Stroke Liaison Workers for Patients and Carers

Dr Graham Ellis
Thesis Submitted for the Award of MD
University of Glasgow

Academic Section of Geriatric Medicine
Submitted 2007

Corrections

Faculty of Medicine **University of Glasgow**

REPORT OF THE CONVENER OF A SPECIAL COMMITTEE ON A THESIS

SUBMITTED FOR THE DEGREE OF MD

NAME OF CANDIDATE: **Graham Ellis**

TITLE OF THESIS: **Stroke liaison workers for patients and carers**

REPORT (please sign & date your report):

The oral examination was carried out in accordance with the regulations of the University. The interrogation of the candidate was rigorous but fair. The candidate appeared confident and fielded the questions well. In general, he argued successfully the case for the thesis.

Dr Ellis acknowledged the potential pitfalls in meta-analyses and that the overall inferences were weakly stated. A final chapter with a clearer summary which reflects pragmatic conclusions was agreed.

Several detailed amendments will be included in the revised manuscript.

- References will be checked and duplication avoided
- Where differences in comparisons are non-significant and type II statistical error is suspected, 95% confidence intervals for differences will be provided to improve informativeness.
- Allowances for multiple statistical comparisons will be incorporated.
- Terminology will be clarified.

A list of the required changes was prepared by the internal examiner and passed to the candidate at the conclusion of the examination.

Signature (Convener): ……. Date: 18 December 2007

Summary

This thesis has developed to explore a specific intervention in a core context. That context is the transition of stroke from hospital to home and from acute illnesses to chronic disease. This includes the change from a rehabilitation focus on the physical effects and complications of stroke (during in-patient stroke unit care) to the psychological, emotional and social consequences of stroke as well as the risk of recurrence.

Specifically it focuses on an intervention in two key problem areas. The first is the risk of stroke or transient ischaemic attack (TIA) recurrence and risk factor modification through lifestyle change. The second is the area of psychosocial problems post stroke. Both these areas may be addressed by a single intervention, and it is that potential intervention that is evaluated in detail in this thesis. Other problem areas such as functional recovery and interventions to affect this are set in context, but not specifically covered here.

Chapter One highlights the association in the literature between the well documented social and psychological consequences of stroke and longer term health outcomes for patients. We can see from the literature that there is a strong association between depression and worse outcomes in terms of rehabilitation, reduced cognitive functioning and increased mortality. In addition patients with poor social support or poor family functioning are recognised to have a longer length of hospital stay and poorer rehabilitation profile. Patients who have a poor understanding of their illness are less likely to comply with treatment advice or re-attend for further treatment. There is therefore a setting for evaluating an intervention that might seek to impact the emotional, informational and social needs of patients post stroke.

Chapter Two describes a randomised controlled trial of a Stroke Nurse Specialist intervention in a behaviour modification programme. This trial was intended to address the risk of Transient Ischaemic Attack (TIA) or Stroke recurrence by aiming to improve the information needs of post stroke and TIA patients, hoping to improve their compliance, lifestyle modification and ultimately risk factor

control. The primary outcome was the proportion of patients who achieved control of all their modifiable risk factors (e.g. smoking, hypertension, diabetes and hypercholesterolaemia) according to predetermined criteria. No significant difference was seen between the groups for the primary outcome (proportion achieving risk factor control: Experiment 46.4% Vs Control 41.7%, p=0.34). Differences were seen between the groups in the reduction in systolic blood pressure (Experiment -9.2mmHg, SD 23.3 Vs Control -1.0mmHg, SD 22.4, p=0.04). In addition patients in the experimental group were more likely to express satisfaction with aspects of liaison and information provision.

Chapter Three evaluates the effects of the short term behaviour modification intervention (detailed in Chapter Two) at over three years after initial enrolment. Rates of follow up of the initial cohort were lower than the initial study (50% compared to 94%). No significant difference exists at three years between the intervention and control groups for the primary outcome of risk factor control. Differences were observed between the groups for the rates of admission to nursing homes (Experiment 0 Vs Control 5, p=0.02), however the small size of this follow up sample limits the conclusions that can be drawn from this result.

Chapter Four attempts to set the randomised controlled trial evaluated in Chapters Two and Three in the context of other outpatient rehabilitation interventions and tries to establish if there is comparability between the interventions and even combinability for subsequent meta-analysis. This process identifies several core themes:

- Physical fitness training after stroke,
- Occupational therapy after stroke,
- Multidisciplinary rehabilitation post stroke,
- Information provision and education post stroke and
- Psychological and social support.

In addition, several trials targeting intervention aimed at carers only were identified.

Chapter Five describes a systematic review and meta-analysis of Stroke Liaison Worker trials – that is trials that evaluated a healthcare worker or volunteer who provided social support, information and liaison with the patient after discharge. This includes the trial described in Chapter Two. Individual patient data meta-analysis was conducted of 16 trials evaluating 18 interventions. Meta-analysis did not demonstrate any benefit of Stroke Liaison Workers compared to usual care for the primary outcomes of subjective health status or extended activities of daily living. In addition there was no benefit from Stroke Liaison Worker on the outcomes of death, institutionalisation, mental health or dependence. Patients were more satisfied that someone had really listened to them. Carers were more satisfied that they had received enough information about the causes of stroke, that they had enough information about recovery, that someone had really listened, and that they did not feel neglected. Subgroup analysis by patient dependence at recruitment revealed that patients with mild to moderate dependence had reduced dependence in the intervention group (OR 0.60, 0.44 – 0.83, p=0.002) as well as a reduction in death or dependence (OR 0.55, 0.39 – 0.78, p=0.0008).

In Chapter Six I was keen to evaluate whether the interventions in the literature and the framework for combining and evaluating them could be mapped onto existing services in Scotland. This was done through a questionnaire of the Scottish Stroke Nurses Forum. This identified 58 Stroke Liaison Workers from around Scotland who identified themselves as providing the services described using the review criteria in Chapter Five. These nurses identified that their commonest requests for help relate to psychological or emotional issues. 62% of respondents believed that their role was effective for all their patients.

In conclusion, Stroke Liaison Workers result in greater satisfaction with certain aspects of service provision but do not appear to result in changes to patient subjective health, extended ADL or carer subjective health. Subgroup analysis suggests that patients with mild to moderate dependence may benefit. Overall there does not appear to be evidence of effectiveness for this complex intervention when applied to all patients or carers.

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Acknowledgement

I would like to acknowledge my gratitude to my supervisor Professor Peter Langhorne for his untiring support. I am grateful for his patience and longsuffering counsel, over many years that began with advice for the Stroke Nurse Specialist (SNS) study. I am indebted to his hard work and sacrificial use of time. I am specifically grateful for his work in securing the Chest Heart and Stroke grant that enabled me to begin full time research. I am also grateful for his humour and his optimistic belief that I could do this.

My thanks also to Professor David Stott for his positive and enthusiastic support. I am grateful for his critical appraisal skills over the years as well as his guidance and support of my research intentions.

I am grateful to Dr Christine McAlpine without whose support I would never have been able to get the SNS study up and running and begin my fledgling research career. Her enthusiasm and trust enabled me enough flexibility to cope with the demands of running the project. I would also like to acknowledge Dr Sara Twaddle whose endorsement enabled me to apply for the Chief Scientist Office mini-grant that supported the SNS study.

Thanks, too, to Lynn Legg for her willingness in taking me on with the Stroke Therapy Evaluation Programme (STEP) team and supporting my research. Working with the STEP team developed my critical appraisal skills and my understanding of Cochrane methodology as well as the complexity of rehabilitation research. The Stroke Therapy Evaluation Programme are: Fiona Couper, Dr Alex Pollock, Lynn Legg, Professor Peter Langhorne and Dr Jonathan McCrea.

I would like to thank Brenda Thomas of the Cochrane Stroke Group for her help with the search strategy for the Meta-analysis.

I am grateful to the Stroke Liaison Workers collaboration who kindly shared their data and time to help answer a difficult and unique question. I am grateful for their patience and willing co-operation. The Stroke Liaison Workers Collaboration are: Han Boter, Martin Dennis, Anil Sharma, David Barer, Michael

Leathley, Caroline Watkins, Jonathan Mant, Anne Forster, Ivan Miller, Allan House, Chris Burton, Suzanne O'Rourke, Thomas Glass, Martha Fay, Kate Tilling, Nadina Lincoln, Judith Frayne, Gary Goldberg, Michael Clark, Thora Haffstainsdottir.

I am grateful to Dr Jonathan Mant for setting the scene with the original Cochrane protocol and his willingness to hand the project on to someone else, as well as his continued interest in the project.

I would like to thank Dr Julie McManus for resurrecting the TIA study nearly four years later and organising its re-evaluation, including the complex process of negotiating ethical approval.

I would like to thank Professor Lorraine Smith for her advice on the design of the questionnaires used in Chapter Six and feedback in relation to stroke nursing roles.

I would like to acknowledge U2, Keane and Coldplay, although I recognise they are unlikely to read this. Their work helped during the long hours of data analysis and literature searching.

Finally and perhaps most importantly I would like to thank my wife and best friend, Joyce for her patience and support. To Fraser and Scott – this dusty old book is the reason Dad was busy and occasionally grumpy. Thanks for letting me get on with it. Does it look worth it?

"It is the glory of God to conceal a matter; to search out a matter is the glory of kings" Proverbs 25:2

Author's Declaration

The work contained in this thesis was carried out at the Academic Section of Geriatric Medicine at the Royal Infirmary, Glasgow. I was supported by a grant from Chest Heart and Stroke Scotland. The trial work carried out in Chapter Two was supported by a grant from the Chief Scientists Office of the Scottish Executive Health Department (Reference CZG/4/2/49). Details of the collaborative contribution of colleagues are detailed below. The writing and illustration of this thesis is all my own work.

Chapter Two: The impact of Stroke Nurse Specialist Input on Risk Factor Modification: A Randomised Controlled Trial

I was responsible for the design of the TIA study, seeking ethics approval, seeking funding and trial co-ordination including supervision, recruitment, data analysis and writing up.

Chapter Three: 3 Years On: Does Behaviour Modification Affect Post Stroke Risk Factor Control?

Julie McManus was responsible for seeking ethics approval for the repeat study, organising follow-up visits and co-ordinating the trial running. I was responsible for advising on study design, database construction and data analysis in addition to writing up.

Chapter Four: Outpatient Rehabilitation Services After Stroke: A Descriptive Analysis of the Randomised Trials

Peter Langhorne was responsible for the original study design in 1999 including the co-ordination of the Collaborator's Meeting. I was responsible for re-running the search strategy, regrouping the trials and reanalysing the groupings.

Chapter Five: Meta-analysis of Stroke Liaison Worker Interventions for Patients and Carers

Jonathan Mant was responsible for the original protocol design which was subsequently modified by myself. I was responsible for the original literature search. Peter Langhorne assisted the author in trial selection and data extraction. I was responsible for contacting the authors, organising the Collaborators Meeting, data collection, data checking and analysis.

Chapter Six: Identifying Stroke Liaison Roles in Scotland

I was responsible for the original design of the questionnaires, data collection and analysis. Professor Lorraine Smith provided advice on questionnaire design.

Glossary and List of Common Abbreviations

AAP	Adelaide Activities Profile (a measure of extended activities of daily living)
ADL	Activities of daily living
Barthel	Barthel Scale of daily living index (a measure of dependence)
BDI	Beck Depression Inventory (a measure of depression)
BP	Blood Pressure
CABG	Coronary Artery Bypass Graft
CCTR	Cochrane Controlled Trials Register
CPD	Cigarettes per day
CSI	Carer Strain Index (a measure of carer subjective health status)
CVA	Cerebrovascular Accident
CES-D	Centre for Epidemiological Studies – Depression Score (a measure of depression)
COOP	Dartmouth Primary Care Co-operative Information Project Charts (a measure of subjective health)
EADL	Extended activities of daily living
EuroQOL	(a measure of subjective health)
FAC	Functional Ambulatory Categories (a measure of dependence)

FAI Frenchay Activities Index (a measure of extended activities of daily living)

FIM Functional Index Measure (a measure of dependence)

FSO Family Support Organiser

FSW Family Support Worker

GDS Geriatric Depression Scale (a measure of depression)

GHQ General Health Questionnaire (a measure of subjective health status). It has several forms including the shortened forms GHQ12, and GHQ28

HADS Hospital Anxiety and Depression scale (a measure of mental health including separate sections relating to depression and anxiety)

HbA1c Haemoglobin A1c

Hope and Acceptance Scale (a measure of mental health)

IADL Instrumental Activities of Daily Living (a measure of dependence)

LHS London Handicap Scale (a measure of dependence)

MRS Modified Rankin Scale (a measure of dependence)

McMaster Family Assessment Device Global Function Scale – Mastery Scale (a measure of social support and family functioning with separate sub-domains)

Medical Coping Modes (a measure of mental health)

Mental Adjustment to Stroke Scale (a measure of subjective mental health)

MI	Myocardial Infarction
mmHg	Millimetres of Mercury
MS	Multiple Sclerosis
NHP	Nottingham Health Profile (a measure of subjective health status)
Nottingham EADL	Nottingham Extended Activities of Daily Living Scale
OARS-SR	Older Americans Resources and Services – Social Resources (a measure of social support)
OARS-ADL	Older Americans Resources and Services – Activities of Daily Living (a measure of physical dependence)
OARS-Physical Health	Older Americans Resources and Services – Physical Health (a subjective measure of physical health)
OARS-Economic Resources	Older Americans Resources and Services – Economic Resources (a measure of economic strain)
OR	Odds Ratio
Pound Satisfaction Scale	A satisfaction questionnaire of stroke services

Questionnaire on Resources and Stress (a measure of subjective health)

QOL	Quality of Life
RBG	Random Blood Glucose
RCT	Randomised Controlled Trial
REI	Recovery Efficacy Index (a measure of subjective health)

Rivermead Mobility Index (a measure of mobility and dependence)

RNLI	Reintegration to Normal Living Index (a measure of subjective health)
RSS	Received Social Support (a measure of social support)
SCQ	Sense of Competence Questionnaire (a measure of subjective mental health)
SF36	Short Form 36 (a measure of subjective health status, including sub-domains for mental and physical health etc.)
SFSW	Stroke Family Support Worker
SLW	Stroke Liaison Worker
SMD	Standardised Mean Difference
SNS	Stroke Nurse Specialist
Social Functioning Examination (a measure of social support and social functioning)	
SSSL-D	Social Support List – Discrepancies (a measure of social support)
TIA	Transient Ischaemic Attack
WMD	Weighted Mean Difference

Chapter One:

Returning to the community

Introduction

Stroke is recognised as a global concern. Worldwide in 2005, the World Health Organisation estimated that stroke accounted for 5.7 million deaths (9.9% of all deaths)(1). It is also widely accepted that stroke is a major cause of disability and handicap, with an incidence in the United Kingdom of 3 to 5 per 1000 in people aged 45 to 84 (2).

There have been major developments in the field of stroke research over recent years with increasing numbers of randomised controlled trials registered with the Cochrane Controlled Trials Register (www.cochrane.org). In addition there has been an expansion in secondary research with greater numbers of Cochrane reviews published (3). This evidence has accumulated over time as research has continued to evaluate better ways to deliver therapy or services. Much of this research has had a focus on pharmacological interventions for stroke with the majority of randomised controlled trials on the Cochrane Controlled Trials Register evaluating pharmacological interventions. Additionally there has been a growth of evidence regarding inpatient interventions (such as organised stroke unit care) (4). In response to the growing evidence base for inpatient stroke interventions there have been the growth of guidelines (5-7) and the development of policy at national level (8) as well as declarations of stroke strategy at international level (9).

These developments are encouraging and should continue to improve outcomes for stroke patients and their families. Large areas of stroke care however lack a firm evidence base (10;11). In particular trials of rehabilitation and longer term community support remain an evolving area. In the absence of robust evidence from controlled clinical trials, recommendations regarding growing service developments are being made (12). The scale of post stroke problems and community support require that health care providers develop services and interventions to meet these needs. Much of this work may be based on presumed best care and remains unevaluated.

The majority of people survive their stroke, but a third to a half remain functionally dependent after one year (13;14). This is associated with significant psycho-social problems for both patients and their carers, which may also occur independent of physical disability (15-17). The burden of such problems may increase as a result of demographic change and reductions in age-specific stroke case fatality (18;19). Importantly, carers form a significant part of stroke patients support networks providing care (20). To date, little research appears to have addressed the needs of this significant group and the impact of interventions on carers remains unknown (21).

Living with Stroke

For many stroke patients, the real challenges and difficulties may only become apparent when they return to the community from a hospital after suffering a stroke. It is at this point that an individual's impaired activities become translated into reduced participation (handicap) and many limits to role related responsibilities are unearthed. For many patients, a stroke may have real financial, relationship, and mental health ramifications that become apparent on returning to the community, and are simply not addressed during inpatient rehabilitation. The prevalence of significant problems post stroke has been documented in the literature. Stroke may cause significant physical, emotional and social difficulties for both patients and their families for years after stroke (22;23). The prevalence of emotional difficulties post stroke has been estimated to be between 19 and 62% (24-26). Depression, for instance after stroke is frequent (27) as is social inactivity (28). Social isolation and impaired social interaction are estimated to be present for 18 - 46% of patients (23;28-30). Patients seek services and support from healthcare and social services, and this is cited as a concern for 13 - 77% of patients. For example transfer of care was identified as a problem in more than 33% of cases and in some contexts was as high as 100% (15;31-33).

Post stroke quality of life has been identified in one series as being strongly associated with perceived emotional support, depression and functional abilities (34). The same study found that family relationships were a main source of satisfaction with life.

Resources and Threats

The long-term outcome for stroke patients appears to depend on a recognised number of resources and threats. Patients with adequate resources appear to suffer fewer negative consequences of stroke, whilst real threats to a positive long-term outcome appear to be recognisable and quantifiable. These could broadly be described as being inversely related. When patient's resources are low, a correlation appears to exist with a poorer outcome. Several key areas of resource and threat appear to occur repeatedly in the stroke literature (See Figure 1.1).

Family and Social Support

Social support is a broad term that encompasses a wide range of relationships and social networks. It has been defined as:

> "The feeling of being loved and cared for, valued and esteemed, and able to count on others should the need arise" (35)

For the majority of stroke patients this might be seen as the key role that an immediate family network might provide. For patients without immediate family, the definition might appropriately be expanded to include a wider circle of relationships.

Stroke patients generally experience a decline in their social activity after stroke as well as a reduction in their social network (28).

A number of studies have sought to identify and quantify social support and its impact on stroke patients. These studies have then sought to correlate social support with defined outcomes.

Social support and poor outcomes

Social support has been found to be important in influencing healthcare outcomes (36). Patients with poor social support networks are said to have an increased mortality after both cardiovascular disease and malignancy or a worse

recovery from cardiovascular illness (37-39). Lower social support is also associated with poorer adjustment to illness or bereavement (40-42) and increased carer burden and depression (43).

Stroke can be considered as having a significant impact on existing social support networks. For a significant proportion of stroke patients who live at home with their families, stroke can have profound influences on families and carers (29) including impacts on emotional health (23), relationships and functioning (30;44).

In addition to this stroke patients with lower social support were found to have a slower recovery from stroke (45), and were more likely to experience a longer length of stay in hospital (46).

Studies have shown that families with poor family functioning were less likely to comply with treatment decisions and less able to help patients with rehabilitation efforts (47). Indeed family function in one series proved a better predictor of patient length of stay than many typical clinical predictors of stroke outcome (46).

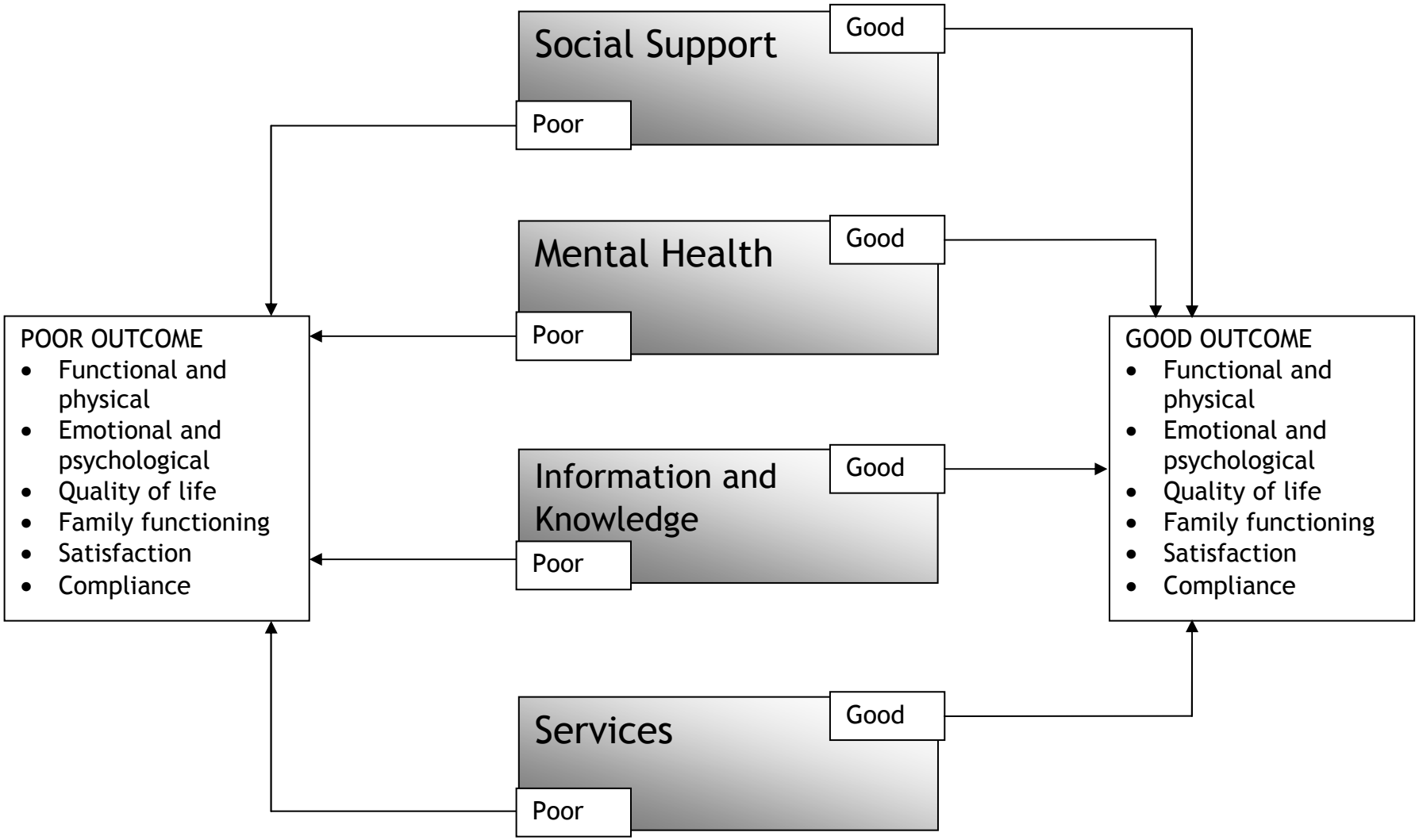


Figure 1.1: Resources and Threats: Hypothesis

Social support networks and good outcomes

Potential beneficial effects of social support have been observed in several studies and include a reduced risk of mortality (37;38;48-50). Beneficial effects have been observed on recovery from serious illness such as cardiovascular disease (51-54) including myocardial infarction (55-58) and optimising treatment outcomes in other chronic conditions such as arthritis (59;60) and cancer (61-63). In addition patients with good social support have been shown to have improved recovery from operations (64). They are said to have enhanced self-esteem and improved survival in some cancers (39) and in hospital contexts to show less distress than patients with lower social support levels (65). In a context of neurological rehabilitation and adjustment, spinal injury patients with higher reported levels of social support admitted to fewer medical problems and claimed to better adjusted to their spinal injury (42).

Carers themselves also appear to benefit from wide social support networks. Carers of Multiple Sclerosis (MS) patients with higher levels of social support reported lower levels of perceived caring burden (40). Carers of Alzheimer's disease patients with social support were less likely to have depression (43). More generally social support appears to mediate the effects of carer burden on caregiver's mental health (66).

The correlation between social support and poor outcome after stroke has been made in a number of population surveys. One survey of post stroke patients in China found that there was a positive correlation between strong social support networks and a patient's functional ability. The positive association of social support on mental health was non significant (67).

Others found that positive outcomes for functional status, depression and social status were significantly associated with higher levels of social support in the first six months of recovery after stroke (68). Only functional status alone was improved when adjustments were made for initial stroke severity and it was suggested that in severely impaired patients that high levels of family support are associated with progressive improvements in functional status early after stroke (68). This finding has been replicated elsewhere (45;69).

Social functioning appears to have been improved by social support in some studies. One randomised trial of specialist nurse support found that mildly disabled stroke patients had improved social functioning when compared to controls (70). Another found that social support was associated with improved relationships with professionals, and improved quality of community relationships early after stroke, although the effect was not sustained (71). Others have reported that social support mediates the impact of handicap over quality of life (72).

Family function may be improved on several domains by a combination of education and social work input for carers of stroke patients who also noted improved carer knowledge and patient adjustment compared to controls (73). Interventions targeted at carers have also shown improved carer confidence in knowledge, improved use of coping strategies and increased social support (74). Others have shown improved problem solving skills, reduced depression, and improvements in social functioning, mental health and reduced limitations due to emotional health (75). One study of a family support worker demonstrated reduced anxiety and hassles in the carers of stroke patients, and whilst not demonstrating a consistent effect for patients, showed improved satisfaction in both groups (76). These effects are echoed in another study of family support organisers that showed improved mental health, reduced pain, improved physical function, improved general health perception and quality of life as well as improved satisfaction for carers of stroke patients (32).

Mental Health

Estimates of the rates of depression after stroke vary and are reported to affect between 25 and 79% (24). Most would place the incidence at over 25% in the first year (25). Much of this variation may arise from differences in diagnostic classification; however, the prevalence of low mood seems well recognised.

Mental health and poor outcome

In an older population, depression and mental health problems have been reported to be associated with greater impairment of quality of life than many

chronic physical diseases (26). In older people depressive illness is associated with greater morbidity and dependency (77). This includes increased use of drugs and alcohol, greater use of healthcare resources and poorer compliance with treatment recommendations (77). The association between medical co-morbidity and depression suggests that medical co-morbidity may be more influential as a cause or factor in depression than social isolation itself (78).

In cardiovascular disease, depression post myocardial infarction (MI) is recognised as a cause of increased mortality, where in one study the risk was more than twice that of non-depressed patients (79). This increased risk has even been noted to exist for patients with mild depressive symptoms not traditionally thought to be at risk (80). Analysis of patterns of ischaemia in depressed patients has shown that patients with mild to moderate ischaemia exhibit an increase in ischaemic episodes both during mental stress testing and during normal life. This has been thought to be a potential explanation for the increased mortality in this group (81). An association has been found between depression and sedentary behaviour as well as smoking, though depression remained an independent predictor of mortality, incompletely explained by these risk factors (82). Depression also proves a reliable predictor of quality of life up to 12 months after a myocardial infarction (83) and may be a factor in compliance with cardiac rehabilitation (84)

Depression prior to surgery has been found to be associated with increased six-month morbidity in patients undergoing coronary artery bypass graft (CABG) surgery including re-hospitalisation, increased surgical pain and failure to return to normal activities (85). In a separate series depression predicted post operative angina recurrence (86). One study found that the presence and severity of depression was likely to independently influence the type of revascularisation procedure performed, with fewer depressed patients undergoing CABG (87).

There is still controversy in the literature as to whether post stroke depression is caused by the stroke lesion itself, or by the patient's psychological response to illness (88). Regardless of the causes of post-stroke depression, it is known that depression may impede rehabilitation (89;90), reduce physical and cognitive function (91) and create additional stress for carers (92).

A survey conducted among 51,119 US veterans with ischaemic stroke found the prevalence of depression to be 5% within three years. Other mental health diagnoses were equally prevalent at 4% within three years of stroke onset. Both post-stroke depression and other mental health diagnoses were associated with an increased mortality rate (OR 1.13, 95% CI 1.06-1.21) (93). This effect was independent of other chronic conditions. This increased mortality rate has been reported elsewhere in the literature (94) and is not fully explained by an increased risk of suicide (95).

Patients with mood disorders reported a reduction in the quantity and quality of relationships as a result of difficulties with personal and social adjustment (96;97).

Carers are also at high risk of mood disorders as a result of caring for patients after stroke, and as a consequence experience impaired social function (15;17).

Mental health and positive outcomes

From the correlation between poor mental health and poorer outcome it might be suggested that "good" mental health might offer a protective effect against these hazards. However a difficulty arises in the definition of "good" mental health. In simple terms, it might be defined as the absence of psychopathology. Viewed in this light "good" mental health could be said to be associated with improved morbidity, dependency and quality of life in older patients when compared to patients with poor mental health (24;77-81).

Some studies have shown that patients who remain depressed tend to remain physically disabled, whilst those whose depression improves demonstrate a reduction in disability (98;99).

Some have tried to define good mental health as the psychosocial resources of mastery, self-efficacy and social support, noting that these factors were responsible for a significant part in the buffering of psychological distress in response to chronic medical conditions (100).

Likewise for caregivers, psychological coping strategies have been identified as potential mediators of the impact of caring on caregiver mental health (66).

Using the criterion of good mental health as the inverse of poor mental health, it could be argued that good mental health status is associated with protection from poor cognitive function, improved physical recovery (91), improved rehabilitation (89;90), improved mortality (93) and improved quantity and quality of social relationships (96;97). However, more specifically, some have suggested that particular models of psychological resource (such as increased efficacy and control, enhanced problem solving and cohesive family systems) might have a beneficial effect on an individuals and a family's recovery from stroke (101). Proof of a causal effect however has not been demonstrated with these models of psychological theory.

Information and Knowledge

Providing information for patients and carers is considered a key part of services for patients and carers (12;102). Educational interventions in healthcare settings can be complex and need evaluated in carefully designed trials (103;104). There is complexity in translating change from education into outcomes and this complexity (as illustrated in Figure 1.2) may be the reason for the limited results of many patient education trials (105).

Poor information and outcomes

Patients with a poor understanding of their illness are less likely to express satisfaction with their health care, less likely to comply with treatment advice, less likely to re-attend for further treatment and less likely to improve (106).

One survey of stroke patients and carers found that over one third of patients and nearly two thirds of carers would have wished more information about the illness (107). A quarter of patients and nearly two thirds of patients and carers respectively had to ask for more information. The reasons patients and carers gave for being unable to get more information were the busyness of hospital staff, staff unavailability or lack of knowledge and the use of medical jargon that was too difficult to understand (108).

Patients whose caregivers had little knowledge of stroke were more likely to be at risk of sub-optimal home care (109). Likewise lack of knowledge or information about their condition are said to exacerbate patients' physical

limitations and emotional distress (110). This perceived lack of information following discharge was directly correlated with expressed dissatisfaction with care for both carers and patients (108). Patients living in the community also express dissatisfaction with the information they had received about stroke disease (33) and continued to have unanswered questions up to two years after stroke (111).

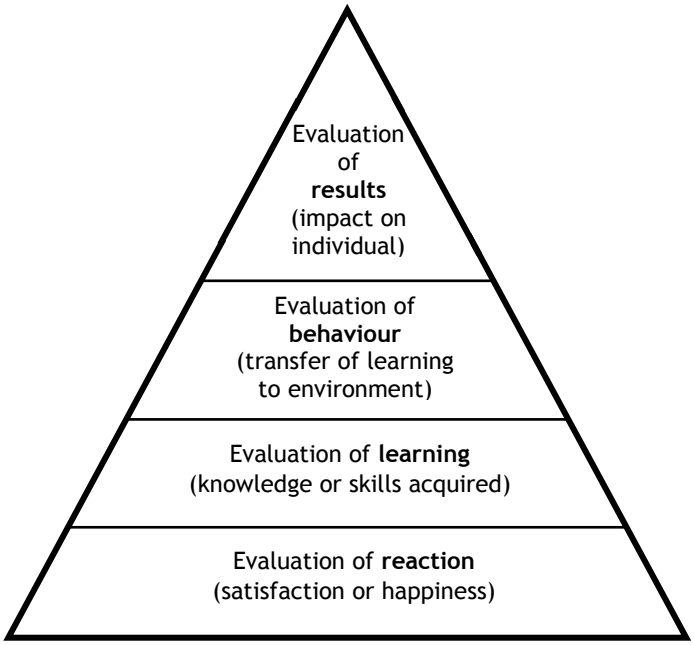


Figure 1.2: Hierarchy of Levels of Education

Adapted from Kirkpatrick (104;105). The complexity of evaluating an educational intervention on behavioural change can be seen in the assessment of that change – as you seek to ascend the outcomes of education, the number of potential confounders and the lack of reliable objective measures limit or reduce the power of the conclusions about the intervention.

Good information and outcomes

Educational programmes for children and adolescents with asthma have been shown to improve lung function, reduce absenteeism from school, and reduce visits to accident and emergency departments (112).

Some nurse led interventions have been shown to be helpful in improving health related behaviour in individuals at high risk of coronary heart disease, including improved dietary intake, increased exercise, reduced smoking and temporary improvements in systolic blood pressure (113). In patients with coronary heart disease, educational interventions have shown improved diet, exercise prophylactic drug use and health status (114). Five-year follow up of this cohort even suggested a non-significant reduction in mortality in the intervention group (115;116). Others have shown additional benefits on health status, reduced role limitations from physical problems, and reduced worsening of chest pain and fewer hospital admissions (117). A review of disease management programmes for coronary heart disease that have included patient education and risk factor management showed non-significant reductions in mortality and recurrent myocardial infarction, whilst showing significant improvements in drug use and hospitalisations (118).

More generally, advice on dietary salt intake has been shown to enable hypertensive patients to maintain a lower blood pressure after the withdrawal of antihypertensive therapy and reduce the long term risk of cardiovascular disease (119;120). Additionally advice on the reduction of dietary fat when maintained for two years, showed potential benefits in reduction in mortality and cardiovascular events (121).

Outwith vascular disease, training Multiple Sclerosis (MS) sufferers in coping skills has been shown to improve their methods of coping, overall satisfaction, and satisfaction with family and socio-economic status (122).

Good knowledge of stroke by stroke carers may improve the quality of discharge home from hospital (109). Patients and carers who feel they have received adequate information are apt to feel more satisfied with the quality of their care – especially the information provision aspects of it (32;76;123;124)

Services

The interface between informal support in the community (carers and family) and formal community support (community care) becomes key to the support of many patients with chronic conditions. Community services can be defined as assistance with care-giving tasks, in-home assistance, and adult day care, Meals – on-Wheels and support groups as well as benefits and financial support (125).

In one qualitative study, comparison was made between health service provision and community or social care provision. Many older patients identified that although a contact point was more readily identifiable for healthcare, users were more likely to take an active role in accessing and choosing social services than healthcare (126). This was often despite an apparent lack of necessary healthcare provision. Similarly in another study, elderly patients on discharge were more than twice as likely to access community home care or nursing care than they were to visit their General Practitioner (127). Elderly patients appeared to value social services and to consider them more accessible than healthcare.

Poor access to resources and outcomes

A survey of carers of elderly or minority group patients have shown that 51-67% of caregivers were in need of one or more community service (including financial needs), and that being in need, they were deemed at risk whilst providing care giving services themselves (128). The lack of choice, access and at-risk status of those who needed social welfare but could not obtain it has also been identified in the qualitative literature (126).

In a stroke context, poor knowledge of stroke services and benefits is noted to be associated with emotional problems and increased physical limitations (129). Patients in the community have expressed dissatisfaction with the level of information they have received about stroke services and information regarding benefits (15;32;33).

Good access to resources and outcomes

Caregivers of Alzheimer's patients in a qualitative study identified that community services were associated with the benefits of renewal, increased

knowledge and a sense of community (125). In addition they perceive their relative (the patient) to benefit. Older patients in particular appear to value social service support and are more likely to express satisfaction with social services than with primary health care (130).

There is an increasing body of evidence on the effectiveness of outpatient therapy post-stroke and services available to community dwelling stroke survivors. Therapy based outpatient services for instance have been shown to reduce deterioration and improve the function of activities of daily living (131). Physical fitness training after stroke has been described as increasing strength and cardiovascular fitness after stroke (132), and information provision and education may benefit both patients and carers (133). In addition to medical and therapy based services, a growing range of locality based social services and financial support are available for patients and carers (134).

Carers

A Carer has been defined as:

> "the person, other than a healthcare professional, perceived by the patient or family as normally being most responsible for day-to-day decision making and care (32)."

Definitions of carers in the literature for older patients, not surprisingly is very similar and equally broad:

> "family caregivers are relatives or friends of an older person who provide, arrange or oversee services that the older person needs because of functional disabilities or health needs (135)."

Definitions of carers are therefore context specific and not permanent and are defined by relationship to the patient.

Approximately 5.2 million people in the UK are estimated to be providing informal care in England and Wales according to the 2001 Census (136). Informal carers provided care that, if costed, would cost the government millions of pounds each year. At any one time 0.5% of the UK population are disabled stroke survivors who are dependent on the help of a carer to perform community

activities, domestic activities or personal activities of daily living (137). Carers therefore form an integral part of a patient's support network and may significantly impact the welfare of patients, but form a vulnerable population in their own right.

Carers' needs

A review of the literature suggests that carers have perceived needs that are independent of a patient's needs and yet are related to their ability to care for the patient. Carers consistently describe needs for information (111;128;138-141) and they may seek means to acquire that information if it is not provided (139). Information was found in one series to be protective against poor carer outcome (141). Additionally caregiver training has been suggested to independently predict a positive outcome for carers at 3 months (140). Social support for carers independent of patients has been identified as important and in one series, social support for a carer was associated with improved caregiver life satisfaction (142). Caregivers also describe needs for support from community services and in one series between 52 and 67% of clearly identified needs were not being met (128).

Risks for Carers

Depression is noted to be frequent in carers when compared to matched controls (143) with an estimated frequency of anywhere between 34 and 52% (144). A number of observational studies have tried to establish risk factors for depression or other markers of poor outcome in carers. Consistently identified factors across many studies appear to be patient dependence (15;92;140;144;145), cognitive impairment (92;144;146;147), behaviour problems in the patient (92;144;147) and emotional problems in the patient such as depression (15;25;144;147).

Outcomes for Vulnerable Carers

Carers who are depressed represent a concern not only in terms of their own health risk, but also in their ability to care for a dependent friend or relative. Depressed carers have been shown to provide poorer standards of caring and, are less able to help the patient in rehabilitation (148). In addition, in a cohort of carers followed for four years, caregivers who registered increased levels of carer strain had a 63% higher mortality rate than comparable non-caregivers (RR

1.63, 95% CI 1.0 to 2.65). Carers who did not show signs of caregiver strain had no significant increase in mortality (149).

Protective Resources for Carers

In addition to identifying the risk for carers, a number of studies have identified potential protective elements that might be exploited in intervention studies. One study identified that carers with a higher perceived self efficacy and greater satisfaction with social support, experienced less strain and better mental health (147). Another reported that carer training was associated with a positive carer outcome at 3 months post stroke (140). Others noted that a carers ability to cope was enhanced by information as well as positive coping strategies (141).

Interventions for Carers

These positive associations which suggest a protective effect should offer real hope of the development of an intervention to improve outcomes for this vulnerable population. A number of different types of interventions have been developed and evaluated in trials. These types of intervention have included education and information provision in the form of written or electronic materials (150;151), group educational classes (74;152-155), counselling (73;156-158), practical caregiver training (21) and liaison (32;70;123). In Chapter Four I will examine where the emerging randomised controlled trials for carers sit within the wider context of community stroke rehabilitation trials. The interventions that involve liaison, information provision and social support for patients and carers in combination are evaluated in a meta-analysis of Stroke Liaison Worker trials in Chapter Five.

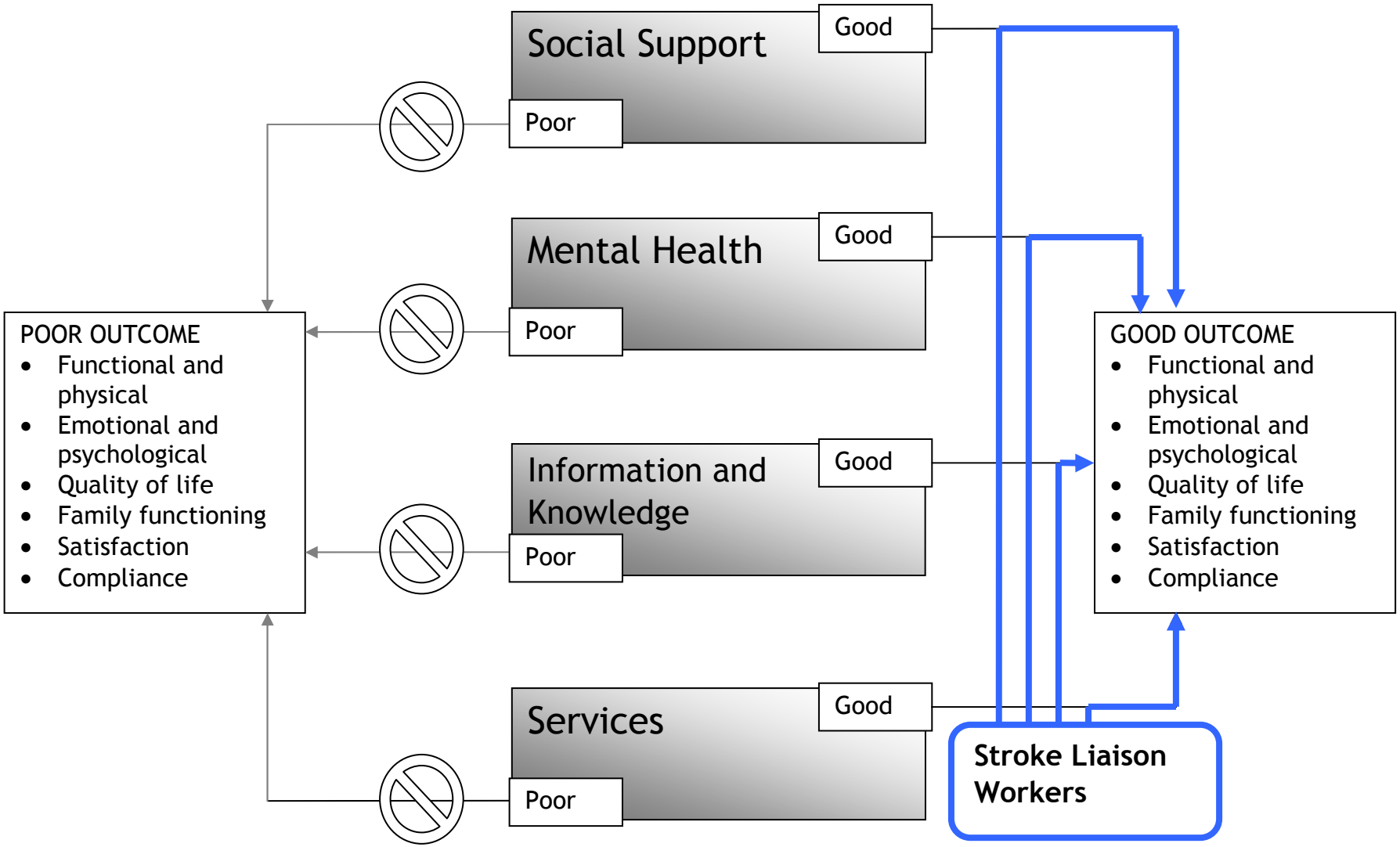


Figure 1.3: Resources and Threats: Roles for a Stroke Liaison Worker

From association to intervention

(See Figure 1.3)

No matter how strong an association may appear between risk and outcome, any intervention (even ones that perfectly mirror favourable and protective elements in the natural world) must be evaluated in appropriately conducted randomised controlled trials to ascertain their effectiveness. Trials evaluating therapy based on social interventions face a number of potential limitations that can introduce the risk of bias. These can include selection bias, where the patient or carer group recruited does not reflect a generalisable population or recruits subjects whose motivation or incentives may be related to personality or other factors that will influence the outcomes. In addition, therapy trials are at risk of performance bias where interventions are not standardised or consistently delivered. Ideally these trials need to be appropriately blinded, particularly where the intervention is complex and the outcome measures may be open to bias. Blinding complex interventions involving health care personnel is potentially difficult (159) but blinding of outcome assessment is usually possible. The assessment of these potential interventions will be developed in depth in subsequent chapters in this thesis.

