ADHERENCE IN BEHAVIOURAL INTERVENTIONS FOR STROKE PATIENTS: MEASUREMENT AND PREDICTION

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Adherence In Behavioural Interventions For Stroke Patients: Measurement And Prediction

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Submitted for the degree of Doctor of Philosophy

University of St Andrews

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ABSTRACT

ADHERENCE IN BEHAVIOURAL INTERVENTIONS FOR STROKE PATIENTS: MEASUREMENT AND PREDICTION

Background: With the increasing incidence in stroke and the resultant high prevalence of residual disability resources are not adequately meeting the needs of the patients. Furthermore patients continue to express dissatisfaction with their care. New interventions are being developed and evaluated. However, when offered these new interventions, patients may refuse or not participate fully. A stroke workbook intervention was developed through a line of research examining the role of perceived control in recovery. During the randomised controlled trial (RCT) evaluating its efficacy patients failed to fully participate in the activities proposed in the workbook. Why, when there is such a dearth of treatment available, do stroke patients not fully participate in or adhere to the interventions offered?

Methods: Three studies were conducted, a predictive study using the intervention group of the RCT exploring the demographic, clinical and psychological factors predicting adherence; a predictive study using one of the intervention groups from a larger 2x2 RCT to examine the predictors of adherence to an easier intervention (video); and a third longitudinal study examining the efficacy of an even simpler intervention (letter) on increasing adherence to the video. The theoretical framework of Leventhal’s Self Regulation Model was used to develop the letter intervention and to explain the findings.

Results: Five types of adherence behaviours emerged from the three studies, all with their own difficulties of definition, measurement and their individual predictor variables. Gender, impairment and illness representations were all predictive of adherence. An easier intervention promoted adherence especially for men and the more impaired. Women appeared to adhere more readily to the complex intervention. These gender differences may be associated with illness representations. A theoretical-based letter does not increase adherence *per se* but may increase the amount of adherence to an easier intervention.

Conclusion: Adherence behaviour is not one type of behaviour and is associated with measurement difficulties. The Self-Regulation model appeared to offer some logical explanations to the findings. The findings have clinical implications and could possibly be associated with patients’ satisfaction with care.

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For my Dad
October 1927 – June 2004
Whose attitude to his illness made this thesis more real, a remarkable man.

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OVERVIEW

CHAPTER 1: WHY, WHEN STROKE PATIENTS CONTINUE TO EXPRESS DISSATISFACTION WITH THE CARE THEY RECEIVE DO THEY FAIL TO PARTICIPATE IN AN INTERVENTION WHEN IT IS OFFERED?

This chapter presents the background to the proposed studies. It presents the epidemiological and individual problems of stroke and evidence of the lack of satisfaction with stroke care. A literature review demonstrates the nature of interventions examined to improve stroke outcomes and discusses their effectiveness. The chapter then goes on to introduce a health psychology perspective of recovery from disability, the stroke workbook study (SWOT) examining the role of perceived control and the non-adherence behaviour to which prompted the central question to this thesis.

CHAPTER 2: DEFINING PATIENT’S BEHAVIOUR AND EXPLAINING IT WITHIN THE CONCEPTUAL FRAMEWORK OF THE SELF-REGULATION MODEL

This chapter describes the concepts of adherence, compliance and concordance and defines the behaviours observed in the SWOT study. It highlights the complexity of the behaviours and the difficulties of measurement. From there the chapter goes onto describe the theoretical framework of Leventhal’s Self-Regulation Model (SRM) used in the proposed studies, its development and its applications to adherence behaviours.

CHAPTER 3: WHAT DEMOGRAPHIC, CLINICAL AND PSYCHOLOGICAL FACTORS PREDICT PARTICIPATION AND ADHERENCE IN A STROKE WORKBOOK INTERVENTION?

This chapter describes an experimental study where the intervention group from the SWOT study was examined for: a) adherence behaviours; participation, active and passive; b) the demographic, clinical and psychological predictors of these behaviours; c) the application of the SRM to explaining the findings.

CHAPTER 4: AN EASIER INTERVENTION: DOES IT INCREASE ADHERENCE?

This chapter describes an experimental study, examining adherence to an easier intervention a) by developing measures of adherence to an easier intervention, a stroke video; b) comparing the adherence to an easier intervention with a complex intervention – the stroke workbook and; c) examining the predictors of adherence to an easier intervention.

CHAPTER 5: A SIMPLE THEORETICALLY DESIGNED LETTER FROM HEALTH PROFESSIONALS: CAN IT INFLUENCE ADHERENCE TO AN EASIER INTERVENTION, ILLNESS REPRESENTATIONS AND OUTCOME?

This chapter describes a 2x2 trial evaluating two simple interventions, a video and a theoretically derived letter including the letter development. It examines; a) the effects of the letter on video adherence; b) the measure of letter adherence; and c) the effects of either intervention on illness representations, disability and mood.

CHAPTER 6: AIMS, FINDINGS, EVIDENCE AND IMPLICATIONS

This chapter recaps the aims of the thesis, the main findings and the evidence, which supports them. The theoretical, methodological and clinical implications are discussed.

CHAPTER 1

WHY, WHEN STROKE PATIENTS CONTINUE TO EXPRESS DISSATISFACTION WITH THE CARE THEY RECEIVE, DO THEY FAIL TO PARTICIPATE IN AN INTERVENTION WHEN IT IS OFFERED?

SUMMARY

This introductory chapter gives the general background to this thesis examining stroke patient’s non-participation in and non-adherence to a specially designed intervention aimed to promote perceived control to reduce disability.

The opening section of this chapter defines stroke and describes it from an epidemiological perspective to emphasise the incidence and the increasing prevalence of the potential residual disability. From here, stroke is described in terms of a medical condition, its consequences and recovery, introducing the idea that recovery from stroke determined disability not only involves physiological but individual psychological and environmental factors.

A literature review of randomised controlled trials testing interventions designed to reduce disability from stroke in terms of functional ability and psychological factors such as mood and satisfaction are discussed to provide a background to a randomised controlled trial (RCT) testing a stroke workbook intervention. This intervention aimed to increase the psychological cognition of perceived control in stroke patients in order to reduce disability and to improve mood and satisfaction outcomes. It was in this study that non-participation and non-adherence behaviours were observed and promoted the overall question to the present thesis. The final section of the chapter describes the stroke workbook study and outlines the research questions that will be addressed in the rest of this thesis to answer the central question; why when patients continue to express dissatisfaction with the care that they receive do they fail to participate in an effective intervention when it is offered?

INTRODUCTION

DEFINITION OF STROKE

> "A stroke can be broadly defined as a cerebrovascular event (either ischaemic or haemorrhagic) with neurological deficit persisting beyond 24 hours".
>
> MacWalter and Shirley (2002)

A stroke is a medical condition affecting the brain. The brain is supplied with oxygen and nutrients by a network of blood vessels. If this blood supply is restricted or cut off, the area of nerve cells, which the blood vessels supply, will be deprived of oxygen and nutrients resulting in tissue damage. Irreversible brain damage is caused within 5-7 minutes, resulting in loss of or reduced function in the part of the body corresponding to the area of brain that has been damaged (Ironside 1996). Similar to a heart attack, the blood vessels in the brain can become occluded by a thrombosis or an embolism. This type of stroke is referred to as a cerebral infarction or ischaemic stroke and accounts for 70 – 80% of strokes. Alternatively a blood vessel can rupture to cause a bleed into the brain tissue, again damaging a specific area; this is referred to as a cerebral haemorrhage or haemorrhagic stroke and accounts for approximately 20 – 30% of strokes. A subarachnoid haemorrhage is where a ruptured blood vessel bleeds into the subarachnoid space (between the brain and the skull) but not into the brain tissue itself. A subarachnoid haemorrhage is not traditionally classified as a stroke as the risk factors, onset, age group and treatment appear to be different to that of thrombotic and haemorrhagic strokes. However a subarachnoid haemorrhage is classified as cerebrovascular disease and therefore is included in some of the mortality statistics in the U.K. accounting for approximately 10% of cerebro-vascular disease, having an average annual incidence of 6 per 100,000 of the population (Clarke 1998). In the empirical work for this thesis subarachnoid haemorrhage is not to be included but the reader needs to be aware that subarachnoid haemorrhage may be included in some of the health statistics quoted in the following sections.

The physical manifestation of a stroke will depend on the area of the brain affected. Generally speaking if the damage is caused in the left hemisphere of the brain, the right side of the body will be affected and vice versa. The effects will correspond to the specific area of the brain that has been damaged and the extent of that damage. For example if the nerve cells are damaged due to an occlusion of the right branch of the middle cerebral artery in the internal capsule of the brain, the patient is likely to clinically present with left limb weakness or hemiplegia. The onset of the weakness may take seconds, minutes or even hours.

"Initially the affected limbs appear flaccid but after a variable period of time the reflexes recover and the weakness recovers gradually over days, weeks, months or even years". (Clarke 1998).

Clinically stroke patients can therefore experience anything from a minor disability such as minimal facial weakness to a major disability of having complete one-sided paralysis. However what may be considered minor to one person may be major to another, which can also be said of the psychological consequences of stroke, which will be discussed later in this chapter. Stroke has implications not only epidemiologically but for the individual as well.

EPIDEMIOLOGICAL PERSPECTIVE

Incidence of Stroke

Stroke is a medical condition of the brain and is the third commonest cause of death in the Western World. It is estimated that around 1 million ischaemic strokes occur in Europe each year causing nearly 400,000 people to die (Giroud et al 2002). The death rates from cerebrovascular disease for England and Scotland for the year 2001 were 483 deaths per 100,000 population (ISD Scotland 2003). Stroke is a condition associated with age and the incidence of stroke rises as the population ages (Wolfe et al 2001). The Registrar's General Office (RGO 2003) states that the number of people aged 75 and over has increased by 29% from 1981. They also estimate that this figure will rise significantly in 30 years time as a result of the 1960s baby boom. "Health in Scotland" (1999), a government paper noted that 75% of people who have a stroke will be aged 65 years and over. These Scottish trends suggest that the incidence of stroke will increase in future decades as the proportion of the population aged 65 years and over rises. This appears to be similar in other western countries (Warlow et al 1996, Hankey 1999, Wolfe et al 2001). In addition, Wolfe and Burney (1992) observed that mortality rates from stroke appeared to be rising in younger age groups, which would have an effect on overall death rates in subsequent decades. Although a common cause of death, rates have declined over the last decade (ISD Scotland 2003), reflecting an improvement in survival rather than a decline in the incidence (Giroud et al 2002). However with an increased survival there is an associated high prevalence of physical disability.

Prevalence of Disability

Stroke is thought to be the main cause of disability in the UK today (Giroud et al 2002, Parahoo et al 2003). Statistics recording the number of people disabled from a stroke are not recorded, as many stroke survivors are in retirement and do not register themselves disabled. However health statistics estimate that 30% of survivors will be totally independent within 21 days increasing to 50% by 6 months (NHS Scotland 2003, Parahoo et al 2003). At one year post-stroke 65% of survivors will live independently whilst 35% remain disabled needing help from family and health services. Around 5% of patients will be cared for in nursing homes or long stay hospitals. Estimated stroke care accounts for 4 - 6 % of the national health expenditure in the UK of the NHS budget (Burton 2000). In terms of numbers between March 2002 to March 2003 in Scotland 10,295 people were admitted to hospital with cerebrovascular disease, 8,313 people survived over 30 days and 16,181 people (including patients who had a stroke before March 2002) were discharged from hospital with a diagnosis of stroke (ISD Scotland 2003).

With the incidence of stroke and the subsequent prevalence of disability, the potential draw on public services is enormous and has prompted the government to address the situation. The literature exposes inequalities in the organisation and clinical care for stroke patients in the UK (Stroke Treatment and Service Delivery Conference Consensus Statement 2000, Wolfe 2001) and recognises an “apparent lack of understanding by health professionals of the stroke patients’ requirements to promote a positive recovery process” (Gibbon 2002). Stroke has been targeted as an area for improvement, with the acknowledgement of the need for comprehensive care with a range of publications from the Royal College of Physicians Intercollegiate Stroke Group (2002), The National Framework for Older People (2001), The Royal College of Physicians Report (2001) and Health in Scotland (1999). Throughout all these reports there has been a great deal of emphasis on secondary care, i.e. promoting recovery from stroke and minimising the risk of re-occurrence. To help explain stroke further the effects of a stroke from an individual perspective are now described.

INDIVIDUAL PERSPECTIVE:

The individual perspective of stroke has been divided into three parts. The first part briefly describes the causes of stroke. The second part describes the effects of the stroke on the individual using the framework of the International Classification of Impairments, Disabilities and Handicaps (ICIDH – 2; WHO, 1998). The third part focuses on the individual’s recovery and the input of rehabilitation.

Causes of Stroke

Stroke, as already defined is caused by an interruption in the blood supply to the brain tissue. The risk factors predisposing to this disruption in the blood supply can be genetic, due to age, co-morbidity, such as diabetes, hypertension, heart disease, previous stroke or lifestyle factors, such as smoking, lack of exercise, poor diet, and excessive alcohol intake. Genetics and age are uncontrollable risk factors whereas lifestyle factors are controllable through adopting a healthier lifestyle (Clarke 1998). Furthermore practicing a healthier lifestyle reduces the risks of co-morbidity. Following a stroke, survivors are encouraged to change their behaviour to live a healthier lifestyle to minimise risk factors associated with stroke and its reoccurrence.

Effects of Stroke

> "Stroke can have a catastrophic impact on the individual, with a wide range of far reaching physical, psychological and social sequelae." Burton (2000)

The current approach to understanding disability is derived from International Classification of Impairments, Disabilities and Handicaps (ICIDH – 2; WHO, 1998), which is a "multi-purpose classification", intended to provide a standardised way of understanding and researching "the function states associated with health conditions" from a multi-disciplinary approach (NHS Scotland 2003). The model not only acknowledges the physiological aspects of disability, but also the contextual factors, environment and personal characteristics. (Figure: 1.1.) The model can be used to describe a "health condition", such as stroke. Stroke is a result of disease (an underlying pathology which leads to damage to the brain), leaving the body with a condition, i.e. the functional effects of the stroke on the body. These functional effects impact on the daily activities of living through impairment, i.e. the loss of body structure, physiological or psychological; through activity, i.e. where the individual is limited in their activity (activity limitation previously known as disability); and participation, i.e. "the nature and extent of a person's involvement with life situations in relationship to impairment, activities, health condition and contextual factors" (Bonetti 1999).

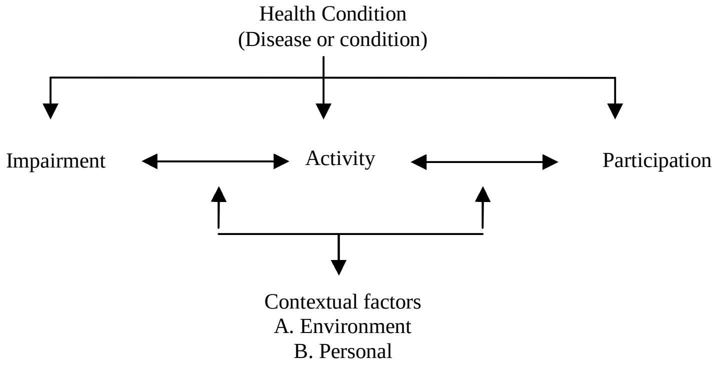

Figure: 1.1: International Classification of Impairments, Disabilities and Handicaps (ICDH-2; WHO, 1998)

These effects may range from minor to major depending on the extent of the brain damage but also range from major to minor depending on the contextual factors, which take into account the individual’s environmental and personal experiences, potentially shaping the way they think about their health condition. For example, stroke can have a functional effect relating to impairment, in that the patient may have a loss (or threatened loss) or abnormality of limbs or physical responses, e.g. swallowing reflex. These impairments can be seen as temporary or permanent and can contribute to activity limitation, such as a stroke patient who may be having difficulty talking and eating in the early stages of their recovery, which may resolve or may not resolve. If this difficulty persists it may limit the patient in participating at a social level and this participation restriction will influence or be influenced by patients’ individual characteristics, i.e. the patient not wanting to eat out socially because: the restaurant does not have the appropriate aids to allow the patient to eat (environment) or the patient may feel embarrassed about his /her difficulty (psychological). Activities are subsequently limited in that patients will have an inability or difficulty in performing a task, for some it may even be impossible.

Traditionally, the performance of functional daily activities such as eating and drinking, toileting bathing, dressing, walking, housework, and shopping have been measured to demonstrate levels of disability. Although these activities may be limited due to the physical consequence of a stroke, researchers are becoming increasingly aware that these activities may be further restricted due to the individual’s environment or more specifically due to the individual’s psychological characteristics such as the way they think about their stroke. Patients who experience minimal disability from their stroke may feel more distressed about it than someone who has had a gross disability. The ICDH-2 model is consistent with past research by Pollard and Johnston (2001) who found no significant correlations between disability (activity limitation) and impairment and

Fisher and Johnston (1996a) who showed that disability could be manipulated without changing impairment. (Their work will be further discussed in relation to interventions to promote recovery later in this chapter). In summary whilst the stroke patient may have activity limitation (disabilities) following a stroke these will be influenced by the contextual factors, environment and personal, as suggested by the model, which may impact on the patient's recovery from their stroke.

Recovery from Stroke

Stroke recovery is of great interest in that patients have a physiological deficit that once occurred does not deteriorate unless the patient is compromised by co-morbidity or complications such as chest infections or further strokes. Anecdotal evidence (M^{c}Crum 2000, Cant 2000) and now empirical evidence (see review below) has shown that patients do recover or adapt following a stroke but how this process occurs remains elusive.

Recovery from a stroke can take a variable amount of time and is influenced by clinical, demographic, and psychological factors (the extent of the pathology, the level of impairment and the contextual factors). It is a spontaneous process that can be influenced with the help of rehabilitation involving a multi-disciplinary approach using the skills of doctors, nurses, physiotherapists, occupational therapists, speech therapists and social services or by means of the patients own coping strategies i.e. in some cases patients "rehabilitate" themselves with out statutory help, intuitively knowing what to do to help themselves. In the acute stages of stroke, patients are stabilised through resuscitation, monitoring of signs and symptoms, confirmation of diagnosis and a regime of medication. Once stabilised medically, patients are referred for rehabilitation depending on the degree of physical effects of the stroke. For example, a patient who has had damage in their left hemisphere will present with right-sided symptoms and usually communication problems and therefore may receive speech therapy to promote speech and comprehension; a patient with a left-sided weakness of the leg will have physiotherapy to build up their strength and improve their gait. Patients are therefore usually referred for rehabilitation where they are taught new ways and supported to adapt to their new circumstances, in an attempt to develop the patient to their "fullest physical, psychological, social, vocational and education potential consistent with his or her physiological, and anatomic impairment and environmental limitations" (Johnston et al 1997). The overriding goal of rehabilitation is to improve the functional independence in every day activities (Johnston et al 1997) and does not escape the influence of the contextual factors. The patient, an individual with his/her own psychological characteristics will be cared for in various environments by health professionals who will also have their own individual psychological characteristics. Some patients appear to respond to rehabilitation more readily than others. This leads authors to question the constituents of rehabilitation, as it appears to be “indistinct” (Johnston et al 1997), “non-explanatory in its process” (Burton 2000) and further described as a “black box” (Whyte and Hart 2003). Statutory rehabilitation appears not to take into account the opinion of the patient, i.e. health professionals may see the patient following rehabilitation, as being fully recovered but, subjectively the patient themselves may not feel as though they have recovered, as they would have liked.

Patient satisfaction has been used within the health services as gauge to indicate the patients “affective” response to the services provided (Weinman 1998). Patient satisfaction not only provides a starting point for health professionals to understand how patients respond to health care; but it is also considered important as it is associated with patients’ cooperation with medical advice (Ley 1996) and their recovery (Morrison et al 2000). Throughout the stroke recovery literature over the last decade authors have acknowledged the lack of satisfaction stroke patients perceive with their care (Ayana et al 2001, Morrison et al 2000), with the lack of information and poor communication being the key issues (Ayana et al 2001). The Stroke Treatment and Service Delivery Conference Consensus Statement (2000) states “the needs of stroke patients are not being adequately met in the UK at present”.

With the current drive for evidence-based medicine, a substantial number of controlled trials have examined the efficacy of pharmaceutical interventions used in the acute stages of stroke, evident by the survival from stroke. Relatively recently controlled trials have been used to examine the efficacy of rehabilitative measures used to promote recovery and in the last two decades there has been an increase in assessing the indicators of stroke recovery (Hostenbach 2001). These indictors not only reveal patient groups who may benefit from specific interventions but more importantly provide outcome measures for future evaluation. Subsequently, increasing numbers of non-pharmacological interventions to maximise recovery operationalising measures of disability usually through functional ability in terms of activities of daily living, mood and satisfaction, including other outcome measures such as, length of stay in hospital, survival, knowledge of stroke and distress of carers have been tested and evaluated in RCTs. A systematic review of these RCTs was performed to see what other interventions had been tested aiming to improve outcome from stroke and the findings are presented in the following section.

A SYSTEMATIC REVIEW OF RCTS TESTING AND EVALUATING NON-PHARMACOLOGICAL INTERVENTIONS

Background

The impact of stroke epidemiologically and psychologically as demonstrated in previous sections of this chapter has given rise to an increasing body of research, which has become more sophisticated and robust as our understanding develops. Initially research, using RCTs involved pharmacological interventions aimed at improving recovery from stroke in its acute stages. More recently, this methodology has been used to test and evaluate non-pharmacological interventions, as there is a general appreciation in the literature that recovery involves more than medication (Johnston 1996). The aim of this review is to identify RCTs testing non-pharmacological interventions with outcome measures of functional ability, mood and satisfaction.

Methods

Using OVID and Web of Science (on-line search engines) CINHAL, EMBASE, MEDLINE, PsycINFO, CDSR (Cochrane database Systematic Reviews) databases were accessed. Using key words, stroke trials, stroke rehabilitation, stroke interventions, cerebrovascular accident, stroke randomised controlled trials, psychosocial rehabilitation papers between the years of November 1993 to November 2003 were identified.

Inclusion Criteria

The trials of interest for this search were RCTs testing interventions aiming to improve recovery from stroke. Interventions were defined as the use of specific therapies or environments to induce a change in the patient's recovery, which was measured in terms of three outcome variables, functional ability, mood and satisfaction. Case studies were not included in this review.

Results

Four hundred and fourteen citations were produced excluding duplications and are broadly summarised in table 1.1.

This summary illustrates the range of research areas being undertaken in stroke recovery over the last 10 years. There were a total 55 RCTs. Six trials were excluded from the present review: 2

trials that tested pharmaceutically derived interventions, 1 trial where the effectiveness of an intervention for patients with acquired brain impairment was tested, not explicitly stroke had their affected limbs immobilised by splinting; 1 trial was a single case study applying a range of interventions randomly; and 2 trials examined the cost effectiveness of home versus hospital care.

GENERAL AREAS OF RESEARCH CITATIONS	NUMBER
A range of review papers including Cochrane Reviews examining quality of care, methodology, intensity of rehabilitation, types of interventions, place of rehabilitation.	67
Methodological issues including assessment of measures and development of new models	41
Pharmaceutical assessment	20
Quality of life	8
Neuro-rehabilitation, including Wallerian degeneration	11
Stroke patient perspectives, carer involvement and their distress	14
Letters/book reviews/editorials	40
Assessment of outcome indicators, clinical, demographic and psychological	53
Stroke services management, including assessments of teamwork, practice guidelines development, advances in rehabilitation	42
Evaluation of preventative measures including knowledge of symptoms	15
Assessment of stroke complications	28
Stroke units evaluation and evaluation of specific therapies – cross-sectional	21
Randomised controlled trials	55

Table 1.1: Summary of Citations from the Literature Review

In this review 49 RCTs testing non-pharmacological interventions to promote recovery from stroke were included taking into account the contextual factors as highlighted in the ICDH-2 model. They were sub divided into 4 groups:

1. Interventions examining the effectiveness of the patient’s environment (n = 25)
2. Interventions examining specific therapies involving a programme of training including physiotherapy, psychotherapy and alternative therapies (n = 14).
3. Interventions examining social support from health, social and voluntary services with no specified programme of training (including occupational therapy) (n = 8).
4. Interventions examining the effectiveness of information and education (n= 2).

These sub divisions will be presented individually followed by individual discussions concluding with a general discussion of all the studies.

1. Environmental Interventions

The tables 1.2a and b show a set of RCTs (n = 25) obtained from the literature search examining the effectiveness of different environments in which stroke patients receive care/rehabilitation.

AUTHOR	INTERVENTION	SURVIVAL	FUNCTIONAL ABILITY	MOOD	SATISFACTION
Aitken P.D. et al 1993	General medical v. geriatric care	Not reported	Earlier improvement	Not reported	No difference
Hui, E. et al 1995	Geriatric day hospital v. conventional care	Not reported	Earlier improvement	No difference	No difference
Kaste, M. et al 1995	Neurology ward v. general medical ward	No difference	↑ in neurology ward	↑ in neurology ward	↑ in neurology ward
Kalra, L. & Eade, J. 1995	Stroke unit v. general wards	↑ in stroke unit	↑ in stroke unit but n. s.	Not reported	Not reported
Indredavik, B. et al 1997	Stroke unit v. general wards	↑ in stroke unit	↑ in stroke unit	Not reported	Not reported
Rudd, A. et al 1997	Early discharge scheme v. conventional care	No difference	No difference	No difference	↑ in early discharge
Widen-Holmqvist, L. et al 1997	Early discharge scheme v. conventional care	No difference	No difference	No difference	No difference
Indredavik, B. et al 1998	Stroke unit v. general wards 5 years on	↑ in stroke unit	↑ in stroke unit	↑ in stroke unit	Not reported
Ronning, O. & Guldevog, B. 1998	Hospital rehab. (HR) v. municipal rehab. (MR)	↑ in HR but n. s.	No difference	No difference	Not reported
Duncan, P. et al 1998	Home based exercise v. conventional care	Not reported	↑ with exercise	Not reported	Not reported
Indredavik, B. et al 1999	Stroke unit v. general wards 10 years on	↑ in stroke unit	↑ in stroke unit	Not reported	Not reported
Mayo, N. et al 2000	Early supported discharge (ESD) v. conventional care	Not reported	↑ with exercise	No difference	↑ with ESD

(Key: v. = versus; ↑ = increased; ↓ = decreased; rehab = rehabilitation; n. s. = non-significant.)

Table: 1.2a: RCTS Examining Environments in Which Stroke Patients Were Cared For

AUTHOR	INTERVENTION	SURVIVAL	FUNCTIONAL ABILITY	MOOD	SATISFACTION
Anderson, C. et al 2000	Home-based rehab. v. in-patient care	No difference	No difference	No difference	No difference
Indredavik, B. et al 2000	Extended stroke unit care v. conventional care –short term effects	No difference	↑ in stroke unit	Not reported	Not reported
Lincoln, N. et al 2000	Stroke unit v. conventional care 5 years on	↑ in stroke unit	↑ in stroke unit	Not reported	Not reported
Kalra, L. et al 2000	Stroke unit v. specialist stroke team v. specialist domicillary care	↑ in stroke unit.	↑ in stroke unit.	Not reported	Not reported
Sulch, D. et al 2000	Integrated care pathway (ICP) for stroke rehab v. conventional care	No difference	↓ in ICP	No difference	Not reported
Ronning, O. et al 2001	Stroke unit. v. conventional care	↑ in stroke unit	Not reported	Not reported	Not reported
Evans, A. et al 2001	Stroke unit v. stroke team care	Not reported	Not reported	No difference	Not reported
Ozdemir, F. et al 2001	Stroke unit v. home care	Not reported	↑ in in-patient care	Not reported	Not reported
Roderick, P. et al 2001	Domicillary care v. day hospital	Not reported	No difference	No difference	No difference
Steiner, A. et al 2001	Nurse-led unit v. conventional care	No difference	No difference	Not reported	Not reported
Sulch, D. et al 2002	Evaluation of integrated pathways	Not reported	Not reported	No difference	Not reported
Bautz-Holter, E. et al 2002	Early supported discharge (ESD) v. conventional care	↑ in ESD but n. s.	↑ in early discharge	No difference	↑ in ESD but n. s.
Fjaertoft, H. et al 2003	Extended stroke unit care v. conventional care –long term effects	↑ in stroke unit	↑ in stroke unit	Not reported	Not reported

(Key: v. = versus; ↑ = increased; ↓ = decreased; rehab = rehabilitation; n. s. = non-significant.)

Table: 1.2b: RCTs Examining Environments in Which Stroke Patients Were Cared For

The main outcome variables in these studies were survival, functional ability, mood and satisfaction. Of the 25 papers reviewed, 8 studies did not report survival as an outcome variable

(Aitken et al 1993, Hui et al 1998, Duncan et al 1998, Mayo et al 2000, Evans et al 2001, Ozdemir et al 2001, Roderick et al 2001 and Sulch et al 2002). Ten studies reported increased survival, of these 8 studies examined the efficacy of designated stroke units and demonstrated significant increases in survival (Kalra and Eade 1995, Indredavik et al 1997, 1998 and 1999, Lincoln et al 2000, Kalra et al 2000, Ronning and Guldevog 2001, Fjaertoft et al 2003), whilst 2 studies, one investigating hospital based rehabilitation (Ronning et al 2001) and the other investigating early supported discharge (Bautz-Holter 2002) showed non-significant trends in increased survival. Seven studies found no difference in survival rates when a examining range of different settings, such as, general medical ward versus neurological ward (Kaste et al 1995), early discharge schemes (Rudd et al 1997, Widen-Holmqvist et al 1997, Indredavik et al 2000), home based rehabilitation (Anderson et al 2000), integrated care pathways (Sulch et al 2000) and a nurse lead unit (Steiner et al 2002). Lincoln et al (2000) suggested in their 5 year follow-up study of patients who had been treated in a stroke unit, patients treated in the stroke unit were more likely to survive than those treated in a conventional ward because of reduced disability, which was an outcome of being cared for in a stroke unit. Less mobile patients are at less risk of medical complications such as chest infections, deep vein thrombosis (Clarke 1998).

Functional ability has not only been assessed by various measures but at different time points, which may account for the variation in results of the reviewed studies. Three papers did not use functional ability as an outcome measure (Ronning et al 2001, Evans et al 2001, Sulch et al 2000). Twenty two papers used functional ability as an outcome with 14 studies showing significant improvements in patients’ functioning (Aitken et al 1993, Hui et al 1998, Kaste et al 1995, Indredavik et al 1997, 1998, 1999 and 2000, Duncan et al 1998, Mayo, et al 2000, Lincoln et al 2000, Kalra et al 2000, Ozdemir et al 2001, Bautz-Holter et al 2002, Fjaertoft et al 2003). Whilst Kalra and Eade (1995) showed a non-significant improvement in functional ability in patients treated in a stroke unit. Six papers showed no difference in functional ability at all (Rudd et al 1997, Widen-Holmqvist et al 1997, Ronning and Guldevog 1998, Anderson et al 2000, Roderick et al 2001, Steiner et al 2002). These studies examined environments other than stroke units therefore the patients assessed were more likely to be less acute than those in the stroke units. Sulch et al (2000) in their study of integrated care pathways actually showed decreased functioning ability in their experimental group.

Thirteen studies used mood as an outcome measure again measured differently in the studies in the review. Of these, 2 studies reported improved mood in the experimental group as well as increased functioning (Kaste et al 1995, Indredavik et al 1998) whereas 11 studies showed no differences in mood between the experimental and control groups (Hui et al 1995, Rudd et al

1997, Widen-Holmqvist et al 1997, Ronning and Guldevog 1998, Mayo et al 2000, Anderson et al 2000, Sulch et al 2000, Roderick et al 2001, Evans et al 2001, Sulch et al 2000, Bautz-Holter et al 2002). Mayo et al (2000) reported increased functional ability but no improvement in mood, whereas Sulch et al (2000) reported lower functional ability and no difference in mood.

Nine studies used satisfaction as an outcome measure with 3 studies recording significant improvements in satisfaction (Kaste et al 1995, Rudd et al 1997, Mayo et al 2000), 1 study showing a non-significant improvement (Bautz-Holter et al 2002) and 5 studies showing no differences in satisfaction between the experimental and control groups (Aitken et al 1993, Hui et al 1995, Widen-Holmqvist et al 1997, Anderson et al 2000, Roderick et al 2001). The improved satisfaction was replicated in studies examining the effectiveness of early discharge schemes. Two studies (Rudd et al 1997, Widen-Holmqvist et al 1997) showed greater satisfaction but no change in functional ability whereas Mayo et al (2000) showed both improved satisfaction as well as improved functional outcome. These findings possibly indicate that patients express greater satisfaction when they are cared for in their own home rather than being an in-patient but greater satisfaction was not associated with improved function.

Discussion of Environmental Interventions

The main issues in this review were the definition of the environments and the various measures used to assess survival, functional ability, mood and satisfaction. Survival is a dichotomous variable but the reported rates of survival are misleading due to the descriptions of the environments. Survival as an outcome measure of being treated in a stroke unit appears logical, as stroke units traditionally tend to take acute patients and stabilize the medical condition whereas the other environments tested would involve patients who are further on in their recovery. This may offer an explanation as to why stroke unit care result in higher survival than care in other environments. The stroke units in this review (n = 11) differed from each other in the care that they offered. Seven studies were carried out in units incorporating acute care and rehabilitation (Indredavik et al 1997, 1998, 1999, 2000, Kalra et al 2000, Evans 2001, Fjaertoft et al 2003), whereas 1 study was carried out in an acute stroke unit where patients were discharged within a week to home or further rehabilitation (Ronning et al 2001) and 3 studies were carried out in units that specialised in rehabilitation (Kalra and Eade 1995, Lincoln et al 2000, Ozdemir et al 2001). Furthermore stroke units potentially differ from each other in the plans of care used to maximise recovery, the resources available within the unit and the team offering the care. There appears to be no standard rehabilitation process addressing the needs of stroke patients (Duffy et al 2003). Gibbon (2003) has also suggested that designated stroke units whilst considered to be effective are unable to cope with the high incidence of stroke. This is possibly one reason as to why stroke patients are selected for rehabilitation in a stroke unit (Kalra 1995, Ronning and Guldevog 1998), which may have a biasing effect on the results of studies evaluating the effectiveness of stroke units.

Environments that were not designated as stroke units revealed differing outcomes, for instance Hui et al (1995) showed better outcomes in a geriatric day hospital than a neurology unit whereas Kaste et al (1995) showed better outcomes in a neurology unit rather than a general medical ward. On closer examination Hui et al (1995) was comparing the out patient care under a neurologist with the patients receiving out patient care under a geriatric day hospital. Whereas Kaste et al (1995) compared a neurology ward with a general medical ward with the neurology ward being described as having a physician interested in stroke, with a multidisciplinary approach to care including standardised procedures for stroke rehabilitation from acute stages through to longer term care which possibly included the same components as some of the stroke units.

Ozdemir et al (2001) showed that in-patient care improved functional ability compared with home care whereas Duncan et al (1998) in their pilot study showed the reverse. Furthermore Anderson et al (2000) showed no difference in functional ability whether the patient was cared for in the home or as an outpatient. These three studies were all very different. Ozdemir et al (2001) used an intensive program of exercise in the hospital and compared it with minimal input in the home based setting, whereas Duncan et al (1998) used an intensive programme of exercise in the home setting and compared it with conventional care in the home setting; Anderson et al (2000) compared community based rehabilitation with hospital out-patient rehabilitation. Therefore it is very difficult to compare these studies with each other as they are examining different aspects of home-based care.

This brings into question as already mooted by Johnston et al (1997), Burton (2000) and Whyte and Hart (2003), what are the components of these environments that induce improvement in survival, functional ability, mood and satisfaction? Furthermore Vitolins et al (2000) questions how the outcomes are being measured, given that the scales of impairment, activity and participation only partially reflect the recovery process, which additionally tends to be physician orientated. Wade (2003) conducted a review of rehabilitation suggesting that rehabilitation is more effective in the patient’s own environment, but improvement appeared to be short-lived and the contents of that rehabilitation was “neither multidisciplinary nor expert”. Evans et al (2000) suggested that whilst stroke units appeared to be beneficial to the patient “the exact nature of stroke unit care remains poorly defined" possibly due to the variations in practice. By using the data from an RCT, Evans et al (2000) compared stroke unit, specialist stroke team and specialist domicillary care (the domicillary care group were not used in this study). They prospectively identified factors using a structured format that could be related to better outcomes in the unit. In the stroke units, patients were more closely monitored and themes of multi-disciplinary teamwork, involvement of patients and relatives and education of staff emerged. Patients in the unit were more likely to have social work assessment, carer skills assessment, and secondary prevention needs addressed. In the stroke unit "patients had clearly defined goals", but who had determined these goals were not explicit. However Evans et al (2000) concluded that no causal relationship between these variables and outcome could be inferred and the individual elements of care still need to be examined more closely. In a review by the Cochrane Stroke group, it concluded that specialist units significantly maximise stroke survivor's independence a year from their stroke but the components of care need to be further examined. Duffy et al (2003) argued that the use of interventions within stroke units not only varies but also are not completely implemented. The current literature appears to be acknowledging a need for the individual components of the care patients receive in stroke units to be more closely examined.

2. Specific Therapy Interventions

From the systematic literature search, 14 RCTs examined the effectiveness of specific therapies, which involved training over a specified period of time (table: 1.3.). These studies did not use survival as an outcome measure and mainly concentrated on functional outcome with a small number of studies (n = 2) reporting mood and satisfaction outcomes. Six studies reported increased functional ability (Werner and Kessler 1996, Kwakkel et al 1999, Van der Lee et al 1999, Lum et al 2002, Fang et al 2003, Ada et al 2003) whereas 8 studies reported no differences in functional ability between the experimental and the control groups (Lincoln et al 1999, 2003a, Shiflet, 2002, Da Cuna et al 2002, Kwakkel et al 2002, Goodwin et al 2003, Moreland et al 2003, Rodgers et al 2003).

In 2 studies patients' physical input was not involved in the intervention. These included Shiflet (2002) who tested the efficacy of Reiki therapy on stroke recovery. She concluded that Reiki therapy did not have an effect on functional ability nor mood. Lincoln et al (2003a) used cognitive behaviour therapy as an intervention in their study where they also found no benefits in functional ability, mood or satisfaction.

Ten studies concentrated specifically on improving function of the upper and/or lower limb using a specified programme of exercise.

AUTHOR	INTERVENTION (Duration of therapy)	FUNCTIONAL ABILITY	MOOD	SATISFACTION
Werner, R. & Kessler, S. 1996	Increased OT and physiotherapy outpatient v. no therapy (12/52)	↑ with therapy	↑ ns	Not reported
Lincoln, N. et al 1999	Intensive arm therapy (5/52)	No difference	Not reported	Not reported
Kwakkel, G. et al 1999	Intensive arm and leg training therapy (20/52)	↑ with therapy	Not reported	Not reported
Van der Lee J. et al 1999	Forced therapy of arm (12 days)	↑ with therapy	Not reported	Not reported
Shifflet S.C. 2002	Reiki Therapy (2.5/52)	No difference	No difference	Not reported
Da Cuna, I. T. et al 2002	Supported treadmill ambulation training (3/52)	No differences	Not reported	Not reported
Kwakkel, G. et al 2002	Intensive arm and leg training 12 months on (20/52)	No difference	Not reported	Not reported
Lum, P. S. & Burgar, C. G. 2002	Robot assisted training – upper limb (8/52)	↑ with therapy	Not reported	Not reported
Goodwin, N. & Sunderland, A. 2003	Wrist extension monitoring (3-4/52)	No difference	Not reported	Not reported
Fang, Y. N., et al 2003	Additional physiotherapy input (4/52)	↑ with therapy	Not reported	Not reported
Moreland, J. D. et al 2003	Progressive resistance strengthening exercises (mean 62 days)	No difference	Not reported	Not reported
Ada, L. et al 2003	Testing treadmill and over-ground walking programme (4/52)	↑ with therapy	Not reported	Not reported
Rodgers, H. et al 2003	Increased-intensity upper limb therapy programme (6/52)	No difference	Not reported	Not reported
Lincoln, N. et al. 2003a	Cognitive behavioural therapy for depression post-stroke (3/12)	No difference	No difference	No difference

(Key: v. = versus; ↑ = increased; ↓ = decreased; rehab = rehabilitation; n. s. = non-significant.)

Table 1.3: RCTs Testing the Effectiveness of Specific Therapies in Stroke Patients

Four studies showed improved limb functioning following an intensive exercise programme (Kwakkel et al 1999, Van der Lee et al 1999, Lum et al 2002, Ada et al 2003) whilst 5 studies showed no differences between the experimental and control groups following intensive exercise (Lincoln et al 1999, Kwakkel et al 2002, Goodwin et al 2003, Moreland et al 2003, Rodgers et al 2003). Two studies concentrated specifically on walking, Ada et al (2003) showed significant improvements in walking in their experimental group whereas Da Cuna et al (2002) showed no difference between the experimental and control groups.

Two studies examined the efficacy of physiotherapy rehabilitation in general and showed improved function when physiotherapy was increased (Werner and Kessler 1996, Fang et al 2003). The only other study to report mood outcomes was Werner et al (1996) who showed a non-significant improvement in mood in those patient receiving intensive physiotherapy.

Discussion of Specific Therapy Interventions

These studies described a specific programme of treatment directed at a specific part of the stroke patient, e.g. impaired limb, depression, apart from the Reiki therapy which was aimed at the "whole" person (Shifflet 2002). However the programmes of treatment varied in duration from 12 days to 3 months, which has time implications when comparing the results of these studies. The therapies were administered at varying times throughout the stroke patient's recovery. Regardless of therapy patients tend to experience an element of spontaneous recovery plus a development of their understanding of their illness, which will have an affect on the way they respond to their therapy. Furthermore baseline and outcome measurements in the reviewed studies were taken at different times. These issues did not appear to be acknowledged in the papers reviewed.

The way patients respond to treatment may have implications for the studies testing intensive exercise programmes as patients are required to actively respond to a treatment programme. Whilst this is important issue in the studies examining environmental interventions, patients' adherence to any of the regimes in that environment may not have been so obvious and possibly not deemed important at the time the studies were carried out. Of the 12 studies examining intensive therapy, 11 studies reported the number of patients who did not continue with the intervention and included general reasons (Werner and Kessler 1996, Lincoln et al 1999, Kwakkel et al 1999, Van der Lee et al 1999, Da Cuna et al 2002, Lum et al 2002, Goodwin et al 2003, Fang et al 2003, Ada et al 2003, Moreland et al 2003, Rodgers et al 2003). Four studies acknowledged levels of adherence to the activities in the programmes of intensive therapy (Lincoln et al 1999, Kwakkel el 2002, Lum et al 2002, Ada et al 2003) but they did not go on to discuss this further and acknowledge the possible implications of that non-adherence on the effectiveness of the intervention.

The effect of health professionals' communication may also have had a role in some of these studies and may account for the variation in the results. For instance Werner et al (1996) and Fang et al (2003) showed improved functional outcome in patients receiving additional physiotherapy. However in some of the studies involving intensive limb, no improvements in functional outcomes were found (Lincoln et al 1999, Kwakkel et al 2002, Moreland et al 2003, Rodgers et al 2003) yet these intensive limb therapies were also administered by physiotherapists. Gustaven and Mengshoel (2003) concluded that the central elements of physiotherapy input was physical functioning and movement but patient participation and environment (contextual factors in the ICDH model) were not taken into account therefore suggesting that specific therapies only address specific parts of the stroke patient's problem.
In the studies offering additional physiotherapy (Werner et al 1996 and Fang et al 2003) patients were encouraged to be more involved in their treatment. One could tentatively suggest that the patients felt more in control of their therapy and possibly more satisfied, which may have impacted on the way they responded to their treatment and possibly the way the health professional responded to them which lead to both studies showing improved functional ability.

Of the 14 studies of specific therapies satisfaction and mood outcomes were only reported in three studies (Werner et al 1996, Shifflet 2002, Lincoln et al 2003a). This is of interest given the large body of research within health psychology showing that functional ability is significantly related to mood and satisfaction (Johnston et al 1999). Lincoln et al (2003a) reported no differences between the experimental and the control group in satisfaction or mood but suggested these findings may have been due to the "small sample size, method of recruitment and selection criteria". Shifflet (2002) reported no difference in mood between the experimental and control groups whilst Werner et al (1996) showed a trend in improvement in their experimental group.

The effects of the psychological characteristics of the patient and the health professional appeared to be over looked in the reporting of these studies which may have accounted for the varying results in the studies testing specific therapies.

3. Social Support Interventions Including Health, Social and Voluntary Services

The RCTs (n = 8) testing the effectiveness of a designated worker to support patients following a stroke are shown in table 1.4. Initially interventions involving occupational therapy were included in the specific intervention category but on further reflection these studies involved therapies that were patient centred and did not offer a specified programme of training and have subsequently been included in this group of papers. Only 1 of these studies improved functional ability (Gilberston et al 2000) whilst the remaining 7 studies showed no effect on functional ability (Forster and Young 1996, Dennis et al 1997, Mant et al 2000, Andersen et al 2002, Parker et al 2001, Logan et al 2003, Lincoln et al 2003b). Furthermore of the 4 studies using mood, as an outcome measures no differences between the experimental and control groups were found (Forster and Young 1996, Dennis et al 1997, Mant et al 2000, Lincoln et al 2003b). Of the 5 studies assessing satisfaction with the intervention 3 studies reported increased satisfaction (Dennis et al 1997, Gilberston et al 2000, Lincoln et al 2003b) whereas 1 study reported no difference in satisfaction between the experimental and control groups (Mant et al 2000).

AUTHORS	INTERVENTION	FUNCTIONAL ABILITY	MOOD	SATISFACTION
Forster, A. & Young, J. 1996	Specialist Community Support Nurse	No difference	No difference	Not reported
Dennis, M. et al 1997	Stroke family care worker	No difference	No difference	↑with therapy
Mant, J. et al 2000	Family support	No difference	No difference	No difference
Gilberston, L. et al 2000	Domiciliary occupational therapy v. conventional follow up	↑ with therapy	Not reported	↑with therapy
Andersen, H.E. et al 2002	Follow up visits by 3 types of professional	No difference	Not reported	Not reported
Parker, C.C. et al 2001	Occupational therapy: activities of daily living v. leisure therapy	No difference	Not reported	Not reported
Logan, P.A. et al 2003	Occupational therapy: activities of daily living v. leisure therapy	No difference	Not reported	Not reported
Lincoln, N. et al. 2003b	Stroke Family Support Organiser	No difference	No difference	↑with therapy

(Key: v. = versus; ↑ = increased; ↓ = decreased.)

Table 1.4: RCT Testing the Effectiveness of Social Support Interventions

In the study by Dennis et al (1997) testing the effectiveness of a stroke family worker (social work trained), the “unmet needs” of the stroke patient and family were addressed. They demonstrated that whilst the intervention group expressed greater satisfaction with certain aspects of care, they developed a greater dependency on the stroke family worker when compared with the control group, which they suggested had implications for developing this type of service.

Discussion of Social Support Interventions

Only 1 study out of 8 showed an improvement in functional ability. In the study by Gilbertson et al (2002) increased functional ability and satisfaction was demonstrated but there were no differences in mood outcomes. The intervention was client centred and included goal setting, which was similar to the studies examining increased physiotherapy input (Werner et al 1996, Fang et al 2003). The increased physiotherapy studies, like Gilbertson et al (2002) showed significant improvements in functional ability. Andersen et al (2002) examined the efficacy of support from three types of health professionals and showed no direct improvement in functional ability but this was not the study's main outcome measure. The patients receiving additional support were significantly less likely to be readmitted to hospital. The authors went on to suggest that functional ability in those patients not readmitted to hospital was probably greater but this was not examined in their study. Dennis et al (1997) highlighted the importance of support being aimed at improving patients' coping rather than encouraging dependency, further acknowledging the patient's role in their own recovery.

4. Information and Education Interventions

Stroke patients and informal carers are entitled to a "clear account of the nature and the causes of their stroke" (Stroke Treatment and Service Delivery Conference Consensus Statement 2001) yet there is evidence to suggest that patients continue to express a lack of understanding (Ayana et al 2001).

AUTHORS	INTERVENTION	FUNCTIONAL ABILITY	MOOD	SATISFACTION	KNOWLEDGE
Mant, J. et al. 1998	Information pack for patients and carers	No difference	No difference	↑ with information but n. s.	No difference
Rodgers, H. et al. 1999	Stroke education program for patients and care givers	No difference	No difference	↑ with program	↑ with program

(Key: v. = versus; ↑ = increased; ↓ = decreased; rehab = rehabilitation; n. s. = non-significant.)

Table 1.5: RCTs Testing the Effectiveness of Giving Information to Stroke Patients

The final two studies identified in this review are shown in table 1.5 and are both related to information giving and education and included an additional outcome of knowledge.

Both interventions showed no effect on functional ability or mood but both appeared to improve satisfaction, although Mant et al (1998) showed a non-significant improvement. Furthermore the study by Rodgers et al (1999) showed a significant increase in knowledge in the intervention group. Both studies were also aimed at supporting the carer.

Discussion of Information and Education Interventions

Information alone whilst important does not appear to change behaviour (Ley 1997, Leventhal et al 1992), which was further demonstrated by the two interventions offering information and education in table 1.5. Furthermore Rodgers et al (1999) found that 58% of patients did not attend to the stroke education programme and 45% of those who did, refused follow up or did not respond to the postal questionnaires assessing their levels of satisfaction that were sent out at a later date. The two interventions tested in these studies were different in the way the information was offered. The stroke education programme spanned six weeks with weekly 1- hour sessions, whereas the information leaflets were sent by post 1 week following discharge and follow up was carried out in both studies six months later. The information pack may have had no effect on knowledge possibly due to the nature of the intervention, many patients may not have read the leaflets, or had but forgotten the contents. The authors noted that 77% of the patients recall receiving the information pack but did not report what the patients could remember of the contents. This result is open to bias through social desirability in that some patients may have said that they had received the information pack to “please” the experimenter. Rodgers et al (1999) went on to say that the stroke education programme gave carers improved understanding of stroke but lowered social functioning. There was no difference between the carers and control group in satisfaction. Rodgers et al (1999) suggested the reasons for this result might be that it was not always viable to provide carers with a positive solution for their problems. This highlights that idea that information alone does not change behaviour and supports the need for psychologically derived interventions designed specifically to change the way the patient thinks about their stroke.

Discussion of the Literature Review

Generally, research on interventions to improve stroke recovery has not produced conclusive results. Even though patients appear to do better in specialist units the evidence remains not entirely consistent. The actual process of recovery and professional intervention appears to be ill defined as Whyte and Hart (2003) suggested, the definitions of rehabilitation have been “characterized as a black box allowing little insight into the active ingredients”.

Fourteen studies in the whole review measured all three outcome measures of functional ability, mood and satisfaction (Hui et al 1995, Kaste et al 1995, Rudd et al 1997, Widen-Holmqvist et al 1997, Mayo et al 2000, Andersen et al 2000, Roderick et al 2001, Bautz-Holter et al 2003, Lincoln et al 2003a/b, Dennis et al 1997, Mant et al, 1997, 2000, Rodgers et al 1999). Only 1 study improved all three outcomes (Kaste et al 1995) and 5 studies showed no difference in any of the outcomes (Widen-Holmqvist et al 1997, Andersen et al 2000, Roderick et al 2001, Lincoln et al 2003a, Mant et al 2000) suggesting that functional ability, mood and satisfaction are potentially related supporting the work of Johnston et al (1999). Mayo et al (2000) and Bautz-Holter et al (2003) showed improved functional ability and improved satisfaction but there were no effects on mood. Four studies improved satisfaction with out improving functional ability and mood (Rudd et al 1997, Dennis et al 1997, Mant et al 1997, Rodgers et al 1999). Hui et al (1995) only showed improved functional ability without improving mood or satisfaction, but this was only significant in the earlier stages of recovery.

All the papers presented in this literature review are more than likely to have had a psychological component to them, i.e. the behaviour of the patient, the health professionals and the family plus the way the interventions were carried out and the interaction between the patients, professionals and carers. These variables are not described in the results of the papers and therefore will have implications for the results, generalisability and replicability. Furthermore the research papers reviewed did not use theoretical frameworks. Although health professionals acknowledge the existence of models from other disciplines they have failed to use them as a framework around which to report their research and findings (Schumaker and Rejeski 2000).

There is an accumulating body of evidence to suggest that psychological factors are pertinent to patients’ recovery. Weinman (1998) states that there could be considerable gains from providing psychological interventions designed to reduce the impact of medical procedures. Could psychological interventions reduce the impact of a medical condition? How patients and health professionals think about illness, their own or others has not really been examined according to the literature review of stoke interventions, as the research has largely been confined to the environment, the person giving the therapy or the therapy itself. How people think about their illness has been extensively researched within the field of health psychology. Examining patient’s cognitions, i.e. the way they think about their illness and their affective response may reflect how they could respond to the various interventions that they have been exposed to in the above research. This work has again used outcome measures of functional ability, satisfaction and mood. Functional ability has been operationalised by measuring the performance of functional daily activities. The subjective measure of satisfaction is often used as it is suggestive of the patient's level of satisfaction with care, predictive of outcome and a measure of how well the care is meeting the needs of the patient and not the needs of the health professional giving the care. Satisfaction whilst important is a difficult concept to measure (Weinman 1998). This has been demonstrated by the various methods used to assess satisfaction in the studies reviewed, but more importantly those studies including satisfaction as an outcome did not appear to acknowledge its relationship with and implications for functional ability and mood. Patients' mood has been examined extensively in health psychology and has been shown to influence recovery from disability (Morrison 1998, Fisher and Johnston, 1996a). Although some of the studies reviewed included mood as an outcome measure its importance from a psychological perspective was not acknowledged. It was more likely discussed medically, in relation to the medical condition of “depression”.

What did the patients do and not do in the intervention reviewed? This was not covered in many of the papers reviewed especially the environmental interventions. The studies examining environment-based interventions described the environment but not the activities the patients were expected to perform (Hui et al 1995, Kaste et al 1995, Indredavik et al 1997, 1998, Rudd et al 1997, Ronning and Guldevog 1998, Mayo et al 2000, Kalra et al 1995, Sulch et al 2002). In the studies by Indredavik (2000), Anderson et al (2000) and Kalra et al (2000), “goals setting” was described as an activity the patients were required to carry out but they did not describe who did or did not set goals and who did and did not achieve them. In the papers reviewing specific interventions where patients were required to take an active part in the intervention, again there was little evidence of what the patients actually adhered to or did not. Numbers of patients lost to follow up or withdrawals were reported but not discussed except in the papers by Mayo et al (2000) and Ada et al (2003) who specifically reported the impact of lost to follow up or withdrawals on their results.

The literature review of the RCTs testing interventions to promote recovery from stroke showed inconclusive findings, which may be accounted for by not taking into account the contextual factors of the patients. Generally the interventions appeared to be prescriptive in their nature and overlooked the patient's cognitions and behaviour in relation to the interventions. They also did not acknowledge the level of patient involvement and its relationship to outcome. Dennis et al (1997) suggested that demographic and clinical factors whilst predictive of outcome are difficult to change. However there is evidence to suggest that psychological variables are also predictive yet they can be changed (Johnston et al 1999).

Patient’s cognitions and behaviour in relation to functional ability, mood and satisfaction outcomes have been extensively examined within the field of health psychology. In 1987 Partridge and Johnston examined how patients recovered from stroke and identified that recovery from physical disability followed a predictable pattern, which may be influenced by clinical, demographic and psychological factors. Previous research has shown that a “greater belief in perceived personal control is associated with more beneficial health outcomes” (Partridge and Johnston 1989). Wallston et al (1987) defined perceived control as a “belief that one can determine one’s own internal states and behaviours, influence one’s environment and/or bring about desired outcomes”. Partridge and Johnston (1989) developed the Recovery Locus of Control Scale (RLOC) and tested it on 20 stroke patients. They showed that patients with high internal beliefs made a better functional recovery. Johnston et al (1992) then went on to study ways of enhancing perceived control and its effects on subsequent recovery. In this RCT all patients were sent a standard letter confirming an appointment for physiotherapy but the experimental group’s letter had additional paragraphs designed to increase their perceived control. The results showed that the experimental group had significantly higher levels of perceived control and tended to be more satisfied than the control group. To further examine the role of perceived control and its relation to recovery from disability, Johnston et al (1999) conducted a longitudinal predictive study examining perceived control, coping and recovery from disability following a stroke. They found that that perceived control predicted recovery from disability, supporting the findings from their previous work (Partridge and Johnston 1989). This was further supported by Frank et al (2000) who showed that reductions in functional limitation in stroke patients were correlated with increases in perceptions of control.

Fisher and Johnston (1996b) showed that disability was not only related to perceived control but also mood. In another RCT they exposed patients with back pain to a mood induction task. Following a normal clinical interview patients were either asked about upsetting events (mood lowering) or positive events (mood-enhancing). They found that those patients who were exposed to the mood-enhancing tasks showed decreased disability. Furthermore Morrison et al (2000) showed that satisfaction with care and treatment predicts mood outcomes. Johnston and her co-workers (Frank et al 2000, Fisher and Johnston 1996b, Morrison et al 2000) suggested that disability was not completely dependent on clinical and demographic variables alone, as evidence had shown that psychological variables could predict disability. Furthermore clinical and demographic variables tend to be static whereas psychological variables can be open to modification.

THE STROKE WORKBOOK INTERVENTION STUDY - SWOT

Drawing on this body of research, a stroke workbook intervention was designed for stroke patients and their carers. The workbook was based on the Heart Manual, a self-help intervention developed and shown to be effective for MI patients (Lewin et al 1992). The aim of the workbook was not just to provide information but behavioural activities using cognitive behavioural therapy techniques allowing the patient to attain coping skills to encourage positive self management.

The stroke workbook was piloted and in a preliminary evaluation by Morrison et al (1998) showed that patients who received the workbook intervention were more satisfied with advice and information than those who did not and that the experimental group were significantly less anxious than the control. In 1998 St Andrews University and Ninewells hospital secured a grant to run a longitudinal RCT to investigate the effects of a stroke workbook intervention on perceived control, disability and mood outcomes in stroke patients. The stroke workbook was updated and tested in the Stroke Workbook Outcomes Trial- SWOT (Bonetti et al 2001).

Materials -The Stroke Workbook

The workbook provided basic information describing stroke, the recovery process, including the patient’s and family’s role and the support from health and voluntary services. It was presented with illustrations, in a 90-page A4 loose-leaf folder (Appendix A). It was written to encourage patients (and their carers) to take an active role in their recovery through learning about their stroke and how it had affected them. To do this, patients were asked to answer “quizzes” about the information they had read, to perform “tasks” designed to encourage them to identify positive past experiences and to draw on those experiences, to identify goals to give them an aim and subsequent feeling of achievement and a diary to monitor their recovery, and express their feelings about their recovery. The patients were encouraged to continue with any activities to promote their recovery and minimise further strokes. A relaxation tape was included with the workbook and used to promote a sense of well-being. Patients were asked to record all of their activities and the use of the relaxation tape to help them monitor their progress. Although the workbook was complex, in that it required commitment and time from the patients, it was written in a positive and encouraging style with a Flesch Reading Ease indicating an average reading level (Flesch Reading Ease score 70.6).

The workbook included five sections:

1. An introduction about the rationale behind the workbook.
2. Information about stroke and how to help recovery.
3. A 10-part section designed to enhance coping to promote recovery, looking at physical and emotional changes following a stroke, the role of physical activity and relaxation in recovery and how to record and monitor the recovery process.
4. A 2-part section about statutory and voluntary support and reducing further stroke risks.
5. A separate diary, which included a front page where patients were asked to identify realistic goals and write them down. Inside the diary there was a page for each day, which provided an opportunity for the patients to break their goals down into manageable activities and to monitor their achievement. A separate page allowed the patients to express their feelings and any thoughts they had about their recovery. A relaxation tape was included. It was a simple relaxation technique asking for progressive muscle relaxation. There was a section in the diary where they could record how often they did this and how they felt.

There was an optional section, which contained further information about risk factors, which was available if requested by the patient.

The workbook intervention spanned 5 weeks. Patients had to fulfil a number of behavioural activities designed to increase perceived control in order to help them to promote their recovery.

- They were asked to read the information about what a stroke is, recovery from a stroke and who to contact for assistance. They were asked to answer 5 simple quizzes to test them on the content of the information they had just read.
- They were asked to complete 15 “tasks”. These involved activities requiring the patient to think about the skills they could draw on to help their recovery. These tasks asked patients to reflect on past experience, recall coping procedures and to develop new ways of thinking about their recovery.
- They were asked to think about activities that they could do and identify achievable goals.
- A diary was included so that the patient could monitor their recovery on a daily basis and record what they had or had not done.

The Five-Week Intervention

Once the patient had been recruited and their baseline measures taken, they were randomly allocated to the experimental or control group. Those patients allocated to the experimental group were entered into a programme of implementer-initiated contact. These patients in the experimental group were contacted by telephone (telephone call 1) by the workbook implementer (SAJ) and a visit was arranged to deliver and introduce the workbook intervention (visit 1). At visit 1 the patient received the workbook plus verbal guidance on how to use it. The implementer went through the workbook with the patient and answered any questions the patient had. Further arrangements were made for a visit the following week (visit 2) at the convenience of the patient to assess how the patient was finding the workbook and to answer any questions. In the meantime the patient was encouraged to call the implementer if they felt they had a need to. At visit 2 patients were assessed for;

- Amount of reading and completion of activities.
- Goal setting and diary keeping. The goals were discussed as to whether they had written any and if they had were they achievable, if they had not written any, possible goals were discussed.
- Relaxation tape use and recording of use. If the patients had not used the relaxation tape the reasons for this were discussed and they were encouraged to use it in the future.
- For any queries regarding the activities in the workbook. These were answered and reassurance that the workbook was theirs to use how they wanted to.

The patient would be asked to continue with the activities in the workbook and that the implementer would telephone them weekly over the next two weeks (telephone call 2 and 3) to answer any queries and to encourage them to complete the workbook activities. The future dates of the telephone calls were written into the workbook along with the implementer’s telephone number. On telephone call 3, a home visit (visit 3) was arranged for the following week where the patient was given the opportunity to express their opinions about the workbook and to complete an evaluation form. A record of the activities the patient had completed was also made.

Evaluation of the Stroke Workbook Intervention

A RCT was conducted to test this intervention. Over a 22-month period 203 stroke patients who were discharged from Ninewells hospital in Dundee following a stroke were recruited. This has been described in a previous report (Bonetti et al 2001). The results showed that the workbook intervention improved functional ability and maintained patient’s confidence in their recovery.

During this study, it was anecdotally noted that some patients who received the workbook did not complete the behavioural activities proposed. Given that the behavioural activities were aimed at increasing perceived control to reduce disability, patients who were not participating in or adhering to the activities were potentially not increasing their perceived control therefore potentially not reducing their functional limitations. Two exploratory evaluations were conducted during the RCT in a bid to investigate this phenomenon and are outlined below:

Outline of Preliminary Study 1

Stroke Patient's And Carer's Evaluation of a Stroke Workbook Intervention (Joice et al 1999)

Background: During the RCT testing the efficacy of the stroke workbook intervention it was noted that 14% patients in the experimental group did not do any of the behavioural activities. Past research has indicated that patients are more likely to adhere to medical advice if they are satisfied with the advice they receive (Ley 1997). The aim of this study was to examine patient's satisfaction with the stroke workbook intervention in terms of its perceived usefulness.

Research questions: 1) Which aspects of the intervention do patients and carers find most useful 2) Are some aspects more or less useful to some subgroups?

Procedure: The participants (n=32) received a workbook between 14 and 21 days following discharge from hospital and were followed up over a 5-week period with 2 further visits and telephone calls in between. Patients were asked to rate aspects of the workbook, with 0 being "not at all useful" to 3 being "very useful". Three satisfaction scales, information (9 items), behaviour (5 items) and social/emotional support (5 items) were created and found to have satisfactory internal consistency (Cronbach's alpha = .83, .69 and .70 respectively). The means scores were used in subsequent analyses.

Results: Repeated measures ANOVA, *F* (2,84 = 44.27 *p* = .005) indicated that information and social support were more useful than behavioural tasks. T-test analyses showed no significant differences between the subgroups of gender, age and disability.

Discussion: The patients rated the behavioural activities as being less important than information and social support aspects of the workbook, suggesting that there may be a relationship between how useful patients find the different aspects of the workbook and the activities they perform. Patients felt more satisfied with information about the nature of stroke and prevention of further stroke, suggesting that these participants felt poorly informed at point of discharge, then again the provision of information did not require activities to be performed.

Outline of Preliminary Study 2

Predicting Satisfaction and Adherence to an Intervention: What about Patients' Attitude towards Receiving the Intervention? (Bonetti et al 2000)

Background: This study followed on from previous work of Joice et al (1999) who found that patients expressed different levels of satisfaction for the informative, supportive and behavioural aspects of the stroke workbook intervention. Bonetti (2000) who examined the concept of "desire for control" and its relation to health outcomes developed a measure to assess patient's attitudes of control, which was included in the stroke workbook study. To validate her questionnaire she included a question asking the patients how much they desired the workbook before it was seen. The aim of this preliminary study is to examine whether attitude toward receiving the intervention, defined as desire for the workbook *before it is seen*, predicts patients' satisfaction with the workbook's usefulness and their adherence to its tasks.

Research Question: Does attitude toward receiving the intervention predict adherence and satisfaction with its usefulness?

Procedure: The participants (n = 36) were asked prior to receiving the stroke workbook intervention how much they would like to receive the workbook on a scale of 1 (not at all) – 5 (as much as possible). Measures of adherence (number of behavioural tasks performed) and satisfaction were taken at 6 weeks following the implementation of the stroke workbook intervention

Results: Compared with controls, patients with high desire for the workbook were significantly more satisfied with the usefulness of the information it provided (t (1.34) = -2.10, *p* = .04) and the tasks they were required to perform (t (1.34) = -2.99, *p* = .005), and adhered significantly better to these tasks (t (1,34) = -2.13, *p* = .04) than patients with low desire for the workbook.

Conclusion: Attitude towards receiving a workbook intervention predicts adherence and satisfaction with its usefulness. Since these variables may influence the effectiveness of any intervention, it would appear that pre-intervention attitudes and the mode of implementation need further investigation.

THE PRESENT THESIS

These two evaluative studies were the catalysts for this thesis. On completion of the SWOT trial, the intervention group appeared to have lower levels of observer-assessed disability and the level of confidence in their recovery had been maintained over three months. However, some patients in the intervention group did not complete the behavioural tasks in the workbook and therefore possibly did not benefit from the intervention. (This will be further examined in chapter 3).
The overall aim of this thesis is to seek a better understanding adherence, by examining stroke patients who failed to adhere to the stroke workbook intervention especially when it was shown to be effective in recovery. In order to achieve this there are three specific aims of this thesis:

1. To examine patient characteristics predicting adherence to the workbook intervention.
2. To examine the workbook intervention characteristics (in terms of complexity and ease) and their relationship to adherence.
3. To see if it is possible to enhance adherence to an alternative intervention using a theoretically derived letter.

These three aims form the basis of the three experimental studies that have been conducted and described in chapters 3, 4, and 5 respectively. There are two further aims:

4. To apply a theoretical framework to explain and understand the findings of the three experimental studies
5. To add to the current research into stroke recovery to enable better recovery for both patients and health professionals alike.

The proposed research questions include:

1. What demographic, clinical and psychological factors predict participation in and adherence to a stroke workbook intervention?
2. Do the same factors predict participation in and adherence to an easier intervention?
3. Can a simple letter increase participation in and adherence to an easier intervention?

The central question of this Ph.D. thesis is: why, when stroke patients continue to express dissatisfaction with the care they receive, do they fail to participate in a specially designed intervention?

CHAPTER 2

DEFINING PATIENTS’ BEHAVIOUR AND EXPLAINING IT WITHIN THE CONCEPTUAL FRAMEWORK OF THE SELF-REGULATION MODEL

SUMMARY

A number of terms could be used to describe the behaviour of the stroke patients who did not involve themselves in the activities recommended by the stroke workbook intervention. This chapter has 4 aims. Firstly to define the behaviour of the stroke patients observed in the stroke workbook study in terms of compliance, adherence and concordance and discuss the appropriateness of each term. Secondly, to introduce Leventhal’s Self-Regulation Model (SRM) which has been used in the past to explain the behaviour of non-compliance/non-adherence as a consequence of patient beliefs about their illness. The third aim is to highlight the difficulties of measuring adherence and its implications for intervention testing. The fourth aim of this chapter is bring together the terms and the theory, proposing a definition of the behaviour observed in the stroke workbook study and providing a theoretical framework within which to present the future studies.

DEFINING PATIENTS' BEHAVIOUR.

A number of concepts have been used to describe patients' participation in activities recommended by health professionals. In the medical and psychological literature, patient's behaviour in taking prescribed medicines has been described in the terms of compliance, adherence and concordance. The following section discusses these terms in relation to the usefulness of the construct and their relevance to the behaviour exhibited by the patients who did not do the activities as recommended by the stroke workbook intervention.

Compliance, Adherence and Concordance

In the medical and psychological literature, patients' behaviour in taking prescribed medicines has been described in the terms of compliance, adherence and concordance. Studies examining diet and exercise interventions generally appear to use the term adherence whereas medical based studies more often use the term compliance. Lutfey and Wishner (1999) claimed that Sackett and Haynes (1976) implied that the term compliance was interchangeable with adherence. This has been demonstrated in papers by Ley (1997), Leventhal et al (2003), Weinman (1998), Brawley et al (2000) and Duncan et al (2001) but with an underlying philosophy that the terms are essentially different.

Sackett and Haynes (1976) defined compliance as "the extent to which the patient's behaviour coincides with the clinical prescription". According to Lutfey and Wishner (1999), Sackett and Haynes intended the term compliance to be "non-judgemental and an avenue for scientific investigation". Gordis (1976) suggested that compliance is not an "all or nothing concept", patients may follow some of the doctor's instructions but not all and therefore Gordis (1976) defined non-compliance "as the point below which the desired preventative or desired therapeutic result is unlikely to be achieved." Following extensive research examining the role of doctor-patient communication, Ley (1988) proposed a cognitive model of compliance based on patients' understanding, level of recall and satisfaction with a medical consultation. This model failed to take into account the patient's health beliefs in that it assumed compliance to be positive and straightforward and that the patient passively follows advice of the health professional without question. Authors have argued that the word compliance is suggestive of the patient's obedience to the health professional's instructions, implying conformity to medical intervention (Leventhal et al 1984, Lutfey and Wishner 1999). Therefore one could suggest that a non-compliant patient could be seen as disobedient, which has negative and possibly stigmatising connotations. However there appears to be no differences in terms of demographic or personality characteristics between non-compliant patients when compared with compliant patients (Leventhal et al 1984).

The term adherence on the other hand “captures the increasing complexity of medical care by characterising patients as independent, intelligent and autonomous people who take an active and voluntary role in defining and pursuing goals” (Lutfey and Wishner 1999). Meichenbaum and Turk (1987) suggested in their review of Ley’s work that his recommendations for improving compliance/adherence should encourage health professionals to explore patients’ concerns and worries and use lay language. This review suggested that Ley’s original model might have had a vague awareness of patients’ beliefs.

Stanton (1987) used the term adherence in his study looking at the factors that determined the reduction of high blood pressure in a sample of hypertensive patients. He developed the model of adherence, in which the model tried to move from viewing the doctor as the expert who gives advice to a compliant patient. Whilst similar to Ley (1988), it incorporated the role of patients’ beliefs emphasizing the “patient’s locus of control, perceived social support and lifestyle disruption” (Stanton 1987). However whilst the model acknowledged the health beliefs of the patient it neglected those of the health professional. Health professionals are individuals who themselves have their own beliefs. Ley (1988) reviewed a number of studies examining non-compliance to guidelines and standards in pharmacists, nurses and doctors. He concluded that non-compliance was high amongst health professionals and the common causes included a lack of knowledge, forgetfulness, low job satisfaction and susceptibility to social pressures. This was further acknowledged in a paper by Marinker (1997) who anecdotally reported that within a multidisciplinary health professional working group (Concordance Co-ordinating Group see later paragraph) examining the concept of non-compliance, members admitted that they personally had at one time or other not taken prescribed medication.

One may suggest that in these studies examining health professionals’ non-compliance to guidelines and standards, non-compliance is the appropriate term. Guidelines and standards for health professionals are statutory in their nature and are there to be followed because the implications are about the care of others. The behaviour of people not following health professionals’ advice usually pertains to themselves and not others.

Historically, in the psychological literature examining health behaviours, the term compliance has been used to describe patients' behaviour towards an intervention, e.g. Leventhal et al (1987), Ley (1988). Adherence is not a new term and was recognised by Leventhal (1984), who suggested that adherence relates to the actual behaviour the patient performs whereas compliance refers to the nature of the individual. He goes on to say that this subtle difference in the terms has had implications for research and theory. However in subsequent research Leventhal et al appears to use both terms interchangeably to describe the patient's behaviour in their papers when their research to support the Self Regulation Model (Leventhal et al 1987, Leventhal et al 2003). Adherence as a term describing behaviour has been more readily used in the psychological literature pertaining to behavioural interventions but not so in the medical literature, which uses the term compliance; often used in relation to medication taking and extended to the patient behaviour related to taking health professionals' advice.

Non-adherence to medication and advice has been recognised by researchers as having implications for research. This increasing awareness prompted a conference specifically to highlight non-adherence and the effects on pharmaceutical and behavioural interventions (see Culos-Reed et al 2000, Martin et al 2000, Rand et al 2000, Sherman et al 2000, Schumaker et al 2000, Vitolins et al 2000, Anderson et al 2000 and Brawley et al 2000). The conference proceedings suggested non-adherence was behavioural, poorly defined and support was provided for examining the behaviour of non-adherence using theoretical models to increase the scientific rigour of clinical trials.

