the last two weeks

---

PS8) **8. During the last two weeks, have you kept up with your housework? This includes cooking, cleaning, laundry, grocery shopping, and errands?**

☐ I did my work well
☐ I did my work well but had some minor problems
☐ I needed help with my work and did not do it well about half the time
☐ I did my work poorly most of the time
☐ I did my work poorly all the time

---

PS9) **9. Have you been ashamed of how you do your housework in the last 2 weeks?**

☐ I never felt ashamed
☐ Once or twice I felt ashamed
☐ About half the time I felt ashamed
☐ I felt ashamed most of the time
☐ I felt ashamed all the time

---

PS10) **10. Have you had any arguments with salespeople, tradesmen or neighbours in the last 2 weeks?**

☐ I had no arguments and got along very well
☐ I usually got along well but had minor arguments
☐ I had more than one argument
☐ I had many arguments
☐ I was constantly in arguments

---

PS11) **11. Have you felt upset while doing your housework during the last 2 weeks?**

☐ I never felt upset
☐ Once or twice I felt upset
☐ Half the time I felt upset
☐ I felt upset most of the time
☐ I felt upset all of the time

---

PS12) **12. Have you found your housework interesting these last 2 weeks?**

☐ My work was almost always interesting
☐ Once or twice my work was not interesting
☐ Half the time my work was uninteresting
☐ Most of the time my work was uninteresting
☐ My work was always uninteresting

---

## SPARE TIME - EVERYONE ANSWER QUESTIONS 13-21

*Check the answer that best describes how you have been in the last 2 weeks.*

PS13) **13. How many friends have you seen or spoken to on the telephone in the last 2 weeks?**

☐ Nine or more friends
☐ Five to eight friends
☐ Two to four friends
☐ One friend
☐ No friends

---

PS14) **14. Have you able to talk about your feelings and problems with at least one friend during the last 2 weeks?**

☐ I can always talk about my innermost feelings
☐ I usually can talk about my feelings
☐ About half the time I felt able to talk about my feelings
☐ I was never able to talk about my feelings
☐ Not applicable, I have no friends

---

PS15) **15. How many times in the last two weeks have you gone out socially with other people? For example, visited friends, gone to movies, bowling, church, restaurants, invited friends to your home?**

☐ More than 3 times
☐ Three times
☐ Twice
☐ Once
☐ None

---

PS16) **16. How much time have you spent on hobbies or spare time interests during the last 2 weeks? For example, bowling, sewing, gardening, sports, reading?**

☐ I spent most of my spare time on hobbies almost every day.
☐ I spent some time on hobbies some of the days
☐ I spent a little time on hobbies
☐ I usually did not spend any time on hobbies but did watch TV.
☐ I did not spend any item on hobbies or watching TV

---

PS17) **17. Have you had any open arguments with your friends in the last 2 weeks?**

☐ I had no arguments and got along very well
☐ I usually got along very well but had minor arguments
☐ I had more than one argument
☐ I had many arguments
☐ I was constantly in arguments
☐ Not applicable, I have no friends

---

PS18) **18. If your feelings were hurt or offended by a friend during the last two weeks, how badly did you take it?**

☐ It did not affect my or it did not happen
☐ I got over it in a few hours
☐ I got over it in a few days
☐ I got over it in a week
☐ It will take me months to recover
☐ Not applicable, I have no friends

---

PS19) **19. Have you felt shy or uncomfortable with people in the last two weeks?**

☐ I always felt comfortable
☐ Sometimes I felt uncomfortable but could relax after a while
☐ About half the time I felt uncomfortable
☐ I usually felt uncomfortable
☐ I always felt uncomfortable
☐ Not applicable, I was never with people

PS20) **20. Have you felt lonely and wished for more friends during the last 2 weeks?**

☐ I have not felt lonely
☐ I have felt lonely a few times
☐ About half the time I felt lonely
☐ I usually felt lonely
☐ I always felt lonely and wished for more friends

PS21) **21. Have you felt bored in your spare time during the last 2 weeks?**

☐ I never felt bored
☐ I usually did not feel bored
☐ About half the time I felt bored
☐ Most of the time I felt bored
☐ I was constantly bored

PS215) *Are you a Single, Separated, or Divorced Person not living with a person of the opposite sex; please answer below:*

☐ Yes. Answer questions 22 & 23.
☐ No. Go to question 24.