Chapter Two:

The Impact of Stroke Nurse Specialist Input on Risk Factor Modification: A Randomised Controlled Trial

Introduction

One of the consistent challenges facing stroke services is in the provision of appropriate education and support for stroke patients and their carers (107;108;110;160;161). Research has sought to establish the effectiveness of various educational interventions on different aspects of patient's and carer's health and well being (162;163). Trials looking at the impact of specific education interventions on patients and caregivers knowledge about stroke have demonstrated an improved level of knowledge (164;165). However most have failed to show an impact on emotional outcomes (164;166-168), perceived health status (164-166;169), physical function (164;168) or health behaviour (165). Some trials have observed improvements in family functioning (164), pain, physical function, mental health (170) and satisfaction with information received (164;167), although this was not universal.

We know that interventions with an educational or counselling component can be effective to encourage smoking cessation (171-174), lower blood pressure (175-177), achieve modest reductions in cholesterol (178;179), and promote weight loss (180). Educational interventions in a cardiac patient population have demonstrated a measurable impact on blood pressure, exercise, diet and mortality (181). Despite evidence that inadequate provision of information has adverse consequences on compliance with secondary prevention and psychosocial outcomes (160), evaluation of the impact of education on physical outcomes is lacking in stroke disease.

We describe a single blind randomised controlled trial of a nurse providing health education and counselling for patients with stroke or transient ischaemic attack (TIA), and its effects on risk factors, satisfaction, mood and perceived health status.

Subjects and Methods

Pilot work and statistical power

We undertook an initial survey of the case-notes of 51 consecutive patients attending our stroke and TIA clinic. We focussed on the more easily measurable, significant modifiable risk factors (blood pressure, smoking, cholesterol and diabetes). The average number of risk factors per patient was three. Of these patients, only 20% had achieved complete risk factor control by the time of discharge from secondary care. We defined risk factor control as risk factor results that fell within the recommended treatment range according to the contemporary national and local treatment guidelines (Table 2.1). We estimated we would need to recruit 89 patients per group to show an increase in the proportion of patients whose risk factors were "on target" from 25% to 50% with 80% power at the 5% significance level. The control group rate of 25% is supported by our pilot work and on other trial data (170;179;182;183).

We then conducted a Randomised Controlled Trial to assess the impact of a nurse specialist led, health education intervention. Our primary outcome was an increase in collective risk factor control (or the proportion of patients with all their risk factors controlled). Secondary outcomes were improvement in individual risk factors, clinical outcomes (death, further cerebrovascular or other vascular events, hospitalisation), perceived health status (184), Geriatric Depression scores (185;186) and satisfaction scores using previously validated stroke service questionnaires (187). Local ethical approval was obtained for the study.

Inclusion and exclusion criteria

All patients with a diagnosis of TIA or stroke, cerebrovascular disease or amaurosis fugax, with any major modifiable risk factor, (blood pressure, smoking, cholesterol, and diabetes) were eligible. Patients with cognitive impairment (defined as an Abbreviated Mental Test score <5) were excluded (188). Patients with communication difficulties were not excluded unless, in the opinion of a Speech and Language Therapist they were felt unable to comprehend the information given or effectively consent to involvement.

Randomisation

Patients were enrolled following the completion of their standard investigations and treatment. After giving informed consent, randomisation was performed by opening a sequentially numbered opaque envelope available within the clinic. These were generated by the use of computer generated random numbers in repeating blocks of six, organised by someone uninvolved in the study. Baseline characteristics demonstrate the similarity of the two groups at randomisation (Table 2.2).

Study participants

208 patients were recruited at their final visit to the stroke clinic or geriatric medical day hospital. Details of the patient recruitment are illustrated in Figure 2.1. Three patients were entered twice in error, both times to the treatment group. These subjects were analysed on their initial data only and subsequent data were excluded from the analysis. One patient in the control group was later found to be ineligible based on information unavailable at the time of enrolment. For the purposes of assessment and data analysis, this patient has been included on an intention to treat basis. The diagnostic classifications of both groups are illustrated in Table 2.2.

Intervention

Patients randomised to control services received usual care, which included generic risk factor advice from medical staff as well as the Stroke Nurse Specialist (SNS). Treatment group patients were reviewed at monthly intervals by the SNS for additional input, which encouraged empowerment with behaviour modification and treatment compliance. These reviews were conducted within the hospital premises as an outpatient consultation; patients were interviewed and given individual counselling on lifestyle changes and the importance of secondary prevention. Additional open questions gave patients the opportunity to bring up other subjects as the patient felt appropriate. The average consultation length was approximately 30 minutes. Patients received on average three counselling sessions with the SNS. All verbal information was backed up by written information that was selected by the SNS as relevant to the individual patient. Personalised patient held records were also given to patients, detailing their risk factors, and the recommended risk factor targets. This record was

updated at each visit, and was considered a key part of the intervention. The SNS did not routinely attempt to contact the patient's GP or hospital specialist in order to influence prescribing. Where a risk factor (e.g. blood pressure) was deemed to be at unacceptable levels, patients were encouraged to consult their GPs with that information. General Practitioners of both treatment and control group patients were informed of the study by letter, and of the form of intervention. At the end of the study, a letter summarising the patient's risk factors as well as our recommended risk factor targets was sent to the GPs of all the patients (treatment and control groups).

Follow up and / outcome measures

All patients were followed up at completion of the study on average 5.3 (SD 1.5) months after enrolment by a researcher blinded to the patients' randomisation category. Assessments included the EuroQOL (184) perceived health status questionnaire, Geriatric Depression Score (185;186) and a validated stroke services satisfaction questionnaire (187). Three patients who were enrolled twice in error were not reviewed after the second enrolment.

Analysis

Data were entered by the principal investigator and analysed using SPSS for Windows version 10.0. Continuous homogeneous variable data were analysed using independent T-tests. Where normality tests were not satisfied, data were analysed using and Mann-Whitney U/Wilcoxon Sum Rank test non-parametric methods. Categorical data were analysed using the $\chi 2$ test. Analysis of covariance with a general linear model (Ancova) was applied where necessary to adjust for differences in baseline variables.

Results

Primary analysis

Cumulative risk factor control was defined as the number of patients whose major, modifiable risk factors were within national or local guidelines. The number of controlled risk factors per patient is illustrated in Table 2.3. Analysis

by $\chi 2$ and Mann-Whitney U non-parametric testing failed to demonstrate a statistically significant difference between the two groups. (Percentage controlled 46 %, 95% CI 39 – 54 Vs 42 %, 95% CI 35 – 49, p= 0.36). (Tables 2.3 and 2.4)

Secondary Analysis – Individual Risk Factor Control and Clinical Outcomes

The initial (planned) analysis of individual risk factors appeared to demonstrate a statistically significant reduction in systolic blood pressure in the treatment group compared to control (-9.2mmHg, 95% CI -15.0 to -3.5 Vs -1.0mmHg, 95% CI -6.3 to 4.3, p=0.04). However the experimental group appeared to have higher baseline systolic blood pressures (156.2mmHg, 95% CI 150.7 – 161.7 vs. 151mmHg, 95% CI 146.0 to 156.3, p=0.19), and achieved only marginally lower mean systolic blood pressures at follow up than the control group (148.0mmHg, 95% CI 142.0 to 154.0 vs. 150mmHg, 95% CI 144.5 to 155.6, p=0.62). The possibility exists that this result reflects regression to the mean. Analysis using a general linear model (Ancova) to adjust for baseline BP did not suggest that the result could be fully explained by regression to the mean. However analysis with adjustment for baseline BP indicated that the difference between groups in systolic blood pressure drop was less marked (-7.8mmHg, 95% CI -13.1 to -2.6 Vs -2.2mmHg -7.1 to 2.7, p=0.13).

Changes in diastolic blood pressure (-2.1mmHg, 95% CI -5.7 to 1.5 Vs -1.2mmHg, 95% CI -4.5 to 4.5, p= 0.71), reported smoking number (-1.6 cigarettes per day, 95% CI -5.1 to 1.8 Vs -0.4cpd, 95% CI -3.7 to 2.8, p= 0.61), serum cholesterol (-0.96mmol/L, 95% CI -1.2 to 0.7 Vs -0.87mmol/L 95% CI -0.9 to 1.1, p=0.63), random blood glucose (+0.92mmol/L, 95% CI -1.9 to 3.7 Vs +0.89mmol/L, 95% CI -1.8 to 3.6, p= 0.99) and HbA1c (-0.25%, 95% CI Vs -0.78 ± 2, p=0.20) did not reach statistical significance.

Other clinical outcomes

Analysis of clinical outcomes between the groups did not demonstrate any significant difference in clinical events not leading to admission (P=0.28) or admissions (P=0.56). There were no deaths in either group during the time-course of the trial.

Medication score

Patients were asked to recall their current medications. This list was compared to a General Practitioners record of the patients prescribing at the time of review. A medication score was given as a percentage correct recall of relevant secondary prevention medication. There was non-significant difference noted between the two groups (Intervention 71% correct, 95% CI 62 to 80 Vs Control 79% correct, 95% CI 70 to 88, p=0.24).

Perceived Health Status (EuroQOL)

Patients were asked to rate their perceived health status (EuroQOL) at baseline and at follow up. There was no significant difference between the groups at baseline or follow up when analysed using a χ^2 test for the separate health categories (mobility, self care, usual activities, pain or anxiety and depression). Comparison of perceived health scale (percentage) by independent T-test showed a non-significant increase in the treatment group in the EuroQOL visual analogue scale (3.5% increase, 95% CI -0.9 to 7.9 Vs 1% increase, 95% CI -3.3 to 5.3, P=0.43).

Depression score (Geriatric Depression Score)

There was no statistically significant difference between the groups in the Geriatric Depression Scale (4.26, 95% CI 3.56 to 4.95 *Vs* 5.06, 95% CI 4.38 to 5.73, P=0.11). When predefined cut-offs are used, there were no differences in those with a "probable" diagnosis of depression (GDS > 5) between the groups (30 Vs 37, p=0.43) or those with a diagnosis of "definite" depression (GDS >10) (5 Vs 10, p=0.29).

Stroke services satisfaction questionnaire

Patients were asked to complete a stroke service satisfaction questionnaire at follow up. There were significant differences between the groups for several of the categories (Table 2.5). Patients in the treatment group were more likely to express satisfaction that they had been able to talk to someone (p=0.03), and that they knew who to contact if required (p=0.03). They also expressed greater satisfaction with the information they had received, both about the causes of stroke (p=0.02) and about their risk factors (p=0.01).

Discussion

Studies examining healthcare workers who typically provide education, liaison and social support (these studies are described in more detail in Chapter 5 under the umbrella title of Stroke Liaison Worker) have varied in their target population, interventions and outcome measures. Most have assessed the impact of educational or counselling based interventions on functional, emotional and educational outcomes (164;166;167;189). These studies have tended not to look at the physical outcomes of health education interventions (162;165), or have shown disappointing outcomes with respect to risk factor modification (190).

The intervention in this randomised controlled trial appeared to be well tolerated, with drop out rates in the treatment group being very similar to the control group.

Overall there was no significant difference between the groups in terms of the proportion of patients who had achieved 100% control of their risk factors. There was a very small and non-significant difference between the groups that favoured the intervention group. The reason for the lack of a more significant result may reflect a type II statistical error, which would be most likely to be due to under-powering.

The unexpected improvement in risk factor control in the control group is surprising when compared to previous studies which gave a more disappointing picture of risk factor control (191).

It may be that part of the reason for improvement in the control group may be due to a smaller number of risk factors in the series than in the pilot survey. It may be easier to gain 100% control of all of a patient's risk factors if they only have one or two risk factors to control (compared to three or four). In addition, hypercholesterolaemia was the most frequent risk factor in both groups. It is ordinarily amenable to statin therapy in contrast to other drug therapy, lifestyle or dietary modification which were the mainstay of treatment in much of the comparable literature.

There was a non-significant trend to improvement in systolic blood pressure in the intervention group, when adjusted for baseline systolic blood pressure. It might be postulated that a reduction as early as three months may reflect improved concordance in addition to lifestyle and dietary changes since it is well established that patients with chronic conditions (such as hypertension) may take as little as half of their prescribed medication (192).

Studies show that many people with stroke are dissatisfied with the content and quality of information given to them (160). Patients who feel inadequately informed seem to be less satisfied with the care they have received, less compliant with medical advice and suffer poorer outcomes (193;194). Improving patient's satisfaction with the level of information they have received and the level of health professional contact may be key to addressing these problems. Patients in the intervention group were statistically more likely to express satisfaction that they had been able to talk to someone about the problems they were having and that they knew who to contact should they have further problems relating to their stroke or TIA. In terms of the information patients received, patients in the intervention group were more satisfied with the amount of information they had received about the causes and nature of their illness and about their risk factors. These findings are not surprising given the nature of the intervention, and reflect other trial evidence (164;167).

In conclusion, nurse specialist led education with tailored risk factor advice and patient held documentation was well tolerated. This form of intervention did not result in significant improvements in risk factor control, and this may reflect under powering. Patients in the intervention group were more satisfied with the amount of information they received, and expressed satisfaction that they felt they had someone that they could contact with regard to their stroke disease. Further research in this area is warranted since optimisation of risk factors is vital for long-term health outcomes.

Figure 2.1: Trial Profile

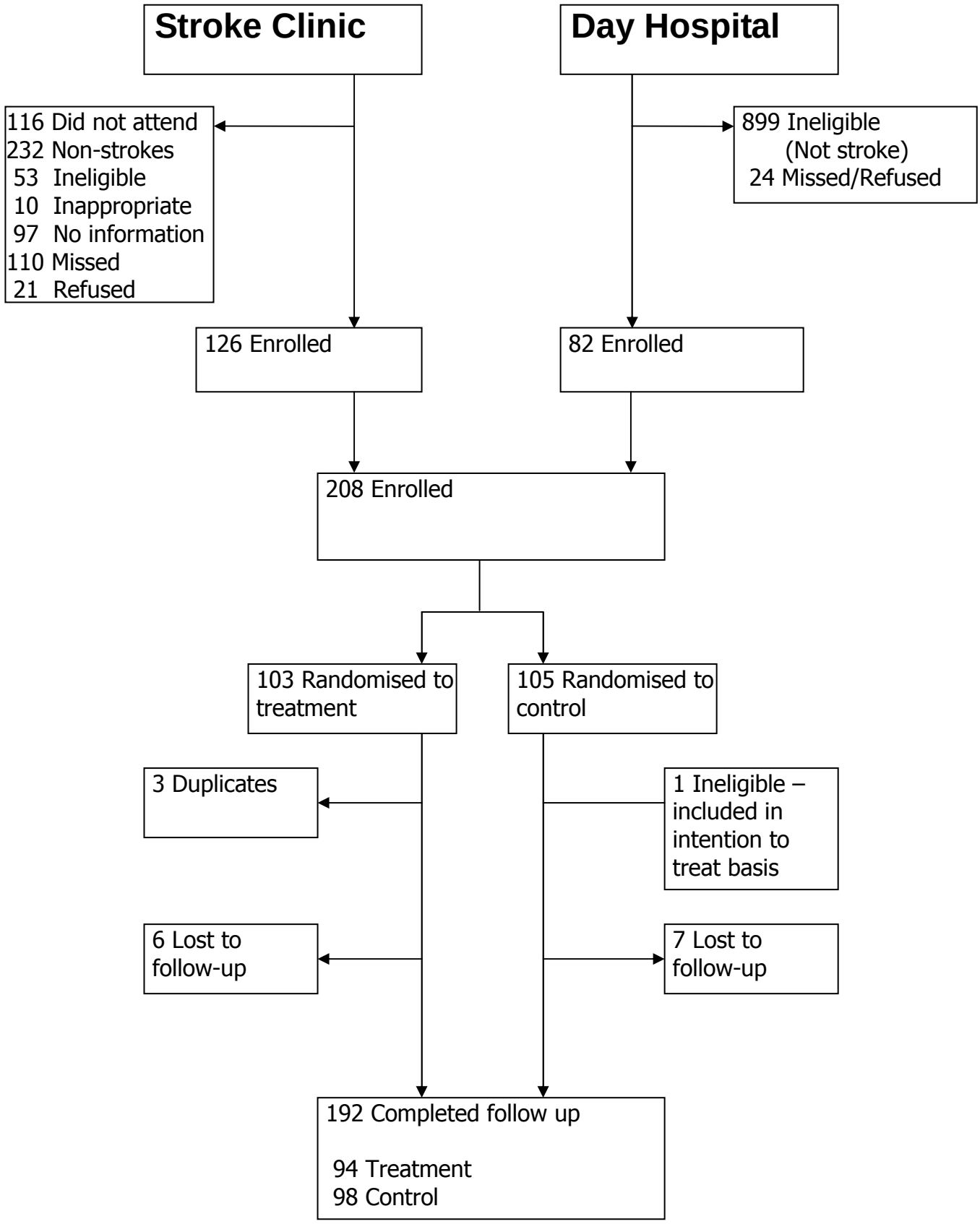


Table 2.1: Modifiable Risk Factor Targets

Risk Factor	*Target*	*Guideline*
Blood Pressure	<140/85	National*
Smoking	Complete Cessation	National†
Cholesterol	<5.0	Local
Diabetes	Random Glucose <8 HbA1c <7.5	Local

*British Hypertension Society Guidelines 1999 (195)
†Scottish Intercollegiate Guidelines Network 1997 (196)

Table 2.2: Summary of Baseline Characteristics

		Experiment	*Control*	p *Value*
		% (n=100)	% (n=105)	
Mean age		64	66	0.25
Sex (Male)		54 (54)	49.5 (52)	0.68
Diagnosis				
Transient Ischaemic Attack		29.0 (29)	25.7 (27)	0.18
Stroke		61.0 (61)	64.8 (68)	0.18
Cerebrovascular Disease		2.0 (2)	3.8 (4)	0.16
Amaurosis Fugax		4.0 (4)	3.8 (4)	0.21
Transient Global Amnesia		2.0 (2)	0.0 (0)	0.13
Retinal Artery Occlusion (embolic)		2.0 (2)	1.9 (2)	0.36
Modifiable Risk Factors				
Smoker		36.0 (36)	40.0 (42)	0.55
Number of Cigarettes per day		13	13	0.99
Hypertensive		66.0 (66)	73.3 (77)	0.26
Systolic BP (mmHg)		156.2	151.1	0.19
Diastolic BP (mmHg)		83.4	80.0	0.18
Diabetic		25.0 (25)	24.8 (26)	0.97
Random Blood Glucose (mmol/L)		10.73	9.94	0.57
HbA1C (%)		7.54	7.89	0.58
Hypercholesterolaemia		79.0 (79)	75.2 (79)	0.52
Total Cholesterol (mmol/L)		5.8	5.7	0.66
Other Risk Factors				
Previous TIA		18.0 (18)	10.5 (11)	0.12
Previous stroke		12.0 (12)	21.9 (23)	0.06
Atrial Fibrillation		2.0 (2)	3.8 (4)	0.45
Number of Modifiable Risk Factors	1	22.0 (22)	24.8 (26)	0.64
	2	49.0 (49)	40.0 (42)	0.20
	3	29.0 (29)	32.4 (34)	0.60
	4	0.0 (0)	2.9 (3)	0.09

For categorical variables, the Chi^2 statistic has been used.
For continuous variables the Student's t-test has been used.

Table 2.3: Number of Controlled Risk Factors at Follow up

	Experiment (n=94)	*Control* (n=98)	*p Value*
	% (n)	% (n)	
None	28.7 (27)	31.6 (31)	0.79
1	46.8 (44)	46.9 (46)	0.98
2	20.2 (19)	20.4 (20)	0.97
3	4.3 (4)	1.0 (1)	0.16
4	0.0 (0)	0.0 (0)	
"All relevant risk factors controlled"	46.4 (95% CI 39.1 – 53.7)	41.7 (95% CI 34.7 – 48.7)	0.34

For categorical variables, the Chi^2 statistic has been used.
The number of risk factors controlled within the study population expressed as numbers of risk factors that fall within the guidelines laid out in Table 1.

Table 2.4: Secondary Outcome Measures including Change in Individual Risk Factors

Variable		Experiment	Control	Student's t-test
Blood Pressure control				
Systolic BP	(mmHg)	-9.2 (SD 23.3, n=64)	-1.0 (SD 22.4, n=72)	P=0.04*
Diastolic BP	(mmHg)	-2.1 (SD 15.1, n=64)	-1.2 (SD 13.8, n=72)	P=0.71
Diabetic control				
RBG	(mmol/L)	0.9 (SD 5.7, n=23)	0.9 (SD 7.4, n=24)	P=0.99
HbA1c	(%)	-0.3 (SD 0.7, n=17)	-0.8 (SD 1.5, n=17)	p=0.20
Cholesterol	(mmol/L)	-1.0 (SD 1.1, n=75)	-0.9 (SD 1.2, n=73)	p=0.63
Smoking No	(cpd)	-1.6 (SD 11.5, n=33)	1.1 (SD 8.1, n=37)	P=0.56
EuroQOL*	(%)	3.5 (SD 20.9, n=94)	1.0 (SD 22.4, n=97)	p=0.43

*Bonferroni correction for multiple comparisons; p=0.28

Table 2.5: Satisfaction with Stroke Services

Question	**Experiment**	**Control**	**Pearson Chi-Square**
	Strongly Agree %(n=94)	Strongly Agree %(n=98)	
I have been treated with kindness and respect by staff at the hospital.	84% (79)	78% (76)	P=0.252
The staff attended well to my needs when I was at the hospital.	78% (73)	75% (73)	P=0.255
I was able to talk to the staff about any problems I might have had.	75% (70)	57% (56)	P=0.027
I have received all the information I want about the causes and nature of my illness.	70% (66)	51% (50)	P=0.022
The doctors have done everything they can to make me well again.	76% (71)	66% (65)	P=0.360
I am satisfied with the outpatient services provided by the hospital.	75% (70)	65% (64)	P=0.080
I have received enough information about my risk factors for stroke.	71% (67)	54% (53)	P=0.010
Somebody has really listened and understood my needs and problems since I attended the hospital.	68% (64)	60% (59)	P=0.212
I am satisfied with the amount of contact I have had with the hospital since I have attended.	73% (69)	62% (61)	P=0.166
I have had enough emotional support since I attended the hospital.	60% (56)	48% (47)	P=0.233
I know whom to contact if I have problems relating to my TIA/stroke.	71% (67)	52% (51)	P=0.034
I am happy with the amount of recovery I have made.	59% (55)	55% (54)	P=0.928
I was given all the information I needed about the allowances or services I might need.	53% (50)	44% (43)	P=0.436

Satisfaction expressed as the percentage that strongly agree with the statements.

Chapter Three:

3 Years On: Does Behaviour Modification Affect Post Stroke Risk Factor Control?

Introduction

Stroke recurrence is well documented and studies have suggested that rates are higher than was initially expected; a 5 year recurrence rate of up to 16% has been quoted (197). As we have examined in Chapter Two, significant progress has been made in secondary prevention (198-201), however, evidence is lacking with regards to the best methods to promote medication adherence and modify health behaviour (202;203). This is despite considerable evidence accumulating in cardiovascular disease regarding both behaviour modification (114;115;204-208) and multiple simultaneous risk factor interventions (208). In addition little is known about persistence with secondary prevention measures in stroke or TIA patients. It is reasonable to assume that compliance in the "real world" might not reflect that recorded in randomised controlled trials (203).

We describe a three year follow up study of a short term intervention (outlined in Chapter Two) to promote behaviour modification and encourage medication concordance.

The original randomised controlled trial evaluated the impact of a three month nurse-led behaviour modification program that included counselling on lifestyle, risk factors and medication concordance post stroke or TIA (209). Patients were randomised to the intervention for three months, or usual care. Those in the intervention group were given counselling and written information regarding their individual risk factors, risk factor targets and medication. Despite not achieving a global improvement in risk factors, there was a statistically significant reduction seen in systolic blood pressure at follow up. Patients were significantly more satisfied with stroke services – specifically about information. We sought to establish if these benefits were maintained in the longer term.

Methods

All contacts from the original study (n=205) were reviewed and cross checked with hospital records to exclude those who had died in the interim. In addition, General Practitioners were contacted to confirm a patient's status. All living contacts were then sent a letter inviting them to participate in a follow up program. General Practitioners were also informed of the study. The letter to patients was followed two weeks later by a telephone call to invite them to participate, and making an appointment at the day hospital facility. Where this was not practical, a home visit was arranged. Where patients did not attend, they were contacted a second time by telephone to offer them one further appointment.

We sought to contact, where possible, every member of the original cohort and to avoid loss to follow up. Where patients did not respond to the letter and could not be contacted by telephone, General Practitioners were contacted to determine if the patient had died or moved and for details of forwarding addresses where available. Residents of Nursing Homes were not contacted. No residents of nursing homes were recruited to the original study.

On attendance, the purpose of the study was explained and written consent was obtained. Assessment reviews were conducted by three researchers blinded to the original patient allocation. Details of patient randomisation from the original study were held on a database that was not accessed until all patient reviews had been completed.

Details of the four main modifiable risk factors were documented. Blood pressure was recorded and smoking history documented. Blood was taken for cholesterol measurement and random blood glucose in all patients irrespective of their previous history of diabetes or hypercholesterolaemia. Serum HbA1c was recorded in all previously established diabetics.

Patients were asked to report whether they had further cerebrovascular or cardiovascular events in the interval period. In addition admissions to hospital and their cause were recorded. Patients were asked to fill in a EuroQOL

questionnaire to record perceived health status, a Geriatric Depression Scale and a follow-up questionnaire on satisfaction with stroke services.

Medication concordance was documented. This was assessed in several ways;

1. Patients were asked to bring all of their current medication and comparison was made to the repeat prescription for inconsistencies.

2. Medication packaging was also checked for any "out-of-date" medication.

3. Patients were also asked whether they considered themselves to be compliant with therapy.

Persistence with therapy was evaluated by comparing medication details at follow-up, with those documented at completion of the initial study.

On completion of the study, General Practitioners were informed of the patient's risk factor status and targets were once again reinforced.

Data were analysed using SPSS version 13. Dichotomous data were analysed using the x^2 statistic. Continuous variables were analysed by an independent samples T-test. Local ethics committee approval was obtained.

Results

The mean length of follow up was 3.6 years (SD 0.43). Of the 205 patients enrolled in the initial study, 102 patients attended for follow-up (Figure 3.1). Reasons for non-attendance are documented (Table 3.2). Twenty five patients had died since the completion of the initial study (11 intervention/14 control, p=0.39). All intervention patients in the initial study were living within the community. At time of follow-up 5 patients from the control group were resident in a nursing home, though no patients from the intervention group had been admitted to a care facility.

Risk factor control

The primary outcome was collective risk factor control. Risk factors were controlled if within local or national guidelines. Table 3.1 demonstrates that there was no significant difference in the percentage of controlled risk factors between groups. In addition there was no significant difference in control of the four main modifiable risk factors (diabetes, smoking status, cholesterol and blood pressure).

There was no significant interval change in risk factor control between the initial and follow-up studies. Overall collective risk factor control was suboptimal in the initial study and disappointingly there was no significant improvement three years on. These results match others described in the literature at 2 years (210). The difference in systolic blood pressure documented in the initial study, appears not to have been maintained.

Clinical outcomes

Clinical events were self reported. There was no attempt to confirm evidence of self reported events or admissions. More than one cerebrovascular event was reported by several patients. The total number of strokes was similar between groups (Table 3.1); however the total number of reported TIA's was higher in the intervention group. One patient in the intervention group reported 10 possible TIA's in the interval between studies. No objective confirmation of these reported symptoms was possible in this study. The actual number of patients with recurrent events between groups was similar and therefore this does not reach statistical significance. Ischaemic heart disease episodes were more frequent in the control group but this was not statistically significant.

Admission rates differ between groups, the number of admissions was higher in the control group, though this was largely due to non-vascular aetiology.

Medication persistence

Details of ongoing prescription of three secondary prevention medications were documented and compared with the initial study data (Table 3.3). Persistence was similar in both groups. Despite apparent differences in reported compliance and the presence of expired medication between groups, this does not reach statistical significance.

Perceived health status

Overall there was no significant difference between perceived health status and Geriatric Depression Score between groups. The number of clinically depressed individuals determined by a cut off score of 5 or more on the short form of the GDS was greater in the control group (Table 3.1); however this did not reach statistical significance.

Patient satisfaction with stroke services was evaluated using a series of questions on a Likert scale, as per the initial study. Overall satisfaction was high, however there was no significant difference in questionnaire scores as shown in Table 3.4. Also highlighted are the previously positive questions in the initial study.

Discussion

It appears that brief intervention with respect to behaviour modification and risk factor control has no long-term benefit. This study may be one of few carried out showing long-term outcomes in post-stroke patients; however there are a number of important limitations. Firstly, in terms of study size, both the initial and follow-up studies were largely underpowered and therefore the results have to be cautiously interpreted. It is unlikely that anything other than major differences between groups would be detected and many results in this paper could represent a type II statistical error.

Attrition is inevitable at long-term follow-up. Attrition bias, where one group of patients systematically drop out of follow-up is an important risk in behaviour modifications. Almost the entire cohort (94%) attended for follow-up during the initial study and had a clear understanding of what was involved. It could be assumed that patients who have been poorly compliant with education and therapy may not be willing to attend for follow-up, where their poor compliance since the initial study could be exposed. Follow-up rates between groups were comparable.

The estimation of recurrent vascular events in this study was based on self-reporting and no formal confirmation was possible. The apparent difference in reported TIAs in the intervention group may be due to increased awareness of symptoms following education, or a heightened level of anxiety.

The gold standard assessment of medication concordance is by electronic or pill-counting methods (211). We sought to use multiple methods in this study to assess adherence behaviour that were felt to be simple and objective.

Medication persistence was reassuringly high in this study. Both groups had similar high levels of persistence with therapy at follow-up; this may explain the similarities in risk factor control. This may simply reflect the fact that patients who participate in studies are more motivated and our results may not be generalisable. Persistence with secondary prevention therapies, in particular antithrombotic therapy, has been shown to be similarly high in other short-term

studies (212-214). However, in comparison to our study, other evidence suggests that persistence falls with time, in particular with antihypertensive therapy (215;216).

A potential confounding factor for patients in the Glasgow area is the introduction of a chronic disease management programme since the initial study. Primary care teams aim to review all patients with a diagnosis of a stroke every six months, aiming to address secondary prevention, assess rehabilitation needs and provide education. This programme is independent of the study and it is likely that both the intervention and control group have undergone review.

The difference between the two groups in terms of rates of institutionalisation raises interesting questions. These differences may be due to chance alone in a small study sample. However, it may be related to real clinical differences in stroke recurrence or cognitive decline. Nursing Home residents were not approached for inclusion in the follow-up study for ethical reasons; therefore we were unable to determine the reason for admission. A disabling stroke and cognitive impairment secondary to vascular disease are common causes of admission to a Nursing Home. In addition, cognition was not evaluated as a clinical outcome in this study.

Satisfaction with stroke services remained high within this study population; however the significant difference between groups has not been maintained long-term. In the initial study, patients in the intervention group felt more satisfied with the information provided to them about stroke disease, risk factors and who to contact in the event of problems. These results have also been replicated in a more recent study of short-term follow-up (217). Further work is required with regards to the most effective method in providing ongoing education over a longer time frame; it may be that that chronic disease management programmes have a role to play.

It is clear that management of risk factors remains suboptimal. Overall collective risk factor control is poor and it is interesting that it remains very similar to results at completion of the initial study. It is disappointing that no significant improvements have been made in the interim despite recent developments.

Despite this study's limitations it remains one of the few studies that describe the realities of risk factor control in a real world setting over a long time period (210). It is the intention of education and behaviour modifying interventions to improve longer term compliance and satisfaction and therefore further long-term research is required.

Figure 3.1: Trial Flow

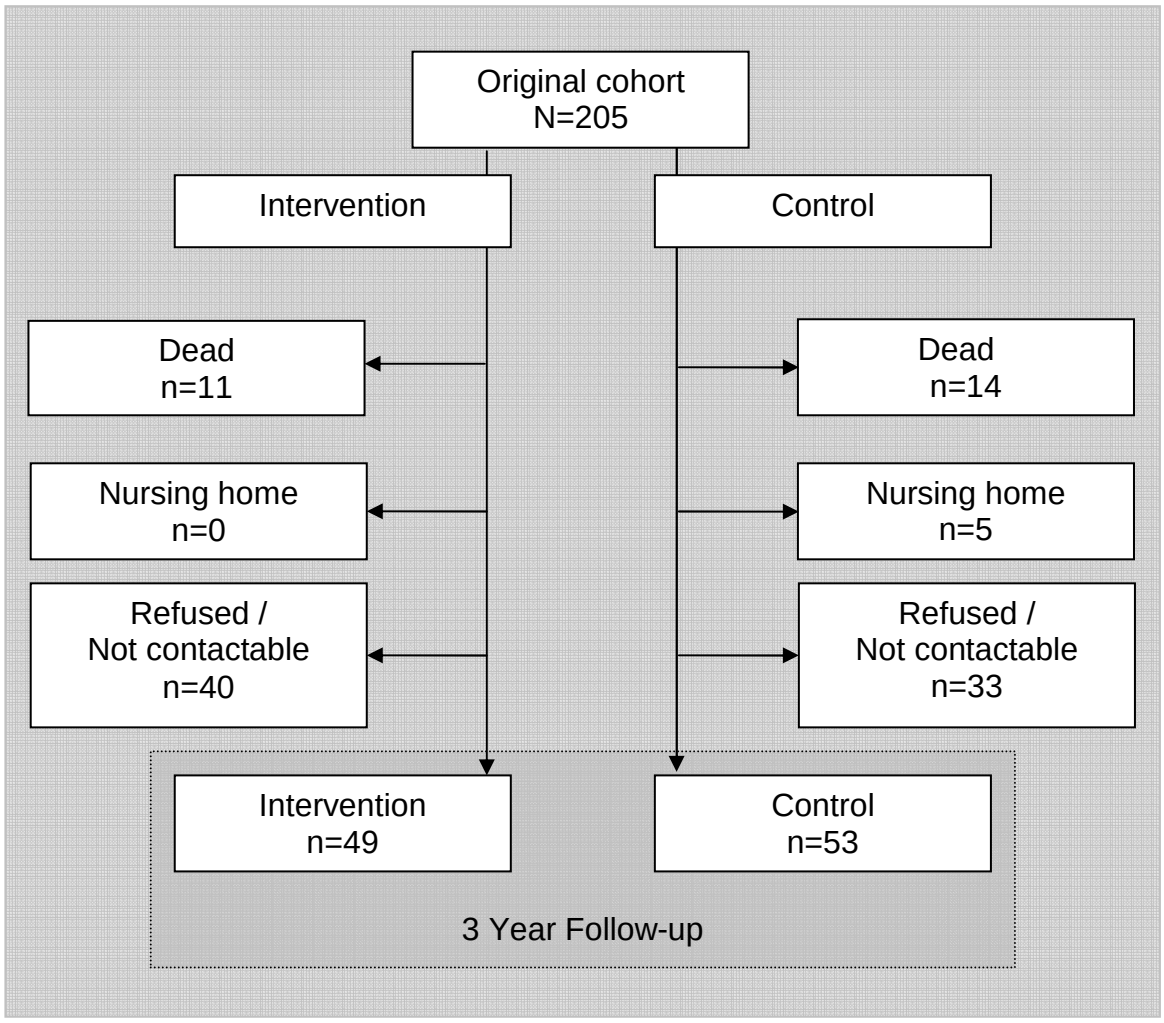


Table 3.1: Outcome data

	Intervention (n=49)	*Control (n=53)*	*Significance*
Risk factor control			
% of controlled risk factors	52% (SD 31.0)	56% (SD 35.4)	p=0.53
Systolic BP (mean)	143 (SD 18.8)	139 (SD 21.6)	p=0.38
Diastolic BP (mean)	74 (SD 10.3)	74 (SD 12.2)	p=0.74
Cholesterol	4.3 (SD 1.2)	4.5 (SD 0.9)	p=0.23
Diabetic control			
Random Glucose (mean)	8.1 (SD 5.7)	7.1 (SD 3.5)	p=0.31
HbA_1c (mean)	8.0 (SD 1.9)	7.5 (SD 1.5)	p=0.43
Cigarettes per day (mean)	13 (SD 7.7)	14 (SD 9.2)	p=0.73
Clinical events			
Recurrent Cerebrovascular events (No. of patients)	25(n=7)	13(n=6)	p=0.78
Total number of TIAs	23	10	
Total number of CVAs	2	3	
Ischaemic heart disease events (No. of patients)	2	6	p=0.27
Total No. of admissions (all cause)	13	22	p=0.31
Vascular admissions	7	11	p=0.69
Perceived Health Status			
EuroQOL (% score)	62% (SD 20.0)	60% (SD 20.5)	p=0.73
Geriatric Depression Score(mean)	3.6 (SD 3.3)	4.3 (SD 4.2)	p=0.36
Depressed (by cut-off)	11	16	p=0.49

For categorical variables, the Chi^2 statistic has been used.
For continuous variables the Student's t-test has been used.

Table 3.2: Reason for Non-attendance

	Intervention (n)	*Control (n)*	*Pearson Chi-Square*
Death	11	14	p=0.39
Institutionalisation	0	5	p=0.02
(Death or institutionalisation)	11	19	p= 0.09
Refused-Unwell	1	0	p=0.31
Refused-No reason	19	11	p=0.09
Not contactable	20	22	p=0.84

Table 3.3: Persistence with Therapy

	Intervention %,(n/N)	*Control %,(n/N)*	*Significance*
Persistence with therapy			
Antiplatelet	95% (44/46)	89% (44/50)	p=0.28
Antihypertensive	97% (36/37)	95% (41/43)	p=0.81
Statin	88% (32/36)	89% (39/44)	p=0.92
Expired medication (packaging)			
"yes"	13% (4/32)	6% (2/34)	p=0.42
"Do you always take your medicines?"			
"yes"	78% (29/37)	92% (36/39)	p=0.10

For categorical variables, the Chi^2 statistic has been used.
For continuous variables the Student's t-test has been used.

Table 3.4: Satisfaction with Stroke Services

Question	% Strongly Agree		
	Intervention (49)	Control (52)	Pearson Chi-Square
I have been treated with kindness and respect by staff at the hospital.	78% (38/49)	75% (39/52)	p=0.52
The staff attended well to my needs when I was at the hospital.	74% (36/49)	75% (39/52)	p=0.59
I was able to talk to the staff about the problems I might have had.*	68% (30/44)	71% (35/49)	p=0.78
I have received all the information I want about the causes and nature of my illness.*	53% (25/47)	50% (26/52)	p=0.54
The doctors have done everything they can to make me well again.	55% (26/47)	67% (35/52)	p=0.25
I am satisfied with the outpatient services provided by the hospital.	54% (26/48)	62% (32/52)	p=0.29
I have received enough information about my risk factors for stroke.*	47% (22/47)	59% (30/51)	p=0.17
Somebody has really listened and understood my needs and problems since I attended the hospital.	48% (19/40)	58% (26/45)	p=0.61
I am satisfied with the amount of contact I have had with the hospital since I have attended.	55% (26/47)	50% (25/50)	p=0.66
I have had enough emotional support since I attended the hospital.	52% (14/27)	50% (17/34)	p= 0.97
I know whom to contact if I have problems relating to my TIA/Stroke.*	43% (21/49)	42% (22/52)	p=0.98
I am happy with the amount of recovery I have made.	57% (28/49)	52% (27/52)	p=0.68
I was given all the information I needed about the allowances or services I might need.	33% (8/24)	42% (14/33)	p=0.59

Satisfaction expressed as the percentage that strongly agree with the statements.
*Previously positive questions

Table 3.5: Change in Secondary Outcomes Over Study Period

Variable	Time	Experiment	Control	Significance
Blood Pressure control				
Systolic BP (mmHg)	3 Months	-9.2 (SD 23.3, n=64)	-1.0 (SD 22.4, n=72)	P=0.04
	3 Year	-8.5 (SD 24.9, n=33)	-10.6 (SD 25.5, n=41)	p=0.73
	Interval (3 Years – 3 Months)	1.8 (SD 26.5, n=32)	-8.3 (SD 25.1, n=43)	p=0.10
Diastolic BP (mmHg)	3 Months	-2.1 (SD 15.1, n=64)	-1.2 (SD 13.8, n=72)	P=0.71
	3 Year	-2.5 (SD 16.0, n=33)	-4.7(SD 15.9, n=41)	p=0.55
	Interval	-3.8 (SD 11.0, n=32)	-5.2 (SD 14.0, n=43)	p=0.64
Diabetic control				
RBG (mmol/L)	3 Months	0.9 (SD 5.7, n=23)	0.9 (SD 7.4, n=24)	P=0.99
	3 Year	0.8 (SD 13.8, n=8)	-0.2 (SD 7.4, n=9)	p=0.85
	Interval	-1.2 (SD 11.0, n=9)	-0.9 (SD 7.1, n=10)	p=0.95
HbA1c (%)	3 Months	-0.3 (SD 0.7, n=17)	-0.8 (SD 1.5, n=17)	p=0.20
	3 Year	-0.6 (SD 2.4,n=8)	-0.5 (SD 1.8, n=8)	p=0.93
	Interval	0.0 (SD 2.0, n=9)	0.0 (SD 1.5, n=8)	p=0.99
Cholesterol (mmol/L)	3 Months	-1.0 (SD 1.1, n=75)	-0.9 (SD 1.2, n=73)	p=0.63
	3 Year	-1.4 (SD 1.25, n=41)	-1.3 (SD 1.1, n=40)	p=0.51
	Interval	-0.4 (SD 1.0, n=40)	-0.2 (SD 1.0, n=39)	p=0.47
Smoking No (cpd)	3 Months	-1.6 (SD 11.5, n=33)	-0.4 (SD 8.1, n=37)	P=0.61
	3 Year	-1.6 (SD11.1, n=15)	1.08 (SD 9.5, n=12)	p=0.51
	Interval	0.8 (SD 9.3, n=15)	1.0 (SD 9.1, n=12)	p=0.96
EuroQOL* (%)	3 Months	3.5 (SD 20.9, n=94)	-1.0 (SD 22.4, n=97)	p=0.43
	3 Year	-4.0 (SD 22.9, n=49)	-5.7 (SD 17.4, n=53)	p=0.68
	Interval	-7.4 (SD 18.9, n=49)	-5.3 (SD 18.8, n=51)	p=0.56
GDS†	Interval (3 Years – 3 Months)	-0.2 (SD 1.9, n=0.49)	-0.6 (SD 3.8, n=51)	p=0.57

Minus values indicate a reduction in the appropriate measure.
*Higher scores indicate a higher quality of life score.
†Higher (positive scores) indicate a greater likelihood of depression.
For categorical variables, the Chi^2 statistic has been used.
For continuous variables the Student's t-test has been used.