> "Adherence in the context of controlled clinical trails implies that people freely choose to undertake behavioural plans, have input into them and have collaborative involvement in developing and adjusting their plans" (Brawley et al 2000)

This definition of adherence given by Brawley et al (2000) involves aspects of the idea of concordance. The working group that Marinker (1997) was referring to in the previous paragraphs was the Concordance Coordinating Group that was set up by The Royal Pharmaceutical Society of Great Britain (1997) to examine the problem of non-compliance to medication. Marinker (1997) suggested compliance had been difficult to improve for two reasons; firstly the patient's reluctance to take medication tends to be instinctive, culturally and disease defined; secondly the concept of compliance is "morally and psychologically flawed". He goes on to describe compliance: -

“The patient presents with a medical problem for which there is a potentially helpful treatment. What the doctor brings to the consultation – scientific evidence and technical skill – is classified as the solution. What the patient brings – “health beliefs” based on experience, culture, personality, family tradition, and so on – is seen by the doctor as the impediment to the solution. The doctor’s task is to overcome the impediment.”

Marinker 1997

In this description of compliance, Marinker (1997) highlighted the issue that both the health professional and the patient have beliefs about the patients’ presenting problem. Whereas Ley (1988) and Stanton’s (1987) model of compliance and adherence respectively, the terms compliance and adherence appear not to acknowledge the health beliefs of both the patient and the health professional. Through this acknowledgment of beliefs the working party from The Royal Pharmaceutical Society of Great Britain (1997) proposed the model of concordance. This model describes the process of the health professional and the patient reaching an agreement about the medication the doctor wishes to prescribe the patient. During this process the doctors acknowledge the patients’ ideas and give the patients the opportunity of understanding the importance of the treatment. Therefore by acknowledging both sets of beliefs, the health professional and the patient can negotiate the patient’s subsequent care and come to an agreement. Concordance requires the patient to be involved in the decision making process. Mullen (1997) suggested that the working party recommended that the term concordance should replace compliance. Whereas Dickson et al (1999) reported the opposite saying that the Concordance Coordinating Group stressed that concordance was not a replacement for compliance. Jones (2003) suggested that concordance differed in two ways from adherence and compliance. It focused on the consultation process rather than the patient’s behaviour and the shared decision-making with an underlying philosophy that was moving away from “paternalism”. Using this definition, patients cannot be non-concordant, only the consultation can be non-concordant where the consultation becomes paternalistic. Concordance implies that patients who do not take their medication are denied real benefits therefore it is essential for the doctor to understand the patient’s beliefs about their treatment and allow the patient to understand that treatment. Concordance only appears to address compliance to medication and does not explicitly acknowledge adherence. Furthermore concordance is the sharing of information rather than beliefs, especially if the doctor has guidelines to follow.

Concordance is a relatively new area and there is an ongoing programme of investigation presently underway by the Concordance Co-ordinating Group. In a special issue of the British Medical Journal - 7419 (2003) the existence of the term was highlighted and its value debated.

> "The notion of compliance is at least explicitly coercive; the danger of concordance is that coercion remains but is concealed" Heath (2003)

According to Heath (2003) and Jones (2003), up to now there appears to have been little research testing the model of concordance and many health professionals have not even heard of the term. Furthermore Dickson et al (1999) conceded that concordance was not really a new concept in that many health professionals have been practising it in their current consultations.

N.B. Throughout the special issue, concordance was only compared to compliance and not adherence.

It is becoming obvious that compliance, adherence and concordance are essentially terms describing different behaviours. Using the information gleaned from the literature the three terms have been summarised below:

Compliance	Non-compliance
A patient characteristic, e.g. the patient is prescribed a drug and takes it without question at the required intervals.	A patient characteristic, e.g. the patient is prescribed a drug and does not take it, again without question.
Adherence	Non-adherence
The behaviour the patient chooses to adopt, e.g. takes the prescribed drug because he/she sees its purpose or may not agree with it but takes it as he respects the doctor's advice.	The behaviour the patient chooses to adopt e.g. does not take the prescribed drug because he/she feels they understand its purpose but feels as though it is not appropriate for them. This may be intentional or non-intentional.
Concordance	Non-concordance
The process between health professional and patient enabling the patient to be adherent with both parties coming to an agreement.	When the process between the health professional and the patient breaks down to becoming a paternalistic approach where the patient is encouraged to be compliant rather than adherent.

In the discussion of these terms authors have acknowledged the importance of beliefs and that these beliefs play a role in compliance, adherence and concordance but they have not been explicit in the definition of these terms. Whilst concordance has gone some way to include the beliefs of the health professional, are the health professional's beliefs those guided by his/her training or work protocol or by his/her personal experience? Compliance, adherence and concordance may all be affected by the belief system of both the health professional and the patient who are individuals with their own experiences and ways of thinking about things. Leventhal's Self-Regulation Model can account for these behaviours and has been described in the following section.

THE SELF-REGULATION MODEL

Leventhal et al (1984) acknowledged both non-compliance and non-adherence to be a challenge as they obstructed the evidence-based advances that have been made in relation to health and disease. For instance there is a greater understanding of the causes of cancer and its prevention, namely a healthier lifestyle (not smoking, exercising, balanced diet), which has been disseminated through health education, the media and social support networks, to the public. However there is evidence to show that people do not take preventative action and continue to smoke, not exercise and eat unbalanced diets. Ley (1988, 1997) suggested, in general about half of all the patients seen by health professionals would not follow instructions. Leventhal et al (1984) suggested that this behaviour of not following advice is as likely for complex, preventative actions as it is for simple prescribed treatments. He goes on to say that non-compliance defines the relationship between the patient and the health professional implying negativity about the characteristics of the patients, thus supporting the arguments of Marinker (1997) and Lutfey and Wishner (1999). Leventhal suggested that the term compliance had its roots in the "medical model" which became redefined into adherence by the behavioural theorists. The behaviourists started to look at what people were doing in terms of their health and if necessary this behaviour could be changed. Leventhal et al (1984) cites the work of Stunkard (1979) as an example. Stunkard (1979) examined the problem of obesity. He interviewed overweight individuals ascertaining their eating habits, i.e. what they ate, where, when, and how much. From here he developed tailored programmes to help these people monitor their intake, reduce the amounts they ate, to eat at specified times and reward themselves for adhering to their new schedule. This new routine was effective in changing eating behaviour in the initial stages but did not continue. Leventhal et al's (1984) explanation for this was that the behaviourists did not see behaviour as future orientated or goal attaining behaviour. Leventhal suggested that neither the medical nor the behaviourist models acknowledged the patient’s own cognitions about a health problem and therefore looked towards the control theories, which he suggested accentuated the idea of the individual as a problem-solver being “pulled towards goals rather than pushed by stimuli” (Leventhal et al 1984) subsequently creating a representation of their illness or health threat.

This was the basis of Leventhal’s Common Sense Model of Self Regulation. It originated from two lines of research, the Health Beliefs Model (HBM) (Becker and Maiman, 1975) and the Drive Reduction Theory (Dollard and Miller 1950). The HBM was developed in the 1950s when American Public Health researchers found the effectiveness of health education was related to patients’ perceptions. The HBM postulated that the patient’s perception of severity and vulnerability to a health threat would motivate a change in health-related behaviour. At the same time the Drive Reduction Theory, which originated from behaviourist theories looking at responses to fear, suggested that if actions failed to remove (fear and) danger “avoidant denial and unrealistic reassurances would remove fear while leaving danger intact” (Leventhal et al 1992). Leventhal et al (1965) tested the Drive Reduction hypothesis by exposing patients to high and low threat messages about tetanus combined with action plans (immunisation). Using a 2x2 design students received one of two letters about the dangers of tetanus. The letters were either low or high fear arousing but both with the same encouragement to have an injection against the disease. A map accompanied half the letters with instructions of the ease of finding the health centre and how having the injection could be incorporated into the student’s daily routine. The results showed that students who received the map and instructions were significantly more likely to go and get the injection regardless of receiving a high or low threat message. Therefore fear itself does not appear to provoke change in behaviour. This was further supported by another study (Leventhal et al 1967) where patients were given specific instructions on how to stop smoking with either low, medium or high fear messages. The authors found that the high fear messages increased the desire to stop smoking but this increased desire did not bring about smoking cessation. However subjects who received the instructions of how to stop smoking plus a fear message no matter what level were more likely to change their smoking behaviour. Both studies supported the Fear-Drive hypotheses, as high fear messages were more effective in changing attitudes than low fear messages, the effects of which were both short lived. But the studies also refuted the Fear-Drive hypothesis in that high fear messages were no more successful than low fear messages in enhancing adherence to recommended health promotion advice. These studies lead to the development of the parallel processing component of the SRM (Figure 2.1).

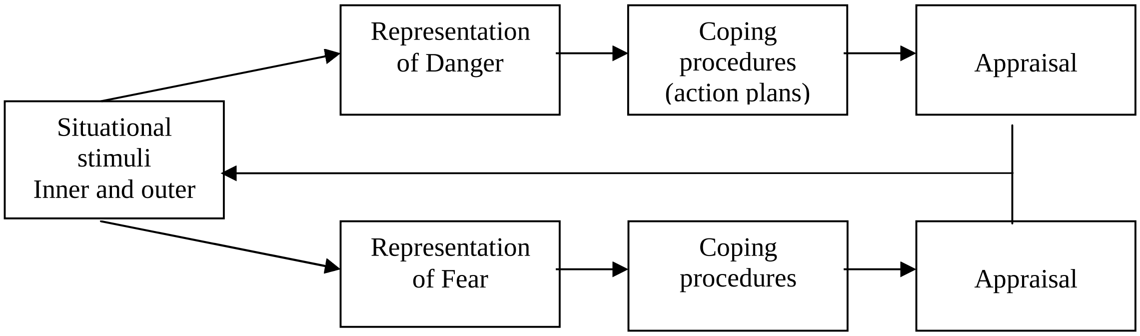

Figure 2.1: The Parallel Process Model (Leventhal 2003)

The parallel process model postulates that the individual processes information about a health threat (situational stimuli) along two “pathways”. The upper pathway (Figure 2.1) corresponds to the construction of a cognitive representation of the perceived danger and the required coping procedures (action plans) to manage it. The lower pathway creates an emotional representation of fear and the required actions plans with which to deal with that fear. The action plans are shaped by the representations to reduce the fear and danger and are actively appraised. This appraisal assesses the efficacy of the action plans adopted and integrates this information into the cognitive and emotional representation.

Leventhal et al (2003) suggested that whilst the experiments using fear messages and action plans supported the idea of the parallel processing model it remained unclear which features of the messages bought about the behaviour change, i.e. having the inoculation against tetanus, giving up smoking. The action plans were both specific and “concrete” and the action could be managed within the person’s normal routine whereas the fear messages were interpreted through the individuals own beliefs system. This led the experimenters to question both the nature of the action plans and the fear messages. Johnson and Leventhal (1974) demonstrated with patients undergoing the medical procedure of [1]endoscopy, that they would respond differently to the procedure depending on how they interpreted the sensations produced by the medical procedure. Potentially the sensations experienced in the procedure could be interpreted as danger and either elicit fear and avoidant

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[1] An endoscopy is where a specially designed camera is incorporated in a tube that can be swallowed by the patient under medical supervision. This camera and tube can allow the doctor to observe the gastro- intestinal system and to take small samples from the area under question.

reactions or be perceived as cues within which to manage the sensations. Patients were given an explanation of the procedure, followed by lay interpretations of the sensations that they may experience, e.g. the feeling of being "bloated" following the insertion of air into the stomach could be likened to the bloated feeling one gets after eating a large and heavy meal. They were also given specific coping strategies, such as ways of breathing when the throat was swabbed and the types of swallowing motions to make as the tube is being passed. The results showed that the sensory information and the coping plans had independent effects in reducing emotional reactions.

> "It was clear that information that prepared an individual to expect specific sensory cues and provided a benign view of these cues could shift the response from fearful avoidance to self regulated problem solving. These results reinforced the idea that health threats were represented on two levels semantically as abstract knowledge and perceptually as concrete experience."
>
> Leventhal et al (2003)

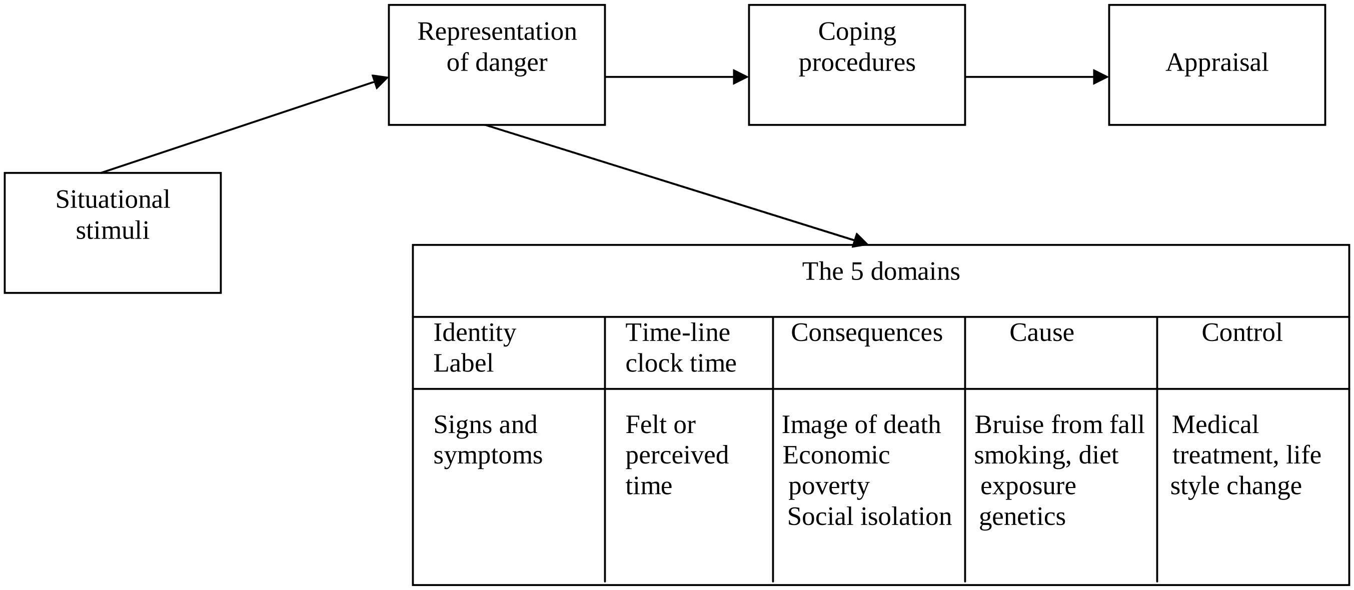
In another study, Easterling and Leventhal (1989) examined women's worries about breast cancer. In this experiment, women in remission from breast cancer were compared with women who had no history of breast cancer. They were asked questions about mood and worries about cancer. The results showed that fear was a product of the interaction of abstract and concrete levels of processing. Worry about getting cancer was associated with presence of symptoms and a belief that one could contract cancer. Furthermore the presence of symptoms would activate a cognitive label and that cognitive label would influence the interpretation of the somatic symptoms. This was defined as "symmetry" between the abstract and the concrete representations, e.g. if patients are given a label for their disease they will come to perceive symptoms and if they have symptoms they will try and find a label. These symptoms are the concrete components of the illness representation and applying the labels are the abstract components. Both components are drawn together to establish the identity of the illness. As Leventhal (2003) wrote, "common sense" suggests that identity is not the only way patients think about their illness and went onto conduct many studies examining how people think about their illness (for a comprehensive review see Leventhal et al (1998) and Brownlee et al (2000)).

The Common Sense Model of Self Regulation began to take shape as it became evident that peoples' representation of danger was characterised by 5 domains, i.e. patients thought about illness threats in terms of identity, time, cause, consequences (Leventhal et al 1980, 1982) and cure/control (Lau and

Hartman 1983). Two influential studies demonstrating the support for these hypotheses have been outlined below.

Meyer et al (1985) conducted a study with two aims to examine non-adherence to medication for hypertension and to examine the notion that patients constructed their own representation about their illness. Hypertension is a disease of raised blood pressure that is generally known to be asymptomatic. Meyer et al (1985) hypothesised that patients had common sense constructions of their illness and thought about their illness in terms of identity (labels and symptoms) causes, consequences and duration. They interviewed 230 patients who were divided into 4 groups of normotensive controls, newly diagnosed hypertensives, continuing treatment hypertensives and re-entry hypertensives (those who had dropped out of treatment but had returned). They found evidence for identity with about 92% of patients in the continuing treatment group indicating that they could tell when their blood pressure was raised by symptoms such as flushed face or headaches. However 80% of this group agreed with the statement “people can’t tell if blood pressure is up”. Meyer et al (1985) saw this as evidence for the patient’s abstract view of identity of their illness and the reporting of the symptoms of raised blood pressure as the concrete view. They also found evidence for duration with 40% of the newly diagnosed group perceiving their illness to be acute and 64% of the re-entry group perceiving their hypertension to be chronic. Some patients believed their illness to be cyclic. Approximately 80% of all the patients had reasons for the cause of their hypertension. They found little evidence for consequences and suggested this was probably due to hypertension tending not to intrude in to the patients’ daily activities. However there were a group of patients who had re-entered into treatment for hypertension, they may have experienced consequences hence their return. This was not discussed in the paper. The authors also went on to show that patients’ representations of identity, time line and cause all impacted on their levels of adherence.

Lau and Hartman (1983) provided further evidence in their study and suggested people think about their illness not in 4 but 5 ways. They asked students to think about a time when they were unwell and to describe in their own words why “they had gotten sick on this occasion”. They were also asked to rate the cause of their illness and how they had recovered from it. In another group, students were asked the same questions but this time they were asked in relation to a serious illness that they had never had. Lau and Hartman (1983) found significant support for both identity and cause and suggested another way in which patients think about their illness, which was cure/control. They found weaker support for consequence and time-line. These findings strengthened the argument for the content of the representation of danger and developed in to the 5 domains, which in turn would influence coping and appraisal. (Figure 2.2)



The 5 domains				
Identity Label	Time-line clock time	Consequences	Cause	Control
Signs and symptoms	Felt or perceived time	Image of death Economic poverty Social isolation	Bruise from fall smoking, diet exposure genetics	Medical treatment, life style change

Figure 2.2: Five Substantive Domains of Illness Representation. (Brownlee et al 2000)

The evidence for people thinking about their illness within the 5 domains has been provided by many studies looking at specific illnesses. For example studies examining hypertension (Meyer et al (1985); motor neurone disease (Earll et al 1993); recovery from hip joint replacement (Orbell et al 1998). Morrison et al (2000), Johnston et al (1999) Earll et al (1993) are examples of studies examining the relationships between illness representation of control and emotional representations of distress and disability. (For a further review see Sharloo and Kaptein 1997).
This work has been further evaluated in recent years with the upsurge of interest in self-regulation and the development of the Illness Perception Questionnaire (IPQ) (Weinman et al 1995) and the updated version the Illness Perception Questionnaire-Revised (IPQ-R) (Moss-Morris et al 2000). This questionnaire and versions of it have been used to examine cardiac rehabilitation (Petrie et al 2002, Petrie et al 1996, Whitmarsh et al 2003, Cooper 1999); cholesterol control (Brewer et al 2002); multiple sclerosis (Jopson et al 2003, Vaughan 2003); chronic fatigue syndrome (Moss-Morris 1996), and Addison’s disease (Heijmans 1999).

Coping procedures, Leventhal et al (1984) defined as the “cognitive and behavioural actions we take (or do not take) to enhance health and to treat (cure/control) and rehabilitate from illness”. These procedures are shaped by the representations of the illness plus three other factors taken from the on-going work of other behaviourists. Leventhal et al (1984) went on to say that whilst illness representations allow the individual to plan and react to their situation, self efficacy, i.e. the belief that one can manage the environment and own behaviour (Bandura 1997), the individual's insight to the problem and alternative action plans, and beliefs in the effectiveness of the action plans (Becker and Maiman 1975) are also required. The ways people cope are numerous, take for example a headache, people may use strategies such as go to bed to sleep it off, take a walk to get some fresh air, apply a cold compress, take an analgesic tablet, go to a general doctor, call an ambulance or go as an emergency to hospital. The outcome of a coping strategy may be positive or negative. Moss–Morris et al (1996) suggested that strategies involving "self blame, emotional venting, and cognitive and behavioural avoidance" have been associated with negative adaptation to an illness whereas "positive reframing, illness acceptance, planning and utilization of social support are associated with positive adaptation to an illness. Heijmans (1999) showed in her study of patients with Addison's disease, patients with high perceptions of seriousness, with several symptoms, who saw their illness as being chronic and uncontrollable, engaged in more negative coping, e.g. avoidance of exercise and seeking social support. Earll et al (1993) showed that patients with motor neurone disease were more likely to engage in positive coping, e.g. looking for information and trying alternative therapies if they experienced more symptoms and perceived greater consequences.

If patients have been given medical advice and choose not to do it, this could be defined as a coping procedure. Coping procedures, Leventhal et al (2003) suggests have both abstract and concrete components and are viewed by the individual as having identities, time-lines, causal routes of action, consequences, and control expectancies. Control expectancies may provide an explanation for the "compliant" patient, preferring someone else to be in control, i.e. the doctor because "the doctor knows best"!

Horne (1997) has shown patients to have beliefs about their treatment and specifically medication in his research. He went on to develop the Beliefs about Medicines Questionnaire (BMQ) (Horne and Weinman 1999) to demonstrate the strength of these beliefs about medication and their relationship with non-adherence to medication. He also suggested that patients held two other types of beliefs about medication, namely necessity and concern: necessity, which pertains to the necessity and efficacy of the prescribed medication and concern, which pertains to the potential harmful effects of the prescribed medication. One could argue that necessity can be explained through the domain of control and concern through domain of either consequence or through an emotional response. However one could logically assume that if patients have beliefs about their medication they will have beliefs about other forms of treatment.

The “appraisals” of the procedures adopted to cope with the health threat, self-selected or medically prescribed, continually revises the illness representation the individual holds. There appears to be very little in the literature measuring appraisal in terms of the SRM, as it appears to be difficult to operationalise. Leventhal et al (1998) suggests:

> “The energy expanded to enhance health and to prevent and cure disease is directed to what is perceived to be the most immediate and urgent threat and is limited by resources and satisfaction rule. Representations evolve over time if symptoms fail to respond to an intervention. The division of natural history of disease episodes into stages appear to capture the texture in the change process, e.g. many episodes begin with an appraisal stage, followed by an illness stage the interval from deciding one is ill and calling for advice and the interval from calling to obtaining care. Additional stages involve diagnosis, treatment and rehabilitation. These stages do not have a sequence and the boundaries are described as fuzzy”.
>
> Leventhal et al (1998)

The appraisal stages are longer for mild ambiguous ailments than severe or acute ones, whereas illness stages are lengthened by the avoidance of care seeking motivated by fear of life threatening illness. Appraisal appears to be subjective by the mere nature of the patient’s feeling about the level of success of the treatment. If the treatment is for a swelling then the appraisal stage can concretely say whether that swelling has reduced or not reduced. In those ailments where symptoms are vague then appraisal will be based on the subjective feelings of the patient e.g. fatigue, myalgia. One way of looking at appraisal is through the subjective feeling of satisfaction, again another concept difficult to define and to measure (Weinman 1998). Satisfaction has been included as an outcome measure for RCTs examining efficacy of stroke interventions (see Chapter 1). This measure has more than likely been included as a measure for consumer satisfaction purposes, rather than the individual’s appraisal of the intervention in relation to themselves and subsequently has been reported on in that way. However satisfaction as an appraisal of the treatment could explain compliance and adherence in the models of Ley (1988) and Stanton (1987). Alternatively satisfaction could be interpreted as a consequence for “pleasing” the health professional (social desirability) by taking prescribed medication or advice, even though no benefit may be gained. This is just a small example of the difficulty of measuring appraisal and will not be discussed further as it digresses from the purpose of this thesis.

In summary the Common Sense Model of Self Regulation sees the individual as an active problem solver within a social context, using a parallel-processing framework to understand a health threat by developing an illness (objective) representation characterised by 5 domains, identity, time-line, consequence, cause and control and an emotional (subjective) representation. These representations guide coping procedures, which are appraised for their effectiveness and the information gleaned goes onto to shape the representations. It is a dynamic model with a goal to achieve a status quo within the individual (Figure 2.3). Within the SRM the beliefs of both the patient and the health professional are acknowledged which appears to have been overlooked by the models of compliance and adherence.

Clarification of the Models Name

According to Brownlee et al (2000) the term self-regulation was not mentioned in the fear studies (Leventhal et al 1966, 1967), nor was it used overtly when presenting the Common Sense Model of Illness Cognition (CSM) (Leventhal et al 1980, Leventhal and Nerenz 1982, Leventhal et al 1984b). However the term self-regulation did appear periodically in papers written in the 1980s (Nerenz and Leventhal 1983, Leventhal et al 1984a,) but became more commonplace in the late 1990s (Leventhal et al, 1998, 2001, 2004), with the terms of CSM and self-regulation being combined in a chapter in a handbook of self-regulation (Leventhal et al 2003). Self-Regulation is more likely to be used when applying the CSM to specific health problems e.g. compliance to treatment (Brownlee et al 2000). Self-regulation has been examined within the realm of educational, organizational, clinical and health psychology with the CSM being specifically related to health. Brownlee et al (2000) goes on to say that the CSM distinguishes itself from other self-regulation models due to the models 5 properties:

1. The combination of illness representations and action plans define health and illness behaviours.
2. It defines 5 specific domains for the representation of threat/danger.
3. The 5 domains for representing threat are bi-level, abstract and concrete processes.
4. Separate cognitive and affective systems interact to affect behaviour

5. It assumes contextual factors, social roles and personality influence behaviour by affecting disease representation and procedures for action.

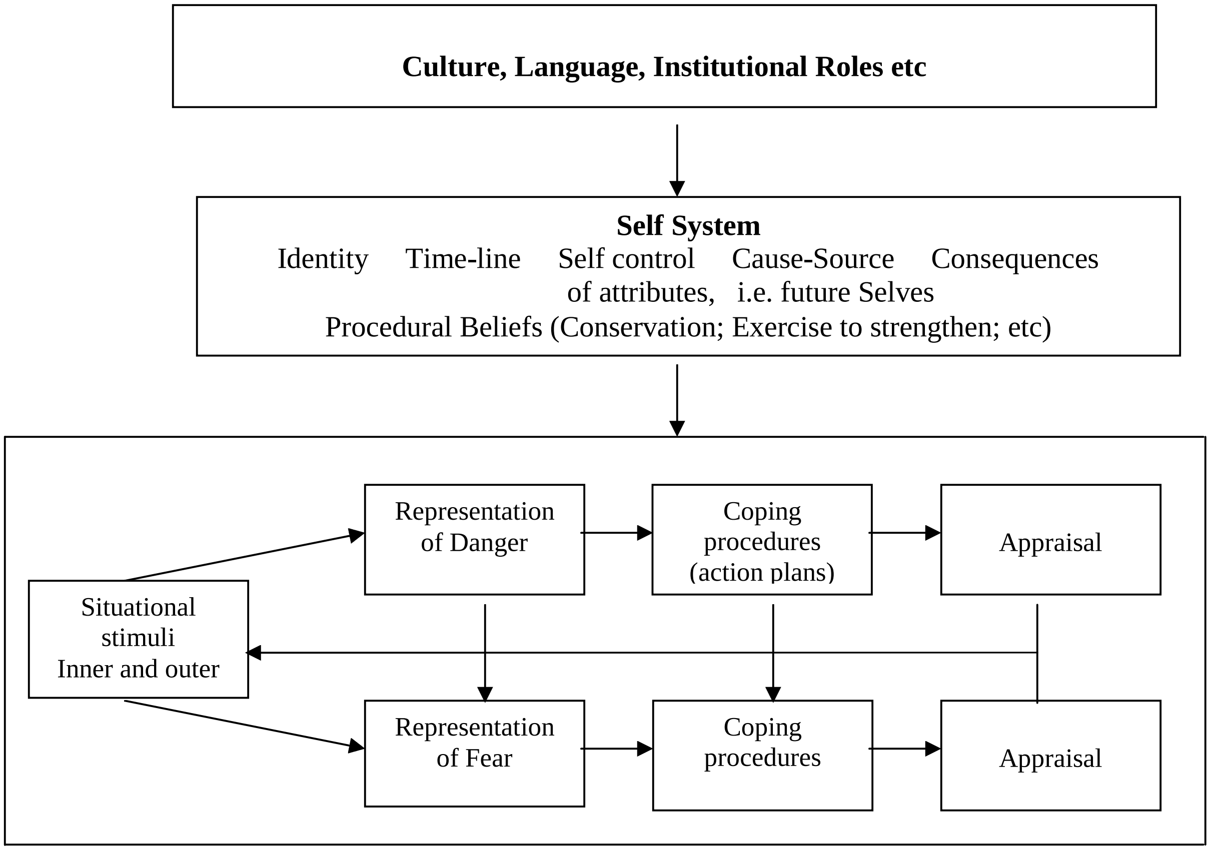


Figure 2.3: Common Sense Model (of Self-Regulation), Leventhal et al (1984, 1992, 1997 2000 and 2004)

To avoid confusion the acronym SRM shall be used though out this thesis to remain in keeping with other research applying the CSM to specific health problems (Brownlee et al 2000). N.B. when talking about the SRM, it is specifically the CSM that is being referred to and not another self-regulation model.

Why This Model?

This model is used in this thesis not only for its historical use in the study of non-adherence behaviours as covered in the previous sections but because the author of this thesis sees the model as being similar to “biological” models describing physical regulation. The SRM model assumes the maintenance of equilibrium of an individual’s cognitions. The biological models acknowledge the regulatory mechanisms for the internal functioning of the body, e.g. temperature control, the “Krebs Cycle” to maintain equilibrium. In this context therefore the studies in the subsequent chapters should be readily understandable to the world of health professionals as well as health psychology.

ADHERENCE – what are we measuring?

The evidence presented in the preceding paragraphs supports the idea of the individual as a “common sense scientist” (Leventhal 1999). However what are individuals doing when they are being adherent or non-adherent? Adherence is not dichotomous and therefore cannot be measured as “did” or “did not”. Weinman (1998) categorised adherence measurement into direct and indirect. Direct measurement refers to the observation of the behaviour e.g. observing medication being taken, or the patient doing the recommended therapy. Indirectly is where the patient reports their behaviour i.e. diary keeping or specific self reporting or counting the number of pills left after a specified time. Weinman (1998) suggested that both direct and indirect measures are inadequate in describing non-adherent behaviour. Direct measures can be difficult to carry out and do not reflect the type of non-adherent behaviour. Indirect measures can be subject to bias, e.g. patients may not keep a diary on a day-to-day basis when asked to but may fill in the days at the end of the week.

Types of Non-Adherence

There is evidence to suggest that patients do not always follow advice and that adherence to advice is not a dichotomous type of behaviour. Dunbar-Jacob and Schlenk (2001) suggested that the numbers of people who “simply fail to start dietary or exercise regimes” is thought to be high although it has not been studied well and is rarely described in research. Patients can start a treatment and then stop. Even patients who have experienced major illness such as heart attacks do not readily take up rehabilitation (Petrie et al 1996). Some patients change their treatment regime, miss days out or forget to take their medication or do their exercise. Dunbar-Jacob et al (1995) reported that 20 – 80% of patients do not adhere to medical prescriptions therefore failing to benefit. Glanz (1979) showed that adherence to low fat diets range from 13% to 76% and Carmody et al (1980) suggest that 50% of patients are likely to drop out of an exercise programme within 3-6 months of starting it. Weinman (1998) listed a number of studies where non-adherence had been observed in different illness groups, namely, asthma, epilepsy, rheumatoid arthritis and diabetes. He suggested that these studies point to the influence of the patient’s beliefs about the "problem" as well as the satisfaction with the consultation. Adherence has been categorised into two types, intentional and unintentional non-adherence, although it is rarely examined as this when addressed in trials testing interventions.

Intentional Non-Adherence

Non-adherence may be the consequence of rational decision-making. In terms of the SRM it could be described as coping with the illness representation. One important factor predicting this behaviour is the patient's beliefs. These beliefs may be about the treatment, the ability to carry out the treatment, or the effectiveness of the treatment. These issues have been examined in several theories, SRM (Leventhal et al 1980); Theory of Planned Behaviour (Ajzen 1991); Self Efficacy Theory (Bandura 1997). Leventhal et al (1984) suggested that if patients do not share the same perceptions about their illness as the health professional, non-adherence can occur e.g. hypertensive patients who believed they could subjectively determine their own blood altered their medication from their original prescription (Meyer et al 1985). Beliefs patients hold about their medication will also be influential in whether they will take them or not (Horne 1997).

Another factor in intentional adherence is the perceived burden factor (Dunbar–Jacob 2001). Decisions to adhere may be dependent on personal costs, stigma from the treatment received and the amount of effort required to fulfil the treatment.

Unintentional Non-Adherence

Non-adherence alternatively may be based on misunderstanding or inadequate information. Patients may intend to adhere to their prescription but may forget or not understand (Dunbar–Jacob 1997). Health professionals may view this form of non-adherence arising from patient deficiencies e.g. ignorance, laziness. Leventhal et al (1984) showed that patients misunderstood the term "hypertension" some mistaking it to mean "high levels of nervous tension". Meichenbaum and Turk (1987) identified the problem that whilst misunderstandings do occur, patients rarely tell the health professionals that they do not understand. The levels of adherence from a SRM perspective may be indicative of a strategic coping response.

The Importance of Studying Non-Adherence

Non-adherence to interventions has been an area of interest to clinicians and researchers for a number of decades because it has an impact on patient care and can also affect the validity of research outcomes (Schumaker and Rejeski 2000). Dunbar-Jacob and Schlenk (2001) noted that the costs of non-adherence in the pharmaceutical world are huge and whilst the costs of behavioural interventions have not been examined, it may probably be quite high. Non-adherence to health advice has implications not only for primary prevention but for secondary and tertiary care too, i.e. promotion of recovery from and prevention of having another stroke. Martin et al (2000) suggested, “The ability to identify patients at risk of non-adherence in RCTs still eludes the researchers and clinicians”. They went on to say that the reasons for this inability may be due to the research being conducted in these areas tends to be without a conceptual framework and a lack of common definitions and measures of predictors and adherence.

Non-adherence is not just an issue for patients. Lewin et al (1998) confirmed in an audit examining health professional adherence to National Cardiac Rehabilitation Guidelines that adherence is poor in many areas. He goes onto say that psychosocial factors were poorly assessed “when it is well established that attention to these is one of the main goals to cardiac rehabilitation” (Lewin et al 1998). The importance of professional’s adherence to national guidelines was demonstrated by Duncan et al (2001) who observed health professionals adherence to stroke rehabilitation guidelines. They found that improved patient outcomes were associated with health professionals’ greater adherence to the guidelines.

APPLYING THE TERMS AND THEORY TO THE BEHAVIOUR IN SWOT

In the initial stages of examining the patient's behaviour in the SWOT study of not involving themselves with the activities in the stroke workbook, the term participation was used to describe their behaviour as at the time this was seen as a neutral term by the present author. On examination of the literature change has occurred! Non-compliance/non-adherence as demonstrated is a complex series of behaviours (Ley 1997) and could have occurred at any point in the use of the stroke workbook intervention.

To recap, the patients were asked to do the following as part of stroke workbook intervention:

- To take part in a study testing an intervention (participation)
- To answer all the questions on the measures.
- To accept the intervention, including the implementer visits
- To use the intervention
    - Read it
    - Do the quizzes
    - Think about ways of coping in relation to the tasks and write them down
    - Identify goals
    - Think about what achievements have been made
    - Record one's progress in a diary
    - Do the relaxation tape

For the purposes of this study compliance/non-compliance will not be used to refer to the patient's behaviour because it does not quite fit into the definition of compliance as defined by Gordis (1976). The investigator does not know if the "desired preventative or desired therapeutic result has been achieved" prior to it being investigated. Furthermore one cannot say that the patient did not do the activities without rational decision because that was not measured.

Using both Ley's (1988) and Stanton's (1987) models of compliance and adherence one might expect that if the stroke patients understood the workbook intervention and were able to recall what they had learnt, they would therefore be satisfied and subsequently participate in and adhere to the activities as required.

The patient's behaviour in the present study does not quite fit into the idea of concordance because although the intervention has been explained to the patients it had been designed on the beliefs of the researchers and the personal beliefs of other patients. Doing the stroke workbook activities did not involve concordance directly as the workbook had already been written based on previous research with similar patients (Johnston et al 1999, Lewin et al 1996). Concordance did not specifically take into account the beliefs of the individual patient it was given to. However it did try to enhance the patient's beliefs about their recovery. Furthermore concordance has been described as a process rather than a behaviour. Non-concordance could exist in the workbook intervention as another individual implemented it. Did the implementer acknowledge the patient's beliefs and relay the appropriate information for that individual about the study? This again was not directly measured. Patients who declined to take part were not assessed for why they did not want to take part, neither were the patients asked why they took part. Patients may have started to do the activities in the stroke workbook not because they had understood it but they could felt obliged to take part.

In keeping with the definition by Brawley et al (2000) there was evidence in SWOT that some patients did adhere to the activities which were objective measures of adherence such as writing down their own goals, writing in appropriate quiz and task boxes. This definition of adherence (Brawley et al 2000) describes more readily the patient's behaviour in the workbook. Furthermore the definition aims towards a standard, which is required for scientific rigour. More importantly it relates to the behaviour exhibited by the patients who did not do any of the activities in the stroke workbook study.

In the present study patients were asked to keep a diary (one measure of adherence) and to complete quizzes and tasks (two further measures of adherence). Unfortunately it is not known if these were completed the night before the implementer saw the patient or done over a period of time as had been anticipated in the study. This will be further discussed in the following chapters.

The SRM implies that adherence is a coping strategy involving the patient's problem-solving abilities assuming that they are motivated and interested in planning and controlling their own actions.
Using the SRM the patient's decision to participate in and adhere to the behavioural activities in the workbook may be influenced by the mental representation of either the danger or fear of their illness (stroke), which in turn shaped their coping procedures i.e. to adhere to or not adhere to the workbook activities. Furthermore the patients may have developed representations about the intervention itself, which again may have influenced their behaviour. Where this fits into the model is open to debate.

Horne (1997) suggests that beliefs about medication fit in between illness representations and coping strategies. One could argue that the intervention itself may be conceptualised as a stimuli, which is thought about in 5 domains, and coping (adhering to the intervention) may be shaped by the representations about the intervention.

Adherence or non-adherence may arise due to either pathway: danger or fear. The coping procedures a patient uses e.g. adhering to the behavioural activities in the workbook are likely to influence stroke recovery outcomes which can measured in terms of disability and distress. If patients feel as though the stroke workbook is improving their recovery they could appraise this subjectively by feeling “satisfied” and go back to the beginning and think about their illness positively and continue to use the workbook. If health professionals communicate with the patients acknowledging the two levels of processing the individual undergoes when faced with a health threat, it is logical to assume the patient will have greater understanding of what the purpose of the treatment is and what to expect. Subsequently this would increase satisfaction and reduce anxiety because the patients feel they understand more and therefore feel more in control of what they have to do in order to achieve the desired outcome.

CONCLUSION

The terms compliance, adherence and concordance are different and apply to different behaviours. To avoid confusion the term used in this thesis from now on describing the involvement the patients had in the behavioural activities of the stroke workbook will be adherence/non-adherence. A second term, participation will be used to describe the behaviour of those patients who consented to take part in the study and continued through the 5-week intervention regardless of the activities they performed.

The SRM will be used as a theoretical framework as it acknowledges the individual as a rational being and fits in with the proposed definition of adherence. The SRM is applicable to all individuals regardless of profession and therefore acknowledges individual beliefs. Furthermore it has a long history of explaining non-adherence. The issues of the difficulties of measuring adherence will be borne in mind when reporting the subsequent studies examining stroke patient’s non-adherence to the stroke workbook intervention.

CHAPTER 3

WHAT DEMOGRAPHIC, CLINICAL AND PSYCHOLOGICAL FACTORS PREDICT PARTICIPATION IN AND ADHERENCE TO A STROKE WORKBOOK INTERVENTION?

SUMMARY

Background: A cohort of eligible stroke patients were invited to participate in a randomised controlled trial to test the efficacy of a self-help workbook designed to enhance perceived control and subsequent recovery. The results showed the workbook to be effective in reducing disability and maintaining confidence in recovery. However during the trial it was noted that some patients did not adhere to the self-help activities, therefore potentially not benefiting. This may have arisen due to the characteristics of the patient or the intervention.

Aim: To investigate the demographic, clinical and psychological factors that predicts participation in and adherence to the stroke workbook intervention (SWOT – chapter 2).

Procedure: Stroke patients were offered the workbook intervention. Prior to the offer, demographic and clinical variables (affected side, stroke event and measures of impairment) were recorded on admission to hospital following the stroke. The psychological measures of illness representations (RLOC, confidence in recovery and desire for the workbook) emotional representations (HADS) and coping (WOC) were recorded prior to receipt of workbook.

Patients were classified as participating, if they remained in the intervention for the 5-week duration. Adherence was assessed from a range of performance measures associated with the intervention. These were classified into scores reflecting a) active adherence, b) passive adherence.

Results: Of the 91 patients who were offered the stroke workbook intervention 14% patients (n = 13) did not participate. This was not predicted by demographic or clinical variables but by the

psychological measures of higher perceived control over recovery, lower anxiety and higher confidence in recovery.

Forty three percent of patients (n = 38) did not actively adhere to the activities in the stroke workbook and 44% of patients (n = 39) did not passively adhere by keeping the workbook. Demographic, clinical and psychological variables of female gender, less impairment and avoidant coping were predictive of active adherence whilst the demographic and psychological variables of female gender and desire for the workbook respectively were predictive of passive adherence. Combining non-participators with non-active patients and comparing them with active adherers, only demographic and clinical variables of female gender and less impairment were predictive of adherence. This result was repeated again when examining the amount of active adherence performed; higher active adherence was associated with female gender and less impairment.

Discussion: Participation in and adherence to interventions are associated with patients' beliefs as well as being a woman and having less impairment. The intervention may have been more amenable to people with less impairment suggesting that an easier intervention may increase adherence with those with more impairment. Furthermore, self-management activities may be less attractive to men. Given the intervention was aimed at improving disability, by making it easier to achieve, adherence may possibly be enhanced for more stroke patients.

BACKGROUND

The Stroke Workbook Outcomes Trial (Bonetti et al 2001) was shown to be effective in reducing disability and maintaining confidence in recovery. However when patient's participation in the intervention group was further analysed 13 (14%) patients refused the intervention or declined to continue with the study and of those who did continue 25 (43%) did not adhere to any of the behavioural activities in the workbook. Furthermore of the 13 patients who declined to continue with the intervention only one actually attempted the behavioural activities. This begs two questions; why do people agree to participate in a trial and then decline? Why do people agree to participate in a trial requiring them to adhere to an intervention without even sampling the activities? Potentially, these patients, i.e. those who stopped or those who did not adhere, would potentially not benefit from an effective intervention. In an attempt to understand this behaviour this study aims to observe the factors that predict participation in and adherence to a stroke workbook intervention.

Adherence behaviour is of interest due to its impact on the assessment of interventions and the subsequent validity of the results (Schumaker and Rejeski 2000). More specifically for this study participating in and adhering to the self-management activities of the intervention being tested not only allows the observation of peoples' behaviour in relation to their recovery from illness but also provides an opportunity to assess the appropriateness of applying the SRM theoretical framework to explain the behaviour. Low rates of adherence are known to be problematic in the treatment of most chronic diseases and have been a significant problem in rehabilitation where patients are required to perform behaviours to improve their recovery (Dunbar-Jacob and Schlenk 2001).

Previous RCTs testing interventions to improve stroke recovery have been described in chapter 1. The stroke workbook in SWOT was implemented in the home with a designated person and it was specifically aimed at changing patients' beliefs in order to improve their control over their recovery. Whilst not directly comparable with the 12 studies in the literature review that used interventions in the home patient participation in and adherence to the interventions being tested was examined. Taking into account deaths, illness and patients moving out of area or into residential care, 5 of the 12 studies reported "loss to follow up" (range 3–20% of the intervention group) but gave no more information as to why this loss occurred (Bautz-Holter et al 2002, Roderick et al 2000, Kalra et al 2000, Mant et al 1999, Rudd et al 1997). Four studies noted that patients refused to participate or withdrew (range 1-7% of the intervention group) (Lincoln et al 2003a, Mayo et al 2000, Forster and

Young 1998, Widen-Holmquist et al 1997). Duncan et al (1998) noted that some patients refused to participate but it was not clear if this was from the intervention group or the control group. Three papers reported no losses to follow up at all (Ozdemir et al 2001, Anderson et al 2000, Gilbertson et al 2000). From the 12 studies, Mayo et al (2000) were the only authors to note the impact of the patient's refusal in their study.

The above studies described the interventions being tested but did not describe the patient's adherence behaviour in relation to them. In the study by Ada et al (2000), which was not a home-based intervention, they noted that 7% of their intervention group withdrew. They went on to describe "compliance" to the intervention but did not examine it statistically. In the study by Rodgers et al (1998) testing a specialised education programme, patients had to come into hospital for the intervention; of the 121 patients randomised to their intervention, 70 patients (59%) did not attend the programme. Rodgers et al noted that attendance was low but did not go on to examine this further. This intervention appeared to be logistically more difficult that the workbook study, as patients were required to attend the hospital whereas the stroke workbook was implemented in the home.

The Heart Manual study (Lewin et al 1992) on which the stroke workbook was on based was tested in a RCT. The heart manual was given to the patient on discharge from hospital following treatment for a myocardial infarction. The patients were contacted over the telephone or visited at home over a 6-week period. One hundred and ninety patients were randomly allocated to the control or experimental group. Fourteen patients withdrew (7 from experimental group and 7 from the control group) prior to their first assessment. The authors went on to report that 8 patients withdrew voluntarily and 6 withdrew due to medical complications. However they did not say from which groups the voluntary withdrawals came from. This study and the previous ones have been used as examples to demonstrate that participation in and adherence to an intervention is not comprehensively reported in the studies testing interventions.

In a recent review assessing reasons for patients consenting or not consenting to participate in trials, Cox and McGarry (2003) suggested that the patient's decision involved beliefs for and against the trial. They also recorded the reasons why patients gave consent to participate in trials, which they summarised; as the hope of personal improvement, pressure from relatives, a desire to help medical research, trust in their physician and the information provided or they felt they had no choice. The most salient reasons given for trial participation, was the hope of receiving the best medical care and to contribute to scientific knowledge (Cox and McGarry 2003).

Theoretically the SRM has been used to examine adherence behaviours. It postulates individuals are problem-solvers, who have beliefs about their illness and one can assume about their recovery and also their treatment. Adherence is indicative of a strategic coping response shaped by the patient’s beliefs (Leventhal and Cameron 1987). Stroke patients may have illness representations about their stroke, their recovery and their treatment, which may influence their involvement in interventions. Whether they adhere or do not may be conceptualised as their coping procedures. Their behaviour towards the intervention may be due to their representations, i.e. their beliefs about the intervention (Leventhal et al 2004, Horne 1997). They may not adhere because of the type of intervention (identity) the time it takes to do it (time-line), because they feel there is no reason (cause), it takes away their feelings of control over their recovery (control) or they cannot see the benefit (consequence). Conversely these representations may be the reasons for adhering to the intervention. Observing patients actively doing something can also be conceptualised as them having control (/cure) over their recovery and can be objectively measured.

There have been a number of studies examining non-attendance to cardiac rehabilitation programmes in relation to patients’ illness perceptions. These programmes offer advice (dietary and exercise) and counselling to promote recovery from and prevention of further myocardial infarction. They appear to have been successful in “reducing physical, psychological and socio-economic consequences of coronary heart disease” (Whitmarsh et al 2003). Again whilst not directly comparable to the stroke workbook intervention as cardiac rehabilitation is not usually performed in the home: the information given to those attending cardiac rehabilitation will more than likely be similar to the information presented in the workbook intervention. Measures of non-participation can be related to non-attendance to such programmes. Whitmarsh et al (2003) examined predictors of cardiac rehabilitation attendance and found that approximately 69% of men did not attend the rehabilitation. However 16% of men were reported to have refused whereas 22% of women refused. Examining the illness representations, poor attenders reported less consequence of their illness and less control. In a previous study by Cooper et al (1999), 60% of patients failed to attend cardiac rehabilitation with 28% of the non-attenders being female. Non-attenders felt their illness had less consequence and they were in less control. Johnston et al (1999) found that beliefs predicted attendance to coronary rehabilitation. They found patients were more likely to attend cardiac rehabilitation if they had a stronger belief in social support and in the health professionals, perceived cardiac rehabilitation as beneficial and were more confident that attendance would help to initiate lifestyle changes. Wyer et al (2001) developed a letter using the Theory of Planned Behaviour (TPB) (Azjen 1991) to encourage patients to attend cardiac rehabilitation. They were successful in increasing patient attendance, with 37 (86%) out of 43 patients in the experimental group attending cardiac rehabilitation compared to 26 (59%) out of the 44 patients in the control group. Wyer et al (2001) found that gender was predictive of attendance, with fewer women likely to accept and attend cardiac rehabilitation.

Illness representations are associated with gender as Martin and Suls explained in their review of gender in relation to cardiac disease (Martin and Suls 2003). They suggested that unlike most diseases women tend to present with cardiac symptoms later than men (Martin et al 2004) and more readily took up domestic duties post discharge from hospital following a myocardial infarction (Lemos et al 2003). In a series of experiments they went onto show that lay people assume that men are more likely to have a myocardial infarction than women and women are more likely to attribute their symptoms to stress rather than a myocardial infarction (Cameron et al 1995).

Petrie et al (1996) used the IPQ (Weinman et al 1996) to interview myocardial infarction patients at admission to hospital and 3 and 6 months later. They showed that attendance to cardiac rehabilitation was related to a stronger belief during hospitalisation that the illness could be controlled/cured and a tendency towards the illness having more consequences. Resuming employment was significantly correlated to perceptions of the illness lasting a short time and having less consequence. They did not examine gender differences in the illness representations, but there were no differences in attendance between men and women.

Petrie et al (2002) went on to develop an intervention using the SRM to promote cardiac rehabilitation attendance and tested this in an RCT. They interviewed patients using the IPQ (Weinman et al 1996) and tailored the cardiac rehabilitation to patients’ responses. The patients in the intervention group were more positive about their myocardial infarction, returned to work quicker and had fewer symptoms at 3 months but the intervention did not increase attendance to cardiac rehabilitation.

Cardiac rehabilitation usually takes place out of the home environment, therefore the patient and possibly their carer has to travel to the venue which may potentially involve practical factors, e.g. organising travel, being tired on arrival. Furthermore cardiac rehabilitation usually involves a group of patients. This contrasts with the stroke workbook intervention, which was carried out in the home with individual patients with or without their carer. The stroke workbook had a programme of activities for the patient to work through to develop their own ways of helping themselves to recover. This may not have been as evident in cardiac rehabilitation as cardiac rehabilitation usually involves a health professional to facilitate the groups. These differences between rehabilitation conducted out the home and in the home highlight the issue of adherence being difficult to measure (Weinman 1996) and is not an all or nothing occurrence but it is intervention specific (Vitolins et al 2000).

The aim of this study is to examine why the patients in the stroke workbook study did not participate in or adhere to the stroke workbook activities using the SRM as the theoretical framework. The stroke workbook study has observable records of adherence, which will be analysed using the SRM in relation to the patient's stroke and the involvement with the workbook as a coping procedure. However the RCT testing the stroke workbook included predictor variables that were not specifically chosen to examine non-participation and non-adherence. Therefore the measures available are limited. Patients' contextual factors of environment can be measured through gender, age, area of residence, employment status and the presence of a carer. Situational stimuli can be represented through the clinical data available including the degree of impairment, mean length of hospital stay, number of strokes and affected side. The patient's illness representations can be investigated by recovery locus of control, desire for the workbook and confidence in recovery and emotional representations by mood. Coping procedures can be indirectly measured by participation in and adherence to the stroke workbook intervention.
The following research questions were posed:

RESEARCH QUESTIONS

1. What psychological, clinical and demographic variables predict <u>participation in</u> the stroke workbook intervention?
2. What psychological, clinical and demographic variables predict <u>adherence to</u> the stroke workbook intervention?

METHODOLOGY[°]

DESIGN

This was a longitudinal predictive study involving the intervention group of an RCT testing a stroke workbook intervention, the Stroke Workbook Outcomes Trial- (SWOT) (Bonetti et al 2001). Demographic, clinical and psychological predictors were assessed prior to random allocation to the workbook group two weeks following discharge from hospital to home and were used to predict participation in and adherence to the workbook intervention.

Participants

	STUDY GROUP	
	Female	Male
Number	41	62
Mean age	69.78 years (s.d.13.26)	68.26 years (s.d. 12.08)

Table 3.1: The Study Group: Gender and Ages

A sequential cohort of stroke patients from a geographically defined area, admitted to Ninewells Hospital, Dundee between September 1998 and May 2001 were invited to take part in the Stroke Workbook Outcomes Trial (Bonetti et al 2001) A total of 203 stroke patients, who were fluent in English consented to take part in the study and passed a cognitive screening test. One hundred and three patients were randomly allocated to the intervention group (table 3.1 and 3.2) and constitute the study group for the current study. There were no significant differences at the *p*<. 05 level between the intervention and the control group in relation to the baseline demographic, clinical and psychological variables. (These details have been reported by Bonetti et al 2001).

MATERIALS

The stroke workbook, which has been described in chapter 1, was offered to the participants who were allocated the intervention group.

[°] A summary of the precise contribution of the author to the design of the study and data collection can be found in Appendix E.

MEASURES

Cognitive Screening Measures

- Clifton Assessment Procedures for the Elderly (CAPE) (Pattie and Gilliard, 1981) with four additional items from the Mental Status Questionnaire (MSQ) (Wilson and Brass, 1973) making an 18-item scale to assess orientation and cognitive functioning. Each item had a maximum score of 1 with a possible range of scores of 0 – 18.

Predictor Variables

Demographical and Clinical Predictors

- Patient’s gender, their age, employment status and the presence of a carer i.e. the person most involved with the patient at home and who had consented to take part in the study was recorded prior to receipt of the workbook.

- Depcat Scores (Carstairs and Morris 1992) is a scale measuring the deprivation of area of residence. This score ranges from 1 (low) to 7 (high) indicating the level of deprivation for specific postcode areas. It has been calculated from a combination of four variables developed from census data, overcrowding, male unemployment, low social class and lack of family car.

- The affected side and stroke event were two simple measures recording the affected side of the patient's body and the number of previous strokes the patient had had according to the medical notes. The patient’s length of stay in hospital was also recorded.

- The Orgogozo Neurological Index (Orgogozo et al.1983) is a 9-item scale to assess neurological impairment giving a total score out of 100 with higher scores reflecting less impairment.

- The NIH (National Institute of Health) Stroke Scale (Biller et al 1987) is a 13-item clinical assessment tool evaluating neurological status giving a score out of 100. In this measure a lower score indicates less neurological impairment.

- The Modified Rankin Scale (MRS) (Rankin, 1957) is a 6-item scale measure of functional independence. The score ranges from no symptoms at all (0) to dead (6) i.e. the lower the score the more functional independence.

- The Barthel Index (Mahoney and Barthel, 1965, Johnston et al 1995), a 10-item scale measuring the ability to perform activities of daily living, which was originally designed for use with people with neuromuscular disease. Originally scores ranged from 0 – 100, with individual scores of 0, 5, 10 or 15, per item. Lower scores indicate the less ability to perform activities of daily living. The Barthel Index used in this study using a scoring system to give a range of 0-20. This scale is well validated and commonly used with stroke patients (Johnston et al 1995).

Psychological Predictors

The following measures were all administered at the T1 interview 2 weeks following discharge from hospital but prior to randomisation.

- The Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983). This measure was designed for patients with a physical illness and has been widely used to assess mood amongst patients, without a psychiatric co-morbidity, in general hospitals. It comprises of 14 items to assess anxiety (7 items) and depression (7 items). Each item is scored from 1 to 3 giving a total score range between 0 – 21 for each scale respectively. Both scales can be combined to indicate mood (range between 0 – 42). Higher scores in both sub-scales indicate greater depression and/or anxiety. The HADS is a widely used measure and has been validated in a number of reviews (Johnston et al 2000). This measure is conceptualised as a measure of fear representation in the SRM.

- The Recovery Locus of Control Scale (RLOC) (Partridge and Johnston 1989) was developed to measure perceived control over recovery. There are 5 items to assess internal beliefs and 4 items to assess external beliefs. Patients are asked to respond to statements on a 5-point Likert-type scale from “strongly agree” (1) to “strongly disagree” (5). Each item is scored from 1 to 5 and totalled to give a score between 9 and 45. The total score reflects the strength of the respondent’s perception of control, i.e. a low score indicates a strong external locus of control and a high score, a strong internal belief. This measure has been found to have satisfactory internal reliability and predictive ability for stroke patients (Partridge and Johnston 1989, Morrison et al 2000). This measure is conceptualised as a measure of the illness representation of control.

- <u>The Ways of Coping Questionnaire</u> (WOC) (Billings and Moos 1981) is a 19-item assessment, which has divided in to 4 sections to describe the "active attempts to resolve stressful events into cognitive and behaviour strategies". The patients are asked to rate on a scale of" almost never" (1) to "almost always" (5) how often they used various strategies when faced with a stressful situation in order to "cope" with that situation. Sets of scores were summed to represent 4 types of coping;
  - i) Active coping; subdivided into:
    - Active cognitive: refers to the appraisal of the situation, e.g. "tried to see the positive side of a situation".
    - Active behavioural: pertains to the explicit attempts to cope, e.g. "took some positive action".
  - ii) Avoidant coping: refers to activities taken to avoid the situation, e.g. "keep my feelings to my self".
  - iii) Problem-focused coping: refers to the efforts to adapt or remove the stressor and is made up of a subset of active coping items.
  - iv) Emotion-focused coping: relates to the activities taken to cope with the emotional consequences of the stressor and is made up of items from active cognitive and avoidant coping scales.

  This measure identifies the coping strategies one adopts when coping with the mental representation of their stroke.

<u>Other Measures</u>

- <u>Confidence in Recovery</u> (Lewin et al 1992, Morrison et al 2000). This single item asked the patient to rate their level of confidence on a scale of 1 (not at all confident) to 10 (totally confident) about making a perfect recovery. This measure was predictive of distress in the study by Morrison et al (2000).

- Desire for the Workbook (Bonetti 1999). This single measure was specifically designed for the SWOT study and asked patients to rate how much they would like to receive the stroke workbook (even though they did not know whether they would be receiving it prior to randomisation). Responses were on a 5-point Likert scale where patients had to rate their desire for the workbook from “definitely do not want it” (1) to “definitely do want it” (5).

Dependent Variables

- Participation This was measured by classifying patients as participators (score 1), i.e. those who completed the intervention without withdrawing (they had been seen at 3 visits and telephoned three times during the 5-week intervention) and non-participators (score 0) those who withdrew during the intervention.

- Adherence This was an observed measure achieved by recording the 4 types of behavioural activities performed by the patients (listed below), and whether the patient retained the workbook. Adherence scores were derived from the number of completed quizzes (maximum of 5) and tasks (maximum of 15) along with identified goals (yes/no) and the number of completed diary days (up to 14 days).

    - Active adherence included quizzes, tasks and diary days, which were each scored individually with 0 (did not do any of the activity) 1 (completed some) and 2 (completed all). The goals were scored as 0 (no goals recorded) or 1 (goals recorded). This gave a score of active adherence from 0 – 7 and also classified the patients into active adherers those scoring 1-7 and non-active, those scoring 0.

    - Passive adherence was scored as 0 for those patients who did not keep the either workbook or relaxation tape, 1 for those who retained one of them and 2 for those who retained both of them. This gave a score of passive adherence of 0-2. Patients who scored 1 or more were classified as passive and those who scored 0 were classified as non-passive. Overall adherence was calculated by summing both passive and active scores.

The scoring for adherence was examined using a principle components analysis and is presented in the results section under "Developing Adherence Measures". Internal consistency and validity for adherence measures and the psychological measures will be presented in the results section.

PROCEDURE

Stroke patients admitted to Ninewells Hospital were seen and screened by the research nurse. (See Appendix B for stroke audit-screening sheet). This information was made available to the SWOT researchers and eligible patients were approached on the wards. Patients who were defined as ineligible were those with communication difficulties i.e. deafness, blindness, verbal communication deficits or cognitive deficits. Patients who were unwell, had co-morbidity of a terminal illness, or were to be discharged to a nursing home or another hospital for continuing care were also excluded. Patients were given an information sheet describing the study and asked to sign a consent form if they were happy to take part. (Appendix B)

After consent was obtained from the patients and prior to their discharge home demographic data was obtained from the stroke audit screening sheet and included, the total scores of the NIH, the Orgogozo and the Modified Rankin scores, as well as the stroke event and affected side of the body. Within 48 hours of admission to hospital a research nurse had routinely made these assessments.

At the T1 interview, 2 weeks following discharge the patients were screened for cognitive and communication difficulties using the CAPE and MSQ to ensure that they were able to use the workbook and to answer questions on the subsequent measures, which included disability (Barthel Index), mood (HADS), perceived control (RLOC), coping (WOC), confidence in recovery and desire for the workbook. These measures were administered in a structured interview, by the researcher in the patient's own home. (See Appendix B for complete questionnaire, including additional measures required for the SWOT trial). If the patient did not pass the screening tests the measures were not administered. If a carer was present the researcher explained that the workbook may not be appropriate for the patient but if the carer would like to use it with the patient, then the carer was recruited for the "Carer Only" arm of the SWOT study. (Not reported in this present thesis). If a carer was not present the appropriateness of the workbook was discussed with the patient, the patient's questions answered and thanks expressed for the interest they had shown in the study.

The duration of the T1 interview lasted between 45 minutes and two hours, depending on the number and length of breaks requested in addition to the pre-scheduled break inserted in the middle of the questionnaire. Following this interview the patients' General Practitioners (GP) were informed of their involvement in the SWOT study. An independent statistician (BP), pre-prepared randomisation numbers and the workbook implementer applied these numbers to the patients who had completed the T1 interview to allocate them to one of the two groups. Within the following 5 days patients who were randomly allocated to the intervention group were contacted by phone (P1) to arrange the first visit (V1) of the intervention and to administer the workbook. Patients were visited again the following week (V2) and telephoned over the next two weeks (P2 and P3 respectively). The final visit (V3) was undertaken in the fifth week of the intervention. During the 5 weeks the patients were asked to:

- Read the workbook
- Identify goals
- Answer the quizzes
- Work through the tasks
- Do the relaxation tape
- Record their progress in the diary

On the final visit the fulfilment of these requirements were recorded as outcome measures of participation and adherence. Patients who did not want to continue with the intervention were allowed to withdraw at any time without giving any reason. Patients who died or became ill were withdrawn from the study. (Two further interviews were conducted later as part of the SWOT trial but are not relevant to the present study.) This study uses the data from those patients allocated to the intervention group who were offered the workbook intervention.

STATISTICAL ANALYSIS

The data were analysed using SPSS (Norusis 1993) computer program. Proof reading and descriptive function of SPSS allowed the accuracy of the database to be examined. All continuous variable values were checked to ensure the scores fell between the minimum and maximum range for each variable. Means and standard deviations were observed to ensure that they were "plausible" (Tabachnick and Fidel 2001). Missing data for the psychological variables were accounted for by replacing with the group mean (Tabachnick and Fidel 2001). All the data were checked for skewness and kurtosis and transformed where necessary.

An exploratory principle components factor analysis with a varimax rotation and Cronbach's alpha was performed on the data used to develop the measure of adherence to ensure construct validity and internal consistency of the questionnaire. To examine group differences t-tests were used for the continuous data and Chi square analysis for the dichotomous and nominal data. Fisher's exact results are reported where the cells have less than 5 expected observations.

To examine relationships between the predictor variables and the outcome variables Pearson's correlations were calculated for continuous data and point bi-serial analysis for the dichotomous data. Multiple and logistic regressions were performed on variables with correlations with probabilities less than or equal to .2 (Hosmer and Lemeshow 1989 cited in Hair et al 1998) to see which combination of variables were the best predictors of participation and adherence.

RESULTS

Missing Data and Psychometrics

Missing data occurred with the clinical measures of NIH, Orgogozo and Rankin due to them not being recorded on the patient's notes; these were not replaced by the group mean. There were two cases of missing data in the psychological measures, RLOC and WOC. This was randomly distributed and in the two cases the scores were replaced by the group means. Apart from the Barthel Index and NIH all data appeared to be normally distributed with skewness falling between ±1 (Hair et al 1997). The Barthel Index score was transformed by cubing the scores and the square root of NIH was calculated to minimize the skewness and kurtosis of their distributions. Six patients had incomplete data pertaining to the behavioural activities used to assess adherence due to implementer oversight.

Post-hoc Power Analyses

An a priori power analysis was performed for the larger SWOT study and has been reported in Bonetti et al (2001). Post-hoc power analysis showed that the patient analyses (n = 103) had power =

0.97 to detect a large effect size (.35), power = 0.61 to detect a medium effect size (.15), power = 0.10 to detect a small effect size (.02). (F-test on means on regression analyses) at alpha=. 05 (Faul & Erdfelder's (1992) GPOWER program).

PARTICIPANTS

One hundred and three patients were allocated to the workbook intervention. Data from twelve patients could not be included as the patients became ill or died (n = 10) or they never received the workbook (n = 2) due to a delivery problem (i.e. those patients who were unobtainable due to wrong address information and therefore never received the workbook to which they were randomly allocated).

On completion of the data collection, 91 surviving patients had received the workbook and were divided into two groups. Patients who had participated in the workbook intervention regardless of the level of adherence (n = 78) were assigned to the "participators" group. The "non-participators" group (n = 13) comprised of the patients who chose to withdraw from the intervention before the end of the 5-week intervention. Three patients declined the workbook, two at the first telephone contact (P1), their reasons being "I do not want one" and 1 patient declined the workbook at the first visit (V1), prior to seeing the workbook, saying that they did not want to do it because "it would all be too much". Ten patients did some of the workbook but declined to carry on with it at V2. Their reasons could be summarised as: the workbook was inappropriate, in that they did not think they were that badly affected by the stroke, they were too busy or quite simply they did not want to do it any more (Table 3.2).

		WOMEN	MEN	TOTAL
Participators	Completed 5-weeks	31	47	78
Non-participators	Declined	2	1	13
	Withdrew	2	8	
TOTAL		35	56	91

Table 3.2: Patient Participation Groups; gender and numbers

The data from the participators group (n = 78) was used to develop a score of adherence. Three patients did not have their behavioural activities recorded due to researcher error and these cases were removed from the analysis (n = 75) (table 3.3).

	FEMALE	MALE
Number	30	45
Mean age	68.16	67.69
Standard deviation	13.40	12.26

Table 3.3: Participators Group with Intact Data Sets; Gender; Numbers and Ages

The number of quizzes, tasks, goals, diary days, and whether the patients retained the stroke workbook and relaxation tape were entered into an exploratory principle components analysis, to explore the component structure. The scree plot of factor variance indicated a three-factor solution with the Eigen value for the third factor being less than 1 (.51) therefore two factors were retained and accounted for 76% of the variance (table 3.4).

Two components emerged, both internally consistent with Cronbach’s alphas of .78 and .92. Component 1 has been labelled as “active adherence”; this includes the activities that the patients would have to do physically and mentally i.e. activities that actually took up their time. Component 2 has been defined as “passive adherence” where the patient has kept the workbook and/or the tape.

A second exploratory principle components analysis was performed on the number of quizzes, tasks, goals, and diary days only. The scree plot of factor variance indicated a two-factor solution with Eigen value for the second component being less than 1 (.53) therefore only one component was retained and accounted for 72% of the variance. This is shown in the last column of table 3.4.

	RANGE	MEAN (SD)	ACTIVE & PASSIVE (6 VARIABLE) PRINCIPLE COMPONENTS ANALYSIS (PCA)		ACTIVE (4 VARIABLE) PCA
			Component 1 Active adherence (α = .78)	Component 2 Passive adherence (α = .92)	Component 1 Active adherence (α = .75)
Diary days	0 - 14	2.33 (4.13)	**.86**	.008	**.82**
Completed goals	0 - 1	----------	**.83**	.18	**.85**
Number of quizzes	0 - 5	2.40 (2.16)	**.80**	.31	**.85**
Number of tasks	0 - 15	3.00 (3.77)	**.86**	.18	**.88**
Keep relaxation tape	0 - 1	---------	.007	**.90**	
Keep workbook	0 - 1	----------	.19	**.88**	

Table 3.4: Principle Components Analysis of Behavioural Activities; range of scores, mean, standard deviation Cronbach's alphas and component loadings

Descriptive Statistics

The internal consistencies of all the multi-item measures apart from the clinical measures were analysed using Cronbach's alpha and reported in table 3.5.

MEASURES	N	CLASSIFICATION/MEAN	STANDARD DEVIATION (SD)	α
DEMOGRAPHIC				
Gender	91	Male n = 56	-----------	-----
Employment	91	Retired n = 68	-----------	-----
With carer	91	On own n = 57	-----------	-----
Age	91	68.66 years	12.73	-----
Depcat	91	3.72	1.94	-----
CLINICAL				
Affected side	89	Left n = 42	----------	-----
Stroke event	91	First n = 74	----------	-----
Orgogozo	85	76.94	20.34	-----
NIH	84			-----
Rankin	81	3.18	1.24	-----
Time in hospital	91	33.59	42.44	-----
Barthel	91	18.18	2.93	.85
PSYCHOLOGICAL				
HADS - Mood	91	12.85	8.99	.88
Anxiety	91	5.97	5.37	.87
Depression	91	6.88	4.55	.77
RLOC	91	35.20	4.41	.57
WOC - Active	91	40.61	8.22	.69
Active cognitive	91	20.59	4.58	.50
Active behavioural	91	20.02	4.81	.55
Avoidant	91	11.31	3.50	.38
Problem focused	91	24.86	5.91	.69
Emotion focused	91	31.12	6.17	.49
Desire for workbook	91	4.05	1.27	-----
Confidence in Recovery	91	7.73	2.36	-----
DEPENDENT VARIABLES				
Participation	91	Participators n = 78	----------	-----
Active adherence	75	Active adherers n = 50	----------	-----
Passive adherence	75	Passive adherers n = 51	----------	-----
Amount of active adherence	75	2.69	2.53	.86

N = number of patients, α = Cronbach's Alpha

Table 3.5: Demographic, Clinical, Psychological and Dependent Variables; number of responses, classification, means, standard deviations and Cronbach's alphas

RESEARCH QUESTION 1: What psychological, clinical and demographic variables predict participation in the stroke workbook intervention?

To answer this question the patients were divided into those who participated (n = 78) and those who did not participate (n = 13). (All the significant results are highlighted in bold print and the results that show a trend (< .1) are highlighted using "^").

Participators versus Non-Participators

Using the data from the 91 patients χ^2 analyses revealed no significant differences on gender, employment status and the presence of a carer. T-tests were performed to examine if the groups differed in age and DEPCAT scores, no significant differences were found (table 3.6).

DEMOGRAPHIC MEASURES	TOTAL	NUMBERS		χ^2 RESULTS
		PARTICIPATORS	NON-PARTICIPATORS	
Number	91	78	13	
Gender: female male	35 56	31 (89%) 47 (84%)	4 (11%) 9 (16%)	χ^2 = .38 (*df 1*) *p* = .54
Employment: retired Not retired	68 23	56 (82%) 22 (96%)	12 (18%) 1 (4%)	χ^2 = 2.48 (*df 1*) *p* = .12 Fisher's Exact *p* = .17
Living: with carer without carer	57 34	46 (81%) 32 (94%)	11(19%) 2 (6%)	χ^2 = 3.10 (*df 1*) *p* = .08^ Fisher's Exact *p* = .12
		MEAN SCORES (STANDARD DEVIATION)		*T*-TESTS RESULTS
Mean age - years	91	67.88 (12.71)	73.31 (12.30)	*t* (89) = 1.43, *p* = .16
Depcat score: 1 – 7	91	3.72 (1.90)	3.77 (2.30)	*t* (89) = .24, *p* = .81

Table 3.6: Demographic Differences between Participators and Non-Participators; χ^2 & *t*-test results

Although living with a carer did not significantly differ between the two groups there was a trend to suggest that patients who lived without a carer were more likely to participate in a trial (χ^2 = 3.10 (*df 1*) *p* = .08^). Due to small cell numbers in this analysis the Fishers Exact test was applied and the probability became non-significant (*p* = .12).

The clinical predictors of affected side and stroke event were analysed using chi square analyses and again no significant differences were found between the two groups on affected side or stroke event (table 3.7).

CLINICAL MEASURES	N	NUMBERS		χ^2 RESULTS
		PARTICIPATORS	NON-PARTICIPATORS	
Affected side: left	42	36 (86%)	6 (14%)	χ^2 = .07 (*df 1*) *p* = .94
right	47	40 (85%)	7 (15%)	
Stroke event: first	74	64 (86%)	10 (14%)	χ^2 = .19 (*df 1*) *p* = .66
previous	17	14 (82%)	3 (18%)	Fisher's Exact *p* = .70
		MEAN SCORE (STANDARD DEVIATION)		*T*-TEST RESULTS
Orgogozo[1]	85	76.99 (20.05)	76.67 (23.00)	*t* (83) = -.05, *p* = .96
NIH (transformed)[2]	84	1.95 (.94)	2.14 (.91)	*t* (82) = .66, *p* = .51
Modified Rankin[2]	81	3.2 (1.26)	3.1 (1.1)	*t* (79) = -.23, *p* = .82
Length of stay in hospital	91	34.87 (45.23)	25.92 (17.61)	*t* (45) = -1.26, *p* = .23
Barthel Index (transformed)[1]	91	6303.95 (2156.85)	6998.92 (1099.54)	*t* (30) = 1.78, *p* = .09^

[1]Orgogozo & Barthel Index: higher score = less impairment [2]NIH and Rankin: lower score = less impairment

Table 3.7: Clinical Differences between Participators and Non-Participators; χ^2 & *t*-test results

Examining the clinical measures t-test analyses were performed and showed no difference between the two groups on Orgogozo, NIH, Modified Rankin, Barthel's Index and length of hospital stay (table 3.7). However there was a trend in the Barthel Index suggesting that Non-Participators were less impaired.