PS22) **22. How many times have you been with a date these last 2 weeks?**

☐ More than three times
☐ Three times
☐ Twice
☐ Once
☐ Never

PS23) **23. Have you been interested in dating during the last 2 weeks. If you have not dated, would you have liked to?**

☐ I was always interested in dating
☐ Most of the time I was interested
☐ About half of the time I was interested
☐ Most of the time I was uninterested
☐ I was completely uninterested

## FAMILY

PS235) *Answer Questions 24-31 about your parents, brothers, sisters, in laws, and children not living at home. Have you been in contact with any of them in the last two weeks?*

☐ Yes. Answer questions 24 & 31.

☐ No. Go to question 30.

PS24) **24. Have you had any open arguments with your relatives in the last 2 weeks?**

☐ We always got along very well
☐ We usually got along very well but had some minor arguments
☐ I had more than one argument with at least one relative
☐ I had many arguments
☐ I was constantly in arguments

PS25) **25. Have you able to talk about your feelings and problems with at least one of your relatives in the last 2 weeks?**

☐ I can always talk about my feelings with at least one relative
☐ I usually can talk about my feelings
☐ About half the time I felt able to talk about my feelings
☐ I usually was not able to talk about my feelings
☐ I was never able to talk about my feelings

PS26) **26. Have you avoided contacts with your relatives these last 2 weeks?**

☐ I have contacted relatives regularly
☐ I have contacted a relative at least once
☐ I have waited for relatives to contact me
☐ I avoided my relatives, but they contacted me
☐ I have no contacts with any relative

PS27) **27. Did you depend on your relatives for help, advice, money or friendship in the last 2 weeks?**

☐ I never need to depend on them
☐ I usually did not need to depend on them
☐ About half the time I needed to depend on them
☐ Most of the time I depend on them
☐ I depend completely on them

---

PS28) **28. Have you wanted to do the opposite of what your relatives wanted in order to make them angry during the last 2 weeks?**

☐ I never wanted to oppose them
☐ Once or twice I wanted to oppose them
☐ About half the time I wanted to oppose them
☐ Most of the time I wanted to oppose them
☐ I always opposed them

---

PS29) **29. Have you been worried about things happening to your relatives without good reason in the last 2 weeks?**

☐ I have not worried without reason
☐ Once or twice I worried
☐ About half the time I worried
☐ Most of the time I worried
☐ I have worried the entire time
☐ Not applicable, my relatives are no longer living

---

*EVERYONE answer Questions 30 and 31, even if your relatives are not living.*

PS30) **30. During the last two weeks, have you been thinking that you have let any of your relatives down or been unfair to them at any time?**

☐ I did not feel that I let them down at all
☐ I usually did not feel that I let them down
☐ About half the time I felt that I let them down
☐ Most of the time I felt that I let them down
☐ I always felt that I have let them down

PS31) **31. During the last two weeks, have you been thinking that any of your relatives have let you down or have been unfair to you at any time?**

☐ I never felt that they let me down
☐ I felt that they usually did not let me down
☐ About half the time I felt they let me down
☐ I usually have felt that they let me down
☐ I am very bitter that they have let me down

---

PS315) *Are you living with your spouse or have been living with a person of the opposite sex in a permanent relationship?*

☐ Yes. Please answer questions 32 & 40.
☐ No. Go to question 41.

---

PS32) **32. Have you had any open arguments with your partner in the last 2 weeks?**

☐ We had no arguments and we got along well
☐ We usually got along very well but had minor arguments
☐ We had more than one argument
☐ We had many arguments
☐ We were constantly in arguments

---

PS33) **33. Have you able to talk about your feelings and problems with your partner during the last 2 weeks?**

☐ I can always talk freely about my feelings
☐ I usually could talk about my feelings
☐ About half the time I felt able to talk about my feelings
☐ I usually was not able to talk about my feelings
☐ I was never able to talk about my feelings

---

PS34) **34. Have you been demanding to have your own way at home during the last 2 weeks?**

☐ I have not insisted on always having my own way
☐ I usually have not insisted on having my own way
☐ About half the time I insisted on having my own way
☐ I usually insisted on having my own way
☐ I always insisted on having my own way