Chapter Four:

Outpatient Rehabilitation Services After Stroke: A Descriptive Analysis of the Randomised Trials

Introduction

Complex interventions, defined as those made up of "various interconnecting parts", encompass the majority of healthcare interventions especially in the context of rehabilitation (218). Ideally rehabilitation trials should follow the MRC framework for complex interventions, which recognises the challenge of developing, describing and researching complex interventions (219). It proposes that their development and testing should follow a series of phases (Figure 4.1).

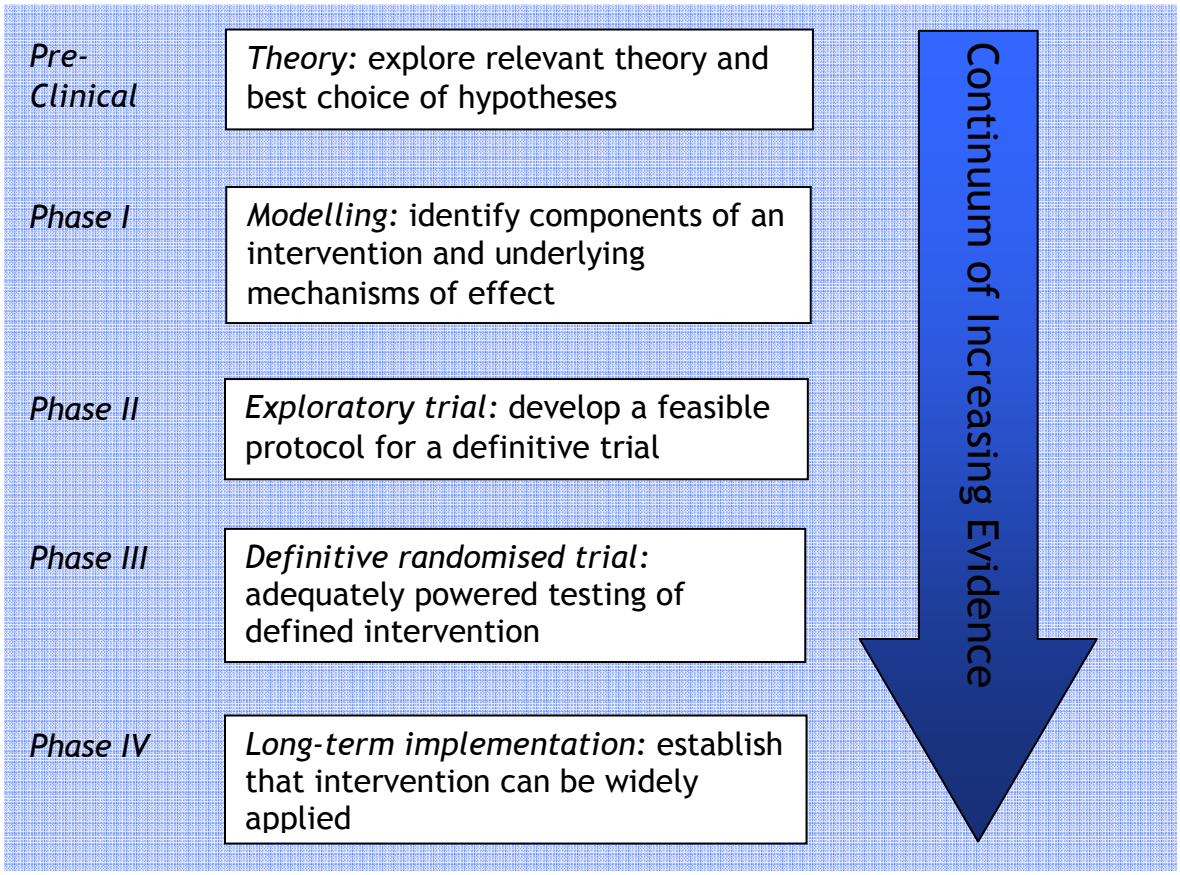


Figure 4.1: MRC Framework for Complex Interventions

The basic sciences underpinning rehabilitation are not well developed and the underlying pathophysiological rationale for, and intention of a rehabilitation intervention are often not clear. Traditionally rehabilitation trials have been developed from an intuitive belief about what may be effective, and most trials of such interventions have not had sufficient statistical power to provide definitive conclusions. Because individual trials are often small, conclusions about the effectiveness of rehabilitation interventions are often based on systematic reviews of all the randomised trials.

In the area of outpatient stroke rehabilitation, the number of randomised controlled trials has increased considerably in recent years (220). Classifying these separate interventions however presents some challenges. Firstly, the nature of stroke rehabilitation is broad, ill-defined and multi-faceted (221). Secondly, a wide variety of outpatient rehabilitation services have been developed which address different aspects of stroke, including impairment, disability (activities), handicap (participation) and mood status. Finally, rehabilitation services rarely operate in isolation and a variety of comparison treatments have been used as controls.

In the absence of a framework for characterising rehabilitation interventions we wished to find a method of identifying and classifying trials of stroke rehabilitation in the community. We therefore sought to develop a simple classification system which categorises interventions by simple descriptive characteristics to assist in the comparison of similar studies.

Methods

Identifying Trials

We set out to identify all randomised controlled trials of outpatient rehabilitation interventions for stroke patients which had been compared with normal care. The definition of outpatient rehabilitation was derived from the World Health Organisation definition of rehabilitation (221); “a problem solving and educational process aimed at reducing the disability and handicap experienced by someone as a result of a disease”. Rehabilitation was therefore considered to be any intervention delivered by a “rehabilitation worker” which

aimed to reduce disability or handicap after stroke. This definition excluded drug and surgical interventions and trials of alternative systems of care (e.g. home versus hospital based rehabilitation). Additionally we narrowed our search to exclude trials that treated only a specific impairment (e.g. treatments for upper limb spasticity) or a specific subgroup of patients (e.g. depressed post stroke patients only, or specific ethnic groups only (222)). Thus the focus of this classification was at the outset to describe interventions delivered to the majority of stroke patients or carers in a community setting. The classification of trials of systems of care or specific treatments for impairments has been attempted elsewhere [www.effectivestrokecare.org].

We searched the Cochrane Controlled Trials Register (8993 trials, search date September 2005). In addition, we searched the reference lists of Cochrane reviews of outpatient interventions (25;131-133;223;224). Further (unpublished) trials were identified by communication with trialists (225-227).

Selecting Trials:

Trials for inclusion were identified using the following criteria:

A randomised controlled trial, recruiting only stroke patients or carers, which evaluated an intervention provided by a rehabilitation worker (in comparison with no routinely provided intervention), which aimed to reduce some aspect of disability or handicap and was carried out in an outpatient setting (i.e. home, clinic, day hospital).

Data collection:

Trial characteristics were obtained from the available published and unpublished sources and recorded in a database. The method of classifying interventions was derived from methods previously discussed at a collaborators' meeting of the Outpatient Trialists Collaboration (228). This used a simple Delphi process (229;230) to develop, collect and categorise data in an iterative process in collaboration with trialists from working in the area. Each trial intervention was described using this classification including the following details:

Trial identifiers (centre, publication year, contact trialists)

Who provided the intervention (profession or discipline)

Domains of the intervention – these were categorised into one of four subcategories;

1. *Behavioural* - interventions which focus on problem solving and adaptation through the active participation of both therapist and patient to bring about changes in task-orientated behaviour (e.g. walking, activities of daily living). This could incorporate some adaptation of the physical environment.

2. *Psychological* – interactions between rehabilitation worker and patient which focus on problem solving and adaptation through psychological interventions and changes in the patient's thought or perspective. This could address emotional needs or symptoms and include activities such as counselling.

3. *Informational* – interventions which focus on problem-solving and adaptation though the provision of information (usually about the disease and its consequences).

4. *Social* – interventions which focus on problem solving and adaptation by addressing social needs and influencing the social environment. This frequently involves liaison with other staff or services.

Delivery of the intervention – whether the intervention was provided on an individual or group basis and whether it was prescriptive in delivery or customised to the individual patient.

1. *Intensity* of the intervention – expressed as the total number of treatment sessions per month and the duration of the intervention.

2. *Timing* of the intervention; whether provided "early" (at hospital discharge or similar time after stroke) or at a later stage after stroke (6 months or more).

3. *Patients/Carers*; whether the intervention was delivered to patients and/or carers, or simply to carers alone.

4. *Intention* of the intervention – were the main and intermediate intentions of the intervention (e.g. to reduce disability by improving mobility). This should be reflected in the primary outcome measure used in a trial.

Where trials had more than one intervention arm, each independent intervention was classified separately.

Numerical Taxonomy:

Once standardised information from the original trials had been obtained, we carried out a simple numerical taxonomy cluster analysis (231). Each individual trial intervention was examined for its similarity to each of the other trial interventions by calculating a similarity index (i.e. the proportion of characteristics which were shared by the two interventions under comparison). Five characteristics which the collaborative group (228) had previously judged to be important in determining the nature of an intervention were selected to calculate the similarity index:

1. *Staff providing the intervention* – categorised as physiotherapy, occupational therapy, nursing, psychology or volunteer staff.

2. *Main domain of the intervention* – categorised as behavioural, psychological, informational or social (see Data Collection above).

3. *Minor domain(s) of the intervention* – i.e. other characteristics which were present in the intervention but not considered to be the main focus of the intervention.

4. *Method of delivery* – categorised as individual or group, customised to the individual or prescriptive.

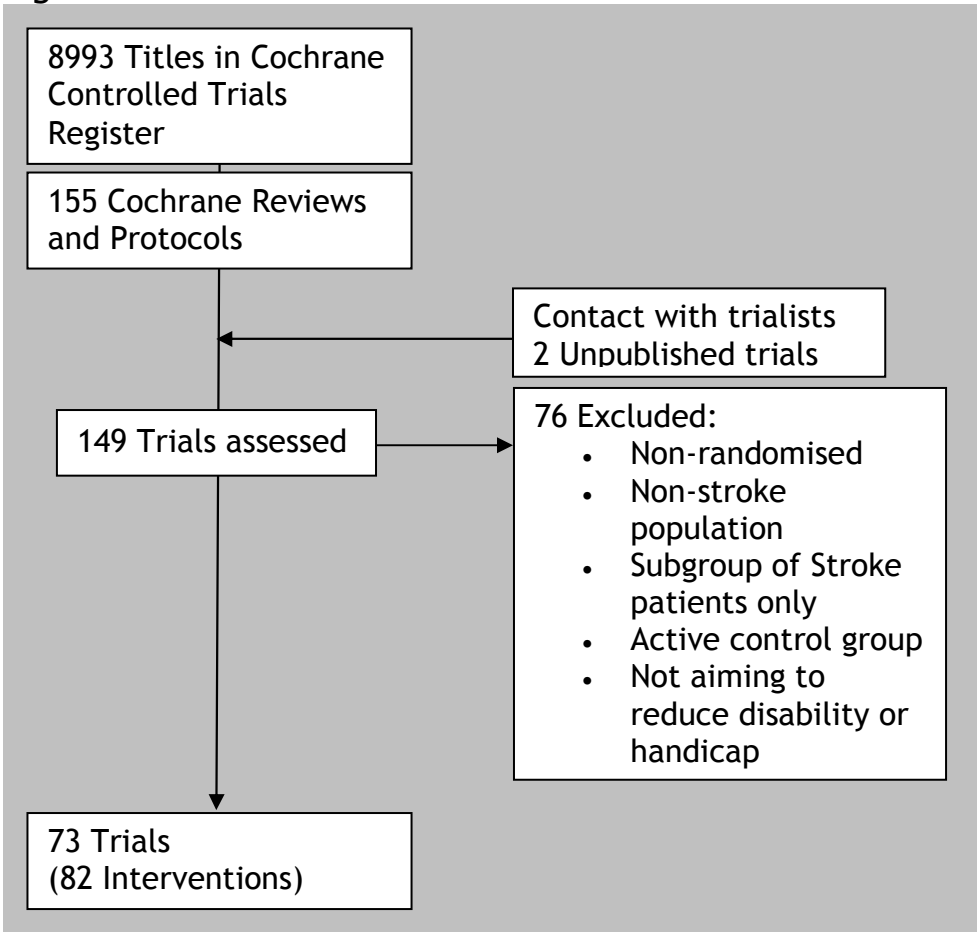
5. *Intention of the intervention* – categorised as focussing on either disability or handicap.

A similarity index was calculated as the proportion of the above five characteristics which were shared by two interventions. The maximum similarity index was 1.0. A numerical taxonomy dendrogram (231) was then developed by first grouping together interventions with a similarity index of 1.0, and then those of 0.8, then 0.6 etc. until all interventions were linked at some level.

Results

8993 titles were reviewed in the Cochrane Controlled Trials register. In addition, 155 Cochrane reviews and protocols were searched. A total of 149 trials were initially identified and assessed for inclusion; 76 were excluded because they were non-randomised, not targeted at stroke patients, were focussed on a subgroup of patients or a specific impairment, had an active intervention in the control group, or did not aim to reduce disability or handicap. (See Figure 4.2)

Figure 4.2: Selection of Trials for Inclusion



The process of trial identification and assessment for potential analysis.

73 trials were finally selected as relevant for inclusion, which studied 82 different interventions (70;71;71;123;152;153;225-227;232-234;234-239;239-241;241-245;245-254;254;255;255;256;256;257;257-274;274-300). We obtained information for 72 trials and limited information regarding 1 trial (301).

Data were complete for the majority of trials. Tables 4.1-4.5 outline the basic characteristics of the identified randomised trials. A wide range of approaches to delivering outpatient rehabilitation interventions have been or are currently being tested. Most trials recruited a relatively mixed group of patients at the time of hospital discharge.

The numerical taxonomy is displayed in Figure 4.3 and shows several clusters of trials which can be characterised under several themes:

Multidisciplinary rehabilitation after stroke

This title includes a broad range of studies that generally evaluated the intervention of a team of therapists providing multidimensional rehabilitation post stroke. They were focused primarily on providing customised input in behavioural domains with the aim of reducing disability. The group overall had a similarity index of >0.8, differing predominantly in the staff who provided the intervention. This group had a moderate similarity (<0.6) with occupational therapy based rehabilitation programmes. They differed from the occupational therapy group in the staff who provided the intervention and the intention of the intervention (disability Vs handicap). They had a low similarity index with other groups (<0.4). Within this broad group it is apparent that there are two further distinct groups that deliver multidisciplinary interventions but with differences that are not distinguished on the basis of this classification alone.

a.) Early Supported Discharge; These trials evaluated a team of therapists providing a multidimensional rehabilitation programme immediately on discharge from hospital. While broadly similar in the timing of the intervention, the co-ordination of these services is often more directly integrated with inpatient care and in some contexts begins there.

b.) Post Stroke Rehabilitation; These trials generally evaluated the impact of input in a behavioural domain early after stroke, providing customised interventions with the aim of reducing disability. The trials had a similarity index of <0.8, differing only in the staff who provided input or whether interventions were customised or prescriptive. Whereas early supported discharge services had a greater degree of overlap or dovetailing with hospital services, post-stroke rehabilitation trials were distinct services.

Occupational Therapy after Stroke;

These were interventions provided by occupational therapists with the aim of reducing handicap and were delivered in a behavioural domain in a generally customised fashion. They have a similarity index of 0.8 – 1.0. Studies differed only in whether the intervention was customised or prescriptive and aimed to reduce disability or handicap. This group of studies had a similarity index of 0.6 to the Early Supported Discharge Trials and the Post Stroke Rehabilitation group as shown above.

Physical Fitness after Stroke;

This group of studies typically evaluated interventions provided by a physiotherapist late after stroke providing a prescriptive exercise intervention intended to improve physical performance or fitness. The trials had similarity index of <0.8 to each other. They differed significantly from the other groupings having a low similarity index of 0.2.

Social and Psychological Support;

This grouping covers a more diverse range of studies with a similarity index of <0.6. Typically they evaluate services provided by a nurse, volunteer or social worker who provides social support, information and liaison with other services aiming to reduce aspects of handicap, especially improving quality of life or reducing depression. Differences between studies existed in the healthcare worker who delivered the intervention, the domain of the intervention (e.g. psychological or social) and whether the intervention was prescriptive or customised. This group showed only moderate similarity to other groups (0.4).

Information Provision;

This disparate group of trials generally evaluated information delivered by differing team members at different stages post stroke with different intentions (e.g. improving knowledge, mood or subjective health status). Overall they have a similarity index of 0.6.

Discussion

The main aim of this was to identify and classify the characteristics of outpatient rehabilitation services for stroke patients after discharge from hospital. We therefore focussed on those randomised trials which have tested the null hypotheses that the routine intervention by a "rehabilitation worker" for stroke patients outwith hospital is no more effective than no routine intervention. We did not include trials examining alternative services to hospital care (e.g. "hospital at home") although we did include services designed to accelerate discharge from hospital.

Before discussing the implication of this analysis, it is important to acknowledge some of the methodological limitations. Because the basic sciences underpinning rehabilitation are not well established, we have sought to develop a classification based on superficial characteristics. For example who was doing what to whom, where, how often and with what intent? This descriptive method may not take into account important components of the intervention.

Secondly, the analysis described here was developed initially by the Outpatient Trialists Collaboration through an iterative process, drawing on their collective experience. As such it might be said to be in part data-driven. The choice of different characteristics might well have produced a different clustering.

The grouping of trials in this taxonomy may not exactly match the choice of trials for the Cochrane reviews previously mentioned, but bears a great resemblance. This similarity is unlikely to be coincidental as these methods of classification were initially employed by the Outpatient Trialists Collaboration in order to identify areas for the development of Cochrane reviews and has informed that process. Similarly, trials that are clustered in the taxonomy may not be included in the Cochrane reviews. This may occur where based on

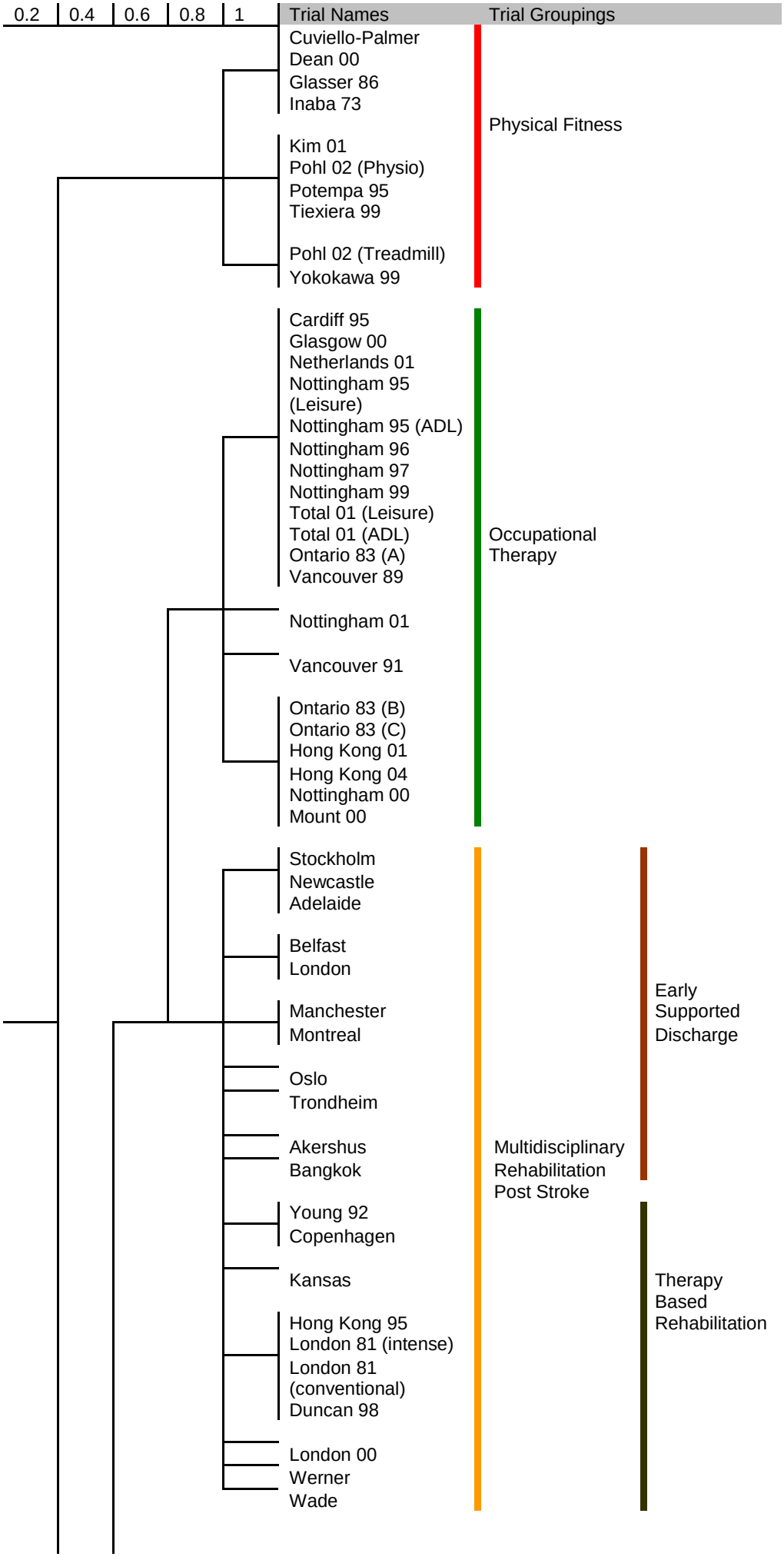
additional information not included in this analysis the reviewers have concluded that the trial does not meet the review inclusion criteria. It is hoped that despite these limitations, this methodology for classifying outpatient interventions may prove useful in informing future reviews.

The current classification does suggest that three major themes emerge from these trials. Firstly there are the "physical rehabilitation" services which are typically delivered by either physiotherapists, occupational therapists or a multi-disciplinary team. These tend to focus on the physical aspects of disability and handicap, and as a whole provide intensive therapy.

The second of the themes concerns what might simply be termed the "psychological impact" of stroke. This more diverse grouping is unified by its intention to impact some aspect of the social, psychological or informational needs of stroke patients and improve their quality of life or mood. They include the use of education, counselling, liaison and social support and are generally less intense than physical rehabilitation interventions.

A separate category is beginning to emerge in stroke rehabilitation trials and it is those trials that seek specifically or exclusively to impact on carers after stroke. Because of the broad inclusion criteria of this analysis, they have not been excluded where they did not intervene with stroke patients, but have been marked with an asterisk in the dendrogram to indicate where they sit within this analysis. These trials represent a growing area of stroke rehabilitation research and may represent the next generation of both primary and secondary research.

In conclusion, we have identified a heterogeneous group of outpatient stroke rehabilitation services which have been tested within randomised controlled trials and provided a simple taxonomy of their content. Most of these interventions can be fitted into one of three descriptive themes. We believe that this can form the basis for future discussion and research, informing the gaps in primary and secondary research.


0.2
0.4
0.6
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1
Trial Names
Trial Groupings
Cuviello-Palmer
Dean 00
Glasser 86
Inaba 73
Kim 01
Pohl 02 (Physio)
Potempa 95
Tiexiera 99
Pohl 02 (Treadmill)
Yokokawa 99
Physical Fitness
Cardiff 95
Glasgow 00
Netherlands 01
Nottingham 95 (Leisure)
Nottingham 95 (ADL)
Nottingham 96
Nottingham 97
Nottingham 99
Total 01 (Leisure)
Total 01 (ADL)
Ontario 83 (A)
Vancouver 89
Nottingham 01
Vancouver 91
Ontario 83 (B)
Ontario 83 (C)
Hong Kong 01
Hong Kong 04
Nottingham 00
Mount 00
Occupational Therapy
Stockholm
Newcastle
Adelaide
Belfast
London
Manchester
Montreal
Oslo
Trondheim
Akershus
Bangkok
Young 92
Copenhagen
Kansas
Hong Kong 95
London 81 (intense)
London 81 (conventional)
Duncan 98
London 00
Werner
Wade
Multidisciplinary Rehabilitation Post Stroke
Early Supported Discharge
Therapy Based Rehabilitation

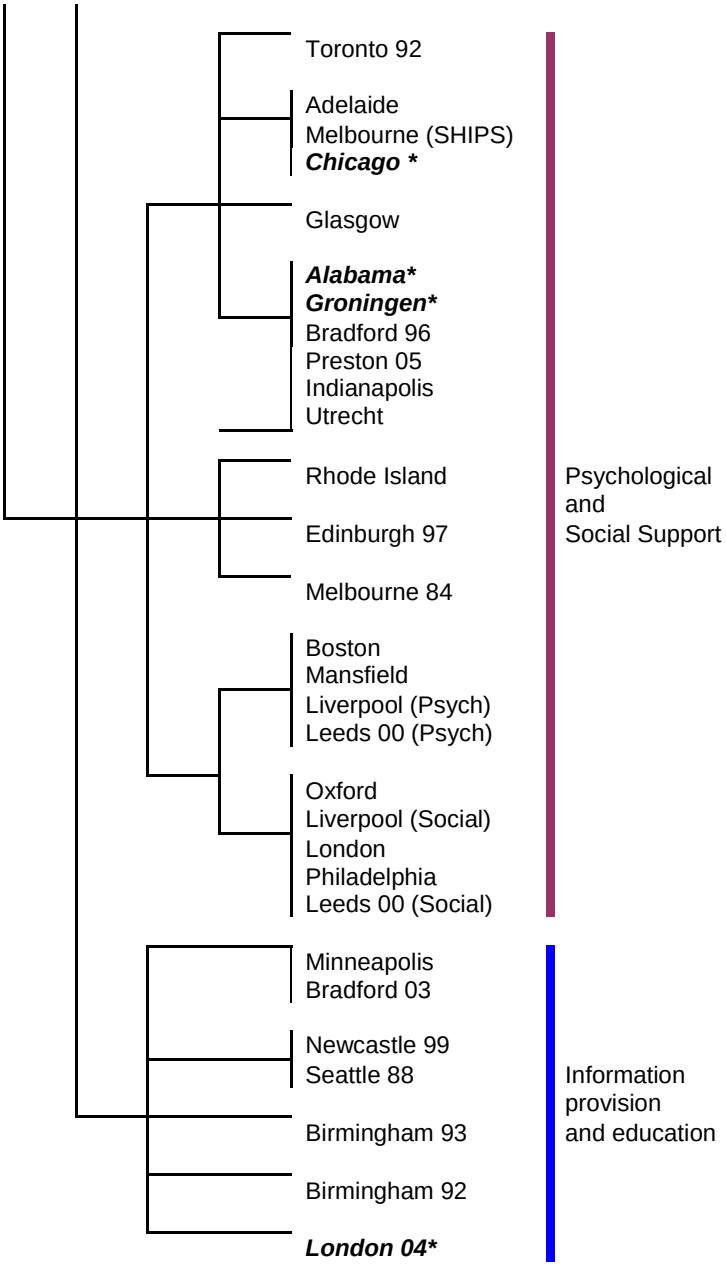


Figure 4.3: Dendrogram of Outpatient Therapy Interventions
*Interventions targeted at carers only

Table 4.1: Therapy Based Rehabilitation and Family Support Trials

Intervention	Ref	Staffing					Domain		Delivery		Timing		Intention
		Physio	OT	Nursing	SW	Other	Major	Minor	Customised	Prescriptive	Early	Late	(Target)
Therapy Based Rehab													
Copenhagen	(272)	•					B	S,I	•		•		Disability, ADL
Hong Kong 95	(273)	•					B,S	I	•		•		Disability, Mood
Kansas	(274)	•					B			•	•		ADL, Mobility
London (intens) 81	(275)	•	•				B		•		•		ADL
London (convent) 81	(302)	•	•				B		•		•		ADL
Vancouver 91	(278)		•				B, S		•			•	Leisure
London 00	(277)	•	•			Med and SLT	B, I	S	•		•		Disability, ADL
Family Support/Carers													
Toronto 92	(71)		•				S			•		•	Social Support
Groningen	(258)			•			I, S	Psy		•	•		Carer strain
Alabama	(75)			•			S, Psy			•	•		Caregiver strain, Social functioning, Mood
London 04	(21)	•	•	•			B	I		•	•		Carer strain, Patient ADL, Dependence

B – Behavioural, I – Information, Psy – Psychological, S - Social

Table 4.2: Physical Fitness Training Trials

Intervention	Ref	Staffing					Domain		Delivery		Timing		Intention
		Physio	OT	Nursing	SW	Other	Major	Minor	Customised	Prescriptive	Early	Late	(Target)
Physical Fitness Training													
Duncan 98	(274)	•	•				B		•		•		ADL, Mobility
Cuviello-Palmer 88	(282)	•					B			•	•		Mobility, Fitness
Dean 00	(284)	•					B			•	•		Mobility, Fitness
Glasser 86	(285)	•					B			•	•		Mobility
Inaba 73	(286)	•					B			•	•		Strength
Kim 01	(287)	•					B			•		•	Strength, Mobility
Pohl 02 (treadmill)	(288)	•					B			•		•	Mobility
Potempa 95	(289)	•					B			•		•	Fitness
Tiexeira 99	(291)	•					B			•		•	Fitness, Strength
Pohl 02 (physio)	(288)	•					B		•			•	Mobility
Young 92	(303)	•					B,I		•		•		Disability, ADL
Werner 96	(304)	•	•				B	S	•			•	Disability, ADL
Yokokawa 91	(301)	•					B, I		•			•	Fitness, Mood
Wade 92	(221)	•					B	I	•			•	Mobility, ADL

B – Behavioural, I – Information, Psy – Psychological, S - Social

Table 4.3: Information Provision and Early Supported Discharge Trials

Intervention	Ref	Staffing					Domain		Delivery		Timing		Intention
		Physio	OT	Nursing	SW	Other	Major	Minor	Customised	Prescriptive	Early	Late	(Target)
Information Provision													
Birmingham 93	(248)			•			I		•		•		Knowledge, Mood
Seattle	(73)		•		•		I	S,B		•	•		Knowledge, Family function
Minneapolis	(153)	•	•	•			I	S,B		•		•	Depression / Mood
Newcastle 99	(152)		•	•	•		I	S, B		•	•		Subjective Health status Knowledge
Birmingham 92	(251)					•	i			•	•		Knowledge
Bradford 03	(155)	•	•	•			I	S,B		•	•		Knowledge, Handicap
Early Supported Discharge													
Stockholm	(269)	•	•		•	•	B	S	•		•		ADL / Disability
Newcastle	(267)	•	•		•	•	B		•		•		ADL / Disability
Adelaide	(259;261)	•	•		•	•	B	I	•		•		Disability
Belfast	(264)	•	•			•	B		•		•		Disability
London	(305)	•	•			•	B		•		•		Disability / ADL
Manchester	(265)	•	•	•		•	B		•		•		Disability
Montreal	(266)	•	•	•		•	B		•		•		Disability
Oslo	(268;306)	•	•	•			B		•		•		Disability
Trondheim	(270)	•	•				B	I,S	•		•		Disability / ADL
Akershus	(262)	•				•	B		•		•		Disability / Length of Stay
Bangkok	(263)			•		•	B		•		•		Disability

B – Behavioural, I – Information, Psy – Psychological, S - Social

Table 4.4: Occupational Therapy Trials

Intervention	Ref	Staffing					Domain		Delivery		Timing		Intention
		Physio	OT	Nursing	SW	Other	Major	Minor	Customised	Prescriptive	Early	Late	(Timing)
OT													
Cardiff 95	(233)		•				B,S	I	•		•		ADL
Glasgow 00	(234)		•				B,S		•		•		ADL, Disability
Netherlands 01	(237)		•				B		•		•		ADL
Nottingham 95 (Leisure)	(276)		•				S, B		•		•		Leisure, Disability
Nottingham 95 (ADL)	(276)		•				B,S		•		•		Disability, Leisure
Nottingham 96	(239)		•				B,S		•		•		ADL
Nottingham 97	(307)		•				B,S		•		•		ADL
Nottingham 99	(241)		•				B,S		•		•		ADL
Total 01 (LEI)	(245)		•				B,S		•		•		Disability, Handicap
Total 01 (ADL)	(245)		•				B,S		•		•		Disability, Handicap
Vancouver 89	(246)		•				B		•		•		ADL, Satisfaction
Nottingham 01	(232)		•				B,S,I		•			•	Dependence, ADL
Ontario 83 (A)	(244)		•				B		•		•		ADL
Ontario 83 (B)	(244)		•				B			•	•		ADL
Ontario 83 (C)	(244)		•				B			•	•		Disability
Hong Kong 01	(308)		•				B			•	•		ADL
Hong Kong 04	(236)		•				B			•	•		ADL
Nottingham 00	(242)		•				B,S			•	•		Disability, Handicap
Mount 00	(309)		•				B			•	•		ADL

B – Behavioural, I – Information, Psy – Psychological, S - Social

Table 4.5: Stroke Liaison Worker Trials

Intervention	Ref	Staffing					Domain		Delivery		Timing		Intention
		Physio	OT	Nursing	SW	Other	Major	Minor	Customised	Prescriptive	Early	Late	(Target)
SLW													
Adelaide	(300)			•			S,I		•		•		QOL / EADL
Glasgow 04	(298)			•			I,B		•		•		Risk Factor Control / QOL
Melbourne (SHIPS)	(299)			•			S,I	B	•		•		ADL / QOL
Chicago	(310)			•			S,I	P	•		•		Mood / Strain
Utrecht	(297)			•			I	B		•	•		Satisfaction / QOL / Mood
Bradford 96	(70)			•			S,I	B		•	•		EADL
Preston	(295)			•			S,i			•	•		EADL
Indianapolis	(311)			•			B	P		•	•		ADL
Rhode Island	(226)				•		P,I	S		•	•		QOL/EADL
Edinburgh 97	(255)				•		S,I	P	•		•		EADL
Melbourne 84	(254)				•		S	P,I	•			•	Institutionalisation/ Disability
Boston	(293)					•	p	I,s	•		•		ADL
Mansfield	(123)					•	P,I	S	•		•		Mood / EADL
Liverpool (Psych)	(227)					•	P,I	S	•		•		QOL / Mood
Leeds House 00 (Psych)	(279)					•	P	I	•		•		EADL
Oxford	(32)					•	S,I		•		•		QOL / EADL
Liverpool (FSO)	(227)					•	S,I	P	•		•		QOL / Mood
London	(296)					•	S,I	P	•		•		EADL
Philadelphia	(257)					•	S,P	I	•		•		EADL/ QOL/ Participation
Leeds House 00 (Volunteer)	(279)					•	S,I		•		•		EADL

B – Behavioural, I – Information, Psy – Psychological, S - Social

Chapter Five:

Meta-analysis of Stroke Liaison Workers for Patients and Carers.

Introduction

As we have seen in Chapter One, for many patients stroke is associated with significant psychosocial problems for both patients and carers. These include depression anxiety, reduced social networks, information needs and dissatisfaction with the diversity in service provision. These might be considered the psychosocial complications of stroke that affect not only the patient but also their social network and carers. As we have seen in Chapter One a potential result of these psychosocial problems is an association with increasing social isolation, depression, poor health and increased mortality (22;23;45-47;89-91;94;96;97).

Support following discharge from hospital, information about stroke and available resources, and practical help have been identified by patients and carers as services that they would value (312). In Chapters Two and Three we evaluated an intervention with a predominantly educational component that attempted to target the informational needs associated with poor compliance and its associated problems. This appeared to result in improved satisfaction with components of information provision and liaison. However, these results did not appear to be maintained at three years post intervention (Chapter Three).

As we have seen in Chapter Four, a number of similar studies exist in the context of outpatient services for stroke and TIA. These interventions as yet have not been evaluated in a systematic review of their effectiveness.

The nurse secondary prevention study in Chapter Two appears to fit into this group of fairly diverse interventions. What unites these interventions is that they are intended for a broad group of stroke patients and the aim of the intervention is to improve some aspect of rehabilitation in its broadest form. Where they differ is primarily in the profession that provides the intervention, or in the primary recipient of the intervention (patient or carer).

While some studies did report positive effects of these interventions (32), none were found to have a significant impact on psychological outcomes or quality of life. This may have been due to small sample size and type II statistical error. Meta-analysis of similar studies offers the potential to overcome type II statistical errors that have resulted from underpowered individual studies (313).

Whilst it is well recognised that there are associations between the psychosocial problems post stroke and worsened clinical outcomes (89;91;94;97), developing an intervention for these problems becomes problematic. It is dangerous to assume that association is the same as causation. The absence of a clear underlying pathophysiology for many rehabilitation interventions means that we remain uncertain as to the mechanisms of some problems post stroke (such as depression) and therefore uncertain as to the mechanisms of an intervention (such as social support or counselling). As a result there has been the testing of a number of "black-box" interventions in randomised controlled trials, which it has been hoped might "happen upon" a mechanism for effective interventions into real problems. Many of these trials are underpowered to detect a real clinical benefit and therefore in combining these studies in meta-analysis we are most likely to see if they are truly effective. For many areas of stroke care it is this process of secondary research that has provided coherent and conclusive evidence where individual trials have been disappointing or conflicting (131;223;314).

Criticism of meta-analysis often centres around its combining of trials and the perceived risk that it combines differing studies (313). The risk of combining irreconcilably different trials is best addressed by careful attention to the methods of the review. In addition it is important that the participant group included in the review are carefully described in advance. These safeguards can be achieved through the pre-planned classification of trials for inclusion, careful attention to the types of intervention, careful description of the comparisons (i.e. what are the control group to receive) and perhaps more fundamentally to the methods of the trial (e.g. randomised controlled trial versus controlled trial or interrupted time series) (313). This assessment must also include a method of trial quality assessment to determine the potential risks of bias within a trial or a review process (313;315). These quality features include the methods of randomisation, the efforts to provide allocation concealment, and the attention to other factors such as blinding and intention to treat analysis (313).

Before attempting a review of these trials we need to consider which are combinable and what descriptives we would give to the intervention. On reviewing the group of studies in more detail, it becomes apparent that there are additional similarities not described by our taxonomy process (Chapter Four).

1. The intervention evaluated in these trials is a multifaceted intervention. That is the intervention has several distinct areas of focus that differentiate them from the trials of (for example) information provision alone. Specifically, the trials appear to provide aspects of information provision, liaison, and social support in combination. The degree to which they provide all three may vary, however it becomes apparent that they provide a comprehensive intervention. The overall intention of these interventions might be described as aiming to return patients and carers to normal roles.

2. The participants in each of these trials can be broadly divided into four groups:

    a. Those interventions that solely address patients and evaluate patient outcomes.
    b. Those that address and evaluate patient and carer outcomes together.
    c. Those that address only caregivers and evaluate caregiver outcomes.
    d. Those that evaluate an intervention for a subset of stroke patients only (e.g. depressed patients).

    It is easy to see that combining trials that evaluate patients and those that evaluate only caregivers raises problems of incompatible populations and outcomes. Additionally trials that evaluate a sub-population of patients (such as depressed patients post stroke) cannot provide generalisation to a general stroke population or permit combination with trials that attempt to address that entire population. The two remaining groups that offer some hope for combination in a review process therefore are those that evaluate patient outcomes alone or those that evaluate patients in combination with caregivers. This could offer some potential additional information about the interventions effects on caregivers.

3. The methods of studies considered for this review process has been implied in our previous chapter on a taxonomy of trials. Randomised controlled trials provide the best available method for evaluating an intervention without the introduction of systematic bias. Combining randomised controlled trials provides the least risk of bias within a meta-analysis.

In summary a stroke liaison worker can be defined as a healthcare worker whose aim is to help return patients and their carers to normal roles. Typically they provide emotional and social support and information to stroke patients and their families and liaise with services with the aim of improving aspects of participation and quality of life for patients with stroke and/or their carers (316). This multi-faceted role distinguishes stroke liaison workers from interventions whose aim is to treat a single problem such as improving activities or knowledge (e.g. trials of information provision). A stroke liaison worker may be a health or social care professional, or be from the voluntary sector. Such services have been evaluated under a range of different names, such as 'social work' (254;281), 'specialist nurse support' (70), 'stroke family care worker' (76), and 'stroke family support organiser' (32). For the purposes of this review, such services have been grouped under the generic title of 'stroke liaison worker'. There has been one descriptive review of published trials of 'support workers' within the context of a broader review of non-drug strategies aimed at reducing psycho-social problems after stroke (317). No meta-analysis of these studies has yet been attempted.

Objectives

To determine the effects of intervention from a stroke liaison worker for patients with stroke and their carers in returning to normal roles, (as measured by improving social activities, participation, and mental health).

Methods

Criteria for considering studies for this review

Types of studies

We wanted to review only randomised controlled trials comparing allocation to intervention from a stroke liaison worker with no intervention or normal care.

Types of participants

We included trials of survivors of acute stroke with or without their closest informal carer. A clinical definition of stroke was used: rapidly developing clinical symptoms and/or signs of focal, and at times global loss of cerebral function (318). Studies that included TIA patients were not excluded since TIA is part of the same disease spectrum and patients with TIAs, while seldom having reduced activities, may have reduced participation and a high level of anxiety regarding stroke recurrence (138). Participants had to be adult (aged 16 or over). Trials that address carer needs alone (and did not include patients) were not considered.

Types of interventions

We considered only trials that evaluated referral to a stroke liaison worker. Such a worker would typically provide a multi-faceted service including more than one of the following: education and information provision; social support; and liaison with other services (228). Often this intervention is provided from the point of patient discharge from hospital. Trials assessing workers of any professional background were considered relevant, and might include health or social care professionals or volunteers. Studies where the intervention was judged to be single faceted were excluded. This distinction is to separate the stroke liaison worker interventions from trials of (for example) information provision alone (133). Similarly, trials of therapist-delivered physical rehabilitation or psychological interventions on their own were excluded. The control group had to receive no intervention or usual care.

Types of outcome measures

Outcomes for Patients

Primary: Subjective Health Status (e.g. GHQ12 (319), SF36 (320), EuroQOL (184)); extended activities of daily living (including social activities e.g. Nottingham EADL (321), Frenchay Activities Index (322)).
Secondary: death; place of residence (institutionalisation); activities of daily living (e.g. Barthel (323), FIM (324)); dependency (e.g. Functional Ambulatory Categories (325), Modified Rankin (326)); mental health - including anxiety and depression (e.g. GDS (327), GHQ (319), HADS (328)); knowledge about stroke; use of services; satisfaction with services; participation (e.g. Reintegration to Normal Living Scale (329)).

Outcomes for Carers

Primary: Subjective Health Status (including measures of carer strain e.g. Carer Strain Index (330), GHQ, SF36).
Secondary: Extended activities of daily living (e.g. Frenchay Activities Index,); mental health (e.g. GHQ, HADS etc.); knowledge about stroke, satisfaction with services.

Search strategy for identification of studies

Relevant trials were identified in the Cochrane Stroke Group's trials register. The register was searched for trials that relate to psychological therapy, counselling, social support, therapists, service provision, support workers, carer training, or information giving.

In addition we searched the following bibliographic databases: Cochrane Central Register of Controlled Trials (latest issue); MEDLINE (from 1966); EMBASE (from 1980); CINAHL (from 1982); ASSIA (Applied Social Science Index and Abstracts, from 1987); PsychINFO (from 1967); and Social Science

Citation Index (from 1956). The search strategy for MEDLINE is shown below. This was adapted for the other databases.