PSYCHOLOGICAL MEASURES	MEAN SCORE (STANDARD DEVIATION)		T-TEST RESULTS
HADS (n = 91)	PARTICIPATORS	NON-PARTICIPATORS	
Mood	13.44 (9.31)	9.31 (5.85)	*t* (89) = 1.54, *p* = .13
Anxiety	**6.50 (5.51)**	**2.77 (2.83)**	***t* (30.07) = -3.72, *p* = .001**
Depression	6.94 (4.60)	6.54 (4.44)	*t* (89) = -.29, *p* = .77
RLOC (n = 91)			
RLOC	**34.73 (4.33)**	**38.08 (3.93)**	***t* (89) = 2.61, *p* = .01**
WOC (n = 91)			
Active coping	40.10 (8.37)	43.69 (6.76)	*t* (89) = 1.47, *p* = .15
Active cognitive	20.27 (4.63)	22.54 (3.86)	*t* (89) = 1.67, *p* = .10
Active behavioural	19.83 (4.85)	21.15 (4.58)	*t* (89) = .92, *p* = .36
Avoidant	11.46 (3.67)	10.38 (1.98)	*t* (89) = -1.03, *p* = .31
Problem focused	24.58 (6.13)	26.54 (4.20)	*t* (89) = 1.11, *p* = .27
Emotion focused	31.01 (6.24)	31.77 (5.92)	*t* (89) = .41, *p* = .68
DESIRE FOR WORKBOOK (n = 91)			
Desire	4.12 (1.19)	3.69 (1.70)	*t* (14.00) = -.87, *p* = .40
CONFIDENCE IN RECOVERY (n = 91)			
Confidence	**7.47 (2.40)**	**9.23 (1.48)**	***t* (24.03) = 3.57, *p* = .002**

Table 3.8: Psychological Differences between Participators and Non-Participators; *t*-test results

T-tests were used to examine differences between Participators and Non-Participators on psychological variables and these results are shown in table 3.8. The two groups differed significantly on three measures. The Non-Participators had greater perceived control, were less anxious and were more confident about their recovery than the patients who participated in the workbook intervention.

Predictors of Participation

Correlational analyses between participation and clinical, demographic and psychological variables were performed (Appendix B). The correlations where probability was .20 or less (Hair et al 1998) included demographic predictors of age (*r* = -.15, *p* = .16), employment status (*r* = -.17, *p* = .12), with carer (*r* = -.19, *p* = .08^), and psychological predictors of RLOC (*r* = -.27, *p* = .01*), active cognitive coping behaviour (*r* = -.17, *p* = .10), anxiety (*r* = .25, *p* = .02*), and confidence in recovery (*r* = -.26, *p* = .01*). These variables were entered into a logistic regression to confirm the relative contribution of each variable in predicting non-participation (table3.9). (Although the combined score of HADS and the combined score of active coping neared .20 in probability these were not entered, as they would be too highly correlated with the subscales of anxiety and active cognitive behaviour respectively.)

VARIABLES ENTERED	B	S.E.	WALD	DF	SIG.	95% CI FOR EXP (B)	
						LOWER	UPPER
Age	-.04	.05	.70	1	.40	.88	1.05
With carer	1.81	.96	3.60	1	.06	.03	1.01
Retired	1.06	1.48	.51	1	.47	.02	6.28
RLOC	**-.22**	**.10**	**4.72**	**1**	**.03**	**.66**	**.98**
Active cognitive	- .00	.11	.00	1	.98	.80	1.24
Anxiety	1.94	.12	2.50	1	.11	.95	1.54
Confidence in recovery	-.52	.30	3.06	1	.08	.33	1.07
Constant	15.95	6.12	6.78	1	.01		

B = logistic coefficient; S.E. = standard error; WALD = Wald statistic; DF = degrees of freedom; SIG. = significance level; CI = Confidence intervals; EXP (B) = exponentiated coefficient.

Table 3.9: Logistic Regression Analyses of Participation Predictor Variables

A one variable model was produced where the log likelihood (-2LL) value decreased from 74.64 to 50.17. The R^2 values ranged from .24 - .42 and the Hosmer and Lemeshow χ^2 value showed a non-significant (χ^2 = 11.25, *p* = .19) indicating a good overall model fit. This model shows that RLOC accounts for the most variance (Wald statistic = 4.72, *p* = .03*). The other demographic and psychological did not significantly account for any additional variance.

In summary, 14% (n = 13) of patients randomly assigned to receive the stroke workbook did not participate in the intervention. There were no differences between Participators and Non-Participators in their demographic and clinical variables. However, patients who did not participate in the workbook intervention appeared to have higher perceived control, were less anxious and expressed more confidence about their recovery in comparison to the patients who participated in the workbook intervention. When entered into a logistic regression analysis anxiety and confidence in recovery were not included in the one variable model suggesting that high perceived control is accounting for the variance explained.

RESEARCH QUESTION 2: What psychological, clinical and demographic variables predict adherence to the stroke workbook intervention?

Active Adherence versus Non-Active

From the 88 patients (no adherence activities were recorded for 3 patients) 43% (n = 38) did not actively adhere to the behavioural activities in the stroke workbook. To examine this further the data from the 75 patients who participated in the stroke workbook intervention was used. These patients were divided into Active Adherers i.e. those patients who attempted some of the workbook activities, therefore scoring at least 1 or more (n = 50) and Non-Active (n = 25) where patients scored 0. The differences between the two groups were initially examined using χ^2 and *t*-tests.

DEMOGRAPHIC MEASURES (n = 75)	NUMBER		χ^2 RESULTS
	ACTIVE ADHERERS	NON-ACTIVE	
Gender: female **male**	**24 (80%)** **26 (58%)**	**6 (20%)** **19 (42%)**	**χ^2 = 4.00 (*df 1*) *p* = .05**
Employment: retired Not retired	37 (67%) 13 (65%)	18 (33%) 7 (35%)	χ^2 = .03 (*df 1*) *p* = .85
Living: with carer without carer	28 (63%) 22 (71%)	16 (37%) 9 (29%)	χ^2 = .44 (*df 1*) *p* = .51
	MEAN SCORES (STANDARD DEVIATION)		*T*-TESTS
Mean age - years	68.22 (11.19)	68.04 (15.42)	*t* (73) = -.06, *p* = .95
Depcat score: 1 – 7	3.68 (1.86)	3.76 (2.11)	*t* (73) = .17, p = .87

Table 3.10: Demographic Differences between Active Adherers and Non-Active; χ^2 and *t*-test results

Using χ^2 and *t*-test analyses, there was one significant demographic difference between the two groups and this was for gender. Of those who actively adhered to the workbook, 80% were more likely to be women whereas 58% were more likely to be men. There were no other significant differences between the groups on demographic predictors (table 3.10).

CLINICAL MEASURES	TOTAL	NUMBERS		χ^2 RESULTS
		ACTIVE ADHERERS	NON-ACTIVE	
Affected side: left	35	26 (74%)	9 (26%)	$\chi^2 = 2.17$ (*df 1*) *p* = .14
right	38	22 (58%)	16 (42%)	
Stroke event: first	61	43 (71%)	18 (30%)	$\chi^2 = 2.15$ (*df 1*) *p* = .14
previous	14	7 (50%)	7 (50%)	Fisher's Exact p = .21
		MEAN SCORE (STANDARD DEVIATION)		*T*-TEST RESULTS
Orgogozo[1]	70	80.00 (20.39)	70.40 (19.09)	*t* (68) = -1.93, *p* = .06^
NIH [2] (transformed)	**69**	**1.79 (1.03)**	**2.28 (.71)**	***t* (67) = 2.13, *p* = .04**
Modified Rankin[2]	**68**	**2.91 (1.29)**	**3.79 (.98)**	***t* (59) = 3.17, *p* = .002**
Length of hospital stay	75	28.74 (40.27)	48.36 (53.79)	*t* (73) = 1.77, *p* = .08^
Barthel Index[1] (transformed)	75	6556.42 (1968.03)	5718.96 (2491.58)	*t* (73) = -1.59, *p* = .12

[1] Orgogozo & Barthel Index: higher score = less impairment [2] NIH and Rankin: lower score = less impairment

Table 3.11: Clinical Differences between Active Adherers and Non-Active; χ^2 and *t*-test results

Significant differences were identified in the clinical variables (table 3.11). Patients were more likely to actively adhere if they scored less impairment on the NIH and the Modified Rankin. Although there were no other significant differences in the other measures of impairment, i.e. the Orgogozo, length of hospital stay and the Barthel Index, they showed non-significant trends in the same direction.

Following the analyses of the psychological variables Active Adherers appeared to be less avoidant but there were no other differences between groups on the other psychological predictors (table 3.12).

PSYCHOLOGICAL MEASURES (n = 75)	MEAN SCORE (STANDARD DEVIATION)		*T*-TEST RESULTS
	ACTIVE ADHERERS	NON-ACTIVE	
HADS			
Mood	12.08 (8.89)	15.08 (9.71)	*t* (73) = 1.34, *p* = .19
Anxiety	5.64 (5.31)	7.60 (5.34)	*t* (73) = 1.51, *p* = .14
Depression	6.44 (4.40)	7.48 (5.06)	*t* (73) = .92, *p* = .36
RLOC			
RLOC	34.78 (4.30)	34.80 (4.61)	*t* (73) = .02, *p* = .99
WOC			
Active	40.74 (7.66)	39.64 (9.82)	*t* (73) = -.53, *p* = .60
Active cognitive	20.36 (4.38)	20.60 (5.12)	*t* (73) = .21, *p* = .83
Active behavioural	20.38 (4.55)	19.04 (5.57)	*t* (73) = -1.12, *p* = .27
Avoidant	**10.66 (3.41)**	**12.64 (3.86)**	***t* (73) = 2.00, *p* = .05**
Problem focused	24.88 (6.06)	24.28 (6.53)	*t* (73) = -.39, *p* = .70
Emotion focused	30.36 (5.97)	32.48 (6.98)	*t* (73) = 1.37, *p* = .18
DESIRE FOR WORKBOOK			
Desire	4.16 (1.18)	4.00 (1.25)	*t* (73) = -.53, *p* = .60
CONFIDENCE IN RECOVERY			
Confidence in recovery	7.46 (2.53)	7.64 (2.22)	*t* (73) = .30, *p* = .76

Table 3.12: Psychological Differences between Active Adherers and Non-Active; *t*-test results

In summary, 43% of patients did not actively adhere to the behavioural activities in the workbook. Of those who participated in the stroke workbook intervention active adherence was more likely to be performed by women, those less impaired and those who use less avoidant methods of coping.

Predictors of Active Adherence

Correlational analysis between active adherence and clinical, demographic and psychological variables was performed (Appendix B). On the basis of probability values for the correlations being equal or less than .20 (Hair et al 1998) an exploratory logistic regression analysis was used to examine the contribution of each independent variable to the predictive model. The predictors of active adherence correlations included gender (*r* = .23, *p* = .05*), affected side (*r* = -.17, *p* = .14), stroke event (*r* = -.17, *p* = .15), Orgogozo (*r* = .23, *p* = .06^), Rankin (*r* = -.34, *p* = .01), NIH (*r* = -.25, *p* = .04*), Length of hospital stay (*r* = -.20, *p* = .08^), Barthel Index (*r* = .18, *p* = .12), avoidant coping (*r* = -.26, *p* = .03*), emotion focused coping (*r* = -.16, *p* = .18) and anxiety (*r* = -.17, *p* = .14). These variables were entered into a logistic regression to examine the relative contribution of each variable in predicting active adherence (table 3.13). A two variable model was produced where the -2LL value decreased from 85.61 to 58.44 The R^2 values ranged from .34 to .47 and the Hosmer and Lemeshow χ^2 value showed a non-significant result indicating a good overall model fit (χ^2 = 4.49 *df* 7 *p* = .72).

VARIABLES ENTERED	B	S.E.	WALD	DF	SIG.	95% CI FOR EXP. (B)	
						LOWER	UPPER
Gender	**-2.46**	**.91**	**7.36**	**1**	**.01**	**.02**	**.51**
Stroke event	.72	.97	.55	1	.46	.31	13.83
Affected side	.87	.83	1.10	1	.29	.47	12.00
Orgogozo	.01	.03	.10	1	.75	.95	1.07
Rankin	**-1.14**	**.55**	**4.20**	**1**	**.04**	**.11**	**.95**
NIH	.62	.70	.80	1	.37	.48	7.32
Length of stay	-.02	.01	2.50	1	.11	.96	1.00
Barthel index	.00	.00	3.18	1	.07	1.00	1.00
Avoidant coping	-.98	.13	.60	1	.44	.71	1.16
Emotion coping	-.03	.07	.20	1	.66	.84	1.11
Anxiety	-.12	.08	2.68	1	.10	.76	1.03
Constant	9.16	4.76	3.71	1	.05		

B = logistic coefficient; S.E. = standard error; WALD = Wald statistic; DF = degrees of freedom; SIG. = significance level; CI = confidence interval; EXP (B) = exponentiated coefficient.

Table 3.13: Logistic Regression Analysis of Active Adherence Predictor Variables

This model shows that gender and impairment (Modified Rankin) accounts for the most variance (Wald statistic = 7.36, *p* = .01, Wald statistic = 4.20, *p* = .04* respectively). (The Modified Rankin negatively correlates with active adherence (r = -.34 p = .01*), indicating that less impairment predicts greater adherence). The other demographic, clinical and psychological did not significantly account for any additional variance.

In summary being female and being less impaired were more likely to predict active adherence to the behavioural tasks in the stroke workbook intervention.

Passive Adherers versus Non-Passive

From the 88 patients, 44% (n = 39) did not passively adhere to the stroke workbook. To examine this further the data from 75 patients who participated in the stroke workbook intervention were used. These patients were divided into Passive Adherers i.e. those people who retained the workbook (n = 49) and Non-Passive (n = 26) those patients who did not keep the workbook. The differences between the two groups were initially examined using χ^2 and *t*-tests.

DEMOGRAPHIC MEASURES (n = 75)	N	NUMBER		χ^2 RESULTS
		PASSIVE ADHERERS	NON-PASSIVE	
Gender: female **male**	**30** **45**	**25 (83%)** **26 (58%)**	**5 (17%)** **19 (42%)**	**χ^2 = 5.40 (*df 1*) *p* = .02**
Employment: retired Not retired	55 20	36 (66%) 15 (75%)	19 (34%) 5 (25%)	χ^2 = .61 (*df 1*) *p* = .43
Living: with carer without carer	44 31	28 (64%) 23 (74%)	16 (36%) 8 (26%)	χ^2 = .93 (*df 1*) *p* = .33
		MEAN SCORES (STANDARD DEVIATION)		*T*-TESTS
Mean age - years	75	67.04 (13.59)	70.54 (10.24)	*t* (73) = 1.20, *p* = .27
Depcat score: 1 – 7	75	3.78 (1.78)	3.54 (2.25)	*t* (37.14) = -.47, *p* = .62

Table 3.14: Demographic Differences between Passive Adherers and Non-Passive; χ^2 & *t*-test results

There was only one significant demographic difference, which was between the genders showing that females were more likely to passively adhere by keeping the workbook (table 3.14).

When the clinical data were examined there were no significant differences between Passive and Non- Passive Adherers (table 3.15)

CLINICAL MEASURES	N	NUMBERS		χ^2 RESULTS
		PASSIVE ADHERERS	NON-PASSIVE	
Affected side: left right	35 38	27 (77%) 22 (58%)	8 (23%) 16 (42%)	χ^2 = 3.06 (*df 1*) *p* = .08^
Stroke event: first previous	61 14	41 (67%) 10 (71%)	20 (33%) 4 (29%)	χ^2 = .09 (*df 1*) *p* = .76 Fisher's Exact p = 1.00
		MEAN SCORE (STANDARD DEVIATION)		*T*-TEST RESULTS
Orgogozo[1]	70	74.89 (23.44)	79.79 (12.20)	*t* (68) = 1.15, *p* = .25
NIH[2] (transformed)	69	1.93 (1.04)	2.03 (.78)	*t* (67) = .38, *p* = .70
Modified Rankin[2]	68	3.19 (1.31)	3.29 (1.15)	*t* (66) = .28, *p* = .78
Length of hospital stay	75	39.31 (50.18)	26.71 (34.14)	*t* (73) = -1.11, *p* = .27
Barthel Index[1] (transformed)	75	6057.53 (2331.12)	6744.21 (1757.72)	*t* (73) = 1.28, *p* = .21

[1]Orgogozo & Barthel Index: higher score = less impairment [2]NIH and Rankin: lower score = less impairment

Table 3.15: Clinical Differences between Passive Adherers and Non-Passive; χ^2 and *t*-test results

Following analyses of the psychological variables (table 3.16) there were no differences between Passive and Non- Passive Adherers except for patients Desire for the Workbook; patients who desired the workbook prior to receiving it were more likely to retain it at the end of the intervention.

PSYCHOLOGICAL MEASURES (n = 75)	MEAN SCORE (STANDARD DEVIATION)		*T*-TEST RESULTS
HADS	PASSIVE ADHERERS	NON-PASSIVE	
Mood	13.35 (9.40)	12.50 (8.98)	*t* (73) = -.37, *p* = .71
Anxiety	6.33 (5.14)	6.21 (5.92)	*t* (73) = -.09, *p* = .93
Depression	7.02 (4.91)	6.29 (3.99)	*t* (73) = -.63, *p* = .53
RLOC			
RLOC	34.88 (4.24)	34.58 (4.73)	*t* (73) = -.28, *p* = .74
WOC			
Active coping	40.76 (7.93)	39.54 (9.40)	*t* (73) = -.59, *p* = .56
Active cognitive	20.41 (4.29)	20.50 (5.31)	*t* (73) = .08, *p* = .94
Active behavioural	20.35 (4.67)	19.04 (5.39)	*t* (73) = -1.08, *p* = .28
Avoidant	11.29 (3.28)	11.38 (4.45)	*t* (73) = .09, *p* = .93
Problem focused	24.69 (6.14)	24.67 (6.40)	*t* (73) = -.01, *p* = .99
Emotion focused	31.27 (5.27)	30.63 (8.32)	*t* (31.97) = -.35, *p* = .73
DESIRE FOR WORKBOOK			
Desire	**4.35 (1.04)**	**3.57 (1.38)**	***t* (72) = -2.73 *p* = .01**
CONFIDENCE IN RECOVERY			
Confidence	7.37 (2.53)	7.83 (2.18)	*t* (73) = .77, *p* = .45

Table 3.16: Psychological Differences between Passive Adherers and Non-Passive; *t*-test results

In summary, 44% of patients did not passively adhere by retaining the stroke workbook. Of those who participated in the stroke workbook intervention passive adherence was more likely to be performed by women and if patients desired the workbook prior to seeing it.

Predictors of Passive Adherence

Correlational analysis between passive adherence and clinical, demographic and psychological variables was performed (Appendix B). Again using the variables with correlation probability of .20 or less an exploratory logistic regression was used to examine the contribution of each independent variable to the predictive model. Correlations where probability was less than .20 included gender(r = .23 p = .05*), affected side (r= -.21 p = .08^) and desire for the workbook (r = .31 p = .01**). These variables were entered into a logistic regression to examine the best predictor of passive adherence. The results of this regression analysis are shown in table 3.17.

VARIABLES ENTERED	B	S.E.	WALD	DF	SIG.	95% CI FOR EXP. (B)	
						LOWER	UPPER
Gender	-1.17	.62	3.52	1	.06	.92	1.05
Affected side	.49	.57	.74	1	.39	.53	5.01
Desire for the workbook	**.52**	**.23**	**5.26**	**1**	**.02**	**1.08**	**2.61**
Constant	-.73	1.03	.56	1	.46		

B = logistic coefficient; S.E. = standard error; WALD = Wald statistic; DF = degrees of freedom; SIG. = significance level; CI = confidence interval; EXP (B) = exponentiated coefficient.

Table 3.17: Logistic Regression Analysis of Passive Adherence Predictor Variables

A one variable model was produced where the -2LL value decreased from 90.21 to 77.66. The R^2 values ranged from .16 to .22. The Hosmer and Lemeshow χ^2 value showed a significant result indicating a poor overall model fit (χ^2 = 14.61, *df* 6, *p* = .02*).

These results suggest that having a strong desire for the workbook is predictive of keeping the workbook.

<u>Active Adherers versus Non-Adherers</u>

To further analyse these results patients who did not participate (n = 13) or were non-active (n = 25) were combined and named "Non-Adherers" (n = 38) and compared to the Active Adherers (n = 50). Using chi-square and *t*-tests, only one significant difference emerged between Active Adherers and Non-Adherers, which was gender (table 3.18).

DEMOGRAPHIC MEASURES (N = 88)	N	NUMBER		χ^2 RESULTS
		ACTIVE ADHERERS	NON-ADHERERS	
Gender: female **male**	**34** **54**	**24 (71%)** **26 (48%)**	**10 (29%)** **28 (52%)**	**χ^2 = 4.28 (*df 1*) *p* = .04**
Employment: retired Not retired	67 21	37 (55%) 13 (62%)	30 (45%) 8 (38%)	χ^2 = .29 (*df 1*) *p* = .59
Living: with carer without carer	55 33	28 (51%) 22 (67%)	27 (49%) 11 (33%)	χ^2 = 2.09 (*df 1*) *p* = .15
		MEAN SCORES (STANDARD DEVIATION)		*T*-TESTS
Mean age - years	88	68.22 (11.19)	69.84 (14.48)	*t* (86) = .59, *p* = .56
Depcat score: 1 – 7	88	3.70 (1.85)	3.80 (2.15)	*t* (86) = .21, *p* = .84

Table 3.18: Demographic Differences between Active Adherers and Non-Adherers; χ^2 & *t*-test results

Examining the clinical variables there were significant differences between the groups on the Rankin and NIH indicating that Active Adherers were less impaired than Non-Adherers (table 3.19).

CLINICAL MEASURES	N	NUMBERS		χ^2 RESULTS
		ACTIVE ADHERERS	NON-ADHERERS	
Affected side: left right	41 45	26 (63%) 22 (49%)	15 (37%) 23 (51%)	χ^2 = 1.83 (*df 1*) *p* = .18
Stroke event: first previous	71 17	43 (61%) 7 (41%)	28 (39%) 10 (59%)	χ^2 = 2.10 (*df 1*) *p* = .15
		MEAN SCORE (STANDARD DEVIATION)		T-TEST RESULTS
Orgogozo[1]	82	80.00 (20.39)	72.43 (20.33)	*t* (80) = -1.67, *p* = .10
NIH[2] (transformed)	**81**	**1.79 (1.03)**	**2.23 (.77)**	***t* (79) = 2.18, *p* = .03**
Modified Rankin[2]	**78**	**2.91 (1.30)**	**3.59 (1.05)**	***t* (76) = 2.50, *p* = .02**
Length of hospital stay	88	28.74 (40.27)	40.68 (45.76)	*t* (86) = 1.29, *p* = .20
Barthel Index[1] (transformed)	88	6556.42 (1968.03)	6156.84 (2190.34)	*t* (86) = -.90, *p* = .37

[1]Orgogozo & Barthel Index: higher score = less impairment [2]NIH and Rankin: lower score = less impairment

Table 3.19: Clinical Differences between Active Adherers and Non-Adherers; χ^2 & *t*-test results

There were no significant differences between Active Adherers and Non-Adherers in terms of their psychological variables (table 3.20).

PSYCHOLOGICAL MEASURES (n = 88)	MEAN SCORE (STANDARD DEVIATION)		*T*-TEST RESULTS
HADS	ACTIVE ADHERERS	NON-ADHERERS	
Mood	12.08 (8.90)	13.11 (8.95)	*t* (86) = .53, *p* = .60
Anxiety	5.64 (5.30)	5.94 (5.15)	*t* (86) = .27, *p* = .79
Depression	6.44 (4.40)	7.16 (4.81)	*t* (86) = .73, *p* = .47
RLOC			
RLOC	34.78 (4.30)	35.92 (4.61)	*t* (86) = 1.20, *p* = .24
WOC			
Active Coping	40.74 (7.66)	41.03 (9.01)	*t* (86) = .16, *p* = .87
Active cognitive	20.36 (4.37)	21.26 (4.77)	*t* (86) = .92, *p* = .36
Active behavioural	20.38 (4.55)	19.76 (5.29)	*t* (86)= -.59, *p* = .56
Avoidant	10.66 (3.41)	11.86 (3.48)	*t* (86) = 1.63, *p* = .11
Problem focused	24.88 (6.06)	25.05 (5.88)	*t* (86) = .13, *p* = .89
Emotion focused	30.36 (5.97)	32.24 (6.57)	*t* (86) = 1.40, *p* = .17
DESIRE FOR WORKBOOK			
Desire	4.16 (1.18)	3.89 (1.39)	*t* (86) = -.97, *p* = .34
CONFIDENCE IN RECOVERY			
Confidence	7.46 (2.53)	8.18 (2.12)	*t* (86) = 1.42, *p* = .16

Table 3.20: Psychological Differences between Active Adherers and Non-Adherers; *t*-test results

Predictors of Active Adherence

Correlational analysis between Active Adherers and clinical, demographic and psychological variables was performed (Appendix B). Again using the variables with correlation probability of .20 or less, an exploratory logistic regression was used to examine the contribution of each independent variable to the predictive model. Correlations where probability was less than .20 were entered into a logistic regression and included gender (*r* = .22, *p* = .02*), with carer (*r* = -.15, *p* = .15), first stroke (*r* = -.16, *p* = .15), affected side (*r* = -.15, *p* = .18), Rankin (*r* = -.28, *p* = .02*), Orgogozo(*r* = .18, *p* = .10), NIH (*r* = -.24, *p* = .03*), time in hospital (*r* = -.14, *p* = .10), confidence in recovery (*r* = -.15, *p* = .16), avoidant coping (*r* = -.17, *p* = .11) and emotional coping (*r* = -.15, *p* = .17) (table 3.21).

VARIABLES ENTERED	B	S.E.	WALD	DF	SIG.	95% CI FOR EXP. (B)	
						LOWER	UPPER
Gender	**-1.63**	**.68**	**5.72**	**1**	**.02**	**.05**	**.75**
With carer	.42	.65	.42	1	.52	.43	5.41
First stroke	.55	.76	.52	1	.47	.39	7.63
Affected side	.47	.67	.50	1	.48	.43	5.91
Orgogozo	-.02	.02	.43	1	.51	.94	1.03
Rankin	**-.78**	**.39**	**3.91**	**1**	**.05**	**.21**	**.99**
NIH (transformed)	.25	.54	.21	1	.64	.45	3.70
Time in hospital	-.01	.01	.55	1	.46	.97	1.01
Confidence in recovery	-.18	.14	1.82	1	.18	.64	1.08
Avoidant coping	-.11	.12	.86	1	.35	.71	1.13
Emotion focused coping	-.03	.07	.14	1	.70	.86	1.09
Constant	7.38	3.58	4.25	1	.04		

B = logistic coefficient; S.E. = standard error; WALD = Wald statistic; DF = degrees of freedom; SIG. = significance level; CI = confidence interval; EXP (B) = exponentiated coefficient.

Table 3.21: Logistic Regression Analysis of Active Adherence Predictor Variables

A two variable model was produced where the -2LL value decreased from 103.32 to 79.75. The R^2 values ranged from .27 to .36 and the Hosmer and Lemeshow χ^2 value showed a non-significant result indicating a good overall model fit (χ^2 = 8.86, *df* 7 p = .26).

These results suggest that being female and low impairment was predictive of active adherence versus non-adherence to the activities in the workbook.

Predictors of the Amount of Active Adherence

Using the score of “amount of active adherence”, where the score ranges from 0 – 7, the higher the score the greater activities completed, correlational analysis was performed and variables with probabilities of .20 were identified (Appendix B) and included, gender (r = .34 p = .00**), Rankin (r = -.26 p = .04*), Orgogozo (r = .21 p = .07^), NIH (r = -.18 p = .14), avoidant coping (r = -.21 p = .07^) and active behavioural coping (r = .15 p = .20) and anxiety (r = -.16 p = .19) (table 3.22).

	AAA	GENDER	ORGOGOZO	RANKIN	NIH	ACTIVE	AVOIDANT
Gender	**.34**						
Orgogozo	.22	-.09					
Rankin	**-.26**	.12	**-.74**				
NIH	-.18	.14	**-.75**	**.75**			
Active	.15	-.20	-.15	.02	**.26**		
Avoidant	-.21	-.07	-.02	.04	.07	.09	
Anxiety	-.16	.07	-.08	-.12	-.03	**-.32**	**.25**

AAA = amount active adherence

Table 3.22: Correlations between Amount of Active Adherence and Predictor Variables (probabilities less than or equal to .2)

Gender, Orgogozo and Rankin correlated significantly with amount of adherence. These variables, plus the non-significant correlations were entered into a multiple regression analysis to examine the best predictors of amounts of active adherence (table 3.23).

VARIABLES ENTERED	B	S.E.	β	t	SIG.
Gender	**2.10**	**.58**	**.41**	**3.61**	**.001**
Orgogozo	3.03^{-02}	.02	.25	1.3	.20
Rankin	-.46	.37	-.24	-1.25	.22
NIH	.26	.54	.10	.48	.63
Active behavioural	6.41^{-02}	.07	.12	.92	.36
Avoidant	-8.79^{-02}	.08	-.13	-1.15	.26
Anxiety	-5.26^{-02}	.06	-.11	-.91	.37

B = unstandardised coefficient; S.E. = standard error; β = standardised coeffiecient; t = t-test; SIG. = significance level.

Table 3.23: Multiple Regression Analysis between Predictor Variables with Probabilities of .20 and Amount of Active Adherence Predictor Variables

Altogether 30% of the variability in overall adherence was predicted by gender (table 3.24) and no other variable entered the equation.

	R	R^2	ADJUSTED R^2	S.E.E.	CHANGE				
					R^2change	F change	df1	df2	Sig. F change
Model	**.55**	**.30**	**.22**	**2.20**	**.30**	**3.61**	**7**	**58**	**.003**

S.E.E = standard error of the estimate, df = degrees of freedom; Sig. = significance level.

Table 3.24: Multiple Regression Analysis Summary Model of Amount of Active Adherence

In summary these results suggest that women are more likely to perform more activities suggested by the workbook, i.e. they are more likely to actively adhere to the interventions recommendations.

POST-HOC QUESTION; Are the more impaired less likely to actively adhere to the workbook?

To examine this in more detail and to include the Non-participators the data from 91 patients was divided into 3 groups (no activities were recorded for 3 patients) (table 3.25).

	NON ADHERENCE	PASSIVE ONLY	ACTIVE & PASSIVE	TOTAL
Workbook	27 (inc 13 non-participators)	11	50	88

Table 3.25: Numbers of Patients in Adherence Categories for Workbook

Modified Rankin scores were divided into low and high impairment. Those scoring 1-3 were classified as low impairment (n = 37) and those scoring 4-5 as high impairment (n = 41). (13 cases of data were missing, 10 Modified Rankin scores and 3 adherences scores). When illustrated (figure 3.1), non-adherence appeared to be greater in the patients with the greater impairment.

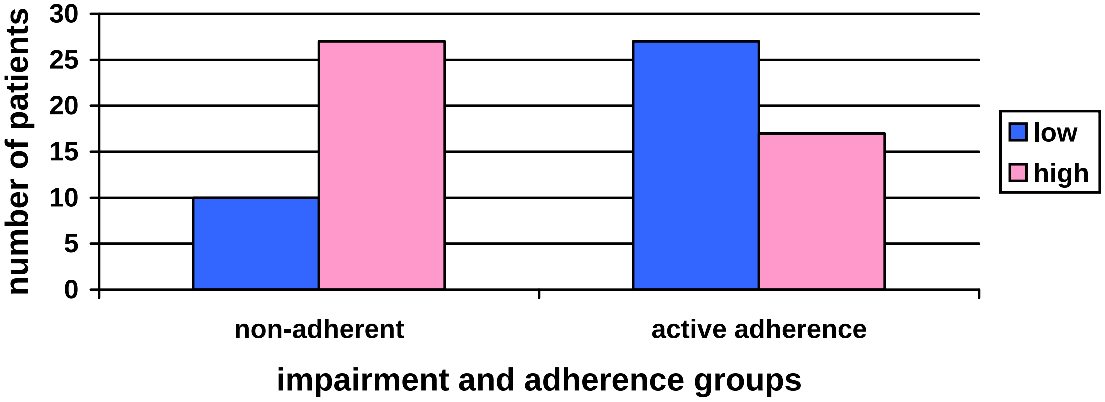


Figure 3.1: Non-Adherent and Active Adherent Patients with High and Low Impairment

Statistical analysis showed that impairment is significantly associated with non-adherence to activities in the stroke workbook (table 3.26).

IMPAIRMENT	COUNT	NON-ADHERENCE (inc passive)	ADHERENT (active)	CHI	*p*
Low	Observed Expected % within impairment	10 16.1 27%	27 20.9 73%	**7.85 (*df* = 1)**	**.01**
High	Observed Expected % within impairment	24 17.9 58%	17 23.1 42%		

Table 3.26: Differences between Non-Adherent and Active Adherent Patients: χ^2 results

In summary, non-participating patients appeared to have higher perceived control, were less anxious and expressed more confidence about their recovery in comparison to participating patients, with high-perceived control accounting for the variance explained. Of those who participated in the stroke workbook intervention women were more likely to actively and passively adhere. Those who were less impaired and used less avoidant methods of coping were more likely to actively adhere and those desiring the intervention prior to seeing it more likely to passively adhere. However being female and less impaired accounted for the variance explained for active adherence and desiring the intervention accounted for the variance explained for passive adherence. Impairment was further examined in a post-hoc analysis including the patients who did not participate and suggesting that non-active adherence may be associated with impairment.

DISCUSSION

This study has possibly demonstrated that the predictors of participation in this intervention are different to those predicting adherence to the intervention activities in those who participate. Furthermore adherence does not appear to be a single behaviour and has active and passive components. This suggests that participation and adherence comprise of different behaviours.

The results of the analysis for the first research question examining the demographic, clinical and psychological factors predicting participation in the stroke workbook intervention has shown that patients who participate to do not differ in terms of demographic or clinical factors. Although living with a carer did not significantly differ between the two groups there was a trend to suggest that patients living without a carer were more likely to participate in the intervention. The presence of a carer is known to influence patients' recovery (Culos-Reed et al 2000) and this trend indicates a possible avenue for future investigation in this area.

Psychological factors do appear to differ in patients who did and did not participate in the workbook intervention. Patients who did not participate had significantly less anxiety, higher perceived control and expressed more confidence about their recovery in comparison to the patients who did participate in the workbook intervention. The patient's emotional representation of their stroke operationalised through the anxiety measure of the HADS was related to participation, patients who were low in anxiety were less likely to participate. Conversely, patients who had greater anxiety were more likely to participate in the workbook. Participating in the workbook may be seen as a form of coping to reduce the anxiety.

According to the SRM patients' illness representation of control (RLOC) and consequence as measured by the confidence in recovery variable appeared to be influential in the patient's decision to participate in the intervention and to withdraw from it. Patients who felt that they were in control of their recovery and who expected less serious consequences from the stroke did not feel the need to participate in a potentially effective workbook intervention, i.e their representations about their illness shaped their coping procedures not to participate and use the workbook or to take part in doing some thing that was aimed at improving their recovery. On further analysis, anxiety and confidence in recovery were not the best predictors of participation but having a high-perceived control was accounting for between 23 – 42% of the variance. Patients were less likely to participate in the workbook intervention if they had greater perceptions of control over their recovery. This may be further supported by the non-significant trend on the Barthel Index score indicating that the Non-Participators had less functional limitation than the Participators perhaps explaining why their illness representations indicated less seriousness and they did not feel the workbook was necessary for their recovery. Anecdotally, during the intervention period a proportion of the patients who expressed that they did not feel that they had been too badly affected went on to say that they thought other people who had been more badly affected might benefit more from the workbook i.e. they gave it back for someone else to use.

In order to predict adherence a measure was developed which consisted of two factors; active adherence, which included activities that the patients would have to do physically and mentally, and passive adherence where the patient chose to keep the workbook. The patients in this study could adhere passively by keeping the workbook without doing the activities, adhere actively by doing the activities but not keep the workbook or do both therefore one patient could perform both types of adherence. This supports the observations of other researchers of adherence not being an all or nothing concept (Vitolins et al 2000).

Whilst participation was not predicted by demographic and clinical factors, adherence to the workbook was. Patients who actively adhered to the behavioural activities differed from those who did not actively adhere in that they were more likely to be female, less impaired and use less avoidant methods of coping with gender and impairment accounting for the most variance. Gender and desire for the workbook were associated with passive adherence with desire for the workbook accounting for the variance explained.

Gender was associated with both active and passive adherence, with women performing both behaviours more than men. Active adherence was defined as patients doing some kind of the activity in the workbook, whether it was one activity or all the activities. When the *amount* of adherence was examined again adherence was predicted by being female. Active adherence was not associated with illness beliefs directly but possibly beliefs about being female, lending support to Martin and Suls (2003) who showed that interpretation of symptoms of cardiac disease and coping was related to gender. Furthermore women are more likely to resume domestic activities quicker than men following a myocardial infarction (Martin and Suls 2003). Do women take “time out” of their chores to read a magazine or do a crossword? Doing the activities in the workbook in the home may have been more amenable to women as it fitted into their “normal routine”. Men traditionally go out to work therefore going out to attend cardiac rehabilitation may be more amenable to them. In the studies examining attendance to cardiac rehabilitation, Whitmarsh et al (2003), Cooper et al (1999) and Petrie et al (1996) all showed that being male, perceiving less consequences and having less control predicted attendance to cardiac rehabilitation. Whilst gender was not predictive of participation in the workbook, lower confidence (consequence) and lower perceived control were predictive. Patient’s who were confident in their recovery, had greater perceived control and less anxiety declined the workbook or withdrew from the intervention, adding support to the findings in the above mentioned cardiac rehabilitation studies.

Maybe people could not actively adhere because they were impaired? The intervention appeared to be more amenable to people with less impairment suggesting that an easier intervention may increase adherence for those with more impairment (anecdotally some patients felt that the intervention was too hard). The clinical measures all appeared consistently to show that patient with less impairment were more likely to actively adhere to the workbook activities although only the NIH and the Modified Rankin show statistically significant differences between active adherers and non-active. Length of stay in hospital did not significantly differ between the two groups but there was a trend toward fewer days in hospital for the Active Adherers. Patients with less impairment and less hospitalisation may have actively adhered because they had the “physical energy/ability” because they have not been so badly affected. Lincoln et al (1999) examined the benefit of additional physiotherapy and found that up to 44% patients did complete the additional physiotherapy intervention. Fang et al (2003) found further similar observations in their study where 28 of 78 patients could not tolerate the extra physiotherapy. They suggested in their discussion that the 28 were more severely affected by their stroke but did not demonstrate this in their results section. Lincoln et al (1999) concluded that levels of impairment were an issue for adherence to the physiotherapy interventions.

Active Adherers scored lower on the WOC subscale of avoidant coping, suggesting that non-avoidant coping is more likely to be associated with active adherence (p = .03*). One tentatively suggests that patients who consider themselves using non-avoidant strategies would be more inclined to actively adhere to activities designed to promote recovery. This result needs to be interpreted with caution because the internal reliability of this subscale was very low (α = .38). This finding may be worth exploring in the future as avoidant coping may be shaped not only by patients' illness representations but also by their impairment.

The results suggest that patients are more likely to adhere passively if they desired the workbook prior to seeing it. Anecdotally patients asked to keep the workbook because they felt "it will come in useful". Some patients therefore may have intended to do the activities. Furthermore patients may not have written in the workbook but they may have been in the process of thinking about the activities or discussed some of the activities with others. Although patients were not asked about their intentions to do the activities in the stroke workbook, statistically there was a significant association between active and passive adherence (Appendix B), suggesting that the more likely the patient was to keep the workbook the more likely they would adhere to the activities.

Desiring the workbook intervention may have been shaped by the patient's beliefs about it. Patients did not know exactly what the workbook entailed before they received it. This may account for non-participation and non-adherence to the intervention; the intervention was not what the patients expected and therefore they did not perceive it to be appropriate to themselves and their recovery.

The desire for the workbook may be defined as taking control for Passive Adherers, by keeping something that would help in the future but also a form of coping in that holding onto to something for future use may make the patients feel as though they were doing something to help themselves.

Women were also more likely to passively adhere by keeping the workbook, which again may have been influenced by beliefs about being a woman but also about by beliefs about the workbook measured by desire for the workbook. The SRM characterises the individual as an "active problem solver" which suggests that not only do they develop beliefs about their illness but they could also develop beliefs about the treatments that would be helpful or not helpful to them (Leventhal 2004). If people believe the intervention to be beneficial and necessary for their recovery then are they more likely to adhere to them. Horne (1997) has examined adherence to medication and has shown that patients form beliefs about medication. He has shown that patients develop beliefs about the "necessity and efficacy of medicines" (Horne 1997).

These findings are difficult to compare to other interventions carried out in the home, as the measures of "loss to follow up" were ill defined in the previous studies. Furthermore the previous studies examined and reported outcome in terms of functional ability, mood and satisfaction and not predictors of these outcomes. However 14% of patients in the stroke workbook did not participate, they withdrew during the study which falls in the range of loss to follow up (3 – 20%) in the studies by Bautz-Holter et al (2002), Roderick, et al (2000), Kalra et al (2000), Mant et al (1999), Rudd, et al (1997). In the studies that reported that the patients refused to continue (Lincoln et al 2003, Mayo et al 2000, Forster and Young 1998, Widen-Holmquist et al 1997) there range was 1-7%, which was less than the stroke workbook study. This may be accounted for by these studies offered either a support worker, addressing the patient's issues (Lincoln et al 2003, Forster and Young 1998) or patients were in an early discharge scheme with services being supplied in the home (Mayo et al 2000, Widen-Holmquist et al 1997). In these studies patients were given the intervention with no record of their own role in the intervention, the patients did not appear to have to do anything for themselves whereas the workbook intervention required patients to actively involve themselves in their recovery. One could assume that these patients were passively adhering to the interventions and the interventions were easy because the patients did not have to do anything for themselves. The stroke workbook intervention may have been perceived as a difficult intervention and this may have been the reason for a higher percentage of patients not continuing with it compared to the other studies reviewed in Chapter 1.

The main limitations of this study were related to the measures used. The SWOT study was carried out to evaluate the efficacy of a stroke workbook intervention not to assess adherence to it. This highlighted the difficulty of measuring adherence to the activities and relating measures designed to measure outcome to understanding participation and adherence.

In this interpretation of participation in, and adherence to a workbook intervention as a type of coping strategy, measures were used whose internal reliability had Cronbach's alphas lower than .60. Hair et al (1998), suggest that the items in measures where the Cronbach's alpha is lower than .60 uses items that do not measure the same conceptual domain. The RLOC had an alpha of α .57 which is very nearly .60 and therefore been deemed an adequate measure of internal reliability although this should be considered when interpreting the results. The Ways of Coping Questionnaire (Billings and Moos 1981) showed low alphas in active-cognitive coping (α .50) and active-behavioural (α .55), but when used as a scale of active coping the alpha increased to .69. Avoidant coping and emotion -focused coping subscales had alphas of .38 and .49 respectively. In the measures with low Cronbach's Alphas namely the Ways of Coping Questionnaire (Billings and Moos (1981) items were dropped in a bid to improve their internal reliability but this did not improve any of the alphas. These results could be interpreted in several ways. Firstly, patients may not have used any of these strategies when coping with stroke recovery. Secondly, the strategies may not have been adequately measured; stroke patients may need to different items to capture these coping strategies. Thirdly, it is also possible that this study simply lacked enough power to detect intervention effects, given that only large effects were most likely to be detected. Whether these results are due to the nature of the measures, the population or the power of the study is difficult to determine.

CONCLUSION

Through limited measures this study has attempted to answer the research questions and the SRM has helped to explain the findings but many of the constructs were not assessed. Furthermore the study has also raised the importance of defining the behaviour of participation and adherence. Patient participation in and adherence to interventions was not only made up of different behaviours but also appeared to be predicted by specific demographical, clinical and psychological variables. Active adherence appeared to be predicted by gender and impairment whilst passive adherence appeared to be predicted by gender and desire for the workbook. Does impairment impede active adherence? Will an easier intervention increase active adherence? Given the difficulty of measuring adherence in the present study and the complexity of the workbook intervention a more simple intervention may offer a clearer measure of adherence and potentially increase adherence, as the demands on the patient will not be so great. This may further the examination of non-adherence and how it can be reduced.

CHAPTER 4

AN EASIER INTERVENTION: DOES IT INCREASE ADHERENCE?

SUMMARY

Background: Forty three percent of patients did not adhere to the activities in the stroke workbook intervention, suggesting that they may have missed out on the benefits. Those patients who did not actively adhere appeared more impaired than those who did. Furthermore women were more likely to be actively and passively adherent to the workbook than men. To maximise the benefit of the stroke workbook intervention patients were required to be adherent to a number of behavioural activities to change the way they thought about their stroke. By offering a simpler intervention, such as a video, adherence could possibly be increased and potential benefits be derived in patients with greater impairment.

Aim: To investigate the demographic, clinical and psychological factors that predict adherence to an easier intervention and compare these with the predictors of adherence to the stroke workbook intervention (as found in Chapter 3).

Procedure: Stroke patients (n = 57) were sent a video pack through the post. Prior to its receipt demographic and clinical variables (affected side, stroke event and measures of impairment) were recorded on admission to hospital following the stroke. The psychological predictors included the same measures as used in SWOT (RLOC, confidence in recovery, desire for the workbook HADS, WOC) and the IPQ-R to further examine the illness representations of the SRM. These measures were recorded prior to receipt of the video.

Patients were classified as adherent, if they remained in the intervention for the 5-week duration and had attempted to watch at least one of the videos. A range of other performance measures was taken to examine the patient’s adherence behaviour.

Results: Significantly more patients participated in the video intervention than the workbook study. Demographic and psychological variables of male gender and desire for the intervention

were predictive of video adherence. When comparing the adherence to the stroke workbook and the video intervention greater adherence appeared to occur in the video group.

Discussion: More patients appeared to adhere to the video than the stroke workbook suggesting that an easier intervention increases adherence. Furthermore patients with greater impairment were more likely to adhere to an easier intervention. However, women had significantly higher impairment in the video group than the men and the women in the stroke workbook group. Men were more likely to watch the videos whereas women were more likely to actively and passively adhere to the workbook activities.

BACKGROUND

As demonstrated in chapter 3, 43% of patients in the stroke workbook intervention group chose not to actively adhere to the behavioural activities outlined in the workbook aimed at improving their recovery. In past research, non-adherence to medication, dietary and exercise interventions have revealed similar results. Dunbar-Jacob et al (1995) reported that 20 – 80% of patients do not adhere to medical prescription potentially failing to benefit. Glanz (1979) showed that adherence to low fat diets range from 13% to 76% and Carmody et al (1980) suggest that 50% of patients are likely to drop out of an exercise programme within 3-6 months of starting it. Cardiac rehabilitation, which has similarities to the stroke workbook in that it promotes medication adherence, exercise and healthy diet plus emotional and medical perspectives has also been poorly attended. Petrie et al (1996) found that only a third of eligible cardiac patients less than 65 years of age attended for rehabilitation and furthermore Rodgers et al (1998) in their specialised educational programme for stroke survivors found that only 41% attended.

There are a number of possible reasons why patients do not participate in activities to promote recovery. Heijmans (1999) suggested patients with a similar medical condition not only experience it differently but also will respond to their treatment differently (Weinman 1996). Little is known about how patients make decisions or prefer one method of treatment to another. As shown in chapter 3, psychological characteristics are different for patients who participated in and those who did not participate in the stroke workbook intervention. Patients who adhered to the workbook differed demographically, clinically and psychologically from those who did not adhere. It is possible that there was an age cohort effect. Patients (of 60-70 years of age) may have found adhering to the intervention too difficult because they were not familiar with goal setting or taking an active role in their recovery (West et al 2003). However, the results of the stroke workbook study showed no significant difference in the ages of the people who participated and those who did not. This supports the findings reviewed by Anderson et al (2000).

Patients with more impairment were less likely to adhere to the activities. A person’s ability to perform a behaviour, e.g. to do the activities in the workbook can be characterised by their perception of how difficult or easy it is to carry out those activities. Perceived difficulty, in the literature is more commonly associated with the Theory of Planned Behaviour (Azjen 1991) in relation to the perception of perceived behavioural control (PBC). Within the SRM perceived control over one’s illness is conceptualised as one of the five domains shaping the beliefs about an illness. If the patient experienced greater impairment and they perceived that impairment as being a greater consequence, the stroke workbook might have appeared too difficult for them to achieve. This may lead to them feeling less control over their illness and therefore use alternative strategies to maximise their perceptions of control, for example, keeping the workbook without doing the activities. Control beliefs are associated with the performance of a variety of health preventative behaviours (Lau and Hartman 1983). Attendance to the education programme in Rodgers et al study (1998) may have reduced due to the level of impairment the cardiac patients experienced. Patients in the stroke workbook study were more likely to adhere to the activities if they were less impaired. This suggests that less burden may enable the more impaired to adhere.

Impairment may have affected the patient’s ability to spend the time needed to think and perform the behavioural activities. The characteristics of the workbook recommendations, the complexity of the recommendations, the duration of the intervention and the degree of behavioural change required could all be used to describe the difficulties the patients encountered when trying to adhere to the activities in the workbook. Patients were required to perform what might be described as complex tasks, requiring thinking, time, and subsequent behaviour change. Gregory and Fried (2003) looked at task performance ease and showed that indeed if patients found the task too difficult they would not continue. In a cross sectional study, Gregory and Fried (2003) asked older adults about the difficulties they had with daily activities of living. They showed that patients related difficulties to modifying their behaviour because of their physical difficulties and the time the task takes to perform. It is interesting to note that whilst patient non-adherence is a problem for health professionals, interventions designed for health professionals to enhance the implementation of evidence-based practice have also been non-adhered by the health professionals, one of the reasons given being the difficulty of changing existing practice (van Bokhoven et al 2003).

This present study aims to examine the predictors of participation in and adherence to an easier intervention. There appears to be little in the current literature about intervention ease. Meichenbaum and Turk (1987) stated “the more complex the demands of the treatment, the poorer the rates of adherence”. This was also supported by an article by Ley (1997) who also highlighted the more simple the schedule and shorter the duration the greater the compliance. This was refuted by Leventhal (1984) who suggested, “Non-compliance is nearly as likely for simple as for complex preventative actions and prescribed treatments”. Meichenbaum and Turk (1987) reviewed treatment variables related to non-adherence. Whilst these variables lend themselves better to medical treatment such as medication and surgery some of them could be applied to the workbook intervention and included; poor reputation of treatment facility, inadequate supervision by professional, expenses incurred, characteristics of treatment recommendations, complexity of treatment regimen, duration of treatment, degree of behavioural change required, inconvenience, characteristics of the treatment, e.g. surgery, tablets, injections, and side effects. In response to these variables the stroke workbook intervention was derived from psychological research and implemented by researchers in psychology, which may have been off putting to the patients who participated. However the non-adherence phenomenon occurs in all types of clinical research not just those run by psychologists. As regards professional supervision the stroke workbook was given out by an implementer who had no pressing time constraints and who maintained contact with the patients over a five-week period. She was also readily available should the patient require any further help. There was no expense incurred by the patients as the implementer came out to the home and therefore little inconvenience about having to get to a different venue. Rodgers et al (1998) experienced a low attendance rate for their in-hospital educational programme improving stroke recovery. This may have been due to the difficulties the patient had to overcome getting to the actual venue.

In relation to the workbook patients may have intended to do the workbook activities but their attitudes changed when they looked through it because they felt they did not have the ability to perform what was being asked of them. Also the carers may have felt the workbook was too much to do after such a health event (the stroke) and encouraged the patient not to do it. The presence of a carer tended to be associated with participation (p = .08^) in the stroke workbook intervention but was not associated with adherence.

The patients may not have been encouraged to do the workbook through messages from the health professionals. Anecdotally a number of patients were told that most recovery occurs in the first three months. The patients went onto assume that no more recovery would occur after three months. The patients may have not performed the workbook activities because they did not feel that they would benefit. Do messages like this affect the patient’s perceptions of control or their perceptions about their impairment? This idea was not reflected in the results looking at participation in the workbook trial in that patients who withdrew had higher levels of internal locus of control as measured by the RLOC than the patients who participated fully. Patients were given the workbook with the instructions that they should work through it at their own pace therefore patients may have intended to do the activities but did not manage to do them in the 5 week intervention period and therefore their non-adherence may have been unintentional. Patients who signed up to taking part in the studies knew that they would be required to perform some type of behaviour and possibly intended to do it but it in reality did not because the intervention was different to what they expected, it may have appeared to have been more difficult than they realised. Furthermore, some patients may have signed up to do it because it was expected of them and when faced with the intervention were unconfident about actively involving themselves (intentional non-adherence).

In this situation the patient would be seen by the SRM to need to regulate the incongruity of their cognitions and possibly do something as a compromise as Sherman et al (2000) suggests in relation to dietary non-adherence, “when faced with complex decisions patients will simplify the choice process to make the behaviour more manageable” such as passive adherence in the stroke workbook intervention or not do it at all rather than adhere to the activities proposed.

It is not the objective problem the SRM describes e.g. the impairment it self (or potentially the workbook) but the individual’s cognitive representation of the objective problem, e.g. the perceived control of the impairment (or the perceived ability to perform the workbook activities). The SRM implies that patients assess their illness individually through illness and emotional representations, subsequently shaping their coping mechanisms and therefore the selection of a coping procedure i.e. whether to do the workbook or not is determined by the patient’s beliefs. Leventhal et al (1992) have shown that if patients identified symptoms then they would be more likely to be compliant with their treatment. However if the treatment did not appear to have any effect over time or their symptoms were reduced then their compliance would diminish. Furthermore if patients believed their own behaviour was the cause of their illness then they were more likely to be involved with preventing further illness by changing their own behaviour (Lau and Hartman 1983).

Within the SRM, adhering to the workbook may be seen as a coping procedure. Theoretically this coping procedure has been shaped by the patient’s representations of the illness but it may also be shaped by the representations of the intervention (Leventhal 2004). Becker and Maiman (1975) posited that patients follow medical advice or prescriptions based on the perceived benefits, e.g. how much a medication or health advice could disrupt their routine or have harmful side effects. Their work has been further supported by Horne et al (2003) who have shown that patients’ beliefs about medication will influence whether they will adhere to their prescribed regime. If patients have beliefs about medication one could assume that they have beliefs about a non-medical intervention. Patients may have perceived the workbook as being too hard in terms of its style, the time it takes to understand what is required, the inconvenience of performing the activities, or the patients having to modify their ways of thinking about helping their recovery. It may have been perceived as difficult because the intervention did not appear to produce obvious quick results or the patients’ control was being taken away from them because they were not used to being told to be actively involved with their recovery. These factors may all have an effect on adherence to the stroke workbook. Furthermore the information contained in the workbook may have been emotive to the individual, which also may have prevented patients from adhering.

Within health services today patients are generally encouraged to take an active role in their health care with the provision of more information and access to support groups. The Health Education Board for Scotland in conjunction with the Chest Heart and Stroke Foundation have produced leaflets and actively promote self-help groups. Together, they developed a video-pack specifically designed to share stroke survivors’ experiences with others. The video was not theoretically designed nor did it require the patients to make changes in their behaviour and record them as they were advised in the stroke workbook intervention. The workbook intervention spanned 5 weeks with a specified number of requirements to be fulfilled incurring active and passive adherence. An easier intervention such as just watching a video incurs both active and passive adherence, i.e. patients have to open the package and put the video into the machine, press buttons, watch it, remove it and put it back in its packaging for the implementer to collect.

By offering a simpler intervention, such as a video, adherence could possibly be increased and be more amenable to patients with impairment. Watching a video, would take less time and effort than the stroke workbook and would be a more familiar type of behaviour to perform, i.e. watching videos is more common than doing self-management interventions. The information in the video may be seen as more acceptable in that the people in the video are themselves stroke survivors and are relating their experiences and not advising patients what to do.

As demonstrated in chapter 3, adherence to the stroke workbook was difficult to measure possibly due to its complexity. A more simple intervention such as a video may allow adherence to be more straightforward to measure. Adherence to the video intervention can be measured subjectively by asking the patients if they had watched it. It can also be measured objectively as in SWOT by observing the usage of the videotapes. Additionally, one could postulate that those who have watched the videos will be able to recognise simple aspects of the footage that can be assessed such as, familiar characters, colours of accompanying booklets.

The purpose of the present study is to test an easier intervention (the video) to see if adherence is increased and whether the predictors of adherence are similar to those found for a complex (the stroke workbook) intervention.

AIMS

- To develop a measure of adherence in the video intervention
- To compare adherence to the video with the stroke workbook
- To compare predictors of adherence to the video with the stroke workbook.

RESEARCH QUESTIONS

1. Does an easier intervention increase adherence?
    a. Is this particularly so for impaired patients?
2. What demographic, clinical and psychological factors predict adherence to an easier intervention?
3. Are the factors that predict adherence to an easier intervention the same or different from the factors that predict adherence to a complex intervention?

METHODOLOGY°

DESIGN

This was a longitudinal predictive study, involving the video intervention group of a RCT 2 x 2 trial testing two interventions, a video and letter; “Following a Stroke Trial” (FAST). This trial is more comprehensively described in chapter 5. The present chapter describes the predictive study of patients in the video groups and is known as the Video Study. Stroke patients were randomly allocated to one of four conditions; condition 1, where the participants received the video pack; condition 2, where the participants received a theoretically derived letter; condition 3, participants received both the video and the theoretical letter and condition 4, received no intervention at all. Demographic, clinical and psychological predictors were assessed prior to random allocation to groups two weeks following discharge to home. The data from patients in conditions 1 and 3 were used to answer the present research questions.

Participants

A sequential cohort of stroke patients from a geographically defined area, admitted to Ninewells Hospital, Dundee between September 2002 and June 2003 were invited to take part in the FAST study, a predictive, longitudinal, RCT, to evaluate two simpler interventions. (For a full

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° A summary of the precise contribution of the author to the design of the study and data collection can be found in Appendix E description of patient recruitment status, see Chapter 5, figure 5.1). Patients who were defined as ineligible were those with communication difficulties i.e. deafness, blindness, verbal communication deficits or cognitive deficits. Patients who were unwell, had co-morbidity of a terminal illness, or were to be discharged to nursing home or another hospital for continuing care were excluded. One hundred and sixteen patients were eligible and consented to take part. Patients randomised to the two video groups (n = 57) will only be used in this study (table 4.1).

	STUDY GROUP	
	FEMALE	MALE
Number	27	30
Mean age (standard deviation)	69.59 (12.06)	65.23 (10.02)

Table 4.1: Patients Randomly Allocated to the Video Study Group; gender numbers and ages.

RECRUITMENT PROCEDURE

All non-elective acute medical patients in the Tayside/North Fife area are admitted to Ninewells medical admissions ward via Accident & Emergency or by the patient's general practitioner. On arrival to the ward the patient's name, identifier number and provisional diagnosis are entered by the nurses, onto the ward's daily admission sheets. The doctor on call for medical admissions assesses the patient and refers the patient to the appropriate speciality. All those patients provisionally diagnosed as having a stroke or TIA are assessed clinically and appropriate tests carried out to confirm actual diagnosis and future care. If a confirmed diagnosis is reached whilst the patient is in the admitting ward, this is entered onto the daily admission sheet with the patient's outcome, i.e. whether the patient is discharged or the ward to which the patient is transferred. In situations where the patient's diagnosis cannot be confirmed the patient is transferred to another ward to continue the investigations and the daily admission sheet confirmed diagnosis section is left empty.

For this study the daily admission sheets were observed from September 1st 2002 to June 30th 2003 to identify any patient with a potential stroke. Where the following terms were used to describe the patient on these admission sheets, these patients were followed up to establish their final diagnosis:

? CVA Left/right hemiparesis
Left/right occipital infarct
Extension of CVA

Collapse with atrial fibrillation
Intra-cerebral bleed
Cerebellar signs

? Space occupying lesion
? Stroke
Dysphasia
? CNS pathology
Left or right sided weakness in the body,
Cerebellar syndrome
Left/right facial numbness
Slurred speech
Acute confusion
TIA

All the patients' diagnosis described as above were recorded and provided the basis of the patient group. The medical notes of these patients were checked to ascertain clinical diagnosis and CT scan requests. The clinical diagnosis of a stroke is taken from the Ad Hoc Committee Classification and Outline of Cerebrovascular Diseases II (1975) and has been summarised by MacWalter and Shirley (2002); the clinical definition being "any patient with a left or right sided weakness that does not resolve within 24 hours." All patient with a provisional diagnosis of stroke usually receive a CT scan. This is not to confirm diagnosis of a stroke but to exclude a haemorrhagic stroke, which will have a different medical treatment to an occlusive stroke, e.g. caused by an embolus, thrombus. The scan can sometimes indicate an occlusive stroke i.e. by reporting areas of attenuation, which can aid diagnosis but this is not always obvious therefore the stroke patient is diagnosed clinically. The CT scan results of the patient are looked up on the hospital computer system. The scan results state whether the patient has had a haemorrhagic stroke, areas of attenuation i.e. signs of an infarct. When there is a confirmed diagnosis of stroke, the patient is screened for the Ninewells stroke audit and this information was made available for this study (screening sheet in Appendix B).

Using the screening sheets all patients with an unresolved left or right weakness (a score of > 0 on the NIH, < 100 on the Orgogozo and > 0 on the Rankin) were invited to participate in this study. Patients with expressive and receptive aphasia were monitored by the principle researcher (SAJ) for improvement and invited to participate when they could communicate effectively.

MATERIALS

THE VIDEO INTERVENTION PACK

The HEBS Stroke Recovery Video pack, “Stroke Matters”: This included two videos and two booklets, which were made by the Health Education Board for Scotland in collaboration with the Chest Heart and Stroke Foundation (Scotland) for stroke survivors. The first video was called “Making Sense of Stoke” which was introduced by a T.V. personality who presents the rationale behind the videos. He is seen interviewing a medical doctor who describes what a stroke is and how it can affect the patient. From here 5 different stroke survivors are introduced to talk about their own experiences of stroke. A yellow booklet accompanied this video with supplementary information.

The second video was called “Facing the Future” which focused on the experiences of the survivors from the first video in relation to their recovery. The video highlighted the physical and emotional changes following a stroke, the role of physical activity, relaxation and the importance of being “positive”. This video also had an accompanying booklet (coloured orange), offering further information, support groups and a glossary.

The videos were modified to obtain an objective measure of adherence. The original HEBS videos were re-recorded and a two-minute introduction added to each video. Two individuals that were familiar to all the patients in the study performed these introductions: the Stroke Physician from Ninewells Hospital (Dr Ron MacWalter) introduced the first video and the principle researcher (SAJ) introduced the second video. The videotapes were given to the patients wound to the point of the beginning of the original footage, i.e. when the patient inserted the tape into the video player the tape would start to play from after the two-minute introductions. The patients would only see the two minute introductions if they rewound the tapes and watched them again. This provided two measures, firstly, evidence that the video had been played as it had been moved from the start point; and secondly, an opportunity to ask the patient who had introduced the videos to confirm whether the video had been watched more than once.

(For patients who did not have a video player a combined television and video player was available for them to use at home).

MEASURES

Cognitive Screening Measures

The cognitive screening measures used in this study were the same as for the SWOT study and have been described in chapter 3, Measures section. They include:

- Clifton Assessment Procedures for the Elderly (CAPE) (Pattie and Gilliard, 1981).
- Mental Status Questionnaire (MSQ) (Wilson and Brass, 1973).

Predictor Variables

Demographic and Clinical Predictors

All these measures were taken from the patients' screening sheets and have previously been described in chapter 3, Measures section. The additional measure of socio-economic group will be described after employment status. The DEPCAT scores for this study have updated and further described under the heading of DEPCAT scores. The demographic measures include:

- Gender
- Age
- Employment status
- The National Statistics Socio-economic Classification (NS-SEC) (A National Statistics Publication 2004) This scale is an occupationally based classification derived from the Registrar General Scale. It has eight classes ranging from 1; "higher managerial and professional occupations" to 8 "never worked and long term employment". The scaling has been applied to the occupations given by the patients (Appendix C).
- Presence of carer
- DEPCAT Scores (Carstairs and Morris 1992) The DEPCAT scores (McLoone 2000, Carstairs and Morris 1992), is a measure of deprivation of an area of residence. This score ranges from 1 (low) to 7 (high) indicating the level of deprivation for specific postcode areas. This was updated for the present study using the scores derived from the 1991 status. In the SWOT study the DEPCAT scores derived from the 1981 census data were used, as they were the most up to date for that time. The 1981 DEPCAT scores are not readily comparable to the scores derived from the 1991 census data because the definitions of the scores had changed (Mcloone 2000). Taking this into account the

DEPCAT scores from study 1 (Chapter 3) have been changed to the 1991 scores to enable comparison of the demographic predictors for the present analysis. To further support this change, the data from SWOT was collected between 1998 and 2000 and for FAST 2002 to 2003. There is a strong possibility that the people in SWOT completed the 1991 census forms therefore DEPCAT scores are derived from 1991 census should be more applicable to the SWOT.

- Affected side and stroke event
- Patient's length of stay in hospital.
- The Orgogozo Neurological Index (Orgogozo et al.1983).
- The NIH (National Institute of Health) Stroke Scale (Biller et al 1987).
- The Modified Rankin Scale (MRS) (Rankin, 1957).
- The Barthel Index (Mahoney and Barthel, 1965).

Psychological Predictors

All these measures have also been described in Chapter 3 apart from the IPQ – R (Moss-Morris et al 2002) and Desire for the Video. The psychological predictors include;

- Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).
- Recovery Locus of Control Scale (RLOC) (Partridge and Johnston 1989).
- The Ways of Coping Questionnaire (WOC) (Billings and Moos 1981).
- Confidence in Recovery (Morrison et al 2000).
- Desire for the Video This single item measure was specifically designed for this study and based on the "Desire for the workbook" measure by Bonetti (1999), which was designed for the SWOT study. This measure was predictive of adherence in the SWOT study and the word "workbook" has been replaced by "video" for the present study. The question asks the patients to rate how much they would like to receive the video (even though they did not know whether they would be receiving it prior to randomisation). Responses were on a 5-point Likert scale where patients had to rate their desire for the video from "definitely do not want it" (1) to "definitely do want it" (5).
- The Revised Illness Perception Questionnaire (IPQ-R) (Moss-Morris et al 2002) was designed to assess the respondent's illness and emotional representations as described in Leventhal's Self Regulation Model and has been developed from an earlier version, IPQ (Weinman et al 1996). The IPQ-R contains 3 sections. Section 1 addresses identity and presents the respondent with 14 items about symptoms a patient may experience. These

items require a response of yes or no. Section 2 has 39 items relating to the representations of time, consequence, control and emotion with additional items about patient's perceived understanding of their condition. Each statement requires a response of "strongly disagree" to "strongly agree" on a 5-point scale. Section 3 has 18 items relating to cause of stroke with the same 5-point scale asking the patient to say which causes they associate with their illness. It also gives the respondent an opportunity to express what they thought the most important three factors were that they thought caused their illness. The first part of section 3 has been analysed using a principle components analysis and is briefly described below. (For a more detailed analysis see chapter 5, results section). The original IPQ and IPQ-R have been widely used and validated by the authors using a number of illness groups (Moss-Morris et al 2002).

Scoring the IPQ-R

The third section measuring the illness representation of cause was subject to a principal components analysis with a varimax rotation (Moss-Morris et al 2002) to identify the item groupings. This was done for the total FAST study (n = 114) and is described in chapter 5 results section. The present study has used the same components that were identified for the FAST study. The four causal factors included "cause –psychological" where patients attributed factors such as stress as being contributory to their stroke. "Cause – controllable personal risk behaviour" attributed present behaviours such as diet and alcohol and "cause – uncontrollable personal risk behaviour" attributed past behaviours such as smoking, past medical care, accidents to the cause of their stroke. "Cause – external risk behaviour" refers to items relating to uncontrollable influences such as immunity, chance, ageing. The mean scores, standard deviations and internal reliability for the IPQ-R items used in the present study have been obtained from patients who received the videos (n = 57). There were two patients in this group who completed the old IPQ (Weinman et 1996) in the early stages of the study before the IPQ-R was available therefore their responses have not been included (n = 55) (table 4.9).

Dependent Variables

Adherence was measured by recording the 5 types of behavioural activities in the video pack. Adherence scores were derived from 3 sources, two self-report measures, two tested recall measures and one objective measure.

- Reported video adherence Patients were asked if they had watched the videos or not, scoring 2 for watching both, 1 for watching one and 0 for watching neither (maximum score = 2).

- Reported booklet adherence Patients were asked if they had looked through the accompanying booklets. Responses were scored 0 if they had looked through neither, 1 if had looked through one and 2 if had looked through both (maximum score = 2).

- Tested video adherence Patients were asked 5 simple multiple-choice questions about what they had seen on the videos. The questions were designed to test familiarity not to test the patients on the contents of the videos. For each question patients were given 5 choices. Each correct answer received a score of one and the total number of correct answers indicated a level of adherence (maximum score = 5).

- Tested booklet adherence Patients were asked to name the colours of the accompanying booklets. They were asked to choose from 5 possible colours If they recalled neither they scored 0, remembered one correctly, score 1 and if they recalled both correctly they scored 2 (maximum score = 2).

- Observed video adherence This measure was taken from the rewound status of the videos. The patient was asked to return the videos at the outcome interview (T2). The videos were observed for signs of being used, i.e. rewound, not rewound, partially rewound or not played at all. Not played at all was easily observed as the returned video tapes were not rewound to the beginning of the tape but to the point of the end of the added introduction by the Stroke Physician and the principle researcher. There were three possible scores, 0, both videos not used (both videos showing no signs of being played); score 1 if one video had been used (one video fully rewound or not rewound score), or score 2 if both videos had been used (two videos fully rewound or not rewound score) (maximum score = 2).

PROCEDURE

Ethical committee approval was sought and granted for the study. Stroke patients admitted to Ninewells hospital from September to June 2003 were identified and screened by the researcher and one of three junior doctors. This information allowed the opportunity to see which patients fulfilled the inclusion criteria. The eligible patients were approached on the wards, given an information sheet (Appendix C) and invited to participate in the current study. Patients who were discharged before they could be seen on the wards were invited to participate over the telephone or by letter (table 4.2).

	NUMBER	PERCENT
On ward	31	54.4
By telephone	21	36.8
By letter	5	8.8
Total	57	100.0

Table 4.2: Recruitment Method; number and percentage of patients

After consent (Appendix C) was obtained from the patients, demographic data, the total scores of the NIH, the Orgogozo and the Modified Rankin were recorded from the patient’s notes, as well as the stroke event and affected side of the body confirmed where possible by CT scan results. (Due to staffing problems some of the screening sheets were not completed at the time of the patient’s admission but recorded later using the patient’s notes. For a comprehensive description of this procedure see Chapter 5).

At the first home interview (T1) two weeks following discharge the patients were screened for cognitive and communication difficulties using the CAPE and MSQ to ensure that they were able to use the video and to answer questions on the subsequent measures, which included disability (Barthel Index), mood (HADS), perceived control (RLOC), coping (WOC), confidence in recovery and desire for the workbook. (For interview schedule including additional measures required for the FAST study see Appendix C). These measures were administered in a structured interview, by the researcher in the patient’s own home. If the patient did not pass the screening tests the measures were not administered. The duration of this interview lasted between 45 minutes to two hours, depending on the number and length of breaks requested in addition to the pre-scheduled break inserted in the middle of the questionnaire. Following this interview the patients’ General Practitioners (GP) were informed of their involvement in the FAST study (Appendix C)) and random allocation to the intervention groups was carried out by an independent statistician. Within 5 days following T1 patients were randomly allocated to the intervention or the control group by an independent researcher (DD), using the random allocation procedure developed by the independent statistician (BP).

The patients allocated to the video group were sent the video pack through the post with an appointment date for the second interview five weeks later and patients in the control group were just sent an appointment date for the second interview (T2) five weeks later. On the fourth week the independent researcher sent a letter to the patients in the video group asking them not to tell the interviewer who came to do the T2 interview about receiving the video until the researcher asked them.

At T2 the patients were asked the same set of questions as at T1. At the end of the interview they were asked if the had received a video through the post. If they said yes they were asked the subjective and tested adherence questions. Patients who did not want to continue with the intervention were allowed to withdraw at any time without giving any reason. Patients who died or became ill were withdrawn from the study. This study uses the data from those patients allocated to the intervention group who received the video pack.

RANDOMIZATION AND BLINDING

This section describes the randomisation and blinding procedure for the full FAST trial using a 2x2 design; the group of interest in this chapter are the patients who received the videos. Two researchers, the principle (SAJ) and an independent researcher (DD) plus statistician (BP) were involved in the randomisation and blinding procedure. Using random numbers (Spiegel 1972) the statistician allocated each patient’s study number to an experimental group, from 1 – 4, video only = 1, video and letter = 2, letter only = 3 and control = 4. The cohort of patient received sequential study numbers and each patient was allocated to the group, which corresponded to their study number.

The principle researcher (SAJ) recruited and interviewed the patients at T1 and T2. Following the interview at T1 the researcher advised the patient that they would receive an appointment for the second interview through the post but this could be rearranged if inconvenient. A contact telephone number was given. They were also told at this time that they may or may not receive a video and that if they did, they must not disclose this to the principle researcher until they were asked to at the next interview. The patients’ study number, address and telephone number were recorded in a book with the date of the first interview and the proposed date of the follow up interview at 6 weeks time. On a weekly basis this book was handed to an independent researcher

(DD) who made a copy of these details and returned the original book to the principal researcher to be used for the patients for the forthcoming week.

The independent researcher contacted the statistician weekly for the allocation to the experimental group for the patients who had completed the T1 interview. The appointment letters also asked the patient not to tell the researcher at the second interview if they had received a video pack or not. One week prior to the T2 interview, patients in the video groups received a letter signed by a medical consultant and a professor in Psychology, to remind them not tell the researcher at the next interview that they had received an intervention.