PS35) **35. Have you been bossed around by your partner these last 2 weeks?**

☐ Almost never
☐ Once in a while
☐ About half the time
☐ Most of the time
☐ Always

---

PS36) **36. How much have you felt dependent on your partner these last 2 weeks?**

☐ I was independent
☐ I was usually independent
☐ I was somewhat dependent
☐ I was usually dependent
☐ I depended on my partner for everything

---

PS37) **37. How have you felt about your partner during the last 2 weeks?**

☐ I always felt affection
☐ I usually felt affection
☐ About half the time I felt dislike and half the time affection
☐ I usually felt dislike
☐ I always felt dislike

---

PS38) **38. How many times have and your partner had intercourse ?**

☐ More than twice a week
☐ Once or twice a week
☐ Once every two weeks
☐ Less than once every two weeks but at least once in the last month
☐ Not applicable, no intercourse in the last two weeks

---

PS39) **39. Have you had any problems during intercourse, such as pain these last two weeks?**

☐ None
☐ Once or twice
☐ About half the time
☐ Most of the time
☐ Always
☐ Not applicable, no intercourse in the last two weeks

---

PS40) **40. How have you felt about intercourse during the last 2 weeks?**

☐ I always enjoyed it
☐ I usually enjoyed it
☐ About half the time I enjoyed it
☐ I usually did not enjoy it
☐ I never enjoyed it

---

## FAMILY UNIT

PS405) *Have you ever been married, ever lived with a person of the opposite sex, or ever had children? Please check:*

☐ Yes. Please answer questions 41 & 43.
☐ No. Go to question 44.

PS41) **41. Have you ever worried about your partner or any of your children without any reason during the last 2 weeks, even if you are not living together now?**

☐ I never worried
☐ Once or twice I worried
☐ About half the time I worried
☐ Most of the time I worried
☐ Not applicable, partner and children not living

PS42) **42. During the last 2 weeks have you been thinking that you have let down your partner or any of your children at any time?**

☐ I did not feel I let them down at all
☐ I usually did not feel that I let them down
☐ About half the time I felt that I let them down
☐ Most of the time I have felt that I have let them down
☐ I let them down completely

PS43) **43. During the last 2 weeks, have you been thinking that your partner or any of your children have let you down at any time?**

☐ I never felt that they let me down
☐ I felt they usually did not let me down
☐ About half the time I felt they let me down
☐ I usually felt they let me down
☐ I feel bitter that they let me down.

---

## FINANCIAL - EVERYONE PLEASE ANSWER QUESTION 44

PS44) **44. Have you had enough money to take care of your own and your family's financial needs during the last 2 weeks?**

☐ I had enough money for needs
☐ I usually had enough money with minor problems
☐ About half the time I did not have enough money but did not have to borrow money
☐ I usually did not have enough money and had to borrow from others
☐ I had great financial difficulty

**Tick the box above the response that you have chosen for each individual question.**

PL1) **How I manage in the future depends on me, not on what other people can do for me.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

PL2) **It's often best just to wait and see what happens.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

PL3) **The doctors are the ones that can help me recover.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

PL4) **It's what I do to help myself that's really going to make all the difference.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

PL5) **My own efforts are not very important, my recovery really depends on others.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

PL6) **My friends and relatives can do little to help me through this.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

PL7) **It's up to me to make sure I make the best recovery under possible under the circumstances.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

---

PL8) **My own contribution to my recovery doesn't amount to much.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

---

PL9) **Only the therapists (physio and / or occupational) can get me back to fitness.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

---

PL10) **Getting better now is a matter of my own determination rather than anything else.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

---

PL11) **I have little or no control over my progress from now on.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

---

PL12) **It doesn't matter how much help you get - in the end it's your own efforts that count.**

| | | | | |
|---|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ | ☐ |
| Strongly Agree | Agree | Neither Agree Nor Disagree | Disagree | Strongly Disagree |

---

**Listed below are several questions asking about your typical thoughts, feelings, and behaviours as they relate to your current illness. Please indicate your answer by ticking the answer which corresponds with your response.**

PC1) **How much do you want to be involved in decisions regarding your treatment?**

☐ Very much ☐ Moderately ☐ Somewhat ☐ Very little

PC2) **How often do you try to talk about your illness with friends or relatives?**