1. stress, psychological/
2. psychosocial$.tw.
3. social adjustment/
4. adaptation, psychological/
5. activities of daily living/
6. exp interpersonal relations/
7. morale/
8. (cope or coping).tw.
9. patient satisfaction/
10. exp emotions/
11. ((psychological or social) and (problem$ or difficult$)).tw.
12. exp social isolation/
13. emotion$.tw.
14. stress/
15. knowledge, attitudes, practice/
16. exp motivation/
17. quality of life/
18. anxiety/
19. caregivers/
20. life change events/
21. depression/
22. life style/
23. social behavior/
24. mental health/
25. knowledge/
26. psychomotor performance/
27. exp family relations/
28. or/1-27
29. patient care management/
30. continuity of patient care/

31. needs assessment/
32. rehabilitation nursing/
33. home nursing/
34. "referral and consultation"/
35. social support/
36. exp professional-patient relations/
37. ((patient$ or carer or caregiver$ or famil$) adj10 support$).tw.
38. patient education/
39. exp social work/
40. community health services/
41. (home or in-home or home-based).tw.
42. health services for the aged/
43. ((patient$ or carer or caregiver$ or famil$) adj10 information$).tw.
44. family health/
45. family care$.tw.
46. outreach.tw.
47. advice.tw.
48. counseling/
49. counsel?ing.tw.
50. nursing assessment/
51. aftercare/
52. volunteer$.tw.
53. exp rehabilitation/
54. communit$.tw.
55. empathy/
56. visitor$.tw.
57. patient-centered care/
58. health education/
59. interview, psychological/
60. exp patient care planning/
61. domiciliary.tw.
62. (liaison or link or contact).tw.
63. Home care services/

64. ambulatory care/
65. or/29-64
66. exp cerebrovascular disorders/
67. (stroke$ or cva$ or cerebrovascular or cerebral vascular or post-stroke or transient isch$ or TIA).tw.
68. (cerebral or cerebellar or brain$ or vertebrobasilar).tw.
69. (infarct$ or isch?emi$ or thrombo$ or emboli$ or apoplexy).tw.
70. 68 and 69
71. (cerebral or brain or subarachnoid).tw.
72. (haemorrhage or hemorrhage or haematoma or hematoma or bleed$ or aneurysm).tw.
73. 71 and 72
74. hemiplegia/ or exp aphasia/ or hemianopsia/
75. (aphasi$ or dysphasi$ or hemianop$ or hemipleg$ or hemipar$).tw.
76. 66 or 67 or 70 or 73 or 74 or 75
77. 28 and 65 and 76
78. limit 77 to human

In order to identify further published and unpublished studies, a citation search was carried out using the Web of Science Citation Indices, the reference lists of identified relevant trials were checked, and authors of relevant papers were contacted. Relevant conference proceedings were reviewed, trials registers were searched, and contact was made with investigators in this area of stroke services trials. Finally, a poster presentation was made at a major international conference to invite interest from trialists (European Stroke Congress 2005).

Methods of the review: Selection of studies

Obviously irrelevant articles were first excluded by me (GE). Two independent reviewers (GE & Peter Langhorne (PL)) then reviewed the retrieved abstracts of papers identified. Papers that clearly did not meet the inclusion criteria were excluded at this stage, and the reason recorded.

A full text copy of all possibly relevant papers was obtained, and two independent reviewers (GE & PL) also assessed these according to pre-defined inclusion criteria. Where there was disagreement, the intention was that Simon Winner and Martin Dennis would moderate. This was not required.

Contact with trialists and data collection

The contact author or lead investigator was contacted and invited to join a collaborative review process. Individual patient data were requested and authors were invited to meet in Glasgow to discuss the development of the review. (The members of this collaborative group are listed at the end of this chapter.)

Authors were asked prior to the meeting for additional information including information on design characteristics, the study population, the intervention, outcome measures used, and length of follow up, as well as additional information regarding the intervention that may not have been apparent in the published papers. Where authors could not be contacted, these trial grids were completed by the author and supervising reviewer (PL) independently. Details on the intervention were then used to construct subgroups according to the apparent emphasis of the intervention (liaison; education and information provision; social support).
The trial grid is attached in Appendix G.

At the trialists meeting (04/03/05), the intentions of the review process and methods were discussed. Trialists were invited to comment on the classification system developed for grouping trials. The trialists felt that the initial system developed (analysis by primary emphasis, Table 5.2) did not adequately describe the similar and differing studies. This discussion led to the development of a subsequent classification (Table 5.1) which was used for the primary analysis.

Following discussion with the trialists, interventions were characterised in three ways:

Proactive and Structured.
These interventions of a consistent intensity sought to contact all patients proactively, and provided input for a defined period of follow up only. They often covered a range of predefined topics against for example a checklist, irrespective of a patients stated needs.

Reactive and Flexible.
These trials typically provided a flexible intervention that met needs as they presented or as requested for a more open-ended time period and variable intensity.

Proactive and Focused.
These trials sought to contact all patients consistently and offer a similar intensity of intervention, but often focussing on a specific issue (such as mental health or risk factor control).

Figure 5.1: Definitions of Intervention Subgroups

Additional subgroup analyses were suggested by the group and are noted in the minutes of the meeting (Appendix H). These included analysis of the intervention by the profession of the individual providing the intervention. The results were also to be presented stratified by timing of referral to stroke liaison worker (less than six months after stroke; more than six months after stroke).

Analysis by patient characteristics included subgroups defined by sex, age (<65 and ≥65), the presence or absence of a main carer and patient functional status at baseline. This last subgroup was considered because one trial in particular had suggested that patients with mild-to-moderate functional dependence had the most to gain from the intervention (70). For this reason the same definitions of dependence were used as in the original; trial (Severe dependence = Barthel <15; Mild to moderate dependence = Barthel 15-19; Independent = Barthel 20). All subgroup definitions were made prior to data analysis and blind to review data.

Assessment of quality

Eligible trials were not given a quality score (331). Nevertheless, the trials were coded with regard to quality of randomisation procedure, method of consent, concealment of treatment allocation, blinding of patients and carers, blinding of outcome assessor, and handling of withdrawals and drop-outs (313).

Analysis

Outcome measures were classified according to which domain they were assessing (activities of daily living; extended activities of daily living; participation; dependency; mental health; subjective health status; knowledge about stroke; use of services; satisfaction with services). Most of the scales used were ordinal. If the same measure had been used in different studies, then a weighted mean difference was calculated across trials using the Cochrane statistical package RevMan 4.2 (Update Software). No meta-analysis was performed where grossly differing outcome measures preclude combination. Where it was possible to dichotomise the data, then odds ratios and 95% confidence intervals were calculated for each study. Where it was not possible to dichotomise the data, the effects on outcome were summarised in terms of direction of effect (in favour of intervention or control), and the size of the effect (in terms of standardised mean differences). Results are presented separately for patients and carers for each domain of outcome.

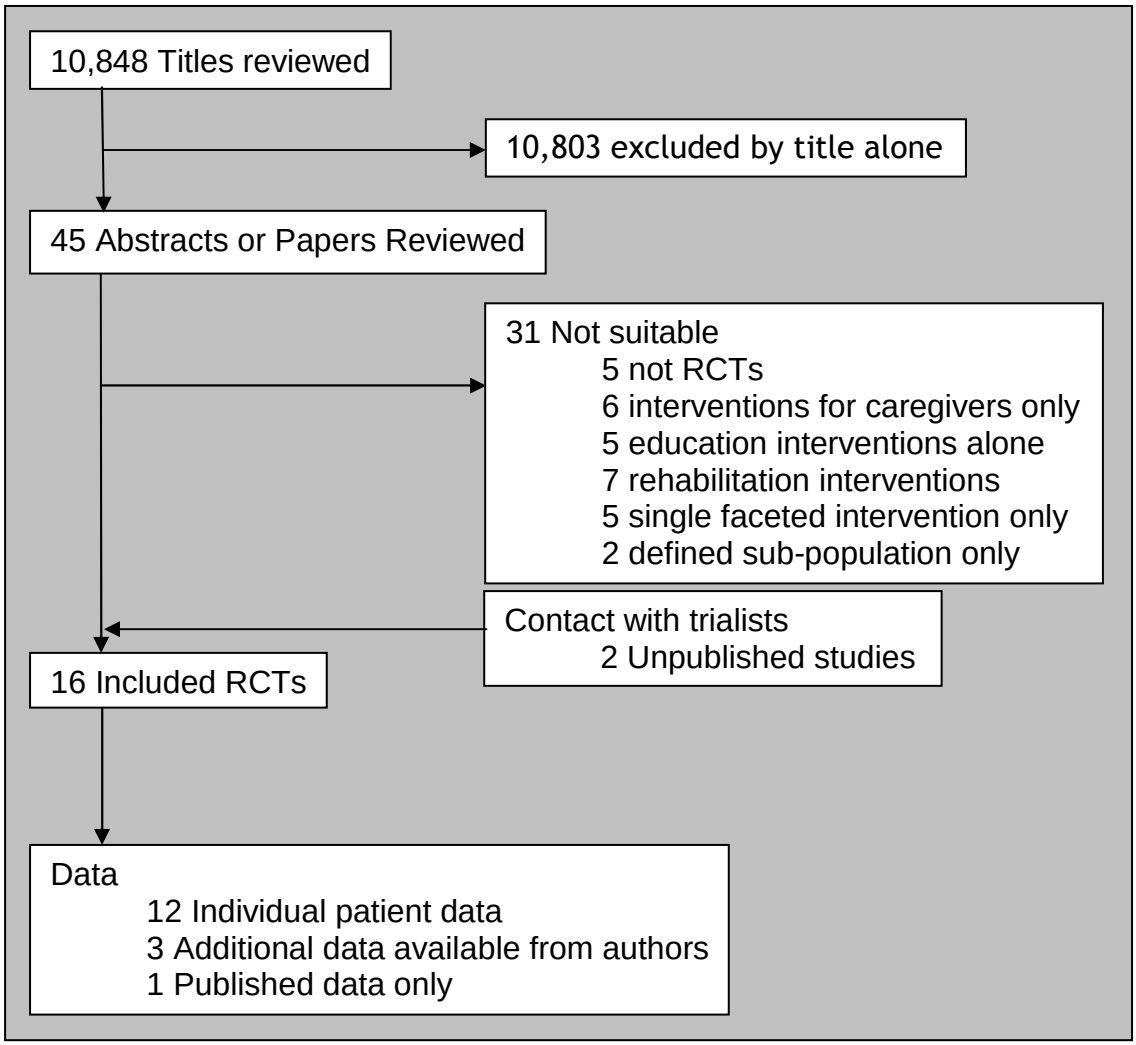
Prior to data analysis, an analysis plan was constructed which included the apriori selection of outcome measures that would be used in the review process. This pre-planned method was used where trialists had evaluated an outcome with more than one outcome measure. Where one measure (e.g. Frenchay Activities Index) was used by several trials, the most commonly used measure was selected. There was the potential risk of the

reviewer selecting an outcome measure that had achieved more positive results, thus influencing the results and it was hoped that the prior planning of analysis would reduce that risk.

In the analysis of satisfaction, due to differences between trials in the questions that were asked, it became necessary to select questions for comparison. An analysis table of satisfaction questions was constructed (Table 5.29). Questions were selected for analysis only if they appeared in two or more studies. All satisfaction questions involved a likert scale with four separate categories of satisfaction (highly satisfied, satisfied, dissatisfied and highly dissatisfied). Results were contracted into a dichotomised outcome (satisfied or dissatisfied) and data were entered into analysis to produce an odds ratio for reporting being satisfied.

Individual patient data was cross checked for completeness on receipt. In addition they were cross checked with published data. For subgroup analysis, data were split into separate databases and analysed separately. Double data entry was used for data entry into RevMan to ensure the avoidance of simple errors. The direction of effect for each outcome measure in each trial was checked and all tables were cross checked on completion for errors and completeness.

Figure 5.2: Trial Selection



Results

Review process results

The search strategy revealed 10,848 titles to be reviewed (search date August 2004). From these titles 45 studies were selected as being of possible relevance to the review. Where possible the full text of these studies was sought or the abstract where a full paper was not available. Of these studies, 31 were considered unsuitable for the systematic review. Five were not randomised controlled trials, six evaluated interventions for caregivers only. A further five studies evaluated education interventions only. Seven studies evaluated some form of physical rehabilitation and a further five evaluated a single faceted intervention only such as social support alone (71). Two additional studies were identified that evaluated only a sub-population (such as post surgical subarachnoid haemorrhages only). Trial selection is illustrated in Figure 5.2.

Selected Trials

The search strategy identified 14 published randomised trials. Two additional unpublished trials were identified following contact with trialists. One (Leeds) evaluated two interventions in separate arms; the input of a volunteer or a psychologist for problem solving therapy compared to usual care. One study (Liverpool – the "Life after Stroke" study) evaluated three separate interventions, alone or combined. These included a stroke family support worker (social), a psychology intervention (psychology) and an occupational therapy intervention (physical). Only the stroke family support worker and the psychology arms of the study were considered relevant for inclusion and where these elements were combined, the data were also excluded.

Individual patient data were obtained for 12 studies, with additional tabulated data obtained for two additional trials (Philadelphia STAIR study and Adelaide). Limited information from one unpublished trial was available from correspondence with the author (Melbourne SHIPS trial). Published data only were available for one additional trial (Melbourne).

The 16 trials came from 4 countries (Australia, Holland, UK and USA). Most were based in city hospitals and evaluated services in urban populations. 13 studies described adequate allocation concealment. (Tables 5.10–5.25) 11 studies performed blinding of the final outcome assessor and two studies performed additional patient blinding by a means of delayed or modified consent (Edinburgh, Utrecht) (159).

The intervention characteristics are shown in Tables 5.10-5.25. Subgroup allocations for the primary analysis are shown in table 5.1. Four interventions were classified as employing a proactive and structured approach to the intervention. Eight interventions were reactive and flexible, whilst six interventions employed a proactive but focussed approach. Subgroup analysis by intervention emphasis is also illustrated in table 5.2.

Publication bias is recognised as potential risk for meta-analysis. Negative studies are less likely to be published or cited and therefore are at risk of not being included in a meta-analysis (313). As a result the review is likely to bias towards a more positive treatment result. Similarly, studies of poorer methodological quality are more likely to show a positive result and give rise to a biased result due to methodological bias. To evaluate the risk of publication bias in this review, we prepared a funnel plot of all included studies for the primary outcome (subjective health status) shown in Figure 5.3.

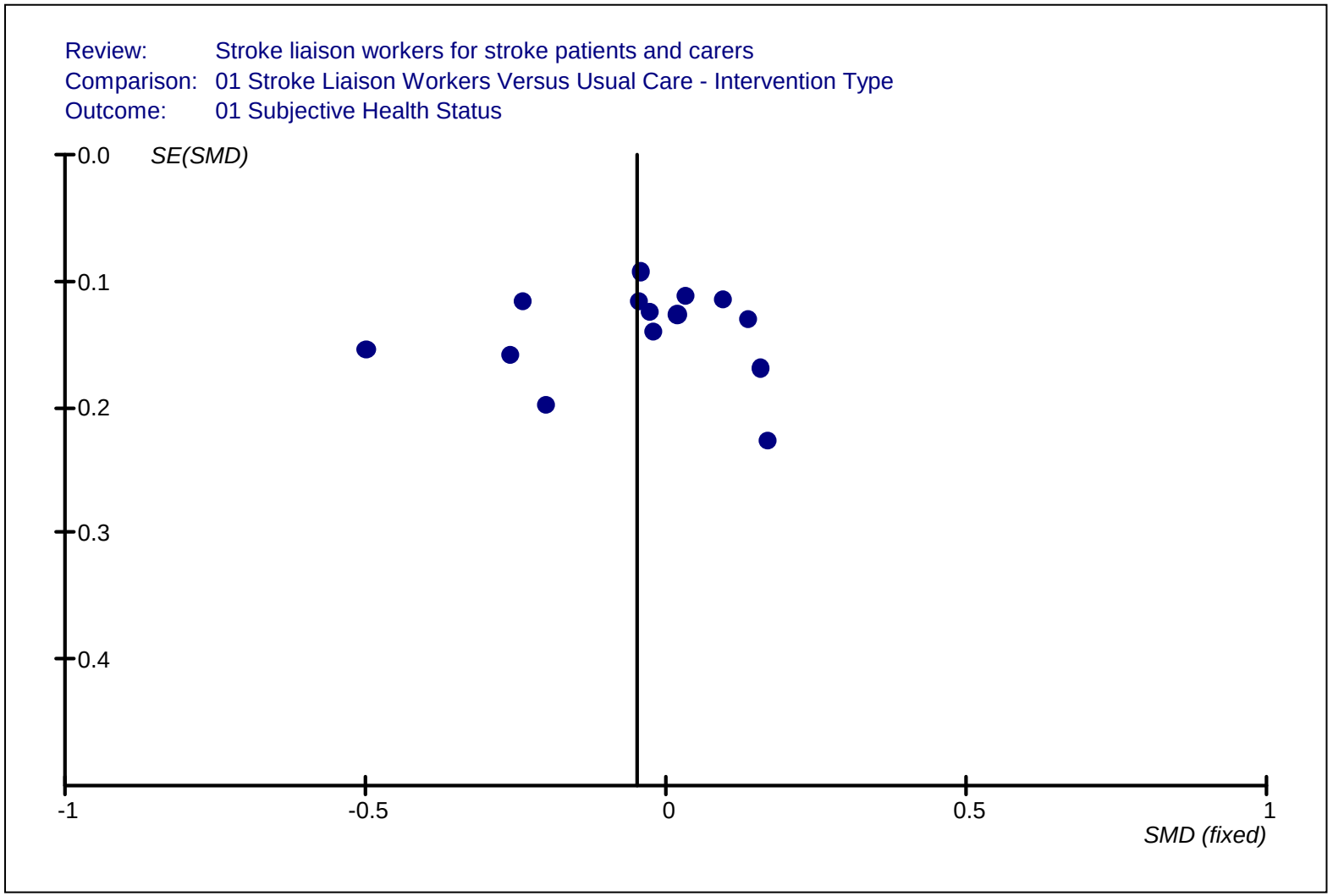


Figure 5.3: Funnel Plot of Included Trials

The analysis plan for each trial and outcome measure is shown in Tables 5.26-28. The satisfaction questions selected for comparison are shown in Table 5.29.

Available data for some outcomes was very limited and not combinable. For instance knowledge was only apparently evaluated in two studies (Oxford/Mansfield). Neither study used validated methods to test that knowledge and data were only available for one study (Oxford). For this reason, no attempt has been made to perform a meta-analysis of knowledge as an outcome. Similarly, data on caregiver knowledge were only available for one study (Oxford). Resource or service usage was reported in several studies (Edinburgh, Liverpool, Melbourne SHIPS, Oxford, Philadelphia and Utrecht). Data were only available for two of these studies (Oxford, Utrecht). Due to variations in service provision, and differences in the available data it was felt to be too difficult to combine and dichotomise these data. For this reason, no meta-analysis of service usage has been performed.

After receipt of data it became apparent that analysis of mental health under one single heading was potentially inaccurate where some general measures of mental health (such as GHQ28) were being combined with more specific measures of depression (such as the HADS-Depression scale) or anxiety (HADS-Anxiety scale). In addition, since it was apparent that some studies had used the Anxiety scale of the HADS, it was felt to be of potential additional value to split mental health outcomes into depression and anxiety in addition to analysis under a generic mental health domain. It was considered plausible that the intervention might reduce anxiety without necessarily reducing depression. This decision was made post-hoc, and therefore the results are presented with that caution alongside generic mental health results as originally planned.

Review results

These data are presented in two stages for simplicity. Overall data have been presented here with subgroups as pre-planned by the collaborative group according to intervention characteristic (Table 5.1, Figures 5.4-5.50).

Primary Patient outcomes

1. Subjective health status: Analysis of data for 3349 participants (13 interventions) did not show a significant overall difference between the intervention and control groups for this outcome, although the direction of effect was in favour of the intervention (SMD -0.05, 95% CI -0.11 to 0.02, p=0.18). Tests for heterogeneity were borderline (Chi^2 heterogeneity p=0.08), however no single subgroup showed a significant effect. Considerable heterogeneity (Chi^2 heterogeneity p=0.007) was present in the Proactive and Structured subgroup, largely due to the positive results of one study (Preston).

2. Extended activities of daily living: Analysis of data for 3258 patients (15 interventions) did not show any benefit of Stroke Liaison Workers over control group for an improvement in extended activities of daily living (SMD 0.04, 95% CI -0.03 to 0.11, p=0.22). In addition there were no positive subgroups. No significant subgroup interaction was present (Chi^2 heterogeneity p>0.05).

Secondary Patient Outcomes

1. Death: There was no significant effect of the Stroke Liaison Worker intervention on the outcome of death. (4181 participants, 16 interventions, OR 0.87, 95% CI 0.72 to 1.06, p=0.17). There was no single subgroup effect and no subgroup interaction (Chi^2 p>0.05).

2. Place of residence (Institutionalisation): Data was more limited for analysis of institutionalisation (1146 participants, 6 interventions), however there was no overall effect (OR 0.83, 95% CI 0.51 to 1.36, p=0.46) and no significant subgroup effect (Chi^2 p>0.05).

3. Activities of daily living: No significant benefit was seen on activities of daily living for the intervention group compared to the control group (3457 participants, 15 interventions, SMD -0.02, 95% CI -0.09 to 0.05, p=0.55). No subgroup interaction existed (Chi^2 p>0.05).

4. Dependency: Data on dependency was more limited (1494 participants, 4 trials) and were not available for one subgroup (Proactive and Focused). No overall benefit was seen for the Stroke Liaison Worker intervention, with the direction of benefit favouring the control group (SMD 0.03, 95% CI -0.07 to 0.14, p=0.53). There was no significant heterogeneity seen between the two remaining subgroups (Chi^2 p >0.05). Few outcome measures for dependency were used, providing only limited outcome data for dependency (four trials, 1,494 participants). In contrast a larger number of studies (12 interventions, 2,906 participants), used the Barthel measure. We therefore decided to dichotomise the Barthel measure as an outcome for dependency. The potential "cut-point" for dependency was discussed with trialists and set at 19/20 (i.e. dependent in one or more activities of daily living). This decision was made prior to analysis of the data without prior knowledge of the results. Analysis using this outcome for dependency yielded greater participant involvement across a greater range of studies. In addition it allowed the use of odds ratios for an identical outcome measure allowing more accurate combination of results. For this reason, subsequent analyses for the outcome of dependency were conducted using this definition of dependency. Overall, there was no significant difference between the treatment and control groups for a reduction in dependence (OR 0.90, 95% CI 0.76 to 1.06, p=0.20). There was a

trend to a reduction in dependence in the Proactive and Structured group (OR 0.72, 95% CI 0.52 to 1.01, p=0.06), although this was not statistically significant and there was no subgroup interaction (Chi^2 p>0.05).

5. Mental Health (Generic): Data were available for 3314 participants from 15 interventions. Overall results did not suggest any beneficial effect of Stroke Liaison Workers compared to control for an improvement in mental health score (SMD -0.02, 95% CI -0.09 to 0.05, p=0.56). One subgroup (the Proactive and Focused subgroup) showed a trend toward benefit from the Stroke Liaison Workers versus control (p=0.09). This might not be surprising given that many of the interventions in this group had a psychological focus, however there was no subgroup interaction (Chi^2 p>0.05) to support this effect.

6. Mental Health (Depression): Analysis of data from 15 interventions (2949 participants) did not show any evidence of a beneficial effect from the input of a Stroke Liaison Worker when compared to the control group, despite the direction of effect favouring the treatment group (SMD -0.05, 95% CI -0.12 to 0.02, p=0.17). Again one group (Proactive and Structured) demonstrated a trend towards a benefit from the Stroke Liaison Workers (p=0.08), however again there was no subgroup interaction to support this effect (Chi^2 p>0.05).

7. Mental Health (Anxiety): Data were available for two subgroups (Proactive and Structured, Reactive and Flexible) involving 5 interventions (1222 participants). No significant benefit was seen for the intervention group (WMD -0.20, 95% CI -0.66 to 0.26, p=0.39). Tests for heterogeneity were borderline overall (p>0.05), predominantly because of one study (Adelaide) that showed a positive treatment effect (-1.7, 95% CI -2.89 to -0.51), however this study reported differences in the groups at baseline that may have accounted for the effect.

8. Participation: Results for participation were more limited in the number of participants (n=886) and only available for one subgroup (Reactive and Flexible). Overall there were no significant differences between the groups (SMD -0.04, 95% CI -0.17 to 0.10, p=0.59) and there was no heterogeneity within the available subgroup (p>0.05).

Primary Caregiver Outcome:

1. Caregiver Subjective Health Status: Data for 1921 caregivers was available from 15 interventions. The predominant measure used was the Carer strain index (9/13 trials). For this reason, this measure was used in the Oxford study, rather than the more positive published Carer SF36. Although the direction of effect was in favour of the control group, there was no overall significant effect (SMD 0.04, 95% CI -0.05 to 0.13, p=0.33) and no significant subgroup or subgroup interaction (Chi^2 p>0.05).

Secondary Caregiver Outcomes:

1. Caregiver extended activities of daily living: Only two subgroups (Proactive and Structured, Reactive and Flexible) had adequate data from 5 trials (776 participants). There was a trend to an improvement in extended activities of living in the control group (SMD -0.13, 95% CI -0.28 to 0.01, p=0.07). No significant subgroup interaction existed (Chi^2 p>0.05).

2. Caregiver mental health: Data for 1777 caregivers was analysed across 13 intervention arms. No significant overall effect or subgroup effect existed. (SMD -0.02, 95% CI -0.12 to 0.07, p=0.62, heterogeneity p>0.05).

Patient Satisfaction Data

Satisfaction data are presented in Figures 5.18-5.34

In summary, only one domain of patient satisfaction reached a statistically significant result with data from three trials (915 participants). Patients in the intervention group were significantly more satisfied that "Someone has really listened" (OR 1.58, 95% CI 1.14 to 2.19, p=0.006). Subgroup results suggested borderline heterogeneity (Chi^2 p=0.07), with one subgroup (Reactive and Flexible) strongly positive (two trials, n=439, p=0.0005) and one (Proactive and Structured) being neutral (one trial, n=470, p=0.61).

Carer Satisfaction Data

Carer Satisfaction data are presented in Figures 5.35-5.50

Four questions for carers yielded statistically significant results.

1. "I received all the information I needed about the nature and causes of the patient's illness" was included in three trials (459 caregivers) from one subgroup (Reactive and Flexible). The question was positive in favour of the Stroke Liaison Worker arm of the trial (OR 1.72, 95% CI 1.04 to 2.85, p=0.03).

2. "I have received enough information about recovery and rehabilitation" was answered favourably by the treatment group in three trials (457 caregivers, OR 1.98, 95% CI 1.25 to 3.14, p=0.004).

3. "Someone has really listened" was answered in two trials (Edinburgh and London), both in the same subgroup, with a smaller number of caregivers (n=300, OR 2.56, 95% CI 1.52 to 4.31, p=0.0004).

4. Caregivers in the Stroke Liaison Workers group were more likely to report that they felt that they were not neglected (OR 2.62, 95% CI 1.44 to 4.77, p= 0.002) than in the control group.

Table 5.1: Subgroup Analysis: Intervention Characteristics

	N in analysis	*Analysis*	*Total [95% CI]*	*Subgroup Heterogeneity (Chi^2)*	*Subgroup Results*		
					Proactive and Structured	**Reactive and Flexible**	**Proactive and Focused**
Primary Outcomes for Patients							
Subjective Health Status	3349	SMD	-0.05 (-0.11, 0.02), p=0.18	>0.05	-0.05 (-0.17, 0.07), p=0.43	0.01 (-0.10, 0.13), p=0.83†	-0.10 (-0.22, 0.01), p=0.08
Extended Activities of Daily Living	3260	SMD	0.04 (-0.03, 0.11), p=0.23	>0.05	0.09 (-0.03, 0.21), p=0.15	0.07 (-0.04, 0.18), p=0.22	-0.05 (-0.18, 0.08), p=0.49†
Secondary Outcomes for Patients							
Death	4183	OR	0.87 (0.72, 1.06), p=0.17	>0.05	1.14 (0.66, 1.95), p=0.64†	0.83 (0.65, 1.06), p=0.14	0.86 (0.59, 1.27), p=0.46
Place of Residence (Institutionalisation)	1146	OR	0.83 (0.51, 1.36), p=0.46	>0.05	1.00 (0.34, 2.94), p=1.00	1.00 (0.42, 2.38), p=1.00	0.67 (0.32, 1.39), p=0.28
Activities of Daily Living	3463	SMD	-0.02 (-0.09, 0.05), p=0.55	>0.05	0.07 (-0.06, 0.20), p=0.32	-0.03 [-0.14, 0.07], p=0.51†	-0.08 [-0.20, 0.05], p=0.22†
Dependence*	2908	OR	0.90 (0.76, 1.06), p=0.20	>0.05	0.72 (0.52, 1.01), p=0.06	0.95 (0.74, 1.21), p=0.67	0.99 (0.73, 1.33), p=0.94
Depression	2949	SMD	-0.05 (-0.12, 0.02), p=0.17	>0.05	-0.13 (-0.28, 0.02), p=0.08	0.03 (-0.08, 0.15), p=0.56†	-0.09 (-0.21, 0.03), p=0.14
Anxiety	1222	SMD	-0.20 (-0.66, 0.26), p=0.39	>0.05	-0.38 (-0.18, 0.42), p=0.35	-0.11 (-0.67, 0.45), p=0.70	NA
Participation	886	SMD	-0.04 (-0.17, 0.10), p=0.59	NA	NA	-0.04 (-0.17, 0.10), p=0.59	NA
Primary Outcome for Carers							
Subjective Health Status	1915	SMD	0.04 (-0.05, 0.13), p=0.33†	>0.05	0.06 (-0.10, 0.21), p=0.46†	0.02 (-0.12, 0.16), p=0.76†	0.06 (-0.12, 0.25), p=0.49†
Secondary Outcome for Carers							
Extended Activities of Daily Living	752	SMD	-0.13 (-0.28, 0.01), p=0.07†	>0.05	-0.10 (-0.35, 0.15), p=0.42†	-0.15 (-0.32, 0.03), p=0.10†	NA
Caregiver Mental Health	1777	SMD	-0.02 (-0.12, 0.07), p=0.62	>0.05	0.02 (-0.15, 0.20), p=0.80†	-0.08 (-0.22, 0.06), p=0.27	0.02 (-0.16, 0.21), p=0.81†

Subgroup analysis was stratified by intervention characteristic
*Defined as Barthel score ≤19
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group.)
SMD = Standardised Mean Difference, OR = Odds Ratio

Figure 5.4: Patients' Subjective Health Status

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 01 Subjective Health Status

Study or sub-category	Treatment N	Treatment Mean (SD)	Control N	Control Mean (SD)	SMD (fixed) 95% CI	Weight %	SMD (fixed) 95% CI
01 Proactive and Structured							
Bradford	120	123.25(115.02)	120	108.80(95.14)		7.23	0.14 [-0.12, 0.39]
Preston	87	158.36(113.82)	89	218.94(127.37)		5.15	-0.50 [-0.80, -0.20]
Utrecht	227	-60.28(20.88)	246	-59.39(20.99)		14.25	-0.04 [-0.22, 0.14]
Rhode Island	62	-54.33(23.28)	82	-57.97(22.71)		4.25	0.16 [-0.17, 0.49]
Subtotal (95% CI)	496		537			30.88	-0.05 [-0.17, 0.07]
Test for heterogeneity: Chi² = 12.20, df = 3 (P = 0.007), I² = 75.4%							
Test for overall effect: Z = 0.79 (P = 0.43)							
02 Reactive and Flexible							
Liverpool	85	3.66(4.10)	77	4.74(4.13)		4.84	-0.26 [-0.57, 0.05]
Edinburgh	156	8.22(7.05)	154	7.57(7.13)		9.35	0.09 [-0.13, 0.31]
Oxford	156	4.39(0.91)	167	4.36(1.00)		9.74	0.03 [-0.19, 0.25]
Adelaide	39	-39.70(6.40)	40	-40.90(7.60)		2.38	0.17 [-0.27, 0.61]
Mansfield	126	16.55(7.62)	124	16.41(7.39)		7.55	0.02 [-0.23, 0.27]
Subtotal (95% CI)	562		562			33.84	0.01 [-0.10, 0.13]
Test for heterogeneity: Chi² = 4.00, df = 4 (P = 0.41), I² = 0%							
Test for overall effect: Z = 0.22 (P = 0.83)							
03 Proactive and Focused							
Leeds (Psychology)	151	4.50(5.26)	150	5.77(5.31)		9.02	-0.24 [-0.47, -0.01]
Leeds (Volunteers)	149	5.52(5.40)	150	5.77(5.31)		9.02	-0.05 [-0.27, 0.18]
Liverpool (Psych)	39	3.90(4.33)	77	4.74(4.13)		3.11	-0.20 [-0.58, 0.19]
Boston (FIRST)	129	2.77(1.05)	134	2.80(1.05)		7.94	-0.03 [-0.27, 0.21]
Glasgow	100	-63.06(21.41)	105	-62.58(22.82)		6.18	-0.02 [-0.30, 0.25]
Subtotal (95% CI)	568		616			35.28	-0.10 [-0.22, 0.01]
Test for heterogeneity: Chi² = 2.57, df = 4 (P = 0.63), I² = 0%							
Test for overall effect: Z = 1.73 (P = 0.08)							
Total (95% CI)	1626		1715			100.00	-0.05 [-0.11, 0.02]
Test for heterogeneity: Chi² = 20.63, df = 13 (P = 0.08), I² = 37.0%							
Test for overall effect: Z = 1.34 (P = 0.18)							

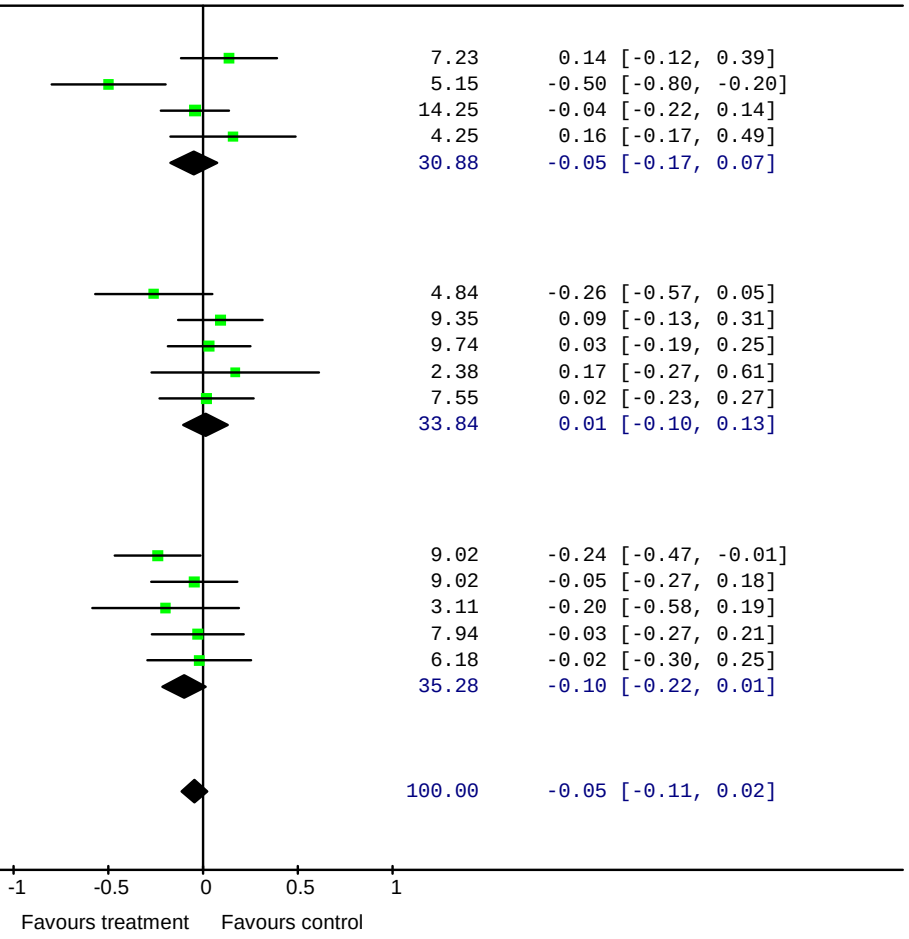


Figure 5.5: Patients' Extended Activities of Daily Living

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 02 Extended Activities of Daily Living

Study or sub-category	Treatment N	Treatment Mean (SD)	Control N	Control Mean (SD)	SMD (fixed) 95% CI	Weight %	SMD (fixed) 95% CI
01 Proactive and Structured							
Bradford	120	13.37(8.73)	120	12.19(9.39)		7.42	0.13 [-0.12, 0.38]
Preston	87	16.02(10.25)	89	14.81(10.64)		5.44	0.12 [-0.18, 0.41]
Utrecht	236	19.34(2.20)	252	19.31(1.75)		15.10	0.02 [-0.16, 0.19]
Rhode Island	63	23.51(10.27)	81	20.75(12.26)		4.36	0.24 [-0.09, 0.57]
Subtotal (95% CI)	506		542			32.32	0.09 [-0.03, 0.21]
Test for heterogeneity: Chi² = 1.60, df = 3 (P = 0.66), I² = 0%							
Test for overall effect: Z = 1.43 (P = 0.15)							
02 Reactive and Flexible							
Liverpool	84	12.70(7.49)	77	12.03(7.45)		4.97	0.09 [-0.22, 0.40]
Edinburgh	164	21.66(9.66)	164	21.24(11.55)		10.16	0.04 [-0.18, 0.26]
Oxford	156	16.23(11.48)	167	15.98(10.56)		9.99	0.02 [-0.20, 0.24]
Adelaide	32	21.60(5.50)	30	18.30(5.10)		1.83	0.61 [0.10, 1.12]
Mansfield	126	23.64(16.48)	124	25.73(16.26)		7.73	-0.13 [-0.38, 0.12]
London	83	-15.06(3.05)	86	-16.00(3.22)		5.18	0.30 [-0.01, 0.60]
Subtotal (95% CI)	645		648			39.86	0.07 [-0.04, 0.18]
Test for heterogeneity: Chi² = 9.23, df = 5 (P = 0.10), I² = 45.8%							
Test for overall effect: Z = 1.24 (P = 0.22)							
03 Proactive and Focused							
Leeds (Psychology)	116	12.74(10.79)	124	15.37(11.97)		7.38	-0.23 [-0.48, 0.02]
Leeds (Volunteers)	124	14.37(11.23)	124	15.37(11.97)		7.68	-0.09 [-0.33, 0.16]
Liverpool (Psych)	39	13.64(7.84)	77	12.03(7.45)		3.19	0.21 [-0.18, 0.60]
Philadelphia (STAIR)	21	31.00(8.30)	21	31.10(10.70)		1.30	-0.01 [-0.62, 0.59]
Boston (FIRST)	133	10.83(3.15)	134	10.68(2.98)		8.27	0.05 [-0.19, 0.29]
Subtotal (95% CI)	433		480			27.82	-0.05 [-0.18, 0.08]
Test for heterogeneity: Chi² = 4.42, df = 4 (P = 0.35), I² = 9.5%							
Test for overall effect: Z = 0.70 (P = 0.49)							
Total (95% CI)	1584		1670			100.00	0.04 [-0.03, 0.11]
Test for heterogeneity: Chi² = 17.81, df = 14 (P = 0.22), I² = 21.4%							
Test for overall effect: Z = 1.23 (P = 0.22)							