To ensure the effectiveness of the blinding the principle researcher (SAJ) recorded whether she thought the patient had received the letter or the video. As shown in table 4.3 blinding was 74 % effective. Thirteen percent of patients either told the researcher they had received the video or had left the videos out for the researcher to observe. Two patients (3%) patients withdrew from the study.

	FREQUENCY	PERCENT
Blinding maintained	42	74
Left video visible	7	12
Told of video	6	11
Withdrew	2	3
Total	57	100.0

Table 4.3: Effectiveness of the Blinding Procedure on the Principle Researcher

STATISTICAL ANALYSIS

The data were analysed using SPSS (Norusis 1993) computer program. Proof reading and descriptive function of SPSS allowed the accuracy of the database to be examined. All continuous variable values were checked to ensure the scores fell between the minimum and maximum range for each variable. Means and standard deviations were observed to ensure they were “plausible” (Tabachnick and Fidel 2001). Missing data was accounted by replacing with the group mean (Tabachnick and Fidel 2001). All the data was checked for skewness and kurtosis and transformed if present.

Exploratory principle components factor analysis with a varimax rotation and Cronbach’s alphas were performed on two sets of data; the data used to develop the measure of adherence and the data from the 3rd section of the IPQ-R (as per instructions from the authors) to ensure component loadings and subsequent construct validity and internal consistency of the measures.

To identify any group differences t-tests and ANOVA analyses were used for the continuous data and Chi square analysis for the dichotomous and nominal data. Fisher’s Exact results are reported where the cells in the Chi square analysis are less than 5 expected observations.

To examine relationships between the predictor variables and the outcome variables Pearson’s correlations were calculated for continuous data and point bi-serial analysis for the dichotomous data. Multiple and logistic regressions were performed on variables with correlations with probabilities of less than or equal to .2 to see which combination of variables was the best predictor of adherence.

RESULTS

Missing Data and Psychometrics

Missing data occurred with the clinical measures of NIH, Orgogozo and Rankin due to them not being recorded on the patient's notes or the notes being difficult to locate. Wherever possible every effort was made to track down the notes. If locating the notes was unsuccessful or the information was not recorded it was accepted that this data was missing and no methods of replacing the data was assumed. There was one case of missing data in the psychological measure, WOC and this was replaced by the group means. Apart from the Barthel Index, NIH and Orgogozo, all data appeared to be normally distributed with skewness all falling between ±1 (Hair et al 1997). The Barthel Index score was transformed by cubing the scores, the square route of NIH was calculated and the Orgogozo scored was squared to minimize the skewness and kurtosis of their distributions.

Post-hoc Power Analysis

A priori power analysis was performed using an ANOVA to calculate a large effect (.40) with an alpha of .05 for a 2x2 design a total of 118 patients will be required to achieve a power of .86. This was a requirement for Tayside Ethical Committee approval. A post-hoc analysis was performed and showed that the patient analyses (n = 114) had power = 0.98 to detect a large effect size (.35), power = 0.63 to detect a medium effect size (.15), power = 0.10 to detect a small effect size (.02). (F-test on means on regression analyses) at alpha=. 05 (Faul & Erdfelder 1992).

PARTICIPANTS

Fifty-seven patients were offered the video intervention with 14 patients reported not to have watched either of the videos. Of these 6 patients gave no reason for their behaviour. Two patients declined the videos prior to receiving them; one explained that his mother died of a stroke and watching the video may remind him of this; the other patient just said that she did not want them. Of the remaining 12, 6 patients gave no reason.

Two patients said they could not watch the videos because they had problems with their video player; one patient claimed that she could not put the videos into the video player because it was too low on the floor, although she lived with a partner who was able bodied: and the other said her video player had broken, she went on to say that she could have watched them at her friends but she decided not to. There were 2 patients without video players who did not have a player delivered to them: one because the independent researcher could not find the patient's house. The family reported that their mother was offered a video player but she declined to take them up on their offer. (This patient said she would not have watched it any way.) The other patient did not receive a player for clerical reasons but had had the opportunity to use her son's video player that was in his bedroom in the same house but again chose not to. These four patients had access to video players through their relatives but still did not watch them therefore they have been included in the Video Non-Adherers group.

One patient declined to continue with the study because she had felt that interview at T1 was "too tiring". The family could not find the videotapes when the principle researcher called to pick them up saying that she had put them away somewhere safe. The patient said she had not watched them and was therefore included in the video non-adherers group. Finally one patient was angry for not receiving a physiotherapy appointment from the hospital and had responded by not watching the video because he had not heard from the hospital.

REASONS FOR NOT WATCHING VIDEO	NUMBER OF PATIENTS
No reason	6
Declined prior to receiving video	2
Problems with access to video player	4
Interview too tiring	1
Patient upset for not receiving appointment	1

Table 4.4: Not Watching Videos; reasons for not watching and patient numbers

Patients who watched one or both videos (n = 43) were assigned to the "Video Adherers" group. Patients who did not watch the videos (n = 14) were assigned to the "Video Non-Adherers" group (table 4.5). These grouping are later confirmed to be correct in the following section "Developing a Measure of Adherence".

GROUPS	REPORTED AND OBSERVED VIDEO ADHERENCE	FEMALE	MALE	TOTAL
Video Adherers	Watched one or both videos	17	26	43
Video Non-Adherers	Watched neither videos	10	4	14

Table 4.5: Patient Adherence Groups; numbers and gender

Due to the nature of the interventions, participation in and adherence to the video intervention is definable but for it to be comparable to the workbook intervention has proved difficult. In the workbook study (Chapter 3) Participators were defined as those patients who completed the intervention without withdrawing (i.e. they had been seen at 3 visits and telephoned three times during the 5-week intervention) and Non-Participators those who did withdraw during the intervention. The workbook intervention required patients to receive visits as well as telephone calls as part of the intervention. Being receptive to the visits, telephone calls keeping the workbook and tape was included in participation. The patients in the video group were sent the video through the post and had no implementer involvement. Two patients withdrew from the video study and therefore may be defined as non-participating using the definition from the stroke workbook intervention. Comparing the data from these patients with the rest of the video intervention would be statistically inappropriate. Therefore it is not possible to compare participation and non-participation in the video study with the stroke workbook study.

The data that measured adherence included two self-report measures, if the patient had watched neither, one or both of the videos (reported video adherence) and if they had looked through neither, one or both of the accompanying booklets (reported booklet adherence). Two measures assessed the patient’s familiarity with the intervention: one recalling information from the videos (tested video adherence) and one recalling the colour of accompanying the booklets (tested booklet adherence). There was one objective measure of observed rewound status of the videotapes (observed adherence).

Reported video adherence and observed video adherence were perfectly correlated, i.e. all those who reported watching the videos returned the video/s used and rewound to the beginning or not rewound at all, whereas those who reported not watching the video returned the videos un-played and wound to the point at which it was delivered, i.e. the end of the added introduction.

Video adherence was defined as patients scoring 1 or more on the observed adherence measure and provided a dichotomous measure of adherence that could be used to compare stroke workbook adherence with video adherence. This measure is highly correlated with the other measures of adherence (table 4.6).

ADHERENCE	REPORTED BOOKLET	TESTED VIDEO	TESTED BOOKLET	OBSERVED	VIDEO ADHERENCE	AMOUNT OF VIDEO ADHERENCE
Reported video	**.65**	**.74**	**.56**	**1.00**	**.98**	**.86**
Reported booklet		**.56**	**.62**	**.65**	**.60**	**.78**
Tested video			**.64**	**.74**	**.74**	**.92**
Tested booklet				**.56**	**.57**	**.80**
Observed					**.98**	**.86**
Video adherence						**.84**

All significant at .001 level

Table 4.6: Correlations between Measures of Adherence to Video Activities

The "amount of video adherence" is the sum over all five measures of adherence, giving a possible range of 0 – 11. The validity of the amount of video adherence score was shown to be highly correlated with all measures of adherence. To check the construct validity observed video, booklet, tested video and booklet adherence were entered into an exploratory principle components analysis to examine the component structure. Reported video adherence and observed video adherence were perfectly correlated therefore reported adherence was not used in the analysis. Furthermore a principle components analysis requires a sample size of over 100 observations but according to Hair et al (1998) but 50 observations can be accepted The scree plot of factor variance indicated a one factor solution with an eigen value of 4.72 accounting for 79% of the variance with good internal consistency with a Cronbach's alphas of .82 (table 47).

	RANGE	MEAN (SD)	VIDEO ADHERENCE (4 VARIABLE) PRINCIPLE COMPONENTS ANALYSIS (PCA)
			Component 1 (α = .82)
Reported booklet adherence	0 - 2	1.07 (1.01)	.71
Tested video adherence	0 - 5	2.39 (1.86)	.97
Tested booklet adherence	0 - 2	0.86 (0.86)	.74
Observed video adherence	0 - 2	1.47 (.87)	.82

Table 4.7: Principle Components Analysis of Adherence Measures; range of scores, mean, standard deviation Cronbach's alphas and component loadings

In summary there are two measures of adherence to the video intervention: a dichotomous measure of "video adherence" and a continuous measure of the "amount of video adherence".

Descriptive Statistics

The internal consistencies of all the measures apart from the clinical measures were analysed using Cronbach's alpha and reported in tables 4.8 and 4.9.

MEASURES (n = 57)	CLASSIFICATION/MEAN	STANDARD DEVIATION (SD)	α
DEMOGRAPHIC			
Gender	Male n = 30	-----------	----
Employment	Retired n = 44	-----------	----
With carer	On own n = 16	-----------	----
Age	67.3	11.15	----
DEPCAT	3.93	1.62	----
CLINICAL			
Affected side	Left n = 27	----------	----
Stroke event	First n = 47	----------	----
Orgogozo (n= 48)	76.77	17.52	----
NIH (n= 48)	5.44	3.84	----
Rankin (n= 48)	2.75	1.19	----
Time in hospital	33.04	47.44	----
Barthel	17.68	2.94	.84
PSYCHOLOGICAL			
HADS - Mood	11.75	7.95	.87
Anxiety	5.61	4.45	.81
Depression	6.14	4.43	.82
RLOC	35.79	4.03	.71
WOC - active	41.12	8.86	.75
Active cognitive	19.96	4.44	.44
Active behavioural	21.16	5.39	.69
Avoidant	11.14	3.17	.21
Problem focused	24.61	6.29	.73
Emotion focused	30.89	4.92	.13
Desire for workbook	3.65	1.43	----
Confidence in Recovery	8.38	2.24	----
DEPENDANT VARIABLES			
Video adherence	Video adherers n = 43	----------	----
Amount of video adherence	5.77	3.95	.82

Table 4.8: Demographic, Clinical and Psychological Dependent Variables; response numbers, classification, means, standard deviations and Cronbach's alpha results

IPQ-R (n = 55)	MEAN	STANDARD DEVIATION (SD)	α
Identity	3.87	2.18	-----
Timeline - chronic	16.36	4.27	.80
Timeline - cyclic	10.53	2.79	.72
Consequence	20.71	3.63	.72
Control - personal	22.71	2.39	.62
Control treatment	19.07	1.81	.45
Illness coherence	14.98	4.25	.87
Emotional representation	17.65	4.62	.81
Cause - emotional	12.53	3.00	.69
Cause – health behaviour	10.36	2.63	.51
Cause – past events	9.64	2.19	.47
Cause – external influences	13.56	2.16	.48

Table 4.9: IPQ-R Scores; means, standard deviations and Cronbach's alpha results

The internal consistency for some of the sub-scales, in the Ways of Coping Questionnaire and IPQ-R are unacceptably low. These include Active Cognitive coping scale (.44), Avoidant coping scale (.21) and Emotion Focused coping scale (.13), plus the causal components of the IPQ-R. The scales of the WOC were examined by removing items to see if the internal consistency could be improved. However no improvement was achieved and therefore the reliability of these measures in subsequent analysis will be considered when reporting the results. The internal consistency of the IPQ-R causal component is further discussed in chapter 5 but will also be considered when reporting the results in the following sections.

RESEARCH QUESTION 1: Does an easier intervention increase adherence?

To ensure the stroke workbook (n = 91) and the video (n = 57) groups were comparable in terms of their demographic, clinical and psychological variables t-tests and chi square analysis were performed. There were no significant differences between the two groups (Appendix C). The data from 88 patients was used for the following analyses (adherence data for three patients was not collected).

Observing the adherence groupings there are 4 groups, non adherent (including non-participants) (n = 27), video adherent (n = 43) passive adherence only (n = 11) and passive and active adherence (n = 50) (table 4.10)

	NON ADHERENT	VIDEO ADHERENT	PASSIVE ONLY	ACTIVE & PASSIVE	TOTAL
Video	14 (2 = non-participant)	43			57
Workbook	27 (13 = non-participant)		11	50	88

Table 4.10: Numbers of Patients in Adherence Categories for Workbook and Video Interventions

The difference between video and workbook groups was assessed in three ways, first comparing non-participation in the interventions (table 4.11), secondly comparing non-adherence (non-active and non-participant patients) with intervention adherence (video, active and passive) (table 4.12) and thirdly comparing non-active adherence (non-active, non-participant and passive patients) with intervention active adherence (video and active) (table 4.13).

INTERVENTION	COUNT	NON-PARTICIPATION	PARTICIPATION	CHI	*p*
Video	Observed Expected % within intervention	2 5.8 4%	55 51.2 96%	**4.47 (*df* = 1)**	**.04**
Workbook	Observed Expected % within intervention	13 9.2 14%	78 81.8 86%		

Table 4.11: Differences between Non-Participant and Participant Patients; χ^2 results

When non-participators were compared with participators; more patients participated in the video intervention than the workbook intervention (table 4.11).

INTERVENTION	COUNT	NON-ADHERENCE	INTERVENTION ADHERENCE (video, passive, active)	CHI	*p*
Video	Observed Expected % within intervention	14 16.2 25%	43 40.9 75%	.64 (*df* = 1)	.42
Workbook	Observed Expected % within intervention	27 24.9 31%	61 63.1 69%		

Table 4.12: Differences between Non-Adherence and Intervention Adherence (passive, active and video watchers); χ^2 results

There was no significant difference in adherence between the two interventions when non-adherent patients were compared with intervention adherent patients. However when non-active adherent patients were compared to intervention active adherent patients there was a significant difference in adherence, with more patients actively adhering to the video than the workbook (table 4.13).

INTERVENTION	COUNT	NON-ACTIVE ADHERENCE (inc. passive)	INTERVENTION ACTIVE ADHERENCE (video &active)	CHI	*p*
Video	Observed Expected % within intervention	14 20.4 25%	43 36.6 75%	**5.21** **(*df* = 1)**	**.02**
Workbook	Observed Expected % within intervention	38 31.6 43%	50 56.4 57%		

Table 4.13: Differences between Non-Active Adherence (including passive adherence) and Intervention Active Adherence: χ^2 results

The measure of adherence used in the above analysis was quite a simple measure in that the patients only had to do one activity in the intervention to be defined as actively adherent, i.e. patients in the workbook group only had to write down one goal and only one video had to have been played. This measure of adherence therefore does not reflect the amount or the quality of adherence the patient performed. In an attempt to address this, the scores of adherence for each intervention were recorded (table 4.14) and standardised by calculating a percentage amount of adherence.

VIDEO		STROKE WORKBOOK			
VIDEO ADHERENCE		ACTIVE ADHERENCE		PASSIVE ADHERENCE	
ACTIVITIES	SCORE	ACTIVITIES	SCORE	ACTIVITIES	SCORE
Observed video	2	Quizzes	5	Keep workbook	1
Tested video	5	Tasks	13		
Reported booklet	2	Goals	1		
Tested booklet	2	Days	14		
TOTAL	11		33		2

Table 4.14: Activities in the Interventions and Maximum Scores

Passive adherence was not used in the following analysis for two reasons; keeping or not keeping the workbook is a dichotomous variable; and patients did not get the choice to keep the videotapes. Patients in the stroke workbook study were given the choice to retain the workbook and the relaxation tape and these measures were both dichotomous.

(Z-scores were the original choice of standardisation within each group but the scores would not be able to be used in a t-test analysis because the means and standard deviation of the standardised scores would be identical for the two groups).

The percentage adherence scores for video adherence and workbook active adherence were entered into a t-test to see if there was a difference in percentage adherence between the two interventions (table 4.15). Patients adhered significantly more to the video than to activities of the stroke workbook.

	MEAN SCORE (STANDARD DEVIATION)		T-TEST RESULTS
	VIDEO ADHERENCE (S)	WORKBOOK ACTIVE ADHERENCE (S)	
% adherence	**52.47 (35.92)**	**20.97 (26.88)**	**t (95.88) = -5.67, *p* = .00**

Table 4.15: Differences in Mean Percentage Adherence between the Video and Stroke Workbook (Active) Adherence; t-test results

The percentage of adherence differed for the two interventions but this did not clearly demonstrate the amount/quality of adherence. Therefore a third analysis was carried out breaking adherence down into meaningful levels and then comparing the groups on these scores. The frequency of adherence activities for both interventions were observed and broken down into where possible, 3 equal groups of performing none, some or most of the activities, except for reported booklet reading and goal setting where patients did all the activities or none of the activities (table 4.16). This gave possible maximum scores of 8 for each group.

VIDEO		STROKE WORKBOOK	
VIDEO ADHERENCE (C)		ACTIVE ADHERENCE (C)	
Activities	Performed (score, range of completed activities)	Activities	Performed (score, range of completed activities)
Observed video	None (score 0) = 14 Some (score 1 - one) = 2 Most (score 2 - both) = 41	Quizzes	None (score 0) = 29 Some (score 1 range 1-4) = 12 Most (score 2 for 5) = 23
Tested video	None (score 0) = 15 Some (score 1 range 1-3) = 22 Most (score 2 range 4-5) = 20	Tasks	None (score 0) = 35 Some (score 1 range 1-4) = 20 Most (score 2 range 5-13) =20
Reported booklet	None (score 0)= 27 Some (score 1 for 1) = 0 Most (score 2 - both) = 30	Goals	None (score 0) = 43 Some (score 1 range 1-2) = 0 Most (score 2 – for 3) = 32
Tested booklet	None (score 0) = 26 Some (1 – one) = 13 Most (2 – both) = 18	Days	None (score 0) = 49 Some (score 1 range 1-6) = 12 Most (score 2 range 7–14) = 14

Table 4.16: Video and Active Adherence Scores Categorised into None, Some and Most Activities Completed

These new adherence grouping scores of none, some and most were analysed using an independent t-test. There was a significant difference in the amount of adherence to the video intervention compared to active adherence in the stroke workbook (table 4.17).

	MEAN SCORE (STANDARD DEVIATION)		T-TEST RESULTS
	VIDEO ADHERENCE (C)	WORKBOOK ACTIVE ADHERENCE (C)	
Mean categorised adherence	**4.47 (2.98)**	**2.41 (2.52)**	***t* (140) = -4.44, *p* = .00**

Table 4.17: Differences in Mean Categorised Adherence Scores between the Video and Stroke Workbook (Active) Adherence; t-test results

In summary, participation is significantly greater in the video intervention than in the workbook intervention. Passive adherence in the easier intervention does not appear to differ to that of the complex intervention when using a dichotomous measure of passive adherence. When examining a dichotomous data of active adherence and video adherence, patients adhered significantly more to the video than the workbook. Furthermore when the percentage of adherence is compared, there is significantly higher percentage of adherence to the video compared to the active adherence in the stroke workbook. This was also confirmed when the amounts of adherence, i.e. when patients did none, some or most of the activities were examined. Patients are more likely to watch a video than do self-management activities.

RESEARCH QUESTION 1a: Is this particularly so for impaired patients?

To further examine impairment and adherence the Modified Rankin scores were divided using a median split to reflect two groups of high and low impairment (table 4.18 and see chapter 3 post-hoc question 1). These groups were examined for their levels of adherence to see if an easier intervention is likely to be of particular benefit to those who are more impaired. (Non-Participation could not be examined due to small numbers in Video Study).

	LOW IMPAIRED (RANKIN SCORE 1-3)	HIGH IMPAIRED (RANKIN SCORE 4-5)
Video	34	14
Workbook	39	42
Total	73	56

Table 4.18 Low and High Impairment Groupings; distribution of patient numbers

<u>Low Impairment and Adherence</u>

The difference in adherence for low impaired patients between video and workbook groups was assessed in two ways, first comparing non-adherent patients with intervention adherent patients (table 4.19) and second comparing non-active patients with intervention active adherent patients (table 4.20).

INTERVENTION	COUNT	NON-ADHERENCE	INTERVENTION ADHERENCE (video, passive, active)	CHI	*p*
Video	Observed Expected % within intervention	7 7.2 21%	27 26.8 79%	.01 (*df* = 1)	.92
Workbook	Observed Expected % within intervention	8 7.8 22%	29 29.2 78%		

Table 4.19 Differences between Non-Adherence and Intervention Adherence in Patients with Low Impairment: χ^2 results

INTERVENTION	COUNT	NON-ACTIVE ADHERENCE (inc. passive)	INTERVENTION ACTIVE ADHERENCE	CHI	*p*
Video	Observed Expected % within intervention	7 8.1 21%	27 25.9 79%	.40 (*df* = 1)	.53
Workbook	Observed Expected % within intervention	10 8.9 27%	27 28.1 73%		

Table 4.20: Differences between Non-Active Adherent and Intervention Active Adherence in Patients with Low Impairment: χ^2 results

In summary there were no significant differences in adherence between the video and the stroke workbook in patients with low impairment.

High Impairment and Adherence

To assess the difference in adherence for high-impaired patients between video and workbook groups, the non-adherent patients were first compared with intervention adherent patients (table 4.21) and second compared with the non-active non-adherent patients with intervention active adherent patients (table 4.22).

INTERVENTION	COUNT	NON-ADHERENCE	INTERVENTION ADHERENCE (video, passive, active)	CHI	*p*
Video	Observed Expected % within intervention	3 4.6 21%	11 9.4 79%	1.09 (*df* = 1)	.30
Workbook	Observed Expected % within intervention	15 13.4 37%	26 27.6 63%	*Fishers exact* *P = .35*	

Table 4.21 Differences between Non-Adherence and Intervention Adherence in Patients with High Impairment: χ^2 results

There was no difference in adherence between the video and the workbook in patients with high impairment when adherence was defined as watching the video, keeping the workbook and actively engaging in the activities (table 4.21). However when intervention active adherence was examined, i.e. video watching and engaging in the workbook activities, patients with high impairment were significantly more likely to watch the video than to do the workbook activities (table 4.22).

INTERVENTION	COUNT	NON-ACTIVE ADHERENCE (inc. passive)	INTERVENTION ACTIVE ADHERENCE	CHI	*p*
Video	Observed Expected % within intervention	3 6.9 21%	11 7.1 79%	**5.75 (*df* = 1)**	**.02**
Workbook	Observed Expected % within intervention	24 20.1 58%	17 20.9 42%		

Table 4.22: Differences between Non-Active Adherence and Intervention Active Adherence in Patients with High Impairment: χ^2 results

The results from table 4.22 have been illustrated in figure 4.1.

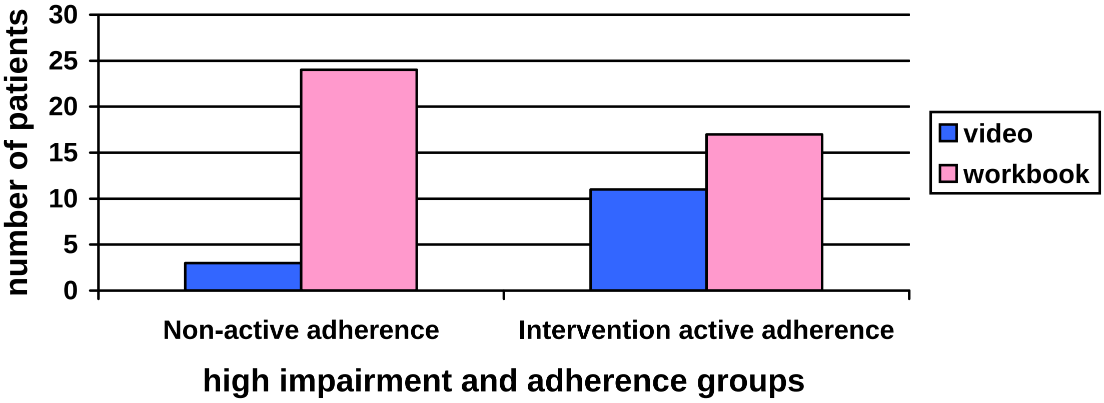

Figure 4.1: Differences between Non-Active Adherence and Intervention Active Adherence in Patients with High Impairment

In summary using different ways to measure adherence to the video and workbook, adherence has been shown to be greater to the video and that patients who are high in impairment are more likely to watch the video than do the workbook activities.

RESEARCH QUESTION 2: What demographic, clinical and psychological factors predict adherence to an easier intervention?

To answer this question the data were examined for differences between patients who were observed to watch at least one video and those who did not watch any at all in keeping with the analysis for the workbook in chapter 3. Tables 4.23, 4.24 and 4.25 show the chi square and t-test results.

DEMOGRAPHIC MEASURES	N	NUMBERS		χ^2 RESULTS
		VIDEO ADHERERS	NON-ADHERERS	
Number	57	43	14	
Gender: female **male**	**27** **30**	**17 (63%)** **26 (87%)**	**10 (37%)** **4 (13%)**	**χ^2 = 4.31 (*df 1*) *p* = .04**
Employment: retired Not retired	44 13	31 12	13 1	χ^2 = 2.59 (*df 1*) *p* = .11 Fishers Exact p = .15
Living: with carer without carer	4 16	30 13	11 3	χ^2 = .41(*df 1*) *p* = .52 Fishers Exact *p* = .74
		MEAN SCORES (STANDARD DEVIATION)		T-TESTS RESULTS
Mean age - years	57	66.26 (11.37)	70.50 (10.17)	t (55) = 1.24, *p* = .22
DEPCAT score: 1 – 7	57	3.86 (1.61)	4.14 (1.70)	t (55) = .56, *p* = .58

Table 4.23: Demographic Differences between Video Adherers and Non-Adherers; χ^2 & t-test results

A significant relationship was found for gender, suggesting that men are more likely to watch at least one of the videos than women (87% vs. 63%). There were no significant differences between video adherers and video non-adherers in terms of their other demographic measures.

CLINICAL MEASURES	N	NUMBERS		χ^2 RESULTS
		VIDEO ADHERERS	NON-ADHERERS	
Affected side: left right	27 30	19 24	8 6	χ^2 = .71 (*df 1*) *p* = .40
Stroke event: first previous	47 10	37 6	10 4	χ^2 = 1.56 (*df 1*) *p* = .21 Fishers Exact p = .24
		MEAN SCORE (STANDARD DEVIATION)		T-TEST RESULTS
Orgogozo [1]	48	6250 (2352.31)	5982.5 (2284.73)	*t* (46) = -.46, *p* = .65
NIH (transformed) [2]	48	2.17 (.85)	2.29 (.61)	*t* (46) = .45, *p* = .67
Modified Rankin[2]	48	2.66 (1.24)	3.1 (.99)	*t* (46) = 1.04, *p* = .30
Length of stay in hospital	57	36.63 (54.42)	22.00 (25.42)	*t* (55) = -1.00, *p* = .32
Barthel Index (transformed)[1]	57	114739.30 (47490.73)	98558.29 (44930.45)	*t* (55) = 1.21, *p* = .27

[1]Orgogozo & Barthel Index: higher score = less impairment [2]NIH and Rankin: lower score = less impairment

Table 4.24: Clinical Differences between Video Adherers and Video Non-Adherers; χ^2 & t-test results

When comparing the clinical measures of the two groups there were no significant differences between them (table 4.24).

There were two significant differences between the groups in terms of the psychological measures (table 4.25). Those patients who desired the video prior to receiving it were more likely to watch one or both of them than those patients who did not desire the videos and those who had a higher score on identity on the IPQ-R were also more likely to adhere to the video.

PSYCHOLOGICAL MEASURES (n = 57)	MEAN SCORE (STANDARD DEVIATION)		T-TEST RESULTS
	VIDEO ADHERERS	NON-ADHERERS	
HADS			
Mood	11.83 (7.93)	11.50 (8.29)	*t* (55) = -1.37, p = .89
Anxiety	5.58 (4.42)	5.71 (4.70)	*t* (55) = .10, p = .92
Depression	6.25 (4.53)	5.78 (4.25)	*t* (55) = -.34, p = .73
RLOC			
RLOC	35.51 (3.97)	36.64 (4.27)	*t* (55) = .91, p = .37
WOC			
Active coping	41.55 (8.87)	39.86 (8.69)	*t* (55) = -.63, p = .53
Active cognitive	20.07 (4.66)	19.64 (3.63)	*t* (55) = -.31, p = .76
Active behavioural	21.49 (5.10)	20.21 (6.11)	*t* (55) = -.77, p = .44
Avoidant	11.23 (3.38)	10.92 (2.37)	*t* (55) = -31, p = .76
Problem focused	24.79 (6.15)	24.07 (6.66)	*t* (55) = -.37, p = .71
Emotion focused	31.07 (5.11)	30.43 (4.22)	*t* (55) = -.42, p = .68
DESIRE FOR VIDEO			
Desire	**4.06 (1.03)**	**2.36 (1.74)**	***t* (55) = -4.50, p = .00**
CONFIDENCE IN RECOVERY			
Confidence	8.14 (2.41)	9.07 (1.27)	*t* (55) = 1.38, p = .17
IPQ-R (n= 55)			
Identity	**4.22 (2.14)**	**2.80 (2.03)**	***t* (53) = -2.04,p = .04**
Timeline - chronic	16.88 (4.53)	14.86 (3.30)	*t* (33.92) =-1.88,p = .07^
Timeline - cyclic	10.80 (2.83)	9.7 (2.58)	*t* (53) = -1.27,p = .21
Consequence	20.98 (3.52)	19.93 (3.97)	*t* (53) = -.93,p = .36
Control - personal	22.90 (2.34)	22.14 (2.51)	*t* (53) = -1.03,p = .31
Control treatment	18.98 (1.89)	19.36 (1.60)	*t* (53) = .68,p = .50
Illness coherence	15.07 (4.29)	14.71 (4.29)	*t* (53) = -.27,p = .79
Emotional representation	17.87 (4.58)	17.00 (4.87)	*t* (53) = -.61,p = .55
Cause: psychological	12.98 (2.99)	11.21 (2.69)	*t* (53) = -1.95,p = .06^
Cause: controllable PR	10.76 (2.74)	9.21 (1.97)	*t* (53) = -1.94,p = .06^
Cause: uncontrollable PR	9.85 (2.33)	9.00 (1.62)	*t* (53) = -1.27,p = .21
Cause: external risk	13.71 (2.33)	13.14 (1.56)	*t* (33.84) = -1.02,p = .32

Table 4.25: Psychological Differences between Video Adherers and Video Non-Adherers; t-test results

There were also three non-significant trends in differences between the video adherers and the non-adherers. Video adherers perceived their illness as being more chronic (t (33.92) = -1.88, *p* = .07^) attributed the cause of their stroke to psychological factors (t (53) = -1.95, *p* = .06^) and to controllable personal risk behaviour (t (53) = -1.94, *p* = .06^). In each case video adherers had higher scores than non-adherers (table 4.25).

Correlational analysis between video adherence and demographic, clinical, and psychological variables was performed (Appendix C). Correlations where probability was .20 or less (Hair et al 1998) included demographic predictors of gender (r = -.28, *p* = .04*) and employment status (r = -.21, *p* = .11) and psychological predictors of desire for the video (r = .52, *p* = .00**), confidence in recovery (r = -.18 *p* = .17), identity (r = .28, *p* = .04*), timeline chronic (r = .21 *p* = .13), cause – psychological (r = .26 *p* = .06^) and cause: controllable personal risk (r = .26 *p* = .06^) were entered into a logistic regression analyses (table 4.26).A one variable model was produced where the -2LL value decreased from 62.40 to 39.26 The R^2 values ranged from .34 - .51 and the Hosmer and Lemeshow χ^2 value showed a non-significant (χ^2 = 13.03 (df 7) *p* = .07) indicating a good overall model fit.

This model shows that desire for the video accounts for the variance explained (Wald statistic = 8.75 (*df* 1) *p* = .003**).

VARIABLES ENTERED	B	S.E.	WALD	DF	SIG.	95% CI FOR EXP (B)	
						LOWER	UPPER
Gender	1.08	.97	1.24	1	.27	.44	19.65
Retired	1.96	1.38	2.03	1	.15	.48	105.93
Desire for the video	**.73**	**.31**	**5.65**	**1**	**.02**	**1.14**	**3.82**
Confidence in recovery	-.17	.26	.42	1	.52	.51	1.40
Identity	.18	.22	.69	1	.41	.78	1.84
Timeline - chronic	.06	.14	.16	1	.69	.80	1.40
Cause: psychological	.23	.19	1.45	1	.23	.87	1.84
Cause: controllable PR	-.05	.23	.05	1	.82	.60	1.50
Constant	4.49	4.62	.95	1	.33		

B = logistic coefficient; S.E. = standard error; WALD = Wald statistic; DF = degrees of freedom; Sig. = significance level; CI = confidence intervals; EXP (B) = exponentiated coefficient.

Table: 4.26: Logistic Regression Analysis of Video Adherence Predictor Variables with Probabilities of .20.

In summary, there appears to be no differences between video adherers and non-adherers in terms of their clinical variables. However patients who did watch one or both of the videos were more likely to be male, score higher on the identity scale of the IPQ-R and have a higher desire for the video pack compared to the group that did not watch the videos. There were three non-significant trends suggesting that patients who adhered to the video perceived a greater time-line chronic, and attributed psychological and their own personal risk behaviour to the cause of their stroke. When entered into a logistic regression analysis gender was not included in the one variable model, which suggested that desire for the video accounts for the variance explained.

RESEARCH QUESTION 3: Are the factors that predict adherence to the easier intervention the same or different from the factors that predict adherence to the complex intervention?

FACTORS	VIDEO	STROKE WORKBOOK	
	VIDEO ADHERENCE	PASSIVE ADHERENCE	ACTIVE ADHERENCE
Gender	✓ (male)	✓	✓ ∗ (female)
Disability			✓ ∗
Desire	✓ ∗	✓ ∗	
Avoidant			✓
Identity	✓		

✓ = univariate analysis; ∗ = logistic regression

Table 4.27: A Summary of the Predictors of Adherence to a Complex and Easy Intervention

Gender, disability, desire for the intervention avoidant coping and identity were found to be in at least one of the two studies predictive variables in the study of adherence to an easy and complex intervention (table 4.27). Since gender appeared to be predictive of all types of adherence with males appearing to adhere to the video more readily than women whilst women adhered to the workbook more readily than men, this was examined in more detail.

Using the complete data sets of the active adherers from the stroke workbook study (n = 75) and complete data sets of the video study (n = 57) the gender distribution for the interventions is shown in table 4.28

	VIDEO		STROKE WORKBOOK	
	MALES	FEMALES	MALES	FEMALES
Numbers	30	27	45	30

Table 4.28: Distribution of Male and Females in the 4 Groups

Adherence using the dichotomous variable of adhered or not adhered between the four groups was examined using a chi square analysis (table 4.29) and illustrated (figure 4.2).

INTERVENTION	GENDER	COUNT	NON-ADHERED	ADHERED	χ2	*p*
Video	Male (mv)	Observed Expected % within gender	4 8.9 13.3%	26 21.1 86.7%	**9.30** **(*df* = 3)**	**.03**
	Female (fv)	Observed Expected % within gender	10 8.0 37.0%	17 19.0 63.0%		
Workbook	Male (mwb)	Observed Expected % within gender	19 13.3 42.2%	26 31.7 57.8%		
	Female (fwb)	Observed Expected % within gender	6 8.9 20.0% 6	24 21.1 80.0%		

Table: 4.29: Difference in Adherence between Intervention and Gender: χ^2 results

This result demonstrates the level of adherence to each intervention by men or women differed for the two interventions. More men than women do not adhere to the stroke workbook and more women than men do not adhere to the video. In other words men are more likely to be actively adherent in the video while women are more likely to be actively adherent to the workbook. Note the low rate of adherence of women in the video and the high rate of non-adherence for men in the workbook (figure 4.2).

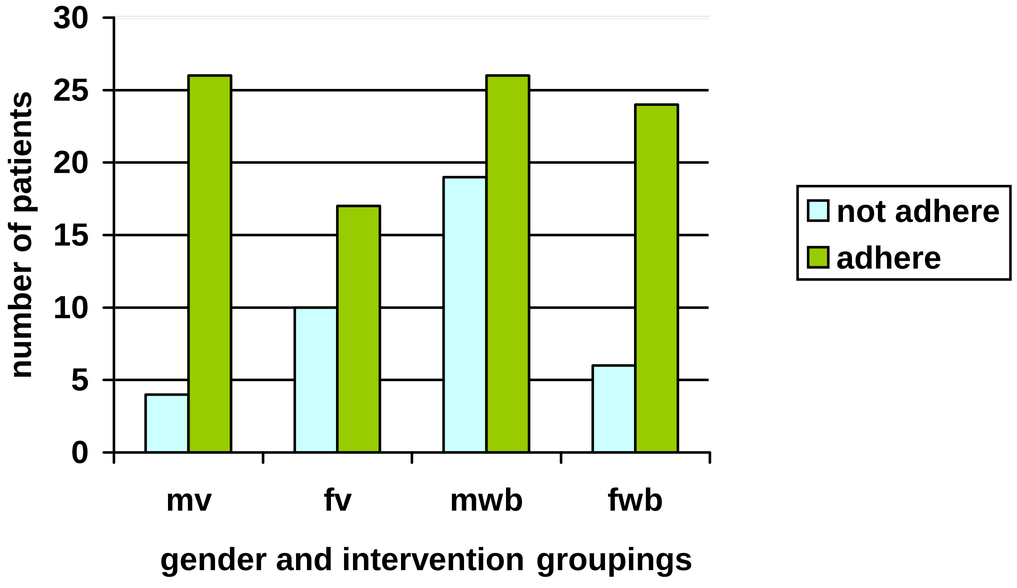

Figure 4.2: Differences in Adherence between Intervention and Gender

These groups were further analysed for demographic, clinical and psychological differences (tables 4.30 a, b and c).

MEASURES		INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	DF	MEAN SQUARE	F	*p*
	T1	Video		Workbook							
DEMOGRAPHIC	α	Men	Women	Men	Women						
Age		65.23 (10.02)	69.59 (12.07)	67.69 (12.26)	68.87 (13.40)	Between groups	319.06	3	106.36	.74	.53
						Within groups	18511.00	128	144.62		
						Total	18830.06	131			
CLINICAL											
Orgogozo		78.40 (16.12)	75.00 (19.13)	78.84 (18.19)	72.96 (23.26)	Between groups	711.93	3	237.31	.64	.59
						Within groups	42240.82	114	370.53		
						Total	42952.75	117			
NIHr		2.09 (.88)	2.30 (.72)	1.86 (.92)	2.14 (.99)	Between groups	3.32	3	1.11	1.39	.25
						Within groups	90.10	113	.80		
						Total	93.42	116			
Rankin		2.52 (1.16)	3.04 (1.11)	3.10 (1.24)	3.41 (1.28)	Between groups	10.54	3	3.51	2.41	.07^
						Within groups	163.33	112	1.46		
						Total	173.86	115			
Time in hospital		32.03 (42.39)	34.15 (53.31)	27.11 (33.95)	47.53 (57.86)	Between groups	7733.98	3	2577.99	1.21	.31
						Within groups	27379-.30	128	2138.99		
						Total	281524.30	131			
Barthel Index		**126656.30 (43180.18)**	**93108.04 (45433.54)**	**116366.87 (50156.660)**	**123977.87 (45773.65)**	**Between groups**	**19457567049.73**	**3**	**6485855683.24**	**3.00**	**.03**
						Within groups	**279192681517.93**	**128**	**2181192824.36**		
						Total	**298650248567.66**	**131**			
PSYCHOLOGICAL											
HADS											
Mood	.87	10.73 (8.59)	12.89 (7.15)	12.44 (9.45)	14.03 (8.95)	Between groups	168.381	3	56.13	.74	.53
						Within groups	9718.61	128			
						Total	9886.99	131			
Anxiety	.85	4.80 (4.64)	6.52 (4.12)	5.80 (5.40)	7.03 (5.31)	Between groups	84.29	3	28.10	1.17	.34
						Within groups	3165.71	128	24.73		
						Total	3250.0	131			
Depression	.77	5.93 (4.70)	6.37 (4.18)	6.64 (4.93)	7.00 (4.19)	Between groups	18.52	3	6.17	.30	.83
						Within groups	2674.47	128	20.89		
						Total	2692.99	131			

[1]Orgogozo & Barthel Index: higher score = less impairment [2]NIH and Rankin: lower score = less impairment

Table 4.30a: Demographic, Clinical and Psychological Differences between Genders and Interventions: ANOVA results

	T1	INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	DF	MEAN SQUARE	F	*P*
		VIDEO		WORKBOOK							
WOC	α	MEN	WOMEN	MEN	WOMEN						
Active coping	.69	43.07 (7.95)	39.00 (9.29)	41.38 (7.92)	38.87 (8.97)	Between groups	367.57	3	122.52	1.71	.17
						Within groups	9173.91	128	71.671		
						Total	9541.48	131			
Active cognitive	.48	21.24 (4.05)	19.79 (4.94)	19.96 (4.15)	19.97 (4.70)	Between groups	39.17	3	13.06	.66	.58
						Within groups	2193.95	110	19.95		
						Total	2233.12	113			
Active behavioural	**.58**	**22.97 (4.60)**	**19.19 (5.48)**	**20.67 (4.56)**	**18.83 (5.29)**	**Between groups**	**313.67**	**3**	**104.56**	**4.29**	**.01***
						Within groups	**3121.21**	**128**	**24.38**		
						Total	**3434.88**	**131**			
Avoidant	.34	11.37 (3.42)	10.93 (2.85)	11.58(3.85)	10.93 (3.40)	Between groups	11.09	3	3.70	.31	.82
						Within groups	1537.67	128	12.01		
						Total	1548.75	131			
Problem focused	**.70**	**27.17 (4.98)**	**21.78 (6.33)**	**25.93 (5.54)**	**22.80 (6.70)**	**Between groups**	**589.54**	**3**	**196.51**	**5.70**	**.001**
						Within groups	**4414.43**	**128**	**34.49**		
						Total	**5003.97**	**131**			
Emotion focused	.39	29.73 (4.37)	32.22 (5.16)	30.89 (6.80)	31.33 (5.73)	Between groups	92.36	3	30.79	.93	.43
						Within groups	4231.64	128	33.06		
						Total	4324.00	131			
RLOC	.56	35.57 (3.75)	36.04 (4.39)	34.18 (4.34)	35.70 (4.32)	Between groups	77.42	3	25.81	1.44	.23
						Within groups	2281.21	128	17.82		
						Total	2358.63	131			
Desire for intervention	-----	**4.13 (1.25)**	**3.11 (1.45)**	**3.96 (1.15)**	**4.33 (1.24)**	**Between groups**	**24.20**	**3**	**8.07**	**5.09**	**.002**
						Within groups	**202.71**	**128**	**1.58**		
						Total	**226.91**	**131**			
Confidence in recovery	-----	8.23 (2.14)	8.52 (2.33)	7.51 (2.39)	7.53 (2.50)	Between groups	24.48	3	8.16	1.48	.22
						Within groups	706.82	128	5.52		
						Total	731.30	131			

Table 4.30 b: Psychological Differences between Genders and Interventions: ANOVA results

MEASURES	N	INTERVENTION				χ^2 RESULTS
		VIDEO		WORKBOOK		
DEMOGRAPHIC		MALE	FEMALE	MALE	FEMALE	
Employment: retired Not retired	99 33	22 8	22 5	33 12	22 8	χ^2 = .76 (*df* 3) *p* = .86
Living: with carer without carer	**85 47**	**21 9**	**20 7**	**33 12**	**11 19**	**χ^2 = 13.14 (*df* 3) *p* = .00**
DEPCAT……..low high	65 67	11 19	12 15	23 22	19 11	χ^2 = 4.60 (*df* 3) *p* = .20
CLINICAL MEASURES						
Affected side: left right	62	16 14	11 16	16 27	19 11	χ^2 = 5.74 (*df* 3) *p* = .13
Stroke event: first previous	108 24	26 4	21 6	35 10	26 4	χ^2 = 1.74 (*df* 3) *p* = .63 (1 expected cell<5)

Table 4.30c: Demographic and Clinical Differences between Genders and Interventions; χ^2 results

Five differences emerged including demographic, clinical and psychological. There was a significant difference between the groups and the presence of a carer (table 4.30c).
Sixty three percent of women in the stroke workbook group were without a carer compared to 27% of men in the workbook group and 30% men and 26% of women in the video group (table 4.31).

INTERVENTION	GENDER	COUNT	WITH CARER	WITHOUT	CHI	*p*
Video	Male (mv)	Observed Expected % within gender	21 19.3 70%	9 10.7 30%	**13.14 (*df* = 3)**	**.00**
	Female (fv)	Observed Expected % within gender	20 17.4 74%	7 9.6 26%		
Workbook	Male (mwb)	Observed Expected % within gender	33 29.0 73%	12 16.0 27%		
	Female (fwb)	Observed Expected % within gender	11 19.3 37%	19 10.7 63%		

Table 4.31: χ^2 Analysis of Presence of a Carer between Gender and Intervention

Clinically there was a significant difference between the genders and interventions on the Barthel Index and a trend in the Rankin (table 4.25a). Presented graphically, males in the workbook group appear to be more impaired than the women in the workbook group and the men in the video group but less impaired than the women in the video group (figure 4.3).

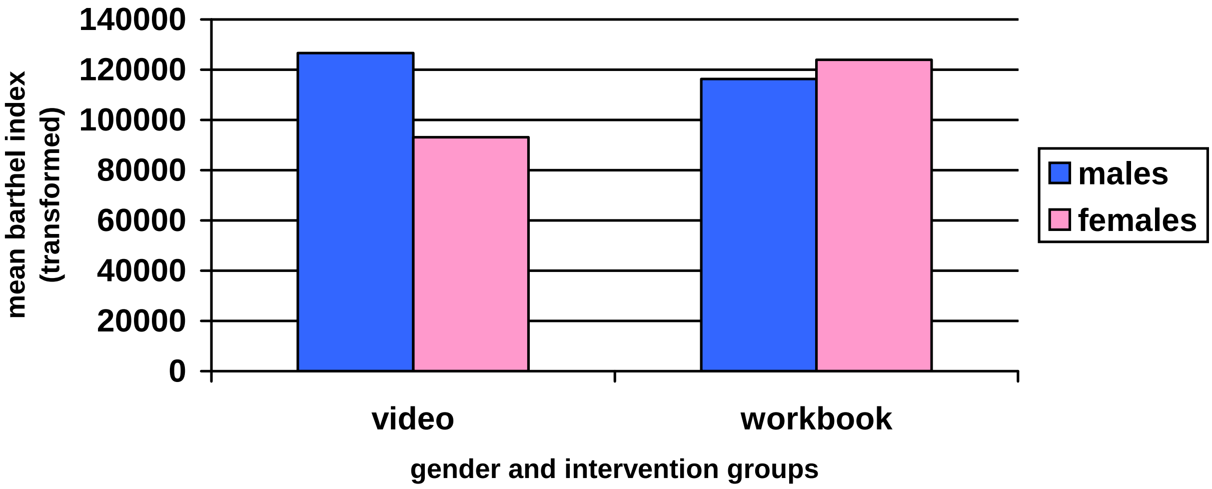

Figure 4.3: Differences in Mean Barthel Index Scores between the Genders and Intervention

Post-hoc analysis of the Barthel Index scores using LSD statistic showed that women in the video group were significantly more impaired than the men in the video group (*p* = .01**), the men in the workbook group (*p* = .04*) and the women in the workbook group (*p* = .01**). When the trend in the Rankin was observed the women in the workbook group were more impaired followed by the men in the stroke workbook group (table 4.30a).

There were three psychological differences between the groups, active behavioural and problem focused coping and desire for the intervention.

Men reported to use more active behavioural ways of coping than the women in both the video and the workbook interventions (table 4.30 b, figure 4.4).

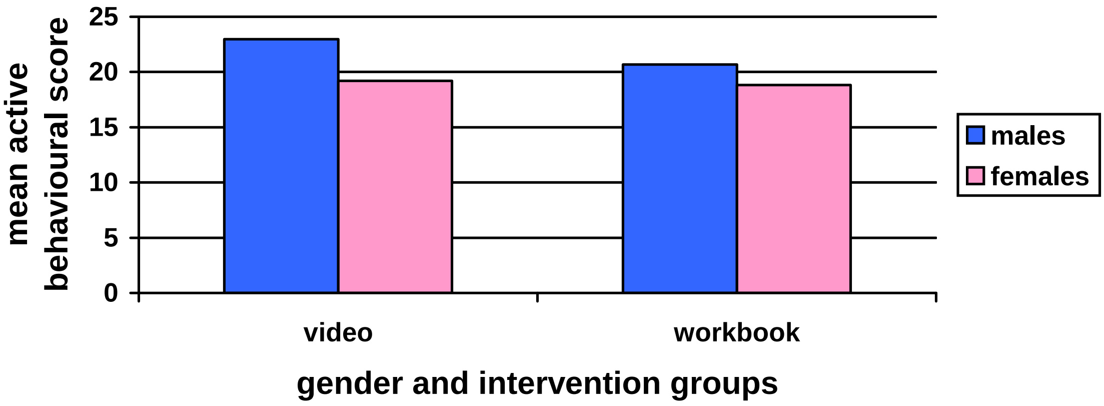

Figure 4.4: Differences in Mean Active Behavioural Coping Scores between the Genders and Intervention

Post-hoc analysis of the mean active behavioural coping scores using LSD statistic showed that men in the video group scored significantly higher on the active behavioural measure from the women in the video group (*p* = .005**) and in the workbook group (*p* = .002**), suggesting that men pertain to use active behavioural ways of coping more than women.

Men appeared to be more problem-focused than women in their ways of coping in both the video and workbook intervention (table 4.30 b, figure 4.5).

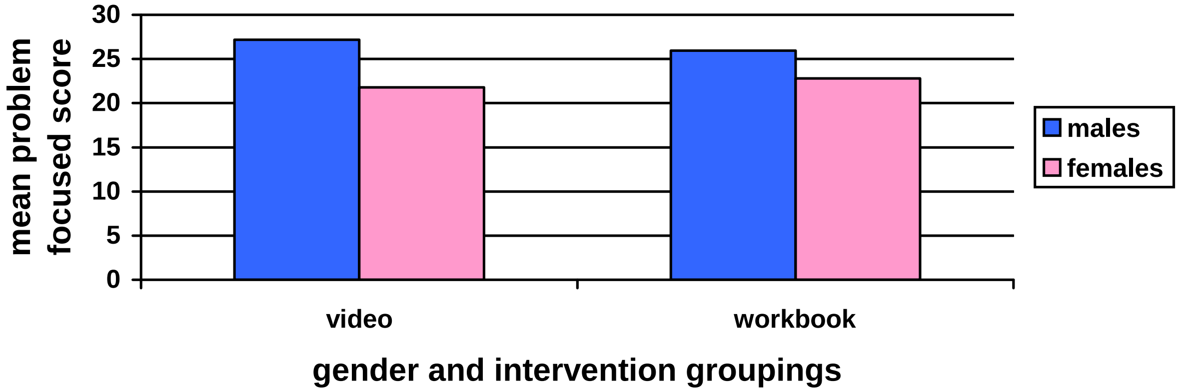

Figure 4.5: Differences in Mean Problem Focused Coping Scores between the Genders and Intervention

Post-hoc analysis of the mean problem-focused coping scores using LSD statistic showed that men in the video group scored significantly higher on the problem focused ways of coping measure than women in the video group (*p* = .001**) and in the workbook group (*p* = .005**). Men in the workbook group also scored significantly higher than women in the video group (*p* = .004**) and from the women in the workbook group (*p* = .03*), suggesting that men appear to use more problem-focused ways of coping than women.

The last psychological significant difference between the men and women in the video and workbook groups was the desire for the intervention. Two measures, desire for the workbook and desire for the video were combined for this analysis to provide a measure of desire for the intervention. However this may not be directly comparable as two different interventions are being referred to and consequently may elicit different responses. This is an issue for interpreting the results and the importance of having a standardised measure for future studies.

The results suggest men desired the video more than the women whereas the women desired the workbook more than the men (table 4.30 b, figure 4.6).

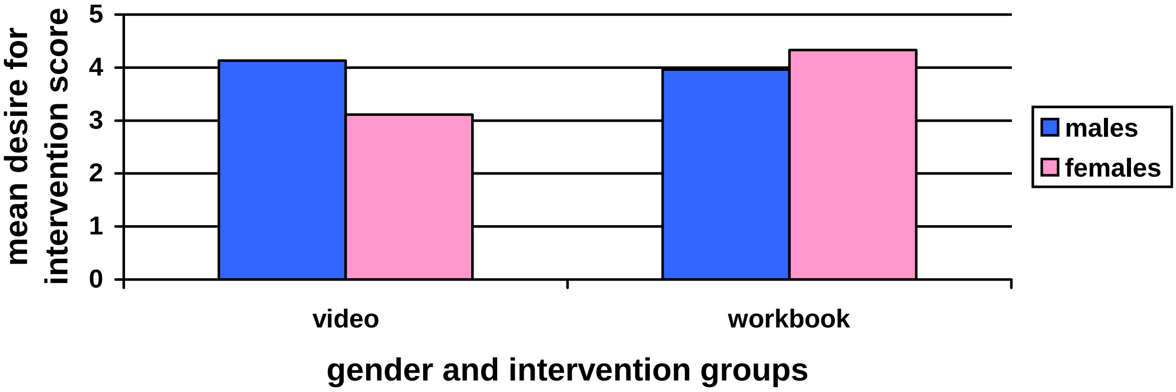

Figure 4.6: Differences in Mean Desire for the Intervention between the Genders and Intervention

Post-hoc analysis using LSD statistic showed that women desired the video intervention significantly less than the men (*p* = .003**) and significantly less than both the women's desire for the workbook (*p* = .00**) and the men's desire for the workbook. (*p* = .007**).

Predictors of Intervention Active Adherence (Video & Active)

Correlational analysis between Intervention Active Adherence and clinical, demographic and psychological variables was performed (Appendix C). Correlations where probability was .20 or less (Hosmer and Lemeshow 1989) included demographic predictors of; age (*r* = -.11, *p* = .20), with carer (*r* = -.11, *p* = .19); employment status (*r* = -.11, *p* = .19); clinical predictors of NIHr (*r* = -.15, *p* = .08), Orgogozo (*r* = .15, *p* = .10), Rankin(*r* = -.27, *p* = .00**), first stroke (*r* = -.16, *p* = .06^); and psychological predictors of RLOC (*r* = -.11, *p* = .18), desire for the intervention (*r* = .23, *p* = .01*), and confidence in recovery (*r* = -.13, *p* = .11). The additional variable of intervention type was also entered as it showed a significant correlation with video and active adherence (*r* = .19, *p* = .02*). These variables were entered into a logistic regression to confirm the relative contribution of each variable in predicting Intervention Active Adherence (table 4.32.

VARIABLES ENTERED	B	S.E.	WALD	DF	SIG.	95% CI FOR EXP (B)	
						LOWER	UPPER
Age	.01	.03	.08	1	.77	.96	1.06
With carer	.89	.50	3.134	1	.08	.91	6.53
Retired	.39	.82	.22	1	.64	.29	7.342
First stroke	**1.29**	**.57**	**5.14**	**1**	**.02**	**1.19**	**11.14**
NIHr	-.13	.41	.09	1	.769	.40	1.96
Orgogozo	-.02	.02	.67	1	.41	.95	1.02
Rankin	**-.60**	**.31**	**3.87**	**1**	**.05**	**.30**	**1.00**
RLOC	-.03	.06	.235	1	.64	.87	1.09
Confidence in recovery	-.16	.10	2.32	1	.13	.70	1.05
Desire for the Intervention	**.52**	**.18**	**7.98**	**1**	**.01**	**1.17**	**2.41**
Intervention type	**-1.54**	**.54**	**8.16**	**1**	**.00**	**.08**	**.62**
Constant	3.28	3.41	.93	1	.34		

B = logistic coefficient; S.E. = standard error; Wald = Wald statistic; df = degrees of freedom; Sig. = significance level; CI = Confidence intervals; Exp (B) = exponentiated coefficient.

Table 4.32 Logistic Regression Analyses of Intervention Active Adherence Variables

A four variable model was produced where the log likelihood (-2LL) value decreased from 161.30 to 124.59. The R^2 values ranged from .26 - .35 and the Hosmer and Lemeshow χ^2 value showed a non-significant ($\chi^2 = 7.30$, $p = .50$) indicating a good overall model fit.

This model shows that first stroke experience, impairment as measured by the Rankin, desire for the intervention and intervention type account for the most variance. The other demographic clinical and psychological did not significantly account for any additional variance.

In summary patients appeared to adhere more readily to the video over the workbook suggesting that an easier intervention is associated with more adherence. Furthermore active adherence is associated with less impairment. However, the factors that are associated with adherence to the complex and easy intervention differ depending on the type of adherence examined, passive, active or video adherence. Women adhered both passively and actively to the workbook more than men therefore the video and workbook groups were further divided into male and female and the differences examined. Women appeared to be more active adherers to the workbook than the men whilst the men were more active to the video. Five significant differences between the four groups emerged when the men and women in both interventions were further examined. Women in the workbook group were less likely to have a carer in comparison to the other groups and women in the video group were more likely to be more impaired than the other three groups. Men in both the video and workbook groups appeared to use more active and problem-focused ways of coping than the women in the video and workbook groups. Women were more likely to have less desire for the video then men, and that desire was less than the men and women's desire for the workbook intervention. A patient's first stroke experience, impairment, desire for the intervention and intervention type appeared to account for the most intervention active adherence.

DISCUSSION

The stroke workbook study showed low levels of adherence to the workbook activities. Adherence to the activities was associated with impairment. It is plausible that more impaired individuals may see their condition as less controllable/curable and therefore less likely to adopt the coping procedures involved in SWOT. By offering an easier intervention would more impaired individuals be able to adhere?

The patients randomly allocated to the video intervention were comparable to the patients randomly allocated to the stroke workbook intervention in terms of demographic, clinical and psychological factors with no significant differences existing between the two groups. There were two non-significant trends; one in the Rankin showing that patients in the workbook group were more impaired than the video group; and one in the desire for the intervention with patients desiring the workbook more than the video. This is of importance in interpreting adherence findings, as the Modified Rankin and Desire for the Intervention were significant predictors of active and passive adherence respectively. Clinical status on admission may have important implications for active adherence to interventions.

Examining adherence in the SWOT study revealed three types of adherence behaviour, participation in the intervention, passive adherence of retaining the stroke workbook and active adherence of engaging in the workbook activities.

Approximately 3 % of patients declined to participate in the Video Study whereas 14% declined to participate in the SWOT (p = .03*), suggesting that patients may be more amenable to the video intervention than the stroke workbook intervention. The patients may have perceived the offer of a video as being easy to watch or more familiar, e.g. videos are possibly more common than self-help workbooks, which may in itself promote greater participation. However upon receipt of the interventions, 25% of patients did not watch the video, whereas 43% of patients did not actively adhere to the workbook and 44% did not passively adhere. These results appear to be in keeping with previous reports of non-adherence to medical prescription (20 - 80%, Dunbar-Jacob et al. 1995), dietary (13 – 76%, Glanz, 1979) exercise interventions (50%, Carmody et al. 1980), cardiac rehabilitation (33%, Petrie et al 1996) and stroke education programme (59%, Rodgers et al 1998). Patients possibly do not adhere when they see the intervention because it is not what they expect.

The results suggest non-participation in the stroke workbook trial is characterised by patients who had a high locus of control, lower anxiety and higher confidence in recovery. These factors may have been the reasons for not choosing to participate in the stroke workbook: they may already have been confident that they could achieve a satisfactory recovery. However when the participators received the stroke workbook they may have realised that it was a much harder intervention than anticipated in that it was possibly going to take longer to do and that more behaviour change was required. Leventhal (1994) argued that non-compliance occurs whether the intervention is easy or complex. The workbook may have potentially further reduced the patient's internal locus of control, heightened their anxiety and further reduced their confidence in recovery and therefore the patients avoided doing the activities. By avoiding the activities in the workbook patients may have maintained their perceptions of control, consequence and emotion. Non-avoidant coping was significantly associated with performing the activities in the workbook, which supports this idea but the internal consistency of WOC Avoidant Coping scale had low internal consistency with a Cronbach's Alpha of .21. The workbook itself may have shaped their coping procedures not to do the workbook activities. Furthermore patients when faced with complex decisions will simplify their choice (Sherman et al 2000) and that may possibly be the reason why more people passively adhered by keeping the workbook rather than actively adhere by performing the activities.

Examining the comparability of the measures of adherence to the video with the measures of the adherence to the workbook was more complex than originally thought. The workbook required patients to adhere actively in a "consciously cognitive" manner by asking patients "to do more thinking" about their recovery and to put that thinking into practice by using monitoring methods (which were supplied). Whereas the video encouraged people to take an active role in their recovery by showing them how other people had recovered from their stroke but did not ask the patients to record their recovery. Although the messages behind both interventions were very similar i.e. encouraging the individual to take control over their recovery, the importance of exercise, diet, routine, information and support, patients in the video group additionally observed how other people had recovered from their stroke but were not given activities to perform as they were in the workbook. The video was initially seen as incurring active adherence but easier to perform, i.e. the effort, time and thought it takes to watch a video and to be part of a trial. Like active adherence, video adherence could be directly measured for example, whether the patients had watched the video, patients writing in the workbook. The only "activity" required in the video group was to actually put the tapes in and take them out of the player and watch them. This behaviour therefore could be defined as passive adherence. This was supported by the desire for the intervention being predictive of passive and video adherence but not active adherence. There were three problems with this observation. Firstly “Desire for the Workbook” and “Desire for the Video” were two different measures and could convey different information to the respondent. Comparisons therefore were not very psychometrically valid. Secondly passive adherence involved the patients choosing to retain the stroke workbook whereas the patients in the Video Study were not given that choice. Thirdly the effects of the video in promoting recovery positive behaviours like the active adherence in the workbook were not recorded. Watching the video may have had not so obvious benefits i.e. patients’ beliefs may have been changed or some patients may have changed their behaviour but this will be examined in chapter 5.

Video adherence, passive adherence and active adherence to the workbook were combined to give an overall measure of intervention adherence and when compared with non-adherence (including non-participation) no difference between the video intervention and the workbook intervention emerged. However when intervention active adherence (video and active) was compared with non-active adherence (non-participation, non-adherence and passive) significantly more patients adhered to the video than the workbook. There was a flaw in the dichotomous measure of adherence in that patients had to only write down one goal in the stroke workbook to be classified as adherent. Adherence is not an “all or nothing concept” (Gordis, 1976) and cannot therefore be fully evaluated by a dichotomous measure (Weinman 1996). To address this, adherence was further examined using the percentage of adherence. The results showed that there was a higher percentage of adherence to the video when compared to the active adherence in the stroke workbook. However this again did not reflect adherence to all the activities that the patient was asked to perform. Patients may have done more of one activity than another and still have the same percentage as someone who adhered to different activities. Therefore a third analysis was performed on the amounts of adherence, i.e. when patients did none, some or most of the activities. This again showed that patients adhered more to the video than the stroke workbook. It is important to note that none of these analyses could account for the nature of the activities. Answering the quizzes and writing down the requirements of tasks involved a different type of effort to watching a video, which suggests that the activities are not directly comparable to watching a video. Nevertheless, these measures go some way to describing the fullness of engaging in the intervention, a critical issue in determining the maximal effectiveness of even the most potent intervention. Neither intervention is expected to have its maximal effects if only engaged in passively.

Whilst the above analysis offers support to the idea that greater adherence occurs in the video study it also highlights the problem of measuring adherence and making it comparable and generalisable to other behaviour change interventions. The results indicate that measuring adherence and being able to compare adherence for different interventions is extremely difficult and consequently difficult to interpret and therefore generalise, thus supporting Violins et al (2000) suggestion of a need for a “gold standard”, i.e. an agreed satisfactory level of adherence.

Patients who adhered to the video were more likely to be male, desire the intervention and score high on the identity scale of the IPQ with desire for the video accounting for the most variance. (Gender and desire will be further discussed when the factors predicting adherence to the video study are compared with SWOT later in the chapter)

Patients who perceived higher identity were more likely to adhere to the video. This cannot be directly compared to the SWOT study because the IPQ-R measure was not used. Within the SRM scoring high on the identity scale could be explained in that patients who have greater perceptions of identity may desire the intervention to help their recovery to reduce these perceptions. Earll et al (1993) showed that patients who had many symptoms were more likely to have tried different types of treatments. She concluded that symptoms and consequences motivated active coping in patients with motor neurone disease rather than other representations of cause and time-line. Patients who adhered to the video perceived a greater number of symptoms than those who did not adhere, but there were no differences in the clinical factors. This suggests that the patients had their own perceptions about the identity of their stroke and this may have promoted them to desire the video to help them to understand and explain the symptoms they were experiencing. This was supported by a significant correlation between identity at time 1 and desire for the video. These results appear to be in keeping with Earll et al (1993) who demonstrated a relationship between identity and active coping.

The adherers in the workbook appeared to be less impaired than the non-adherers, while the video adherers appeared to have high illness identity (though they do not differ on clinical measures). It may be that different interventions are likely to elicit adherence depending on the patients’ personal representations of their condition.

There were three non-significant trends when the video adherers were compared with video non-adherers, which are worthy of note and future investigation in the next study. Video adherers tended to perceive higher time-line chronic, and have greater perceptions of psychological and controllable personal risk behaviours as contributing to the cause of their stroke. Lau and Hartman (1983) had previously demonstrated that patients who attribute their behaviour as a cause of their illness were more likely to engage in self-management. Illness representations measured by the IPQ-R were only recorded for the Video study group and will be examined in chapter 5.

When the predictors of video adherence were compared to the active and passive adherence of the stroke workbook, disability was associated with active adherence, desire for the intervention with video and passive adherence and gender was associated with each type of adherence

Gender was a predictor of all three types of adherence, significantly to passive and video. Women were significantly more likely to adhere to the workbook actively and passively. Men were significantly more likely to watch the video. Do men and women have different representations about their illnesses? The data were examined by comparing the male and females in the intervention groups.

Women in the workbook group were more likely to be without a carer. Women being on their own may have had more time in which to do the activities because they had the opportunity to look after their selves rather than their partner or family (Culos-Reed 2000). Furthermore patients without a carer tended to participate in the intervention.

The Barthel index indicated that women in the video group were significantly more impaired than the men in the video group and the men and women in the workbook group. There was a trend to indicate that the women in the workbook group were more impaired followed by the men in the stroke workbook group. One possible explanation for this was that all the other clinical observations, NIH, Orgogozo and Rankin were completed on admission to hospital and indicated a level of impairment as judged by a health professional. The Barthel Index measure was assessed after the patient was discharged. Patients may have not been able to verbally respond to the doctor on admission. Furthermore the patients responded to the items therefore it was they themselves that made the judgement about their abilities not the health professional.

Impairment was related to adherence. When the predictors of intervention active adherence were examined using a logistic regression the Modified Rankin significantly contributed to the variance explained. Patients with high impairment are less likely to actively adhere to an intervention. As already noted patients in the stroke workbook intervention tended to have higher levels of impairment to those in the video intervention but not significantly so. This may have been due to the situation where the stroke workbook study was carried out over a longer period of time and therefore would have included patients who would have been in hospital longer. Patients with higher impairment are more likely to stay in hospital longer. Impairment may have implications in that patients may be physically impaired to be able to carry out physical activity to enhance their recovery, or impairment may influence the patient’s representation of their illness (Leventhal et al 1984). Joice et al (2003) noted that the most significant symptom stroke patients reported following their stroke were feelings of fatigue. If patients were very tired attending to a stroke workbook may have been more difficult than attending to a video. Gregory and Fried (2003) in their cross-sectional study showed that patients related difficulties to modifying their behaviour because of physical difficulties.

The level of the patient’s impairment may influence the advice and care of the health professional caring for the patient whilst in hospital (Marteau and Johnston 1990). The health professional’s assessment and care may have provided the patient with a label on which to base their representation of how the stroke had affected them. Depending on how this information was interpreted by the health professional may have influenced the communications with the patient and the professional and therefore influenced the patient’s representation of their illness and possibly the intervention.

Psychological differences between the four genders and intervention groups included, active behavioural and problem focused coping behaviours and desire for the intervention. Men scored higher on the active behavioural and the problem focused subscales of the Ways of Coping questionnaire indicating that they used these ways of coping more than the women. This was not demonstrated when active involvement in the workbook was examined. Women performed more of the activities in the workbook than the men. This brings into question of the definition of active coping.

Evidence exists to show that men engage in physical activity more readily than women (Trost et al 2002). Attending cardiac rehabilitation involves actively getting to the venue where it is being carried out. In Wyer et al’s study (2001), men were more likely to attend cardiac rehabilitation than women whereas Petrie et al (1996) found no differences between men and women in attendance to cardiac rehabilitation in their study. However whilst more men initially attended cardiac rehabilitation in the study by Whitmarsh et al (2003), 35% of them did not continue with the rehabilitation programme compared to 25% of women. Active coping may have physical and cognitive dimensions that are possibly being misinterpreted. Active coping may involve “effort” of looking through a self-help book, watching a video, relearning to dress one’s self, walking to cardiac rehabilitation which are all different behaviours. Women may have reported they were not active “copers” in both the workbook and the video because their perception of “active” may be different from the men. By being actively adherent to activities of a self-management workbook does not necessarily demonstrate being physically active or being able to attend a programme at another venue.

Desire for the intervention differed significantly between the genders and interventions. Women did not appear to desire the video as much as the men. Desire for the intervention was statistically predictive of adherence as already discussed. If patients desired the video they were likely to watch the video and if patients desired the workbook they were more likely to retain the workbook but not necessarily actively adhere to the workbook. However when the predictors of intervention active adherence were examined using a logistic regression desire for the intervention significantly contributed to the variance explained. Therefore patients' desire for an intervention may be an important variable for investigation rather than the ease or difficulty of an intervention. Furthermore this finding adds support to Leventhal (1994) who argued that non-compliance occurs whether the intervention is easy or complex, it is dependent on the patient's representations of their illness and treatment. The desire for the intervention may have been shaped by the representation of the intervention. Subsequently if a more difficult intervention is desired over an easier one then designing an easier intervention may not possibly be the answer to encourage patients to adhere to an intervention to promote recovery. What might be perceived as easy to perform to one person might not be to another.

It has already been demonstrated when examining adherence to the stroke workbook that patients had a great desire for the intervention but adhered less. Leventhal (1998) suggests that illness representations are dynamic and change over time. Consequently by the time the patients received the intervention their representations of their illness and recovery may have evolved, e.g. they may have gained more function or perceived themselves to be getting better or they may have perceived themselves as making no change or perceived that they could not do anything to help their recovery. Furthermore the workbook may not have been what they had expected, their representations of the treatment potentially could have been altered because the workbook was more complex than they expected. Meichenbaum and Turk (1987) reported that the degree of expected behaviour change the intervention incurred would reduce adherence. The workbook's activities were directed at behaviour change to promote an active role in the patient's own recovery. The video intervention did not directly ask for a change in behaviour, except to watch the video, therefore was probably adhered to more.

Patients may have defined their coping not necessarily about their own recovery but about the recovery of others. Patients' desire for the intervention may have been due to patients expressing a wish to help medical research (Cox and McGarry 2003), and this was supported anecdotally.

When recruiting for the study it was common to hear patients say that if they could do anything to help others in the same situation as themselves, they would be happy to take part in the stroke workbook study or the FAST study. Patients' desire for the intervention may be a means of gaining more understanding and information (Cox and McGarry 2003).

"Desire for the workbook" was a measure originally designed for the stroke workbook study, asking patients to rate how much they desired the stroke workbook prior to seeing it. This statement was altered for use in the video study and the word "video" replaced the word "workbook". The name of the type of intervention itself may have influenced patient's adherence. The choice of a coping response e.g. to do the intervention or not do the intervention "is influenced by whether it makes sense in the light of the patients own ideas about the illness and personal experience of symptoms" (Horne 1997). The name "workbook" may have been attractive to some people and not for others. It may have been less familiar than a video. Generally speaking the public is exposed to television and video usage on a large scale as demonstrated by the availability of televisions, video and DVD players and video hire shops. One suggests that workbooks may be not so familiar. The "workbook" may be associated with school and education and be associated with positive or negative schooling experiences. Videos may be associated with leisure activities or the negative experiences associated with technology, e.g. using the video player. Furthermore when the workbook was offered patients might have desired it because it was something different or they may not have desired it because it was something different! When the predictors of intervention active adherence were examined using a logistic regression intervention type significantly contributed to the variance explained. This may infer that patients have beliefs about interventions, supporting the work of Horne (1999) who has shown that patients have beliefs about medication pertaining to necessity and specificity as well as their illness, these beliefs impact on adherence behaviours.

First stroke experience contributed to the variance explained in intervention active adherence. Having a stroke for the first time is apparently very frightening. Leventhal et al (1967) showed that patients presented with a fear message and a plan are more likely to adhere to advice within the plan. First time stroke patients may have engaged more actively with an intervention because it was a plan for their recovery.

Methodological Limitations

The methodological limitations in carrying out this study included the problem of comparing the two types of adherence in the stroke workbook, active adherence, where the patients were seen to be completing the activities in the workbook and passive adherence where patients were given the opportunity to retain the stroke workbook. Patients in the video study were not given the opportunity to retain the video packs and therefore it was difficult to establish if two types of behaviour emerged from doing an easier intervention. Different interventions require different forms and amounts of adherence in order to reach the full potential of the intervention.

In an attempt to make the studies as comparable as possible the video study was designed to be as similar as possible as the stroke workbook study by allowing the interventions to be carried out over 5 weeks. This caused a problem in that many people watched the video in the week they received it and therefore by week five some of them could not remember what they had seen which therefore potentially compromises the measure of adherence using tested recall.