☐ Never ☐ Sometimes ☐ Frequently ☐ All the time

PC3) **In conversations about your illness, how often do you find yourself thinking about other things?**

☐ Never ☐ Sometimes ☐ Frequently ☐ All the time

PC4) **How often do you feel there is really no hope for your recovery?**

☐ All the time ☐ Frequently ☐ Sometimes ☐ Never

PC5) **In the past few months, how much have you learned about your illness from talking with others who know something about it, such as doctors, nurses, etc.?**

☐ Very little ☐ Some ☐ Quite a bit ☐ Very much

PC6) **How often do you feel that you don't care what happens to you?**

☐ Never ☐ Sometimes ☐ Frequently ☐ All the time

PC7) **To what extent do you like talking to your friends and family because you won't have to think about your illness?**

☐ Very little ☐ Some ☐ Quite a bit ☐ Very much

PC8) **How much has your illness caused you to think about certain things in your life in a more positive way?**

☐ Very little ☐ Some ☐ Quite a bit ☐ Very much

PC9) **When you think about your illness, how often do you try to distract yourself by doing something else?**

☐ All the time ☐ Frequently ☐ Sometimes ☐ Never

PC10) **How often do you ask your doctor for advice about what to do concerning your illness?**

☐ All the time ☐ Frequently ☐ Sometimes ☐ Never

PC11) **When friends or relatives try to talk to you about your illness, how frequently do you try to change the subject?**

☐ Never ☐ Sometimes ☐ Frequently ☐ All the time

PC12) **In the past few months, how much have you learned about your illness from reading books, magazines, or newspapers?**

☐ Very much ☐ Moderately ☐ Somewhat ☐ Very little

PC13) **How often do you feel like just giving in to your illness?**

☐ All the time ☐ Frequently ☐ Sometimes ☐ Never

PC14) **To what extent do you try to forget about your illness?**

☐ Very little ☐ Some ☐ Quite a bit ☐ Very much

---

PC15) **How many questions have you asked your doctor about your illness?**

☐ None ☐ Some ☐ Many ☐ A lot

---

PC16) **When you meet someone with your kind of illness, how much do you talk about the details of the illness?**

☐ Very little ☐ Some ☐ Quite a bit ☐ Very much

---

PC17) **How often do you go to the movies or watch TV in order not to think about your illness?**

☐ Never ☐ Sometimes ☐ Frequently ☐ All the time

---

PC18) **To what extent do you feel there is nothing you can do about your illness?**

☐ Very much ☐ Quite a bit ☐ A little ☐ Not at all

---

PC19) **When close relatives or friends ask you about your illness, how often do you talk to them about it?**

☐ All the time ☐ Frequently ☐ Sometimes ☐ Never

---

## What the Patient Actually Does:

PB1) **Feeding** ☐

2 = Independent
1 = Needs some help
0 = Needs to be fed

PB2) **Bathing** ☐

1 = Able to wash all over
0 = Needs help

PB3) **Grooming** ☐

1 = Totally independent
0 = Dependent in some way

PB4) **Dressing** ☐

2 = Independent
1 = Needs help with some items
0 = Unable to do anything without help

PB5) **Bowels** ☐

2 = No accidents
1 = Occasional accidents/help with enema
0 = Incontinent

PB6) **Bladder** ☐

2 = No accidents
1 = Occasional accidents (max, once per 24 hours)
0 = Needs to be fed

PB7) **Toilet** ☐

2 = Independent (on/off, dressing and wiping)
1 = Needs some help, but can do something alone
0 = Dependent / unable to use

PB8) **Transfer Bed /Chair** ☐

3 = Totally independent
2 = Minor help (verbal or physical, can sit)
1 = Major help (one or two people, can sit)
0 = Unable, no sitting balance

PB9) **Mobility** ☐

3 = Independent
2 = Walks with the help of one person (verbal or physical)
1 = Wheelchair independent (including corners)
0 = Unable

PB10) **Stairs** ☐

2 = Independent
1 = Needs help (verbal, physical, carry aid)
0 = Unable

**TOTAL SCORE** ☐

# Appendix C

# The Secondary Patient Questionnaire

# PATIENT

Name:...................................................................................................

Patient Number:......................................................................................

Address:...............................................................................................

.............................................................................................................

Today's Date:.........................................................................................