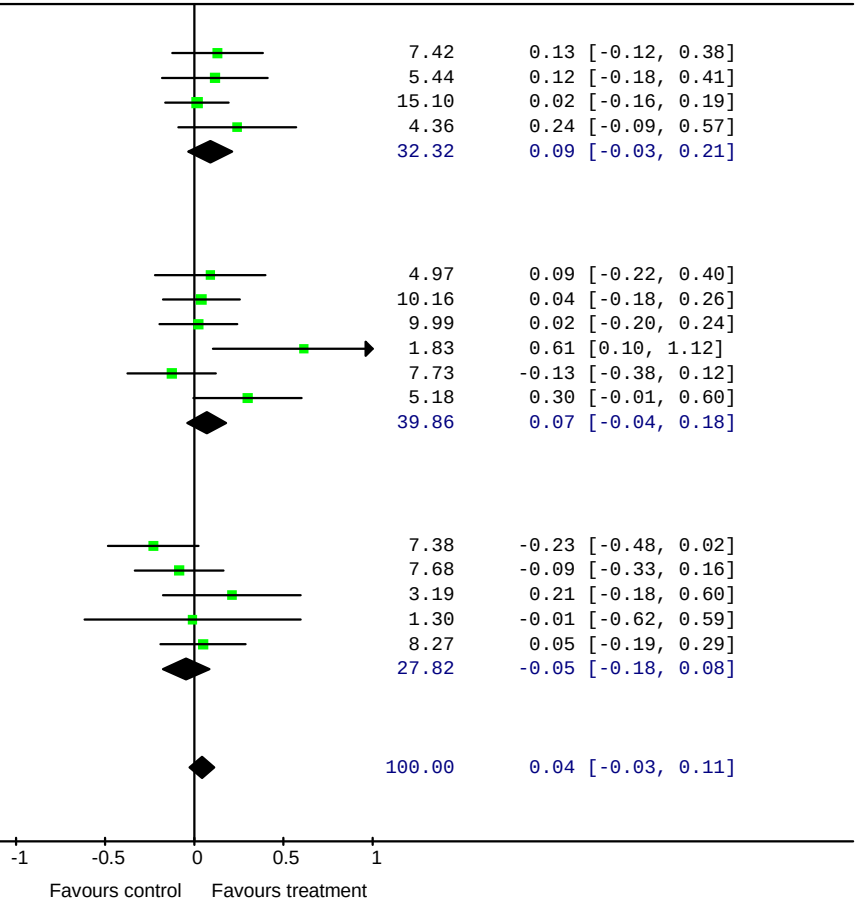


Figure 5.6: Death

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 03 Death

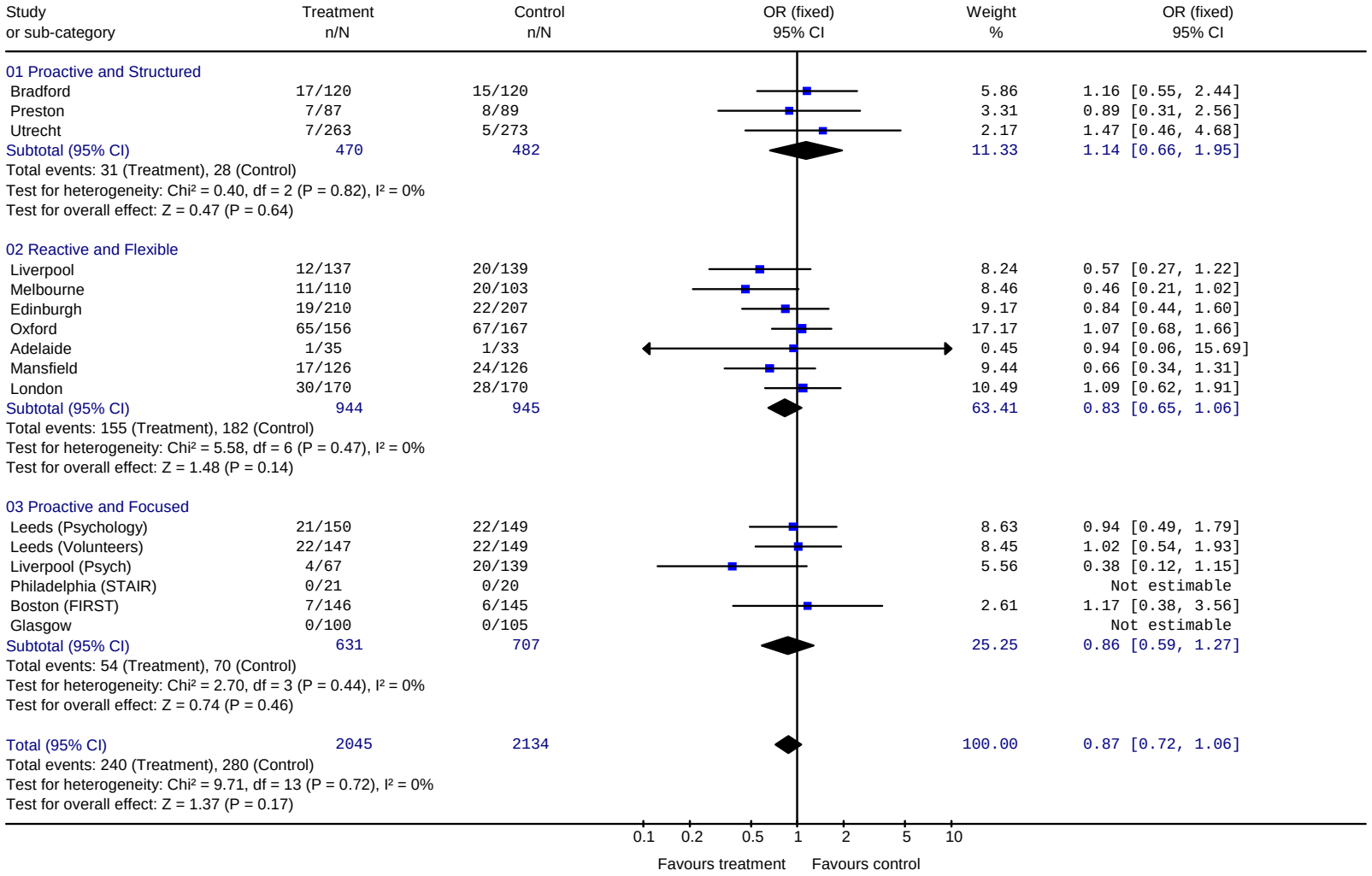


Figure 5.7: Institutionalisation

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 04 Place of Residence

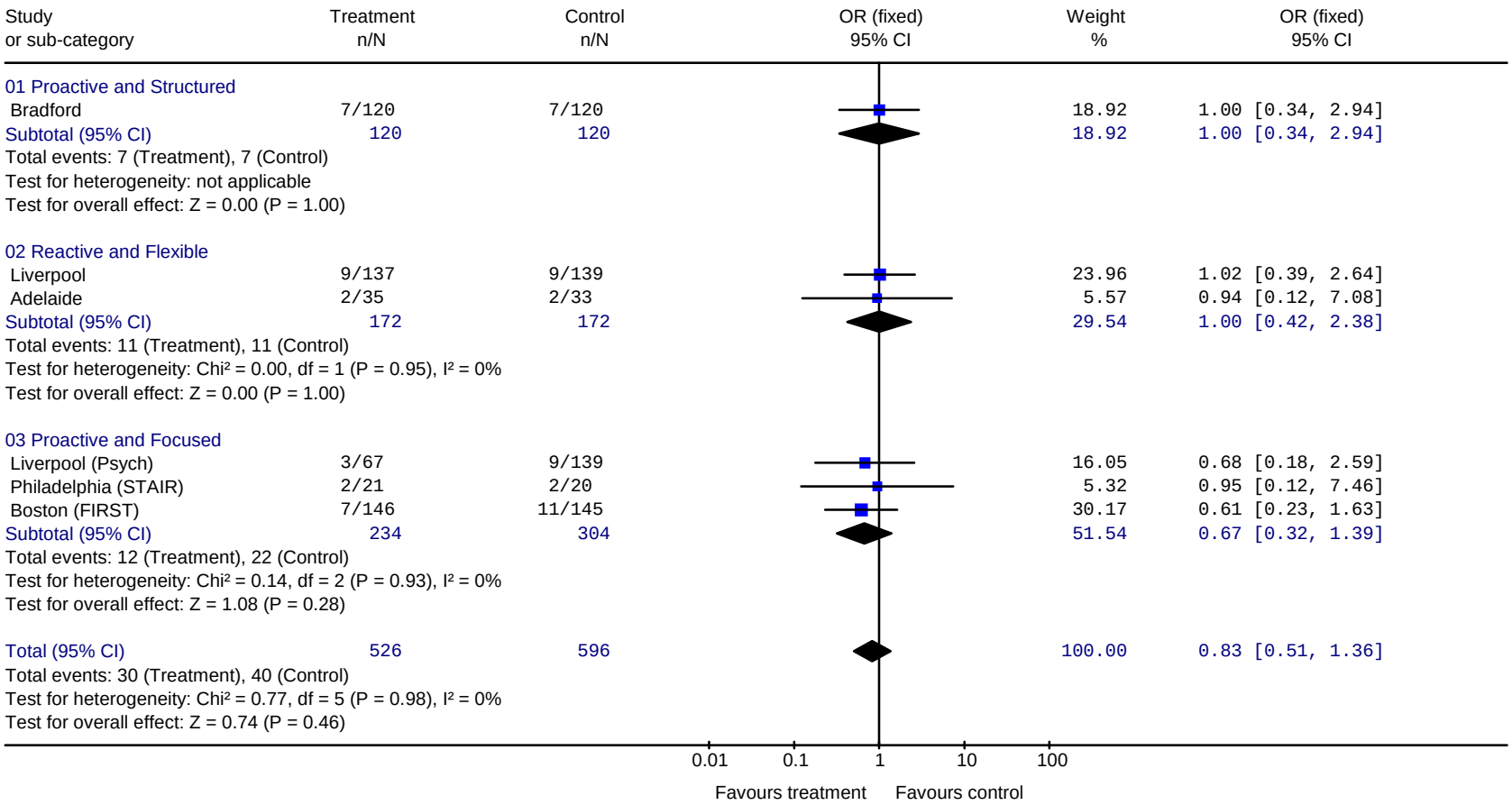


Figure 5.8: Patients' Activities of Daily Living

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 05 Activities of Daily Living

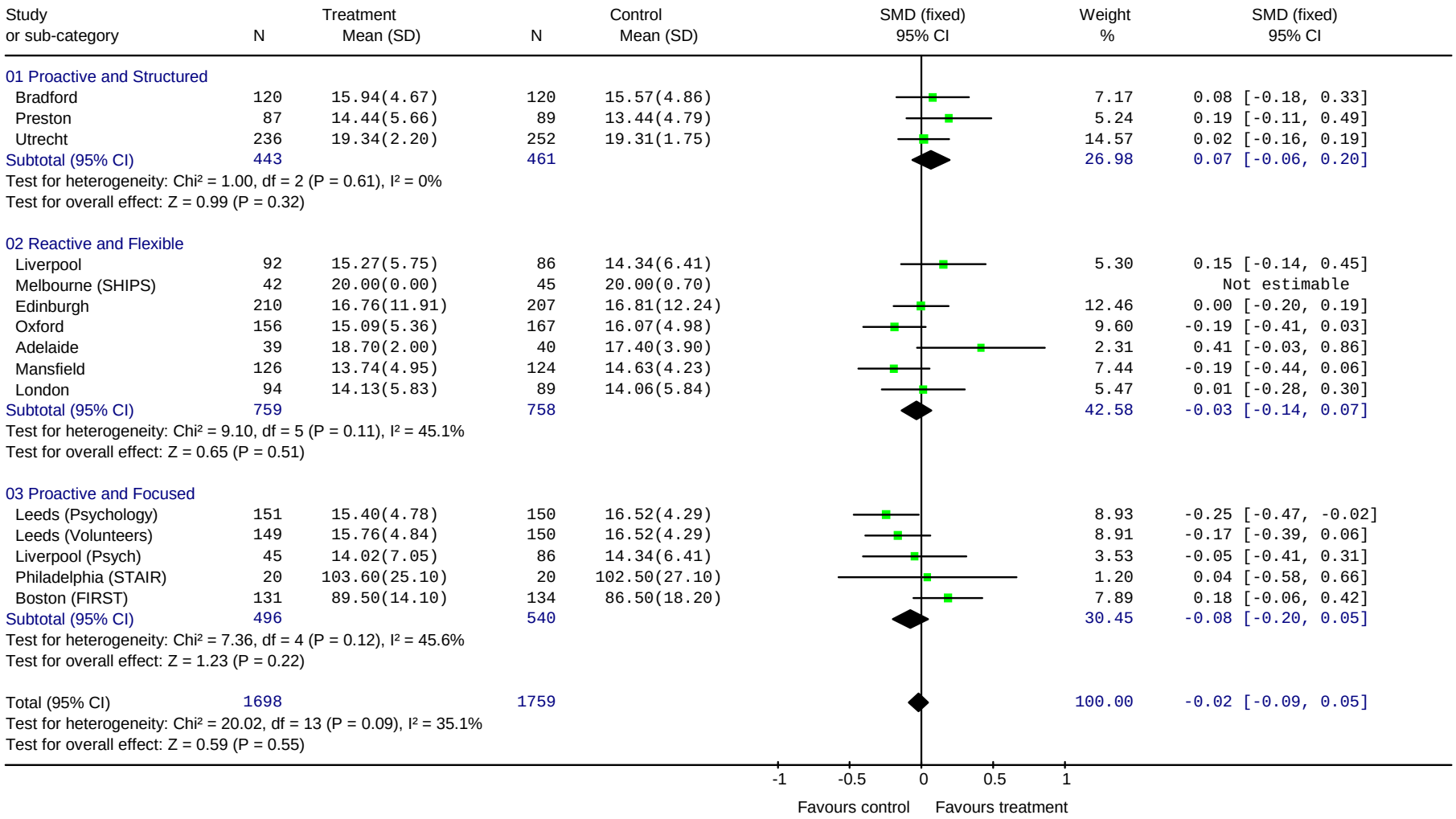


Figure 5.9: Patient Dependency

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 06 Dependency

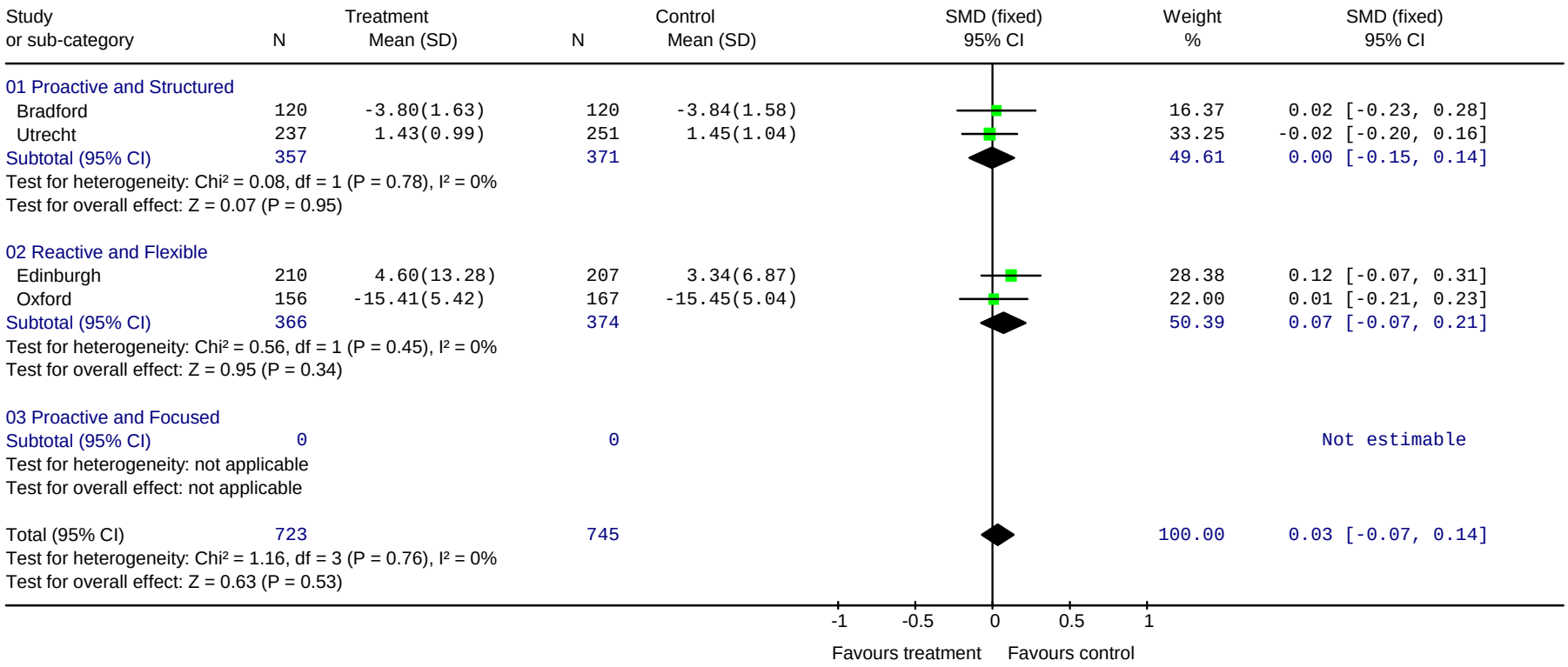


Figure 5.10: Patient Dependence (Defined as Barthel ≤19)

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 10 Dependence (Defined as a Barthel </= 19)

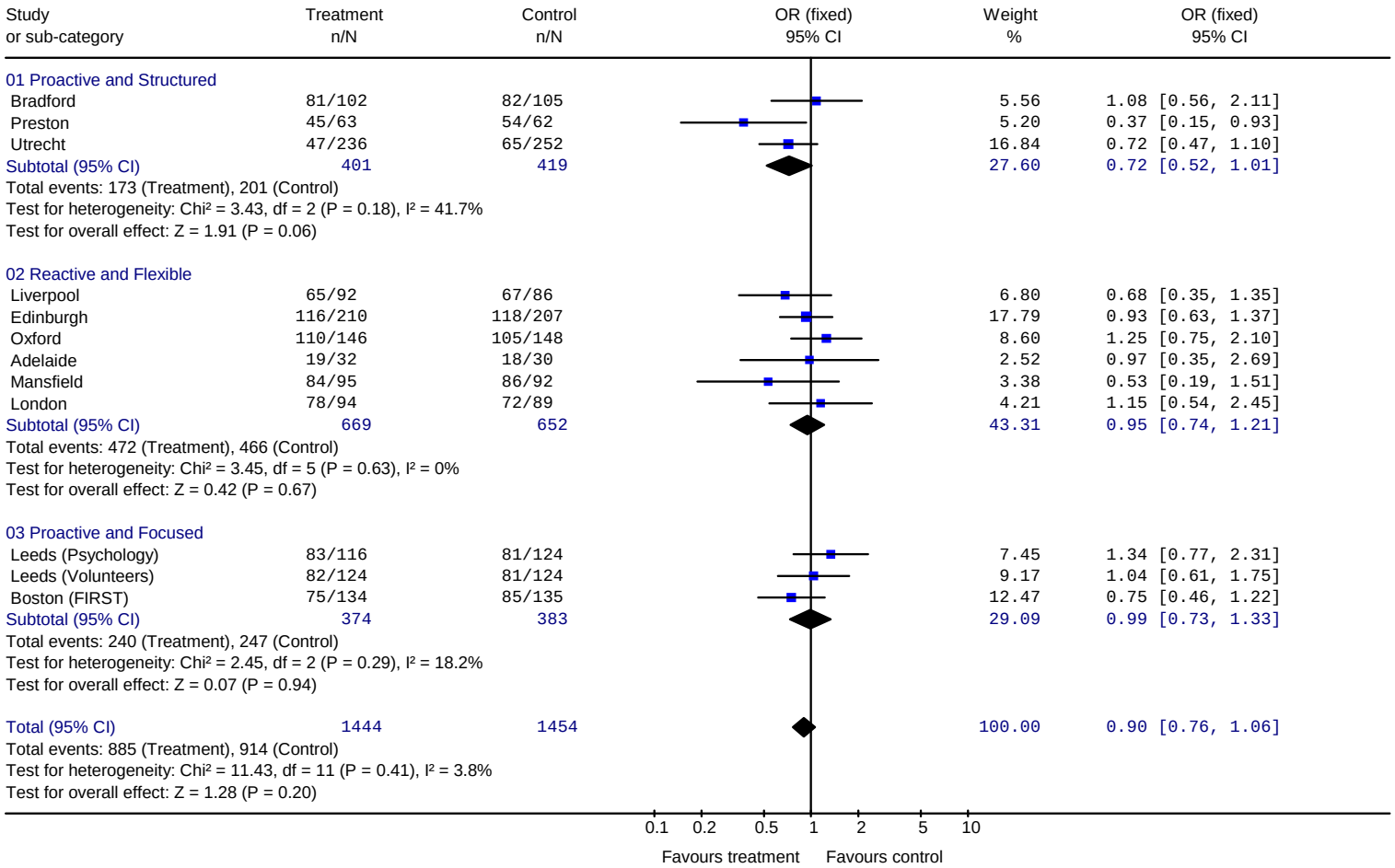


Figure 5.11: Patients' Mental Health (Generic Measures)

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 07 Mental Health - Generic

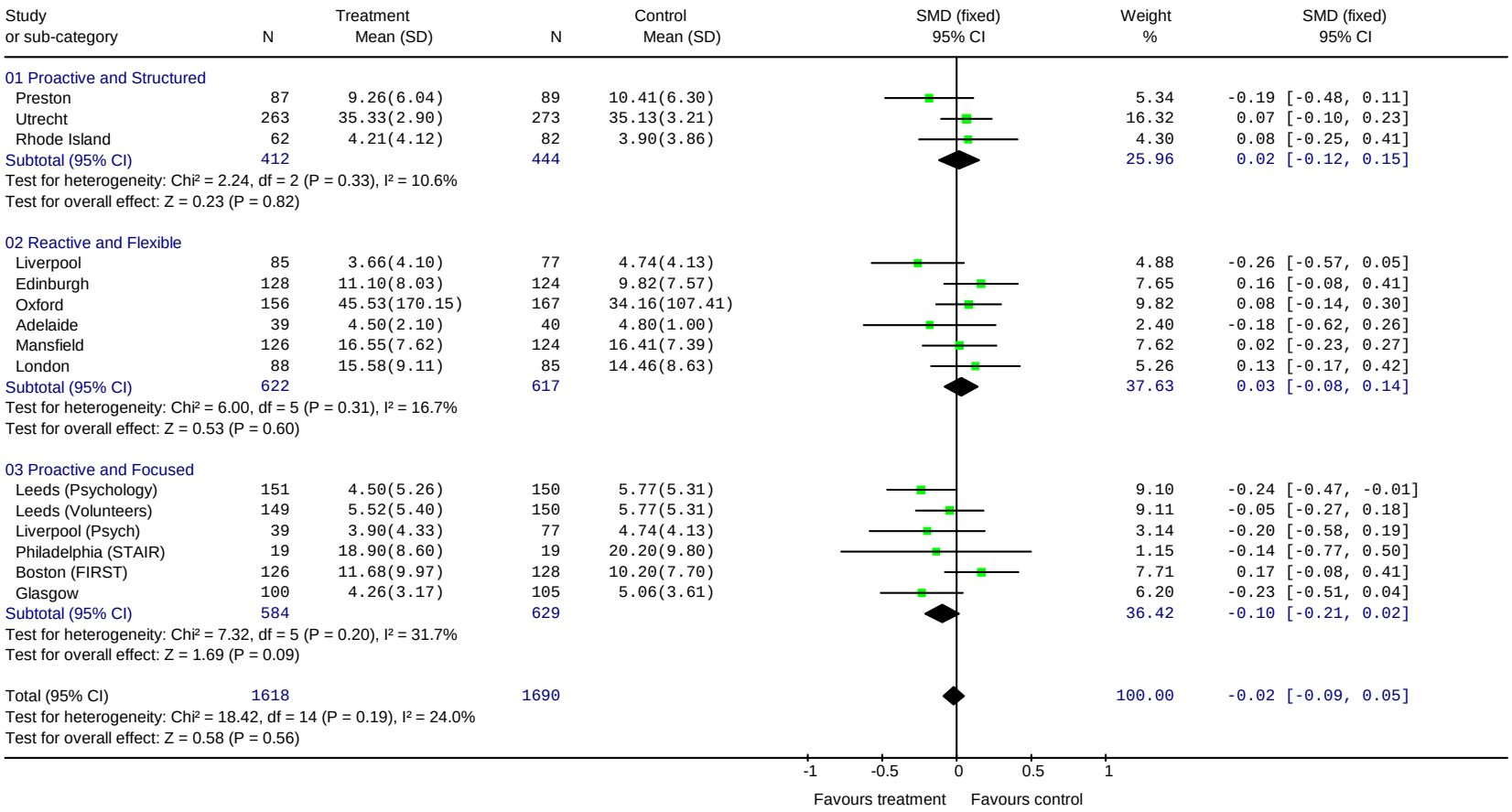


Figure 5.12: Patient Depression (Specific Measures)

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 51 Mental Health: Depression

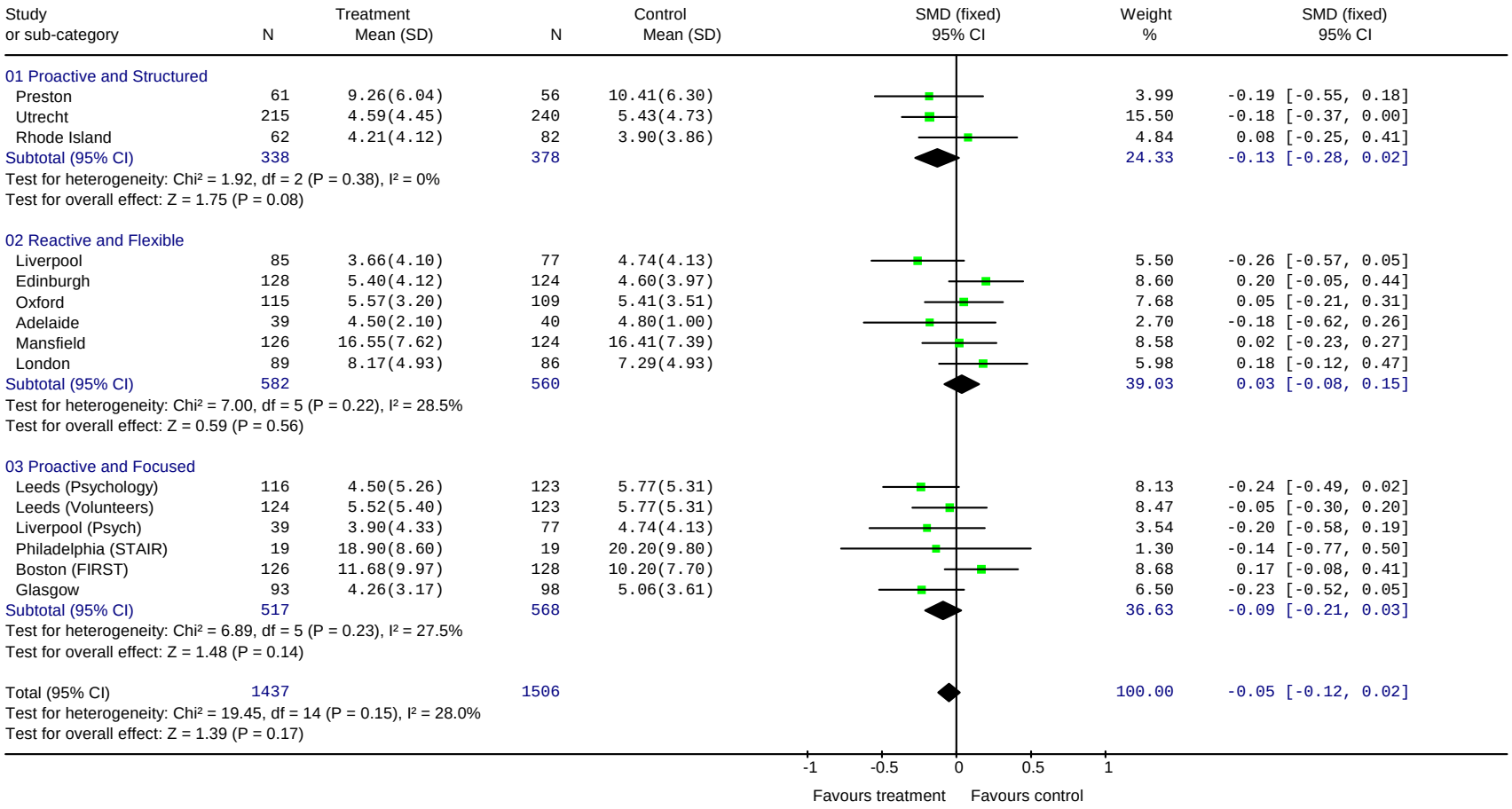


Figure 5.13: Patient Anxiety (Specific Measures)

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 52 Mental Health: Anxiety

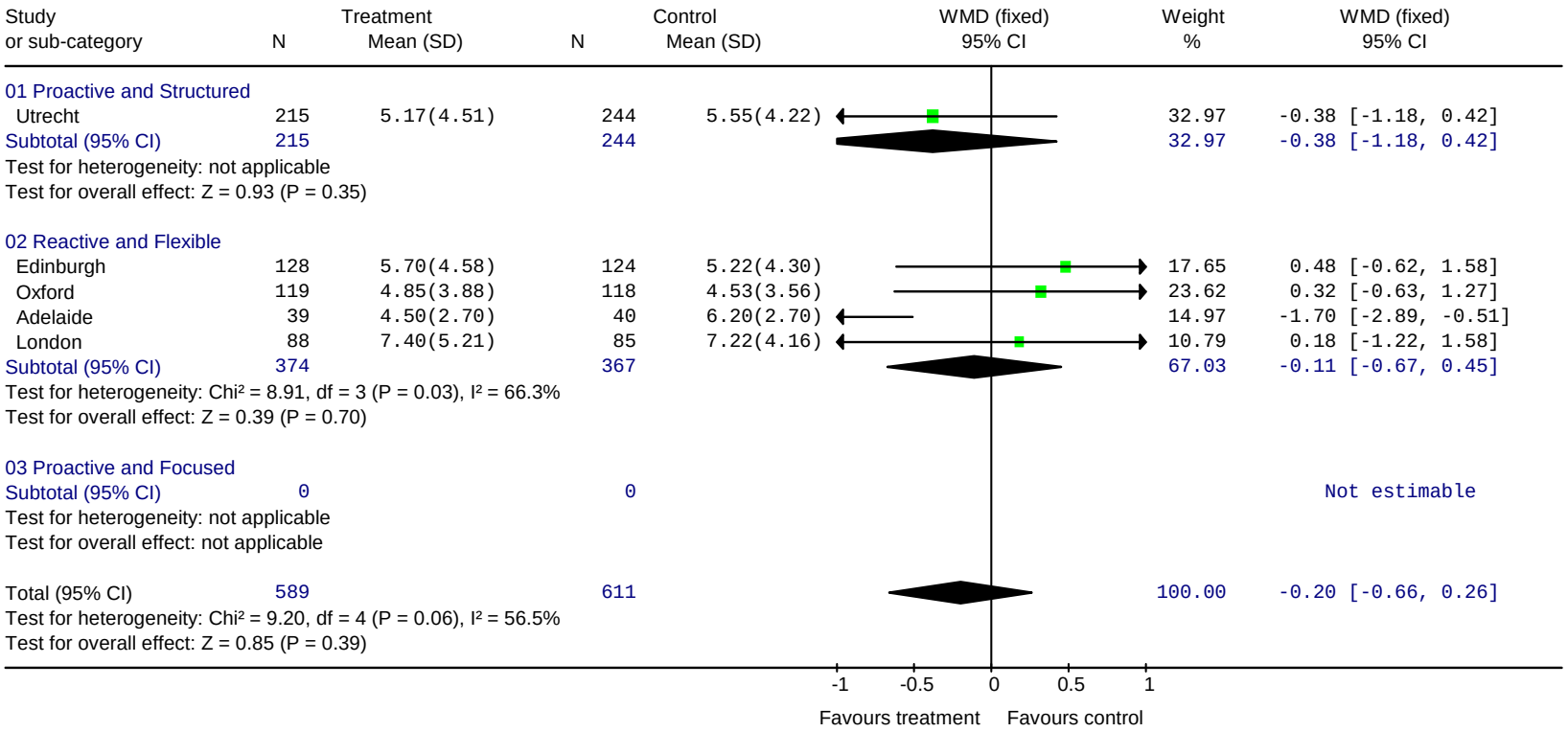


Figure 5.14: Patients' Participation

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 11 Participation

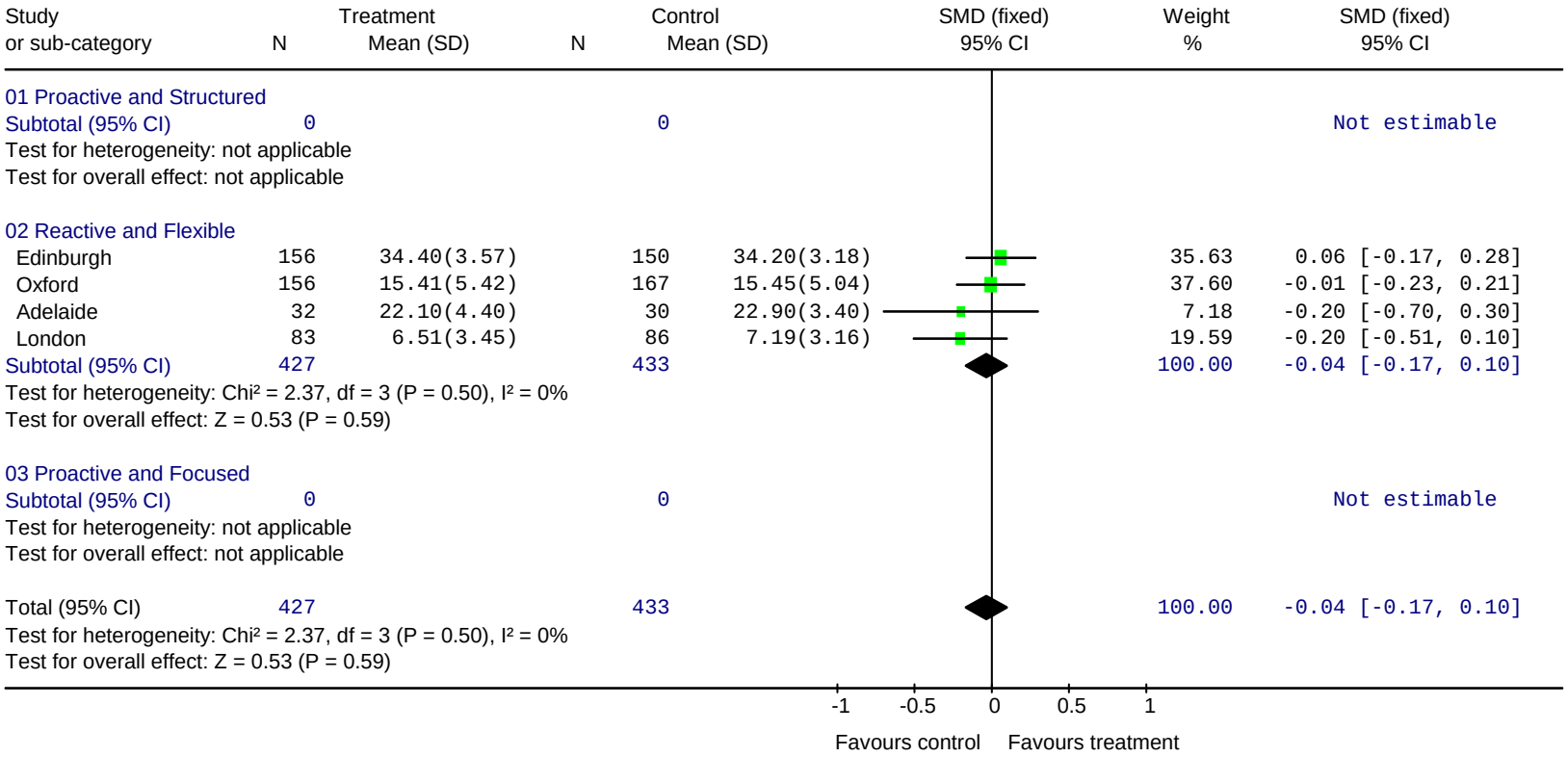


Figure 5.15: Carer Subjective Health

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 12 Caregiver Subjective Health Status

Study or sub-category	Treatment N	Treatment Mean (SD)	Control N	Control Mean (SD)	SMD (fixed) 95% CI	Weight %	SMD (fixed) 95% CI
01 Proactive and Structured							
Bradford	56	4.04(5.07)	55	4.24(5.62)		5.88	-0.04 [-0.41, 0.33]
Preston	37	4.08(2.63)	36	5.11(2.28)		3.78	-0.41 [-0.88, 0.05]
Utrecht	145	22.99(3.14)	179	22.43(3.35)		16.91	0.17 [-0.05, 0.39]
Rhode Island	58	4.00(3.49)	79	3.57(3.63)		7.07	0.12 [-0.22, 0.46]
Subtotal (95% CI)	296		349			33.65	0.06 [-0.10, 0.21]
Test for heterogeneity: Chi² = 5.38, df = 3 (P = 0.15), I² = 44.2%							
Test for overall effect: Z = 0.74 (P = 0.46)							
02 Reactive and Flexible							
Liverpool	61	3.93(4.02)	52	4.23(3.43)		5.94	-0.08 [-0.45, 0.29]
Melbourne (SHIPS)	20	3.50(2.80)	28	3.00(4.20)		2.47	0.13 [-0.44, 0.71]
Edinburgh	68	10.44(17.18)	69	13.38(15.93)		7.23	-0.18 [-0.51, 0.16]
Oxford	107	3.86(2.98)	100	3.51(3.01)		10.93	0.12 [-0.16, 0.39]
Adelaide	32	-48.20(12.10)	30	-49.40(13.70)		3.28	0.09 [-0.41, 0.59]
Mansfield	74	5.55(3.64)	69	5.25(3.41)		7.56	0.08 [-0.24, 0.41]
London	43	21.58(3.93)	49	21.49(3.58)		4.85	0.02 [-0.39, 0.43]
Subtotal (95% CI)	405		397			42.26	0.02 [-0.12, 0.16]
Test for heterogeneity: Chi² = 2.45, df = 6 (P = 0.87), I² = 0%							
Test for overall effect: Z = 0.30 (P = 0.76)							
03 Proactive and Focused							
Leeds (Psychology)	87	4.52(3.16)	88	4.43(3.59)		9.27	0.03 [-0.27, 0.32]
Leeds (Volunteers)	90	5.08(3.72)	88	4.43(3.59)		9.39	0.18 [-0.12, 0.47]
Liverpool (Psych)	22	4.41(3.39)	52	4.23(3.43)		3.27	0.05 [-0.45, 0.55]
Philadelphia (STAIR)	21	42.70(8.00)	20	44.70(8.40)		2.15	-0.24 [-0.85, 0.38]
Subtotal (95% CI)	220		248			24.09	0.06 [-0.12, 0.25]
Test for heterogeneity: Chi² = 1.56, df = 3 (P = 0.67), I² = 0%							
Test for overall effect: Z = 0.69 (P = 0.49)							
Total (95% CI)	921		994			100.00	0.04 [-0.05, 0.13]
Test for heterogeneity: Chi² = 9.57, df = 14 (P = 0.79), I² = 0%							
Test for overall effect: Z = 0.96 (P = 0.33)							

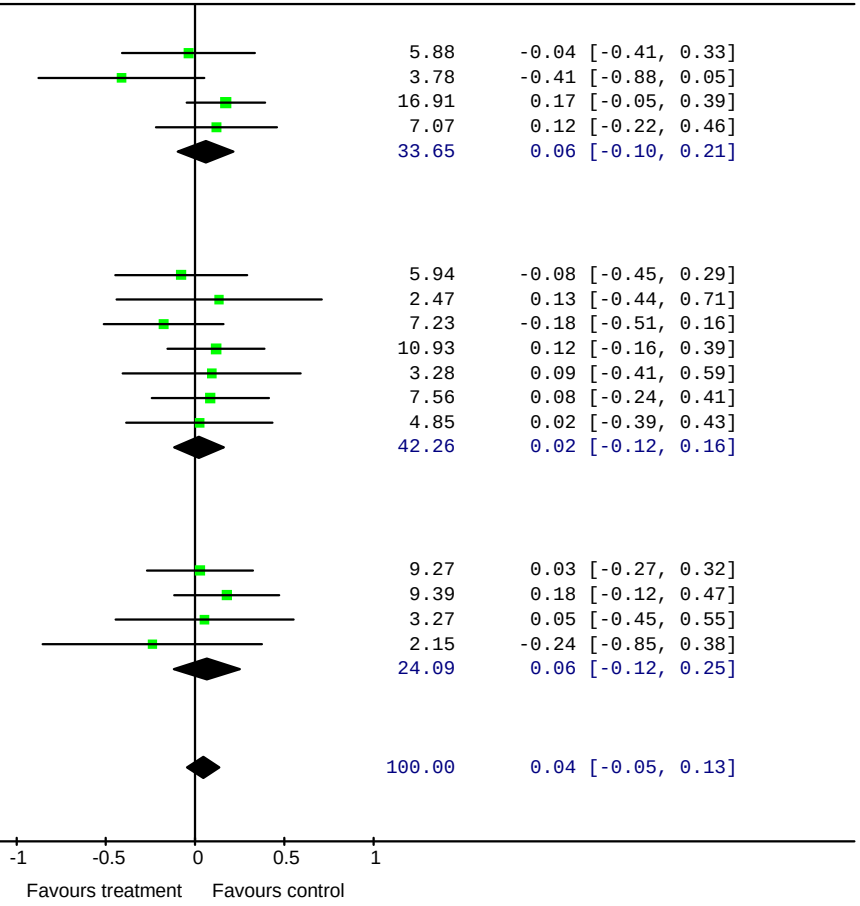


Figure 5.16: Carers' Extended Activities of Daily Living

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 13 Caregiver Extended Activities of Daily Living

Study or sub-category	Treatment N	Treatment Mean (SD)	Control N	Control Mean (SD)	SMD (fixed) 95% CI	Weight %	SMD (fixed) 95% CI
01 Proactive and Structured							
Bradford	56	27.39(7.39)	61	27.64(5.57)		15.68	-0.04 [-0.40, 0.32]
Rhode Island	56	29.63(7.96)	78	30.92(7.92)		17.45	-0.16 [-0.51, 0.18]
Subtotal (95% CI)	112		139			33.13	-0.10 [-0.35, 0.15]
Test for heterogeneity: Chi² = 0.23, df = 1 (P = 0.63), I² = 0%							
Test for overall effect: Z = 0.81 (P = 0.42)							
02 Reactive and Flexible							
Edinburgh	87	47.00(3.57)	84	48.00(2.14)		22.63	-0.34 [-0.64, -0.03]
Oxford	103	31.03(6.69)	96	31.07(7.12)		26.69	-0.01 [-0.28, 0.27]
Mansfield	67	51.42(18.96)	64	53.34(14.72)		17.55	-0.11 [-0.45, 0.23]
Subtotal (95% CI)	257		244			66.87	-0.15 [-0.32, 0.03]
Test for heterogeneity: Chi² = 2.55, df = 2 (P = 0.28), I² = 21.5%							
Test for overall effect: Z = 1.63 (P = 0.10)							
03 Proactive and Focused							
Subtotal (95% CI)	0		0				Not estimable
Test for heterogeneity: not applicable							
Test for overall effect: not applicable							
Total (95% CI)	369		383			100.00	-0.13 [-0.28, 0.01]
Test for heterogeneity: Chi² = 2.86, df = 4 (P = 0.58), I² = 0%							
Test for overall effect: Z = 1.80 (P = 0.07)							

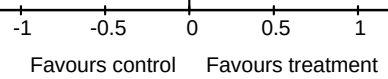


Figure 5.17: Carers' Mental Health

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 14 Caregiver Mental Health

Study or sub-category	Treatment N	Treatment Mean (SD)	Control N	Control Mean (SD)	SMD (fixed) 95% CI	Weight %	SMD (fixed) 95% CI
01 Proactive and Structured							
Bradford	56	19.80(11.34)	55	20.64(12.84)		6.39	-0.07 [-0.44, 0.30]
Utrecht	126	84.48(9.85)	163	84.22(8.72)		16.36	0.03 [-0.20, 0.26]
Rhode Island	47	9.28(6.70)	74	8.68(5.62)		6.61	0.10 [-0.27, 0.46]
Subtotal (95% CI)	229		292			29.36	0.02 [-0.15, 0.20]
Test for heterogeneity: Chi² = 0.40, df = 2 (P = 0.82), I² = 0%							
Test for overall effect: Z = 0.26 (P = 0.80)							
02 Reactive and Flexible							
Liverpool	64	2.69(3.78)	53	3.11(3.03)		6.66	-0.12 [-0.48, 0.24]
Edinburgh	94	7.22(8.32)	92	8.36(7.62)		10.68	-0.14 [-0.43, 0.15]
Oxford	93	3.66(4.29)	90	4.00(4.68)		10.52	-0.08 [-0.37, 0.21]
Adelaide	32	-46.40(6.80)	30	-48.40(6.20)		3.52	0.30 [-0.20, 0.80]
Mansfield	75	14.08(5.70)	70	14.77(7.47)		8.33	-0.10 [-0.43, 0.22]
London	45	12.67(8.77)	55	13.71(8.35)		5.69	-0.12 [-0.52, 0.27]
Subtotal (95% CI)	403		390			45.40	-0.08 [-0.22, 0.06]
Test for heterogeneity: Chi² = 2.53, df = 5 (P = 0.77), I² = 0%							
Test for overall effect: Z = 1.11 (P = 0.27)							
03 Proactive and Focused							
Leeds (Psychology)	82	5.02(5.25)	85	5.33(6.18)		9.61	-0.05 [-0.36, 0.25]
Leeds (Volunteers)	88	5.58(6.55)	85	5.33(6.18)		9.95	0.04 [-0.26, 0.34]
Liverpool (Psych)	22	2.73(3.10)	53	3.11(3.03)		3.57	-0.12 [-0.62, 0.37]
Philadelphia (STAIR)	19	21.40(10.40)	19	16.60(6.60)		2.10	0.54 [-0.11, 1.19]
Subtotal (95% CI)	211		242			25.24	0.02 [-0.16, 0.21]
Test for heterogeneity: Chi² = 3.02, df = 3 (P = 0.39), I² = 0.8%							
Test for overall effect: Z = 0.23 (P = 0.81)							
Total (95% CI)	843		924			100.00	-0.02 [-0.12, 0.07]
Test for heterogeneity: Chi² = 7.08, df = 12 (P = 0.85), I² = 0%							
Test for overall effect: Z = 0.49 (P = 0.62)							

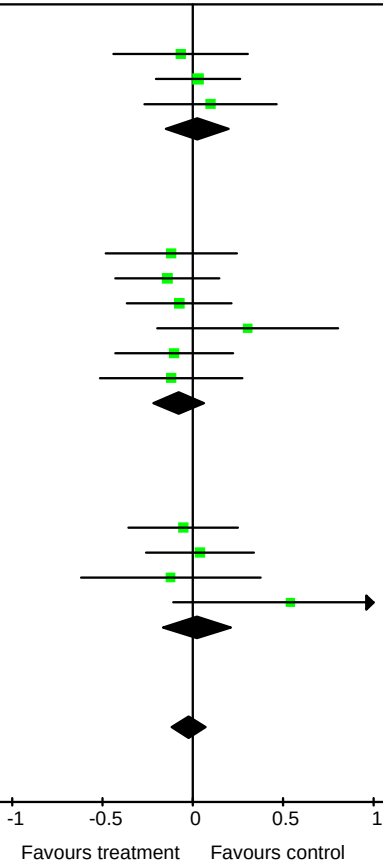


Figure 5.18: Patient Satisfaction; “I have been treated with kindness and respect”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 34 "I have been treated with kindness and respect" - patient