The stroke workbook study was not designed to have its adherence examined to the extent this thesis has attempted and as a result a number of measures that would have been useful in examining non-adherence were not included. Furthermore some possible measures were over looked in the video study. For instance levels of activity the patients performed prior to their stroke may have shaped the patients coping strategies for recovering from their stroke. The educational status of the patient was not included in the SWOT study, which may have had implications for adherence. However the National Statistics Socio-economic Classification (NS-SEC) was included in the FAST study and will be examined in the following chapter.

Patients were not interviewed about their reasons why they did not adhere, or how difficult they perceived the intervention to be and furthermore the opportunity to examine the concepts of intentional and unintentional adherence were also missed as no standard question asking patients why they did not adhere to the interventions was included. Anecdotally there was one patient in this study who intentionally did not adhere in “retribution” for the hospital not sending out a physiotherapy appointment!

The Video study was shown to lack sufficient power to detect a medium effect. This lack of power may have resulted in significant results being missed.

CONCLUSION

Patients are encouraged to take an active role in their recovery by adhering to interventions that have been shown to benefit recovery. The behaviour of adherence appears to be multifaceted, which is further highlighted when trying to measure it. This present study has indicated that demographic, clinical and psychological factors all contribute to the phenomenon of adherence to interventions. It has also potentially demonstrated the difficulty of comparing interventions that appear to demand different types of adherence behaviours.

First stroke experience, impairment, desire for the intervention and intervention type accounts for the most intervention active adherence.

The results suggest that less impaired patients are more likely to adhere to an easier intervention but their levels of adherence, types of adherence and predictors of adherence all vary. Furthermore, whilst there are similar factors that appear to predict adherence to both a complex and simple intervention, there are also predictive factors that are different. In general adherence to interventions appear to be associated with gender, impairment, and beliefs about disability and recovery. Previous evidence has suggested illness beliefs are associated with adherence and will be further examined in the next chapter.

CHAPTER 5

A SIMPLE THEORETICALLY DESIGNED LETTER FROM HEALTH PROFESSIONALS: CAN IT INFLUENCE ADHERENCE TO AN EASIER INTERVENTION, ILLNESS REPRESENTATIONS AND OUTCOME?

SUMMARY

Background: In the previous chapters, patients' demographic, clinical and psychological characteristics and difficulty of intervention have been examined in the quest to understand why patients do not adhere to interventions. The evidence suggests that communications between health professionals and patients can affect adherence to interventions. Simple communications in the form of a letter have been used to change patients' cognitions and have lead to greater uptake of services and improvements in disability.

Aim: To examine the effects of a theoretically derived letter on adherence to an easy (video) intervention, illness representations and subsequent recovery in terms of mood and disability

Procedure: One hundred and fourteen stroke patients were randomly allocated to one of four groups, to receive a video pack, a theoretically derived letter, both a video pack and letter or control group. On admission to hospital following the stroke and prior to randomisation, demographic and clinical variables (affected side, stroke event and measures of impairment) were recorded. The psychological measures of illness representations (IPQ-R, RLOC, confidence in recovery and desire for the intervention) emotional representations (HADS) and coping (WOC) were recorded before the receipt of an intervention, following discharge from hospital in the patient's own home.

Results: Patients who received the video were classified as video adherent if they remained in the intervention for the 5-week duration and had attempted to watch at least one of the videos. Patients who received the letter were classed as letter adherent if they remained in the intervention for the 5-week duration and reported that they had received the letter and read it.

There was no difference in video adherence between those who received the letter and those who did not. However when the patients were divided into those who adhered to (i.e. read) the letter and those who did not, patients who adhered to the letter were more video adherent than those that did not read it. The intervention may have had an affect on illness perceptions; patients who were randomised to receive the video & letter had greater perceived control over their recovery. The intervention had no effect on disability or mood.

As the four groups did not clearly represent those patients who actually adhered to either intervention the patients were divided into two groups: those who were exposed to an intervention (i.e. adherent) and those who were not (i.e. non-adherent plus control). Patients who were exposed to one of the interventions appeared to have significantly greater perceptions of time-line fluctuation, greater consequence and attributed their stroke to their own behaviour.

Discussion: The letter did not appear to increase the adherence to the video, but a large number of patients who were sent the letter reported not receiving it or reading it. Since those patients who read the letter showed more evidence of watching the video, this highlights the possible importance of priming patients to receive an intervention. Exposure to the interventions appeared to influence illness representations tentatively indicating that patients’ beliefs are open to manipulation. The interventions had no effect on disability or mood outcomes.

BACKGROUND

In continuing to examine why stroke patients do not adhere to effective interventions, it has been shown in previous chapters that patient characteristics and intervention may be related to adherence. In this third study the influence of health professional communication on adherence is examined by attempting to operationalise the 5 domains of the SRM in the form of a letter signed by a Stroke Physician and Professor in Health Psychology to promote video adherence. This creates an opportunity to examine the effects of health professional's communication on adherence but also to test the applicability of the SRM.

According to the SRM people are seen as problem solving individuals striving to maintain equilibrium, suggesting that people are self-stimulated to maximise their health or in the case of stroke patients, their recovery. Generally speaking the information and advice patients receive from the healthcare services appears to acknowledge this and encourages individuals to have responsibility for their own health and to adopt behaviours to promote a healthy lifestyle. Information for patients recovering from stroke follows the same philosophy by encouraging patients to help themselves to recover by giving out recovery promoting advice and literature, and encouraging the use of available resources.

"Effective communication is necessary to ensure not only the patient problems and concerns are understood by the health care professional but also that relevant information, advice and treatment received and acted upon by the patient." (Weinman 1998)

As already demonstrated in previous chapters the effective passage of information has been fraught with difficulties because there is a large body of evidence to show that patients continue not to follow the advice they have been given. Communicating health related advice is commonly performed along three channels, face-to-face communication, through the media, e.g. television, video, and more specifically in relation to this study, through written materials. Research examining health professional face-to-face communication has resulted in communication skills being an integral part of health professional training (Weinman 1998). However evidence has shown that face-to-face communication yields information that is both misunderstood and often forgotten. Both Ley's (1988) and Stanton's (1987) models of compliance/adherence suggest that if the patient understands the information they have received they will be able to recall it and if they can recall it then they are more likely to be satisfied and adhere to the advice they have been given.

Health professional communication may account for some of the variation in the success of specialised stroke units on stroke recovery in that some units may have staff with more effective communication skills than others. Health professional communication may also explain the variation in success in other forms of intervention. Campbell et al (2000) suggests that evaluation of complex interventions such as stroke units has to consider the expertise of various health professionals as well as investigations, treatment guide lines including both drug and rehabilitation regimes and eventual discharge and follow up. In the studies reviewed in Chapter 1 (tables 1.2a and b), both adherence to activities in the stroke units and health professionals communication was not been fully reported. In the studies examining specialised stroke care environments (units or early discharges) the general descriptions of the care the patient received included, a multi-disciplinary team approach (Kaste et al 1995, Kalra and Eade 1995, Indredavik et al 1997, Rudd et al 1997, Widen Holmquist et al 1997, Ronning and Guldevog 1998, Mayo et al 1999, Anderson et al 2000, Kalra et al 2000, Sulch et al 2000, Evans et al 2001, Ozdemir et al 2001, Roderick et al 2001, and Bautz-Holter et al 2002), the importance of carer (Hui et al 1995, Kaste et al 1995, Widen Holmquist et al 1997, Ronning and Guldevog 1998) and tailored or individualised programs of rehabilitation (Kalra and Eade 1995, Widen Holmquist et al 1997, Rudd et al 1997).

In some of the studies itemised the intervention programs within the unit. These included goal setting (Kalra and Eade 1995, Ronning and Guldevog 1998), education to improve knowledge (Widen-Holmquist et al 1997, Ronning and Guldevog 1998), problem solving activities (Widen-Holmquist et al 1997), functional training (Indredavik et al 1997) and supervised or directed activities (Widen-Holmquist et al 1997). Two studies encouraged adherence to the activities in the programs (Kalra and Eade 1995, Widen-Holmquist et al 1997) and one study specified the importance of the underlying philosophy of the stroke unit to avoid “undue nilhism about stroke outcome” (Kalra and Eade 1995).

However Cant (1997) in his anecdotal paper about his experiences of health professional communications in a rehabilitation unit following his stroke noted: -

“I was aware that some therapists were very special, and I had a feeling that they were doing their job because they really cared about the patient, and the salary they received mattered little and was only incidental. Others, I felt simply provided therapy because it was their job. This was not to deny the high quality of their care.

…being addressed by someone who sounds like a middle class Mrs Merton character is not conducive to successful therapy. Indeed it can result in therapy sessions being anticipated with the same trepidation as felt when one needs to visit the dentist!”

This argument has been further supported by a paper by Marteau and Johnston (1990) when they concluded that the behaviour and attitudes of health professionals would influence the health outcomes of the patients.

In a bid to improve communication Ley (1988) argued that health professional advice can be supplemented by providing written information and advice because the content of written information can cover all the salient points and provides a record for the patient to keep. A large body of evidence exists to suggest that patients prefer to be given written material (for review see Ley 1988) and continue to request information (Joice et al 1999). Ley (1990) suggested that for information to be followed it has to be understood and remembered. Ley (1983) reviewed studies examining the efficacy of health-advice leaflets and concluded that less than half the population would understand approximately 70% of written communication. Ley and colleagues (1990) have examined written information and the readability scores (Flesch Formula 1948 – from Ley 1988) and have shown that by simplifying the information in the leaflets more people would understand them. However whilst information may increase knowledge and satisfaction, it may not necessarily increase adherence (Leventhal 1992).

Mant et al (1998) demonstrated this in the study where information packs were sent to stroke patients regarding stroke and stroke recovery. Their study showed non-significant improvements in knowledge and satisfaction in the intervention group, but there was no change in functional outcome. In the study by Rodgers et al (1998) all patients were given information leaflets, prior to being randomised to the stroke education program; again knowledge and satisfaction improved but there was no improvement in functional outcome. Both studies demonstrated the use of written material supplementing health professional communications to improve knowledge and satisfaction. However did the lack of improvement in functional outcome occur because the patients did not adhere to the information and advice they received?

Previous research has shown that patients with different illnesses have different representations, for example Meyer et al (1985) and hypertension, Johnston et al (1992) and disability, Earll et al (1993) and motor neurone disease. More recently with the introduction of the Illness Perception Questionnaire (Weinman et al 1996) and the revised version, IPQ-R (Moss-Morris et al 2002) quantitative data has been collected examining illness representations related to myocardial infarction (Petrie et al 1996), cholesterol control (Brewer et al 2002), pain (Moss-Morris et al 2002), multiple sclerosis (Jopson et al 2003, Vaughan et al 2003). In a preliminary analysis, Joice, et al (2003) gave evidence to show that patients who had had a stroke differed in their illness representations. Using the IPQ-R, the mean scores from the stroke patients were compared with the mean scores of patients with acute and chronic pain (Moss-Morris 2002). Stroke patients perceived significantly fewer symptoms, less fluctuation and saw their condition as less chronic than the chronic pain patients. They also expressed less consequence, more control both personal and treatment, and felt they had greater coherence and less distress. When compared with patients with acute pain patients, stroke patients perceived significantly more symptoms, greater fluctuation and saw their condition as more chronic than patients with acute pain. Stroke patients also perceived greater consequences, better understanding and more distress. However there was no significant difference between stroke patients and acute pain patients in the amount of control they felt they had over their condition. The way patients think about their illness impacts on the strategies they use to cope with their illness and therefore their adherence to treatment and interventions (Whitmarsh et al 2003, Cooper et al 1999, Petrie et al 1999). By changing illness representations can adherence to treatment and rehabilitation be promoted?

In a study by Fisher and Johnston (1996a) patients’ cognitions of perceived control were altered experimentally by asking chronic pain patients during their consultation about times when they felt they had control or no control over their pain. Patients asked to recall having control performed better in lifting tasks than those who were asked to recall when they had low control. Furthermore Johnston et al (1992) designed a simple communication designed to improve perceived control in patients attending physiotherapy. It was tested in an RCT where 39 patients were randomly selected to receive the letter prior to their appointment with the physiotherapist. The patients were interviewed a week later and the experimental group were found to have higher levels of perceived control. Partridge et al (1985) went on to show that patients who made a good recovery from illness had higher levels of perceived control and from this developed the Recovery Locus of Control scale (RLOC). This scale used statements selected from the comments made by participants in earlier interviews and was psychometrically valid. Johnston et al (1999) showed that patients who scored high on the RLOC showed greater recovery from disability than those who scored low. Frank et al (2000) found that improvement in functional limitations was significantly correlated with increases in perceptions of control in patients recovering from stroke. This suggested that patients develop a mental representation of their illness that is predictive of recovery. Johnston et al (1999) found this to be the case whether recovery is measured by self-report or observed performance.

Evidence suggests that patients frequently do not attend cardiac rehabilitation following a myocardial infarction (Johnston et al. 1999, Ades et al 1992). Examining patients' beliefs in relation to non-adherence to cardiac rehabilitation, Wyer et al (2002) developed a letter using the theory of planned behaviour to encourage patients to attend cardiac rehabilitation. The intervention was successful in increasing patient attendance, 37 (86%) out of 43 patients in the experimental group attended cardiac rehabilitation compared to 26 (59%) out of the 44 patients in the control group. Petrie et al (1996) examined illness beliefs of patients who had survived a myocardial infarction using the SRM as a framework. They found that patients who had a strong belief that their illness could be controlled or cured were more likely to attend cardiac rehabilitation. In a further study Petrie et al (2002) used the SRM not only to identify the patients' beliefs about their illness and perceptions to cardiac rehabilitation but as a framework around which to individualise interventions to change these beliefs and perceptions. The authors were successful in changing the patient's beliefs about their illness to being more positive. Furthermore Petrie et al (2002) report that the intervention group patients "were better prepared to leave hospital" and more likely to return to work quicker. However the intervention group did not attend cardiac rehabilitation significantly more than the control group. 74% of patients attended from the intervention group compared with 55.9% of the controls (Petrie 2002).

The present study developed and tested a letter specific to stroke patients, encouraging them to think about their stroke recovery within the five domains of the SRM (identity, cause, timeline, consequence and control/cure). The letter, signed by health professionals (a consultant and a professor of health psychology) is written to encourage patients to represent their illness in a way, which allows them to take a more positive role in their recovery. Using strategies suggested by Ley (1997) to enhance adherence the letter was designed to be easy to read and be specific to stroke to allow the patient to feel as though they can make a decision about their treatment i.e. to watch or not watch the video. The letter is hypothesised to have three effects:

1. Change patient's cognitions about the stroke recovery.
2. Change their cognitions about the interventions that they are offered.
3. Act as a prime to encourage the patients to be more readily accepting of an intervention (the video).

The evidence suggests that patients develop their own representations of their illness, which can be manipulated. Furthermore patients appear to prefer written advice, although it has to be written in a manner that is easy to understand. Psychological models are now being used to develop interventions to understand patient's behaviour in relation to their illness. This evidence can be combined to develop a theoretical intervention, using the five domains of the SRM to encourage people to think about their illness in a positive manner and to take control over their recovery by adhering to an easy intervention.

AIMS

- To develop a theoretical letter using the 5 illness representation domains and the emotional representation of the SRM.
- To observe the effects of the letter and video on the patients' illness and emotional representations, functional limitations and mood.
- To promote adherence to the easy intervention of the video.

RESEARCH QUESTIONS

1. Does a personalised theoretical letter, influence how patients adhere to a video intervention?
2. Do the letter and video influence the patient's illness representations?
3. Do the letter and video influence patient's outcomes in terms of disability and mood?

METHODS[°]

DESIGN

This was a randomised controlled 2 x 2 trial evaluating two simple interventions, a video pack and a theoretical letter, Following a Stroke Trial (FAST). Demographic, clinical and psychological variables were assessed prior to random allocation to one of four conditions, two weeks following discharge to home (T1). Outcome data of adherence, illness representations, disability and mood were assessed at home 6 weeks later (T2).

PARTICIPANTS

A sequential cohort of stroke patients from a geographically defined area, discharged from Ninewells Hospital between September 2002 and June 2003 were invited to take part in the Following a Stroke Trial (FAST) (Figure 5.1) Four hundred and forty one patients were clinically diagnosed with stroke and 233 patient were deemed eligible to take part. Patients who were defined as ineligible were those with communication difficulties i.e. deafness, blindness, verbal communication deficits or cognitive deficits. Patients who were unwell, had co-morbidity of a terminal illness, or were to be discharged to nursing home or another hospital for continuing care were also excluded. A total of 160 stroke patients, who were fluent in English, had passed a cognitive screening test consented to take part with 116 patients actually being interviewed. Two of the patients found the interview too tiring and could not complete the measures therefore their data was omitted from this analysis. Consequently 114 patients were randomised to one of four groups; video only group, video & letter group, letter only group and control group using random numbers (Spiegel 1972) (table 5:1). Participants are discussed further in the results section.

[°] A summary of the precise contribution of the author to the design of the study and data collection can be found in Appendix E.

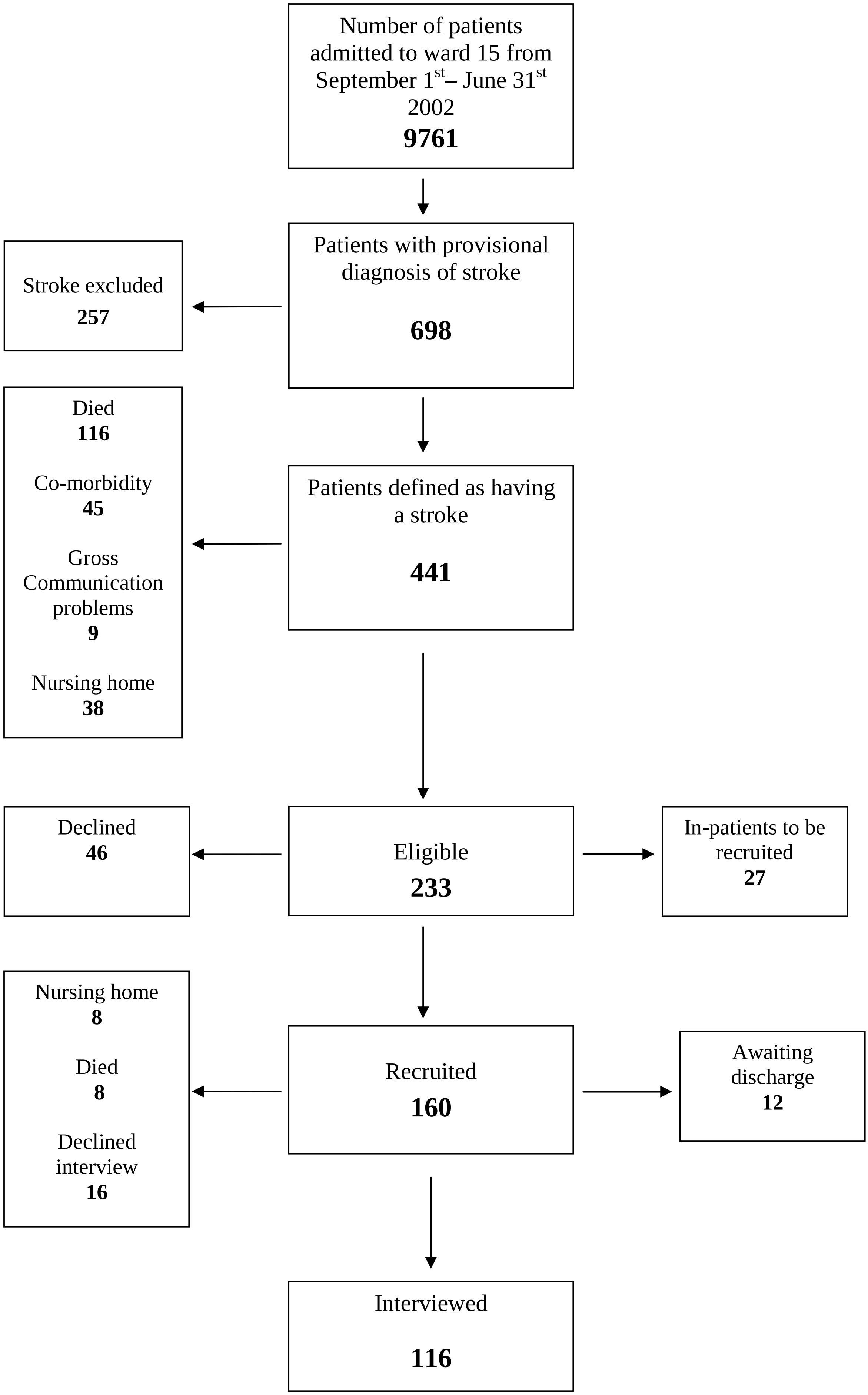

Figure 5.1: Patient Recruitment for FAST Study

Ten patients did not go through to the second interview; 3 patients died and 7 patients declined to do the second interview (figure 5.2). Included in these 7 was a patient who did not respond to three arranged appointments, i.e. she was not in at the arranged times. Also the correspondence from the study that was posted out to her was returned via the postal service to the researcher.

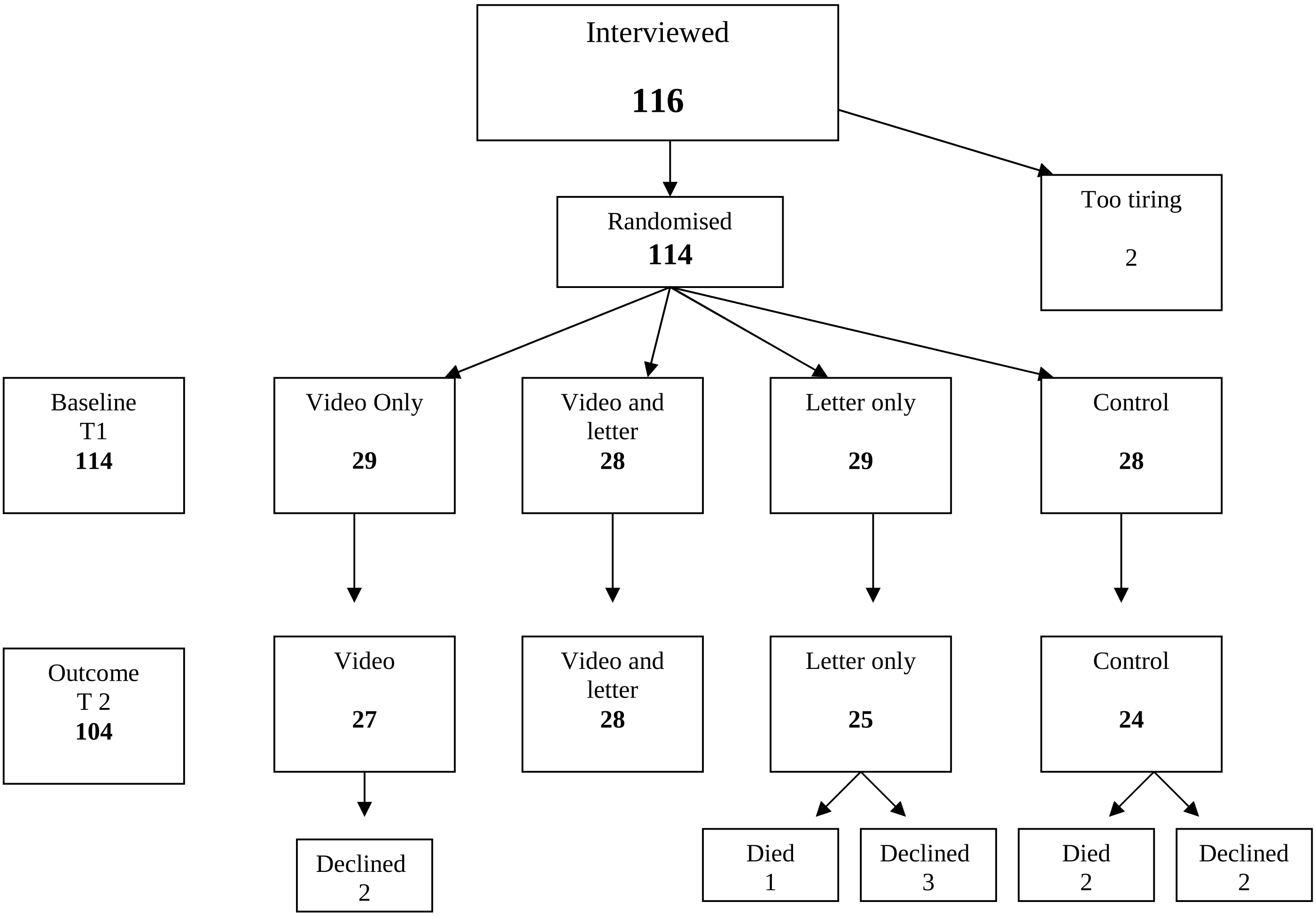

Figure 5.2: Numbers of Patients in Each Condition at T1 and T2 and Reasons for Non-Participation in the Trial

The distribution of men and women in the study group and their ages are displayed in table 5.1 and are further discussed in the results section.

	VIDEO	VIDEO & LETTER	LETTER ONLY	CONTROL	TOTAL
Number	29	28	29	28	114
Male/female	14/15	16/12	14/15	18/10	62/52
Mean age in years (standard deviation)	68 s.d. 10.3	67 s.d. 12.2	70 s.d.12.4	68 s.d. 10.4	68 s.d 11.3

Table 5.1: The FAST Study; Numbers, gender and age per group

RECRUITMENT PROCEDURE

This has previously been described in Chapter 4.

MATERIALS

THE VIDEO INTERVENTION

The HEBS Stroke Recovery Video pack “Stroke Matters”, which includes two videos, made by the Health Education Board for Scotland in collaboration with the Chest Heart and Stroke Foundation Scotland (2000) for stroke survivors. These have been previously described in Chapter 4.

THE LETTER INTERVENTION

The letter (Appendix D) was developed using the SRM (Leventhal et al 1999) as described in Chapter 2. The introductory paragraph acknowledges the principle that people are problem-solvers and when faced with an illness they will try to make sense of their illness by thinking about it in 5 different ways. The following 5 paragraphs went on to describe each of the 5 illness representations of the SRM relating them to the patient’s stroke and recovery, with additional questions asking the patient to think about their recovery in relation to the specific representation. For example, the paragraph pertaining to “identity” suggested that a stroke can affect people in different ways and gave some brief examples. The patient is then asked to think about how their stroke has affected their every day activities and how they could improve this. Each paragraph is written in a positive and encouraging manner suggesting that the reader take an active role in their recovery. The final paragraph pertains to the emotional representations and again describes possible feelings and asks the patient to think about ways of helping them self to feel better.

The finished letter was given out to the Health Psychology group at the University of St Andrews to clarify the letter and gain a consensus regulating the way each illness representation had been described and illustrated. The letter was written on headed paper, and illustrated with colour and the suggestions for patients to think about were put in to “thought bubbles” otherwise known as callouts. The reading ease was slightly easier (Flesch Formula 75.1) than the average adult reading ability (Flesch Formula 60-70). Two health professionals, a medical consultant and a professor in psychology signed the letter. The experimental letter was put into an envelope with the appointment letter for the outcome assessment. These envelopes were either posted out alone or with the video packs, depending on which group they were being sent to.

MEASURES

The following measures have been used in the previous studies and are more fully described in Chapters 3 and 4.

Cognitive Screening Measures

- Clifton Assessment Procedures for the Elderly (CAPE) (Pattie and Gilliard, 1981)
- Mental Status Questionnaire (MSQ) (Wilson and Brass, 1973)

Predictor Variables

Demographic and Clinical Predictors

All these measures have previously been described in Chapter 3. The DEPCAT scores were further described in Chapter 4 where an updated scoring system was introduced. The scoring system used in Chapter 4 is also used in this study examining the theoretical letter. The demographic measures include:

- Gender
- Age
- Employment status
- The National Statistics Socio-economic Classification (NS-SEC) (A National Statistics Publication 2004)
- Presence of carer
- DEPCAT scores-deprivation area of residential address.
- Affected side and stroke event
- Patient's length of stay in hospital
- The Orgogozo Neurological Index (Orgogozo et al.1983)
- The NIH (National Institute of Health) Stroke Scale (Biller et al 1987)
- The Modified Rankin Scale (MRS) (Rankin, 1957)
- The Barthel Index (Mahoney and Barthel, 1965)

Psychological Predictors

All these measures have also been described in Chapter 3 apart from the IPQ – R (Moss-Morris et al 2002) and desire for the video (Bonetti 1999), which have been described in Chapter 4. The psychological predictors include:

- Hospital Anxiety and Depression Scale (HADS) (Zigmond and Snaith, 1983).
- Recovery Locus of Control Scale: (RLOC) (Partridge and Johnston 1989)
- The Ways of Coping Questionnaire (WOC) (Billings and Moos 1981)
- Confidence in Recovery (Morrison et al 2000)
- Desire for the video
- The Revised Illness Perception Questionnaire: (IPQ-R) (Moss-Morris, Weinman et al (2002)

Dependent Variables

- Letter adherence; patients were asked three questions. The first question asked if they received a letter asking them to think about their recovery, the response being no (score 0) or yes (score 1). A copy of the letter was shown to them to act as an "aide memoire". The second question asks if they read it, no (score 0) or yes (score 1). Thirdly they were asked about the contents of the letter and to choose from a list of possible contents, score ranged from 0 – 9. Patients who received the letter were classed as letter adherent if they remained in the intervention for the 5-week duration and reported that they had received the letter and read it.

- Adherence to the video; This measure was described in Chapter 3, where adherence was scored yes if the patient had not withdrawn from the 5-week study and had watched at least one video.

- Observer Assessed Disability (Partridge et al 1987) a scale asking patients to perform 18 movements. A score of 1 is given to each movement observed with a maximum score of 18.

PROCEDURE

Stroke patients admitted to Ninewells hospital between September 2002 and June 2003 were identified and screened by the principle researcher (SAJ) and one of three junior doctors. This information allowed the opportunity to see which patients fulfilled the inclusion criteria. The eligible patients were approached on the wards and invited to participate in the current study. Patients who were discharged before they could be seen on the wards were invited to participate over the telephone or by letter (table 5.2)**.**

METHOD OF RECRUITMENT	NUMBER	PERCENT
On ward	62	54.4
By telephone	42	36.8
By letter	10	8.8
Total	114	100.0

Table 5.2: Recruitment Method: number and percentage of patients

After consent was obtained from the patients and prior to the patient's discharge demographic data and clinical data, including the total scores of the NIH, the Orgogozo Neurological and the Modified Rankin scores were recorded from the audit screening sheet, as well as the stroke event and affected side of the body confirmed where possible by CT scan results.

The data from clinical notes was obtained within the first 48 hours of the patient's admission and normally transferred to Ninewells Stroke Audit database, but this did not occur during FAST due to staff vacancy. Therefore the principal researcher (SAJ) completed this task while the patients were participating in this study.

To examine reliability the principle researcher completed screening sheets independently on 6 patients who had already been screened at admission by a doctor. These were compared and there was complete agreement on all the clinical scores for each of the patients. The demographic and clinical information from the screening sheets used in this study are described in Chapter 3.

At the first baseline interview (T1) following discharge the patients were screened for cognitive and communication difficulties using the CAPE and MSQ to ensure that they were able to use the video, read the letter and answer the questions on the subsequent measures, which included disability (Barthel Index), mood (HADS), perceived control (RLOC), coping (WOC), IPQ-R, confidence in recovery and desire for the video. These measures were administered in a structured interview, by the researcher (SAJ) in the patient's own home. If the patient did not pass the screening tests the measures were not administered. The duration of this interview lasted between 45 minutes to two hours, depending on the number and length of breaks requested in addition to the pre-scheduled break inserted in the middle of the questionnaire.

Following this interview the patient's General Practitioners (GP) were informed of their involvement in the FAST study (see appendix C for details of GPs letters, consent forms, information sheet and complete questionnaire, including additional measures). Within the week following T1, patients were randomly allocated to the intervention groups or the control group by an independent researcher (DD), using the random allocation procedure developed by the independent statistician (BP).

The interventions were sent through the post within 1 week of T1 by an independent researcher (DD). A date for the outcome assessment (T2) was included with the interventions or sent out separately to the control group.

During the 5-week intervention the patients were asked to watch the videos and read the booklets or read the theoretical letter or do both. At T2, 6 weeks after T1, the fulfilment of these requirements were recorded as the outcome measures of adherence (see measures).

Patients who did not want to continue with the intervention were allowed to withdraw at any time without giving any reason. Patients who died or became ill were withdrawn from the study.

After visiting 30 patients at T2 the principle investigator (SAJ) questioned if the letters were being sent out because anecdotally more patients than she expected were saying that they had not received a letter. The independent researcher randomising and sending out the intervention (DD) assured that the letters were being sent and had kept a strict record. Between the independent researcher and the principle investigator it was ensured that the experimental letter was placed in front of the appointment letter in the envelope so that when the envelope was opened the experimental letter would be the first letter to be seen.

RANDOMISATION AND BLINDING

The following description outlines the procedure of randomisation and blinding because this has been previously described in Chapter 4.

The principle researcher (SAJ) recruited and interviewed the patients at T1 and T2. Following the T1 interview the researcher advised the patient that they would receive an appointment for the second interview through the post, which could be rearranged if inconvenient. A contact number was ensured. They were also advised about receiving or not receiving a video and asked not to tell the researcher at T2 whether they had or had not until they were asked. The patients' study number, address and telephone number were recorded in a small book with the date of T1 and the proposed date of T2. An independent researcher (DD) made a copy of these details and used this information to randomise the patients to their respective groups, to receive a video only, video & letter, a letter intervention only, or no intervention at all. Being aware of the proposed T2 interview date the independent researcher posted out the interventions. A week prior to T2 patients in the video groups received a letter signed by a medical consultant and a professor in psychology, to remind them not tell the researcher at the next interview.

To assess the effectiveness of the blinding, the principle researcher (SAJ) recorded whether patients had told her about the interventions or left them out for her to observe during the interviews. Blinding was maintained in 91 cases suggesting that blinding was approximately 80% effective. Eleven percent of patients either told the researcher they had received the video or had left the videos out for the researcher to observe (table 5.3).

	FREQUENCY	PERCENT
Blinding maintained	91	79.8
Video but not letter	7	6.1
Told about interventions	6	5.3
Died	4	3.5
Withdrew	6	5.3
Total	114	100.0

Table 5.3: Effectiveness of the Blinding Procedure on the Researcher

STATISTICAL ANALYSIS

The data was analysed using SPSS (Norusis 1993) computer program. Proof reading and descriptive function of SPSS allowed the accuracy of the database to be examined. All continuous variable values were checked to ensure the scores fell between the minimum and maximum range for each variable. Means and standard deviations were observed to ensure they were “plausible” (Tabachnick and Fidel 2001). Missing data was accounted by replacing with the group mean (Tabachnick and Fidel 2001). All the data was checked for skewness and kurtosis and transformed if present. Cronbach’s alpha was performed to assess internal consistency of clinical and psychological variables used.

To confirm the causal section of the IPQ-R principal components analysis with varimax rotation were carried out as per instructions (Moss-Morris et al 2002). Group differences were examined using t-tests and ANOVA analysis for the continuous data and chi square analysis for dichotomous and nominal data. Fisher’s exact results are reported where the cells in the chi square analysis are less than 5 expected observations. Groups were examined using the intention to treat principle, followed by analyses of groups exposed to the interventions.

To examine relationships between the dependent and independent variables Pearson’s correlations were calculated for continuous data and point bi-serial analysis for the dichotomous data. Multiple and logistic regressions were performed to see which variables were the best predictors of letter adherence.

RESULTS

Missing Data and Psychometrics

Missing data occurred with the clinical measures of NIH, Orgogozo and Rankin due to them not being recorded on the patient's notes or the notes being difficult to locate. Wherever possible every effort was made to track down the notes. If the notes were eventually made available the principle researcher (SAJ) identified the information from the notes and recorded this onto the stroke audit screening sheets. If locating the notes was unsuccessful or the information was not recorded it was accepted that this data was missing and no methods of replacing it was assumed. There was one case of missing data in the psychological measure, WOC and this was replaced by the group means. Apart from the Barthel Index, NIH and Orgogozo, all data appeared to be normally distributed with skewness all falling between ±1 (Hair et al 1998). Both the Barthel Index score and the Orgogozo were transformed by cubing the scores; the square route of NIH was calculated to minimize the skewness and kurtosis of their distributions. These transformations were successful in bringing the clinical measures into a normal distribution with skewness and kurtosis falling between ± 1.

The first 8 patients were given the IPQ (Weinman et al 1996) and the IPQ-R was introduced for the rest of the patients. The items on the IPQ were similar to those items on the IPQ-R but not identical therefore to minimise any misinterpretation the data from the first 8 patients was not used when the IPQ-R was analysed.

Scoring the IPQ-R

Using the IPQ-R data from T1 (n = 106), the first two sections of the IPQ-R including identity, time, consequence, control, and emotion with additional items about patient's perceived understanding of their condition (coherence) coding was carried out according to the IPQ-R instructions (Moss-Morris et al 2002). The third section pertaining to the illness representation of cause was subject to a principal components analysis with a varimax rotation as directed by the instructions (Moss-Morris et al 2002). Using this method, 7 components with Eigen values greater than one emerged explaining 61% of the variance (table 5.4).

This solution was different from Moss-Morris et al (2002) who originally validated the IPQ-R. The results of their principal components analysis with a varimax rotation showed 4 components, which accounted for 57% of the variance. They labelled their four components (IPQ-R CLASSIFICATION) as psychological causes (Ψ), risk factors (*Risk*), chance (*Chance*) and immunity (*Immunity*) (table 5.4).

ITEM	IPQ-R CLASSIFICATION	COMPONENTS LOADINGS > .10						
		1	2	3	4	5	6	7
12	Ψ-emotional state	**.70**	-.17	.22	.15			
18	*Immunity* - altered	**.63**	.21		.15			.24
4	*Risk* - diet		**.67**	.14			-.16	.24
8	*Risk* – own behaviour	.30	**.49**	.16	-.14	.21		-.37
11	Ψ - overwork	-.15	**.73**		.23	-.11		
14	*Risk* -alcohol	.41	**.52**	-.13	-.21	.27	.23	
2	*Risk* - hereditary	.23	-.18	**.49**				
6	*Risk* - past medical care	-.10	.14	**.79**				.18
9	Ψ – mental attitude	.37	.22	**.57**	.27	.23		
15	*Risk* - smoking		.35	**.44**	.19		.30	-.18
1	Ψ - stress	.34	.25	-.16	**.75**	.14		
10	Ψ – family worries		-.13	.33	**.76**			
5	*Chance* – bad luck	.40		.13	-.12	**-.63**	.10	-.22
17	Ψ - personality	.27			.11	**.79**		
3	*Immunity* - germ	.15			.22	-.30	**.66**	
16	*Chance* -accident			.16		.18	**.82**	
7	*Immunity* - pollution					.13		**.76**
13	*Risk* -ageing	.43	.11			-.15	.19	**.55**
	Alphas	*.41*	*.55*	*.51*	*.52*	*.54*	*.41*	*.28*

Table 5.4: Principal Component Analysis with Varimax Rotation of the “Cause” Items from the IPQ-R (7 components)

In another study using the IPQ-R to examine illness representations of patients with multiple sclerosis, Jopson and Moss-Morris (2003) omitted 3 items (as they were considered to be unrelated to multiple sclerosis) prior to performing a principal components analysis and found three components emerged and named them psychological, genetic and physiological causes.

The 7 component solution (table 5.4) for this study did not reflect the findings of the other two studies and appears to be too “unwieldy” for further analysis therefore a second principal components analysis was carried out limiting it to a four-component solution to allow for generalising and comparing to other studies (table 5.5).

ITEM	IPQ-R GROUPINGS/ITEMS	GROUP NAMES	COMPONENTS LOADINGS > .10			
			1	2	3	4
1	Ψ - stress	Cause - Psychological (5 items)	**.63**	.23		
9	Ψ – mental attitude		**.60**	.25	.37	
10	#Ψ- family worries		**.50#**	-.20	.45#	-.16
12	Ψ – emotional state		**.66**			.34
17	Ψ – personality		**.63**			-.29
4	*Risk* - diet	Cause - Controllable personal risk (4 items)		**.66**		.13
8	*Risk*– own behaviour		.25	**.57**		
11	Ψ - overwork			**.67**	.15	
14	*Risk* - alcohol		.20	**.61**	-.14	.18
2	#*Risk* - hereditary	Cause - Uncontrollable personal risk (4 items)	.29	-.16	**.34#**	.15
6	*Risk* – past medical care			.11	**.69**	
15	*Risk* - smoking		.17	.33	**.56**	
16	*Chance* - accident				**.50**	
3	*Immunity* - viral	Cause - External risk (5 items)			.35	**.45**
5	*Chance* – bad luck					**.58**
7	#*Immunity* - pollution					**.22#**
13	*Risk* - ageing			.13		**.65**
18	#*Immunity* - altered		.44#	.25		**.48**
	Alphas		*.65*	*.55*	*.40*	*.40*
	Alphas-#items omitted		*.60*		*.39*	*.30*
	Alphas-#items>.4 added		*.66*		*.45*	

Table 5.5: Principal Component Analysis with Varimax Rotation of the "Cause" Items from the IPQ-R Forced into a Four-Component Solution

In this analysis the four-component solution accounted for less variance than Moss-Morris et al (2002) but showed similar item loadings onto four components. Using Moss-Morris et al's (2002) classification as criteria to examine this present solution, 5 psychological items loaded onto the first component giving an internal reliability score of .65. However item 10 could possibly load onto two components so a Cronbach's alpha was performed on component 1 omitting item 10 which reduced the internal reliability to .60. Item 18 could also load onto the first component although the factor loading was slightly greater for the fourth component so a further reliability analysis was performed to include item 18, yielding a Cronbach's alpha of .66, minimally increasing the internal reliability. Items loading onto components 3 and 4 both produced a Cronbach's alpha of .40 indicating a very low internal reliability also low component loadings (less than .4 which was used in Moss-Morris et al 2002). When this was examined further by omitting items that were lower than .4 or those that loaded onto more than one component the internal reliability was further reduced (table 5.5). With three items loading onto component 3 a Cronbach’s alpha of .39 was achieved and 3 items loaded onto component 4, a Cronbach’s alpha of .30. Examining component 3 and including item 10 in the analysis (this could load onto component 1 or 3), the Cronbach’s alpha increased to .45. Following this analysis the logic of the principal components analysis with the varimax rotation was examined.

The first component comprised of psychological attributions and has been named “Psychological Cause”. The second component comprised of three risk factor items, diet, own behaviour and alcohol intake and one psychological item, “overwork”. A possible explanation for this is that for some people overwork may be defined as a risk rather than a psychological attribution as defined by Moss Morris et al (2002). Overwork may be perceived as being a risk of the job, an external necessity i.e. the job is demanding by its’ nature, an individual feels that they have to work and therefore overwork is not directly controllable and therefore a risk. These four items could be described as present risk factors that could be perceived as controllable if necessary and therefore have been named “Controllable personal risk” (Controllable PR). Similarly, component three contained three risk factors, hereditary, past medical care, and smoking, plus one chance attribution pertaining to accident or injury again which may be defined as a risk in relation to day to day activities. The items in this grouping all appear to have an uncontrollable element to them or could have happened in the past. Some people feel that they have an inability to give up smoking therefore they could perceive this behaviour as uncontrollable. However it should be noted that when patients answered these questions many of them had given up smoking at the time of the stroke or had given up in the past and did not relate smoking as a cause now that they had given up. These items were defined as “Uncontrollable personal risk” (Uncontrollable PR). Component number four contains all three immunity elements, viral, pollution altered immunity plus one chance item (bad luck), and one risk item (ageing). Logically these items could all fall into this group because they pertain to causes over which the individual has little control and have therefore have been labelled as “External Risk”. Components 3 and 4 do have low Cronbach’s alphas suggesting that internal reliability of these items is poor.

In summary, subjecting 18 causal items from the cause section of the IPQ-R to a principal components analysis with the varimax rotation as per instructions revealed a 7-component solution, which appeared to be unwieldy for future analysis. Forcing the items into a 4-component solution resulted in low component loadings and poor internal reliability. This was examined further to see if the internal reliability could be improved and to observe any logical item groupings that may be present. In light of these observations the groupings are kept to the forced 4-component solution principal component analysis with varimax rotation (table 5.5) as they could be explained logically and this method maintained a marginally higher internal reliability. At best this measure is poor and this needs to be considered when interpreting future analysis using this measure. This measure will be further discussed in the discussion section of this chapter.

DEVELOPING ADHERENCE MEASURES - to the letter intervention

To measure letter adherence, patients were asked if they had received a letter and if so did they read it; and those who said yes to both were asked about the contents of the letter. The letter was sent to 57 patients; one patient died and therefore his data was not included (n = 56). Thirty patients claimed not to have received a letter, 4 people chose not to read it and 22 claimed to have read it once or more (figure 5.3).

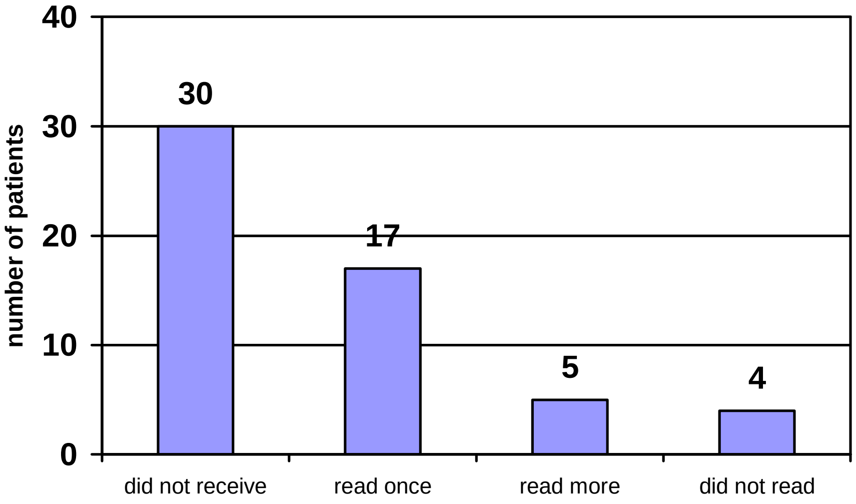

Figure 5.3: Patients Response to Question Asking If They Had Received or Read the Letter

When patients were asked about the contents of the letter, 7 of the 22 patients said they had read it but could not recall anything. In light of the poor response patients were classified as “readers” if they reported receiving and reading the letter (n = 22). Two patients withdrew from the study prior to the receiving the letter and completing T2 outcome assessment. Their data was combined with the patients who reported that they did not receive the letter or did not read it and were classified as “non-readers” (n = 34). These groups are examined after the presentation of the general descriptive data.

Descriptive Statistics

The data from 114 stroke patients were analysed and the general descriptive statistics of the demographic and clinical variables are reported in table 5.6.

MEASURES	N	T1	CLASSIFICATION/MEAN (S.D)			
			VIDEO		NO VIDEO	
DEMOGRAPHIC		α	Letter	No letter	Letter	No letter
Gender: male/female	114		16/12	14/15	14/15	18/10
Age: in years	114		67 (12.6)	68 (10.3)	70 (12.4)	68 (10.4)
Employment, retired: yes/no	114		22/6	22/7	22/7	25/3
Depcat: 1-3/4-6	114		14/14	9/20	17/12	15/13
Registrar general: 1-4/5-8	112		13/15	11/18	13/15	12/15
With carer: yes/no	114		21/7	20/9	20/9	19/9
CLINICAL						
Time in hospital	114		41.21 (61.59)	25.14 (26.70)	39.1 (50.52)	30.64 (37.61)
Affected side: left/right	114		15/13	12/17	18/11	16/12
Stroke event: first /previous	**114**		**27/1**	**20/9**	**25/4**	**25/3**
Orgogozo	100		76.1 (15.28)	77.61 (20.41)	78.85 (17.45)	83.65 (13.97)
NIH	100		5.52 (4.14)	5.33 (3.51)	4.54 (4.60)	4.27 (3.17)
Rankin	100		2.89 (1.01)	2.57 (1.39)	2.73 (1.40)	2.27 (1.15)
Barthel Index	114	.82	17.05 (2.77)	17.86 (3.14)	17.93 (3.01)	18.39 (2.13)

Table 5.6: Demographic and Clinical Variables; number of responses; classification, means, standard deviations and Cronbach's alphas.

One-way ANOVAs and Chi ^{2} analyses revealed only one difference between the four groups. There were significantly fewer patients in the video & letter group who had had a previous stroke (table 5.6).

INTERVENTION	COUNT	FIRST STROKE	PREVIOUS STROKE	CHI	*p*
Video only	Observed Expected % within intervention	20 24.7 69%	9 4.3 31%	**9.20 (*df* = 3)**	**.03**
Video & letter	Observed Expected % within intervention	27 23.8 96%	1 4.2 4%		
Letter only	Observed Expected % within intervention	25 24.7 86%	4 4.3 14%		
Control	Observed Expected % within intervention	25 23.8 89%	3 4.2 11%		

Table 5.7: Differences between the Four Groups of History of Previous Stroke: χ^2 results

By examining the contingency table (table 5.7) four cells included an expected frequency of less than five. To resolve this problem recoding was applied but this reduced the number of groups and therefore required the video groups and the letter groups to be examined separately. A Chi ^{2} analysis was used to examine the association between patients who received the video and those who did not and no significant result was obtained (table 5.8).

INTERVENTION	COUNT	FIRST STROKE	PREVIOUS STROKE	CHI	*p*
Video	Observed Expected % within intervention	47 48.5 83%	10 8.5 17%	.62 (*df* = 1)	.43
No video	Observed Expected % within intervention	50 48.5 88%	7 8.5 12%		

Table 5.8: Differences between Those Who Did and Did Not Receive the Video and History of Previous Stroke: χ^{2} results

A further Chi ^{2} analysis was used to examine the association between patients who received the letter and those who did not and again no significant result was obtained although there was a trend towards significance (table 5.9). Those receiving the letter tended to have fewer strokes, but examination of table 5.7 indicates that this is only for the video & letter group.

INTERVENTION	COUNT	FIRST STROKE	PREVIOUS STROKE	CHI	*P*
Letter	Observed Expected % within intervention	52 48.5 91%	5 8.5 9%	3.39 (*df* = 1)	.07^
No letter	Observed Expected % within intervention	45 48.5 79%	12 8.5 21%		

Table 5.9: Differences between Those Who Did and Did Not Receive the Letter and History of Previous Stroke: χ^{2} results

Statistically this is a problem therefore as a precaution first and previous strokes are controlled for in future analyses.

The general descriptive statistics for the psychological and dependent variable measures are displayed in table 5.10 and ANOVA results in Appendix D.

PSYCHOLOGICAL MEASURES	T1	MEAN (S.D)			
		VIDEO		NO VIDEO	
HADS (n= 114)	α	Letter	No letter	Letter	No letter
Mood	.85	10.54 (8.19)	12.93 (7.67)	11.93 (6.94)	12.68 (7.66)
Anxiety	.82	5.14 (4.91)	6.07 (3.98)	5.55 (4.56)	6.00 (4.41)
Depression	.78	5.39 (4.32)	6.86 (4.45)	6.38 (4.11)	6.69 (4.25)
RLOC (n = 114)					
RLOC	.69	36.54 (4.06)	35.07 (3.95)	35.28 (3.82)	35.75 (3.49)
IPQ-R (n = 106)					
Identity	----	3.59 (1.82)	4.14 (2.48)	4.11 (2.45)	4.88 (2.80)
Timeline - chronic	**.82**	**14.81 (3.66)**	**17.86 (4.34)**	**16.37 (3.87)**	**17.17 (4.76)**
Timeline – cyclical	.72	10.52 (3.18)	10.54 (2.41)	10.89 (3.08)	11.13 (2.77)
Consequence	.71	19.81 (4.22)	21.57 (2.78)	20.48 (3.83)	19.75 (3.95)
Control – personal	.61	23.19 (2.32)	22.25 (2.40)	21.93 (2.22)	23.00 (2.32)
Control - treatment	.48	19.07 (1.77)	19.07 (1.88)	18.52 (2.10)	18.63 (1.84)
Illness coherence	.84	14.59 (4.04)	15.36 (4.49)	14.48 (3.52)	14.04 (3.74)
Emotional representation	.83	17.78 (5.32)	17.54 (3.94)	18.59 (5.06)	18.63 (4.69)
Cause: psychological	.65	12.67 (3.22)	12.39 (2.80)	11.96 (2.53)	12.96 (2.71)
Cause: controllable PR	**.55**	**9.67 (2.35)**	**11.04 (2.76)**	**9.26 (1.81)**	**9.79 (2.17)**
Cause: uncontrollable PR	.40	9.78 (2.10)	9.50 (2.30)	9.52 (2.10)	9.08 (1.86)
Cause: external risk	.40	13.56 (1.93)	13.57 (2.39)	13.44 (1.95)	13.21 (2.38)
WOC (n = 114)					
Active coping	.70	40.79 (8.28)	41.48 (9.36)	41.24 (6.54)	41.93 (8.72)
Active cognitive	.46	19.96 (4.15)	19.97 (4.70)	21.24 (4.05)	19.79 (4.91)
Active behavioural	.60	20.82 (5.28)	21.52 (5.47)	20.00 (4.30)	22.14 (4.57)
Avoidant	.31	10.96 (3.40)	11.34 (2.92)	11.62 (3.51)	11.50 (3.69)
Problem focused	.70	24.68 (6.04)	24.55 (6.51)	24.14 (5.55)	25.21 (6.00)
Emotion focused	.28	30.39 (5.11)	31.41 (4.69)	32.00 (5.71)	31.46 (6.06)
DESIRE FOR VIDEO (n = 114)					
Desire	----	3.61 (1.50)	3.96 (1.39)	3.48 (1.46)	3.82 (1.52)
CONFIDENCE IN RECOVERY (n = 114)					
Confidence	----	8.54 (1.97)	8.21 (2.46)	8.28 (2.31)	8.32 (2.26)

Table 5.10: Psychological Variables: classification, Cronbach’s alphas, mean scores, and standard deviations taken at T1

Again the four groups were examined for differences and two differences occurred. These results suggested that patients who received the video & letter perceived their stroke to be less chronic ($F_{(3,102)} = 2.68$ $p = .05$*) (table 5.11) and patients in the video only group perceived controllable personal risk behaviour attributing to the cause of their stroke ($F_{(3,102)} = 3.05$, $p = .03$*) (table 5.11).

PSYCHOLOGICAL	SOURCE OF VARIANCE	SUMS OF SQUARES	DF	MEAN SQUARE	F	SIG.
Time line-chronic	**Between groups**	**139.13**	**3**	**46.38**	**2.68**	**.05**
	Within groups	**1767.13**	**102**	**17.33**		
	Total	**1906.26**	**105**			
Cause: Controllable PR	**Between groups**	**48.66**	**3**	**16.22**	**3.05**	**.03**
	Within groups	**542.11**	**102**	**5.32**		
	Total	**590.76**	**105**			

Table 5.11: ANOVA Output for Time-Line Chronic and Cause: Controllable Perceived Risk

A post-hoc analysis using LSD examined time-line chronic and showed a significant difference between the video & letter group and the video only group (*p* = .01**) and between the video & letter and the control group (*p* = .05*) (figure 5.4)

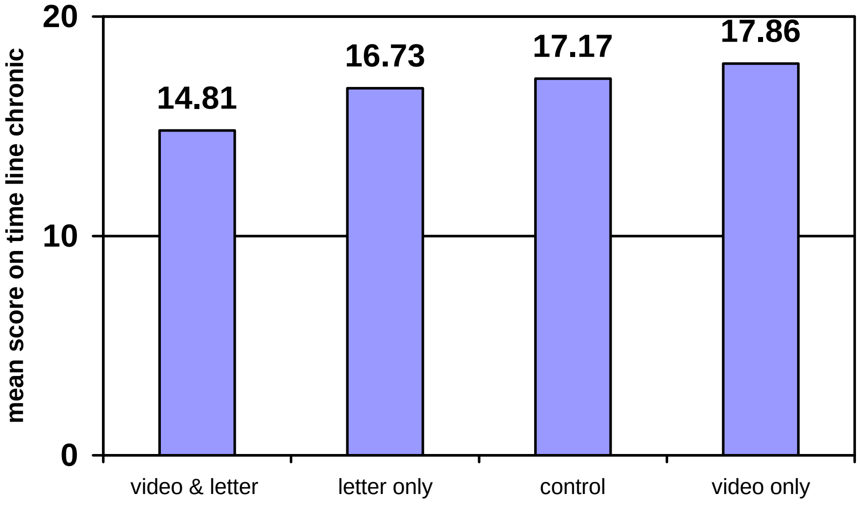

Figure 5.4: Mean Score for Time Line-Chronic (IPQ-R) for Each Group

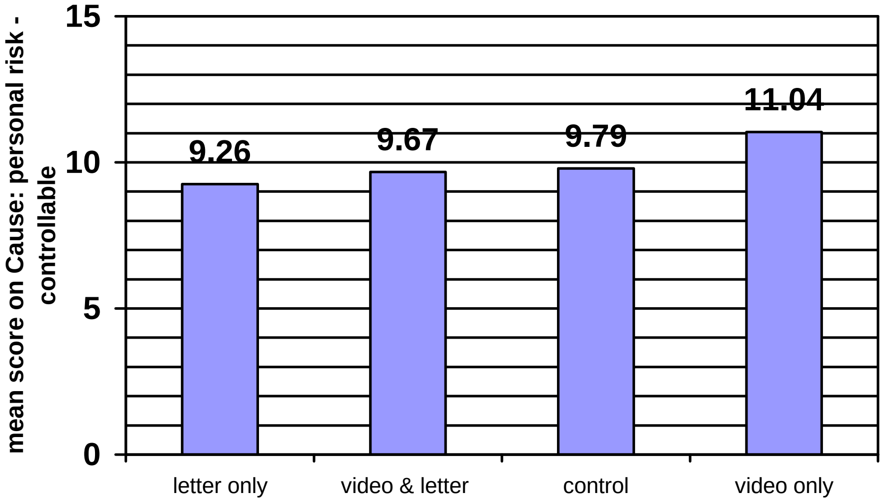

Figure 5.5: Mean Score on Cause: Controllable Personal Risk (IPQ-R) for Each Group

A post-hoc analysis using LSD examined Cause: controllable personal risk and showed a significant difference between the video & letter group and the video only groups (*p* = .03*) and between the video only and the letter only groups (*p* = .01**).

Given the group differences in previous strokes reported earlier, time-line chronic and cause: personal risk controllable were examined for those who had had a first or previous stroke. Two t-tests were performed and no significant differences were found, (table 5.12).

PSYCHOLOGICAL MEASURES	N	MEAN SCORE (STANDARD DEVIATION)		T-TEST
		First stroke	Previous stroke	
Time-line chronic	106	16.37 (4.13)	17.56 (4.95)	t (104) = -1.04, *p* = .30
Cause: controllable PR	106	9.98 (2.38)	9.81 (2.37)	t (104) = .26, *p* = .80

Table 5.12: Patients Who had First or Previous Stroke and their Perception of Time-Line Chronicity and Cause: Controllable Personal Risk; t-test results

In summary there appears to be three differences between the groups at baseline. These are history of previous stroke, time-line chronic and cause: controllable personal risk, which can all be controlled in future analyses.

Implications of Reading or Not Reading the Letter

Letter adherence has been previously described and needs to be examined before answering the research questions because 34 (61%) patients claimed not to have received the letter. One suggests that patients who are not exposed to the letter cannot be influenced by the information.

T-tests and chi square analyses were performed on the demographic, clinical and psychological variables to examine differences between readers (n = 22) and non-readers (n = 34) (tables 5.13, 5.14, 5.16 respectively).

DEMOGRAPHIC MEASURES	N	NUMBERS		χ^2
		Readers	Non-readers	
Gender: female male	26 30	12 10	14 20	χ^2 = .96 (*df* 1) *p* = .33
Employment: retired not retired	43 13	16 6	27 7	χ^2 = .34 (*df* 1) *p* = .56
Living: with carer without carer	41 15	17 5	24 10	χ^2 = .30 (*df* 1) *p* = .58
DEPCAT: 1-3 4-6	30 26	10 12	20 14	χ^2 = .96(*df* 1) *p* = .33
Socio-economic gp: 1-4 5-8	26 30	9 13	17 17	χ^2 = .44 (*df* 1) *p* = .51
		MEAN SCORES (STANDARD DEVIATION)		T-TESTS
Mean age - years	56	65.59 (12.92)	69.56 (11.36)	*t* (54) = 1.21, *p* = .23
DEPCAT score: 1 – 6	56	3.77 (1.63)	3.47 (1.54)	*t* (54) = .70, *p* = .49

Table 5.13: Demographic Differences between Letter Readers and Non-Readers: χ^2 & t-test results.

There were no difference between readers and non-readers in terms of demographic variables. The patients' reading ability may have had an effect on patients' letter reading. The only indicator of reading ability available was the National Statistics Socio-Economic Classification. When patients were divided into socio-economic groups of high (1-4) and low (5-8) and compared with reading or not reading the letter no significant association was found between the two groups (χ^2 = .44 (*df* 1) *p* = .51).

CLINICAL MEASURES	N	NUMBERS		χ^2
		Readers	Non-readers	
Affected side: left **right**	**32** **24**	**9** **13**	**23** **11**	**χ^2 = 3.90 (*df* 1) p = .05**
Stroke event: first previous	51 5	21 1	30 4	χ^2 = .86 (*df* 1) p = .36 Fishers Exact p = .64
		MEAN SCORE (STANDARD DEVIATION)		T-TEST
[1]Orgogozo (transformed)	52	466357.95 (237535.81)	559133.33 (257520.68)	t (50) = 1.33, p = .19
[2]NIH (transformed)	52	2.27 (.83)	1.90 (.94)	t (50) = -1.43, p = .16
[2]Modified Rankin	52	2.90 (1.15)	2.73 (.1.28)	t (50) = -.51, p = .61
Time in hospital	56	47.18 (61.05)	36.32 (53.22)	t (54) = -.70, p = .49
[1]Barthel Index (transformed)	56	5691.36 (2087.48)	6123.88 (2160.96)	t (54) = .74, p = .46

[1]Orgogozo & Barthel Index: higher score = less impairment 2NIH and Rankin: lower score = less impairment

Table 5.14: Clinical Differences between Letter Readers and Non-Readers: χ^2 & t-test results

There was one significant difference between letter readers and non-readers in relation to clinical variables (table 5:14). Patients who read the letter were more likely to have a right-sided weakness than those patients who did not read the letter (table 5.15).

LETTER INTERVENTION	COUNT	LEFT SIDE	RIGHT SIDE	CHI	*p*
Readers	Observed Expected % within intervention	9 12.6 41%	13 9.4 59%	**3.90** **(*df* = 1)**	**.05**
Non - readers	Observed Expected % within intervention	23 19.4 68%	11 14.6 32%		

Table 5.15: Chi ^{2} Analysis Contingency Table for Analysis of Left and Right Sided Weakness and Adhering To the Letter or Not

There were no psychological differences between readers and non-readers (table 5.16). The only possible difference that existed between the patients who adhered to reading the letter and those who did not was affected side, which is controlled for in subsequent analyses.

PSYCHOLOGICAL MEASURES	MEAN SCORE (STANDARD DEVIATION)		T-TEST
HADS (n = 56)	Readers	Non-readers	
Mood	11.86 (7.57)	10.65 (7.62)	*t* (54) = -.58, *p* = .56
Anxiety	5.77 (4.84)	4.91 (4.61)	*t* (54) = - .60 *p* = .51
Depression	6.09 (4.84)	5.74 (3.87)	*t* (54) = -.30 *p* = .76
RLOC			
RLOC	35.77 (3.20)	36.03 (4.46)	*t* (54) = .23, *p* = .82
IPQ-R (n = 53)			
Identity	4.25 (2.12)	3.48 (2.06)	*t* (51) = -1.29, *p* = .20
Timeline - chronic	16.65 (3.03)	15.00 (4.18)	*t* (51) = -1.53, *p* = .13
Timeline – cyclical	10.95 (3.43)	10.39 (2.83)	*t* (51) = -.64, *p* = .53
Consequence	20.75 (4.02)	19.76 (4.06)	*t* (51) = -.87, *p* = .39
Control – personal	21.90 (2.27)	22.97 (2.35)	*t* (51) = -1.63, *p* = .11
Control - treatment	18.70 (1.42)	18.82 (2.24)	*t* (51) = -.21, *p* = .83
Illness coherence	14.70 (3.73)	14.52 (3.86)	*t* (51) = -.17, *p* = .87
Emotional representation	19.00 (5.45)	17.58 (5.01)	*t* (51) = -.97, *p* = .34
Cause: psychological	11.75 (2.67)	12.61 (3.04)	*t* (51) = 1.04, *p* = .30
Cause: controllable PR	9.25 (2.10)	9.58 (2.14)	*t* (51) = .54, *p* = .59
Cause: uncontrollable PR	9.40 (1.93)	9.85 (2.20)	*t* (51) = .75, *p* = .46
Cause: external risk	13.45 (1.79)	13.45 (2.00)	*t* (51) = .01, *p* = .99
WOC (n = 56)			
Active coping	41.81 (6.53)	40.38 (8.01)	*t* (54) = -.70, *p* = .49
Active cognitive	21.05 (4.03)	20.17 (4.15)	*t* (54) = -.78, *p* = .44
Active behavioural	20.77 (4.77)	20.21 (4.91)	*t* (54) = -.43, *p* = .67
Avoidant	11.14 (3.24)	11.47 (3.64)	*t* (54) = -35, *p* = .73
Problem focused	25.32 (4.51)	23.79 (6.49)	*t* (54) = -.96, *p* = .34
Emotion focused	30.95 (6.30)	31.29 (4.96)	*t* (54) = -.23, *p* = .82
DESIRE FOR VIDEO			
Desire	3.64 (1.29)	3.50 (1.60)	*t* (54) = -.35, *p* = .74
CONFIDENCE IN RECOVERY			
Confidence	8.23 (1.75)	8.50 (2.40)	*t* (54) = .46, *p* = .65

Table 5.16: Psychological Differences between Letter Readers and Non-Readers: t-test results

Correlational analyses between all variables and patients reported reading the letter were performed (Appendix D). Patient's report of reading the letter was only significantly correlated with affected side, i.e. patients who had a right sided weakness were more likely to read the letter than those who had a left sided weakness. Correlations where probability was .20 or less (Hair et al 1998) included clinical predictors of affected side (r = .26 *p* = 0.05*), NIH (transformed) (r = .20 *p* = .16), and Orgogozo (transformed) (r = -.18 *p* = 0.19) and psychological predictors of identity(r = .18 *p* = .20), time-line chronic (r = .21 *p* = .13) and personal control (r = -.22 *p* = .11). These variables were entered into a logistic regression to confirm the best predictor of letter adherence (table 5.17).

The -2LL value decreased from 67.03 to 59.05. The R^2 values ranged from .15 - .21 and the Hosmer and Lemeshow χ^2 value showed a non-significant (χ^2 = 13.04 (*df* 8) *p* = .11) indicating a good overall model fit. However in this model no variable significantly predicted letter adherence.

VARIABLES IN THE EQUATION	B	S.E.	WALD	DF	SIG.	EXP (B)
Affected side	-1.11	.66	2.81	1	.09	.33
NIH (transformed)	.15	.55	.07	1	.79	1.16
Orgogozo (transformed)	.00	.00	.18	1	.68	1.00
T1 identity	.10	.18	.34	1	.56	1.11
T1 time-line chronic	.05	.11	.25	1	.62	1.06
T1 personal control	-.18	.16	1.32	1	.25	.84
Constant	3.08	4.80	.41	1	.52	21.81

B = logistic coefficient; S.E. = standard error; WALD = Wald statistic; DF = degrees of freedom; Sig. = significance level; EXP (B) = exponentiated coefficient.

Table: 5.17: Logistic Regression Analysis of Letter Adherence Predictor Variables with Probabilities of .20

In summary, although patients (n = 56) were randomly allocated to receive the letter 34 (61%) of that group reported that they did not read the letter. There were no significant demographic or psychological differences between readers and non-readers. Clinically, patients with a right-sided weakness were more likely to report reading the letter than those patients with a left-sided weakness. However, when this variable was entered into a logistic regression analysis along with variables that were correlated with letter adherence no single variable predicted patients reading the letter, suggesting that there are no clear predictors of letter adherence.

RESEARCH QUESTION 1: Does a personalised theoretical letter, influence how patients adhere to a video intervention?

A chi square analysis was calculated using video adherence categories from study 2 Chapter 4 and compared those patients allocated to receive the letter with those who were not. There appeared to be no difference in adherence between those who received the letter and those who did not (table 5.18).

INTERVENTION	COUNT	VIDEO ADHERENCE	NON ADHERENCE	CHI	*p*
Video only	Observed Expected % within intervention	21 21.9 72%	8 7.1 28%	.29 (*df* = 1)	.59
Video & letter	Observed Expected % within intervention	22 21.1 79%	6 6.9 21%		

Table: 5.18: Effect of Receiving the Theoretical Letter on Video Adherence: χ^2 results

Given that not all the patients read the letter, patients from the video & letter group were divided into those who claimed to have read the letter (n = 12) and those who did not (n = 16) and another chi square analysis was performed (table 5.19).

DEPENDENT VARIABLE	COUNT	VIDEO ADHERENCE	NON ADHERENCE	CHI	*p*
Letter readers	Observed Expected % within intervention	11 9.4 50%	1 2.6 16.7%	2.4 (*df* = 1)	.14 Fishers Exact *p* = 20
Non-readers	Observed Expected % within intervention	11 12.6 50%	5 3.4 83.3%		

Table 5.19: Effect of Reading the Letter on Video Adherence: χ^2 results

Again there appears to be no significant association between video adherence and reading the letter. This was further confirmed by Fishers Exact test (reported in table 5.19) to account for the two cells in the analysis that had expected frequencies lower than five. To minimise expected frequencies lower than five the video only group (n = 29) was included in the analysis increasing the letter non-readers to 45 participants (table 5.20).

DEPENDENT VARIABLE	COUNT	VIDEO ADHERENCE	NON ADHERENCE	CHI	*p*
Letter readers	Observed Expected % within intervention	11 9.1 92%	1 2.9 8%	2.16 (*df* = 1)	.14 Fishers Exact *p* = 26
Non-readers Inc. video only group	Observed Expected % within intervention	32 33.9 71%	13 11.1 29%		

Table 5.20: Effect of Reading the Letter on Video Adherence Including the Video Only Group: χ^2 results

Although there was only one cell with expected frequencies less than 5 (table 5.21), again no association between letter adherence and video adherence was found.

To complete the analyses for this question the amount of adherence in relation to the video as recorded from Chapter 4 was used for the next analysis. A t-test analysis was calculated using the video adherence score from study 2, Chapter 4 for 28 patients in the video & letter group and compared those patients who read the letter and those who did not. There appears to be a significant difference in the amount of adherence to the video between those who read the theoretical letter and those who did not (table 5.21).

PSYCHOLOGICAL MEASURES	N	MEAN SCORE (STANDARD DEVIATION)		T-TEST
		Readers	Non-readers	
Video adherence score	**28**	**7.92 (2.87)**	**5.06 (4.34)**	**t = 2.09 (*df 25.7*) *p* = .05**

Table 5.21: Video Adherence Score; Differences between Readers and Non-Readers: t-test result

In summary, a simple communication letter did not appear to increase adherence to a self-help video. However if it is read, the amount of adherence in the video intervention, i.e. watching both videos, recalling the contents and looking through the associated booklets in the package appears to be greater than those people who did not read the letter.

RESEARCH QUESTION 2: Do the letter and video influence the patient's illness representations?