The following questions are about the treatment and help you have received, and how you are feeling about your stroke now.

If you have only visited the hospital as a outpatient please think of the questions as referring to your outpatient visits.

It is very important that you answer **__every__** question even if you do not think it applies to you.

We really appreciated your help and value your opinions and by answering every question you will give us a more compete picture of your experience.

**A number of statements are given below which describe people's reactions to having a stroke. Please tick the appropriate box, indicating how far it applies to you at present.**
***Please answer every question, even if you do not feel it applies to you.***

PM011) **I have been doing things that I believe will improve my health, e.g. changed my diet.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM021) **I feel I can't do anything to cheer myself up.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM031) **I feel that problems with my health prevent me from planning ahead.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM041) **I believe that my positive attitude will benefit my health.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM051) **I don't dwell on my illness.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM061) **I firmly believe that I will get better.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM071) **I feel that nothing I can do will make any difference.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

PM081) **I've left it all to my doctors.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM091) **I feel that life is hopeless.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM101) **I have been doing things that I believe will improve my health, e.g. exercise.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM111) **Since my stroke I now realise how precious life is and I'm making the most of it.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM121) **I've put myself in the hands of God.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM131) **I have plans for the future, e.g. holiday, jobs, housing.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM141) **I worry about the stroke returning or getting worse.**

| | | | |
|---|---|---|---|
| ☐ | ☐ | ☐ | ☐ |
| Definitely does not apply to me | Does not apply to me | Applies to me | Definitely applies to me |

---

PM151) **I've had a good life and what's left is a bonus.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

---

PM161) **I think my state of mind can make a lot of difference to my health.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

---

PM171) **I feel that there is nothing I can do to help myself.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

---

PM181) **I try to carry on my life as I've always done.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

---

PM191) **I would like to make contact with others in the same boat.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

---

PM201) **I am determined to put it all behind me.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

***<u>Please answer every question</u>***

---

PM211) **I have difficulty in believing that this happened to me.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM221) **I suffer great anxiety about it.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

---

PM231) **I am not very hopeful about the future.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

---

PM241) **At the moment I take one day at a time.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

---

PM251) **I feel like giving up.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

---

PM261) **I try to keep a sense of humour about it.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

---

PM271) **Other people worry about me more than I do.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

***Please answer every question***

---

PM281) **I think of other people who are worse off.**

☐ Definitely does not apply to me
☐ Does not apply to me
☐ Applies to me
☐ Definitely applies to me

PM291) **I am trying to get as much information as I can about strokes.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM301) **I feel that I can't control what is happening.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM311) **I try to have a very positive attitude.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM321) **I keep quite busy, so I don't have time to think about it.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM331) **I avoid finding out more about it.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM341) **I see my illness as a challenge.**

☐ Definitely does not apply to me ☐ Does not apply to me ☐ Applies to me ☐ Definitely applies to me

PM351) **I feel fatalistic about it.**

| | | | |
|---|---|---|---|
| ☐<br>Definitely does not apply to me | ☐<br>Does not apply to me | ☐<br>Applies to me | ☐<br>Definitely applies to me |

---

PM361) **I feel completely at a loss about what to do.**

| | | | |
|---|---|---|---|
| ☐<br>Definitely does not apply to me | ☐<br>Does not apply to me | ☐<br>Applies to me | ☐<br>Definitely applies to me |

---

PM371) **I feel very angry about what has happened.**

| | | | |
|---|---|---|---|
| ☐<br>Definitely does not apply to me | ☐<br>Does not apply to me | ☐<br>Applies to me | ☐<br>Definitely applies to me |

---

PM381) **I don't really believe I had a stroke.**

| | | | |
|---|---|---|---|
| ☐<br>Definitely does not apply to me | ☐<br>Does not apply to me | ☐<br>Applies to me | ☐<br>Definitely applies to me |

---

PM391) **I count my blessings.**

| | | | |
|---|---|---|---|
| ☐<br>Definitely does not apply to me | ☐<br>Does not apply to me | ☐<br>Applies to me | ☐<br>Definitely applies to me |

---

PM401) **I try to fight the illness.**

| | | | |
|---|---|---|---|
| ☐<br>Definitely does not apply to me | ☐<br>Does not apply to me | ☐<br>Applies to me | ☐<br>Definitely applies to me |

---

**Please read through each statement and tick the answer which is nearest to your view. There are no right or wrong answers, it is your opinion we are interested in.**
***It is important you answer every question.***

## Hospital care and treatment (or outpatient visit)

PT1) **I have been treated with kindness and respect by the staff at the hospital.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT2) **The staff attended well to my personal needs while I was in hospital,** (for example, I was able to get to the toilet whenever I needed).