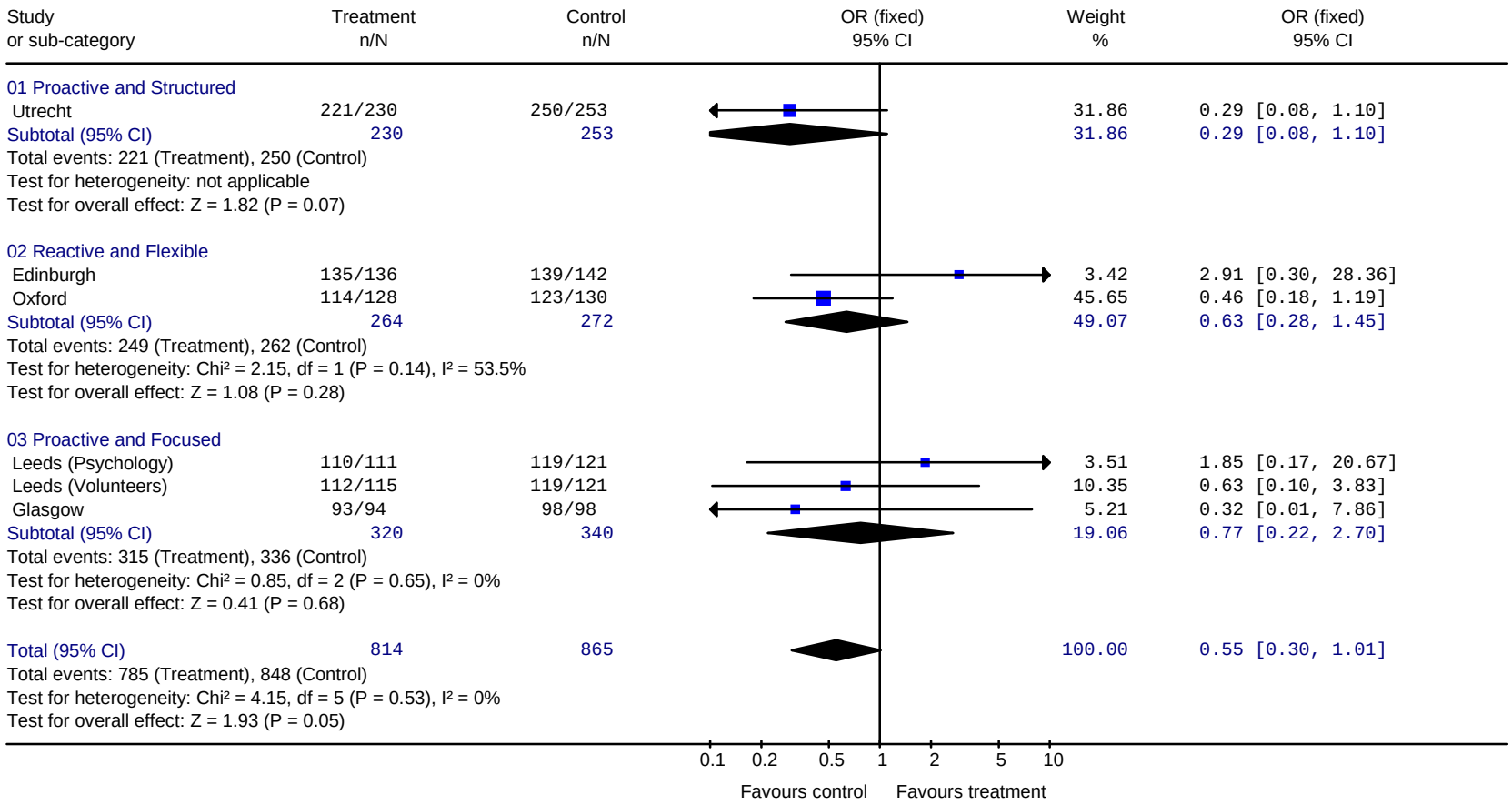


Figure 5.19: Patient Satisfaction; “The staff have attended well to my personal needs”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 35 "The staff attended well to my personal needs" - patient

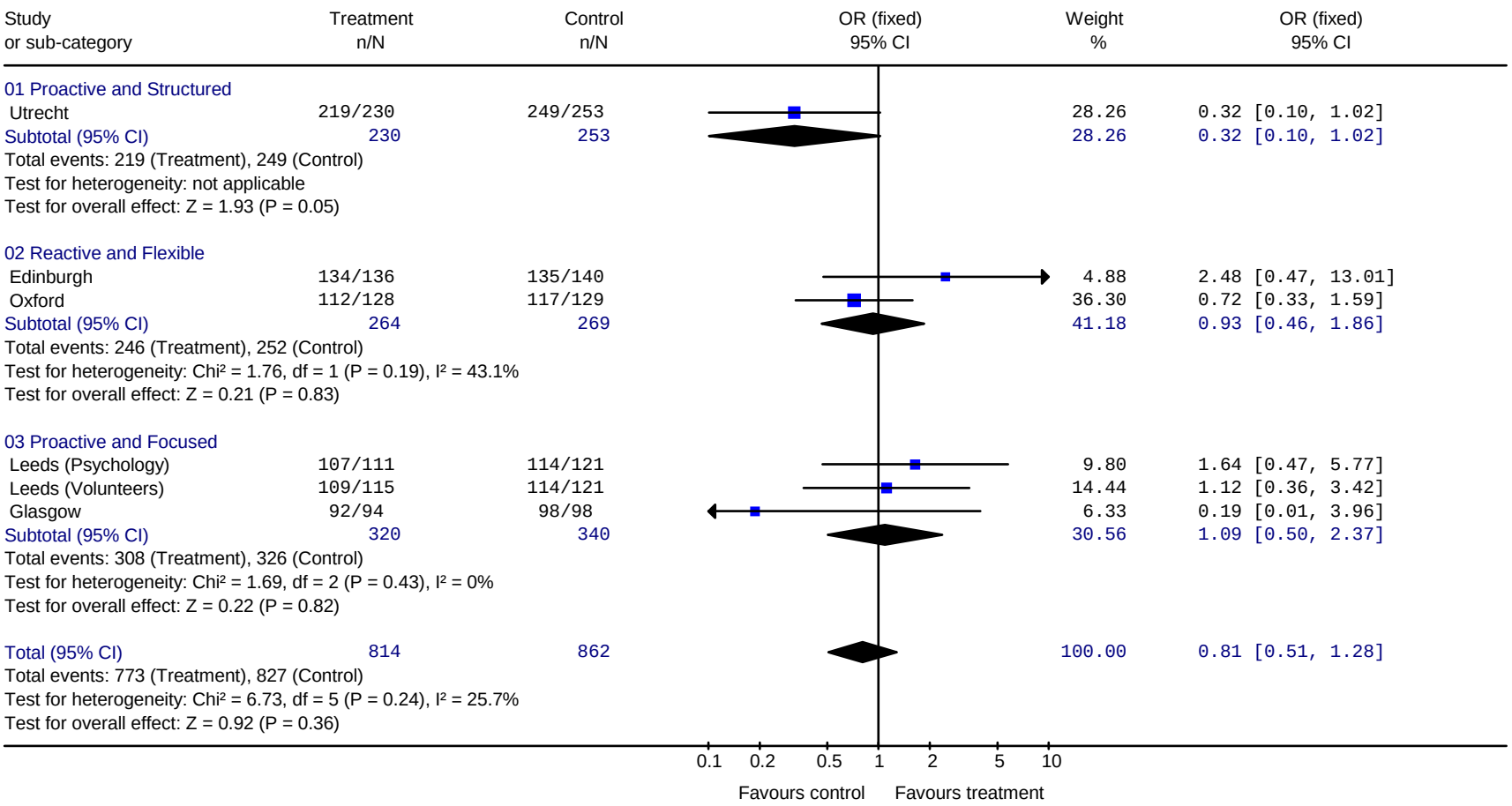


Figure 5.20: Patient Satisfaction; “I was able to talk to the staff about any problems”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 36 "I was able to talk to the staff about any problems" - patient

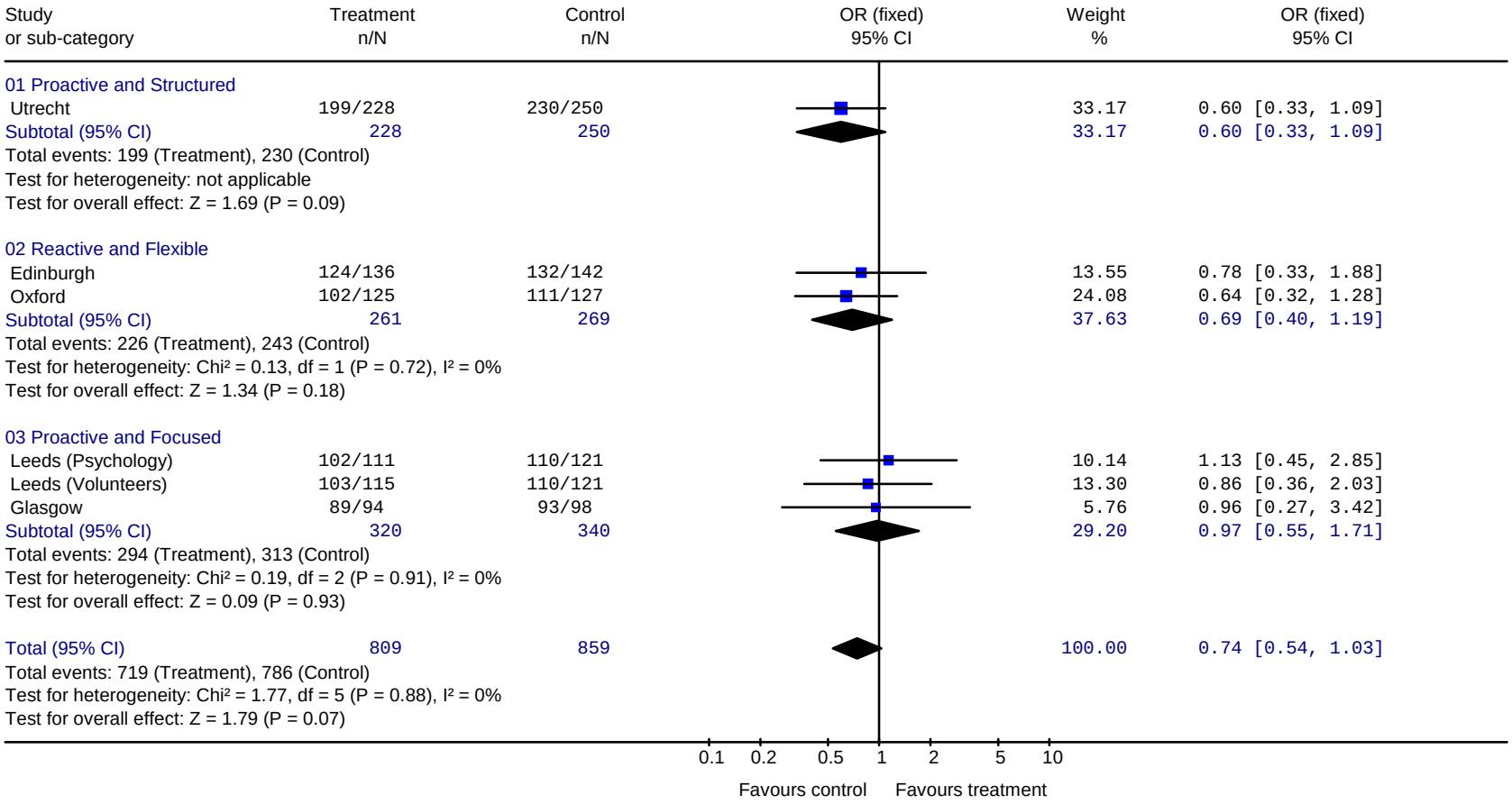


Figure 5.21: Patient Satisfaction; “I received all the information about the causes and nature of my disease”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 37 "I received all the information I want about the causes and nature of my disease" - patient

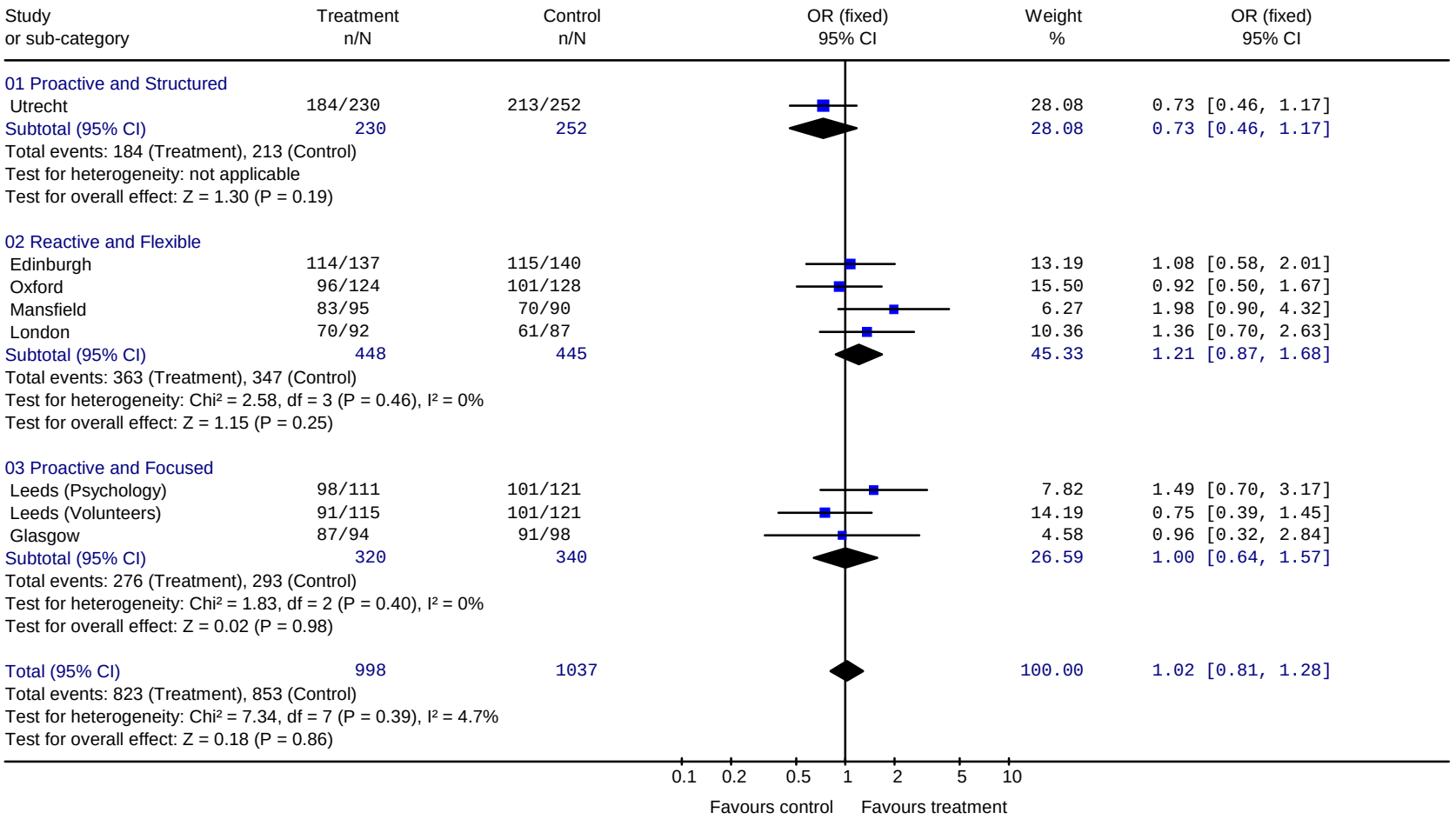


Figure 5.22: Patient Satisfaction; “The staff have done everything to make me well”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 38 "The staff have done everything to make me well" - patient

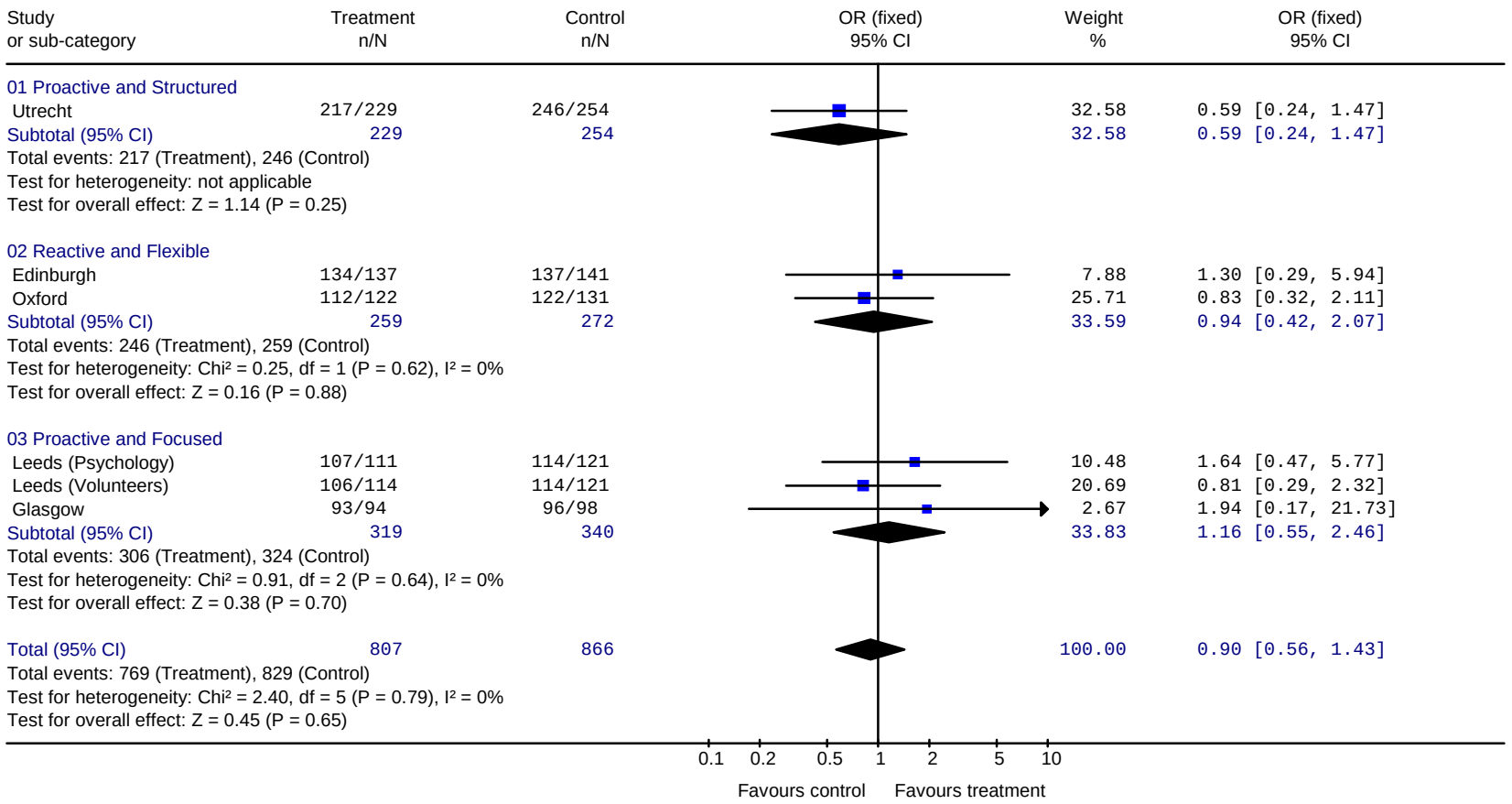


Figure 5.23: Patient Satisfaction; “I am happy with my recovery”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 39 "I am happy with my recovery" - patient

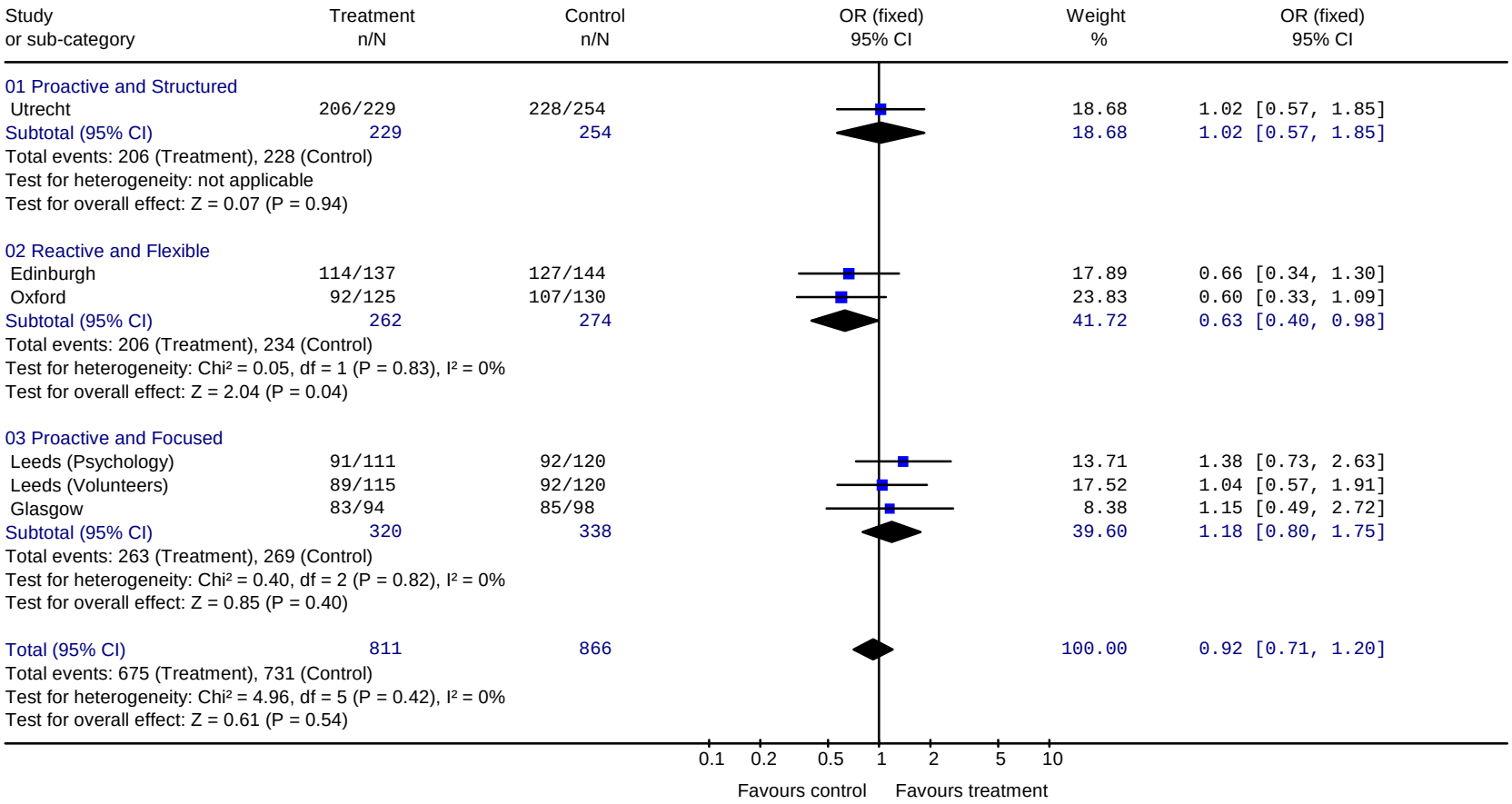


Figure 5.24: Patient Satisfaction; “I am satisfied with the type of treatment I have received”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 40 "I am satisfied with the type of treatment I have received" - patient

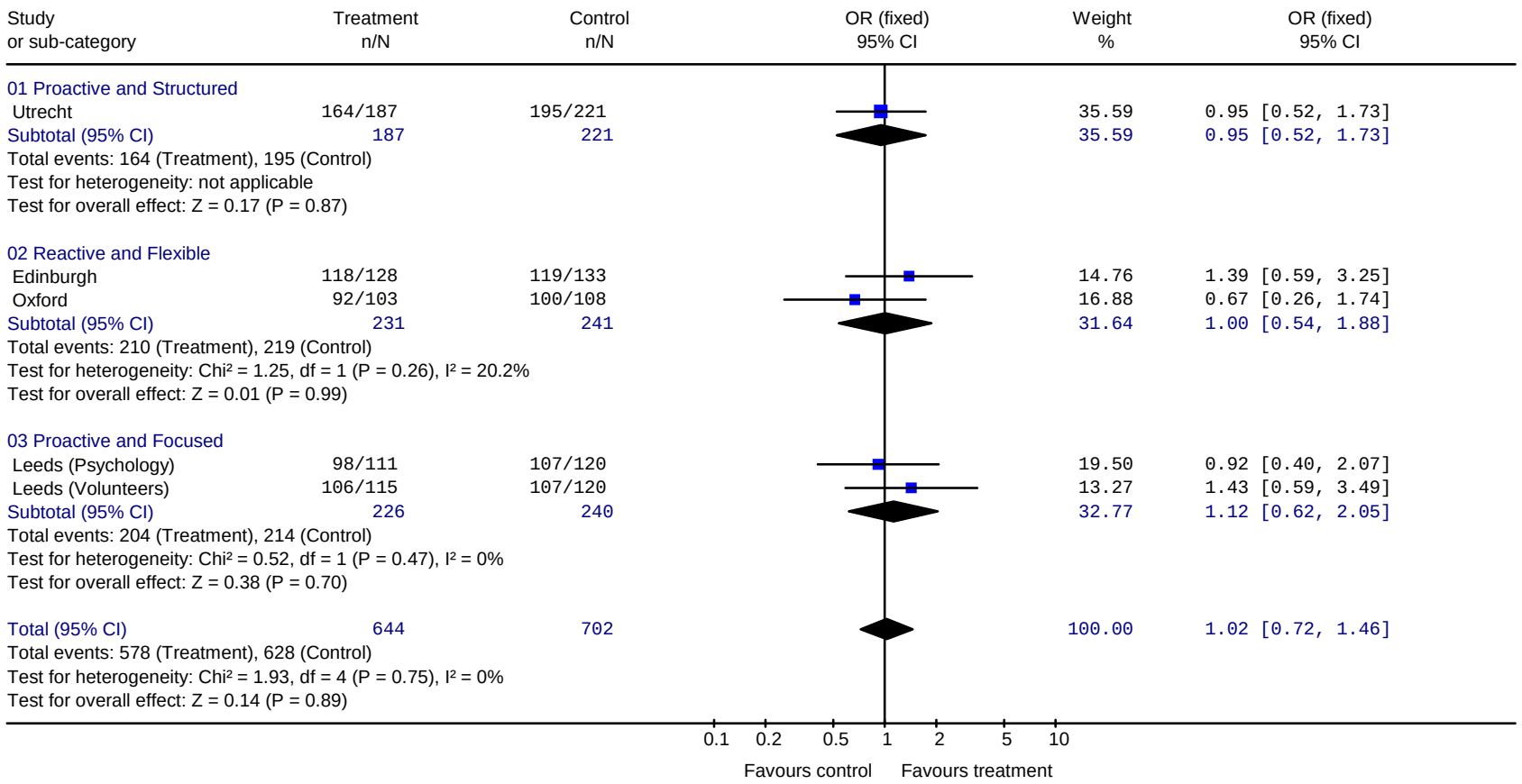


Figure 5.25: Patient Satisfaction; “I was given all the information I needed about allowances”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 41 "I was given all the information I needed about allowances" - patient

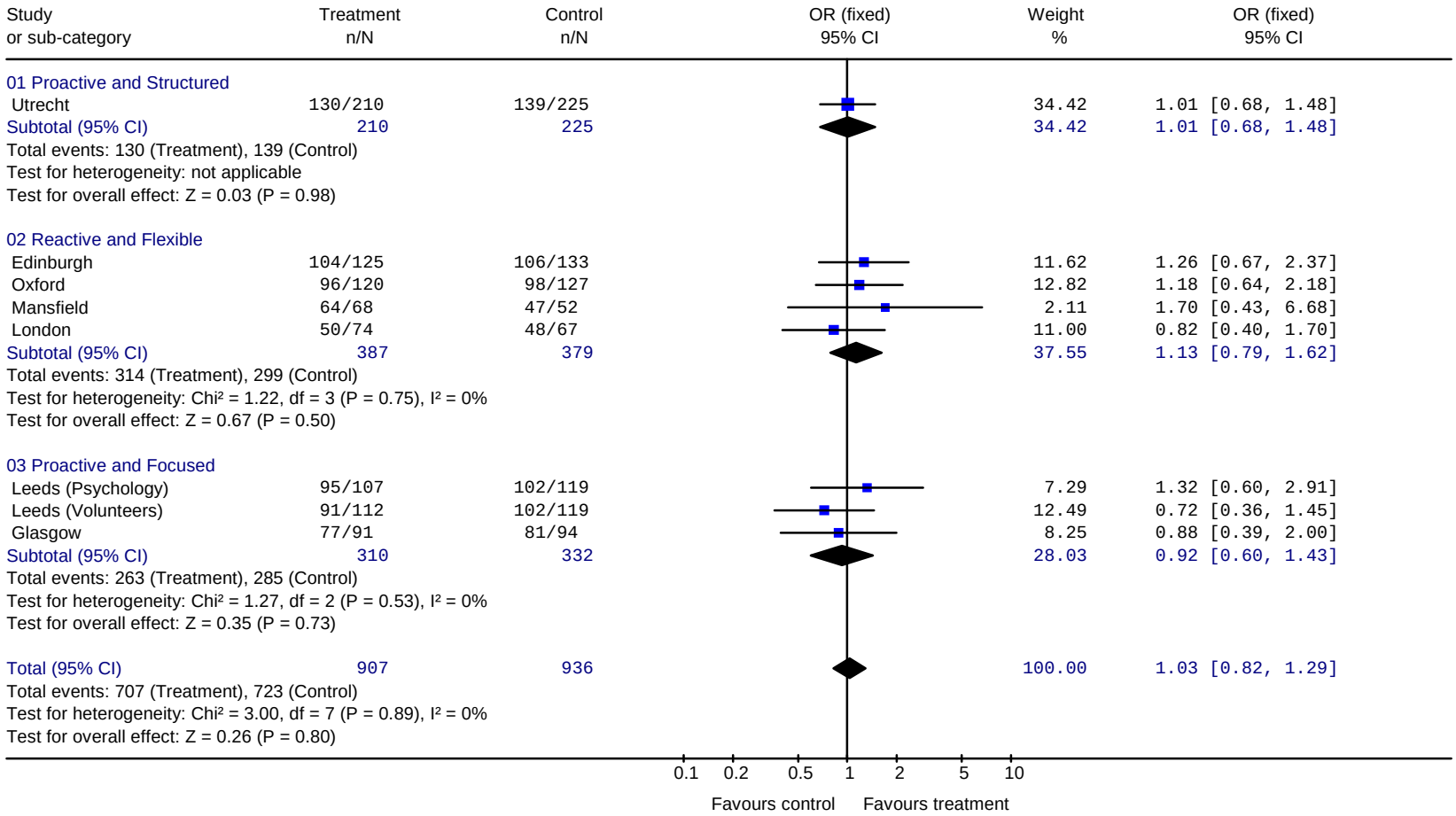


Figure 5.26: Patient Satisfaction; “Things were well prepared for my return home”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 42 "Things were well prepared for my return home" - patient

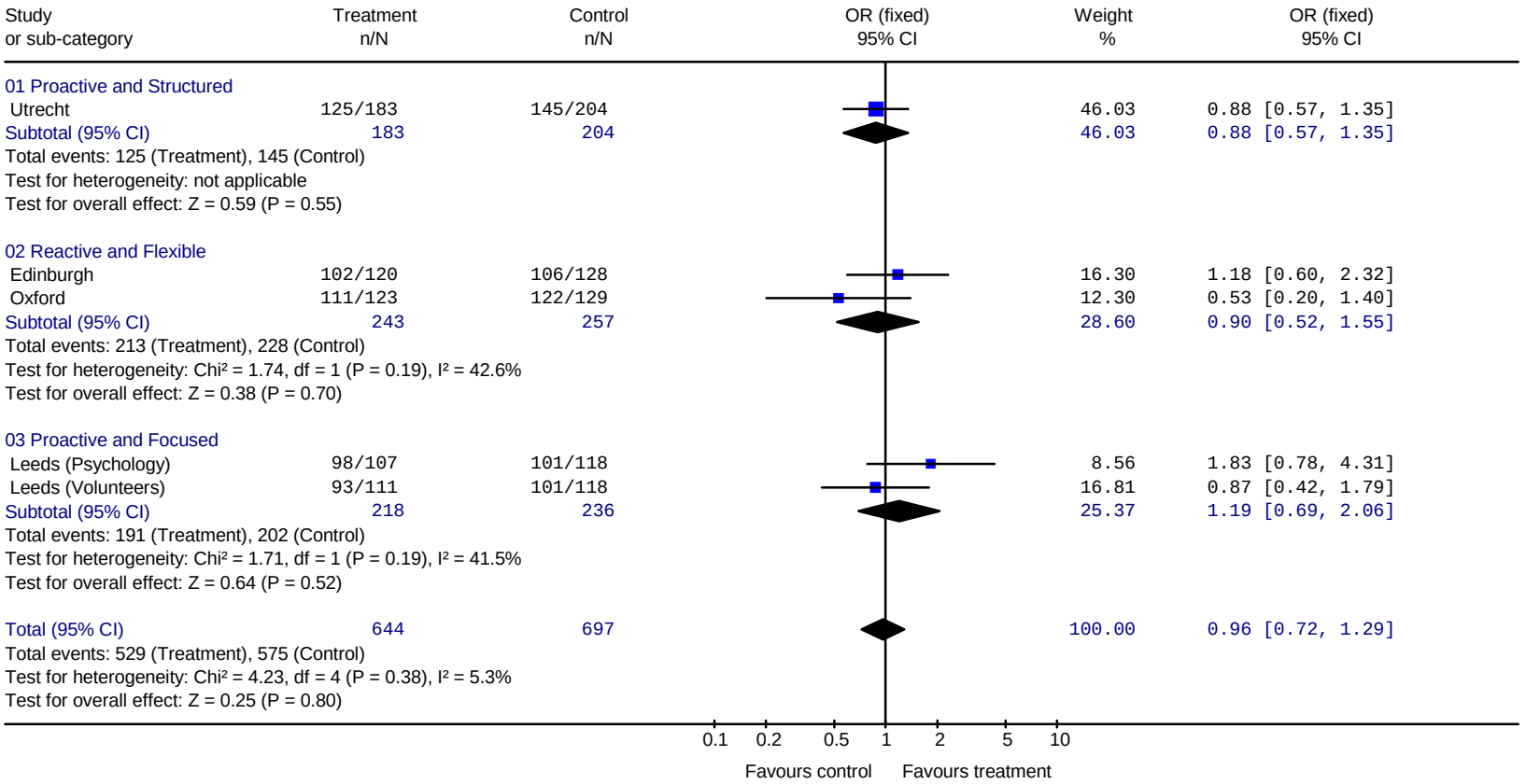


Figure 5.27: Patient Satisfaction; “I get all the services I need”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 43 "I get all the services I need" - patient

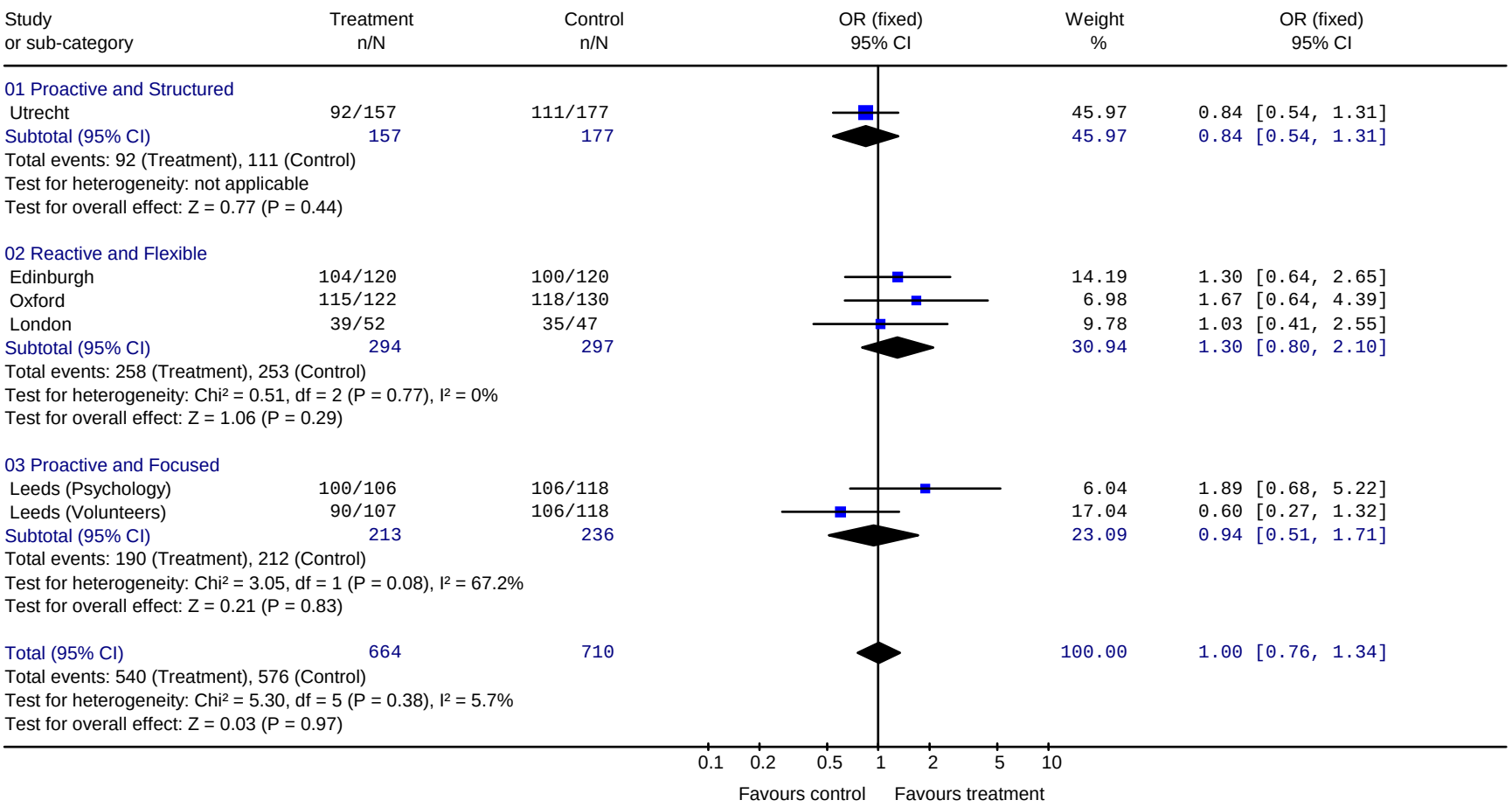


Figure 5.28: Patient Satisfaction; “I am satisfied with the outpatient services”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 44 "I am satisfied with outpatient services" - patient

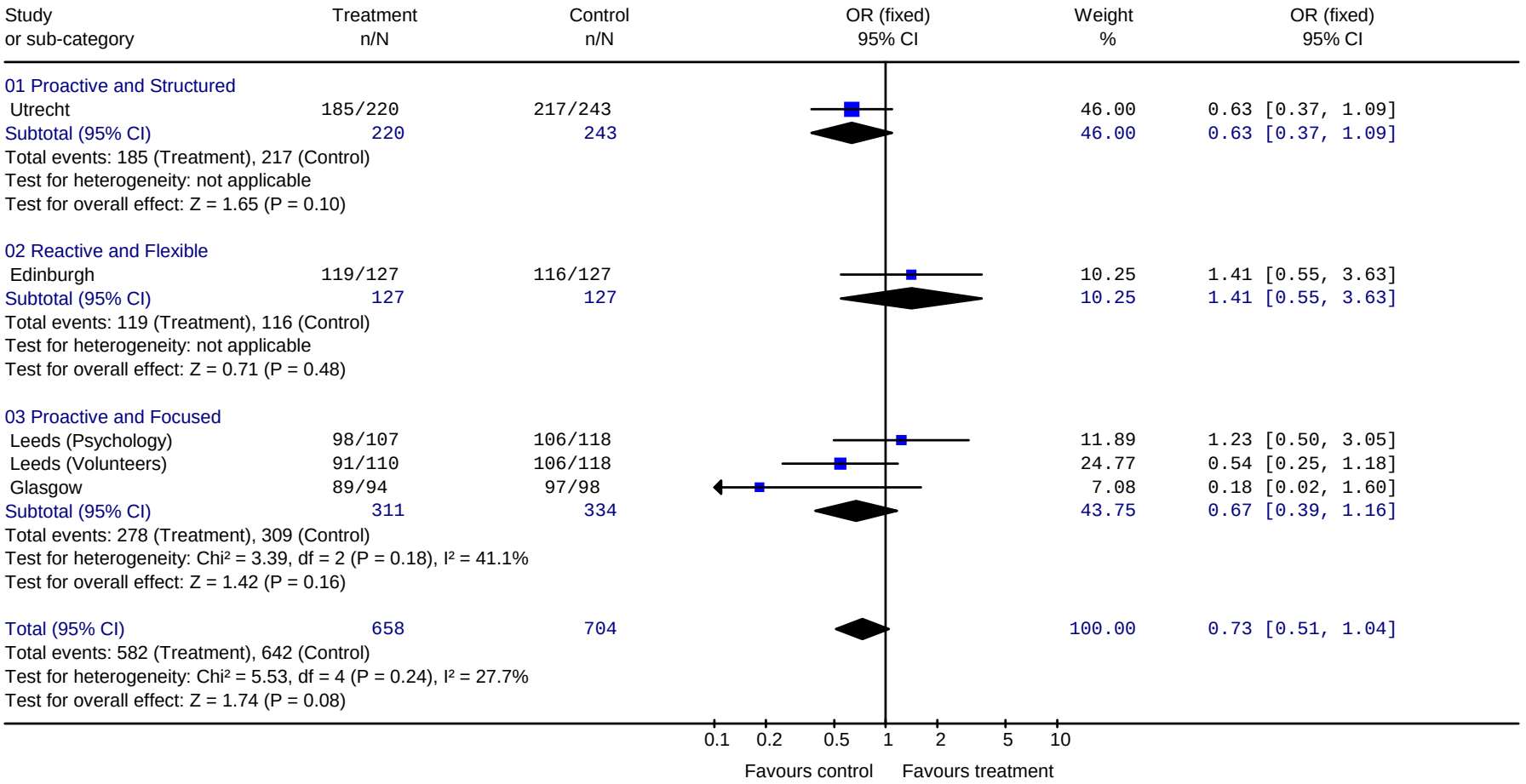


Figure 5.29: Patient Satisfaction; “I am satisfied with the practical help I have received”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 45 "I am satisfied with the practical help I have received" - patient