To answer this question the data from 97 patients were used to analyse the IPQ-R (8 patients did not complete the IPQ-R at T1 and one of these patients died by T2 see page 19) and 104 patients to analyse the remaining psychological variables (see figure 5.2 for attrition). Individual 2x2 between-subject ANOVAs were carried out on the four groups and the dependent variables measuring illness representations taken at T2, controlling for previous stroke, affected side, time-line-chronic at T1 and Cause: controllable personal risk (table 5.22 a, b, c and d)

MEASURES	T2	INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	*df*	*F*	*p*
		VIDEO		NO VIDEO						
IPQ-R	α	Letter	No letter	Letter	No letter					
Identity		3.26 (1.97)	3.12 (2.44)	3.43 (2.06)	3.48 (2.56)	Main effects; video	.05	1	.01	.92
						letter	.06	1	.01	.91
						2 way interaction	.41	1	.09	.77
						Error	406.35	89		
						Total	1539.00	97		
Time-line chronic	.78	17.78 (3.89)	17.92 (4.30)	16.78 (4.38)	15.38 (3.80)	Main effects; video	17.57	1	1.40	.24
						letter	3.62	1	.29	.59
						2 way interaction	17.40	1	1.38	.24
						Error	1121.16	89		
						Total	28085.00	97		
Time-line cyclic	.87	10.78 (2.98)	10.92 (3.27)	10.78 (3.75)	9.24 (1.97)	Main effects; video	21.05	1	2.25	.14
						letter	11.45	1	1.22	.27
						2 way interaction	14.19	1	1.52	.22
						Error	833.15	89		
						Total	11591	97		
Consequence	.78	19.78 (4.40)	20.50 (3.22)	19.35 (5.00)	18.43 (4.11)	Main effects; video	47.15	1	3.40	.07^
						letter	11.04	1	.80	.36
						2 way interaction	1.13	1	.08	.78
						Error	1233.93	89		
						Total	38955.00	97		
Control -personal	**.64**	**23.44 (1.97)**	**21.73 (2.34)**	**22.17 (3.11)**	**23.33 (1.85)**	Main effects; video	.28	1	.05	.82
						letter	.20	1	.04	.85
						2 way interaction	**31.20**	**1**	**5.66**	**.02***
						Error	490.37	89		
						Total	30380.00	97		
Control - treatment	.60	18.93 (2.11)	18.35 (2.08)	18.83 (2.27)	19.48 (2.27)	Main effects; video	9.00	1	1.89	.17
						letter	0.07	1	.02	.90
						2 way interaction	10.84	1	2.28	.13
						Error	422.77	89		
						Total	349802.00	97		

Table 5.22a: Difference in Mean Score of Illness Representations in the Four Groups: ANOVA results

MEASURES	T2	INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	*df*	*F*	*p*
		VIDEO		NO VIDEO						
IPQ-R	α	Letter	No letter	Letter	No letter					
Illness Coherence	.83	16.19 (3.61)	15.77 (4.55)	15.35 (3.42)	15.24 (3.85)	Main effects; video	1.8	1	.12	.73
						letter	8.28	1	.54	.46
						2 way interaction	4.78	1	.31	.58
						Error	1358.07	89		
						Total	25242.00	97		
Emotional	.87	17.81 (5.50)	17.46 (4.20)	16.43 (4.56)	16.90 (4.76)	Main effects; video	21.71	1	1.00	.32
						letter	3.53	1	.16	.69
						2 way interaction	16.03	1	.74	.39
						Error	1932.78	89		
						Total	30852.00	97		
Cause: psychological	.69	13.30 (3.12)	12.04 (2.29)	12.04 (2.29)	12.38 (2.67)	Main effects; video	3.43	1	.44	.51
						letter	6.67	1	.86	.36
						2 way interaction	15.15	1	1.92	.17
						Error	692.70	89		
						Total	15821.00	97		
Cause: controllable PR	**.74**	**10.78 (2.52)**	**10.54 (2.73)**	**10.35 (2.25)**	**9.86 (1.77)**	Main effects; video	.39	1	.15	.70
						letter	**23.69**	**1**	**8.93**	**.00**
						2 way interaction	3.32	1	1.25	.27
						Error	236.10	89		
						Total	11052.00	97		
Cause: uncontrollable PR	.44	9.85 (2.16)	9.46 (2.47)	9.48 (1.97)	9.71 (1.71)	Main effects; video	.62	1	.14	.71
						letter	3.73	1	.86	.36
						2 way interaction	8.6	1	1.97	.16
						Error	387.71	89		
						Total	9414.00	97		
Cause: external risk	.31	14.07 (1.82)	13.65 (2.45)	13.74 (1.74)	13.71 (2.49)	Main effects; video	.03	1	.01	.94
						letter	2.77	1	.61	.44
						2 way interaction	1.86	1	.41	.53
						Error	406.32	89		
						Total	18913.00	97		

Table 5.22b: Difference in Mean Score of Illness Representations in the Four Groups: ANOVA results

MEASURES	T2	INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	*df*	*F*	*p*
		VIDEO		NO VIDEO						
WOC	α	Letter	No letter	Letter	No letter			IPQ-R	α	Letter
Active	.74	40.00 (9.38)	41.80 (9.52)	40.74 (7.23)	40.81 (7.72)	Main effects; video	21.62	1	.01	.92
						letter	.62	1	.01	.91
						2 way interaction	.46	1	.09	.77
						Error	6644.35	89		
						Total	166948.00	97		
Active cognitive	.49	19.70 (4.57)	20.54 (5.09)	20.61 (3.75)	19.62 (4.89)	Main effects; video	1.72	1	.08	.76
						letter	.53	1	.03	.87
						2 way interaction	15.71	1	.75	.39
						Error	1864.08	89		
						Total	41206.00	97		
Active behavioural	.61	20.30 (5.59)	20.46 (4.97)	20.13 (4.61)	21.19 (4.34)	Main effects; video	11.15	1	.46	.50
						letter	2.29	1	.09	.87
						2 way interaction	10.79	1	.44	.39
						Error	2170.56	89		
						Total	43032.00	97		
Avoidant	.22	10.56 (3.57)	11.08 (3.03)	9.74 (2.58)	10.76 (2.83)	Main effects; video	8.36	1	.96	.35
						letter	10.77	1	1.19	.29
						2 way interaction	2.26	1	.24	.63
						Error	848.96	89		
						Total	11679.00	97		
Problem focused	.73	23.81 (6.41)	25.35 (6.16)	24.00 (5.86)	24.81 (5.55)	Main effects; video	.3.64	1	.10	.75
						letter	12.26	1	.33	.57
						2 way interaction	.00	1	.00	.99
						Error	3273.42	89		
						Total	61579.00	97		
Emotion focused	.35	29.41 (6.70)	29.42 (5.25)	30.22 (4.30)	31.62 (5.01)	Main effects; video	41.53	1	1.42	.24
						letter	25.92	1	.89	.35
						2 way interaction	2.85	1	.10	.76
						Error	2596.10	89		
						Total	90620.00	97		

Table 5.22c: Difference in Mean Score of Ways of Coping in the Four Groups: ANOVA result

MEASURES	T2	INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	***df***	***F***	***p***
		VIDEO		NO VIDEO						
	α	Letter	No letter	Letter	No letter					
RLOC	.64	35.07 (3.42)	34.85 (3.55)	34.40 (4.11)	35.62 (2.97)	Main effects; video	.02	1	.00	.97
						letter	9.56	1	.76	.39
						2 way interaction	9.81	1	.78	.38
						Error	1115.57	89		
						Total	119662.00	97		
Confidence in Recovery		8.56 (1.50)	7.47 (2.94)	8.13 (2.03)	8.00 (1.55)	Main effects; video	.10	1	.02	.87
						letter	1.68	1	.42	.52
						2 way interaction	.24	1	.06	.81
						Error	357.67	89		
						Total	6702.00	97		

Table 5.22d: Difference in Mean Score of RLOC and Confidence in Recovery in the Four Groups: ANOVA results

Significant results were found for illness representation of personal control (table 5.22a) and cause: controllable personal risk. There was a significant interaction between video and letter conditions on patients' representation of personal control (F (1,90) = 5.98, *p* = .02*) at T2 (table 5.22a). Patients who received the video only or the letter only had significantly reduced personal control (figure 5.6).

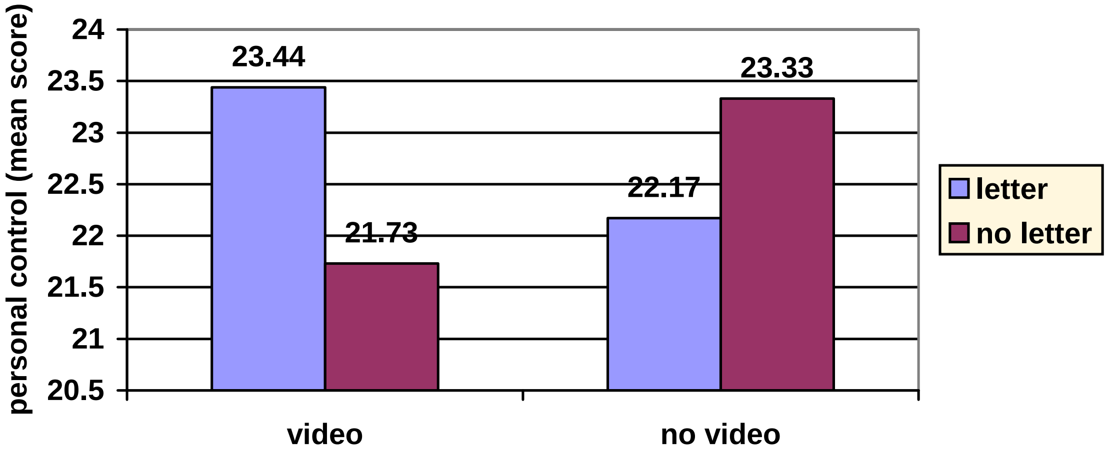

Figure 5.6: Mean Score on Personal Control Scale of the IPQ-R

There was also a significant main effect of the letter on cause: controllable personal risk (F (1,89) = 8.96, *p* = .04*) at T2 (table 5.22b), which is illustrated in figure 5.7. This shows that patients who received the letter had a greater perception of their own controllable risk behaviours being the possible cause of their stroke.

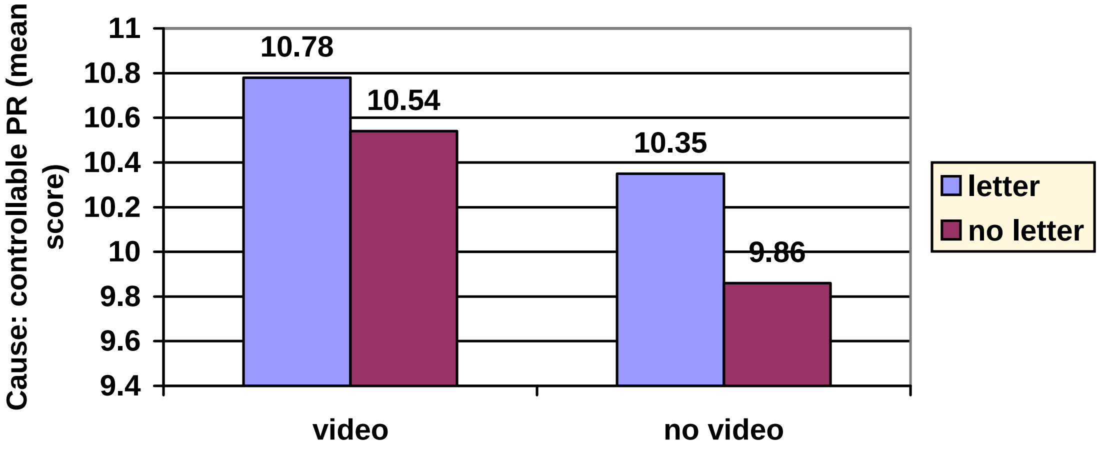

Figure 5.7: Mean Score on Cause Controllable Personal Risk Scale of the IPQ-R

In summary, patients in the video only and the letter only groups appeared to have less perceived control than the patients in the video & letter and control groups and patients receiving the letter appeared to have greater perceptions of their stroke being caused by their own behaviour. There was a non-significant trend in perceptions of consequence; patients who received the video had higher perceptions of consequence ($F_{(1,89)} = 3.34$, *p* = .07^). There were no differences in patients coping strategies, recovery locus of control or confidence in recovery.

Effects of Exposure to Interventions on Illness Representations

Patient's illness representations following adherence to the video and reading the letter were further examined. Are patients' illness representations influenced after exposure to one of the interventions i.e. the video and/or the letter? A 2 (video, letter) by 3 (video adherence yes, no, control) by 3 (letter adherence yes, no, control) between subjects ANOVA was found to be inappropriate because there was only one patient who did not adhere to the video but did read the letter only in the video & letter group resulting in one person in that group. Instead the sample was divided into 2 groups representing those patients who were "exposed" (n = 53) to an intervention i.e. adhered to the video only (n = 20), letter only (n = 10) or video & letter (n = 23) and those who were "not exposed" to an intervention, i.e. those who did not adhere to any intervention (n = 58) (table 5.23). Three data sets were excluded as they belonged to patients who died.

INTERVENTION GROUPS	EXPOSED	NOT EXPOSED
Video & letter;		
Video only	11	
Letter only	1	
Both	11	5
Video only	20	9
Letter only	10	18
Control	0	26
Total	53	58

Table 5.23: Patients Exposed or Not Exposed to an Intervention; intervention groups and numbers

To include the control group with the patients who were not exposed, the control group (n = 26) was compared to the patients who did not adhere to the interventions (n = 32), the t-tests and chi square analysis was performed on baseline data (Appendix D). One significant difference emerged; patients in the control group reported significantly more symptoms on the IPQ-R scale of identity (t (52) = -2.48, *p* = .02*) than those patients who were not exposed to any intervention. There were no demographic or clinical differences between the two groups. The exposure groups' baseline data were then analysed using independent t-tests and chi squared analyses at T1 to ensure "homogeneity" of the scores (Appendix D). Prior to patients being offered the video or sent the letter there were no significant demographic or clinical differences between the patients who were exposed to an intervention and those who were not exposed to an intervention following randomisation. There were two non-significant clinical trends between the two groups. Patients with a left-sided weakness were more likely not to be exposed to one of the interventions ($\chi^2 = 3.20$ (*df 1*) *p* = .07^) and patients who scored higher on the Orgogozo (t (95) = 1.7, *p* = .09^).

AFFECTED SIDE	COUNT	EXPOSED	NOT EXPOSED	CHI	*p*
Left side	Observed	23	35	3.19 (*df* = 1)	.07^
	Expected	27.7	30.3		
	% within exposure	43%	60%		
Right side	Observed	30	23		
	Expected	25.3	27.7		
	% within exposure	57%%	40%		

Table 5.24: Differences between Intervention Exposure and Affected Side: χ^2 results

In previous analyses impairment has been related to adherence and these trends raised the question of levels of impairment in patients with left or right-sided weaknesses. Therefore the data was examined further by looking at differences in impairment in those patients with a left or right-sided weakness (table 5.25)

CLINICAL MEASURES	N	MEAN SCORE (STANDARD DEVIATION)		T-TEST
		Right side	Left side	
^{1}Orgogozo (transformed)	97	580130.4 (255243.24)	527985.30 (256993.35)	t (95) = -.10, *p* = .32
^{2}NIH (transformed)	97	2.06 (.67)	2.08 (.97)	t (95)= .12, *p* = .90
^{2}Modified Rankin	97	2.50 (1.13)	2.75(1.37)	t (95) = .96, *p* = .34
Time in hospital	111	33.09 (48.63)	35.45 (44.37)	t (109) = .27, *p* = .79
^{1}Barthel Index (transformed)	**111**	**126426.8 (38777.56)**	**106008.05 (50257.05)**	**t (109) = -2.38, *p* = .02**

^{1}Orgogozo & Barthel Index: higher score = less impairment ^{2}NIH and Rankin: lower score = less impairment

Table 5.25: Differences in Impairment between Those with Left and Right Sided Weakness: t-test results

Patients with a left-sided weakness appeared more impaired at T 1 on the Barthel Index (table 5.25).

There was only one difference between the exposure groups on the psychological measures (Appendix D) patients who were exposed to an intervention were more likely to attribute the cause of their stroke to controllable personal risk, t (87) = -2.45, *p* = .02*.

In summary, prior to dividing the study population into patients who were exposed to an intervention and those who were not the control group was compared with the patients who did not adhere to any intervention. One difference was found, the control group reported more symptoms on the identity scale of the IPQ-R. The control group were included with the patients who did not adhere to an intervention and were named the “not exposed” group. The baseline data from this group was compared with the baseline data of the exposed group and only a difference of cause: controllable personal risk emerged. A trend in the data indicated that patients who were less impaired were also less likely to be exposed to an intervention. Baseline data of identity and cause: controllable personal risk will be controlled for in future analyses plus time-line chronic and previous stroke from comparing the four intervention groups in research question 2.

POST-HOC QUESTION 5.1: Are patient’s illness representations influenced after exposure to one of the interventions i.e. the video and/or the letter?

To examine if there was an effect of the interventions on patient’s illness representations following exposure to an intervention t-test analysis was performed on the IPQ-R measure, RLOC, WOC and confidence in recovery (n = 104). Variables of previous stroke, affected side, identity, time-line-chronic and the cause: controllable personal risk taken at T1 were not controlled for in t-test analysis but are later in the repeated measures ANOVAS.

PSYCHOLOGICAL MEASURES	MEAN SCORE (STANDARD DEVIATION)		T-TEST
IPQ-R (n = 104)	Exposed	Not exposed	
Identity	3.47 (2.32)	3.37 (2.23)	*t* (102)= -.22, *p* = .82
Timeline - chronic	16.85 (4.35)	15.88 (3.92)	*t* (102)= -1.19, *p* = .24
Timeline – cyclic	**11.17 (3.37)**	**9.90 (2.75)**	***t*** **(99.37) = -2.10,** ***p*** **= .04**
Consequence	**20.30 (3.94)**	**18.63 (4.30)**	***t*** **(102) = -2.07,** ***p*** **= .04**
Control – personal	22.43 (2.62)	22.82 (2.35)	*t* (102)= .80, *p* = .43
Control - treatment	18.71 (2.14)	18.90 (2.17)	*t* (102)= .45, *p* = .66
Illness coherence	15.81 (4.04)	15.55 (3.69)	*t* (102)= -.35, *p* = .73
Emotional representation	17.64 (4.81)	16.54 (4.77)	*t* (102)= -1.16, *p* = .25
Cause: psychological	12.68 (2.84)	12.29 (2.63)	*t* (102)= -.72, *p* = .48
Cause: controllable PR	**11.13 (2.52)**	**9.76 (1.90)**	***t*** **(102)= -3.11,** ***p*** **= .00**
Cause: uncontrollable PR	9.49 (2.15)	9.55 (2.05)	*t* (102)= .14, *p* = .89
Cause: External risk	13.98 (2.05)	13.51 (2.12)	*t* (102)= -1.15, *p* = .25
RLOC (n = 104)			
RLOC	34.81 (3.50)	35.02 (3.40)	*t* (102) = .31, *p* = .76
WOC (n = 104)			
Active coping	40.30 (9.69)	40.31 (7.28)	*t* (96.38) = .01, *p* = 1.00
Active cognitive	20.09 (4.92)	19.98(3.93)	*t* (102) = -.13, *p* = .90
Active behavioural	20.21 (5.62)	20.33 (4.22)	*t* (96.37) = .13, *p* = .90
Avoidant	10.45 (3.20)	10.57 (2.79)	*t* (102) = .20, *p* = .85
Problem focused	24.43 (6.69)	24.04 (5.47)	*t* (99.45) = -.33, *p* = .74
Emotion focused	29.09 (5.96)	30.94 (4.54)	*t* (96.92) = 1.78, *p* = .08^
CONFIDENCE IN RECOVERY			
Confidence	7.90 (2.42)	8.14 (1.89)	*t* (102) = .54, *p* = .59

Table 5.26: Differences in Illness Representations between Those Who Were Exposed to an Intervention and Those Who Were Not (T2); t-test results

There were three significant differences between those patients exposed to an intervention and those who were not (table 5.26). Patients who were exposed to an intervention appeared to report a greater time-line cyclic, greater consequences and a stronger cause related to controllable personal risk.

POST-HOC QUESTION 5.2: Had being exposed to an intervention had effect on the variables, time-line cyclic, consequence and cause: controllable personal risk factors?

Three repeated measures ANOVAs were performed on time-line cyclic, consequence and cause: controllable personal risk factors controlling for previous stroke, affected side, identity, time-line-chronic and where possible the cause: controllable personal risk taken at T1
Data from 97 patients was included in the analyses because the IPQ –R was not recorded for 7 patients at the beginning of the study (see page 19)

Time-line cyclic

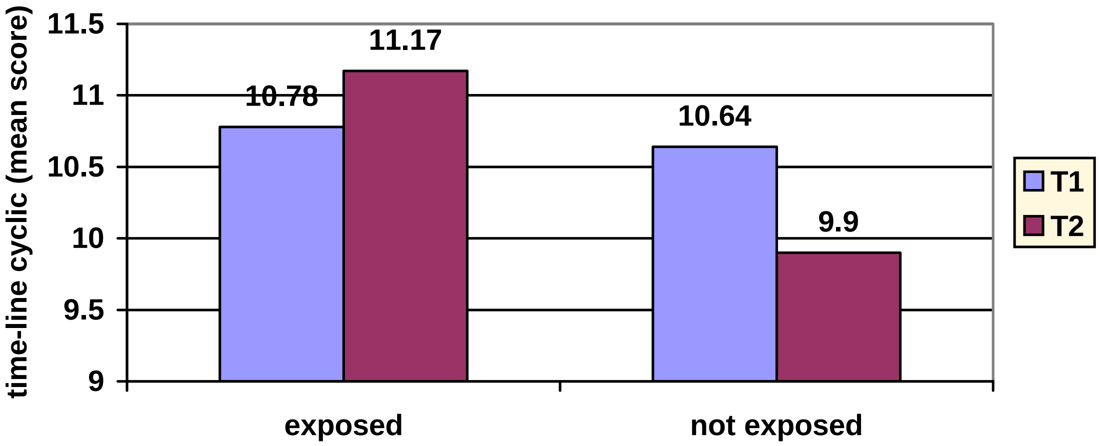

Figure 5.8: Mean Score on Time-Line Cyclic Scale of the IPQ-R

When the time-line cyclic means scores were examined for T1 and T2, patients who were exposed to an intervention reported slightly greater cyclical time-line at T1 than those patients not exposed to an intervention (Figure 5.8). Following the intervention patients exposed to the intervention reported further increases in their time-line cyclic perceptions whereas patients not exposed reported a decline in their perceptions of time-line cyclic. A repeated measures ANOVA, controlling for first stroke, affected side identity, time-line chronic and controllable personal risk at T1, shows a significant interaction effect suggesting that there is a significant change in perceptions of time-line cyclic from T1 to T2 (table 5.27).

Dependent variable: time-line cyclic

SOURCE	SUMS OF SQUARES	DF	F	SIG
T1/T2	.77	1	.24	.62
T1/T2 x first stroke	15.43	1	4.88	.03
T1/T2 x affected side	.34	1	.11	.74
T1/T2 x identity	5.81	1	1.84	.18
T1/T2 x chronic	.02	1	.01	.94
T1/T2 x controllable personal risk	.80	1	.25	.62
T1/T2 x exposure	**13.25**	**1**	**4.19**	**.04***
Error	284.64	90		

df = degrees of freedom; sig. = significant

Table 5.27: Repeated Measures ANOVA of Timeline Cyclic of Patients Exposed or Not Exposed to an Intervention

This was further examined using paired-sample t-tests (table 5.28), which showed that patients who were exposed to an intervention did not differ significantly from T1 to T2 in their perceptions of time line cyclic. However patients who were not exposed did show a non-significant trend from T1 to T2 suggesting that they may perceive their condition as less cyclic.

TIME LINE CYCLIC	N	MEAN SCORE (STANDARD DEVIATION)		T-TEST
		T1	T2	
Patients exposed	50	10.78 (2.97)	11.12 (3.37)	t (49)= -.99, *p* = .33
Patients not exposed	47	10.53 (2.69)	9.81 (2.68)	t (46) = 1.87, *p* = .07^

Table 5.28: Differences in Timeline Cyclic Mean Scores between T1 and T2 in Those Who Were Exposed or Not Exposed to an Intervention; t-test results

Consequences

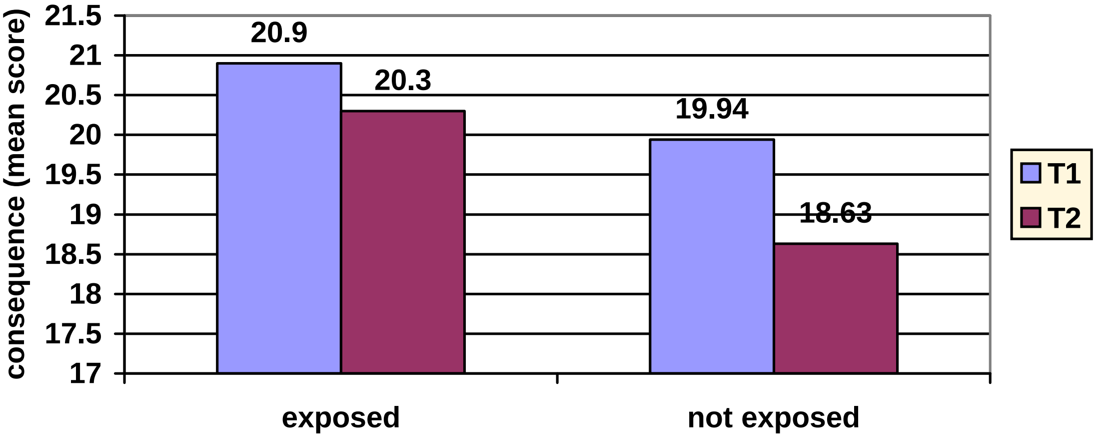

Figure 5.9: Mean Score on Consequence Scale of the IPQ-R

When the consequence means scores were examined for T1 and T2, patients who were exposed to an intervention reported a greater consequence at T1 than those patients not exposed to an intervention at T1 (figure 5.9). Following the intervention patients exposed to the intervention reported a decrease in their consequence perceptions, as did patients not exposed. A repeated measures ANOVA, controlling for affected side and controllable personal risk at T1 shows no significant interactions or main effects suggesting that exposure to an intervention does not significantly alter perceptions of consequence (table 5.29).

Dependent variable: consequence

SOURCE	SUMS OF SQUARES	DF	F	SIG
T1/T2	5.09	1	1.27	.26
T1/T2 x first stroke	19.43	1	4.86	.03
T1/T2 x affected side	1.34	1	.34	.56
T1/T2 x identity	8.48	1	2.12	.15
T1/T2 x chronic	.46	1	.12	.74
T1/T2 x controllable personal risk	4.57	1	1.14	.29
T1/T2 x exposure	8.pp	1	2.00	.16
Error	360.17	90		

df = degrees of freedom; sig. = significant

Table 5.29: Repeated Measures ANOVA of Consequence of Patients Exposed or Not Exposed To an Intervention

<u>Cause: Controllable Personal Risk</u>

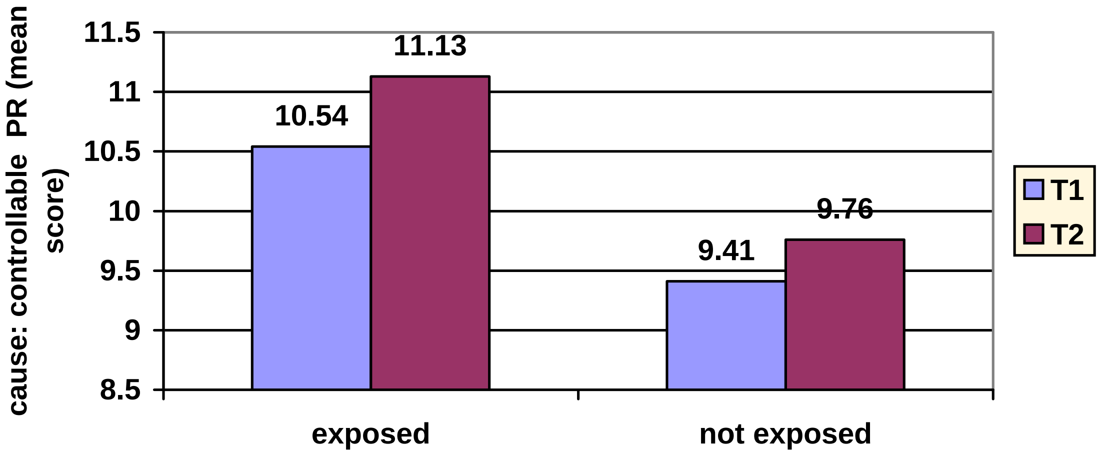

Figure 5.10: Mean Score on Cause Controllable Personal Risk Scale of the IPQ-R

When the cause: controllable personal risk means scores were examined for T1 and T2, patients who were exposed to an intervention reported a greater perception of their controllable personal risk behaviour being a cause of their stroke at T1 than those patients not exposed to an intervention at T1 (figure 5.10). Following the intervention patients exposed to the intervention reported an increase in their perceptions of controllable risk, as did patients not exposed. A repeated measures ANOVA shows no significant interactions or main effects suggesting that exposure to an intervention does not significantly alter perceptions of cause; controllable personal risk (table 5.30).

Dependent variable: Cause: controllable personal risk

SOURCE	SUMS OF SQUARES	DF	F	SIG
T1/T2	1.09	1	.62	.43
T1/T2 x first stroke	4.80	1	2.74	.10
T1/T2 x affected side	.14	1	.08	.78
T1/T2 x identity	1.10	1	.63	.43
T1/T2 x chronic	1.03	1	.59	.45
T1/T2 x exposure	2.30	1	1.31	.26
Error	1.75	90		

df = degrees of freedom; sig. = significant

Table 5.30: Repeated Measures ANOVA of Cause; Controllable Personal Risk of Patients Exposed or Not Exposed to an Intervention

POST-HOC QUESTION 5.3: Is there a gender difference between those who are exposed to an intervention and those who are not exposed to an intervention?

In light of the previous findings in the Video Study demonstrating gender differences in adherence a chi square analysis was performed on gender and exposure (table 5.31).

GENDER	COUNT	EXPOSED	NOT EXPOSED	CHI	*p*
Male	Observed Expected % within exposure	31 29.2 57%	29 30.8 51%	.48 (*df* = 1)	.49
Female	Observed Expected % within exposure	23 24.8 43%	28 26.2 49%		

Table 5.31: Differences Between Gender and Intervention Exposure: χ^2 results

There were no difference in gender between those exposed to an intervention and those who are were not.

Summary for Research Question 2

In summary, patients randomised to receive the video and the letter appeared to have greater personal control over their recovery than those who received the video or letter only. As this result did not take fully into account those patients who had adhered or had been exposed to an intervention and those who had not, the patients were divided into two groups; patients who had been exposed to the intervention and those who had not to see if the interventions had had any effect on the patient's illness representations. At baseline the control group differed from patients who had not adhered to a letter and or a video in identity only. The exposure groups, exposed to an intervention and not exposed to an intervention differed in affected side and in perceptions of cause: controllable personal risks. Previous analyses of the four intervention groups had revealed significant baseline differences of first stroke event and perceived time-line chronic, therefore these five variables were controlled for in the subsequent analysis which suggested that when the illness representations were examined following the intervention at T2 patients exposed to an intervention reported greater perceptions of time-line cyclic, greater perceptions of consequence and greater perceptions of cause: controllable personal risk. Further analyses suggested that being exposed to an intervention did not have significant effect on perceptions of consequences or cause; controllable personal risk but did have an effect on perceptions of time-line cyclic. Patients not exposed had significant decreases in perceptions of time-line cyclic from those who were exposed. This potentially suggests that being exposed to an intervention maintains patient's perceptions of time-line cyclic whereas not being exposed decreases patients' perceptions of time-line cyclic.

RESEARCH QUESTION 3: Do the letter and video influence patient's outcomes in terms of disability and mood?

To answer this question 2x2 between-subject ANOVAs were carried out on the four groups for the dependent variables measuring disability and mood taken at T2, controlling for affected side, time-line-chronic at time one and previous stroke (table 5.32)

There were no significant differences between the four groups on disability and mood.

MEASURES	T2	INTERVENTION MEANS (STANDARD DEVIATIONS)				SOURCE OF VARIANCE	SUMS OF SQUARES	***df***	***F***	***p***
		VIDEO		NO VIDEO						
DISABILITY	α	Letter	No letter	Letter	No letter					
Barthel Index		126257.00 (40780.01)	125042.80 (49452.80)	125825.70 (47846.41)	133262.7 (43420.65)	Main effects; video	250361841.02	1	.14	.71
						letter	22514489827.21	1	1.36	.25
						2 way interaction	455831265.11	1	.25	.62
						Error	165967696216.66	90		
						Total	1766455771199.00	97		
OAD		15.33 (3.79)	14.76 (4.54)	15.35 (3.75)	16.67 (2.73)	Main effects; video	12.42	1	1.01	.32
						letter	28.52	1	2.33	.11
						2 way interaction	.00	1	.00	.99
						Error	1404.38	89		
						Total	24372.00	96		
HADS										
Mood		10.41 (7.14)	11.85 (8.42)	10.95 (7.09)	10.81 (7.07)	Main effects; video	5.54	1	.11	.75
						letter	.01	1	.00	.99
						2 way interaction	.40	1	.01	.93
						Error	4673.37	90		
						Total	16992.00	97		
Anxiety		5.26 (4.31)	5.85 (4.91))	5.22 (4.44)	5.38 (4.89)	Main effects; video	2.767	1	.13	.72
						letter	.061	1	.00	.96
						2 way interaction	.299	1	.01	.91
						Error	1868.18	90		
						Total	4869.00	97		
Depression		5.15 (3.54)	6.00 (4.38)	5.74 (4.1)	5.43 (3.20)	Main effects; video	.48	1	.03	.85
						letter	.03	1	.00	.96
						2 way interaction	1.39	1	.10	.75
						Error	1252.21	90		
						Total	4423.00	97		

Table 5.32: Difference in Mean Score of Disability and Mood in the Four Groups; ANOVA result

POST-HOC QUESTION 5.4: Are patient's disability and mood influenced after exposure to one of the interventions i.e. the video and/or the letter?

Analysing the data observing the four groups does not take into account the patients who adhered to the interventions and those that did not, therefore the patents were divided into those who were exposed and those who were not to an intervention and again no significant differences between the two groups were found for disability or mood (table 5.33).

OUTCOME MEASURES	MEAN SCORE (STANDARD DEVIATION)		T-TEST
DISABILITY (n = 104)	Exposed	Not exposed	
Barthel Index (transformed)	131319.87 (40411.56)	124873.43 (47130.32)	*t* (102)= -.75, *p* = .46
OAD	33.51 (3.77)	34.02 (4.61)	*t* (102)= .62, *p* = .54
MOOD (n = 104)			
HADS	10.92 (7.11)	10.86 (7.61)	*t* (102) = -.43, *p* = .97
Anxiety	5.51 (4.34)	5. 41 (4.71)	*t* (102) = -42, *p* = .68
Depression	5.41 (3.73)	5.73 (4.01)	*t* (102) = .41, *p* = .68

Table 5.33: Differences in Disability and Mood between Those Who Were Exposed to an Intervention and Those Who Were Not (T2); t-test results

In summary, there were no significant differences in disability or mood between patients who were randomly allocated to one of the four groups. When the groups were divided into the patients who were exposed to the interventions and those who were not, there were no differences in outcome.

DISCUSSION

This study investigates the effectiveness of a theoretically derived letter sent from health professional on adherence to a video intervention. To discuss the findings and draw conclusions this discussion section has been divided into 6 sections covering the descriptive baseline data, implications of letter adherence, research questions 1, 2 and 3 and limitations before going on to the concluding comments. Throughout all the sections the findings and observations will be related to the SRM.

Descriptive Baseline Data

On examination of the baseline data three differences between the four groups emerged. Firstly there were fewer patients with a history of previous stroke randomised to the video & letter group. This may have had an effect on the way the patients in the video & letter group thought about their stroke. Patients having a stroke for the first time may have different expectations to those who had experienced one before. This may be supported by the second baseline difference, patients in the video & letter group perceived their stroke to be significantly less chronic than the other groups. This appears to be understandable using the SRM as the model describes the individual as a problem solver shaped by his or her environment and experience. Having not had the experience of a stroke previously may have shaped the patients perception of their stroke as less chronic. The third baseline difference showed that patients in the video only group perceived greater perceptions of their stroke being caused by their own controllable personal risk behaviours. There were no significant differences between the groups in terms of disability. This supports the SRM in that people may think about their illness differently despite there being no difference in levels of disability. On further examination, when the patients in the video & letter group's scores on the IPQ-R time-line chronic were observed no differences were found on patients' perceptions of chronicity between those who had a previous stroke and those who had had their first stroke, although the patients with a previous stroke did score higher on the IPQ-R time-line chronic than those with a first stroke. To be cautious previous strokes and IPQ-R score on timeline chronic and controllable personal risk were controlled for in all analyses using the four groups.

Implications of Low Rate of Letter Adherence

Reading the experimental letter was examined, as the effectiveness of the letter would be difficult to assess if patients did not read it. It emerged that 61% of the letter group could not remember receiving a letter. All the patients received an appointment letter for the outcome assessment. If patients were randomised to receive an experimental letter and or a video this was sent with the appointment letter. Three practical questions were asked; did all of study group allocated to receive a letter receive one through the post, did they see it in the envelope and/or did the patients have difficulty reading it?

Anecdotally some patients said they did not receive a letter, which cannot be confirmed, as there was no measure of delivery. The letters were posted using the Royal Mail, as were the videos. All the videos posted out were received because they were all returned to the principle researcher (SAJ) at the end of the intervention period. Therefore one may assume that if the patients received the video, those in the video & letter group would have certainly received the letter. Furthermore if all the patients randomised to receive the video received it then one could assume that all the patients randomised to receive a letter should have received a letter as both interventions were sent via the same route, the Royal Mail. Anecdotally on the day of the outcome assessment only a few patients said that they did not realise that they were being interviewed that day, information that accompanied the experimental letter. This was similar to patients' responses in previous studies such as SWOT.

Since it was possible that patients simply did not notice the letter, the principle researcher, following reports of not receiving the letter in the first 30 interviews, rearranged the ordering of the letters in the envelope. From this time point the appointment letter for the outcome assessment was put behind the experimental letter so the experimental letter would be the first letter to be seen when taken out of the envelope. This still did not appear to resolve the problem.

To investigate whether the patients could or could not read the letter was examined by the readability ease of the letter and the patients the National Statistics Socio-Economic Classification group. The readability of the letter was confirmed with the Flesch formula, which showed a reading ease of 76.2. The average adult reading ability ranges from 60 - 70 with the higher score indicating easier to read, therefore the experimental letter was within easy range of readability. The patients reading ability was assessed using the National Statistics Socio-Economic Classification as the patient's level of education was not recorded in this study. There was no significant difference between patients who read the letter and did not read the letter in terms of the National Statistics Socio-Economic Classification.

Patients may have read the letter but had forgotten its contents due to the concepts the letter tried to convey (Ley 1988). Although the letter was simple in its readability there were some difficult concepts such as taking control…to some patients what does this mean…is this something they have to learn? The advice in the letter could have been seen as general and not specific which also made it difficult for the people to remember (Ley 1996).

Taking these observations into account, may be the patients genuinely forgot about the letter by the time the principle researcher visited for the outcome assessment. Some patients within this group may have received the letter and potentially read it, but just could not remember reading it when asked 5 weeks later at the outcome assessment. Furthermore those patients may have received the letter and intended to read it but did not get round to it and had subsequently forgotten about ever receiving it. In the study by Mant et al's (1996) testing the efficacy of stroke information leaflets they noted that 77% of the patients recalled receiving the information pack but they did not report what the patients could remember of the contents. Furthermore the information packs had no effect on functional ability, mood, or knowledge but did slightly improve satisfaction although this was non-significant. In the video & letter group 3 patients said that they were so pleased to receive the video that they neglected to look at the letter.

Discrimination between intentional and unintentional adherence was difficult to distinguish in the present study. Four patients reported that they had received the letter and chose not to read, 30 patients said they did not receive it at all which goes against the findings of Ley (1988) who suggests that self-report of adherence is usually good or over estimated.

The role of the carer was overlooked and not recorded. Carers may have read the letter to the patient or may have read the letter and considered it not important for them to give it to the patients. The letter may have been beneficial to the carer in encouraging the patient to watch the video but this again is speculation as no correct method of recording carer input was incorporated into the study.

To explore the issue of letter adherence statistically, the patients who claimed to have read the letter were compared with the patients who claimed not to have and there were no significant demographic or psychological differences between letter readers and letter non-readers. However clinically patients with a right-sided weakness were more likely to report reading the letter than those patients with a left-sided weakness. This appears to be counter intuitive in that patients with a right-sided weakness would be more likely to have a communication disorder because the areas of the brain associated with communication are located in the left hemisphere of the brain

(Clarke 1998). One could suggest that these patients would be less likely to read the letter. The SRM proffers a possible explanation in that patients with a right-sided weakness tend to have a potential language disorder therefore they may have read the letter as a form of coping, practicing to improve their reading skills and therefore aiding their recovery.

The variables that were correlated with letter adherence were entered into a logistic regression analysis. The results showed that there were no strong predictors of letter adherence and that the variables predictive of adherence to SWOT and the Video Study were not predictive of letter adherence. Adherence to the stroke workbook, the video and a letter are all essentially different behaviours.

The above points raised about letter adherence highlight the importance of recording adherence to interventions in trials as the implications have been well documented (Dunbar-Jacob and Schlenk 2001).

To overcome the issue of letter adherence, in order to answer the research questions as comprehensively as possible the data was not only analysed by examining the four groups as a 2x2 design (intention-to-treat) but also by examining the data by dividing the patients in to those who were exposed to an intervention and those who were not. This was not entirely satisfactory, as this did not address the patients who adhered to the letter only and whether the actual letter had an effect on illness representations, disability and mood. The patient numbers were insufficient for statistical analysis. However the effects of exposing oneself to an intervention may aid our understanding of the effects of adherence to interventions.

Does A Personalised Theoretical Letter, Influence How Patients Adhere To A Video Intervention?

There was no significant difference in video adherence between the patients who were randomly allocated to receive the video & letter or those who received the video only. When the data of the patients who read the letter was examined in relation to video adherence again no difference in video adherence was found. When amount of adherence was examined, patients who read the letter in the video & letter group were more video active, performing significantly more activities associated with the video intervention than the patients who did not read the letter, i.e. they watched both videos, could recall more information about the video, read the books that came with the video. The patients who read the letter may have changed their thinking about their recovery and the effort they may have to put in differently to those who did not read the letter potentially supporting the idea of the SRM that people are problem-solving individuals. Alternatively patients who read the letters may have had similar beliefs being predisposed to do activities to promote recovery, e.g. read letters, watch videos, read booklets. It is of note that the amount of adherence measure was very crude and can only act as a pointer for further research.

Do The Letter and Video Influence the Patient's Illness Representations?

Patients who received both video & letter and the control group reported greater personal control over their recovery than those who received the video or letter only. Firstly this result did not distinguish between those who adhered to an intervention and those who did not. Secondly having a single intervention reduced perceptions of personal control. One could suggest that the letter and the video increased perceived control and this variable may have been the reason for patients adhering to more of the activities associated with the videos. Observing the means of the 4 groups following the interventions, patients in the video & letter group had greater illness coherence, greater emotional representations and stronger ideas about the cause of their illness than the video only, the letter only and the control groups, although these were not statistically significant. This potentially could suggest that patients who had both interventions understood their illness better and consequently, understood the causes, were more realistic about their recovery, because they had seen the video of other peoples experiences, thought about their role in their recovery through receiving the letter therefore more emotive but with all this much more in control of their recovery. The letter did appear to increase the amounts of adherence to the video intervention, which might account for the interaction effect. However patients having decreased perceived control in the single intervention groups may have been due to chance and may not have been bought about by the intervention.

To further examine the effects of the interventions the data were analysed using the two groups, those who were exposed to an intervention and those, including the control group, who were not. These groups were compared at baseline. There were no demographic or clinical differences between the groups although there were two non-significant trends in affected side and Orgogozo. Clinically patients with a left sided weakness were less likely to be exposed to an intervention and there was a trend in the Orgogozo score to suggesting that patients less impaired were not exposed to an intervention. These were further examined in the light of previous findings indicating that impairment was related to stroke workbook adherence with a post hoc t-test to look at the differences in impairment between patients with a left or a right-sided weakness. Patients with a left sided weakness scored lower on the Barthel index indicating that they were more impaired. This was not apparent in the other measures of impairment and a potential explanation could be that patients answered the questions on the Barthel Index, which may have reflected the perceptions of the way the stroke had affected them: whereas the other clinical measures were observations of the clinicians.

There was only one psychological difference between the exposed and the not exposed groups at baselines cause – personal risk controllable. Patients who were exposed to an intervention had a significantly higher score on the cause component of attributing the cause of their stroke to their own behaviour. Does this suggest that recognising ones own role in the cause an illness prompts someone with that awareness that they have a role in their own recovery and what they can do to help them selves recover? This may be further supported by the insignificant trend in that patients in the exposed group had a greater desire for the video intervention (patients were not asked if they desired the letter intervention). This finding offers support to the work of Lau and Hartman (1983) who suggested that if patients believe their behaviour to be the cause of their illness they are more likely to take more recovery promoting action. The baseline scores on the IPQ-R showed that patients who were exposed to an intervention had higher mean scores for identity, on time line – chronic and cyclic, consequences and illness coherence. Whilst not statistically significant these were in keeping with the logic of SRM. Patients who have stronger illness representations are more likely to have more positive coping procedures, e.g. expose themselves to interventions, supporting the work of both Whitmarsh et al (2003) and Cooper et al (1999) who found that patients who attended cardiac rehabilitation were more likely to have stronger illness representations.

The research question asked if the letter and the video could influence patient’s illness representations. Examining the scores of the IPQ-R for the exposed and unexposed groups at T2, controlling for variables showing significant differences between the groups at T1 (affected side and cause – personal risk controllable), there appeared to be three differences between the groups in their illness representations. Patients exposed to an intervention perceived greater fluctuation, greater consequence and a further acknowledgement of their own behaviour being attributable to their stroke. Patients exposed to an intervention perceived stronger illness perceptions about their illness than those who were not exposed. These patients may perceive the opportunity for recovery due to the cyclical nature of their illness, the greater consequences may provide the thinking for doing something positive towards their recovery and if they perceive their own behaviour as contributing to their stroke their coping procedures may be subsequently shaped by doing something positive such as doing an intervention.

Initial examination of the data patients appear to have different illness representations depending on the stroke being their first or second. Joice et al (2003) showed that patients with stroke define their illness representations differently to those with other diseases, namely patients with chronic and acute pain (Moss-Morris et al 2002). The relationships between the illness representations were also different for each illness. Petrie et al (1996) showed that myocardial infarction patients who believed their illness to be controllable had less strong representations of time and consequence. The stroke patients in a preliminary analysis of the FAST study perceived high levels of control but also stronger perceptions of time and consequence (Joice 2003). As stroke is prevalent and associated with age, stroke patients may have had experience of knowing someone close who had survived a stroke and seen the length of time it took to improve therefore had more realistic ideas about the length of time recovery takes. Furthermore stroke patients are older than patients who had had a myocardial infarction and the effects of the stroke yield different outcomes.

Do The Letter and Video Influence Patient’s Outcomes In Terms Of Disability and Mood?

The third question asked if the video & letter influenced outcomes in terms of disability and mood. There were no significant effects of the video and/or letter on disability or mood. Given the poor adherence to the letter and the length of time from watching the video to being assessed this is not a surprising finding.

Limitations of Study

Measures of letter adherence: Mmeasuring letter adherence and the apparent low adherence rate were major limitations of this study. There was no objective record of the patients reading the letter as there was for both the video and the workbook. A measure testing the patient on the content of the letter was used but this was probably administered too late. Patients would have received the letter a week following T1 interview, potentially read it and then forgotten about it by the time the T2 interview carried out 5 weeks later. Patients may have adhered to the letter but could not remember. This uncertainty could have been avoided by using recorded delivery to ensure the letters delivery. This would have made the letter more “official” and therefore more noticeable. A more attractive or prominent envelope marked that it contains information relevant to the patients recovery may have improved the adherence. A telephone call may prompt a person to read it or assessing the patient with a more robust recognition and recall test at an earlier time i.e. earlier than five weeks after it has been sent may also improve letter adherence. The T2 interview could be carried out earlier as anecdotally patients tended to watch the video in the first week it was received and then did not watch it again by T2, forgetting what they had seen. The study procedure was designed to emulate the stroke workbook study to allow comparison to be as scientific as possible, but this did not take into account the amount of time patients would spend reading the letter and watching the video which would be very different from working through a specifically designed workbook.

Exposure to an intervention was used as a means of overcoming this problem. However dividing the groups into exposed and not exposed was not subject to random allocation and therefore it is impossible to know how much the results are affected by patients choosing to be exposed to an intervention and how much is due to the effect of exposure to an intervention.

IPQ-R scoring: The main difficulties encountered with the measures included the measurement of patient's illness representations. There were three main difficulties using the IPQ-R. Firstly the IPQ-R asks patients about their "illness". For example patients were asked if "their illness would last for a long time". The illness, stroke, is an occurrence therefore the stroke itself does not last for a long time but the consequences may last for a long time. Patients often found it difficult to respond to some of the items. Prior to carrying out this study the possibility of modifying the IPQ-R was by replacing the word "illness" with "stroke" but this would have primed the patient with the researcher's labelling of stroke and not the patient' own representation and label. In hindsight the word "illness" potentially could have been replaced with the word "recovery", which would have made the items on the questionnaire more applicable to the stroke patient. However this would be assessing patient's representations of recovery and not illness. Furthermore recovery could be defined as a coping procedure or may already be incorporated in the domain of time-line chronic. In hindsight the word "condition" may have been more appropriate as it appears to be a more neutral expression and is removed from the actual stroke occurrence.

Another area where the patients had difficulty in answering questions was with the "treatment-control" component. Patients considered treatment as medication and often responded to the items on this part of the questionnaire "but I am not taking any treatment". This was probably reflected in the low alpha for that set of items. Future use of the IPQ-R might benefit from a clearer item referring to treatments other than medication.

These issues question the validity of the responses to the questionnaire and whether the patient's true illness representations were assessed. However the internal reliability for the other sections appeared to be satisfactory.

The second problem with the IPQ-R was scoring the "cause" component. Due to having to perform a varimax rotation principle components analysis the results potentially cannot be compared to other publications. Furthermore component loading showed a different interpretation of the items compared to the work of Moss Morris et al (2002).

Thirdly patients found some of the items on the "cause" component difficult to understand. Overall the IPQ-R was "easy" to understand according to the reading ease score of 73.1. When the cause component was assessed the reading ease score was 47.9 indicating that it was more difficult to understand. Patients separated "bad luck and chance" as being two different items although they were presented to the patient as one item. Furthermore a noticeable number of patients questioned what was meant by "altered immunity".

Education level: Measurement of education level was another limitation of the study. Patient's ability to read was not taken into account although socio-economic status and level of adherence were not significantly related. However this does not completely reflect the patient's level of education and therefore their potential ability to understand the concepts in the letter. As Ley (1988) and Stanton (1987) found understanding the information related to the ability to recall it, be satisfied with it and to adhere to it. Somewhere along this process adherence may have been affected. The reading ease of the letter was addressed but the concepts or contents of the letter may have been difficult to recall, the general message behind the letter not specific enough to allow the patients to be satisfied and therefore they did not adhere. It is of note that patients who were not retired scored higher on the illness coherence items of the IPQ-R. Does understanding diminish as one retires from work or as one gets older?
Bias of the interviews was minimised as blinding was successful in 80% of cases. Blinding to the letter was 86% more than likely due to it being easier to hide from the interviewer. Whilst blinding appeared to be satisfactory ideas for improvement were noted. Better communication with the patient, possibly a telephone call to say the when the intervention would be sent out and when they should receive it by, asking the patients to contact the experimenter when they had received the intervention may have increased blinding and possibly adherence.

Power of The Study: Power represents the probability of correctly rejecting the null hypothesis (Bannajee 2003). Although the FAST study used research questions as part of its design and the power will still have an effect on the interpretation of the results. An a priori power analysis was required for ethical approval from Tayside Ethics Committee, which has been described in Chapter 4, page 114. Post-hoc power analysis in the Video study showed that potentially the FAST study was underpowered hence significant differences between the groups may have been missed. Furthermore due to multiple testing the significant results that were obtained may have occurred by chance.

Future Research

Neither the letter or video appeared to be overtly effective interventions, but they have shown some avenues of investigation. For future research they could be improved in a number of ways. Closer examination of the language used would be beneficial in conveying the concepts in a clearer manner to the patients. Inclusion of clearer patient instructions of what behaviour the researchers are expecting from the patient. If patients know they are supposed to read a letter to increase video adherence clear instructions about reading the letter then watching the video should be given. If patients are given clear, easy, concise understandable guidelines to carry out they are more likely to perform the behaviour (Ley 1988). Efforts were made to make sure the letter was obvious, it was written in an appropriate language and it presented in an attractive way. This may need to be more closely addressed.

CONCLUSION

The results of this study suggest that a theoretical letter may promote the amount of adherence to a video intervention. However, the measure of adherence was quite rudimentary and may not be generalisable to other studies. Furthermore a simple explanation may be that people who read letters do more activities in general. Although there was no significant increase in the numbers of people who adhered to the video after reading the letter there was evidence of greater adherence on average.

Reading the letter was not predicted by the same variables as the workbook and the video, which suggests that adherence to an intervention is not one type of behaviour. The simplest intervention, reading the letter was adhered to the least. Could it be so simple people did not notice it or was it over simplified to the point that it was not noticeable or appeared unimportant? This has straightforward implication; non-adherence may not only be due to a conscious decision, it may also be due to non-awareness supporting the notion of unintentional non-adherence (Dunbar-Jacob 1997).

The original aim of letter was not meant to benefit but to prime patients into adhering to the intervention. The letter increased the likelihood of patient being more involved in the video intervention therefore such a letter might also have increased adherence to the workbook. Given the increased attendance to Cardiac Rehabilitation using a letter based on the Theory of Planned behaviour (Wyer et al 2001) and increased attendance to cardiac rehabilitation using the SRM as a framework on which to base the patient care plan (Petrie et al 2000) using a letter to increase adherence to an intervention appears to be feasible. Furthermore Johnston et al (1992) showed that a simple letter could change perceived control. The influence of health professionals' advice through an experimental letter in the present study tentatively affects adherence to an easier intervention, possibly influencing patients' illness representations but not disability or mood outcomes.

CHAPTER 6

AIMS, FINDINGS, EVIDENCE AND IMPLICATIONS

SUMMARY

This chapter runs through the aims of this thesis, the research questions, the main findings and the evidence, that supports them. It then discusses the theoretical, methodological and clinical implications. The aims include:

1. To examine patient characteristics predicting adherence to the workbook intervention.
2. To examine the workbook intervention characteristics (in terms of complexity and ease) and their relationship to adherence.
3. To see if it is possible to enhance adherence to an alternative intervention using a theoretically derived letter.

These three aims form the basis of the three experimental studies that have been conducted and described in chapters 3, 4, and 5 respectively. There are two further aims:

4. To apply a theoretical framework to explain and understand the findings of the three experimental studies
5. To add to the current research into stroke recovery to enable better recovery for both patients and health professionals alike.

The proposed research questions include:

1. What demographic, clinical and psychological factors predict participation in and adherence to a stroke workbook intervention?
2. Do the same factors predict participation in and adherence to an easier intervention?
3. Can a simple letter increase participation in and adherence to an easier intervention?

The central question of this Ph.D. thesis is: why, when stroke patients continue to express dissatisfaction with the care they receive, do they fail to participate in a specially designed intervention?

INTRODUCTION

The literature review (reported in chapter 1) showed that the emphasis of interventions to aid stroke recovery was on improving functional outcome. The studies rarely considered the impact of the psychological characteristics of the patient's cognitions. Often the mood and satisfaction outcomes were measured but the cognitions behind these variables or their relationship to functional outcome were neglected. Much effort is exerted within the research field trying to find treatments and interventions to promote recovery yet the well known phenomenon of non-adherence to these treatments and interventions and the implications are often over looked (Dunbar-Jacob and Schlenk 2001, Brawley et al 2000, Schumaker and Rejeski 2000).

> "Indeed, clinicians in all walks of health care still puzzle about those patients who fail to follow apparently logical, but non-negotiable, assignments or prescriptions without question when they are clearly designed to improve health status, detect or reduce health risk behaviour and combat disease" Brawley et al 2000

It is possible that approaching adherence from a psychological rather than a medical perspective may more successfully increase our understanding of this non-adherence phenomenon.

The studies conducted in this thesis and the results have been summarised in table 6.1a to 6.1c for reference and to allow the discussion to follow a consistent structure.

STUDY 1	WHAT DEMOGRAPHIC, CLINICAL AND PSYCHOLOGICAL FACTORS PREDICT PARTICIPATION AND ADHERENCE IN A STROKE WORKBOOK INTERVENTION? (SWOT)
What psychological, clinical and demographic variables predict participation in the stroke workbook intervention?	1. Three types of adherence, participation, active and passive 2. 14% patients did not participate in the stroke workbook intervention 3. Participators (vs. Non-Participators): a. Are significantly more anxious, have lower perceived control and lower confidence b. Tend to be less impaired (Barthel Index) 4. RLOC accounts for between 24 – 42% of the variance in participation
What psychological, clinical and demographic variables predict adherence to the stroke workbook intervention?	1. 43% patients did not actively adhere to the workbook activities 2. Active adherers (vs. Non-Active): a. Are significantly more likely to be women, less impaired (NIH and Rankin) and less avoidant (low reliability) b. Tends to be less impaired on other measures (Orgogozo, Barthel, inpatient stay) 3. Gender and Rankin accounts for between 34 – 47% of the variance in active adherence 4. 44% patients did not passively adhere i.e. did not retain the workbook 5. Passive adherers (vs. Non-Passive): a. Are significantly more likely to be female and desire the workbook b. Tend to have a left-sided weakness 6. Desire for the workbook accounts for between 16 – 22% of the variance in passive adherence 7. Active Adherers (vs. Non Adherers including non-active + non-participatory): a. Are significantly more likely to be women and less impaired (NIH and Rankin) 8. Gender and Rankin accounts for between 27 – 36% of the variance in active adherence 9. Gender accounts for 30% of the variance in amount of active adherence suggesting women perform more activities 10. Impairment is significantly associated with non-active adherence

Table 6.1a: Summary of Results of Study 1

STUDY 2	AN EASIER INTERVENTION: DOES IT INCREASE ADHERENCE? (Video Study)
Does an easier intervention increase adherence?	1. One type of adherence observed 2. Non-participation is more likely to occur in the workbook intervention 3. Adherence to easier intervention dependent on measures of adherence a. Non-adherence vs. intervention adherence (video, passive & active) → no significant difference b. Non-active adherence (including passive) vs. intervention active adherence (video & active) → significantly more adherence to video c. Percentage adherence → significantly more adherence to video d. Categorised adherence → significantly more adherence to video 4. Patients who have greater impairment are more likely to watch the video than do the workbook activities.
What demographic, clinical and psychological factors predict adherence to an easier intervention?	1. Video adherers (vs. non-adherers): a. Are significantly more likely to be male, desire the intervention and perceive more symptoms b. Tend to perceive greater chronicity, cause –psychological and controllable PR 2. Desire for the video accounted for between 34 –51% of the variance in video adherence
Are the factors that predict adherence to an easier intervention the same or different from the factors that predict adherence to a complex intervention?	1. Adherence to different interventions appears difficult to examine; a. Predictors of video = gender and desire with desire accounting for most variance b. Predictors of active = gender, impairment and avoidant coping with gender and impairment accounting for the most variance c. Predictors of passive = gender and desire with desire accounting for most variance 2. Gender = Men are more likely to watch video, women are more likely to do the workbook and keep it 3. Women vs. men and video vs. stroke workbook a. Women in the workbook group are significantly less likely to have a carer. b. Women in the video group are significantly more impaired and had less desire for the video c. Men in the video group are significantly more likely to report using active behavioural methods of coping d. Both men in the video and workbook groups reported significantly higher problem-focused ways of coping. 4. First stroke experience, impairment, desire for the intervention and type of intervention accounts for between 26 – 35% of the variance in Intervention active adherence (video & active workbook groups).

Table 6.1b: Summary of Results of Study 2

STUDY 3	A SIMPLE THEORETICALLY DESIGNED LETTER FROM HEALTH PROFESSIONALS: CAN IT INFLUENCE ADHERENCE TO AN EASIER INTERVENTION, ILLNESS REPRESENTATIONS AND OUTCOME? (FAST)
Does a personalised theoretical letter, influence how patients adhere to a video intervention?	1. Video & letter, video only, letter only, control; a. Video & letter group appeared to have significantly less people with previous stroke and perceived their stroke to significantly less chronic b. Video only group scored significantly higher on the cause- controllable personal risk scale 2. 61% patients claimed not to have received the letter 3. Letter readers (vs. non-readers): a. Are significantly less likely to have a left-sided weakness 4. No predictor of letter reading found 5. Receiving the letter did not influence adherence to video 6. Letter readers performed significantly more activities associated with video
Do the letter and video influence the patient's illness representations?	1. Letter & video, video only, letter only control: a. Personal control was significantly reduced in the single intervention groups b. Cause - controllable personal risk was significantly greater in letter group c. Trends in patients who received video to perceive greater consequence 2. Post hoc; exposed (vs. not exposed): a. Patients exposed to an intervention more likely to attribute cause of stroke to controllable personal risk b. Trend to show that patients with a right-sided weakness tend to expose themselves to an intervention c. Patients with a left-sided are significantly more impaired on Barthel Index 3. Exposed patients at T1 (vs. not exposed at T1): a. Perceived significantly greater time-line cyclical, greater consequences, greater controllable personal risk b. Tend to be less emotion focused 4. Patients exposed at T2 (vs. not exposed at T2): a. Perceived significantly greater time-line cyclical b. No significant difference in consequence and controllable PR
Do the letter and video influence patient's outcomes in terms of disability and mood?	1. No significant effects or interactions of the letter on disability or mood. 2. Exposed patients did not differ in mood and disability

Table 6.1c: Summary of Results of Study 3

WHAT DEMOGRAPHIC, CLINICAL AND PSYCHOLOGICAL FACTORS PREDICT PARTICIPATION AND ADHERENCE IN A STROKE WORKBOOK INTERVENTION?

Finding 1: Adherence behaviour is not one type of behaviour.

Evidence from the literature: Weinman (1997) suggested that it is impossible and undesirable to describe adherence as an all or nothing concept as the “percentage of adherence necessary to achieve the desired effect varies between treatments and between and within individuals”. This was demonstrated in the literature review in Chapter 1 where levels of adherence to the interventions being tested were either not mentioned (Hui et al 1995, Kaste et al 1995, Indredavik et al 1997, 1998, Rudd et al 1997) briefly mentioned (Rodgers 1998) or its implications noted (Mayo et al 2000, Ada et al 2003).

Evidence from study 1: Different types of adherence were demonstrated in the first study, examining the demographic, clinical and psychological factors predicting adherence to a workbook intervention. Three obvious types of behaviours emerged; participation, where patients could participate or not participate in the trial, passive adherence, where patients chose to or not to retain the workbook and/or the relaxation tape and active adherence, where patients performed or did not perform the activities in the workbook. Furthermore patients could perform all these behaviours, i.e. participate, actively and passively adhere or some of them or none of them. To complicate matters further patients could actively adhere completely or incompletely, i.e. do some of the activities or all of them. Therefore adherence to an intervention is not a single type of behaviour.

Evidence from study 2: This study demonstrated two other types of adherence behaviours when an easier intervention was examined. Patients could adhere to the video intervention by watching neither, one or both videos and reading neither, one or both booklets that accompanied the videos.

Evidence from study 3: In this study, patients were sent a letter to read to promote adherence to the video therefore the behaviour of reading the letter was another behaviour that emerged. Patients may not read the letter read some of it or read all of it. Furthermore it could have been read to the patient.

Comments: Just by observing the behaviours of the patients in the three studies highlights that adherence is not dichotomous by its nature and that it is defined by the intervention requirements. Leventhal et al (2001) suggests that these types of behaviours occur because of the way the patient thinks about their illness. The way the patient thinks about their illness in turn shapes their coping responses to behave in specific ways for example, watching a video or not watching a video. Representations of illness are dynamic and change over time therefore watching a video may be dependent on what the patient's representation is at that time. This is also shaped by the patients representation of the intervention and the representation of both the illness and the intervention for some may be altered by just doing part of the intervention, e.g. patients may have watched one video and the patient may have changed their representation about their illness or about the intervention which will have had consequences on whether they continue to watch all of it or not. Dunn et al (2003) argue that patients that do some activity within an intervention to promote recovery may have derived benefit even though they do not adhere completely to an intervention. This brings into question what level of adherence do the patients have to assume before they glean the therapeutic benefits? Whilst this question will not be answered in the present thesis, the actual measurement of adherence (which is discussed below) potentially has implications for this question and therefore would need to be considered in future research testing therapeutic interventions.

Finding 2: Adherence is difficult to measure and compare

Evidence from the literature: According to Martin et al (2000), adherence has different definitions making it difficult to measure and compare across studies. Vitolins et al (2000) reviewed ways of measuring adherence and suggested that inadequate measurement of adherence can reduce the effectiveness of an intervention. They also went on to recognise that there is no gold standard for measuring adherence. Measuring adherence has usually involved direct and indirect methods, but both are fraught with difficulties. The only direct method of measurement is to observe the subject 24 hours a day, which would be ethically unsound and open to bias. Therefore methods using diaries, patients' report of their behaviours, are the more usual methods, but these too have their limitations. The accuracy of self-report is dependent on the intervention (Meichenbaum and Turk 1987). Adherence to medication taking versus lifestyle change will be different due to the nature of the behaviours required to perform the activities. Adherence to the interventions tested in the review (Chapter 1) would be difficult to measure and assess as different behaviours were being examined within what appeared to be a single intervention. Only a small number of studies actually described the behaviours the patients were required to perform (Indredavik, 2000, Anderson et al, 2000 and Kalra et al 2000) but did not go on to say who did or did not perform the activities. Keeping diaries to monitor progress or presenting patients with quizzes or tasks to complete revealed the patient’s adherence to a point but when and how that behaviour was carried out may be different to the researchers’ expectations (Dunbar-Jacob and Schlenk 2001). As already mentioned the patient may have performed all the activities the night before the patient was seen by the researcher. Weinman (1998) suggested that time and place has an effect on patients’ self-report as well as the type of intervention under investigation. Patients may have adhered less to a non-pharmacological intervention because the intervention may not have carried as much “importance” as taking medication.

How to compare adherence behaviours to different interventions again is very difficult because different behaviours are being assessed. The methodological procedures for comparing adherence to different interventions appear not to have been examined greatly in the research literature.

Evidence from study 1: As already observed in study 1 three types of behaviour emerged and were measured using objective measures such as the answers to the quizzes in the workbook and whether the patient chose to keep the workbook. When observing the workbook for evidence of adherence there was no way of telling if the patients performed the activities over a period of time or the night before the implementer returned. Also it was not recorded who did the activities so possibly in some cases the activities may have been performed by the carer rather than the patient. How much time the patients spent on the activities was also an issue, as some patients may have put more thought into their performance whereas others may have not. These issues were also reflected in study 2.

Evidence from study 2: Patients measurement of adherence was assessed in two ways; self-report by asking the patient if they had watched the video and objectively by observing if the videotapes had been played. There was a perfect correlation between the self-report measure and the objective measure indicating that people can be “honest”! Furthermore patients may have watched the videos more than once, which could be ascertained by the video play status. However when the patients watched them and who with may have had implications for the results. Furthermore patients may have forgotten the video contents therefore there may have been no positive benefit of the intervention because it was either short lived or carried out over too longer period. Anecdotally one patient said that he had watched the video the night prior to the outcome assessment as a reminder should he be asked any questions.

Evidence from study 3: Patients said that they did not receive a letter let alone read a letter, which brings in the issue of memory. Did some of the patients receive and read the letter but not recall that they had done this when asked? For those patients who did read the letter but could not recall did the letter have a subconscious effect that the research did not clearly pick up? The purpose of the letter was to increase adherence but if it was not read how can it have an effect?

Comparing video adherence with workbook adherence: To ensure comparability of the Video Study with the SWOT study the Video study was designed to be as similar as possible to SWOT. Video adherence was initially thought of as being the same as active adherence in the stroke workbook. The reasons for this were that watching the videos involved a level of patient activity, as did performing the activities in the workbook. However when the predictors of video adherence assessed they were the same as passive adherence, namely gender and desire for the intervention.

Comments: Measuring and comparing adherence in both the workbook and video appears to be evolving into a much larger area of consideration than was originally thought at the outset of this thesis. The measures do not reflect amount or quality of adherence, which in theory should have implications for recovery from stroke. Nor does the literature highlight the psychometric issues surrounding the measurement of adherence. The findings in the present thesis are only the “tip of the iceberg” to indicate the difficulties of measurement and comparison, which will potentially be present in other studies but may have been overlooked. These findings support the reasons behind the special conference on “Adherence to Behavioural and Pharmacological Interventions in Clinical Research on Older Adults” in Controlled Clinical Trials journal (2000), which spans both medical and psychological research. One delegate Martin et al (2000) concluded, the prediction of adherence is complicated and depends on the behaviour under study and the methods used to assess. Taking medication and lifestyle change are very different behaviours. Furthermore the conference highlighted the “need for theory to orientate adherence research” in the future (Shumaker and Rejeski 2000). Adherence and participation have been demonstrated in this thesis to be different behaviours. This highlights the need for a “gold standard” format of collecting data about intervention adherence, which should also acknowledge the patient’s interpretation of the intervention instructions, their perception of what is expected of them and the objective measures of what they actually do in the intervention.

For the purpose of the thesis it has to be accepted that adherence is not one type of behaviour, it is difficult to measure and subsequently difficult to compare. This needs to be borne in mind when reading through the findings of the 3 studies described in this thesis and that attempts were made to overcome these difficulties.

Finding 3: Psychological factors rather than clinical and demographic appear to predict participation in the workbook intervention trial

Evidence from the literature: From an experimental methodology perspective, patients who do and do not participate in studies may bias the results of a given experiment (Dunn et al 2003, Schumaker and Rejeski 2000). By examining this phenomenon one can gain an understanding of non-participating patient behaviour and design new ways of improving participation, subsequently maximising benefit to the patient and also improving experimental methodology. Cox and McGarry (2003) reviewed the literature examining patients’ participation in clinical trials. They examined a number of studies and concluded that the decisions to participate in trials are “complex and multifaceted” but generally involve “a weighing up of beliefs for and against the trial”. Whilst there was an acknowledgement of the importance of beliefs about the trial they did not examine the patient’s beliefs about the illnesses. They suggested reasons for participating may include the desire to help others and/or participating may help their disease. The papers in the literature review (Chapter 1) only examined the outcome of the interventions under examination and only a proportion included the psychological variables of satisfaction and mood, for example, Kaste et al (1995) and Indredavik et al (1998) reported mood outcomes and Rudd et al (1997) and Widen-Holmqvist et al (1997) reported satisfaction outcomes; but the authors did not appear to link these variables to the other outcome measures under investigation in their papers. Leventhal et al (1987) has shown that compliance may be seen as a coping procedure based on the patient’s representations of their illness, consequently participating in trials may be also be seen as a means of coping. Horne (1997) suggests that patients have beliefs about medication in relation to concerns and benefits therefore participating in trials may also be dependent on the patients’ beliefs about concerns and benefits to themselves and others (Cox and McGarry (2003). Historical evidence claims that adherence behaviours are characterised by clinical and demographic factors, which are largely unchangeable (Dennis et al 1997). Yet Johnston et al (1998) and others before her have highlighted the importance of psychological factors in that not only do they influence adherence but are also open to manipulation.

Evidence from study 1: Participation in SWOT did not appear to be predicted by demographic or clinical variables but by the psychological measures of lower perceived control over recovery, higher anxiety and lower confidence in recovery. Patients who declined to participate in the trial after being randomised to the intervention group reported high confidence, high perceptions of control and low anxiety. These perceptions were not significantly correlated with impairment, suggesting that patients who declined the workbook intervention were no more or less impaired than those who continued with the five-week intervention. Participation in a trial may be seen as a coping strategy.

Research conducted within the health service testing medication and interventions are now commonplace and patients may consider taking part because of their beliefs not only about their illness but also about the intervention. This supports the work of Horne (1997) who suggests that patients think about the concerns and benefits of interventions in relation to themselves. Non-participation may be explained through the notion that when the patient saw the intervention for the first time it was not what they expected and therefore may not help their recovery. This appears to be reflected in the results in that patients who expressed high levels of personal control, more confidence and less anxiety were less likely to participate in the trial. They did not appear to see the workbook as being beneficial to their recovery. This finding suggests two possible explanations; the patient's representation about their illness shaped their response of whether to participate in the trial or not or the patients perception of the intervention lead them to believe it would not benefit their recovery.

Although living with a carer did not significantly differ between the participators and non-participators there was a trend to suggest that patients living with a carer were less likely to participate in a trial. This result may be worthy of future investigation as the presence of a carer may influence patient participation in other interventions and may influence how people recover (Culos-Reed 2000, Anderson et al 2000).

Evidence from study 2: Participation was not measured in the Video Study due to the design of the trial. There was no involvement of an implementer visiting the patient to give them an opportunity to withdraw from the study. Furthermore the video interventions were sent through the post so the patient would have to make an effort to contact the principle researcher to say they did not want to continue. This did happen with one patient who withdrew from the trial because being involved with a trial using stroke patients reminded him about his mother's stroke, which he found very emotive.

Evidence from study 3: Again the patients did not have the opportunity to withdraw from the FAST study as they did in the workbook study because the letter intervention was sent out to the patient via the post. One patient's letter came back from the post office as the patient was apparently not living there although she had been interviewed a week before the letter was sent out. The address was checked, the letter re-sent and returned by the royal mail.

Comments: Participation in SWOT was defined as a type of adherence. Patients participating in a trial but not necessarily involving themselves with the intervention could be seen as a coping procedure. This may have been shaped by the representations of their illness, or the intervention. These may have been shaped by the patient's own experiences (Leventhal et al 1998) or by the messages they received from health professionals (Marteau and Johnston 1990). It begs the question if the RLOC predicts participation why does it not predict other types of adherence? The SRM would account for this by suggesting patients were unsure of the intervention and what they would be required to do. They had beliefs about their illness and beliefs about the intervention, which were possibly altered by the time they received the intervention or when they received the intervention and found out what was required.

Finding 4: Gender may predict adherence

Evidence from the literature: There is a wealth of literature examining gender differences in response to health care. Differences have been highlighted but as Wardle et al (2004) described in their paper, a report by the Institute of Medicine, gender difference is an important variable that is being overlooked in clinical research. Current research on recovery from a myocardial infarction has shown that women tend to have a shorter recovery period than men and tend to return to their household duties more quickly then men (Lemos et al 2003). In the interventions reviewed in Chapter 1 gender was not raised as an issue. However gender was highlighted in the attendance to cardiac rehabilitation (Wyer et al 2001). Dunbar-Jacob and Schlenk (2001) in their review of adherence demonstrated that gender has not been consistently related to adherence.

Evidence from study 1: In SWOT women were more likely to adhere to the behavioural activities in the workbook and retain the workbook than men.

Evidence from study 2: In the Video Study men were more likely to watch the video than women.

Evidence from study 3: In the FAST study there were no significant gender differences between patients who read the experimental letter and those who did not suggesting again that different behaviours were predicted by different factors.

Comments: Women and men may adhere to different interventions more readily due to their perceptions or beliefs about what they perceive will help their recovery.

The behavioural activities in the workbook were aimed at encouraging the patients to think about their recovery and ways of taking control. These activities could be seen as problem-solving activities. Do women prefer problem-solving activities as a way of coping more than men? Women may have not watched the video due to their representations of the video. They may have associated it with a leisure pursuit and therefore not as engaging in ones recovery. Navigating the video player may also have been an issue for some women, as it is commonly expressed that "women are not as technically enlightened as men". This may support the idea that women return to household duties following a myocardial infarction more quickly than men (Lemos et al 2003). Men appear to take a longer recovery period than women therefore possibly watching the video is "more permissible". Gender was not examined in the Heart Manual study (Lewin et al 1992) but Johnston (2004) suggested that men might prefer a "manual" because of its name rather than a workbook. This was why the name "stroke workbook" was used rather than a "self-help manual" to imply that a patient had to "work" i.e. be involved with their recovery. This idea may be further supported by the genders expressing different desires for the interventions. The SRM would account for this behaviour in that men and women may have different representations about illness due to the cultural and social influences that they had experienced. (This will be further discussed under finding 8).