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT3) **I was able to talk to the staff about any problems I might have had.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT4) **I have received all the information I want about the causes and nature of my illness.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT5) **The doctors have done everything they can to make me well again.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT6) **I am happy with the amount of recovery I have made.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT7) **I am satisfied with the type of treatment the therapists have given me.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

## DISCHARGE AND AFTER

*Please answer every question*

PT8) **I was given all the information I needed about the allowances or services I might need after leaving hospital,** (e.g. home help, district nurse, meals on wheels).

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT9) **Things were well prepared for my return home,** (i.e. aids such as stair rails or wheelchairs had been organised if necessary).

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

***Please answer every question***

PT11) **I get all the support I need from services such as meals on wheels, home helps, district nursing etc.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT12) **I am satisfied with the outpatient services provided by the hospital, (**e.g. the day hospital appointments with doctors or therapists).

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT13) **I think the ambulance service is reliable.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT14) **I am satisfied with the practical help I have received since I left hospital.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT15) **I have received enough information about recovery and rehabilitation after stroke.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT16) **Somebody has really listened and understood my needs and problems since I left hospital.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

PT17) **I have not felt neglected since I left hospital.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

---

PT18) **I have had enough emotional support since I left hospital.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

---

PT19) **I have received enough special equipment,** (e.g. rails, wheelchairs, commode etc.).

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

---

PT20) **I know who to contact if I have problems relating to my stroke.**

☐ Strongly Agree ☐ Agree ☐ Disagree ☐ Strongly Disagree

---

**COMMENTS:**

**Is there anything else you would like to tell us about your experience of stroke?**

**We would like to know about any special care you have received since you left hospital. Please tick the appropriate box.**

**It is very important that you answer every question.**

---

## Physiotherapy

Have you seen a physiotherapist since leaving hospital? Yes ☐ No ☐

**If yes where did you see the physiotherapist?**

If no go to occupational therapy

☐ Day Hospital ☐ Western General Hospital ☐ Home ☐ Other ________________

How often did you see the physiotherapist?

☐ Once ☐ Occasional visits ☐ Regularly

If regularly, how many times each week? __________ times each week.
If regularly, for approximately how many weeks?________________

---

## Occupational Therapy

Have you seen an occupational therapist since leaving hospital? Yes ☐ No ☐

**If yes where did you see the occupational therapist?**

☐ Day Hospital ☐ Western General Hospital ☐ Home ☐ Other ________________

How often did you see the physiotherapist?

☐ Once ☐ Occasional visits ☐ Regularly

If regularly, how many times each week? __________ times each week.
If regularly, for approximately how many weeks?________________

**Speech Therapy**

Have you seen a speech therapist since leaving hospital? Yes ☐ No ☐

**If yes where did you see the speech therapist?**

☐ Day Hospital ☐ Western General Hospital ☐ Home ☐ Other ________________

How often did you see the speech therapist?

☐ Once ☐ Occasional visits ☐ Regularly

If regularly, how many times each week? __________ times each week.

If regularly, for approximately how many weeks?________________

---

**Visits to G.P.**

Have you visited your G.P. since you left hospital? Yes ☐ No ☐

If yes, approximately how many times? ____________

---

**G.P. Visits to Your Home**

Has your G.P. visited you at home since you left hospital? Yes No

If yes, approximately how many times? ________________

---

**District Nurse / Health Visitor**

Have you seen a health visitor since you left hospital? Yes ☐ No ☐

**If yes where did you see the health visitor?**

☐ Home ☐ G.P.'s Surgery ☐ Other ________________

**If yes, how often did you see the health visitor?**

☐ Once ☐ Occasional visits visits ☐ Regularly

If regularly, how many times each week? __________ times each week.