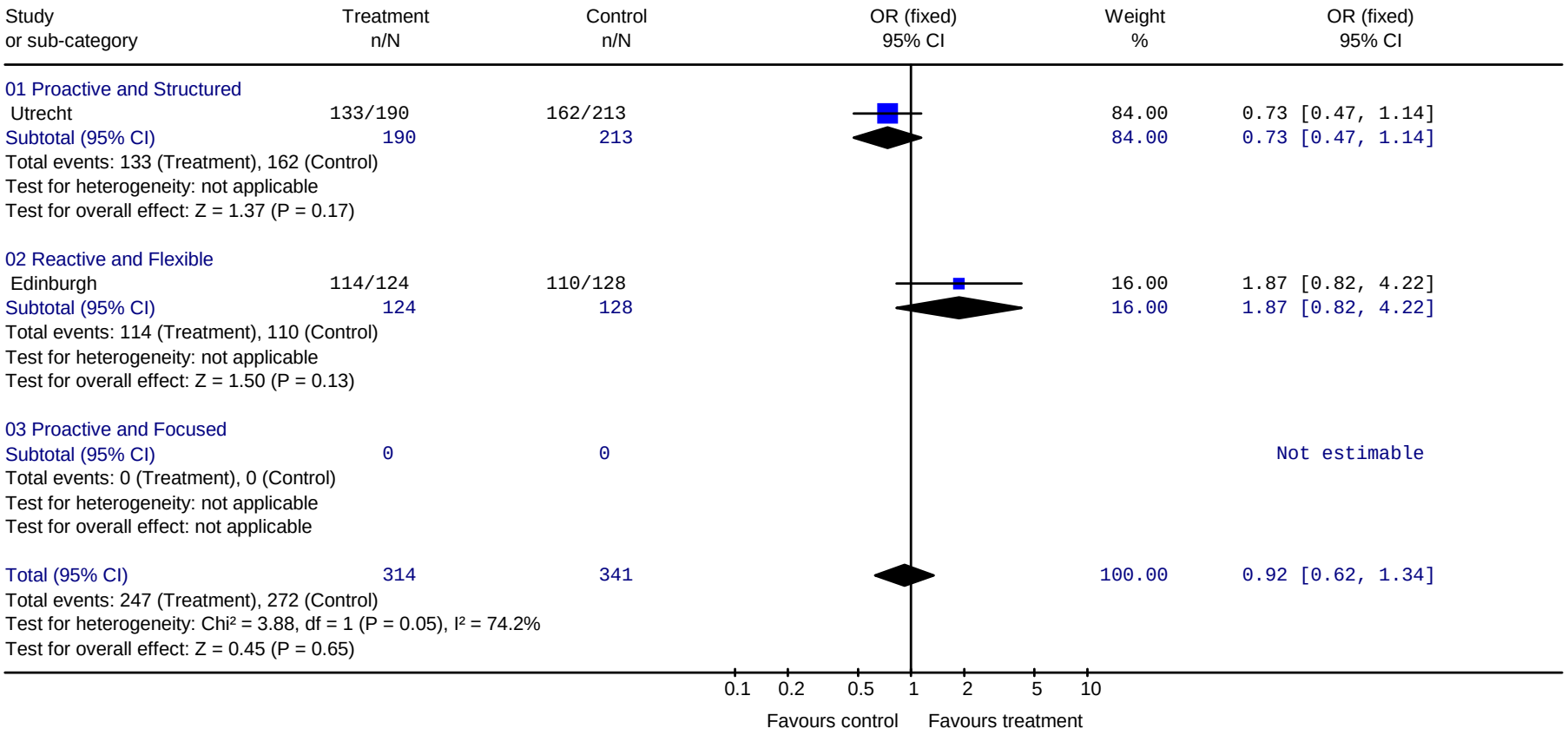


Figure 5.30: Patient Satisfaction; “I have had enough information about recovery and rehabilitation”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 46 "I have had enough information about recovery" - patient

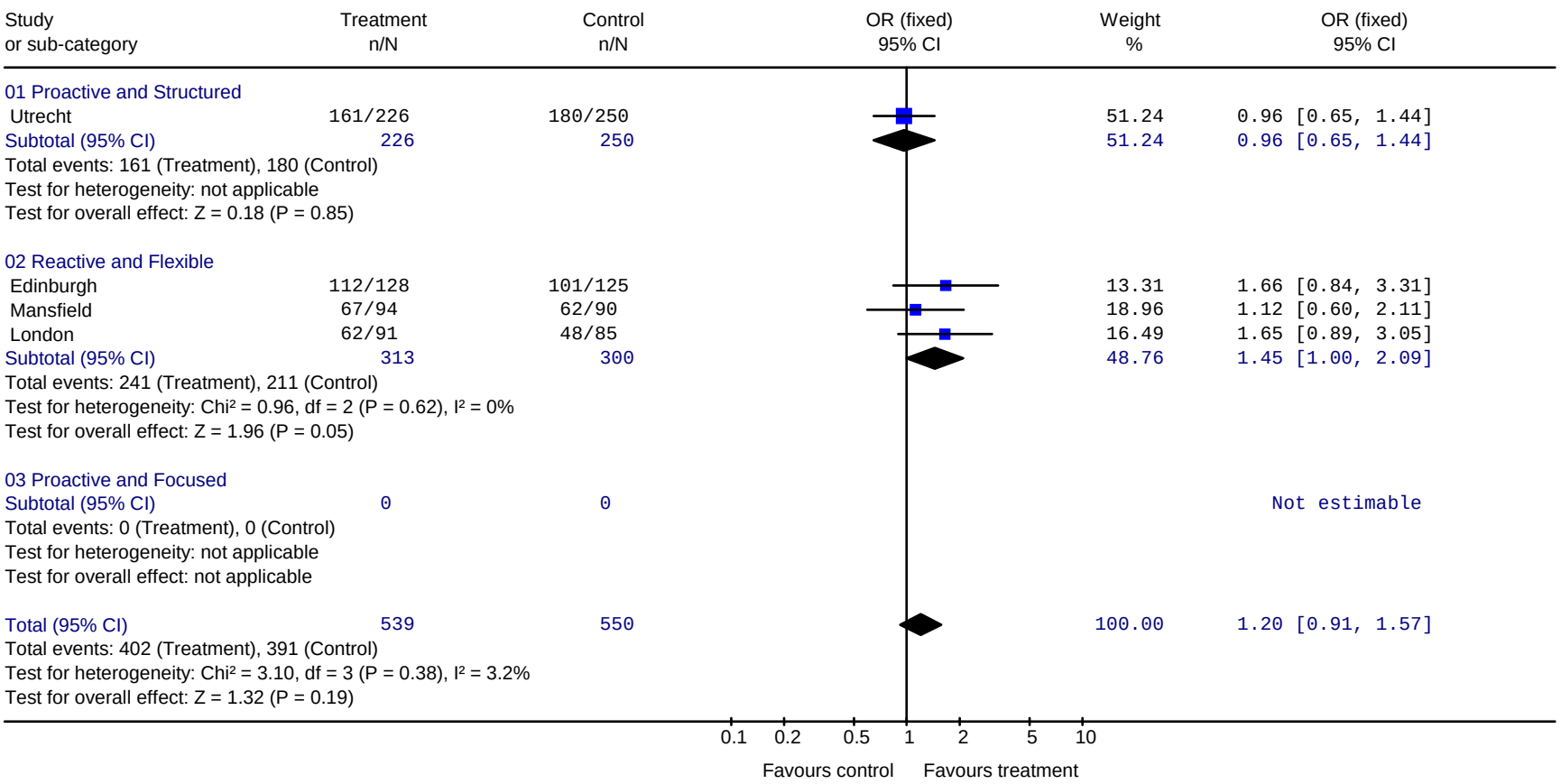


Figure 5.31: Patient Satisfaction; “Someone has really listened”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 47 "Someone has really listened" - patient

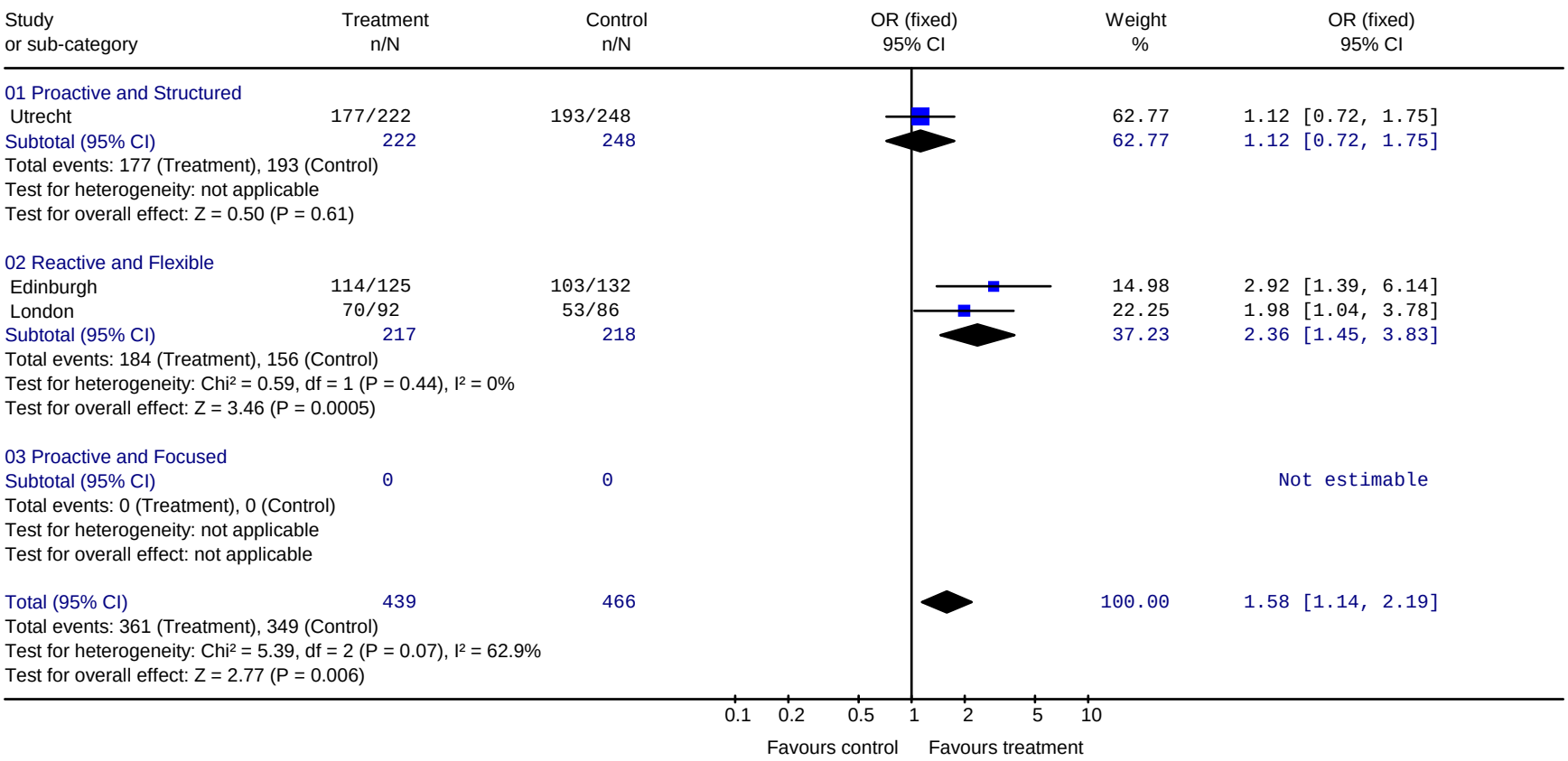


Figure 5.32: Patient Satisfaction; “I have not felt neglected”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 50 "I have not felt neglected" - patient

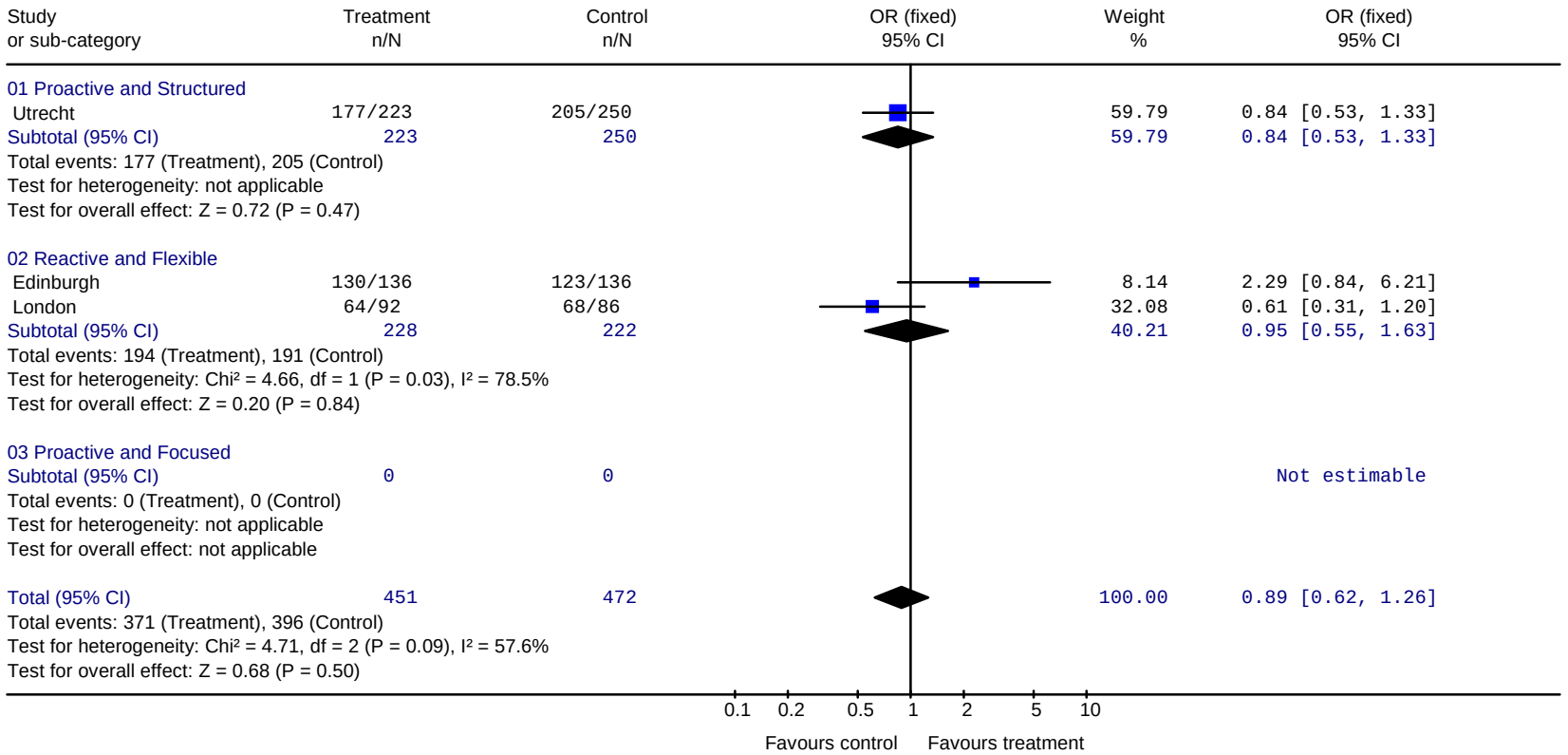


Figure 5.33: Patient Satisfaction; “I have had enough emotional support”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 48 "I have had enough emotional support" - patient

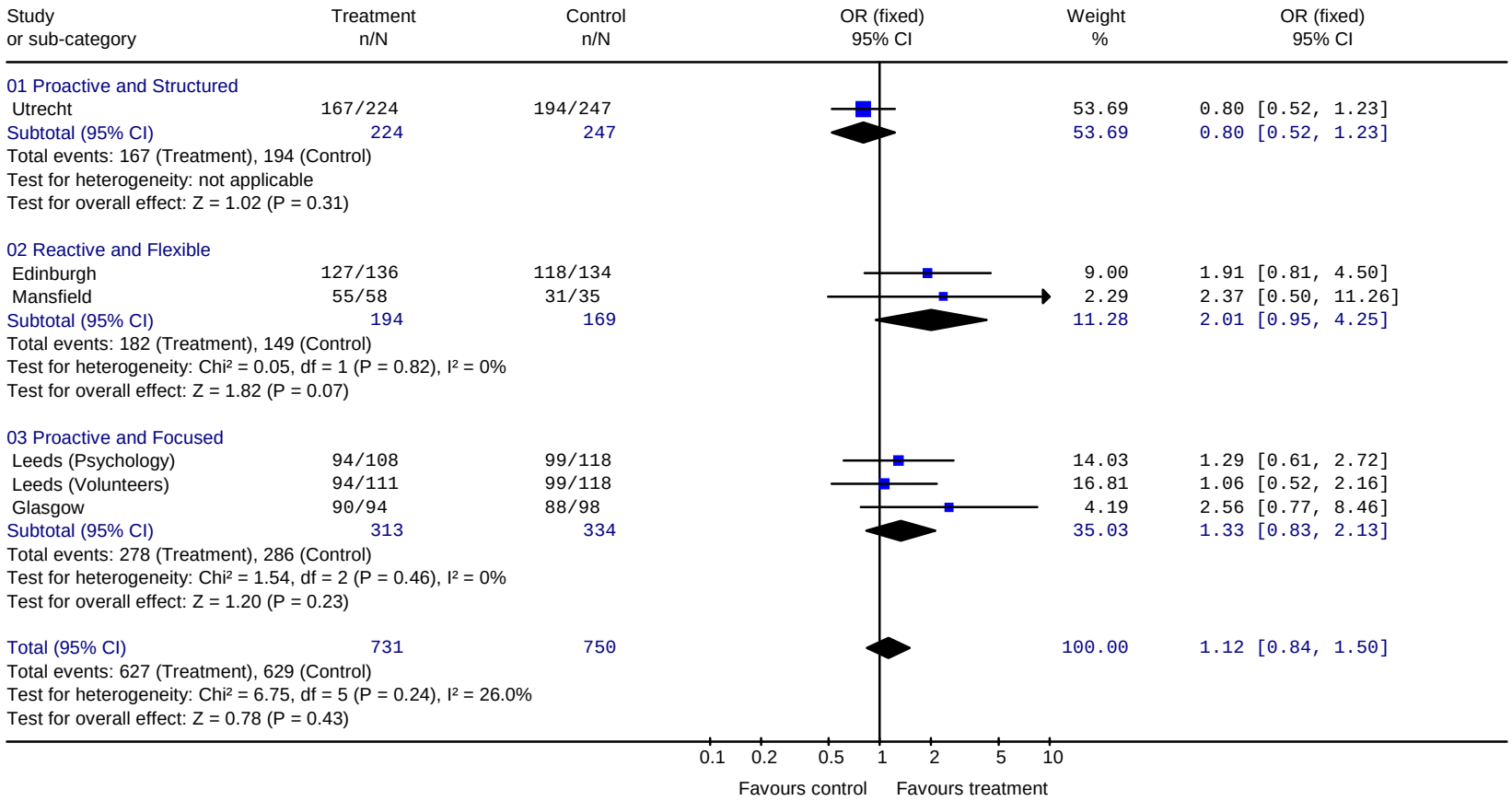


Figure 5.34: Patient Satisfaction; “I know who to contact”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 49 "I know who to contact" - patient

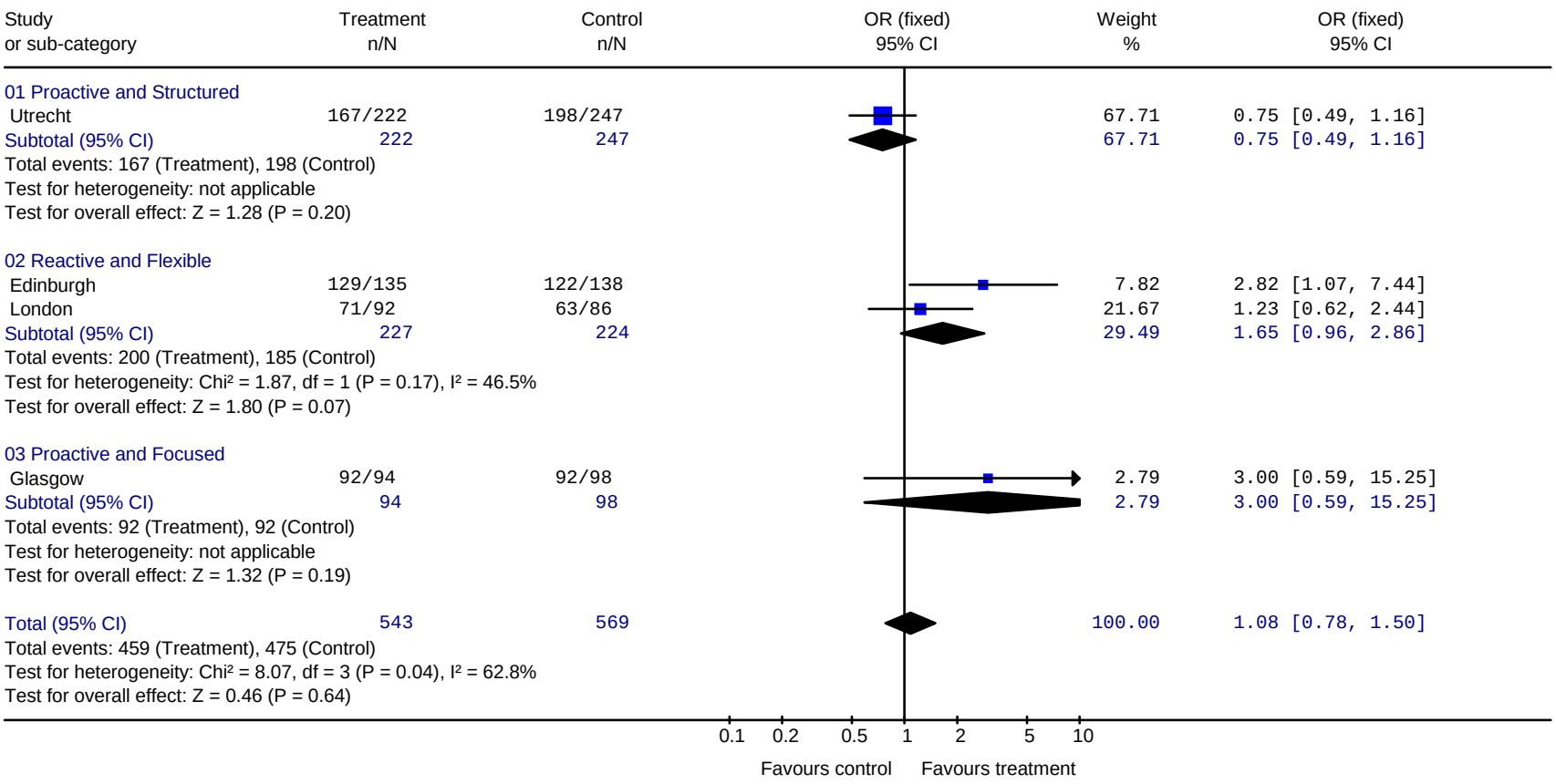


Figure 5.35: Carer Satisfaction; “The patient has been treated with kindness and respect”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 53 "The patient has been treated with kindness and respect" - carer

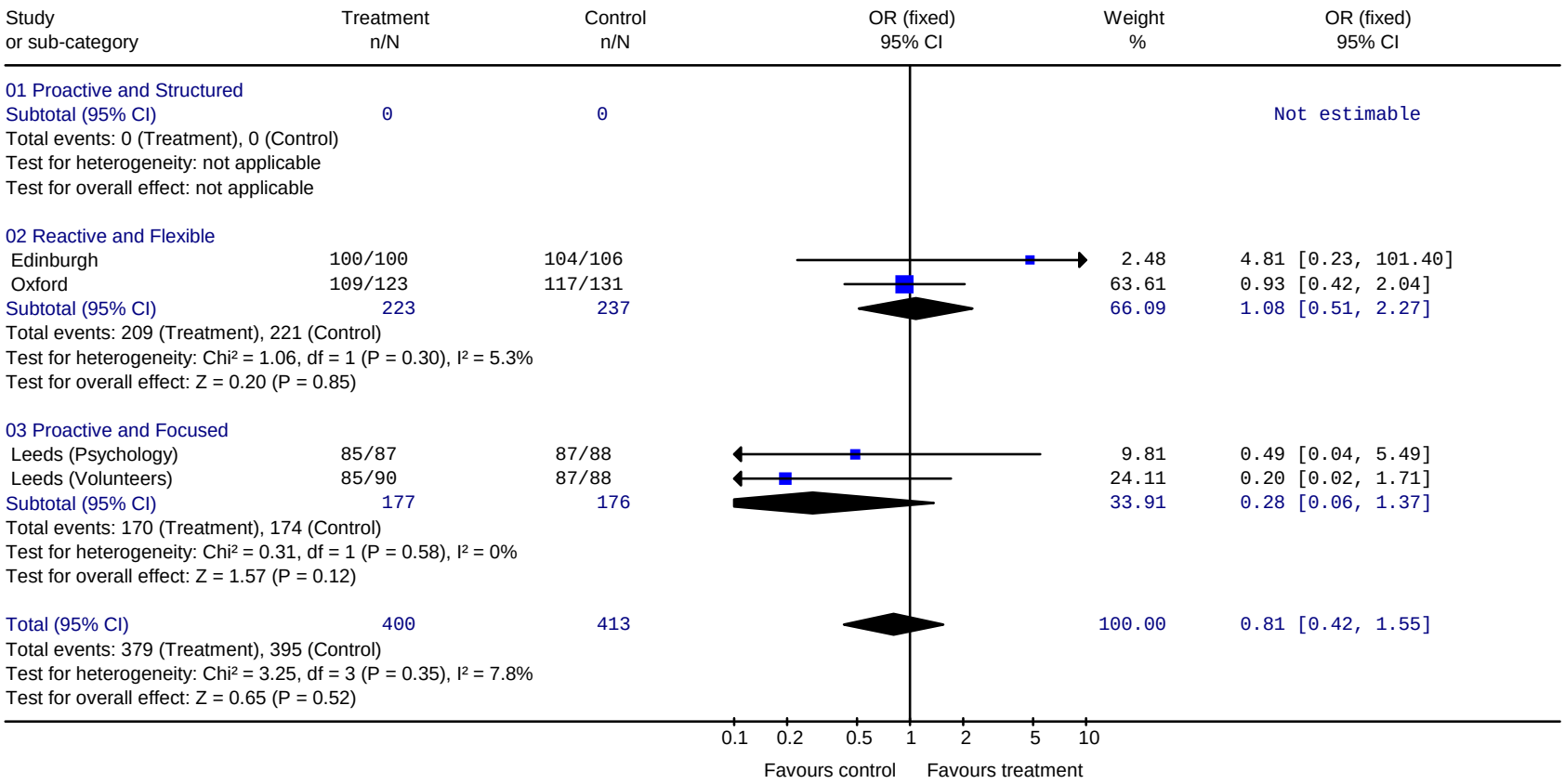


Figure 5.36: Carer Satisfaction; “The staff have attended to my needs”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 54 "The staff have attended to my needs" - carer

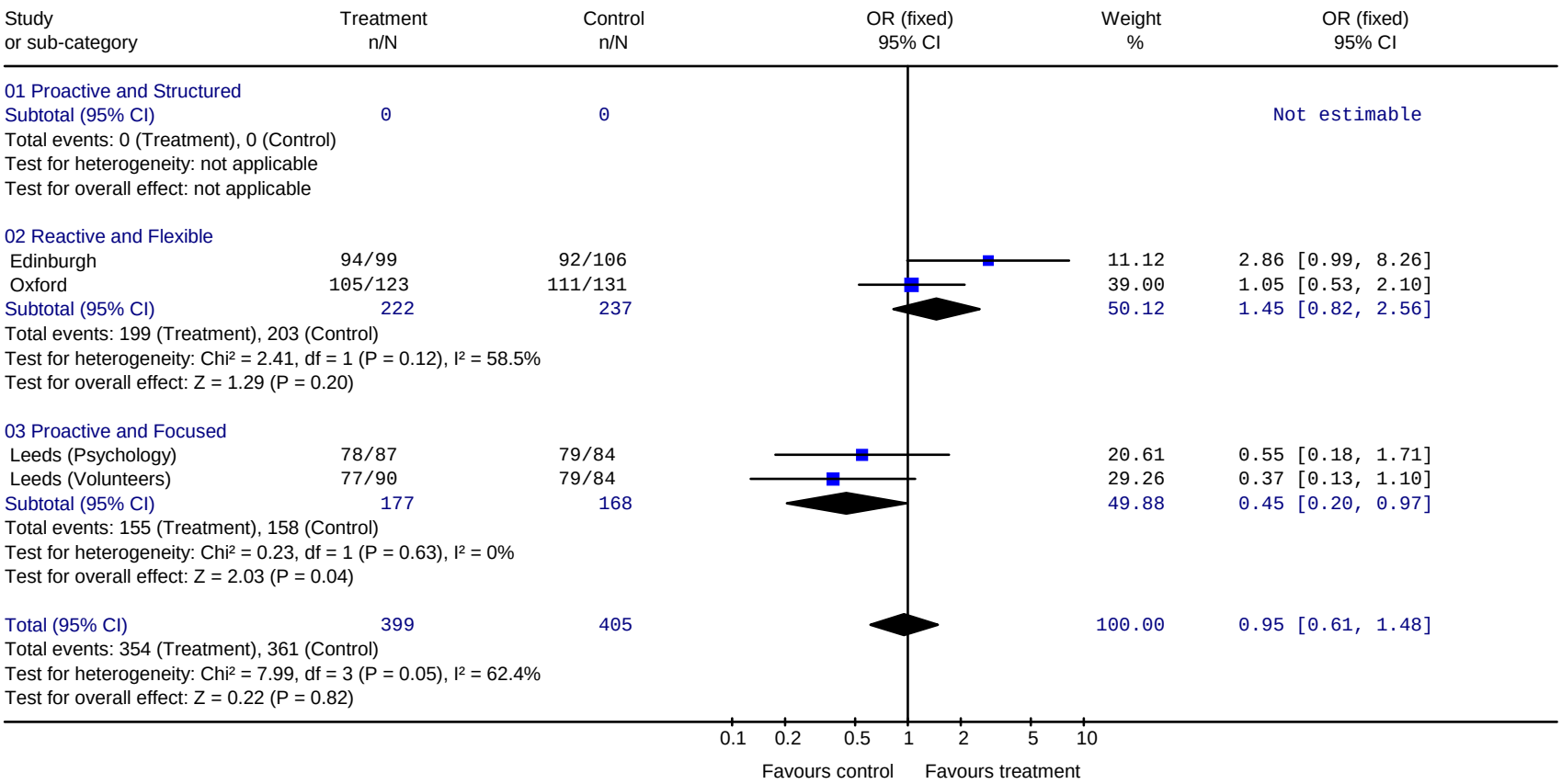


Figure 5.37: Carer Satisfaction; “I received all the information I needed about the nature and causes of the patient’s illness”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 55 "I received all the information I needed about the nature and causes of the patients illness" - carer

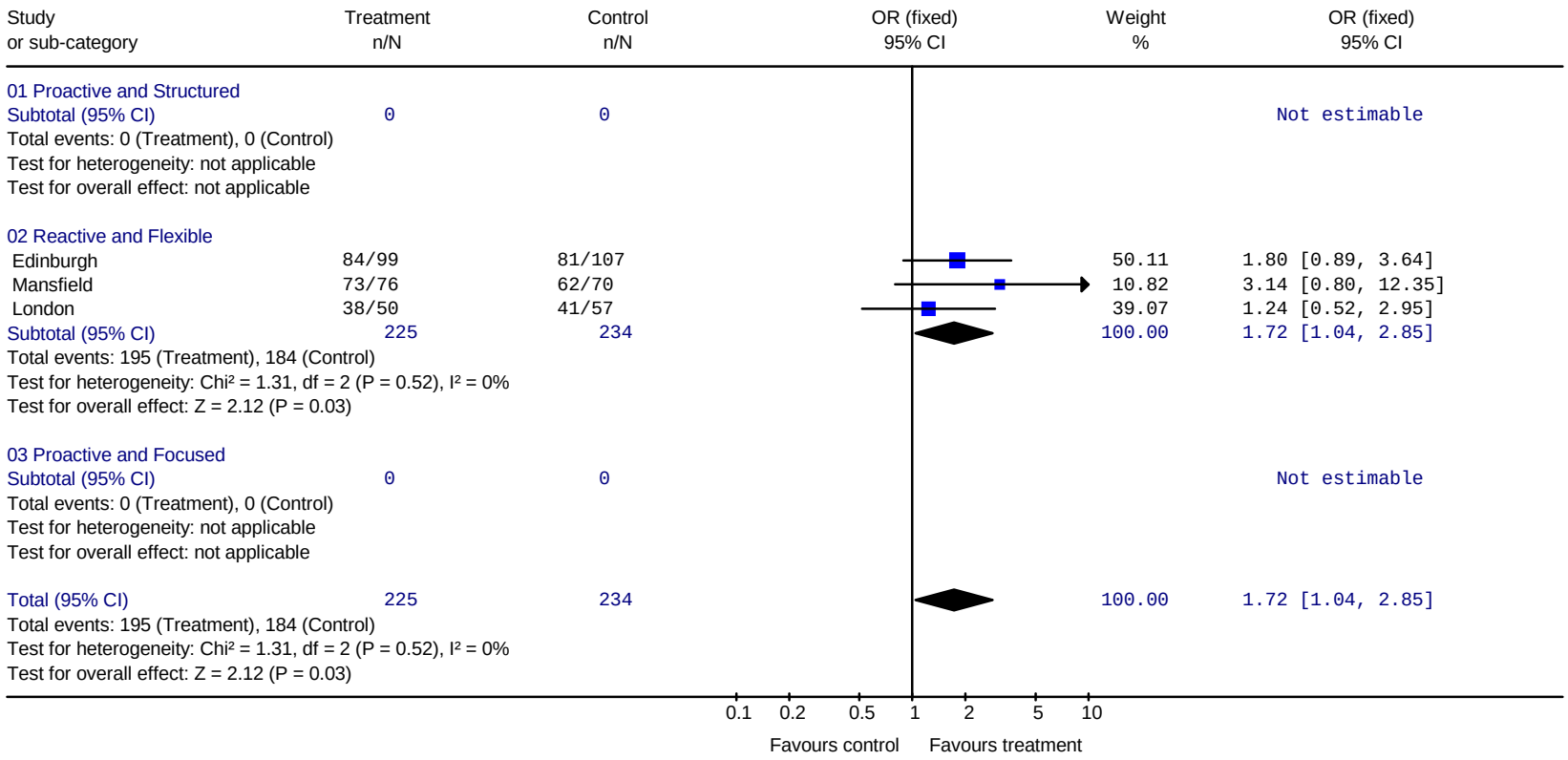


Figure 5.38: Carer Satisfaction; “The staff have done everything to make the patient well”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 56 "The staff have done everything to make the patient well" - carer

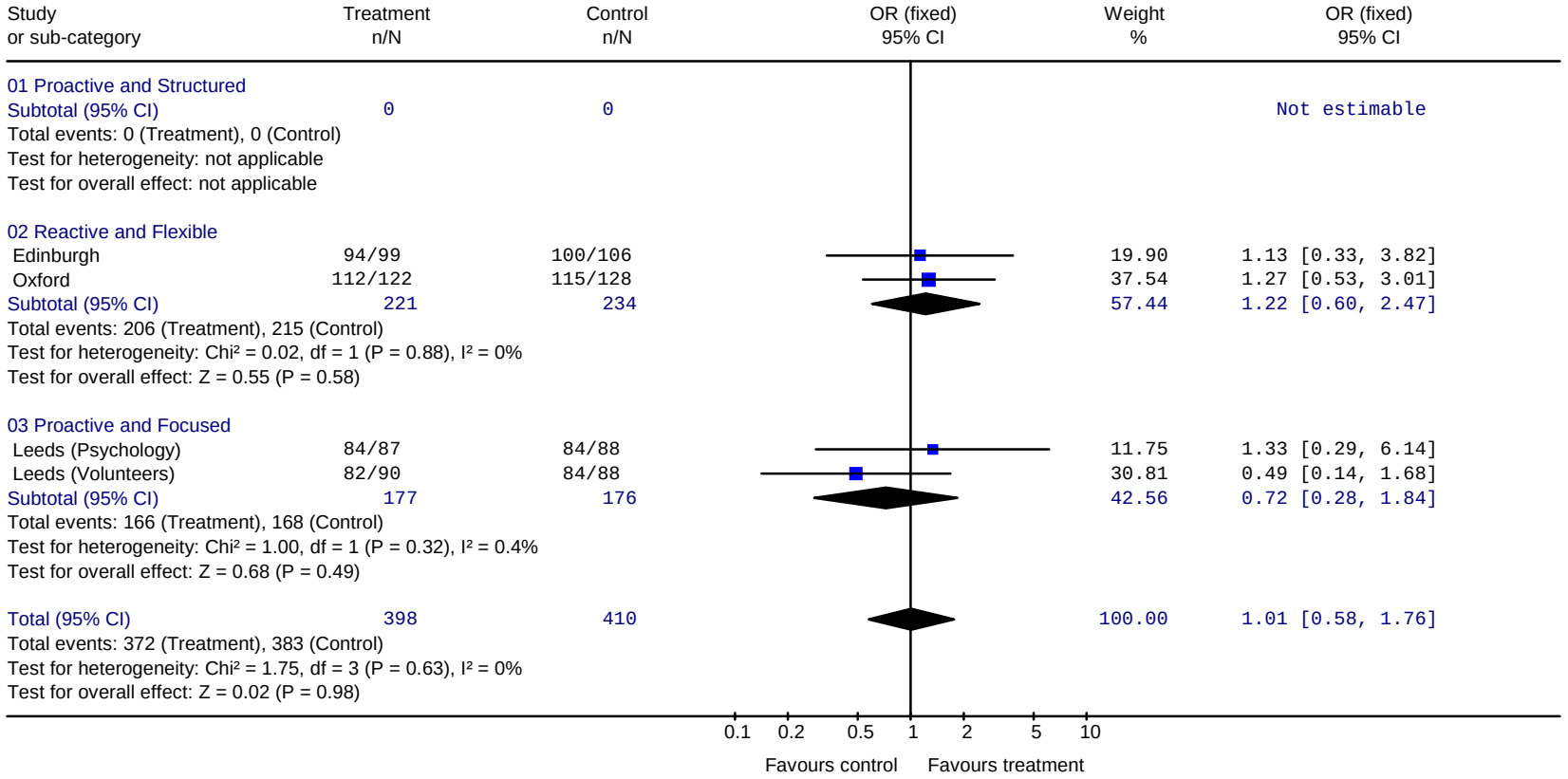


Figure 5.39: Carer Satisfaction; “I am satisfied with the type of treatment the patient received”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 57 "I am satisfied with the type of treatment the patient received" - carer

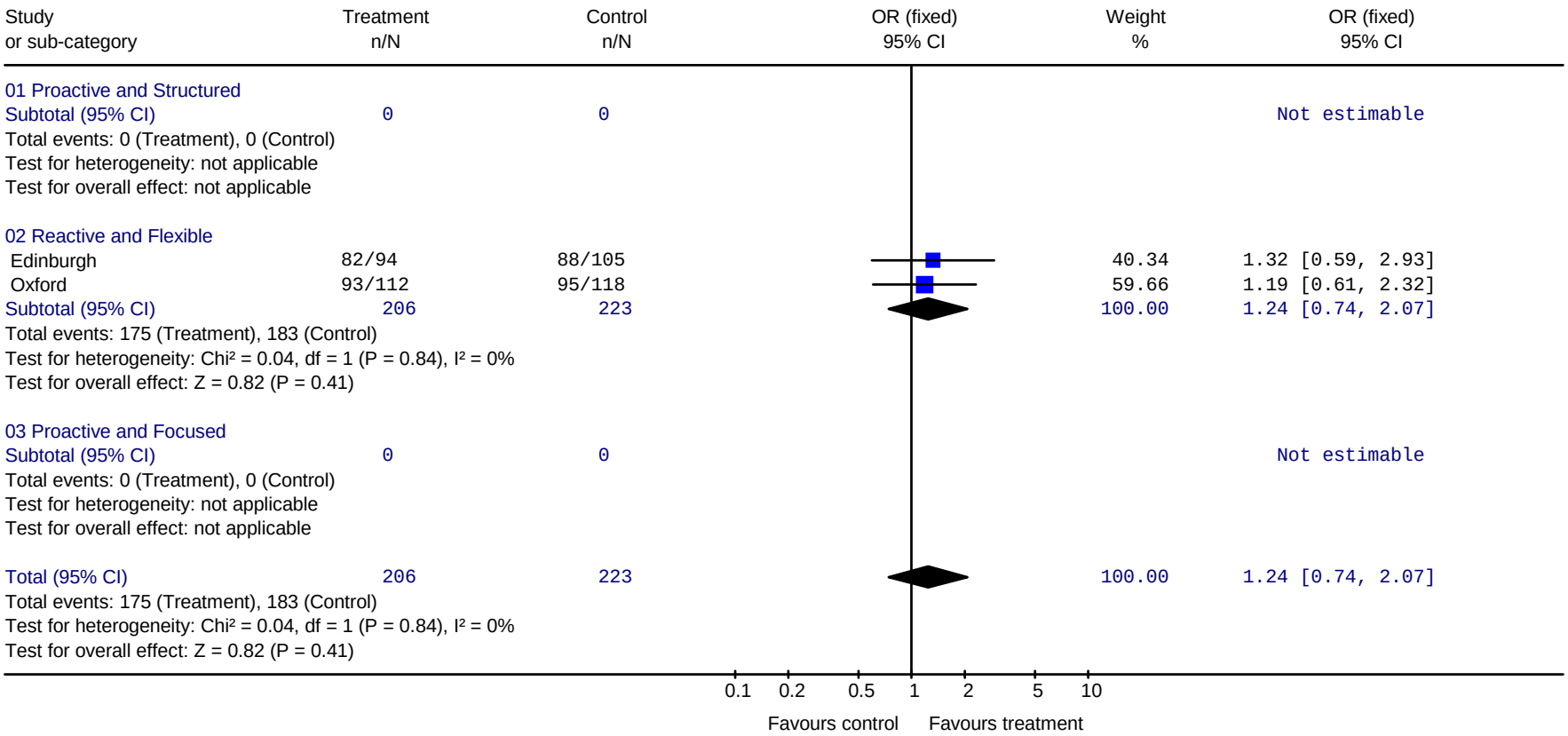


Figure 5.40: Carer Satisfaction; “The patient has had enough therapy”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 58 "They have had enough therapy" - carer

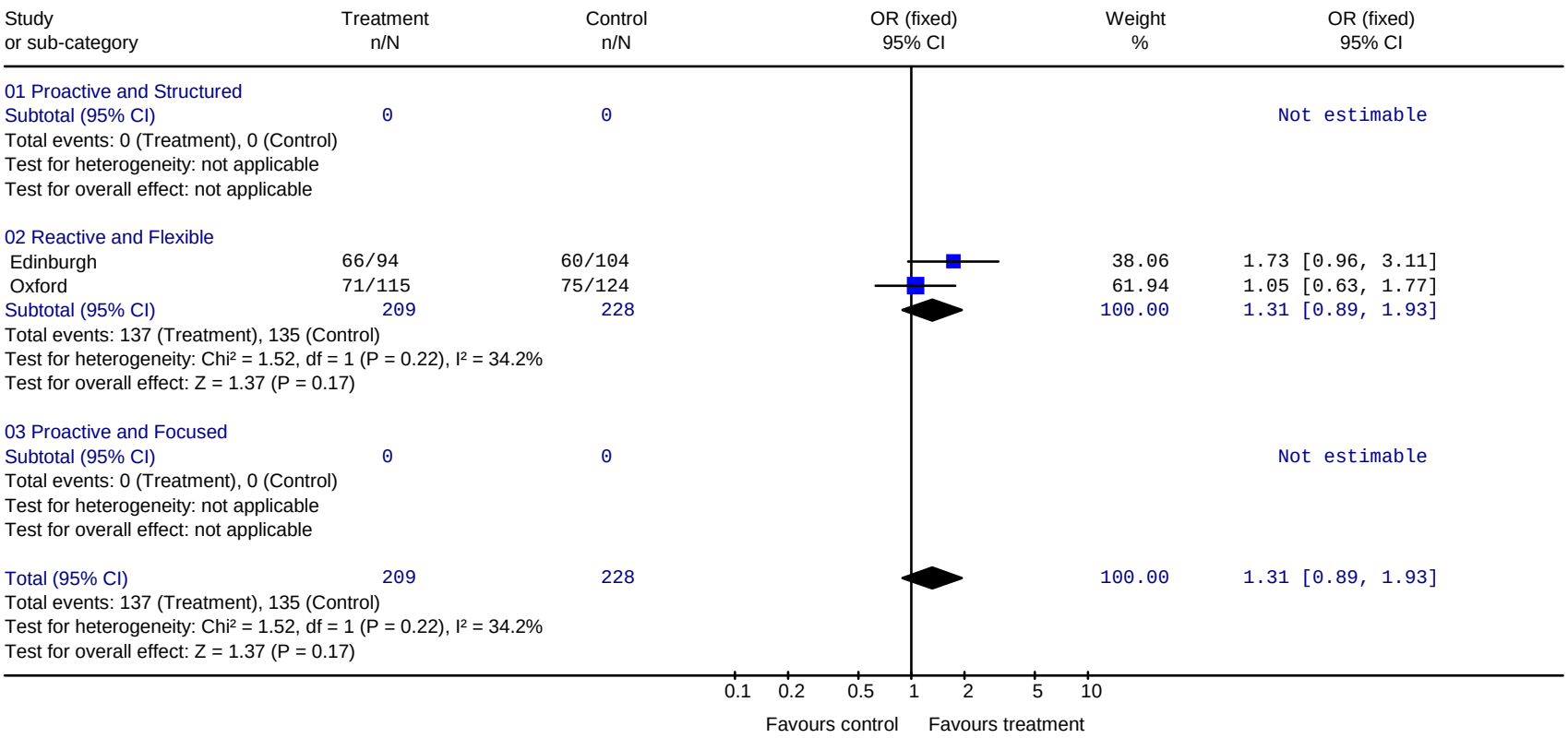


Figure 5.41: Carer Satisfaction; “I was given enough information about allowances available”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 59 "I was given enough information about allowances available" - carer