Finding 5: Desire for the workbook appears to be associated with adherence

Evidence from the literature: Bonetti (1999) in her PhD thesis examining perceived control, observed the variable of patients' cognition of desire for control. High desire for the workbook prior to seeing it was significantly correlated with adherence to the behavioural activities (Bonetti et al 2001). A recent study by Cvengros et al (2004) examined the relationship between perceived control, desire for information and adherence. They found patients with low perceived control with a greater desire for information showed low levels of adherence to their treatment. However in the case of patients with high, perceived control, their desire for information had no effect on their levels of adherence.

Evidence from study 1: In SWOT patients expressed high desire for the workbook prior to seeing it but desire did not predict active adherence. However those who expressed a greater desire for the workbook were more likely to passively adhere by choosing to keep the workbook. There was a significant relationship between performing the activities and retaining the workbook, which suggested that those that kept the workbook were likely to perform some of the behavioural activities in the future.

Evidence from study 2: In the Video Study men not only desired the video intervention but also were more likely to adhere to it.

Evidence from study 3: In the FAST study the patients were not asked if the would like to receive a letter and therefore desire for the letter was not observed in the letter intervention.

Comments: Desire for the intervention appears to be a variable that is important in patient's adherence. Findings from study 1 lent some support for the findings of Cvengros et al (2004), although study 2 showed that patients are more likely to be adherent if they desired the intervention. This also brings in the idea of concordance. If patients are given the opportunity to express their beliefs including desires about their treatment, the health professional can advise the patient more fully and potentially offer a choice of treatment. The treatment the patient desires may potentially predict their level of adherence to that treatment. This choice/desire also gives the patient more control over their illness and recovery. This was reflected in the finding that the intervention type was significantly related to adherence.

Within the SRM, desire for the intervention could be conceptualised as a coping procedure for taking control of ones recovery, e.g. "If I have this video/workbook, it will help my recovery therefore I am in control therefore I desire the video/workbook". The workbook may not have been what patients expected, whereas a video may have been more acceptable due to their common usage in every day life, further supporting Horne (1997) and his work on representations about medications.

Finding 6: Impairment may affect adherence.

Evidence from the literature: Impairment may have implications in that patients may be too physically impaired to be able to carry out physical activity to enhance their recovery, or impairment may influence the patient's representation of their illness (Leventhal et al 1984). Furthermore the level of the patient's impairment may influence the advice and care of the health professional caring for the patient (Marteau and Johnston 1990). Gregory and Fried (2003) found that patients rated task difficulty as being related to low exercise tolerance and pain. Furthermore they found patients saw tasks as being difficult if they took a long time to complete or having to do the task differently. This may be pertinent to stroke recovery because a lot of the rehabilitation is about adapting to new situations. Gregory and Fried (2003) found no differences in gender.

Evidence from study 1: Active adherence appeared to be performed by those with less impairment as measured by the Rankin and NIH with non-significant trends on the Barthel Index, Orgogozo and duration of in-patient stay. There was a trend in the Barthel Index to suggest that participation in SWOT may have been associated with impairment. However this was statistically non-significant and the other measures did not support this trend. Patients who were more likely to passively adhere tended to have a left sided weakness, which may be suggestive of greater impairment.

Evidence from study 2: There were no differences in impairment between those who adhered to the video and those who did. However patients who adhered to the video perceived greater identity than the patients who did not adhere. When impairment was examined in both SWOT and the Video study patients with greater impairment were more likely to watch the video than do the workbook activities. When gender differences were examined women in the Video Study were significantly more impaired than the men and women in SWOT and the men in the Video Study. Patients who adhered actively to the workbook or watched the videos appeared to be predicted by impairment.

Evidence from study 3: In the FAST study patients who did not remember reading the letter were more likely to have had a left-sided weakness, which can be indicative of impairment. Patients with a right-sided weakness were more likely to have cognitive impairment, which would appear to be counter intuitive for them to read a letter. Patients with a left-sided weakness appeared to be more impaired on the Barthel Index.

Comments: The women in the Video group appeared to be more impaired than the men in the video group and both the men and women in the stroke workbook study. Women appeared to be less adherent to the video than the men. This impairment may have impacted on their ability to use the video player. Anecdotally one patient said the reason for not watching the video was that she could not bend down to put the video into the player; she lived with an able-bodied carer. The Barthel Index was the measure showing that women were more impaired in the Video Study, which was not reflected by the other measures of impairment. The Modified Rankin showed a non-significant trend indicating that women in the SWOT study were more impaired. This result may have occurred because the Barthel Index score was taken after hospital discharge and was a measure of what the patients said about their functional ability. The Modified Rankin was taken by the health professional when the patient was admitted to hospital. The SRM may account for this by suggesting that the patient’s perception of their ability may be affected by their representations of their illness but their representation of their illness may be affected by their ability (Leventhal et al 1984) and therefore will respond to the Barthel Index from a subjective perspective. When impairment was assessed using the clinical measures of the Modified Rankin, the Orgogozo and the NIH this bought in the beliefs of the health professional who assessed the patient. This may be supported by the lack of relationship between hospital stay and the clinical measures.

The interventions appeared to be more amenable to people with less impairment suggesting that an easier intervention may increase adherence with those with more impairment (anecdotally some patients felt that the workbook intervention was too hard). Furthermore watching the video was significantly related to the number of symptoms the patient perceived. Patients with a high number of symptoms were more likely to watch the video than those with fewer symptoms. Greater impairment appeared to lead to less adherence in SWOT but high identity lead to greater adherence to FAST, which may be explained through the SRM that being more impaired impinges on the ability to perform the tasks but being more impaired may motivate engagement in an easier intervention. This explanation may be supported further where the patient's with a right-sided weakness were more likely to read the letter. The explanation using the SRM being that the letter was possibly read by those with a cognitive deficit as a means of measuring their level of recovery from their stroke. However patients who had severe cognitive deficits would not have been eligible for both studies therefore patients with a right-sided weakness in these studies would possibly only have had a mild impairment. If the patients perceived this cognitive deficit to be mild and within control they may have coped by practising cognitive activities such as reading letters more readily than someone who is badly cognitively impaired. Furthermore patients with a left-sided weakness tend to be more functionally impaired, they therefore may not have been in a situation to retrieve the letter after the postman had posted it into the patient's home. This may have been a reason why the patients did not recall receiving the letter.

There may several reasons why impairment may affect adherence. Patients with greater disability may be having more input from Primary care and did not feel they had the time to do the interventions, the interventions were given out too early in their recovery, i.e. they had just been discharged home and were coming to terms with new routines. The SRM may explain this as the patients being faced with the health threat of surviving being discharged home rather than the threat of the stroke itself. Patients who were less impaired also did not expose themselves to the intervention because they perceived that their stroke was not bad enough to warrant doing anything regards recovery or they may have been in denial. If patients do not perceive themselves as having a health threat then they will not think about it within the 5 domains of the SRM. Patients with a left sided weakness may have had less physical impairment and felt there was less to need to read the letter. This was reflected by the clinical scores of impairment, which were not significantly different but did indicate that patients who did not read the letter were less impaired than those who did.

AN EASIER INTERVENTION: DOES IT INCREASE ADHERENCE?

Finding 7: An easier intervention possibly increases adherence

Evidence from the literature: Meichenbaum and Turk (1987) stated “the more complex the demands of the treatment, the poorer the rates of adherence”. This was also supported by an article by Ley (1997) who also highlighted the more simple the schedule and shorter the duration the greater the compliance. Rand and Sevick (2000) suggested that patients would be least adherent when the treatment is preventative rather than curative, when the illness is asymptomatic and when treatment is over a long period of time. Watching the video would take less time than the activities in the workbook although the intervention period was designed to be five weeks like the SWOT study. . Also watching the video required minimal thought, i.e. the patients were encouraged to think about taking control of their recovery in the SWOT study. This was not assessed in the Video or the FAST study.

The interventions in the literature review were not assessed in terms of ease or difficulty. Interventions testing environment such as Indredavik et al (1997, 1998, 1999 and 2000), Duncan et al (1998), Mayo, et al (2000) did not examine the amount of involvement the patients had with the activities within those environments. Patients may have passively or actively adhered/responded to the units in which they were cared for. This may have had implications for the results of these studies. This was further reflected in the studies examining specific therapies such as Kwakkel et al (2002), Goodwin et al (2003), Moreland et al (2003) and Rodgers et al (2003). They did not report the patient’s perception of difficulty nor ease, which may have accounted for the lack of effect on functional outcome. These therapies may have been perceived as difficult for some patients and easy for others.

Evidence from study 1: In the SWOT study the stroke workbook was described as a complex intervention as the patients were required to perform a number of cognitive behavioural activities. However patients were also asked if they would like to keep the workbook and those who responded “yes” were seen as passively adhering to the workbook intervention. Passive adherence may be described as an easier behaviour to perform with over 50% of patients keeping the workbook. Forty three percent of patients did not actively adhere to the behavioural activities in the workbook.

Evidence from study 2: In the Video Study 75% patients watched at least one video. Adherence to the video intervention was increased depending on the measures used to measure adherence. Where adherence was measured using a dichotomous measure i.e. yes/no, there was no difference in the amounts of adherence to the workbook compared with the video. When comparing patients, who actively adhered to the behavioural activities and watched the videos with those who did not participate, were non-active or passive only significantly more patients adhered to the video intervention. When percentage adherence or adherence was measured as all, some, none there was greater adherence to the video intervention.

Evidence from study 3: In the FAST study patients were sent an experimental letter. Receiving and reading letter would take less effort than watching a video so therefore could be described as an even “easier” intervention. However 61% patients reported not reading the letter. This potentially confounds the idea that an easier intervention is easier to adhere to.

Comments: Patients adhere more readily to an easier intervention but this is dependent on how adherence is measured and with what it is compared with. Leventhal et al (1992) argues that non-compliance occurs whether the intervention is easy or complex. Furthermore what may be complex to one person may be easy to another, problem-solving activities may be easy for women but not for men. Intervention ease can be dictated by what the patient thinks prior to receiving the intervention; combining the data for both SWOT and the Video study the type of intervention was predictive of adherence further supporting the ideas that patients have representations about the intervention before seeing it. Furthermore the patient’s behaviour may be to do with passivity rather than ease or difficulty. The SRM could describe patients thinking about interventions ease/difficulty as a consequence “how difficult/easy will it be for me to do something about my recovery?” It may also be seen as a means of taking control.

If some patients hold perceptions of their own role in their recovery as being important (active or high levels of perceived control) but other patients hold the view that their recovery is in the hands of others (passive or low levels of perceived control) then this may effect their levels of adherence to an intervention. However one cannot say if passive adherence is more or less effective than active adherence.

Patients did not read the letter intervention, which appeared to be the easiest intervention of all, but may be they did not remember they had read it because the time between reading and outcome assessment was 5 weeks. This finding supports Ley (1988) who suggested that for information to be followed it has to be understood and remembered. Furthermore the letter may have involved some concepts that may have been difficult to understand in the context it was presented such as “taking control”. Although the reading ease of the letter was ensured to be of within the national norms it still may have been difficult for some to understand and therefore to respond to.

Finding 8: Gender differences in adherence may possibly be due to illness representations

Evidence from the literature: Wyer et al (2001) demonstrated gender differences using a theoretical letter to increase attendance to cardiac rehabilitation supporting the findings by McGee and Horgan (1992) but not of Whitmarsh et al (2003). Dunbar-Jacob and Schlenk (2001) suggested that gender and adherence is not consistent. There is little evidence in the literature looking at gender differences and illness representations. McGee et al (2000) found that women had higher self-efficacy for adherence to medication when they examined gender differences in relation to myocardial infarction. Furthermore Rene et al (2004) in their studies of the illness representation of identity have found that symptoms of a myocardial infarction in women are more likely to be associated with stress whereas the symptoms of a myocardial infarction in men will be associated with a myocardial infarction.

Evidence from study 1: In the SWOT study women adhered actively and passively more than the men to the workbook, supporting the work of McGee et al (2000). Patients who were less avoidant were more likely to actively adhere to the workbook. Avoidant coping was predictive of active adherence to the stroke workbook. Patients who reported using less avoidant coping strategies were more likely to engage active adherence. Women scored lower on the WOC avoidant coping scale suggesting they were less avoidant than men but this was not significantly different when the groups were compared in study 2. Avoidant coping did not significantly contribute to the variance when entered into a logistic regression. Furthermore avoidant coping had low internal reliability, which is further discussed in the limitations.

Evidence from study 2: Gender differences were examined more closely in the Video Study. In the Video Study men adhered to the video more than the women but in the workbook study they adhered less than the women. Men in the Video Study were more likely to describe themselves as using significantly more active and problem focused ways of coping than women yet they still performed less of the behavioural activities in the stroke workbook but more in the video intervention. Women appeared to have less desire for the video intervention than the men.

Evidence from study 3: Gender differences between patients who were exposed or not exposed to either the letter or the video in the FAST study were only briefly examined. There were no differences between gender in those who were exposed to an intervention and those who were not exposed.

Comments: These findings were only preliminary as the statistics used were not the most sophisticated, but they appeared to indicate that men and women do possibly have different illness representations. This would be explained through the SRM as the cultural and environmental effects of upbringing and cultural expectations of the genders. For example a myocardial infarction is seen as “man’s disease” (Wardle et al 2004) and women would attribute cardiac symptoms to stress rather than a myocardial infarction (Rene et al 2004). Oman and King (2000) showed in their study of life events and exercise adherence that men and women rate stressful life events differently and therefore respond differently. They went onto show that men significantly increased their levels of exercise in response to a life event more than women.

The women in SWOT were also less avoidant in their coping. Avoidant coping did not account for any variance, which may have been due to the unreliability of the measure. Avoidant coping is worthy of examining, as avoidant copers may be more passive or non-adherent.

A SIMPLE THEORETICALLY DESIGNED LETTER FROM HEALTH PROFESSIONALS: CAN IT INFLUENCE ADHERENCE TO AN EASIER INTERVENTION, ILLNESS REPRESENTATIONS AND OUTCOME?

Finding 9; Receiving and reading a letter does not appear to increase adherence

Evidence from the literature: Information alone does not increase adherence (Ley 1988) although receiving advice through in the form of a letter has been shown to alter cognitions (Fisher and Johnston 1996a). Furthermore Wyer et al (2001) showed that a letter increased adherence to cardiac rehabilitation.

Evidence from study 1 and study 2: There is no evidence related to this finding from studies 1 and 2.

Evidence from study 3: Receiving a letter whether patients read it or did not did not appear to influence adherence to the video. This result may be accounted for by 61% patients claimed that they did not receive letter. Of the patients who claimed to have received the letter 31% could not remember any thing about the contents of the letter. The letter did not appear to increase the adherence to the video, but those patients who read the letter performed more of the activities to do with the video depending on adherence measured.

Comments: Taking these observations into account maybe the patients genuinely forgot about the letter by the time the principle researcher visited for the outcome assessment. Some patients within this group may have received the letter and possibly read it, but just could not remember reading it when asked 5 weeks later at the outcome assessment. Ley (1988) has shown that written materials need to be understood and remembered before it can be acted upon. The letter intervention may have been sent out at the wrong time in the patient's recovery and may have quite simply been overlooked. Furthermore whilst the results showed that patients who read the letter appeared to do more of the activities related to the video the results may be explained that patients who actively engage in one recovery enhancing activity may intuitively be more likely to engage in another recovery enhancing activity.

Finding 10: Patients exposed to an intervention appeared to have differences in their illness representations

Evidence from the literature: As already presented in finding 2, patients who participate in clinical trials differ in their illness representations from those who not participate. This has not been readily examined using the IPQ-R but researchers have shown that the reasons for participation or exposing oneself to an intervention may be due to their beliefs about contributing to medical research or possible being open to better treatment (Cox and McGarry 2003). Furthermore being exposed to an intervention may possibly affect patients' responses to questions due to expectations of performance (social desirability) (Brawley et al 2000).

Evidence from study 1: Patients who participated in the workbook study appeared to have different representations than those who did not. They had significantly lower levels of perceived control, less confident about their recovery and were more anxious.

Evidence from study 2: Patients who adhered to the video desired the intervention and scored higher on the identity scale of the IPQ-R. There were trends to suggest that video adherers perceived greater time-line chronic and attributed psychological factors and their own behaviour as contributing to the cause of their stroke.

Evidence from study 3: Patients who were exposed to an intervention appeared to have different illness representations to those who are not exposed to an intervention. They appeared to have a greater time-line cyclic, perceived greater consequence and attributed the cause of their stroke to their own personal controllable risk behaviours. Following exposure to either intervention time-line cyclical appeared to be further influenced by exposure whereas consequence and personal controllable risk behaviours were not.

Comments: Evidence suggests that illness representations exist and have an effect on patient's behaviour (Leventhal et al 2004). Exposure to the interventions significantly influenced illness representations indicating that patients' beliefs are open to manipulation; patients who were exposed to an intervention perceived their illness to be more cyclic therefore possibly open to further recovery. This offers further support to Fisher and Johnston (1996a). The SRM would explain this by saying that those who have a stronger time line-cyclic representation their illness is open to change and therefore cope by exposing themselves to an intervention. Patients in SWOT who did not participate had higher levels of confidence in their recovery and according to the SRM did not feel the necessity for a workbook to help them.

Finding 11: Patients exposed to an intervention appeared to have no differences in functional and mood outcomes

Evidence from the literature: Interventions aimed at improving recovery from stroke do not have consistent findings as demonstrated in Chapter 1. These inconsistencies could be accounted for by examining the adherence to the interventions being tested as suggested by the work of Dunbar-Jacob and Schlenk (2001). These inconsistencies may be accounted for by the lack of acknowledgment of the implications of the patient's psychological cognitions, such as mood, satisfaction and illness representations. Johnston et al (submitted), Fisher and Johnston (1996a) and Morrison et al (2000) have consistently demonstrated improvements in patient's recovery following the use of intervention to change cognitions. Lewin et al (1992) and Petrie et al (1996, 2000) have further supported psychological interventions to promote recovery from myocardial infarction. By increasing adherence to interventions potentially more patients can benefit.

Evidence from study 1: Both functional and mood outcomes were not assessed in study 1. In the larger RCT patient's confidence in recovery was significantly maintained and observer assessed disability reduced in the intervention group, i.e. those who received the stroke workbook (Bonetti 1999, Johnston et al submitted).

Evidence from study 2: Outcome in the Video study was not assessed.

Evidence from study 3: In the FAST study there were no effects of the interventions on mood and disability outcomes.

Comments: Improved patient outcomes in the SWOT study may have been better than in the FAST study for a number of reasons. The FAST study was initially designed to improve adherence not functional and mood outcomes. Furthermore the stroke workbook was theoretically designed using evidence-based strategies to improve outcome. The Videos in the FAST study were not theoretically designed nor did they actively encourage patients to do something active about their recovery. Patients in the workbook study were given guidelines to help them to improve their recovery and the involvement of an implementer supporting them to work through the workbook. Furthermore repetition of information and advice are important in promoting adherence (Ley 1988) and may have been more prevalent in the SWOT than in the FAST study. The power to detect improvements in the FAST study may also be an issue, which will be discussed later.

Summary: In response to the research questions factors influencing adherence to a stroke workbook intervention appear to be clinical, demographic and psychological. An easier intervention does appear to increase adherence depending on how adherence is measured. Factors predicting adherence to an easier intervention have similarities to that of a complex intervention but also differ depending on the type of adherence examined. The messages patients receive from health professionals in the form of a theoretical letter did not obviously affect adherence to an easier intervention. If the patients remembered reading the letter then they were more likely to perform more of the activities associated with the video. This higher performance to the video may not necessarily been promoted by the letter, patients who adhere to letters may logically adhere to other interventions. Patients exposed to an intervention, whether it be a video or a letter have different representations to those who are not exposed. This needs to be examined further to observe the role of choosing or not choosing to be exposed to an intervention. The effects of the letter and the video were not huge which was possibly due to the design of the intervention and the time patients were assessed following the receipt of the interventions.

Limitations of Studies

Recruitment: One of the difficulties during patient recruitment for both projects was the definition of stroke. The definition used in this thesis was based on MacWalter and Shirley (2003) because this is the definition used in Ninewells hospital for the patients to be identified for assessment by the stroke team at Ninewells hospital. Using this definition was a bid to maintain consistency when recruiting patients. However health professionals' recording of patient's diagnosis was not consistent in its description of stroke and therefore a true cohort cannot be confirmed. As the reader noted from Chapter 3, a large number of "phrases" were included to try and identify patients with stroke. Furthermore anecdotal experience of recruiting showed that many health professionals relied heavily on the CT scan report before confirming that the patient had had a stroke or not which had implications for recruitment. The principle investigator could not approach a patient on the ward to recruit for either study if the staff had said that they did not know whether the patient had had a stroke or not even though the patient had had a left or right-sided weakness for over 24 hours. This was for two reasons. Firstly, the researcher would be going against the professional information of the staff and secondly the researcher could run the risk of assuming the patient had a stroke when they had not had one. Often it was recorded in the patient's notes that clinically they had had a stroke, even though the nursing staff said that the CT scan had not confirmed a stroke. This has obvious implications for recruiting a true cohort but furthermore patients may have missed out on the opportunity to take part in the research. This also adds support to the idea that not only patients receive different messages from health professionals but also other professionals possibly receive different messages from each other.

Measures: A number of limitations of these studies became obvious as they were being carried out some of which were related to the measures. The SWOT study was aimed to test the effectiveness of an intervention not to observe adherence behaviours. Therefore the measures that were included were not chosen by the principle researcher to observe non-adherence and the role of illness representations. This could have been amended in the Video study but there was a necessity to make the FAST study as similar as possible to the SWOT study so that they could be more readily compared. Furthermore in hindsight other measures could have been taken. These could have included: previous activity levels, as the literature has shown that previous physical activity is related to exercise adherence; a question asking patients about whether they performed problem-solving activities which may have predicted the active adherence to the workbook. Possibly some patients did problem-solving activities as a hobby in their spare time therefore workbook activities were more familiar. Furthermore asking patients about video use may have predicted video use. Education status was another factor that could have been included, as education has been related to adherence in past research. However it has been shown that increases in knowledge do not predict changes in behaviour. Another factor, which needed more consideration in hindsight, was the amount of involvement the carer had with the interventions. This was attempted in the SWOT study but not at all in the Video and FAST studies. This could have been clarified if it was recorded that the carers were the individuals to write in the workbook or put the video in the video player.

There was a missed opportunity in the stroke workbook study to measure the adherence to the activities at the points of contact with the implementer. This would have provided a clearer pattern of adherence, which would have aided understanding of the levels of adherence. Furthermore in both SWOT and FAST patients were not asked why they did not do the activities therefore a clear idea of the reasons for non-adherence was not established.

The IPQ –R (Moss-Morris et al 2002) as already discussed in Chapter 5 had 3 obvious limitations, which may have affected the responses the patients made. These included patients having difficulty responding to the statements addressing their illness as they were thinking more about their recovery rather than their stroke, the scoring of the cause component of the questionnaire being difficult to compare with other study groups and the reading ease of the questionnaire. The questionnaire is relatively new and the authors are open for it to be further developed (Moss-Morris et al 2001)

The Ways of Coping questionnaire (Billings and Moos 1989) used in the three studies in this thesis showed low internal reliability. Active cognitive, avoidant and emotion-focused coping had consistently low Cronbach's alphas never achieving reliability greater than .50. One of the reasons for this may be due to the items being used for more than one measure e.g. item 1 is used to measure active, active cognitive and emotion focused coping. Furthermore the questionnaires ways of coping may have become dated, e.g. "praying for guidance and strength" is not such a common way of coping in this current society. This was further reflected when the internal reliability increased when this item was removed from the measure. Items relating to exercise, and smoking also caused problems in that stroke patients may be impaired following their stroke and therefore cannot exercise and many of them have given up smoking so do not see themselves as coping by smoking more.

A measure of satisfaction was not included in the FAST study although it had been measured in the SWOT, which was in relation to health care services. Satisfaction about the intervention and its relationship to the predictor variables might have offered another explanation of the non-adherence observed in the studies.

Non-participation: When patients declined to be recruited or withdrew from the study their reasons for doing so were not effectively explored. Consent forms for patients to take part in trials say that patients can withdraw without giving reason, which anecdotally prevents the researcher from enquiring further. If the patient volunteers a reason this may be recorded in a bid to understand but rarely does the enquiry take a standardised form. This situation, one assumes leads to a loss of valuable information, which may have shed more light on the findings. This needs to be assessed and possibly the patient could be asked why they do not want to take part or continue, obviously without coercion, but this may give a greater insight to why patients do not take part in trials. Just because the consent form says that patients do not have to give a reason does not means to say the researcher cannot ask why in the form of a standardised format that may reveal peoples' beliefs about the interventions that are being evaluated.

Adherence labels: On further reflection the labels given to the types of adherence behaviours in the stroke workbook may have been unclear. Was the behaviour the patients were performing active thinking or being physically active? Given the patients were asked to set goals including physical activity and to monitor their progress in achieving these goals patients may have been both physically and mentally active. This was never separated in the stroke workbook study; physical activity was not measured but may have impacted on the patient's involvement with the workbook.

Patient's instructions: When testing the efficacy of an intervention attention needs to be paid to the instructions the patient receives and the measure of adherence to those behaviours. In the stroke workbook patients were asked to work through the workbook at their own pace and to use it how they saw fit. Many patients had not performed the activities by week five because they were taking it at their own pace.

Carer's involvement: The three studies failed to acknowledge the impact of the presence of a carer on adherence. No measure was included to measure the amount of involvement they had with the patient. Many carers may have performed the activities for the patient. Women traditionally have a caring role and they may have encouraged the male patient to watch the video, given that the presence of a carer was more common to men than women.

Multiple testing: Multiple testing was another limitation of the study as not only was a large battery of questionnaires analysed, but also the questionnaires were sub-grouped into further variables. Furthermore the study groups were divided into different groups to enable the exploration of different group behaviours. Regression analysis was used to minimise the risk of the differences being due to chance (type I error). Also the data were examined to ensure that it made logical sense. Bonferroni's correction could have been applied but this may have increased the likelihood of a type II error (Perneger 1998). This thesis set out to explore the possible reasons for non-adherence to interventions and therefore was interested in findings that may lead us to a better understanding. The underlying philosophy of the studies was exploratory therefore multiple testing was used and regression analyses tried to reduce the effects of multiple testing by being confirmatory. The use of hypotheses instead of research questions may also reduced have reduced the number of tests used and is discussed below.

Power to detect differences: There was no a priori power analysis for study 1 examining the characteristics of those who adhered to the stroke workbook intervention. The reason for this was study was developed along side SWOT study (Bonetti et al 2000). An a priori power analysis was performed for the FAST study, to determine the required sample size. However, more variables were included in the analyses than originally planned for in the research questions. Post-hoc analyses indicated that both studies were sufficiently powered to detect a large effect but not a medium one. This power issue could have possibly been reduced if hypotheses were included as part of the study design rather than research questions. There were three main reasons why hypotheses were not derived for the studies described in this thesis. Firstly the SWOT study identified research questions rather than hypotheses and therefore the FAST study followed the same format to maximise the comparability of both studies. Secondly the grant awarding body specified that research questions be asked when writing out the studentship application rather than hypotheses. Thirdly the use of research questions allows the research to be more pragmatic and available to the health services arena. The results in the studies in the thesis were underpowered and therefore ran the risk of not being able to detect a difference or relationship when one may have existed. Furthermore generalising the results from small studies such as these would not be appropriate as they would not be as representative of the stroke population as one had initially hoped for. The FAST study was a relatively a large RCT to carry out by one researcher and within the time constraints of the PhD process. If there had been more time and more resources a larger study may have revealed more significant results. The present studies have been exploratory in their nature in an attempt to understand the problem of non-adherence to interventions but as Parahoo (1997) suggested “research findings must always be treated with caution”.

Implications for stroke care: Logically there seems to be no point in giving patients interventions if they do not desire them therefore establishing if a patient would like a certain intervention may predict the adherence to it. These studies appear to lend support to the philosophy of concordance. If patients are given the opportunity to express their beliefs about their illness and treatment and in return the health professional can share their beliefs about the illness and treatments available better adherence to medical regimes may arise. This would potentially avoid the wasted costs of non-adherence to the health service in general.

Theoretical considerations: The present thesis has further demonstrated the need for a "gold standard measure" of adherence. Adherence to an intervention is not a single behaviour therefore attention to the way it is measured is essential for it to be assessed and for the testing of interventions in general. The SRM appears to be able to explain the behaviours observed in the studies and suggests that individuals develop representations about all aspects of life not just ill health. Representations furthermore appear to be associated with gender, which has been largely overlooked in the literature (Wardle et al 2004).

Future Research: To measure adherence several considerations need to be taken into account: what is being measured, what instructions are given to the patient, and whether instructions and the outcome behaviour are consistent with the measurement of adherence. Attention to their reliability, validity and sensitivity are essential. This thesis has further demonstrated the need for a "gold standard" of measuring adherence.

The amount of adherence to a non-pharmacological intervention to produce "a desired clinical outcome" (Dunbar-Jacob and Schlenk 2001) is also worthy of future consideration since insufficient adherence to an intervention "can adversely impact the effectiveness of an intervention" (Vitolins et al 2000). How much does a patient have to do to gain benefit?

The relationship between gender, representations and adherence could be further examined in light of the provisional findings of this thesis.

Health professionals' illness and emotional representations and their effects on patients' outcome could also be an avenue to further explore given that effective doctor-patient communication has been shown to be related to intervention adherence. The health professionals' own beliefs about adherence may influence the patients that they care for.

Furthermore the impact of previous adherence to un-prescribed interventions, e.g. the patient's previous health behaviour may shed light on patients' future adherence to interventions aimed at improving their health.

Ethical Considerations: If patients do not try something that may be beneficial then this has implications for the design and implementation of interventions. However patients may not try an intervention, which could help them recover because some patients may not want to recover! Adherence by health professionals to stroke guidelines have been shown to be beneficial to stroke patient's outcome (Duncan et al 1999). But can stroke patients be coerced into doing something that they do not want to even though the benefit has been demonstrated?
The findings from these studies suggest that it is important to increase or encourage adherence supporting the recommendations of Wyer et al (2001) but there are ethical considerations to be aware of, for example it may be stressful and detrimental to some to feel they were being coerced into doing something that they do not want to do. It may also be negligent if patients are not encouraged to be helped if the intervention has been shown to be effective.

CONCLUSION

In conclusion stroke patients fail to adhere to interventions when offered due to clinical, demographic and psychological factors. To unravel these factors would appear to be complex. Clinical, demographic and psychological factors of both the patient and the caregiver whether they are a family member or friend or health professional appear to be the active ingredients of the black box of rehabilitation (Whyte and Hart 2003). Therefore to understand non-adherence behaviours to medical interventions these three factors cannot be considered in isolation, psychological factors impact on clinical and demographic factors. Furthermore patient characteristics may influence their expression of satisfaction (Pound et al 1999).

Leventhal's SRM can offer a plausible explanation for the behaviour exhibited by the patients who adhered and did not adhere to both a complex and an easy intervention.

The description of stroke within the medical literature and in the opening chapter demonstrate the 5 domains of the SRM, identity of what a stroke is, its causes, its consequences, on the individual and on the health service, the duration of recovery and the current understanding of how to prevent stroke. It appears to be "common sense" for the individual to think about their illness in that way.

This thesis also offers support to Horne’s (1997) work examining patient’s treatment representations. Furthermore adherence has been shown to be a multi-faceted behaviour dependent on the type of intervention being tested. Instead of fully answering the research questions this thesis appears to have raised more and has raised an awareness of the flaws that may possibly exist in the reporting of trials testing interventions.

“In this complex area, the greater adherence of clinicians, and researchers to the suggestions made about integrating experience and using this knowledge is essential for scientific and clinical progress in the next decade”.
Brawley and Culos-Reed (2000).

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APPENDIX A

Workbook Contents.

HELPING YOURSELF AFTER A STROKE: A WORKBOOK FOR PATIENTS AND CARERS

APPENDIX B

1. Patient Screening sheet used in SWOT and FAST
2. Patient Information Sheet
3. SWOT Consent Form
4. Interview schedule used for SWOT and FAST
5. Statistics for Study 1.

PATIENT SCREENING SHEET

PATIENT HOSPITAL LABEL **GOES HERE!**	**TELEPHONE NUMBER**		**NOK TELEPHONE**	
	RETIRED YES/NO			
	PREVIOUS OCCUPATION			
	HOSPITAL WARD		CONSULTANT	
	CT			
	NIVA			
		GIVEN BOOKLET	YES	NO

DATE ADMITTED	TIME ADMITTED	REHAB PLANS
DATE SCREENED	TIME SCREENED	
ENTERED STUDY YES/NO	NAME OF STUDY	

HT	WT	P	BP	T	SPO2

ADMISSION NOTES

SMOKER circle response	NON EX	NO/DAY
ALCOHOL unit/day		
COFFEE – cups/day		
TEA – cups/day		
DATA RE: PRESENTATION	YES	NO
GP REFERRAL		
999 REFERRAL		
SELF REFERRAL		
LETTER WITH PT		
TEL. IN PTs HOUSE		
LIVING ARRANGEMENTS PRIOR TO STROKE		
ALONE		
WITH SPOUSE		
WITH OTHER		
INSTITUTIONAL SETTING		
IF YES WHAT TYPE		

HELP AT HOME	NONE	ONCE/WK	MORE/WK
HOME HELP (COUNCIL)			
PRIVATE HELP			
DISTRICT NURSE/HV			
FAMILY HELP			
VOLUNTARY HELP			
MOW			
OTHER			

IMPAIRMENTS	YES	LIMITED	NO
VISION WITH GLASSES			
HEARING WITH AID			
EXP. COMMUNICATION			
REC. COMMUNICATION			

WHERE DID STROKE HAPPEN?

MOBILITY & ADL PRIOR TO STROKE	NO HELP	ASST. DEVICE	PERSONAL HELP	TOTALLY DEPENDENT
WALKING				
USES WHEELCHAIR				
TRANSFERS - in/out bed/chair				
STAIRS				
BATHS/SHOWERS				
DRESSES- (gets clothes & dresses)				
GROOMS (teeth/hair/shave)				
USES TOILET (to/from, cleaning self & transfer)				
FEEDING				
CONTINENCE – BLADDER (circle response)	No help	Asst. devices	Odd accident	Incontinent
CONTINENCE –BOWELS (circle response)	No help	Asst. devices	Odd accident	Incontinent

MOBILITY & ADL FOLLOWING ACUTE STROKE	NO HELP	ASST. DEVICE	PERSONAL HELP	TOTALLY DEPENDENT
WALKING				
USES WHEELCHAIR				
TRANSFERS - in/out bed/chair				
STAIRS				
BATHS/SHOWERS				
DRESSES- (gets clothes & dresses)				
GROOMS (teeth/hair/shave)				
USES TOILET (to/from, cleaning self & transfer)				
FEEDING				
CONTINENCE – BLADDER (circle response)	No help	Asst. devices	Odd accident	Incontinent
CONTINENCE –BOWELS (circle response)	No help	Asst. devices	Odd accident	Incontinent

INSTRUMENTAL ADL PRIOR TO STROKE	NO HELP	PERSONAL HELP	UNABLE
PREPARE A **LIGHT** MEAL			
DO LIGHT **HOUSE WORK**			
SHOP FOR GROCERIES			
MANAGE FINANCES			
USE TELEPHONE			
USE TRANSPORTATION			
DRIVES (circle response)	YES	NO	USED TO

TODAY'S MONTH		AGE	
TODAY'S DATE		MONTH OF BIRTH	
TODAY'S YEAR		YEAR OF BIRTH	
THIS TOWN		PRIME MINISTER	
PRESENT SITUATION		PREVIOUS PRIME MINISTER	
		TOTAL	

EXPRESSIVE DYSPHASIA		**PAST MEDICAL HISTORY**	PREVIOUS AF
RECEPTIVE DYSPHASIA		PREVIOUS CVA INFARCT/BLEED	
Dysarthria		PREVIOUS TIA	
TEDS		PREVIOUS MI	
UTI		HYPERTENSION	
FAMILY HISTORY OF STROKE		DIABETES	

NIH		score	
Level of consciousness	Alert Not alert-arousable by minor stimulation to obey Not alert – repeated stimulation to attend or painful stimuli Responds only with reflex motor or autonomic effects, unresponsive, flaccid	0 1 2 3	
LOC Questions /month age	Answers both questions correctly Answers one question correctly Answers neither question correctly	0 1 2	
LOC Commands Open & close eyes Grip & release normal hand	Performs both tasks correctly Performs one task correctly Performs neither task correctly	0 1 2	
Best gaze	Normal Partial gaze palsy Forced deviation or total gaze paresis not overcome by oculocephalic manoeuvre	0 1 2	
Visual fields	No visual loss Partial Hemianopia Complete Hemianopia Bilateral Hemianopia (blind)	0 1 2 3	
Facial palsy	Normal Minor paralysis (asymmetry on smiling) Partial paralysis (total or near of lower face) Complete paralysis of one or both upper & lower face	0 1 2 3	
Motor arm	No drift- limb holds 90 degree for 10 secs Drift limb holds 90 degrees but drifts down before full 10 seconds, does not hit the bed. Some effort against gravity, limb cannot get to or maintain (if cued 90 degrees, drifts but has some effort against gravity. No effort against gravity No movement Amputation, joint fusion	0 1 2 3 4 9	
Motor leg	No drift- limb holds 45 degree for 5 secs Drift limb holds 45 degrees but drifts down before full 5 seconds, does not hit the bed. Some effort against gravity, limb cannot get to or maintain (if cued 45 degrees, drifts but has some effort against gravity No effort against gravity No movement Amputation, joint fusion	0 1 2 3 4 9	
Limb ataxia Finger/nose Heel/shin	Absent Present in one limb Present in two limbs	0 1 2	
Sensory	Normal Mild to moderate, dullness to pinprick Severe to total sensory loss	0 1 2	
Best language	No aphasia Mild to moderate aphasia Severe aphasia Mute global dysphasia	0 1 2 3	
Dysarthria	Normal Mild to moderate some words Severe slurred to unintelligible Intubated or physical barrier	0 1 2 3	
Extinction and inattention Formerly neglect	No abnormality Visual, tactile. Auditory, spatial or personal inattention or extinction to bilateral simultaneous stimulation Profound hemi-inattention	0 1 2	

ORGOGOZO			
CONSCIOUSNESS normal drowsy reacts to verbal command stupor	15 10 5 0		
SPEECH VERBAL COMMUNICATION normal no aphasia Limited vocabulary or incoherent speech/difficult More than yes/no but no longer sentences/difficult Only yes/no, difficult or impossible	10 5 5 0		
EYE MOVEMENTS No gaze palsy Gaze palsy or gaze failure Conjugate eye deviation/forced	10 5 0		
FACIAL PALSY None/dubious/slight paresis Present paralysis or marked paresis	5 0		
ARM MOTOR Raises with normal strength Raises with reduced strength/possible Raises – flexion in elbow/incomplete Can move but not against gravity paralysis	10 10 5 0 0		
HAND MOTOR Normal strength Reduced strength - skilled movements Fingertips do not reach palm - useful Paralysis - useless	15 10 5 0		
UPPER LIMB TONE Normal – even if brisk reflexes Overtly spastic or flaccid	5 0		
LEG MOTOR Raises with normal strength Raises with reduced strength Raises with flexion in the knees Can move but not against gravity Paralysis	15 10 5 0 0		
FOOT DORSIFLEXION Against resistance/normal Against gravity Foot drop	10 5 0		
LOWER LIMB TONE Normal even if brisk reflexes Overtly spastic or flaccid	5 0		
TOTAL			

LABORATORY DATA	
PV	
WBC	
RBC	
HGB	
HCT	
MCV	
MCH	
MCHC	
PLTS	
MPV	
NA	
K	
UREA	
CREAT	
ALT	
BIL	
AP	
ALB	
CA	
CA COR	
GLUC	
T4	
TSH	
URATE	
CHOL	
TRIG	
HDL	
HDL%	
CKI	
CKII	
TROPO MIN	

CXR	
normal	
cardiomegaly	
Cardiac failure	
Aortic unfolding	
Pneumonic ↖	
COPD	

ECG	
normal	
AF	
Heart block specify	
MI	
Ischaemic ↖	
LVH	

DRUGS ON ADMISSION

DRUGS ON DISCHARGE

	TOTAL SCORE				
NEURO ASSESSMENT 2			STROKE HANDICAP – MODIFIED RANKIN		ALLERGIES
Motor deficit (side)	R	L	0; No symptoms at all		
Sensory loss	R	L	1; No significant disability, able to carry out usual activities		
Sensory inattention	R	L	2; Slight disability – unable to carry out previous activities/can look after own affairs		
Hemianopia	R	L	3; Moderate disability – requires some help but walks unaided		
Dysphagia	R	L	4; Moderate		
Plantars	R	L	5. Severely disabled – immobile? incontinent		
Reflexes score 0 absent 1, 2, brisk	R	L	6; Comatose/unrousable		
Handedness	R	L			

PATIENT INFORMATION SHEET for the STROKE WORKBOOK STUDY

What is the study called?

A randomised controlled trial of a workbook-based intervention for stroke patients: Effects on disability and distress in patients and partners

Who is running the study?

Dr RS MacWalter, Consultant Physician in General Medicine and Honorary Senior Lecturer in Medicine, Department of Medicine, Ninewells Hospital Dundee **and Professor Marie Johnston**, Professor of Psychology, University of St. Andrews, and **Dr Valerie Morrison**, a psychologist, are in charge and special personnel, under their supervision have been appointed to run the study.

Why is the research desirable?

At present it is almost impossible to predict just how much disability and distress, if any, will be present in the weeks and months after stroke. It is possible that certain ways of thinking about the condition and its treatment can lead to a better outcome. We have devised a workbook containing topics of interest about your stroke, its effects and what you can do about it. We hope to show that completing the workbook can aid recovery by setting out some simple exercises, giving advice about living a more healthy lifestyle, and reducing feelings of depression. If this is the case, such workbooks may become part of the standard treatment helping future patients and their family and friends recover from stroke more fully and more quickly.

Why are you a suitable person to participate in this study?

You have recently had a stroke and we hope, as you do, that you will recover quickly. We would like to know the way you feel about your condition and the rehabilitation process and perhaps have you complete the workbook over the next month. Only half of the participants will be given the workbook. As with most studies, the allocation of this workbook is done randomly (like tossing a coin), so you will not know until you enter the study whether you get a workbook or not. This will not affect the normal treatment of your condition in any way.

What are the procedures?

Step 1 Involves the completion of some simple, short **questionnaires** by you and your partner/carer. Trained personnel will see you just before or soon after your discharge from Ninewells Hospital and guide you through the questions. They will answer any questions you may have.

Step 2 If you are allocated a **workbook**, you will receive a visit at home within the next week when you and your partner will receive your workbook and some advice about how to use it. The researcher will visit again in a week and keep in contact through weekly telephone calls for the next four weeks. Again, you may ask questions at any time.

Step 3 You will be **visited** at your home in *six weeks* and then again in *six months* time to repeat the questionnaires whether or not you have been using the workbook. If you do not have a telephone or if you do not want the researcher to call at your home, alternative arrangements can be made.

Normal examinations by your doctor will also take place during the study and information will be gathered from your medical records. Your GP will be notified if you choose to participate in the study. All the information collected from you during the course of this study will be treated in the strictest confidence; no one outside the research team will have access to it. The Tayside medical Research Ethics Committee monitors all medical research in Tayside. They occasionally need to see patient information, but again this is in the strictest confidence.

What effects will be experienced at the time of the study or later?

Apart from having to talk about how you feel about your condition and its treatment there will be no effects.

Are there any risks or side-effects?

There are no known risks or side effects.

Are there any expenses?

You should incur no expenses through participation in the study. The researcher will visit your home, so you do not have to make extra trips to the hospital. If, however, you prefer to come to the hospital this can be arranged and your transportation costs reimbursed.

Where can I get more information?

If you have any questions now or during the study you can contact The Researcher (to be appointed), on ph. 01334-463055, Professor M. Johnston or Dr R.S. MacWalter.

What happens if you don't want to take part or decide you have had enough?

Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw at any time without having to give a reason and without this affecting your future medical care.

CONSENT FORM

I have read the information sheet and am willing to take part. I understand that I take part voluntarily and I can withdraw at any time, without affecting my treatment.

NAME:________________________________DoB:______________ SEX: M☐ F☐

PH. ___________________ ADDRESS _____________________________________

SIGNATURE:____

Who at home will be most involved with your recovery?
NAME____

PH. ___________________ ADDRESS _____________________________________

Relationship: Spouse ☐ Other ____________________________

Do you think this person would like to take part in the study? Yes No

INTERVIEW SCHEDULE (T1)

First I would just like to thank you for taking part in this project. Now I am going to ask you about yourself and then some questions, in order to do a little check on your memory.

Can you tell me when you had the stroke:___________
Is this the only stroke you've had?___________ (when was the first?___________)

Which side of the body was affected? Left Right

Y☐ N☐ Can I just check your full name?
Y☐ N☐ How old are you? *(Present age in years, or predicted age next birthday)*
Y☐ N☐ *Day* What is your date of birth? *(Day, month, year must all be correct)*
Y☐ N☐ *Month*
Y☐ N☐ *Year*
Y☐ N☐ Can you tell me what is this place, that is, where you are now? (In hospital/at home)
Y☐ N☐ Can you tell me this address? (Need number or name of home **and** street)
Y☐ N☐ What is the name of this town?
Y☐ N☐ Can you tell me who is the Prime Minister? (Surname is sufficient)
Y☐ N☐ Can you tell me who was the previous Prime Minister? (Surname is sufficient)
Y☐ N☐ Can you tell me who is the monarch?
Y☐ N☐ Who is the President of the United States? (Surname is sufficient)
Y☐ N☐ What are the colours of the national flag, the Union Jack? (Red, white and blue)
Y☐ N☐ Can you tell me what are the years of the First World War?
Y☐ N☐ Can you tell me the time? (To the nearest hour)
Y☐ N☐ What day is it?
Y☐ N☐ Can you tell me today's date?
Y☐ N☐ What month is it?
Y☐ N☐ What year is it?
Y☐ N☐ Now, can you please count backwards from 20 to 1 for me?
(No errors, but may correct self)
***Yes** Count (**Ignore blocked questions**) ________ (If more than 6, go on with questionnaire)*

Now, I am going to ask you a series of questions about how you are feeling, and about what you think about things connected to your health and your recovery. This is not a test - there are no right or wrong answers. All strokes are different, and everyone will have different problems and be at different stages in their recovery - so what is right for some people, won't be right for others. The main thing to remember is to tell us what **you** are feeling, and what **you** think about things, not what you think you **should** feel or think - remember, your answers are completely confidential. Try not to take too long in giving your answers - because what first comes to your mind is more likely to be what you really think. We will take a break about half way. If you miss something, just ask me to repeat it. If you get tired, or want a break for any reason, just say. Shall we start?
Would you now tell me which comes closest to how you have been feeling in the past 7 days.

1. I feel tense or 'wound-up':
1. Most of the time ☐
2. A lot of the time ☐
3. Time to time, occasionally ☐
4. Not at all ☐

2. I still enjoy the things I used to enjoy:
1. Definitely as much ☐
2. Not quite so much ☐
3. Only a little ☐
4. Hardly at all ☐

3. I get a sort of frightened feeling as if something awful is about to happen:
1. Very definitely and quite badly ☐
2. Yes, but not too badly ☐
3. A little, but it doesn't worry me ☐
4. Not at all ☐

4. I can laugh and see the funny side of things:
1. As much as I always could ☐
2. Not quite so much now ☐
3. Definitely not so much now ☐
4. Not at all ☐

5. Worrying thoughts go through my mind:
1. A great deal of the time ☐
2. A lot of the time ☐
3. From time to time but not too often ☐
4. Only occasionally ☐

6. I feel cheerful:
1. Not at all ☐
2. Not often ☐
3. Sometimes ☐
4. Most of the time ☐

7. I can sit at ease and feel relaxed:
1. Definitely ☐
2. Usually ☐
3. Not often ☐
4. Not at all ☐

8. I feel as if I am slowed down:
1. Nearly all the time ☐
2. Very often ☐
3. Sometimes ☐
4. Not at all ☐

9. I get a sort of frightened feeling like 'butterflies' in the stomach:
1. Not at all ☐
2. Occasionally ☐
3. Quite often ☐
4. Very often ☐

10. I have lost interest in my appearance:
1. Definitely ☐
2. I don't take so much care as I should ☐
3. I may not take quite as much care ☐
4. I take just as much care as ever ☐

11. I feel restless as if I have to be on the move:
1. Very much indeed ☐
2. Quite a lot ☐
3. Not very much ☐
4. Not at all ☐

12. I look forward with enjoyment to things:
1. As much as I ever did ☐
2. Rather less than I used to ☐
3. Definitely less than I used to ☐
4. Hardly at all ☐

13. I get sudden feelings of panic:
1. Very often indeed ☐
2. Quite often ☐
3. Not very often ☐
4. Not at all ☐

14. I can enjoy a good book or radio or TV programme:
1. Often ☐
2. Sometimes ☐
3. Not often ☐
4. Very seldom ☐

Now, I am going to ask you some questions about some everyday activities. If you turn to the first page of this booklet (give binder), you will see these activities listed. Can you see this okay - do you need reading glasses?

1. Grooming In the last 24 hours have you been able to comb your hair, clean your teeth, shave, wash your face by yourself, or does someone help you?	0=needs help 1=independent (implements can be provided by carer)
2. Feeding Have you been able to feed yourself, or do you need help? Is this help with cutting, spreading, or is it more than this?	0=unable 1=needs help (food cut up, feeds self) 2=independent
3. Bowels How have your bowels been over the last week? Have you had any accidents during the day or night?	0= incontinent 1=occasional accident (once a week) 2=continent
4. Bladder How have your waterworks been over the last week, have you had any accidents during the day or night?	0=incontinent 1=occasional accident 2= continent
5. Toilet use Have you been able to get to the toilet yourself over the last 24 hours or do you use a commode (Can you manage on and off the commode yourself?); Can you manage with your underclothing/zips or do you need some help? Are you able to clean yourself after using the toilet, or does someone help you?	0=dependent 1=needs some help, but can do something alone 2=independent(on/off, dress, wipe)
6. Transfer: from bed to chair, and back Over the last 24 hours have you been able to move yourself from a lying position on the bed to a sitting position on a chair? Do you need some help, if so, what with? (sitting up/transfer)	0=unable, no sitting balance 1=major help (one or two people; can sit) 2= minor help (needs supervision) 3=independent
7. Mobility Have you been able to walk anywhere in the last 24 hours or do you use a wheelchair? (Can you manage on your own or do you need someone to push you) Do you need to use a zimmer or stick or does someone support you?	0=immobile 1= wheelchair independent (can corner) 2=with help from one person 3= independent (may use aid)
8. Dressing In the last 24 hours have you dressed and undressed yourself? Did you need help with any items of clothing?	0=dependent 1=needs some help, can do about half 2=independent: zips, buttons and laces
9. Stairs In the last 24 hours have you been up and down any stairs? Did anyone assist you (physically) or did someone go with you just to make sure you were alright?	0=unable 1=needs help 2=independent (can carry walking aid)
10. Bathing/Showering Have you been able to have a bath or shower in the last 24 hours by yourself, or does someone help you?	0=dependent 1=independent: in and out, washes self

The following statements are about your current health and how the stroke may have influenced your everyday life.
Listen to each statement, think of yourself today and tell me if it describes you or not. If you agree or disagree you should tell me.
I will then ask "Is this due to your health"- Please answer yes or no. Ask me to repeat a statement or slow down if you do not understand.
(Read down the list of items within each category. As soon as the patient agrees with a statement you must ask whether this is due to their health, if the answer to this is yes, tick the statement and move to the next category)
The following statements describe walking and use of stairs. Please think of yourself *today*, and tell me if you agree or disagree with the statement, *and if this is due to the state of your health*.

1. I do not walk at all. ...... (126)
2. I get about in a wheelchair. ...... (121)
3. I do not use stairs at all. ...... (106)
4. I only walk with help from somebody else. .... (98)
5. I get about only by using a walking frame, crutches, stick, walls, or hold on to furniture (96)
6. I only go up and down stairs with assistance from somebody else. ...... (87)
7. I only use stairs with a physical aid; for example, special rail, stick or crutches. ...... (82)
8. I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg ...... (71)
9. I do not walk up or down hills. ...... (64)
10. I go up and down stairs more slowly; one step at a time or I often have to stop ...... (62)
11. I walk shorter distances or often stop for a rest. ...... (54)
12. I walk more slowly. ...... (39)
13. I do not walk as well as I did before my stroke (not in flp)

PFB-body care and movement items (124) The following statements describe how you move about, bath, go to the toilet, dress yourself **today**. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

13. I am in a restricted position all the time. ...... (124)
14. I do not have control of my bowels. ...... (124)
15. I do not have control of my bladder. ...... (122)
16. I stay lying down most of the time. ...... (120)
17. I use a bedpan with help. ...... (107)
18. I do not bathe myself at all, but am bathed by someone else. ...... (100)
19. I do not get in and out of bed or chairs without the help of a person or mechanical aid. . (100)
20. I only stand up with someone's help. ...... (93)
21. I do not keep my balance. ...... (93)
22. I do not bathe myself completely; for example I need help with bathing. ...... (85)

23. I make difficult movements with help; for example getting in or out of the bath or car ..... (82)

24. I hold on to something to move myself around in bed. ...... (82)

25. I only get dressed with someone's help. ...... (82)

26. I get in or out of bed or chairs by grasping something for support or by using a stick or a walking frame....... (79)

27. I spend most of the time partly dressed or in pyjamas. ..... (75)

28. I do not fasten my clothing; for example I require assistance with buttons, zips, and shoelaces. (68)

29. I only stand for short periods of time. ...... (67)

30. I move my hands or fingers with some difficulty or limitation. ...... (66)

31. I kneel, stoop or bend down only by holding on to something. ..... (61)

32. I have trouble putting on my shoes, socks or stockings. ...... (54)

33. I change position frequently. ...... (51)

34. I am very clumsy. ...... (47)

35. I dress myself, but do so very slowly. ...... (43)

PFM-Mobility (114) These next statements describe how you get about the house and outside. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

36. I stay in bed most of the time. ...... (114)

37. I stay in one room. ...... (101)

38. I stay in bed more. ...... (91)

39. I stay at home most of the time. ...... (79)

40. I only get about in one building. ...... (76)

41. I only go out if there is a lavatory nearby. ...... (64)

42. I do not get about in the dark or in places that are not lit unless I have someone to help... (57)

43. I do not use public transport now. ...... (52)

44. I do not go into town. ...... (47)

45. I only stay away from home for short periods. ...... (46)

PFH-Household management (90) The following statements describe your daily work, around the home. When you answer, think of yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

46. I do not do any of the daily household chores that I would usually do. ...... (90)

47. I do not do any of the shopping that I would usually do. ...... (84)

48. I do not do any of the cleaning that I would usually do. ...... (78)

49. I have difficulty using my hands; for example, turning taps, using kitchen gadgets, sewing or doing repairs. (78)

50. I do not do any of the maintenance or repair work that I would usually do in my garden. ...... (75)

51. I do not do any of the clothes washing that I would usually do. ...... (75)

52. I have given up taking care of personal or household business affairs;

for example, paying bills, banking or doing household accounts. ...... (69)

53. I do not do heavy work around the house. ...... (59)

54. I only do housework or work around the house for short periods of time or I rest often.... (50)

55. I do less of the daily household chores than I would usually do. ...... (37)

PFR-Recreation (91) The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

56. I am not doing any of my usual inactive pastimes; e.g., I do not watch TV, or read...... (91)

57. I am not doing any of my usual physical recreation or more active pastimes .... (81)

58. I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less,

or read less (50)

59. I am doing more inactive pastimes instead of my other usual activities... ...... (43)

60. I am cutting down on some of my usual physical recreation or more active pastimes.... (34)

61. I spend shorter periods of time on my hobbies and recreation. ...... (32)

62. I go out less often to enjoy myself. (27)

63. I take part in fewer community activities. ...... (25)

PFS-Social (109) These statements describe your contact with family and friends today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

64. I refuse contact with my family; for example, l turn away from them. ...... (109)

65. I frequently get angry with my family; e.g., hit them, scream or throw things at them...... (103)

66. I isolate myself as much as I can from the rest of my family. ...... (100)

67. I stay alone much of the time. ...... (91)

68. I do not go out at all to visit people....... (91)

69. I am disagreeable with my family; for example, l act spitefully or stubbornly. ….. (86)

70. I make many demands on other people; for example, l insist that they do things for me or tell them how to do things...... (76)

71. I avoid having visitors (73)

72. I do not look after my children or family as well as I usually do. ...... (66)

73. My sexual activity is decreased. ...... (64)

74. I am often irritable with those around me; e.g., I snap at people or criticize easily. ...... (64)

75. I pay less attention to the children. ...... (59)

76. I show less interest in other people's problems; I don't listen when they tell me about their problems; I don't offer to help. (50)

77. I show less affection. (44)

78. I often express concern over what might be happening to my health. ...... (44)

79. I talk less with other people. ...... (44)

80. I do not joke with members of my family as much as I usually do. ...... (38)

81. I am cutting down the length of visits with friends. ...... (31)

82. I go out less often to visit people. ...... (31)

83. I take part in fewer social activities than I used to; for example, I go to fewer parties or social events...... (25)

PFE-Emotion (141) The next statements describe your feelings and behaviour. Think of yourself today **and if it is due your health.**

84. I have attempted suicide. ...... (141)

85. I talk hopelessly about the future. ...... (96)

86. I say how bad or useless I am; for example, that I am a burden on others. ...... (89)

87. I am irritable and impatient with myself; for example, l run myself down, l swear at myself, l blame myself for things that happen. ...... (79)

88. I often moan and groan because of pain or discomfort. ...... (67)

89. I keep rubbing or holding areas of my body that hurt or are uncomfortable. ...... (59)

90. I laugh or cry suddenly. ...... (58)

91. I get sudden frights. ...... (56)

92. I behave nervously or restlessly. ...... (48)

PFAL-Alertness (115) These statements describe your general alertness today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

93. I sometimes get confused; e.g., I do not know where I am, who is around, or what day it is. (115)

94. I have more minor accidents; I drop things, I trip and fall, or I bump into things. (90)

95. I forget a lot; for example, things that happened recently, where I put things, or to keep appointments. (85)

96. I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things. (78)

97. I am confused and start to do more than one thing at a time....... (74)

98. I have difficulty doing things which involve thought and concentration. (71)

99. I do not keep my attention on any activity for long....... (52)

100. I react slowly to things that are said or done (52)

101. I make more mistakes than usual. (49)

102. I do not finish things I start (45)

PFSL-Sleep (111) These statements describe your sleep and rest activities today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

103. I sleep or doze most of the time, day and night. ...... (111)

104. I spend much of the day lying down to rest. ...... (96)

105. I sleep less at night; for example, I wake up easily, I don't fall asleep for a long time, or I keep waking up. ….. (86)

106. I sit around half asleep. ...... (84)

107. I sleep or doze more during the day. ...... (80)

108. I lie down to rest more often during the day. ...... (72)

109. I sit for much of the day. ...... (62)

PFEAT-Eating (143) The following statements describe your eating and drinking habits. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

110. I eat no food at all except by tubes or intravenous infusion. ...... (143)

111. I do not feed myself at all but have to be fed. ..... (121)

112. I eat no food at all, but I take liquids. ...... (113)

113. I feed myself with help from someone else. **......** (95)

114. I feed myself but only with specially prepared food or special utensils. **......** (76)

115. I eat special or different food; for example, l follow a soft food, bland, low salt, low fat, or low sugar diet.**......** (52)

116. I just pick or nibble at my food. **......** (39)

117. I eat much less than usual. **......** (34)

118. I drink less fluids. **......** (33)

PFC-Communication (127) I am going to read out some statements about how much you talk to other people and write. Please think about yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

119. I communicate mostly by nodding my head, pointing, using sign language, or gestures**..** (127)

120. My speech is understood only by a few people who know me well.**......** (94)

121. I am understood with difficulty.**.....** (89)

122. I don't write except to sign my name.**.....** (84)

123. I speak with difficulty; l get stuck for words, l stutter, stammer, or slur my words.**.....** (76)

124. I carry on a conversation only when very close to other people or looking directly at them. (59)

125. I often lose control of my voice when I talk; for example, my voice gets louder or softer or changes unexpectedly**...**(59)

126. I have trouble writing or typing.**......** (50)

127. I do not speak clearly when I am under stress.**......** (47)

Ask P to please turn over the page. This time I would like you to tell me, on the scale one to five,

How important it is for you to:	**Not at all** Important				**Extremely** Important
1. Receive information about your illness.	1	2	3	4	5
2. Ask advice about your recovery.	1	2	3	4	5
3.					

The information sheet you were given in the hospital mentioned that only half of the participants will be given the workbook. Keeping in mind that the decision about who does or does not get the workbook will be made randomly, we would still like to know how much you <u>would like to receive</u> the workbook

Definitely don't want it		Don't care		Definitely do want it
1	2	3	4	5

Ask P to please turn over the page. **The next page shows a score from one to ten. If you put a score out of 10 on how confident you feel about making a perfect recovery, 10 being absolutely sure you'll make a full recovery - what would you score your confidence as?**

Not confident at all									Completely confident
1	2	3	4	5	6	7	8	9	10

The next questions list some of the ways people cope with stressful events. Please turn to the next page. Now tell me, if 1 is Almost Never and 5 is Almost Always, how often do you make use of each way in order to cope with stress:

	Almost Never	Some-times	In Between	Often	Almost Always
1. Try to see the positive side of the situation	1	2	3	4	5
2. Try to step back from the situation and be more objective	1	2	3	4	5
3. Pray for guidance or strength	1	2	3	4	5
4. Take things one step at a time	1	2	3	4	5
5. Consider several alternatives for handling the problem	1	2	3	4	5
6. Remember that I was in a similar situation before, and draw on my past experience.	1	2	3	4	5
7. Try to find out more about the situation	1	2	3	4	5
8. Talk with a professional (e.g. doctor, clergy) about the situation	1	2	3	4	5
9. Take some positive action	1	2	3	4	5
10. Talk with spouse or other relative about the problem	1	2	3	4	5
11. Talk with friend about the situation	1	2	3	4	5
12. Exercise more	1	2	3	4	5
13. Prepare myself for the worst	1	2	3	4	5
14. Take it out on other people when I feel angry or depressed	1	2	3	4	5
15. Try to reduce the tension by eating more	1	2	3	4	5
16. Try to reduce the tension by smoking more	1	2	3	4	5
17. Keep my feelings to myself	1	2	3	4	5
18. Get busy with other things in order to keep my mind off the problem	1	2	3	4	5

19. Think that everything will be okay and not worry about it. 1 2 3 4 5

Now I'm going to ask you some questions about the person you feel is most involved with your recovery at home. Can you tell me who that is?
Name/pronoun given :___________________________*(Interviewer: substitute this person's name/pronoun below where appropriate)*

If one is not at all and five is very much, can you tell me **how** important you feel this person is to your recovery:

1. Not at all 1 2 3 4 5 Very Much

If you will just turn to the next page. If one is never, and seven is always:

	Never		Sometimes			Always	
2a) Can you trust, talk frankly and share your feelings with... (Name)..?	1	2	3	4	5	6	7
b) What rating would your ideal be for this, given your current condition?	1	2	3	4	5	6	7
3a) Can you lean on and turn to... (Name)...in times of difficulty?	1	2	3	4	5	6	7
b) What rating would your ideal be for this, given your current condition?	1	2	3	4	5	6	7
4a) Does... (Name)...give you practical help?	1	2	3	4	5	6	7
b) What rating would your ideal be for this, given your current condition?	1	2	3	4	5	6	7
5a) Can you spend time with... (Name)...socially?	1	2	3	4	5	6	7
b) What rating would your ideal be for this, given your current condition?	1	2	3	4	5	6	7

If 1 is Strongly Agree and 5 is Strongly Disagree, tell me the extent to which you agree or disagree with the following statements.

		Strongly Agree		***Uncertain***		***Strongly Disagree***
1.	How I manage in the future depends on me, not on what other people can do for me	1	2	3	4	5
2.	It's often better just to wait and see what happens	1	2	3	4	5
3.	It's what I do to help myself that's really going to make all the difference	1	2	3	4	5
4.	My own efforts are not very important, my recovery really depends on others	1	2	3	4	5
5.	Its up to me to make sure that I make the best recovery possible under the circumstances	1	2	3	4	5
6.	I have little or no control over my progress from now on	1	2	3	4	5
7.	My own contribution to my recovery doesn't amount to much	1	2	3	4	5
8.	Getting better now is a matter of my own determination rather than anything else	1	2	3	4	5
9.	It doesn't matter how much help you get - in the end it's your own efforts that count .	1	2	3	4	5
10.	I would prefer to be in charge of my recovery rather than just follow instructions	1	2	3	4	5
11.	I am careful to do all I can to prevent my illness recurring	1	2	3	4	5
12.	I don't like to ask the doctor or nurse lots of questions about my recovery	1	2	3	4	5
13.	I like to get a good idea of how an activity or treatment will help my recovery before I start it.	1	2	3	4	5
14.	I would rather decide myself instead of just following orders about what to do to get better.	1	2	3	4	5
15.	I wish I could avoid many of the decisions I have to make which concern my recovery	1	2	3	4	5
16.	I prefer to avoid situations where someone else has to tell me what to do to get better.	1	2	3	4	5
17.	When it comes to my recovery, I want to just wait and see what happens.	1	2	3	4	5
18.	I prefer to manage my recovery completely on my own.	1	2	3	4	5
19.	I think it is better for others to be in charge of my recovery.	1	2	3	4	5
20.	I wish that I could be completely in control of my progress from now on.	1	2	3	4	5
21.	I wish that my recovery was not left entirely up to me	1	2	3	4	5

Reference for questions on ambulation activities: The question to ask is written beside each activity.
EG. IF 1. I do not walk at all **IS ANSWERED YES, AND SO TICKED, FILL IN THE BLANK PART OF All QUESTIONS (1-9) WITH:…. walk at all….**

TICKED ACTIVITY	**USE (REMEMBER TO FILL IN THE BLANKs FOR ALL NINE QUESTIONS WITH THE SAME PHRASE):**
1. I do not walk at all	**. walk at all**
2. I get about in a wheelchair	**….. Get about without a wheelchair**
3. I do not use stairs at all	**….. Use stairs**
4. I only walk with help from somebody else	**......Walk without help from somebody else**
5. I get about only by using a walking frame, ETC	**…. Get about without using a walking frame ETC**
6. I only go up and down stairs with assistance	**…. Go up and down stairs without assistance**
7. I only use stairs with a physical aid;	**Use stairs without a physical aid**
8. I walk by myself but with some difficulty;	**Walk by myself without the difficulty I mentioned**
9. I do not walk up or down hills	**...... Walk up or down hills**
10. I go up and down stairs more slowly	**...... Go up and down stairs as fast as I used to**
11. I walk shorter distances or often stop for a rest	**......Walk further or not stop for a rest**
12. I walk more slowly	**......Walk as fast as I used to**
13. I do not walk as well as I did before my stroke	**......Walk as well as I used to before my stroke**

SECTION B

That is most of the questionnaire completed. The next section only takes about 5-10 minutes and, we leave it to the end because it asks questions which concern your general recovery and what you think will happen over the next month. So, would you like to take a break first or are you happy to continue? Now, I just want to ask a bit more your walking (and use of stairs) and, what you think will happen over the next month.

1. (PBC). If 1 is No Control at all and 5 is Complete Control, how much control do you feel you have over whether you…over the next month?
2. (SE). If 1 is Not at all confident and 5 is Extremely Confident, how confident are you that you will …… over the next month? ☐
3. (LOC). If 1 is Strongly Agree and 5 is Strongly Disagree, do you think that it is entirely up to you whether you……over the next month? ☐
4. (I). If 1 is Definitely Yes and 5 is Definitely no, do you intend to try to…… over the next month ☐
5. (DFC). If 1 is Definitely Would Like and 5 is Definitely Would Not Like, how much you would like to …… over the next month? ☐
6. (PBCp). If 1 is Not at all Difficult and 5 is Extremely Difficult, how difficult will it be for you to… over the next month ☐
7. (SN). If 1 is Definitely Should and 5 is Definitely Should Not, do you think ….(name of partner) feels you should …… over the next month? ☐
8. (I). If 1 is Definitely Yes and 5 is Definitely no, do you plan to …… over the next month? ☐
9. (DFC). If 1 is Not very Much and 5 is As Much as Possible, how much do you <u>care</u> about whether you…… over the next month? ☐

10. (SNp). If 1 is Not very Much and 5 is As Much as Possible, how much would you try to … over the next month in order to please your relative? ☐

Now, I am going to ask you some general questions about your recovery. You will notice that these questions will seem to be very alike, but they are different. I'd like you listen carefully to each question and to answer by telling me which number best fits for you in each case. Try not to be worried about how you have answered before and don't try to be consistent. It is because the different questions can mean different things to people that we ask them in this way.

A. If 1 is Not at all confident and 5 is Extremely confident,

1. How confident are you that you now can make a full recovery 1 2 3 4 5
2. How confident are you that you now can make a good recovery 1 2 3 4 5
3. How confident are you that you now can influence your recovery 1 2 3 4 5
4. How confident are you that you now can help yourself recover 1 2 3 4 5

B. If 1 is Not at all Difficult and 5 is Extremely difficult

1. How difficult are you finding it to make a full recovery 1 2 3 4 5
2. How difficult are you finding it to make a good recovery 1 2 3 4 5
3. How difficult are you finding it to influence your recovery 1 2 3 4 5
4. How difficult are you finding it to help yourself recover 1 2 3 4 5

C. If 1 is No Control at all and 5 is Complete Control

1. How much control do you have over whether you make a full recovery 1 2 3 4 5
2. How much control do you have over whether you make a good recovery 1 2 3 4 5
3. How much control do you have over whether you influence your recovery 1 2 3 4 5
4. How much control do you have over whether you help yourself recover 1 2 3 4 5

One last question. How have you found the interview? Was there anything that you found difficult, or anything you would like to comment on? **N.B.-You must remember when I come to visit you again not to tell me whether you got the workbook or not as it is to be kept secret from me, so I treat everyone in the same way.**

STATISTICS FOR STUDY 1

Key to variable names:

Psychological including HADS, RLOC, WOC, desire for intervention and confidence in recovery.		IPQ-R	
Mood	mood	Identity	Ident.
Anxiety	anx	Time chronic	T. Chro.
Depression	dep	Time cyclic	T. Cycl.
RLOC	RLOC	Consequence	Conseq.
Active coping	A. cop.	Control -Personal	C. pers.
Active cognitive	A. cog.	Control -Treatment	C. treat.
Active behavioural	A.beh.	Coherence	Coher.
Avoidant	Avoid.	Emotion Representation	Emot.R.
Problem focused	Prob.F.	Cause – Psychological	C-psyc
Emotion focused	Emot.F.	Cause – controllable personal risk	C-PRC
Desire for intervention	Des.	Cause - uncontrollable personal risk	C-PRU
Confidence	Conf.	Cause - External	C-Ext

Correlations between the sets of variables

N= 91	Employment	With carer	Age	Depcat
Gender	.04	-.28**	.07	-.05
Employment		-.14	.75**	-.10
With carer			-.15	-.03
Age				-.16

Table b1; Correlations between demographic variables of the study groups (n = 91)

N = 78-91	Stroke event	Orgogozo	NIH t	Rankin	Barthel t	Time
Affected side	.00	-.16	.31**	.14	.05	-.14
Stroke event		.04	-.03	.08	-.24*	-.06
Orgogozo			-.78**	-.70**	.41**	-.56**
NIH t				.71**	-.30**	.51**
Rankin					-.34**	.53**
Barthel t						-.52**

Table b2: Correlations between clinical variables of the study group (n = 91)

N = 91	Gender	Employment	With carer	Age	Depcat
Affected side	-.25*	-.02	.16	.01	-.00
Stroke event	-.90	-.05	-.10	.01	.02
Orgogozo	-.21*	-.04	-.18	.02	-.09
NIH t	.19	.19	.08	.16	.00
Rankin	.16	.18	.05	.14	-.14
Barthel t	.00	-.08	-.22*	-.09	-.12
Time	.26*	.10	.12	.13	.01

Table b3: Correlations between clinical and demographic variables of the study group (n=91)

N = 91	Anx	Dep	RLOC	A.Cop	A.Cog	A.Beh	Avoid	Prob.F.	Emot.F.	Desire	Confi
Mood	.92**	.89**	-.18^	-.43**	-.38**	-.38**	.29**	-.43**	.01	.07	-45**
Anx.		.64**	-.20^	-.40**	-.34**	-.36**	.32**	-.41**	.05	.06	-.43**
Dep.			-.12	-.39**	-.35**	-.33**	.20*	-.36**	-.05	.07	-.39**
RLOC				.14	.23*	.02	-.23*	.13	-.07	-.12	.20^
A. Cop					.87**	.88**	-.03	.91**	.48**	.11	.43**
A. Cog.						.53**	-.02	.72**	.54**	-.05	.36*
A. Beh.							-.03	.87**	.31**	.24*	.40**
Avoid.								-.10	.63**	.09	-.15
Prob.F.									.20*	.12	.36**
Emot. F.										.14	.15
Desire											.14

Table b4: Correlations between psychological variables of the study group (n=91)

N = 91	Gender	Employment	With carer	Age	Depcat
Mood	.12	-.15	-.08	-.14	.20^
Anx.	.16	-.22*	-.17	-.22*	.26*
Dep.	.10	-.05	.03	-.02	.08
RLOC	.16	.02	.12	.02	-.06
A. Cop	-.10	.18	.06	.19^	-.19^
A. Cog.	-.00	.19^	.00	.22*	-.21*
A. Beh.	-.16	.12	.10	.12	-.13
Avoid.	-.04	-.02	-.04	-.12	-.00
Prob.F.	-.18	.08	.11	.13	-.15
Emot. F.	.05	.20^	-.12	.10	-.06
Desire	.20^	-.18	-.07	-.16	-.01
Confi.	.01	-.04	.18^	-.06	-.08

Table b5: Correlations between psychological and demographic variables of study group (n= 91)

N = 91	Affected side	Stroke event	Orgogozo	NIH t	Rankin	T in H	Barthel t
Mood	-.05	.13	-.06	.07	-.06	.06	-.33**
Anx.	-.01	.14	.00	-.03	-.17	.01	-.24*
Dep.	-.10	.09	-.12	.14	-.09	.10	-.37**
RLOC	.08	-.06	-.23*	.13	.13	.16	.02
A. Cop	.12	.03	-.18	.30**	.09	.13	-.03
A. Cog.	.11	.04	-.16	.28*	.07	.08	.04
A. Beh.	.10	.01	-.15	.26*	.08	.14	-.09
Avoid.	-.03	.07	.03	.05	-.01	.10	-.13
Prob.F.	.14	-.01	-.20^	.25*	.05	.06	-.02
Emot. F.	.03	.08	-.04	.28**	.12	.15	-.09
Desire	-.11	.09	-.11	.08	.11	.11	-.06
Confi.	.12	-.14	-.03	.18	.02	-.07	.24*

Table b6: Correlations between psychological and clinical variables of study group (n= 91)

Correlations between Participation, Active, Passive, Scored and Percentage Adherence (amount of active adherence) And Clinical, Demographic and Psychological Variables

	Participation (n = 91)	Active (n = 75)	Passive (n = 75)	AAA * (n = 75)	Percentage (n = 75)
Gender	.07	.23*	.27*	.34**	.36**
Employment	-.17	-.02	-.09	-.01	-.01
With carer	-.19^	-.08	-.11	-.05	-.06
Age	-.15	-.01	-.13	-.10	-.10
Depcat	-.03	-.20	.06	-.07	-.09

*AAA = amount of active adherence

Table b7 Correlations between demographic variables and adherence

	Participation (n = 91)	Active (n = 75)	Passive (n = 75)	AAA (n = 75)	Percentage (n = 75)
Affected side	-.01	-.17	-.21^	-.07	-.03
Stroke event	-.05	-.17	.04	-.12	-.09
Time in hosp	.07	-.20^	.13	-.14	-.07
Orgogozo	.01	.23^	-.12	.21^	.18
NIH t	-.07	-.25*	-.05	-.18^	-.13
Rankin	.03	-.34**	-.04	-.26*	-.20
Barthel t	-.12	.18	-.15	.12	.11

Table b8: Correlations between clinical variables and adherence

	Participation (n=91)	Active. (n=75)	Passive (n =75)	AAA (n =75)	Percentage (n =75)
Mood	.16	-.15	.04	-.15	-.14
Anx.	.25*	-.17	.01	-.16	-.14
Dep.	.03	-.11	.07	-.12	-.11
RLOC	-.27*	-.00	.03	.05	.06
A. Cop	-.15	.06	.07	.09	.10
A. Cog.	-.17	-.03	-.01	-.01	.02
A. Beh.	-.10	.13	.13	.15	.15
Avoid.	.11	-.26*	-.01	-.21^	-.14
Prob.F.	-.12	.05	.00	.03	.03
Emot. F.	-.04	-.16	.05	-.09	-.03
Desire	.12	.06	.31**	.11	.15
Confi.	-.26*	-.04	-.09	-.01	-.01

Table b9: Correlations between psychological variables and adherence

	Active adherers and non-adherers (n=88)
Gender	.22*
Employment	-.06
With carer	-.15
Age	-.06
Depcat	-.02

Table b10: Correlations between demographic variables and active adherers and non-active adherers.