If regularly, for approximately how many weeks?________________

---

## Home Help

Have you had a home help? Yes ☐ No ☐

How many times each week?____________ times each week

For approximately how many weeks?____________________

---

## Meals on Wheels

Have you had meals on wheels? Yes ☐ No ☐

How many times each week?____________ times each week

For approximately how many weeks?____________________

---

## Social Worker

Have you seen a social worker since you left hospital? Yes ☐ No ☐

If yes, approximately how many times?______________________

---

## Chiropodist

Have you seen a chiropodist since you left hospital? Yes ☐ No ☐

If yes, approximately how many times?______________________

---

## Chiropodist

Have you been admitted for respite care? Yes ☐ No ☐

If yes, approximately how many times?______________________

Where?_____________________________________________

---

**Please tell us if you have been given any of the following items.**
***Please tick one box on each line.***

---

**Kitchen Aids**

Special cup Yes ☐ No ☐
Special cutlery Yes ☐ No ☐
Other Yes ☐ No ☐ Please tell us ____________

---

**Bath Aids**

Bath rail Yes ☐ No ☐
Bath seat Yes ☐ No ☐
Bath hoist Yes ☐ No ☐
Other Yes ☐ No ☐ Please tell us ____________

---

**Seating Aids**

Special armchair Yes ☐ No ☐
Special stool Yes ☐ No ☐
Other Yes ☐ No ☐ Please tell us ____________

---

**Walking Aids**

Walking frame / zimmer Yes ☐ No ☐
Walking stick Yes ☐ No ☐
Grab rail Yes ☐ No ☐
Other Yes ☐ No ☐ Please tell us ____________

---

**Toilet Aids**

Rails Yes ☐ No ☐
Raised toilet seat Yes ☐ No ☐
Commode Yes ☐ No ☐
Other Yes ☐ No ☐ Please tell us ____________

**Stair Aids**

| | | |
|---|---|---|
| Rails | Yes ☐ | No ☐ |
| Ramps | Yes ☐ | No ☐ |
| Stair lift | Yes ☐ | No ☐ |
| Other | Yes ☐ | No ☐ Please tell us ____________ |

______________________________________________

**Wheelchair** Yes ☐ No ☐ Please tell us ____________

If you have a wheelchair, please tell us what type it is:

______________________________

______________________________________________

If you have received equipment did you have to pay for any of it?

Yes ☐ No ☐ Please tell us____________

______________________________________________

Doctors are aware that emotions play an important part in most illnesses. If your doctor knows about these feelings he will be able to help you more. This questionnaire is designed to help your doctor to know how you feel. Read each item and place a firm tick in the box opposite the reply which comes closest to how you have been feeling in the past week. Don't take too long over your replies: your immediate reaction to each item will probably be more accurate than a long thought out response.

***Please answer every question.***

PH1) **I feel tense or 'wound up':**

☐ Most of the time
☐ A lot of the time
☐ Time to time, occasionally
☐ Not at all

---

PH2) **I still enjoy the things I used to enjoy:**

☐ Definitely as much
☐ Not quite so much
☐ Only a little
☐ Hardly at all

---

PH3) **I get a sort of frightened feeling as if something awful is about to happen:**

☐ Very definitely and quite badly
☐ Yes, but not too badly
☐ A little, but it doesn't worry me
☐ Not at all

---

PH4) **I can laugh and see the funny side of things:**

☐ As much as I always could
☐ Not quite so much now
☐ Definitely not so much now
☐ Not at all

---

***Please answer every question.***

PH5) **Worrying thoughts go through my mind:**

☐ A great deal of the time
☐ A lot of the time
☐ From time to time, but not too often
☐ Only occasionally

---

PH6) **I feel cheerful:**

☐ Not at all
☐ Not often
☐ Sometimes
☐ Most of the time

---

PH7) **I can sit at ease and feel relaxed:**

☐ Definitely
☐ Usually
☐ Not often
☐ Not at all

---

PH8) **I feel as if I am slowed down:**

☐ Nearly all the time
☐ Very often
☐ Sometimes
☐ Not at all

---

PH9) **I get a sort of frightened feeling like 'butterflies' in the stomach:**

☐ Not at all
☐ Occasionally
☐ Quite often
☐ Very often

---

***Please answer every question.***

PH10) **I have lost interest in my appearance:**

☐ Definitely
☐ I don't take as much care as I should
☐ I may not take as much care
☐ I take just as much care as ever