	Active adherers and non-adherers (n=88)
Affected side	-.15
Stroke event	-.16
Time in hosp	-.14
Orgogozo	.18
NIH t	-.24*
Rankin	-.28*
Barthel t	.10

Table b11: Correlations between clinical variables and active adherers and non active adherers.

	Active adherers and non-adherers (n=88)
Mood (HADS)	-.06
Anxiety	-.03
Depression	-.08
RLOC	-.13
WOC - active	-.02
Active cognitive	-.10
Active behavioural	.06
Avoidant	-.17
Problem focused	-.01
Emotion focused	-.15
Desire for workbook	.10
Confidence in Recovery	-.15

Table b12: Correlations between psychological variables and active adherers and non-active adherers.

	Active	Passive	Scored	Percentage
Participation (n = 91)	.42**	.44**	.33**	.31**
Active (n = 88)		.46*	.87**	.65**
Passive (n = 91)			.37*	.35**
Scored (n = 85)				.96**

Table b13: Correlations between measures of adherence to stroke workbook activities

APPENDIX C

1. The National Statistics Socio Economic Classification
2. FAST Patient Information Sheet
3. FAST Consent Form
4. Interview Schedule for TI and T2
5. General Practitioners letter
6. Statistics for study 2

APPENDIX C

The National Statistics Socio Economic Classification

1. Higher managerial and professional occupations
    - Large employers and higher managerial occupations
    - Higher professional occupations
2. Lower managerial and professional occupations
3. Intermediate Occupations
4. Small employers and own account workers
5. Lower supervisory and technical occupations
6. Semi-routine occupations
7. Routine occupations
8. Never worked long term employment

PATIENT INFORMATION SHEET:
FOLLOWING A STROKE TRIAL (FAST STUDY)

We invite you to participate in a research project. Before you decide whether or not you wish to participate, you need to be sure that you understand Firstly why we are doing it, and secondly what it would involve if you agreed. We are therefore providing you with the following information.
Read it carefully and be sure to ask any questions you have, and if you want, discuss it with other people. We will do our best to explain and to provide any further information you may ask for now or later. You do not have to make an immediate decision.

What is this study called?
Stroke patient's uptake of treatment when offered: Factors predicting participation in two interventions. (Following a Stroke Trial (FAST Study)

Who is running this study?
Sara Joice who is a PhD student at St Andrews University will be involved with the day to day running of this study. Three people will supervise her:

- Dr R. S. MacWalter, Consultant Physician in General Medicine and Honorary Senior Lecturer in Medicine, Ninewells Hospital, Dundee.
- Professor Marie Johnston, Professor of Psychology, School of Psychology, University of St Andrews
- Professor Ronan O' Carroll, Professor of Psychology School of Psychology, University of St Andrews

Why is the research desirable?
It is possible that certain ways of thinking about your stroke and its treatment can lead to a better recovery. Over the last few years we have been looking at the usefulness of a workbook intervention designed to promote recovery from stroke. We would like to compare this to an alternative – a video intervention.
The Health Education Board for Scotland in collaboration with Chest, Heart and Stroke Scotland produced a video for stroke patients. This video gives an insight into the lives of people recovering from their stroke and shares with you their experiences. We would like to know how useful this video is for patients recovering from a stroke.
If the video is beneficial to patient's recovery, such videos may become part of the standard treatment to help future patients and their family and friends.
Taking part in this research will not affect your normal treatment in any way

Why are you a suitable person to participate in this study?
You have recently had a stroke and we are inviting all patients who have had a stroke to participate.

What are the procedures?
Step 1 Involves the completion of some simple, short questionnaires by you. Trained personnel will see you at home soon after your discharge from Hospital and guide you through the questions. They will answer any questions you may have. This interview will take about less than an hour.
Step 2. Some patients will get the video, some will not. As with most studies, the allocation of this video is done randomly (like tossing a coin), so you will not know until you enter the study whether you get a video or not.
Step 3 If you are allocated a video, you will receive a video through the post within the next week. If you do not have a video player another researcher will contact you and alternative arrangements will be made.
Step 4 All patients will receive an appointment letter to confirm their second interview.
Step 5 All patients will be visited at home six weeks after the first interview to repeat the questionnaires. This interview will take a little over an hour.
At the end of this interview you will be asked if you received a video if so a few further questions will be asked.

If you do not have a video player, telephone or if you do not want the researcher to call at your home, other arrangements can be made.

Your GP will be notified and will get this information sheet.

All the information collected from you during the course of this study will be treated in the strictest confidence. No one outside the research team will have access. The Tayside Medical Research Ethics Committee monitors all medical research in Tayside. They occasionally need to see patient information to monitor our procedures to ensure confidentiality but again this will be treated in confidence.

What effects will be experienced at the time of the study or later?
Apart from having to talk about how you feel about your condition and its treatment there will be no effects.

Are there any risks or side effects?
There are no known risks or side effects.

Are there any expenses?
You should incur no expenses through participation in the study. The researcher will visit your home, so you do not have to make extra trips to the hospital. If, however, you prefer to come to the hospital this can be arranged and your transportation costs reimbursed.

What happens if I do not want to take part?
Participation in this study is entirely voluntary and you are free to refuse to take part or to withdraw at any time without having to give a reason and without affecting your future medical care.

Thank you for reading this information sheet

Sara Joice 01334 462091

Stroke patient's uptake of treatment when offered: Factors predicting participation in two interventions.
(Following a Stroke (FAST) Study)

Consent Form

(The patient should complete this form himself/herself - PLEASE CROSS OUT AS NECESSARY)

Have you read the Patient Information Sheet? YES/NO

Have you had an opportunity to ask questions and discuss this study? YES/NO

Have you received satisfactory answers to all of your questions? YES/NO

Have you received enough information about the study? YES/NO

Who have you spoken to? Dr./Mr./Mrs. ....

Do you understand that participation is entirely voluntary? YES/NO

Do you understand that you are free to withdraw from the study at any time;
without having to give a reason for withdrawing? YES/NO
without this affecting your future medical care? YES/NO

Do you agree to take part in this study? YES/NO

Patient's Signature .... Date ....

Patient's name in block letters ....

Interview Schedule for TI and T2

PNumber in Study______________ Interview 1

Sex: M F Age;____________

Date stroke occurred;___________________________________

Admission Date:____________________

Discharge Date:______________________________________

Name of Recruiting Officer:____

Date of Interview:_________________________Time:___________

Place: Home / Hospital

Name of Interviewers:____

Notes: (eg. 2nd stroke)

Consent ☐

PATIENT QUESTIONNAIRE *MSQ/CAPE*

First I would just like to thank you for taking part in this project. Now I am going to ask you about yourself and then some questions, in order to do a little check on your memory.

Can you tell me when you had the stroke:___________

Is this the only stroke you've had?___________ (when was the first?___________)

Which side of the body was affected? Left Right

Y☐	N☐	Can I just check your full name?
Y☐	N☐	How old are you? *(present age in years, or predicted age next birthday)*
Y☐	N☐ *Day*	What is your date of birth? *(day, month, year must all be correctly given)*
Y☐	N☐ *Month*	
Y☐	N☐ *Year*	
Y☐	N☐	Can you tell me what is this place, that is, where you are now? (hospital/home)
Y☐	N☐	Can you tell me this address? (need number or name of home **and** street)
Y☐	N☐	What is the name of this town?
Y☐	N☐	Can you tell me who is the Prime Minister? (surname is sufficient)
Y☐	N☐	Can you tell me who was the previous Prime Minister? (surname is sufficient)
Y☐	N☐	Can you tell me who is the monarch?
Y☐	N☐	Who is the President of the United States? (surname is sufficient)
Y☐	N☐	What are the colours of the national flag, the Union Jack? (red, white and blue)
Y☐	N☐	Can you tell me what are the years of the first world war?
Y☐	N☐	Can you tell me the time? (to the nearest hour)
Y☐	N☐	What day is it?
Y☐	N☐	Can you tell me today's date?
Y☐	N☐	What month is it?
Y☐	N☐	What year is it?
Y☐	N☐	Now, can you please count backwards from 20 to 1 for me?

***Yes** Count (**Ignore blocked questions**)________ (If more than 6, go on with questionnaire)*

HADS

Now, I am going to ask you a series of questions about how you are feeling, and about what you think about things connected to your health and your recovery. This is not a test - there are no right or wrong answers. All strokes are different, and everyone will have different problems and be at different stages in their recovery - so what is right for some people, won't be right for others. The main thing to remember is to tell us what **you** are feeling, and what **you** think about things, not what you think you **should** feel or think - remember, your answers are completely confidential. Try not to take too long in giving your answers - because what first comes to your mind is more likely to be what you really think. We will take a break about half way. If you miss something, just ask me to repeat it. If you get tired, or want a break for any reason, just say. Shall we start?

Would you now tell me which comes closest to how you have been feeling in the **past 7 days?**

1. I feel tense or 'wound-up':
Most of the time ☐
A lot of the time ☐
Time to time, occasionally ☐
Not at all ☐

2. I still enjoy the things I used to enjoy:
Definitely as much ☐
Not quite so much ☐
Only a little ☐
Hardly at all ☐

3. 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 ☐
Not at all ☐

4. 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 al ☐

5. 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 ☐

6. I feel cheerful:
Not at all ☐
Not often ☐
Sometimes ☐
Most of the time ☐

7. I can sit at ease and feel relaxed:
Definitely ☐
Usually ☐
Not often ☐
Not at all ☐
Hardly at all ☐

8. I feel as if I am slowed down:
Nearly all the time ☐
Very often ☐
Sometimes ☐
Not at all ☐

9. I get a sort of frightened feeling like 'butterflies' in the stomach:
Not at all ☐
Occasionally ☐
Quite often ☐
Very often ☐

10. I have lost interest in my appearance:
Definitely ☐
I don't take so much care as I should ☐
I may not take quite as much care ☐
I take just as much care as ever ☐

11. I feel restless as if I have to be on the move:
Very much indeed ☐
Quite a lot ☐
Not very much ☐
Not at all ☐

12. I look forward with enjoyment to things:
As much as I ever did ☐
Rather less than I used to ☐
Definitely less than I used to ☐

13. I get sudden feelings of panic:
Very often indeed ☐
Quite often ☐
Not very often ☐
Not at all ☐

14. I can enjoy a good book or radio or TV programme:
Often ☐
Sometimes ☐
Not often ☐
Very seldom ☐

BARTHEL

Now, I am going to ask you some questions about some everyday activities. If you turn to the first page of this booklet (give binder), you will see these activities listed. Can you see this okay - do you need reading glasses?

1. Grooming In the last 24 hours have you been able to comb your hair, clean your teeth, shave, wash your face by yourself, or does someone help you?	0=needs help 1=independent (implements can be provided by carer)	
2. Feeding Have you been able to feed yourself, or do you need help? Is this help with cutting or spreading, or is it more than this?	0=unable 1=needs help (food cut up, patient feeds self) 2=independent	
3. Bowels How have your bowels been over the last Week? Have you had any accidents during the day or night?	0= incontinent 1=occasional accident (once a week) 2=continent	
4. Bladder How have your waterworks been over the last week, have you had any accidents during the day or night?	0=incontinent 1=occasional accident (max. once per 24 hrs) 2= continent	
5. Toilet use Have you been able to get to the toilet yourself over the last 24 hours or do you use a commode (Can you manage on and off the commode yourself?); Can you manage with your underclothing/zips or do you need some help? Are you able to clean yourself after using the toilet, or does someone help you?	0=dependent 1=needs some help, but can do something alone 2=independent (on/off, dress, wipe)	
6. Transfer: from bed to chair, and back Over the last 24 hours have you been able to move yourself from a lying position on the bed to a sitting position on a chair? Do you need some help, if so, what with? (sitting up/transfer)	0=unable, no sitting balance 1=major help (one or two people; can sit) 2= minor help (needs supervision) 3=independent	
7. Mobility Have you been able to walk anywhere in the last 24 hours or do you use a wheelchair? (Can you manage on your own or do you need someone to push you) Do you need to use a zimmer or stick or does someone support you?	0=immobile 1= wheelchair independent (can corner) 2=with help from one person 3= independent (may use aid)	
8. Dressing In the last 24 hours have you dressed and undressed yourself? Did you need help with any items of your clothing?	0=dependent 1=needs some help, can do about half 2=independent: zips, buttons and laces	
9. Stairs In the last 24 hours have you been up and down any stairs? Did anyone assist you (physically) or did someone go with you just to make sure you were alright?	0=unable 1=needs help 2=independent (can carry walking aid)	
10. Bathing/Showering Have you been able to have a bath or shower in the last 24 hours by yourself, or does someone help you?	0=dependent 1=independent, in and out, washes self	

MOD FLP

The following statements are about your current health and how the stroke may have influenced your everyday life. Listen to each statement, think of yourself today and tell me if it describes you or not. If you agree or disagree you should tell me. I will then ask "Is this due to your health"- Please answer yes or no. Ask me to repeat a statement or slow down if you do not understand. *(Read down the list of items within each category. As soon as the patient agrees with a statement you must ask whether this is due to their health, if the answer to this is yes, tick the statement and move to the next category of items.)*

The following statements describe walking and use of stairs. Please think of yourself *today*, and tell me if you agree or disagree with the statement, *and if this is due to the state of your health*.

1.	I do not walk at all.	......	(126)
2.	I get about in a wheelchair.	......	(121)
3.	I do not use stairs at all.	......	(106)
4.	I only walk with help from somebody else.	......	(98)
5.	I get about only by using a walking frame, crutches, stick, walls, or hold on to furniture	……	(96)
6.	I only go up and down stairs with assistance from somebody else.	......	(87)
7.	I only use stairs with a physical aid; for example, special rail, stick or crutches.	......	(82)
8.	I walk by myself but with some difficulty; for example, I limp, wobble, stumble or I have a stiff leg	......	(71)
9.	I do not walk up or down hills.	......	(64)
10.	I go up and down stairs more slowly; for example, one step at a time or I often have to stop	......	(62)
11.	I walk shorter distances or often stop for a rest.	......	(54)
12.	I walk more slowly.	......	(39)
13.	I do not walk as well as I did before my stroke		… (not in flp)

PFB-body care and movement items (124) The following statements describe how you move about, bath, go to the toilet, dress yourself **today**. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

13. I am in a restricted position all the time. ...... (124)
14. I do not have control of my bowels. ...... (124)
15. I do not have control of my bladder. ...... (122)
16. I stay lying down most of the time. ...... (120)
17. I use a bedpan with help. ...... (107)
18. I do not bathe myself at all, but am bathed by someone else. ...... (100)
19. I do not get in and out of bed or chairs without the help of a person or mechanical aid. ...... (100)
20. I only stand up with someone's help. ...... (93)
21. I do not keep my balance. ...... (93)
22. I do not bathe myself completely; for example I need help with bathing. ...... (85)
23. I make difficult movements with help; for example getting in or out of the bath or car. ...... (82)
24. I hold on to something to move myself around in bed. ...... (82)
25. I only get dressed with someone's help. ...... (82)
26. I get in or out of bed or chairs by grasping something for support or by using a stick or a walking frame. ...... (79)
27. I spend most of the time partly dressed or in pyjamas. ...... (75)
28. I do not fasten my clothing; for example I require assistance with buttons, zips or shoelaces. ...... (68)
29. I only stand for short periods of time. ...... (67)
30. I move my hands or fingers with some difficulty or limitation. ...... (66)
31. I kneel, stoop or bend down only by holding on to something. .... (61)
32. I have trouble putting on my shoes, socks or stockings. ...... (54)
33. I change position frequently. ...... (51)
34. I am very clumsy. ..... (47)
35. I dress myself, but do so very slowly. ..... (43)

PFM-Mobility (114) These next statements describe how you get about the house and outside. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

36. I stay in bed most of the time. ...... (114)
37. I stay in one room. ...... (101)
38. I stay in bed more. ...... (91)
39. I stay at home most of the time. ...... (79)
40. I only get about in one building. ...... (76)
41. I only go out if there is a lavatory nearby. ...... (64)
42. I do not get about in the dark or in places that are not lit unless I have someone to help. ...... (57)
43. I do not use public transport now. ...... (52)
44. I do not go into town. ...... (47)
45. I only stay away from home for short periods. ...... (46)

PFH-Household management (90) The following statements describe your daily work, around the home. When you answer, think of yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

46. I do not do any of the daily household chores that I would usually do. ...... (90)
47. I do not do any of the shopping that I would usually do. ...... (84)
48. I do not do any of the cleaning that I would usually do. ...... (78)
49. I have difficulty using my hands; for example, turning taps, using kitchen gadgets, sewing or doing repairs. ...... (78)
50. I do not do any of the maintenance or repair work that I would usually do in my garden. ...... (75)
51. I do not do any of the clothes washing that I would usually do. ...... (75)
52. I have given up taking care of personal or household business affairs; for example, paying bills, banking or doing household accounts. (69)
53. I do not do heavy work around the house. ...... (59)
54. I only do housework or work around the house for short periods of time or I rest often. ...... (50)
55. I do less of the daily household chores than I would usually do. (37)

PFR-Recreation (91) The following statements describe the activities you usually do in your spare time, for relaxation, entertainment or just to pass the time. Again, think of yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

56. I am not doing any of my usual inactive pastimes; for example, I do not watch TV, play cards, or read ...... (91)
57. I am not doing any of my usual physical recreation or more active pastimes .... (81)
58. I am cutting down on some of my usual inactive pastimes; for example, I watch TV less, play cards less, or read less. ...... (50)
59. I am doing more inactive pastimes instead of my other usual activities. ..... (43)
60. I am cutting down on some of my usual physical recreation or more active pastimes. ...... (34)
61. I spend shorter periods of time on my hobbies and recreation. ...... (32)
62. I go out less often to enjoy myself. ...... (27)
63. I take part in fewer community activities. ...... (25)

PFS-Social (109) These statements describe your contact with family and friends today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

64. I refuse contact with my family; for example, I turn away from them. ...... (109)
65. I frequently get angry with my family; for example, I hit them, scream or throw things at them. ...... (103)
66. I isolate myself as much as I can from the rest of my family. ...... (100)
67. I stay alone much of the time. ...... (91)
68. I do not go out at all to visit people. ...... (91)
69. I am disagreeable with my family; for example, I act spitefully or stubbornly. ...... (86)
70. I make many demands on other people; for example, I insist that they do things for me or tell them how to do things. ..... . (76)
71. I avoid having visitors. ...... (73)
72. I do not look after my children or family as well as I usually do. ...... (66)
73. My sexual activity is decreased. ...... (64)
74. I am often irritable with those around me; for example, I snap at people or criticize easily. ...... (64)
75. I pay less attention to the children. ...... (59)
76. I show less interest in other people's problems; for example, I don't listen when they tell me about their problems; I don't offer to help. ...... (50)
77. I show less affection. ...... (44)
78. I often express concern over what might be happening to my health. ...... (44)
79. I talk less with other people. ...... (44)
80. I do not joke with members of my family as much as I usually do. ...... (38)
81. I am cutting down the length of visits with friends. ...... (31)
82. I go out less often to visit people. ...... (31)
83. I take part in fewer social activities than I used to; for example, I go to fewer parties or social events ...... (25)

PFE-Emotion (141) The next statements describe your feelings and behaviour. Think of yourself today, **and if it is due your health.**

84. I have attempted suicide. ...... (141)
85. I talk hopelessly about the future. ...... (96)
86. I say how bad or useless I am; for example, that I am a burden on others. ...... (89)
87. I am irritable and impatient with myself; for example, I run myself down, I swear at myself, I blame myself for things that happen. ...... (79)
88. I often moan and groan because of pain or discomfort. ...... (67)
89. I keep rubbing or holding areas of my body that hurt or are uncomfortable. ...... (59)
90. I laugh or cry suddenly. ...... (58)
91. I get sudden frights. ...... (56)
92. I behave nervously or restlessly. ...... (48)

PFAL-Alertness (115) These statements describe your general alertness today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

93. I sometimes get confused; for example, I do not know where I am, who is around, or what day it is ...... (115)
94. I have more minor accidents; I drop things, I trip and fall, or I bump into things. ...... (90)
95. I forget a lot; for example, things that happened recently, where I put things, or to keep appointments. ...... (85)
96. I have difficulty reasoning and solving problems; for example, making plans, making decisions, or learning new things. ...... (78)
97. I am confused and start to do more than one thing at a time. ...... (74)
98. I have difficulty doing things which involve thought and concentration. ...... (71)
99. I do not keep my attention on any activity for long. ...... (52)
100. I react slowly to things that are said or done. ...... (52)
101. I make more mistakes than usual. ...... (49)
102. I do not finish things I start. ...... (45)

PFSL-Sleep (111) These statements describe your sleep and rest activities today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

103. I sleep or doze most of the time, day and night. ...... (111)
104. I spend much of the day lying down to rest. ...... (96)
105. I sleep less at night; for example, I wake up easily, I don't fall asleep for a long time, or I keep waking up . ... (86)
106. I sit around half asleep. ...... (84)
107. I sleep or doze more during the day. ...... (80)
108. I lie down to rest more often during the day. ...... (72)
109. I sit for much of the day. ...... (62)

PFEAT-Eating (143) The following statements describe your eating and drinking habits. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

110. I eat no food at all except by tubes or intravenous infusion. ..... (143)
111. I do not feed myself at all but have to be fed. ...... (121)
112. I eat no food at all, but I take liquids. ...... (113)
113. I feed myself with help from someone else. ...... (95)
114. I feed myself but only with specially prepared food or special utensils. ...... (76)
115. I eat special or different food; for example, I follow a soft food, bland, low salt, low fat, or low sugar diet. ...... (52)
116. I just pick or nibble at my food. ...... (39)
117. I eat much less than usual. ...... (34)

118. I drink less fluids. ...... (33)

PFC-Communication (127) I am going to read out some statements about how much you talk to other people and write. Please think about yourself today. Please tell me if you agree or disagree with the statement, **and if it is due to the state of your health.**

119. I communicate mostly by nodding my head, pointing, or using sign language, or other gestures. ...... (127)
120. My speech is understood only by a few people who know me well. ...... (94)
121. I am understood with difficulty. ...... (89)
122. I don't write except to sign my name. ...... (84)
123. I speak with difficulty; I get stuck for words, I stutter, stammer, or slur my words. ...... (76)
124. I carry on a conversation only when very close to other people or looking directly at them...... (59)
125. I often lose control of my voice when I talk; for example, my voice gets louder or softer or changes unexpectedly. ...... (59)
126. I have trouble writing or typing. ...... (50)
127. I do not speak clearly when I am under stress. ...... (47)

DFI

Ask P to please turn over the page. This time I would like
you to tell me, on the scale one to five, **how important** it is for you to:

Receive information about your illness.

1	2	3	4	5
Not at all Important				**Extremely Important**

Ask advice about your recovery

1	2	3	4	5
Not at all Important				**Extremely Important**

The information sheet you were given in the hospital mentioned that only half the of the participants will be given the video... Please turn to the next page. Bearing in mind that the decision about who does or does not get the video will be made randomly, we would still like to know how much you <u>would like to receive the video</u>

1	2	3	4	5
Definitely don't want it		**don't care**		**Definitely do want it**

Ask P to please turn over the page. **The next page shows a score from one to ten. If you put a score out of 10 on how confident you feel about making a perfect recovery, 10 being absolutely sure you'll make a full recovery - what would you score your confidence as?**

1	2	3	4	5	6	7	8	9	10
Not confident at all									**completely confident**

WOC

The next questions list some of the ways people cope with stressful events. Please turn to the next page. Now tell me, if 1 is Almost Never and 5 is Almost Always, how often do you make use of each way in order to cope with stress:

		Almost Never	Some times	In between	Often	Almost never
1.	Try to see the positive side of the situation	1	2	3	4	5
2.	Try to step back from the situation and be more objective	1	2	3	4	5
3.	Pray for guidance or strength	1	2	3	4	5
4.	Take things one step at a time	1	2	3	4	5
5.	Consider several alternatives for handling the problem	1	2	3	4	5
6.	Remember that I was in a similar situation before, and draw on my past experience	1	2	3	4	5
7.	Try to find out more about the situation	1	2	3	4	5
8.	Talk with a professional (e.g. doctor, clergy) about the situation	1	2	3	4	5
9.	Take some positive action	1	2	3	4	5
10.	Talk with spouse or other relative about the problem	1	2	3	4	5
11.	Talk with friend about the situation	1	2	3	4	5
12.	Exercise more	1	2	3	4	5
13.	Prepare myself for the worst	1	2	3	4	5
14.	Take it out on other people when I feel angry or depressed	1	2	3	4	5
15.	Try to reduce the tension by eating more	1	2	3	4	5
16.	Try to reduce the tension by smoking more	1	2	3	4	5
17.	Keep my feelings to myself	1	2	3	4	5
18.	Get busy with other things in order to keep my mind off the problem	1	2	3	4	5
19.	Think that everything will be okay and not worry about it	1	2	3	4	5

RLOC

Ask P to please turn over the page.

If 1 is Strongly Agree and 5 is Strongly Disagree, tell me the extent to which you agree or disagree with the following statements.

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
1. How I manage in the future depends on me, not on what other people can do for me	1	2	3	4	5
2. It's often better just to wait and see what happens					
3. It's what I do to help myself that's really going to make all the difference	1	2	3	4	5
4. My own efforts are not very important, my recovery really depends on others	1	2	3	4	5
5. Its up to me to make sure that I make the best recovery possible under the circumstances	1	2	3	4	5
6. I have little or no control over my progress from now on					
7. My own contribution to my recovery doesn't amount to much	1	2	3	4	5
8. Getting better now is a matter of my own determination rather than anything else					
9. It doesn't matter how much help you get - in the end it's your own efforts that count.	1	2	3	4	5
1. I would prefer to be in charge of my recovery rather than just follow instructions	1	2	3	4	5
2. I am careful to do all I can to prevent my illness recurring					
3. I don't like to ask the doctor or nurse lots of questions about my recovery	1	2	3	4	5
4. I like to get a good idea of how an activity or treatment will help my recovery before I start it					
5. I would rather decide myself instead of just following orders about what to do to get better.	1	2	3	4	5
6. I wish I could avoid many of the decisions I have to make which concern my recovery	1	2	3	4	5
7. I prefer to avoid situations where someone else has to tell me what to do to get better.	1	2	3	4	5
8. When it comes to my recovery, I want to just wait and see what happens	1	2	3	4	5
9. I prefer to manage my recovery completely on my own.					
10. I think it is better for others to be in charge of my recovery.	1	2	3	4	5
11. I wish that I could be completely in control of my progress from now on.					
12. I wish that my recovery was not left entirely up to me	1	2	3	4	5

Reference for questions on ambulation activities

THE QUESTION TO ASK IS WRITTEN BESIDE EACH ACTIVITY.
EG. IF 1. I do not walk at all **IS ANSWERED YES, AND SO TICKED, FILL IN THE BLANK PART OF All QUESTIONS (1-9) WITH:…. walk at all….**

SO: 1. If 1 is No Control at all and 5 is Complete Control, how much control do you feel you have over whether you… *walk at all* … over the next month
2. If 1 is Not at all confident and 5 is Extremely Confident, how confident are you that you will … *walk at all* … over the next month

TICKED ACTIVITY USE (REMEMBER TO FILL IN THE BLANKS FOR ALL NINE QUESTIONS WITH THE SAME PHRASE):

1. I do not walk at all **….. walk at all**
2. I get about in a wheelchair **….. get about without a wheelchair**
3. I do not use stairs at all **….. use stairs**
4. I only walk with help from somebody else **...... walk without help from somebody else**
5. I get about only by using a walking frame, ETC **…. get about without using a walking frame ETC**
6. I only go up and down stairs with assistance **…. go up and down stairs without assistance**
7. I only use stairs with a physical aid; **...... use stairs without a physical aid**
8. I walk by myself but with some difficulty; **...... walk by myself without the difficulty I mentioned**
9. I do not walk up or down hills **...... walk up or down hills**

10. I go up and down stairs more slowly **...... go up and down stairs as fast as I used to**
11. I walk shorter distances or often stop for a rest **...... walk further or not stop for a rest**
12. I walk more slowly **......walk as fast as I used to**
13. I do not walk as well as I did before my stroke **......walk as well as I used to before my stroke**

SECTION B

PC

That is most of the questionnaire completed. The next section only takes about 5-10 minutes and, we leave it to the end because it asks questions which concern your general recovery and what you think will happen over the next month. So, would you like to take a break first or are you happy to continue?

Now, I just want to ask a bit more your walking (and use of stairs) and, what you think will happen over the next month.
(Interviewer: Use answer from flp- The ref page overleaf will tell you how to fill in the blanks for the following questions.)

1. (PBC). If 1 is No Control at all and 5 is Complete Control, how much control do you feel you have over whether you…… over the next month? ☐
Ask P to please turn over the page.

2. (SE). If 1 is Not at all confident and 5 is Extremely Confident, how confident are you that you will …… over the next month? ☐

Ask P to please turn over the page.

3. (LOC). If 1 is Strongly Agree and 5 is Strongly Disagree, do you think that it is entirely up to you whether you……over the next month? ☐

Ask P to please turn over the page.

4. (I). If 1 is Definitely Yes and 5 is Definitely no, do you intend to try to…… over the next month ☐

Ask P to please turn over the page.

5. (DFC). If 1 is Definitely Would Like and 5 is Definitely Would Not Like, how much you would like to …… over the next month? ☐

Ask P to please turn over the page.

6. (PBCp). If 1 is Not at all Difficult and 5 is Extremely Difficult, how difficult will it be for you to…… over the next month ☐

Ask P to please turn over the page.

7. (SN). If 1 is Definitely Should and 5 is Definitely Should Not, do you think ….(name of partner) feels you should …… over the next month? ☐

Ask P to please turn over the page.

8. (I). If 1 is Definitely Yes and 5 is Definitely no, do you plan to …… over the next month? ☐

Ask P to please turn over the page.

9. (DFC). If 1 is Not very Much and 5 is As Much as Possible, how much do you care about whether you…… over the next month? ☐
Ask P to please turn over the page.

10. (SNp). If 1 is Not very Much and 5 is As Much as Possible, how much would you try to …… over the next month in order to please your relative? ☐
Ask P to please turn over the page. *PBC/RSE*

Now, I am going to ask you some general questions about your recovery. You will notice that these questions will seem to be very alike, but they are different. I'd like you listen carefully to each question and to answer by telling me which number best fits for you in each case. Try not to be worried about how you have answered before and don't try to be consistent. It is because the different questions can mean different things to people that we ask them in this way.

A. If 1 is Not at all confident and 5 is Extremely confident,

1. How confident are you that you now can make a full recovery	1	2	3	4	5
2. How confident are you that you now can make a good recovery	1	2	3	4	5
3. How confident are you that you now can influence your recovery	1	2	3	4	5
4. How confident are you that you now can help yourself recover	1	2	3	4	5

Ask P to please turn over the page.

B. If 1 is Not at all Difficult and 5 is Extremely difficult

How difficult are you finding it to make a full recovery	1	2	3	4	5
How difficult are you finding it to make a good recovery	1	2	3	4	5
How difficult are you finding it to influence your recovery	1	2	3	4	5
How difficult are you finding it to help yourself recover	1	2	3	4	5

Ask P to please turn over the page.

C. If 1 is No Control at all and 5 is Complete Control

How much control do you have over whether you make a full recovery	1	2	3	4	5
How much control do you have over whether you make a good recovery	1	2	3	4	5
How much control do you have over whether you influence your recovery	1	2	3	4	5
How much control do you have over whether you help yourself recover	1	2	3	4	5

PLQ

One last question. How have you found the interview? Was there anything that you found difficult, or anything you would like to comment on? No ☐ Yes ☐

General Practitioners letter

Dear Doctor

Re patient Chi number

Address

I am writing to advise you that the above patient has consented to take part in the Following a Stroke Trial (FAST). We will be visiting the patient at home and asking a set of questions about their stroke and recovery. Some patients will be randomly allocated to a group who will be asked to watch the HEBS Stroke Matters video and their thoughts about the video. Five weeks following the first visit all patients will be interviewed with a similar set of questions about their continuing recovery. The patient information sheet is enclosed.

This study has been funded by the Scottish Office and has ethical approval from Tayside Ethics Committee.

If you know of any medical reasons why this patient should not take part this study please inform me as soon as possible. Thank you in anticipation.

Yours faithfully

Sara Joice
Researcher

APPENDIX C STATISTICS

Demographic, Clinical and Psychological Differences between SWOT and Video Study

Demographic Measures	**Total**	**Numbers**		**χ^2 results**
		Swb (n=91)	Video (n=57)	
Gender: female	62	35	27	χ^2 = 1.14 (*df 1*) *p* = .29
male	86	56	30	
Employment: retired	112	68	44	χ^2 = .12 (*df 1*) *p* = .73
Not retired	36	23	13	
Living: with carer	98	57	41	χ^2 = 1.35 (*df 1*) *p* = .25
without carer	50	34	16	
		Mean Scores (standard deviation)		**t-tests results**
Mean age - years	148	68.66(12.73)	67.30 (11.15)	t(146) = .66, *p* = .51
Depcat score: 1 – 7	132	3.66 (1.72)	3.93 (1.62)	t(146) = -.95, *p* = .34

Table c1: Demographic differences between SWOT and Video study groups: χ^2 and t-test results

Clinical Measures	**Total**	**Numbers**		**χ^2 results**
		Swb (n= 91)	Video (57)	
Affected side: left	69	42	27	χ^2 = .00 (*df 1*) *p* = .98
right	77	47	30	
Stroke event: first	121	74	47	χ^2 = .03 (*df 1*) *p* = .86
previous	27	17	10	
		Mean Score (standard deviation)		**t-test results**
Length of stay in hospital	148	33.59 (42.44)	33.04 (47.44)	t(146) = .07, *p* = .94
Orgogozo	133	76.94 (20.34)	76.77 (17.52)	t(131) = .05, *p* = .96
NIH (transformed) [2]	132	1.97 (.93)	2.19 (.80)	t(130) = -1.76 *p* = .22
Modified Rankin[2]	129	3.19 (1.24)	2.77 (1.15)	t(127) = 1.89, *p* = .06^
Barthel Index (transformed)[1]	148	122074.5 (45775.69)	110765.00 (47005.78)	t(146) = 1.45, *p* = .15

Table c2: Clinical differences between SWOT and Video study groups: $\chi^{2\text{ and}}$ t-test results

Psychological Measures	**Mean Score (standard deviation)**		**t-test results**
	swb	**video**	
HADS (n =148)			
Mood	12.85 (8.99)	11.75 (7.94)	t(146) = .75, *p* = .45
Anxiety	5.97 (5.37)	5.61 (4.45)	t(146) = .42, *p* = .68
Depression	6.89 (4.55)	6.14 (4.43)	t(146) = .97, *p* = .33
RLOC	35.21 (4.41)	35.79 (4.03)	t(146) = -.81, *p* = .42
WOC			
Active coping	40.62 (8.22)	41.14 (8.78)	t(146) = -.37, *p* = .71
Active cognitive	20.59 (4.58)	19.96 (4.40)	t(146) =.82, *p* = .41
Active behavioural	20.02 (4.81)	21.17 (5.33)	t(146) = -1.36, *p* = .18
Avoidant	11.31 (3.50)	11.16 (3.14)	t(146) = .26, *p* = .79
Problem focused	24.86 (5.91)	24.61 (6.23)	t(146) =.24, *p* = .81
Emotion focused	31.12 (6.17)	30.09 (4.88)	t(146) = .22, *p* = .83
Desire for video	4.05 (1.27)	3.65 (1.43)	t(146) = 1.80, *p* = .08^
Confidence in recovery	7.73 (2.36)	8.37 (2.22)	t(146) = -1.70, *p* = .10

Table c3: Psychological differences between SWOT and Video study groups: χ^2 and t-test results

Correlational Analysis between Demographic, Clinical and Psychological Variables in Video Study

N= 57	Employment	With carer	Age	Depcat	Reg.gen
Gender	.10	.05	.20	.02	-.38**
Employment		-.34**	75**	-.16	-.13
With carer			-.26*	.12	-.02
Age				-.26	.00
Depcat					-.12

Table c4: Correlations between demographic variables of the video only and video and letter group (n = 57)

N = 57	Stroke event	Orgogozo	NIH t	Rankin	Barthel t	Time
Affected side	.07	.08	.10	.07	.37**	-.03
Stroke event		.06	-.02	-.06	.07	-.19
Orgogozo			-.69**	-.73**	.31*	-.33*
NIH				.67**	-.31*	.51**
Rankin					-.36*	.32*
Barthel						-.27*

Table c5: Correlations between clinical variables of the video only and video and letter group (n = 57)

N = 57	Gender	Employment	With carer	Age	Depcat	Reg
Affected side	.13	-.35**	-.05	-.33*	-.02	.10
Stroke event	.12	.03	-.02	-.03	-.24^	.07
Orgogozo	-.10	-.04	.15	.17	-.06	.23
NIH	.13	-.03	-.27^	-.21	-.04	-28*
Rankin	.24	.02	-.02	-.07	-.07	-.24
Barthel	.36**	-.41**	-.04	-.35**	.08	.19
Time	.02	-.16	.05	-.05	.00	.17

Table c6: Correlations between clinical and demographic variables of the video only and video and letter group (n= 57)

N = 57	Anx	Dep	RLOC	A.Cop	A.Cog	A.Beh	Avoid	Prob.F.	Emot.	Des.	Confi	Ident	T.Chro.	T.Cycl.	Conseq	C.Pers.	C.treat	Coher.	Emot R.	C-Psyc	C-PRC	C-PRU	C-ext
Mood	.90**	.90**	-.12	-.22	-.30*	-.11	.27*	-.18	.01	.21	-35**	.31*	.17	.56**	.34**	-.03	-.04	-.36**	.76**	.32*	-.01	.17	.13
Anx.		.60**	.02	-.07	-..16	.01	.31*	-.06	.15	.19	-.26*	.24^	.08	.52**	.25^	.06	-.00	-.38**	.77**	-.36	.02	.17	.08
Dep.			-.24^	-.32*	-.39**	-.20	.16	-.26*	.13	.19	-.36**	.33*	.23	.50**	.37**	-.11	-.07	-.28*	.61**	.23	-.04	.14	.15
RLOC				.21	.12	.25^	.10	.22	.13	.03	.22	-.19	-.33**	-.24^	-.32*	.44**	.33*	.12	-.10	-.03	-.20	-.06	-.09
A. Cop					.88**	.92**	.05	.93.**	.48**	.10	.19	.18	.12	.03	.17	.09	-.29*	-.08	-.14	-.08	.16	.09	-.20
A. Cog.						.62**	-.06	.77**	.51**	.03	.23	.08	.00	.02	.18	-.10	-.35**	-.14	-.14	-.17	.13	.05	-.01
A. Beh.							.13	.90**	.36**	.15	.13	.24^	.20	.03	.13	.23^	-.17	-.01	-.12	.00	.15	.12	-.32*
Avoid.								.08	.56**	.03	-.10	.07	-.01	-.09	-.13	.16	.15	.06	.19	.35**	.23^	.22	.13
Prob.F.									.29*	.15	.09	.15	.17	-.02	.18	.16	-.22	.06	-.14	-.01	.24^	.15	-.21
Emot. F.										-.08	.24	.04	-.15	-.07	-.09	-.07	-.04	-.19	.09	.01	.06	.18	.13
Desire											.02	.29*	.12	.19	.23	.16	-.08	.02	.05	.26*	.20	.16	.02
Confi.												-.21	-.61**	-.16	-.29*	.19	.20	.01	-.39**	-.08	-.25^	.01	-.20
Ident.													.36**	.36**	.35**	.18	-.04	.01	.20	.05	.04	.11	-.19
T. Chro														.14	.54**	-.25^	-.27*	.20	.24^	-.05	.37**	.09	-.06
T. Cycl															.51**	.01	-.24^	-.36*	.68**	.35**	.02	.17	.15
Conseq.																-.14	-.40**	-.14	.48**	.25^	.29*	.04	-.07
C. Pers.																	.26*	.04	-.08	.24^	-.04	-.04	-.22
C. Treat.																		.28*	-.03	.09	-.16	-.10	-.14
Coher.																			-.39**	-.08	.19	.02	-.33*
Emot. R.																				.37**	.08	.16	.20
C-Psyc																					.22	.30*	.05
C-PRC																						.15	.14
C-PRU																							.19

Table c7: Correlations between psychological variables of the video only and video and letter group (n= 57)

N = 57	Gender	Employment	With carer	Age	Depcat	Reg
Mood	.14	.19	-.10	-.05	.21	.23
Anx.	.20	.08	.10	-.15	.15	.29*
Dep.	.05	.27*	-.11	.07	.22	.13
RLOC	.06	-.50	-.17	.00	-.14	-.10
A. Cop	-.23	-.21	.00	-.27*	-.15	-.25^
A. Cog.	-.03	-.24^	.06	-.29*	.11	-.16
A. Beh.	-.36**	-.14	-.05	-.20	-.22	-.27*
Avoid.	-.01	-.12	.06	-.21	.12	.08
Prob.F.	-.44**	-.19	-.04	-.31*	-.19	-.28*
Emot. F.	.26*	-.18	.12	-.24^	.13	.16
Desire	-.36**	-.16	-.10	-.21	-.04	-.18
Confi.	.07	-.10	.05	-.02	-.16	-.10
Ident.	.02	.01	-.15	-.10	-.16	-.22
T. Chro	-.12	-.05	-.03	-.14	.11	-.02
T. Cycl	.15	-.05	-.02	-.18	-.13	.08
Conseq.	-.02	-.18	.12	-.26*	.11	.03
C. Pers.	-.33*	-.01	.11	-.07	-.21	-.20
C. Treat.	.08	-.05	.14	.09	-.22	-.14
Coher.	.24^	-.31*	.10	-.17	-.10	-.25^
Emot. R.	.25^	.01	.17	-.16	.14	.22
C. Emot	-.18	-.00	.10	-.11	-.20	.21
C. Own	-.47**	-.32*	.15	-.38**	-.02	-.04
C. Oth	-.11	-.07	-.01	-.40**	.23	.40**
C.Ext	.11	.15	-.13	.05	.13	.23

Table c8: Correlations between psychological and demographic variables of video only and video and letter group (n= 57)

N = 57	Stroke event	Affected side	Time	Orgogozo t	NIH t	Rankin	Barthel t
Mood	-.09	-.01	-.04	.11	-.09	-.07	-.31*
Anx.	-.08	.03	-.11	.10	-.16	-.03	-.20
Dep.	-.08	-.05	.30	.08	.00	-.09	-35*
RLOC	-.14	.06	-.02	-.02	.04	.10	.24^
A. Cop	.15	.23	.06	.02	.02	.06	.23
A. Cog.	.14	.33*	.06	.01	.07	.09	.22
A. Beh.	.13	.11	.05	.02	-.02	.03	.19
Avoid.	-.08	.20	-.13	.01	.01	.04	.10
Prob.F.	.13	.23	.01	-.04	.06	.06	.25^
Emot. F.	.15	.20	-.05	.00	.01	.09	.15
Desire	-.05	.14	.13	.12	-.01	-.15	.14
Confi.	.13	.05	-.09	.19	-.05	-.02	.36*
Ident.	.09	.05	.16	-.19	.20	.21	-.16
T. Chro	.22	.06	.14	-.24	.11	.07	-.25^
T. Cycl	-.01	-.00	-.00	-.02	.04	-.03	-.32*
Conseq.	.13	-.06	.26*	-.16	.26^	.15	-.39**
C. Pers.	-.06	-.13	-.01	.00	-.05	.07	.27*
C. Treat.	.09	-.08	-.26*	.19	-.22	-.19	.20
Coher.	.14	.21	.11	-.12	.18	.12	.23
Emot. R.	-.14	-.13	.16	-.12	.02	.05	-.47**
C-Psyc	-.16	-.10	.03	.09	-.01	-.04	-.03
C-PRC	.04	.12	-.01	-.06	-.09	-.09	.24^
C-PRU	-.10	.23	-.09	-.12	.10	.06	.16
C-Ext	-.10	.06	-.03	-.05	-.04	-.17	-.09

Table c9: Correlations between psychological and clinical variables of video only and video and letter group (n= 57)

	Tested	Read	Booklet colour	Video adherence
Observed	-.74**	.65**	.56**	.98**
Tested		.56**	.64**	.74**
Read			.62**	.60**
Booklet colour				.57**

Table c10: Correlations between measures of adherence to video activities

	Video adherence	Intervention Adherence	Intervention active adherence
Gender	-.28*	.07	.40
Employment	-.21	-.12	-.11
With carer	.08	-.14	-.11
Age	-.17	-.13	-.11
Depcat	-.08	.00	.02
Regen	-.06	-.09	-.07

Table c11 Correlations between demographic variables and adherence measures

	Video adherence	Intervention Adherence	Intervention active adherence
Affected side	.11	-.07	-.05
Stroke event	-.17	-.15	-.16
Time in hosp	.13	-.01	-.03
Orgogozo	.05	.11	.15
NIH t	-.07	-.18*	-.15
Rankin	-.15	-.17	-.27**
Barthel t	.15	.07	.80

Table c12: Correlations between clinical variables and video adherence

	Video adherence N = 57	Intervention Adherence	Intervention active adherence
Mood	.02	.01	-.05
Anx.	-.01	.04	-.03
Dep.	.05	-.02	-.06
RLOC	-.12	-.19*	-.11
A. Cop	.08	-.01	.09
A. Cog.	.04	-.08	.04
A. Beh.	.10	.06	.07
Avoid.	.04	-.05	-.09
Prob.F.	.05	-.01	.02
Emot. F.	.06	-.07	-.07
Desire	.52**	.25**	.23*
Confi.	-.18	-.19*	-.13
Ident.	.28*		
T. Chro	.21		
T. Cycl	.17		
Conseq.	.13		
C. Pers.	.14		
C. Treat.	-.09		
Coher.	.04		
Emot. R.	.08		
C-Psyc	.26^		
C-PRC	.26^		
C-PRU	.17		
C-Ext	.12		
intervention	.12		.19*

Table c10: Correlations between psychological variables and video adherence

APPENDIX D

1. The theoretical letter
2. Statistics for study 3

The Theoretical Letter

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Dear

Thank you for taking part in the FAST study. Following a stroke, many people try to make sense of what has happened to them and how they are going to deal with it. Often this leaves people overwhelmed and confused. In our research we have found that people have their own ways of thinking about stroke due to their own life experiences, which help them to progress and which maybe helpful to you.

How has the stroke affected me?
A stroke can affect people in different ways. It can change how they move and care for themselves, how they go about their household jobs, their relationships, their work and their social life.

Think ……..how your stroke has affected your everyday activities. What activity would you like to improve?

Why did it happen?
People have ideas about what caused their stroke and fear having another one. Learning about a stroke - from other stroke survivors, friends and health services - can help you to understand why it happened and how to reduce the chances of having another one. Finding out more about diet, medication, smoking, alcohol, exercises, and relaxation may be helpful.

Think….is there any thing you think you could do to reduce the chances of another one happening?

How long will it go on for?
People make a lot of progress in the early days but over time progress is slower. This is very normal but recovery can go on improving for many years. Sometimes people do not notice small improvements they make.

Think…. about when you first had your stroke compared to now. What improvements have you made?

Think….what new skills have you learned that help your recovery?

What will happen in the future?
Nobody knows exactly what will happen in the future. Some people recover completely whilst others continue to be affected. The effects a stroke can have on one's quality of life can be influenced by how they think about it. What happens in the future can depend on the person who has had the stroke. Relearning or learning new skills will help in the future.

Can I do anything about it?
Others will help, but people thinking about what they can do for themselves is very important. Taking control over one's own progress will improve recovery. By being open to new ways of thinking, for instance, having a plan with achievable goals help one to be in control. Keeping a note of successes increase confidence. If one way of doing things does not work try a different way.

Think…what have you done that you think has helped your recovery?

Think ….is there something you do that makes you feel better?

How do I feel about it?
It is not uncommon for people to feel frightened, sad, anxious, angry, depressed or moody. It can be difficult to make an effort to do things, even those little things you know you can do. Letting others know about your feelings or doing new activities such as learning to relax or engaging in physical activities may help you to feel better about your thoughts.

We hope these ideas can help you to make sense of your stroke. We wish you well in making the most of your recovery

Dr Ronald S. MacWalter Professor Marie Johnston

Word count; 550
Flesch reading ease 76.2 (standard 60 – 70; ↑ easier to understand)
Flesch grading 5.2 (standard 7-8; ↓ easier to read)

Statistics for study 3

Measures	Intervention Means (standard deviations)				Source of variance	Sums of squares	df	Mean square	F	*p*
	video		No video							
	Letter	No letter	letter	No letter						
Orgogozo t	489930.56 (247283.50)6	546047.62 (268602.78)	550682.69 (251286.48)	628975.96 (241992.93)	Between groups	258591170014.88	3	86197056671.63	1.36	.26
					Within groups	6075463314360.11	96	63286076191.25		
					Total	6334054484375.00	99			
Rankin	2.89 (1.01)	2.57 (1.40)	2.73 (1.40)	2.27 (1.15)	Between groups	5.52	3	1.84	1.19	.32
					Within groups	148.04	96	1.54		
					Total	153.56	99			
NIH t	2.23 (.77)	2.145 (.87)	1.89 (1.01)	1.93 (.74)	Between groups	2.07	3	.69	.96	.42
					Within groups	69.48	96	.72		
					Total	71.55	99			
Barthel t	105646.21 (47820.35)	115707.31 (46502.38)	116621.03 (46552.35)	122339.82 (42527.72)	Between groups	4047882348.26	3	1349294116.09	.640	.591
					Within groups	231804219388.00	110	2107311085.35		
					Total	235852101736.25	113			
Time in hospital	41.21 (61.60)	25.14 (26.70)	39.10 (50.52)	30.64 (37.61)	Between groups	4805.71	3	1601.90	.76	.52
					Within groups	232047.28	110	2109.52		
					Total	236853.00	113			

Table d1 Clinical Differences between the intervention groups; ANOVA results

Measures		Intervention Means (standard deviations)				Source of variance	Sums of squares	df	Mean square	F	*p*
	T1	video		No video							
HADS	α	letter	No letter	letter	No letter						
Mood	.85	10.54 (8.19)	12.93 (7.67)	11.93 (6.94	12.68 7.66)	Between groups	98.13	3		32.71	.63
						Within groups	6390.80	102			
						Total	6488.92	105			
Anxiety	.82	5.14 (4.91)	6.07 (3.98)	5.55 (4.56)	6.00 (4.41)	Between groups	15.79	3	5.26	.026	.85
						Within groups	2202.46	110	20.02		
						Total	2218.25	113			
Depression	.78	5.39 (4.32)	6.86 (4.45)	6.38 (4.11)	6.69 (4.25)	Between groups	36.27	3	12.09	.66	.58
						Within groups	2029.06	110	18.45		
						Total	2065.33	113			
RLOC	.69	36.54 (4.06)	35.07 (3.95)	35.28 (3.82)	35.75 (3.49)	Between groups	36.10	3	12.03	.82	.49
						Within groups	1617.87	110	14.71		
						Total	1653.97	113			
IPQ-R											
Identity		3.59 (1.82)	4.14 (2.48)	4.11 (2.45)	4.88 (2.80)	Between groups	21.04	3	7.01	1.21	.31
						Within groups	589.24	102	5.78		
						Total	610.27	105			
Time line-chronic	**.82**	**14.81 (3.66)**	**17.86 (4.34)**	**16.37 (3.87)**	**17.17 (4.76)**	**Between groups**	**139.13**	**3**	**46.38**	**2.68**	**.05**
						Within groups	**1767.13**	**102**	**17.33**		
						Total	**1906.26**	**105**			
Time line-cyclical	.72	10.52 (3.18)	10.54 (2.41)	10.89 (3.08)	11.13 (2.77)	Between groups	6.23	3	2.21	.27	.85
						Within groups	843.00	102	8.27		
						Total	849.62	105			
Consequence	.71	19.81 (4.22)	21.57 (2.78)	20.48 (3.83)	19.75 (3.95)	Between groups	57.87	3	19.29	1.40	.25
						Within groups	1410.17	102	13.83		
						Total	1468.04	105			
Control -personal	.61	23.19 (2.32)	22.25 (2.40)	21.93 (2.22)	23.00 (2.32)	Between groups	28.72	3	9.57	1.79	.16
						Within groups	547.18	102	5.36		
						Total	575.90	105			
Control - treatment	.48	19.07 (1.77)	19.07 (1.88)	18.52 (2.10)	18.63 (1.84)	Between groups	6.87	3	2.29	.63	.60
						Within groups	370.08	102	3.63		
						Total	376.94	105			
Illness coherence	.84	14.59 (4.04)	15.36 (4.46)	14.48 (3.52)	14.04 (3.74)	Between groups	23.73	3	7.91	.50	.68
						Within groups	1612.65	102	15.81		
						Total	1636.38	105			

Table d2 Psychological differences between the intervention groups; ANOVA results

Measures		Intervention Means (standard deviations)				Source of variance	Sums of squares	df	Mean square	F	*p*
	T1	video		No video							
IPQ-R	α	letter	No letter	letter	No letter						
Emotional	.83	17.78 (5.32)	17.54 (3.94)	18.59 (5.06)	18.63 (4.69)	Between groups	24.87	3	8.29	.36	.78
						Within groups	2323.77	102	22.78		
						Total	2348.64	105			
Cause: Psychological	.65	12.67 (3.22)	12.39 (2.80)	11.96 (2.53)	12.96 (2.71)	Between groups	13.86	3	4.62	.58	.63
						Within groups	818.60	102	8.03		
						Total	832.46	105			
Cause: Controllable PR	**.55**	**9.67 (2.35)**	**11.04 (2.76)**	**9.26 (1.81)**	**9.79 (2.17)**	**Between groups**	**48.67**	**3**	**16.22**	**3.05**	**.03**
						Within groups	**542.11**	**102**	**5.32**		
						Total	**590.76**	**105**			
Cause: Uncontrollable PR	.40	9.78 (2.10)	9.50 (2.30)	9.52 (2.10)	9.08 (1.86)	Between groups	6.22	3	2.07	.47	.71
						Within groups	452.24	102	4.43		
						Total	458.46	105			
Cause: External influences	.40	13.56(1.93)	13.57 (2.39)	13.44 (1.95)	13.21 (2.38)	Between groups	2.12	3	.71	.15	.93
						Within groups	480.15	102	4.71		
						Total	482.26	105			
WOC											
Active coping	.70	40.79 (8.28)	41.48 (9.36)	41.24 (6.54)	41.93 (8.72)	Between groups	19.13	3	6.38	.09	.96
						Within groups	7559.12	110	68.72		
						Total	7578.25	113			
Active cognitive	.46	19.96 (4.15)	19.97 (4.70)	21.24 (4.05)	19.79 (4.94)	Between groups	39.17	3	13.06	.66	.58
						Within groups	2193.95	110	19.95		
						Total	2233.12	113			
Active behavioural	.60	20.82 (5.28)	21.52 (5.47)	20.00 (4.30)	22.14 (4.57)	Between groups	72.74	3	24.25	.99	.40
						Within groups	2670.78	110	24.28		
						Total	2743.52	113			
Avoidant	.31	10.96 (3.40)	11.34 (2.92)	11.62 (3.51)	11.50(3.69)	Between groups	6.91	3	2.30	.20	.90
						Within groups	1263.34	110	11.49		
						Total	1270.25	113			
Problem focused	.70	24.68 (6.04)	24.54 (6.51)	24.14 (5.55)	25.21 (6.00)	Between groups	16.81	3	5.60	.15	.93
						Within groups	4005.44	110	34.41		
						Total	4022.25	113			
Emotion focused	.28	30.39 (5.11)	34.41 (4.69)	32.00 (5.71	31.46 (6.06)	Between groups	38.31	3	12.77	.44	.73
						Within groups	3224.68	110	29.32		
						Total	3262.99	113			
Confidence in recovery	-----	8.54 (1.97)	8.21 (2.46)	8.28 (2.31)	8.32 (2.26)	Between groups	1.71	3	.57	.11	.95
						Within groups	561.62	110	5.12		
						Total	563.33	113			

Table d3 Psychological differences between the intervention groups; ANOVA results

	Letter Adherence
Gender	.13
Employment	.08
With carer	.07
Age	-.16
DEPCAT	.09
SEC	.08

Table d4 Correlations between reported letter adherence and demographic variables

	Letter Adherence
Affected side	.26*
Stroke event	-.12
Time in hosp	-.01
Orgogozo t	-.18
NIH t	.20
Rankin	-.13
Barthel t	.04

Table d5 Correlations between reported letter adherence and clinical variables

	Letter Adherence
Mood	.08
Anx.	.09
Dep.	.04
RLOC	-.03
A. Cop	.09
A. Cog.	.10
A. Beh.	.01
Avoid.	-.05
Prob.F.	.13
Emot. F.	-.03
Desire	.05
Confi.	-.06
Ident.	.18
T. Chro	.21
T. Cycl	.09
Conseq.	.12
C. Pers.	-.22
C. Treat.	-.03
Coher.	.02
Emot. R.	.13
C. Emot	.14
C. Own	-.08
C. Oth	-.10
C. Ext	-.00

Table d6 Correlations between reported letter adherence and psychological variables

Demographic Measures	**Total**	**Numbers**		χ^2
		Not Exposed	Control	
Gender: female male	28 30	18 14	10 16	χ^2 = 1.82 (*df 1*) *p* = .18
Employment: retired Not retired	49 9	26 6	23 3	χ^2 = .57 (*df 1*) *p* = .63
Living: with carer without carer	42 16	24 8	18 8	χ^2 = .24(*df 1*) *p* = .86
Registrar General 1-4 5-8	30 18	14 18	11 15	χ^2 = .01(*df 1*) *p* = .91
Decat level 1-3 4-6	30 18	15 17	15 11	χ^2 = .67(*df 1*) *p* = .41
		Mean Scores (standard deviation)		**t-tests**
Mean age - years	58	69.84 (11.18)	67.85 (10.58)	t (56) = .69, *p* = .49
Depcat score: 1 – 6	58	4.00 (1.68)	3.54 (1.73)	t (56)= 1.03, *p* = .31

Table d7: Demographic differences between control group and non-exposure to an intervention; χ^2 & t-test results.

Clinical Measures	**Total**	**Numbers**		χ^2
		Not exposed	Control	
Affected side: left right	35 23	21 11	14 12	χ^2 = .83 (*df 1*) *p* = .36
Stroke event: first previous	49 9	25 7	24 2	χ^2 = 2.20 (*df 1*) *p* = .14
		Mean Score (standard deviation)		**t-test**
[1]Orgogozo (transformed)	48	564583.33 (265458.18)	629682.29 (250244.61)	t (46)= -.87, *p* = .39
[2]NIH (transformed)	48	1.93 (1.01)	2.04 (.64)	t (46)= -.43, *p* = .67
[2]Modified Rankin	48	2.79 (1.35)	2.29 (1.20)	t (46)= -1.36, *p* = .18
Time in hospital	58	31.69 (47.85)	31.07 (38.56)	t (56) = .05, *p* = .96
[1]Barthel Index (transformed)	58	108531.41 (48260.82)	125325.88 (42702.11)	t (56) = -1.39, *p* = .17

Table d8: Clinical differences between control group and non-exposure to an intervention; χ^2 & t-test results.

Psychological Measures	Mean Score (standard deviation)		t-test
	Not Exposed	Control	
HADS(n=58)			
Mood	12.62 (7.84)	12.77 (7.90)	t (56)= -.07, *p* = .94
Anxiety	6.00 (4.66)	5.96 (4.48)	t (56)= .03, *p* = .98
Depression	6.63 (4.15)	6.81(4.39)	t (56)= -.16, *p* = .87
RLOC	35.84 (4.21)	36.04 (3.41)	t (56)= -.19, *p* = .85
IPQ-R (n=54)			
Identity	**3.19 (2.10)**	**4.87 (2.87)**	**t (52)= -2.48, *p* = .02**
Timeline - chronic	15.65 (3.90)	16.95 (4.75)	t (52)= -.11, *p* = .27
Timeline – cyclical	10.26 (2.59)	11.17 (2.82)	t (52)= -1.24, *p* = .22
Consequence	20.19 (3.64)	19.61 (3.97)	t (52)= .56, *p* = .58
Control – personal	22.29 (2.19)	23.22 (2.11)	t (52)= -1.56, *p* = .13
Control - treatment	18.77 (2.17)	18.78 (1.70)	t (52)= -.02, *p* = 1.00
Illness coherence	14.52 (3.91)	14.13 (3.79)	t (52)= .36, *p* = .72
Emotional representation	18.10 (5.02)	18.56 (4.78)	t (52)= -.35, *p* = .73
Cause: psychological	12.06 (2.97)	13.00 (2.76)	t (52)= -1.18, *p* = .24
Personal risk - controllable	9.12 (1.63)	9.78 (2.21)	t (52)= -1.25, *p* = .22
Personal risk - uncontrollable	9.64 (2.27)	9.04 (1.89)	t (52)= 1.03, *p* = .31
External risk	13.32 (1.87)	13.26 (2.42)	t (52)= .11, *p* = .92
WOC(n=58)			
Active coping	40.19 (7.66)	41.73 (8.89)	t (56)= -.71, *p* = .48
Active cognitive	20.06 (4.19)	19.50 (4.93)	t (56)= .47, *p* = .64
Active behavioural	20.12 (4.63)	22.23 (4.66)	t (56)= 1.72, *p* = .09^
Avoidant	11.66 (3.47)	11.53 (3.82)	t (56)= .12, *p* = .90
Problem focused	23.69 (6.24)	25.15 (5.90)	t (56)= -.91, *p* = .37
Emotion focused	31.75 (4.66)	31.35 (6.27)	t (45.15)= .27, *p* = .79
Desire for video	3.12 (1.72)	3.92 (1.47)	t (56)= -1.88, p = .07^
Confidence in recovery	8.56 (2.27)	8.53 (1.79)	t (56)= .04, p = .97

Table d9: Psychological differences between control group and non-exposure to an intervention; t-test results

Demographic Measures	**Total**	**Numbers**		χ^2
		Exposed	Not exposed	
Gender: female male	51 60	23 30	28 30	χ^2 = .27 (*df 1*) *p* = .61
Employment: retired Not retired	88 23	39 14	49 9	χ^2 = 2.00 (*df 1*) *p* = .16
Living: with carer without carer	79 32	37 16	42 16	χ^2 = .09 (*df 1*) *p* = .76
Registrar General 1-4 5-8	48 63	23 30	25 33	χ^2 = .01 (*df 1*) *p* = .98
Decat level 1-3 4-6	54 57	24 29	30 28	χ^2 = .46 (*df 1*) *p* = .50
		Mean Scores (standard deviation)		**t-tests**
Mean age - years	111	66.84 (11.49)	68.94 (10.86)	t (109) = .98, *p* = .33
Depcat score: 1 – 6	111	3.68 (1.55)	3.79 (1.70)	t (109)= .37, *p* = .72

Table d10: Demographic differences between those who were exposed to an intervention and those who were not; χ^2 & t-test results.

Clinical Measures	**Total**	**Numbers**		χ^2
		Exposed	Not exposed	
Affected side: left right	58 53	23 30	35 23	χ^2 = 3.20 (*df 1*) *p* = .07^
Stroke event: first previous	95 16	46 7	49 9	χ^2 = .12 (*df 1*) *p* = .73
		Mean Score (standard deviation)		**t-test**
[1]Orgogozo (transformed)	97	509201.53 (250014.15)	597132.81 (257315.68)	t (95)= 1.7, *p* = .09^
[2]NIH (transformed)	97	2.16 (.83)	1.98 (.84)	t (95)= -1.06, *p* = .29
[2]Modified Rankin	97	2.71 (1.24)	2.54 (1.29)	t (95)= -.67, *p* = .50
Time in hospital	111	37.51 (49.26)	31.41 (43.55)	t (109) = -.69, *p* = .49
[1]Barthel Index (transformed)	111	115427.08 (46380.72)	116059.97 (46232.65)	t (109) = .07, *p* = .94

[1]Orgogozo & Barthel Index: higher score = less impairment [2]NIH and Rankin: lower score = less impairment

Table d11: Clinical differences between those who were exposed to an intervention and those who were not; χ^2 & t-test results

Psychological Measures	Mean Score (standard deviation)		t-test
	Exposed	Not exposed	
HADS(n=111)			
Mood	11.21 (7.46)	12.69 (7.81)	t (109)= 1.02, *p* = .31
Anxiety	5.24 (4.33)	5.98 (4.54)	t (109)= .87, *p* = .38
Depression	5.96 (4.45)	6.71(4.22)	t (109)= .90, *p* = .37
RLOC	35.51 (3.85)	35.93 (3.84)	t (109)= .57, *p* = .57
IPQ-R (n=104)			
Identity	4.34 (2.21)	3.91 (2.57)	t (102) = -.92, *p* = .36
Timeline - chronic	16.86 (4.24)	16.20 (4.29)	t (102) = -.78, *p* = .44
Timeline – cyclical	10.78 (2.97)	10.65 (2.71	t (102) = -.24, *p* = .81
Consequence	20.90 (3.75)	19.94 (3.76)	t (102) = -1.30, *p* = .20
Control – personal	22.56 (2.48)	22.69 (2.19)	t (102) = .27, *p* = .79
Control - treatment	18.94 (1.78)	18.78 (1.97)	t (102) = -.44, *p* = .66
Illness coherence	15.06 (4.12)	14.35 (3.83)	t (102) = -.91, *p* = .37
Emotional representation	17.80 (4.65)	18.29 (4.88)	t (102) = .53, *p* = .60
Cause: psychological	12.48 (2.80)	12.46 (2.89)	t (102) = -.03, *p* = .98
Personal risk - controllable	**10.54 (2.73)**	**9.40 (1.91)**	**t (87) = -2.45, *p* = .02**
Personal risk - uncontrollable	9.60 (2.11)	9.30 (2.11)	t (102) = -.51, *p* = .61
External risk	13.60 (2.20)	13.32 (2.11)	t (102) = -.72 *p* = .47
WOC (n=111)			
Active coping	41.70 (8.36)	40.88 (8.19)	t (109)= -.52, *p* = .60
Active cognitive	20.49 (4.37)	19.81 (4.51)	t (109)= -.81, *p* = .42
Active behavioural	21.21 (5.28)	21.07 (4.72)	t (109)= -.15, *p* = .88
Avoidant	11.15 (3.16)	11.60 (3.61)	t (109)= .70, *p* = .49
Problem focused	24.91 (5.88)	24.34 (6.09)	t (109)= -.49, *p* = .62
Emotion focused	30.94 (5.51)	31.57 (5.40)	t (109)= .60, *p* = .55
Desire for video	3.89 (1.17)	3.48 (1.65)	t (103)= -1.50, *p* = .14
Confidence in recovery	8.18 (2.25)	8.55 (2.05)	t (109)= .89, *p* = .38

Table d12: Psychological differences between those who were exposed to an intervention and those who were not (T1); t-test results.

APPENDIX E

1. The authors contribution

THE AUTHORS CONTRIBUTION TO THE STUDIES

The Stroke Workbook Study

The Intervention

The stroke workbook for SWOT had been piloted in earlier studies, (Morrison 1998, Johnston et al 1999). Before it could be further implemented it had to be considerably amended. The author improved its reading ease, included more cognitive behavioural tasks, more information on benefits and where to get local support. The author introduced three original characters (Pet, Peggy and Pat the Cat) to illustrate the concepts and to give the workbook a new user-friendly look.

Design of the study 1

The author:

- Designed of study examining the intervention group of the larger SWOT study (Bonetti et al 2001).
- Developed and tested a questionnaire to evaluate the workbook, which was used in the preliminary studies (see Chapter 1, pages 29 and 30).
- Developed the research questions from her experience of implementing the stroke workbook (see Chapter 3, page 60).

Development of measures

The author:

- Collected the objective data from the workbooks of 88 patients
- Developed the measures of participation and adherence (see Chapter 3 pages 65 and 70).

Recruitment

The author was responsible for recruitment (see Chapter 3, page 66).
This included:

- Liaising with the Research Nurse

- Examining the stroke audit sheets of all patients who had been admitted with a stroke to determine, where they were (in the hospital, in a nursing home or had been discharged home), if there had been a misdiagnosis and if the patient had any co-morbidity.
- Going to the wards to introduce myself to the patients, describing the study and inviting them to participate.
- Obtaining the patients consent.
- Recording the demographic and clinical data from the stroke audit sheets for the patients who consented to participate in the study

The author did this recruitment over a period of 14 months and saw approximately 150 (46%) patients.

Baseline assessment

The author carried out approximately 80 (35%) baseline assessments at the T1 interview (Chapter 3, page 66).

Randomisation

The author carried out the randomisation procedure (Chapter 4, page 111).

Stroke workbook implementation

The author carried out the five-week intervention (Chapter 1, page 27) with 93 (90%) of patients from July 1998 to May 2000.

The FAST Study

Design of the studies 2 & 3

The author:

- Drafted a studentship research proposal to the Chief Scientists Office at the Scottish Executive.
- Obtained Ethical Approval from Tayside Ethics Committee
- Designed the theoretical letter (see Chapter 5, page 162 and Appendix D).
- Designed the patient information sheet (Appendix C).
- Developed the randomisation and blinding protocols (Chapter 4, page 111, Chapter 5, page 167)
- Liaised with HEBS and obtained permission to use their video and to record the introductions.
- Added video footage to the HEBS videos to provide an objective score of video adherence.

Recruitment

The author recruited all the patients in the FAST study (n = 160) from September 2002 – June 2003, (see Chapter 4 page 103/Chapter 5 page160). The author:

- Attended the medical admitting ward two to three times per week to find patients who had been admitted with a stroke.
- Examined and interpreted approximately 300 CT scans.
- Assessed patients using the measures on the stroke audit sheets.
- Established patient eligibility by reading patients notes, discharge letter or liaising with the doctor involved with the patients care to establish diagnosis in those cases where the diagnosis was not clear.
- Obtained 100% of patients consent.
- Recorded the demographic and clinical data from the stroke audit sheets for the100% of patients who consented to participate in the study.

Baseline and Outcome assessments

The author:

- Contacted 206 patients discharge to home and arranging home visits for 116 patients for T1 and T2 interviews
- Administered 114 (100%) baseline assessments
- Administered 94 (90%) outcome assessments.

Randomisation

The randomisation protocol, was developed and organised by the author, (see Chapter 4 page 111)

Data collection and analysis

The author:

- Developed and collected the objective measure of video use (Chapter 4 page 105)
- Administered the self-report questions assessing familiarity with the videos and booklets to 104 patients.
- Developed letter adherence measures.
- Performed 100% of all data analysis