---

PH11) **I feel restless as if I have to be on the move:**

☐ Very much indeed
☐ Quite a lot
☐ Not very much
☐ Not at all

---

PH12) **I look forward with enjoyment to things:**

☐ As much as I ever did.
☐ Rather less than I used to
☐ Definitely as much as I used to
☐ Hardly at all

---

PH13) **I get sudden feelings of panic:**

☐ Very often indeed
☐ Quite often
☐ Not very often
☐ Not at all

---

PH14) **I can enjoy a good book or radio or TV programme:**

☐ Often
☐ Sometimes
☐ Not often
☐ Very seldom

---

# Appendix D

# Declaration of my Contribution

## Declaration of my contribution

I joined the study as a researcher to evaluate the role of a Stroke Family Care Worker (SFCW) in October 1992. The SFCW was already in post and the randomisation of patients to the trial had just begun. I therefore was not involved in the grant application process or the design of the randomisation process.

**The entry of patients into the study:**

In order to keep me blind to treatment allocation I had no part in the entry of patients to the study or the randomisation process.

**The collection of baseline data:**

The examining physician recorded all patients' baseline data as part of the Lothian Stroke Register. The Lothian Stroke Register team were responsible for the punching of all baseline data.

**Design of follow up:**

During the six months, prior to patients being due for follow up, I was responsible for conducting a detailed literature review of the available measures of psychosocial outcome and ascertaining which had been used previously in stroke. I chose which domains of outcome were to be assessed and designed our two follow up questionnaires using the results of my literature review to guide my choice.

**Organisation of follow up:**

I designed an administrative system to allow the smooth follow up of patients at six months, this involved:

a) my producing a summary sheet of patient contact information for every patient entered into the study.

b) the weekly listing of patients due for follow up.

c) a member of the Lothian Stroke Register team telephoning patients' GPs to confirm their details.

d) a secretary sending letters of introduction.

e) my recording all patient contacts on the summary sheet.

f) my contacting all patients personally to arrange a time for interview.

g) my logging and filing all returned patient questionnaires.

**The follow up interview:**

I personally interviewed all 372 assessed patients and their 231 carers in their place of residence. Interviews normally lasted between one and three hours.

**The psychiatric follow up:**

Dr. Siobhan MacHale conducted all psychiatric follow up interviews (refer to 2.6.2.).

**Data handling:**

I designed and created the computerised databases (one for each follow up questionnaire) into which I punched the collected data. I was responsible for coding all completed questionnaires and punching the data into the respective data bases. At the end of the project I 'cleaned' all the databases and checked their information.

**Data Analysis:**

I chose the topics and methods of analysis and conducted all data analysis for the project.

**Help and Guidance Received:**

Throughout the project I was able to call on the help and assistance of departmental statisticians and computer programmers when I experienced difficulties.

# Appendix E

# Publications arising from this thesis

# Publications resulting from the work in this thesis

Dennis MS, O'Rourke SJ, Slattery J, & Warlow CP, Evaluation of a Stroke Family Care Worker - a randomised controlled trial. Submitted to the British Medical Journal.

O'Rourke SJ & Dennis MS. (1995) Can the Clinical Classification of Stroke Help Identify Patients at Risk of Mood Disorders? Age and Ageing, vol 25, suppl.1., 33 (Abstract).

O'Rourke SJ, Dennis MS, Slattery J. (1995) Are Medical Coping Modes Associated with Mood Disorder After Stroke? Abstract of the British Psychological Society's Division of Health Psychology Annual Conference.

O'Rourke SJ, Dennis MS, Slattery J & Warlow CP. (1995) Preliminary Results From a Randomised Trial of a Stroke Family Care Worker; Patients' outcome six months post stroke. Age and Ageing, vol. 25, suppl.1., 32 (Abstract).

O'Rourke SJ, MacHale S, Signourini D & Dennis MS, (1995) Detecting Depression After Stroke: A Comparison of the General Health Questionnaire and the Hospital Anxiety and Depression Scale. Abstract of the British Psychological Society's Division of Clinical Psychology's Annual Conference.

O'Rourke SJ, MacHale S, Signourini D, & Dennis MS, Detecting Depression After Stroke: A Comparison of the General Health Questionnaire and the Hospital Anxiety and Depression Scale. Submitted to the British Journal of Psychiatry.

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