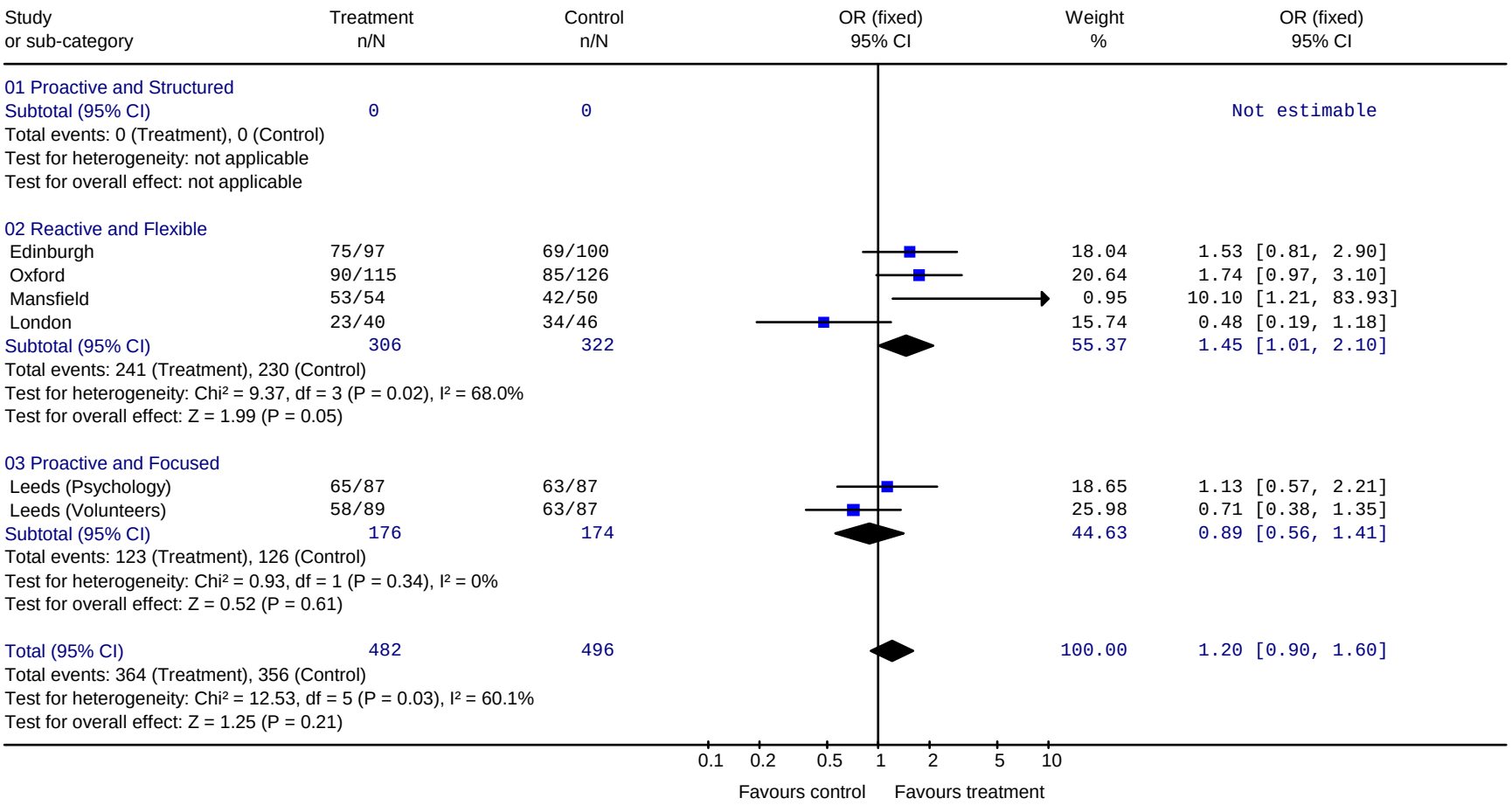


Figure 5.42: Carer Satisfaction; “Things were well prepared for their return home”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 60 "Things were well prepared for their return home" - carer

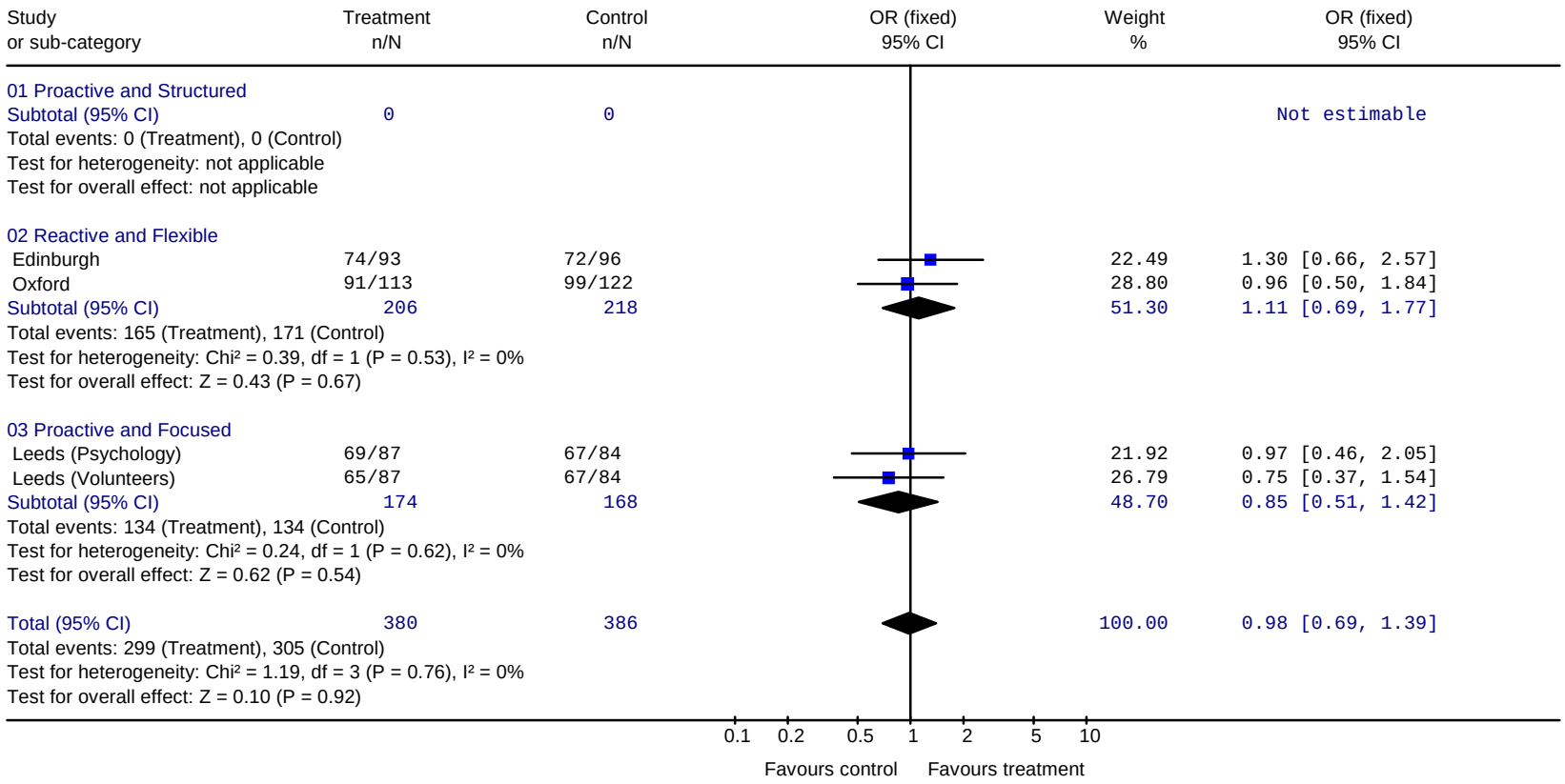


Figure 5.43: Carer Satisfaction; “I get all the support I need from services”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 61 "I get all the support I need from services" - carer

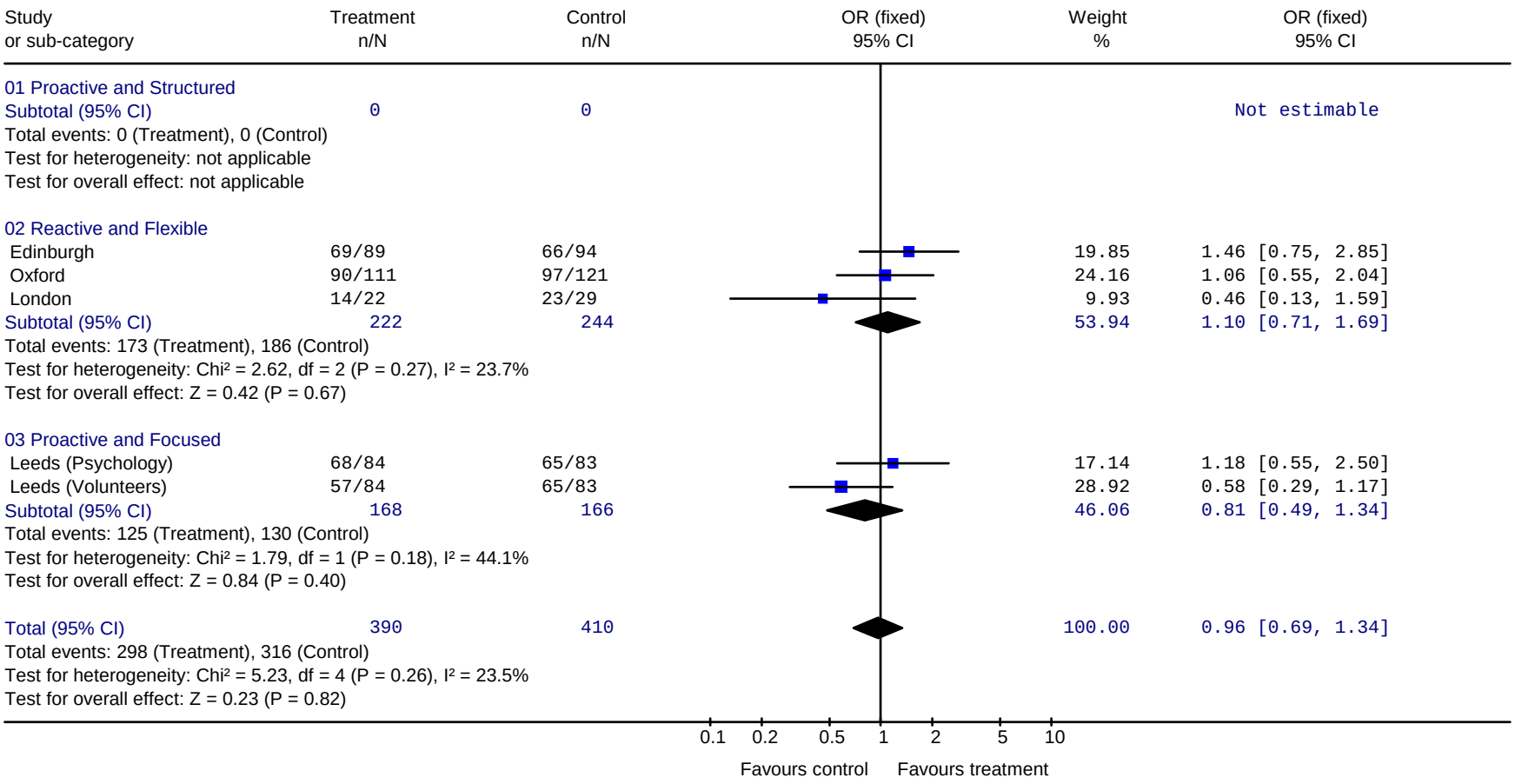


Figure 5.44: Carer Satisfaction; “I have received enough practical help”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 62 "I have received enough practical help" - carer

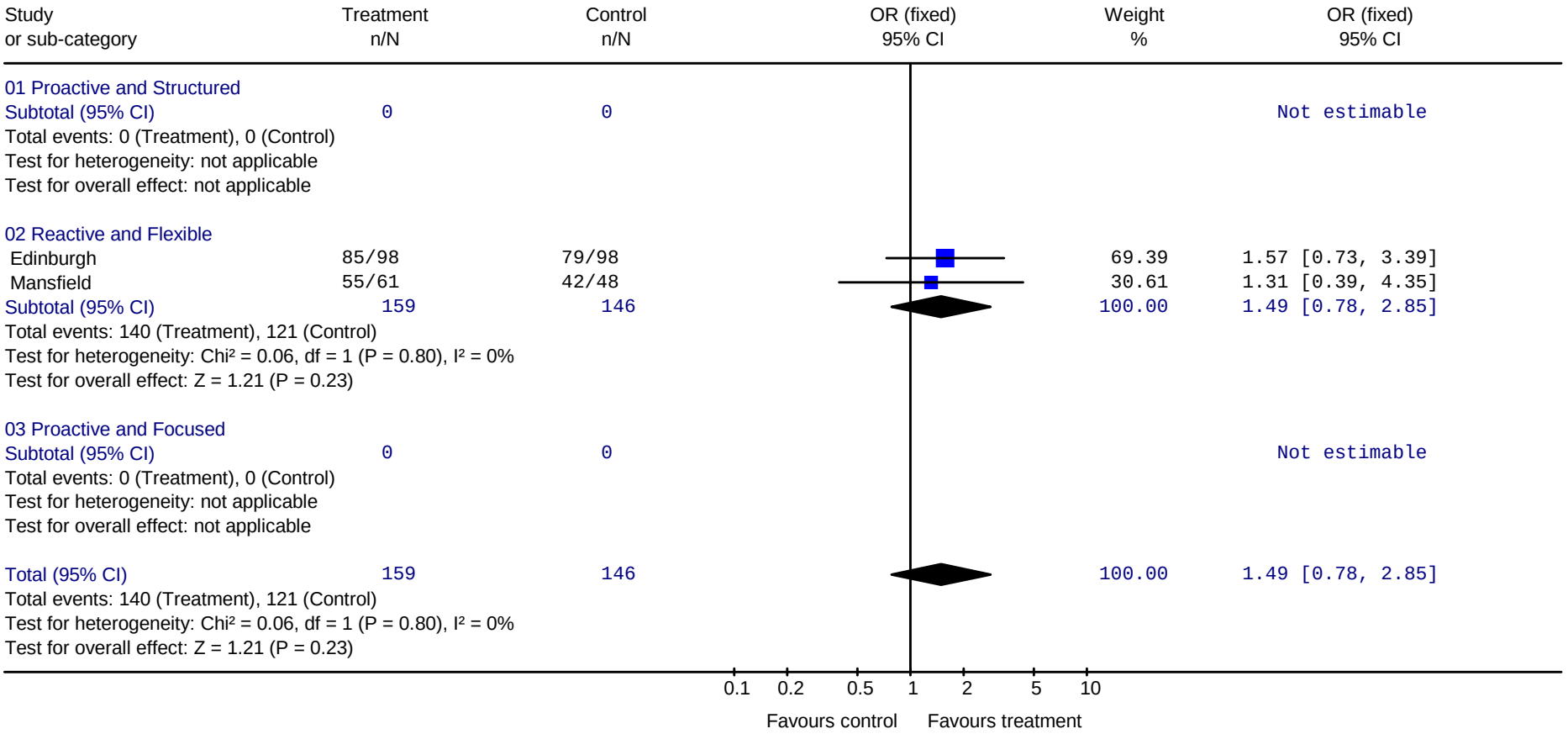


Figure 5.45: Carer Satisfaction; “I have received enough information about recovery and rehabilitation”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 63 "I have received enough information about recovery and rehabilitation" - carer

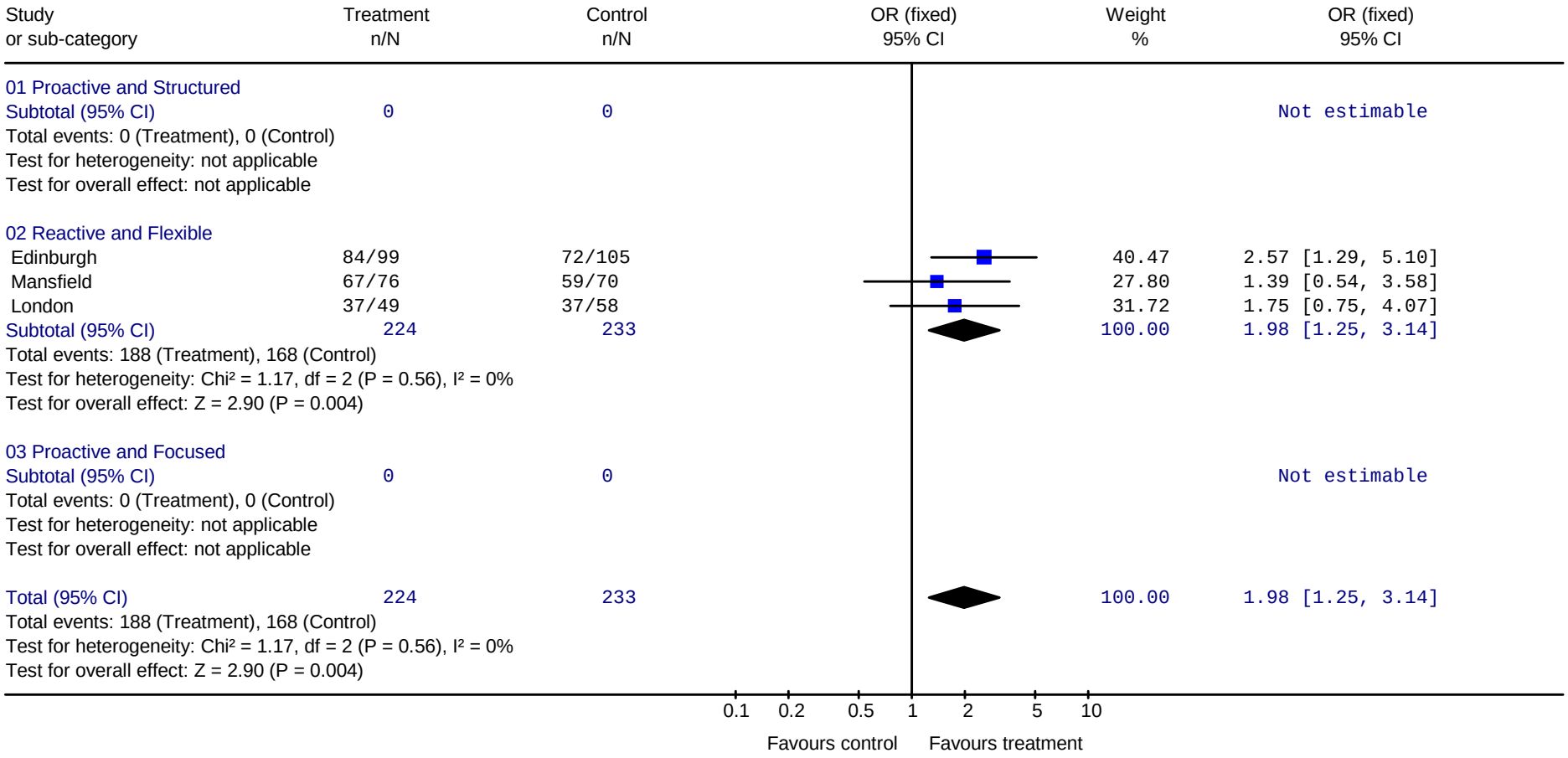


Figure 5.46: Carer Satisfaction; “Someone has really listened”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 64 "Someone has really listened" - carer

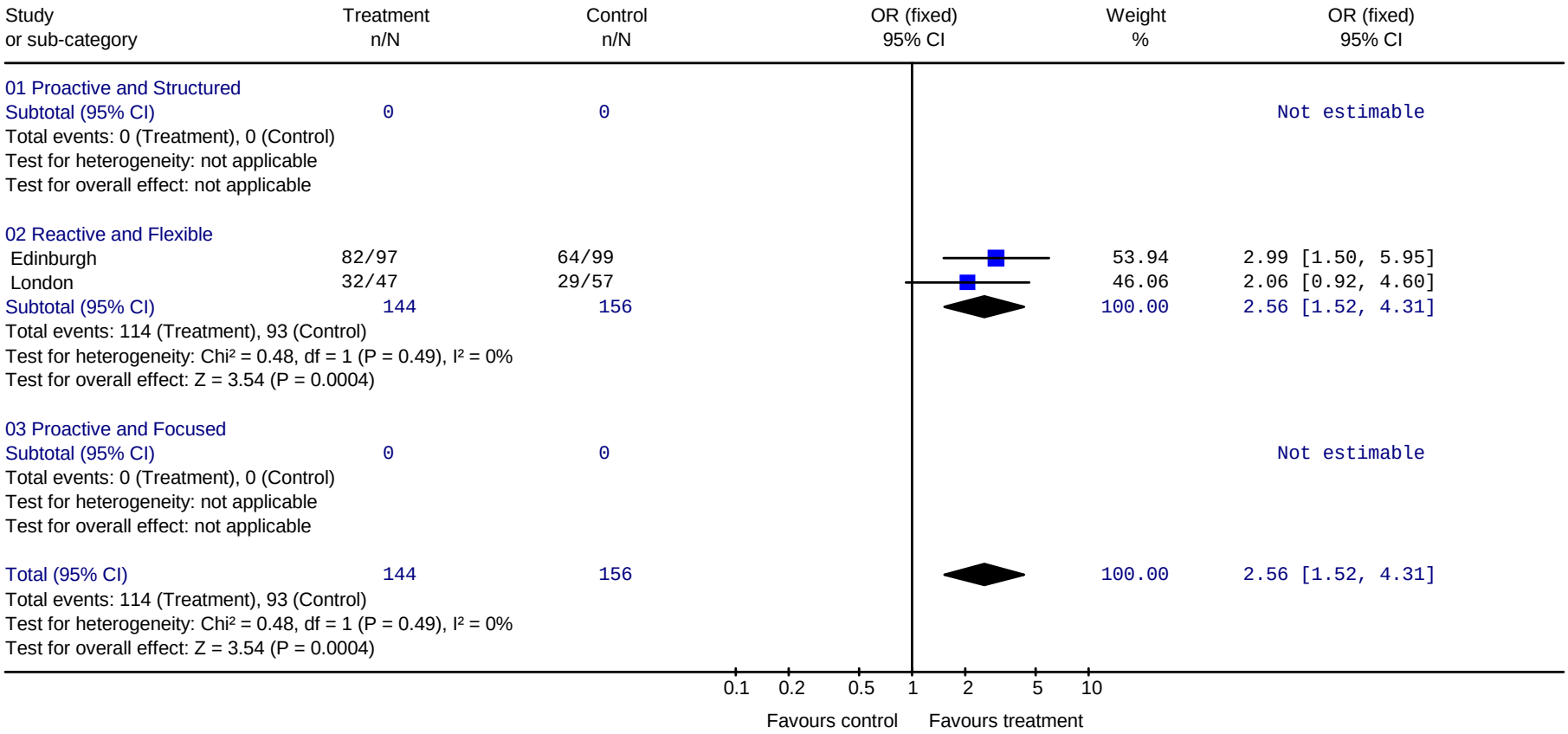


Figure 5.47: Carer Satisfaction; “I have not felt neglected”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 65 "I have not felt neglected" - carer

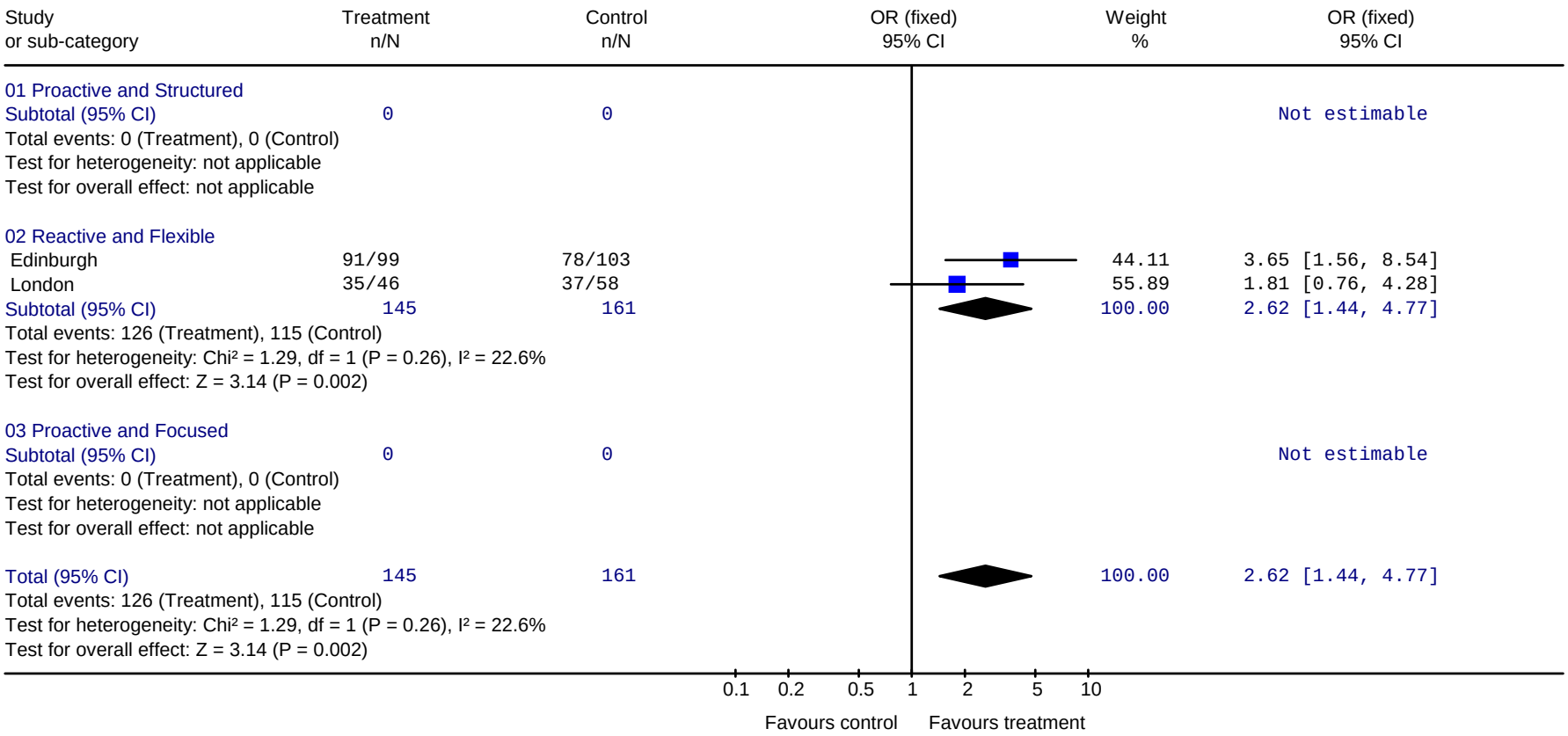


Figure 5.48: Carer Satisfaction; “I have received enough emotional support”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 66 "I have received enough emotional support" - carer

Study or sub-category	Treatment n/N	Control n/N	OR (fixed) 95% CI	Weight %	OR (fixed) 95% CI
01 Proactive and Structured					
Subtotal (95% CI)	0	0			Not estimable
Total events: 0 (Treatment), 0 (Control)					
Test for heterogeneity: not applicable					
Test for overall effect: not applicable					
02 Reactive and Flexible					
Edinburgh	81/97	72/98		21.95	1.83 [0.91, 3.68]
Mansfield	45/46	16/18		0.93	5.63 [0.48, 66.32]
Subtotal (95% CI)	143	116		22.88	1.98 [1.01, 3.88]
Total events: 126 (Treatment), 88 (Control)					
Test for heterogeneity: Chi² = 0.74, df = 1 (P = 0.39), I² = 0%					
Test for overall effect: Z = 2.00 (P = 0.05)					
03 Proactive and Focused					
Leeds (Psychology)	60/87	57/86		33.05	1.13 [0.60, 2.14]
Leeds (Volunteers)	51/87	57/86		44.07	0.72 [0.39, 1.34]
Subtotal (95% CI)	174	172		77.12	0.90 [0.58, 1.39]
Total events: 111 (Treatment), 114 (Control)					
Test for heterogeneity: Chi² = 0.99, df = 1 (P = 0.32), I² = 0%					
Test for overall effect: Z = 0.48 (P = 0.63)					
Total (95% CI)	317	288		100.00	1.14 [0.79, 1.65]
Total events: 237 (Treatment), 202 (Control)					
Test for heterogeneity: Chi² = 5.48, df = 3 (P = 0.14), I² = 45.2%					
Test for overall effect: Z = 0.73 (P = 0.47)					

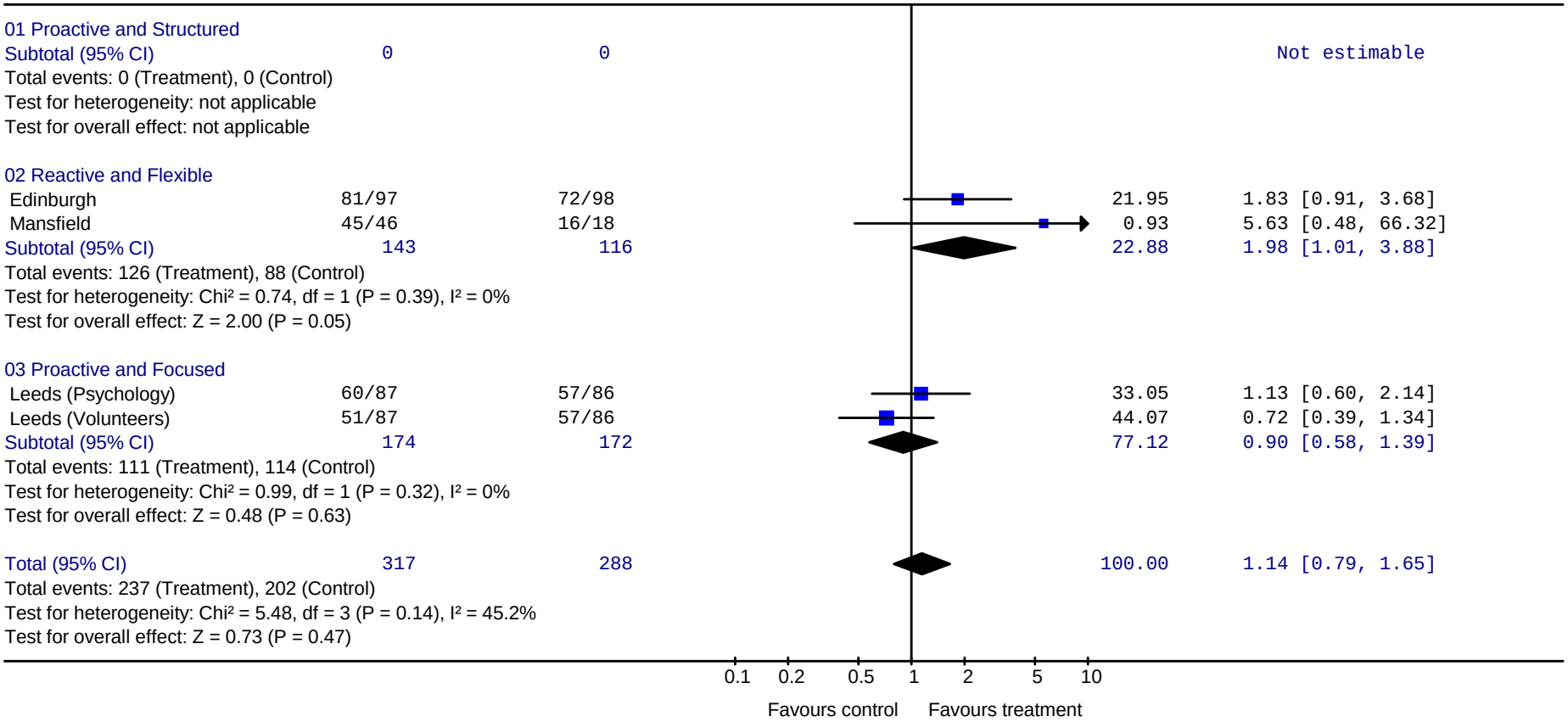


Figure 5.49: Carer Satisfaction; “I have received enough special equipment”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 67 "I have received enough special equipment" - carer

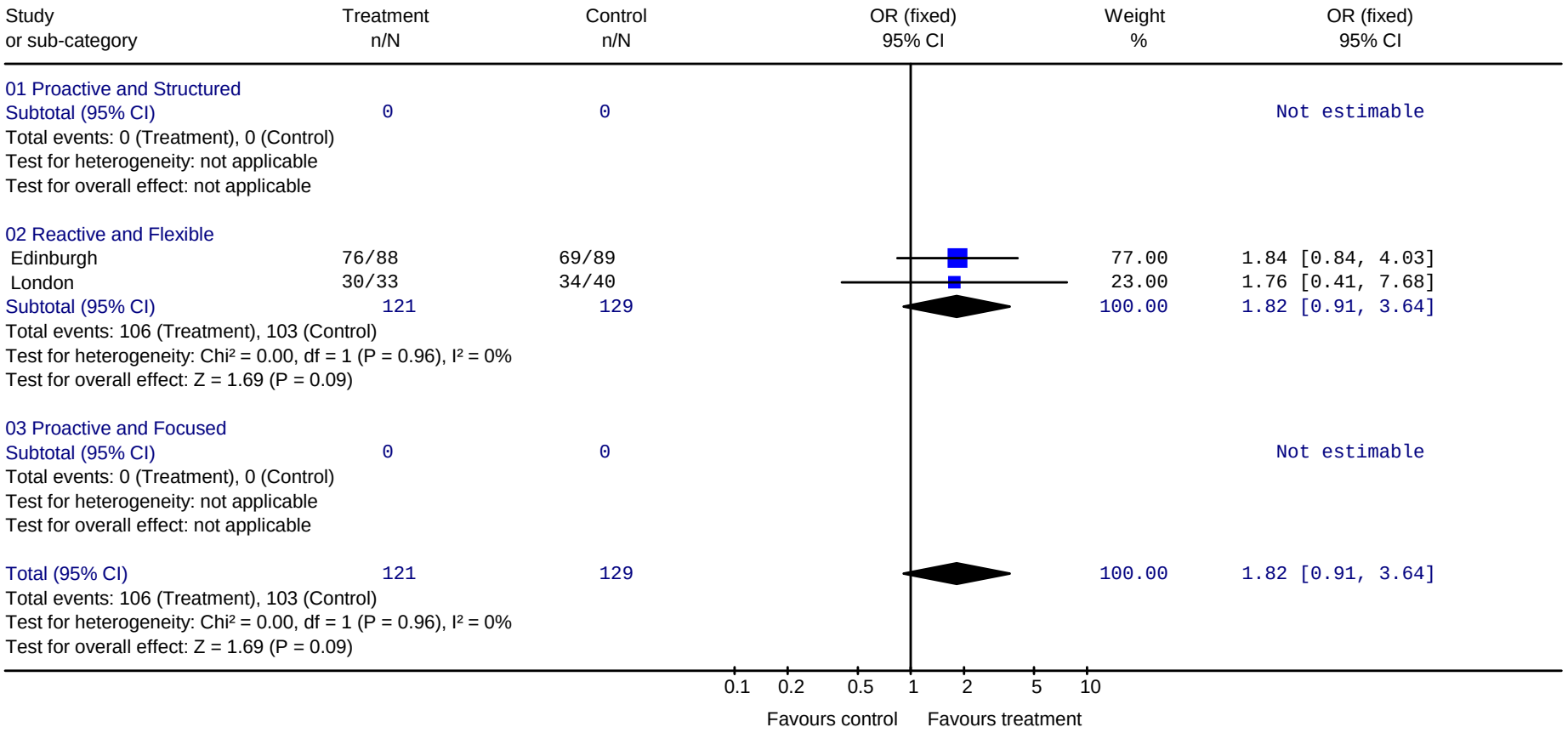
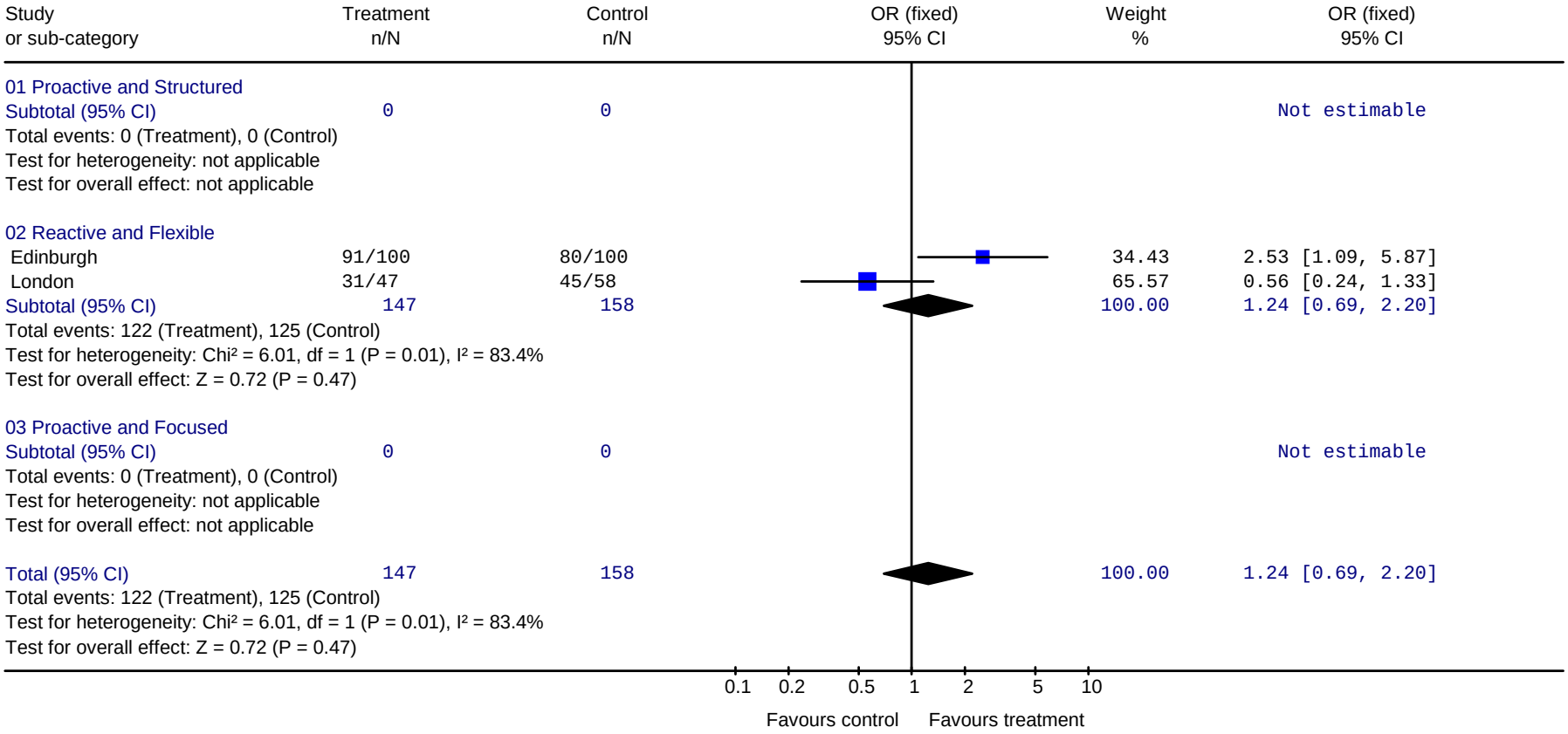


Figure 5.50: Carer Satisfaction; “I know who to contact”

Review: Stroke liaison workers for stroke patients and carers
Comparison: 01 Stroke Liaison Workers Versus Usual Care - Intervention Type
Outcome: 68 "I know who to contact" - carer



Subgroup analyses

Within a systematic review, sub-grouping of trials offers a potentially useful method of trying to establish which aspects of an intervention are most effective or which patient group are likely to benefit most. This last grouping according to patient characteristics is only largely possible with individual patient data.

In order to find out which aspects of the Stroke Liaison Worker intervention might be effective, and which might not, an attempt was made to form meaningful intervention subgroups. This sub-grouping was based on external or pragmatic factors rather than on a known mechanism of effect for the intervention. Because individual trials were conflicting, it could not be clearly established which aspects of the intervention might be resulting in a positive benefit (170) and which might result in harm (76). These subgroups were agreed by the trialists at the meeting. They are presented here with their rationale and results. Satisfaction data are presented for sub-grouping according to intervention type rather than for patient characteristics.

Prior to the meeting of trialists, an attempt was made to form a classification based on the dominant emphasis of an intervention (education and information provision; social support; liaison). In order to acquire more detailed information about the types of intervention, trialists were asked to complete a "grid" detailing different aspects of the Stroke Liaison Workers role and function (Appendix G). Trials were then allocated to a subgroup (education and information provision; social support; liaison) according to the dominant emphasis of a particular trial. Where trialists could not be contacted, PL and GE completed trial grids independently.

The results of the trial grids is illustrated in Table 5.2

Results are presented in Table 5.3. Results are discussed here where there was a significant subgroup or subgroup interaction.

	Trialists Rating			Education and Information Provision						Social Support							Liaison				
Trial	Education	Social Support	Liaison	Stroke (general)	Stroke risk factors or preventing another stroke	Stroke consequences and complications	Stroke services and benefits	Stroke treatments and therapies	Other	Informal and emotional support	Informal counselling	Formal counselling	Family support / problem solving	Individual support / problem solving	Organising of other social support	Other	With patient / carer	With community services	With primary care	With secondary care	Other
Glasgow	●			●	●	●		●		●				●			●				
Preston	●				●	●	●	●		●			●		●		●	●	●	●	
Edinburgh		●			●		●		●	●	●		●	●	●		●	●	●	●	
Bradford	●	●	●	●			●	●		●			●	●	●		●	●			
Adelaide	●	●		●	●	●	●			●		●	●	●	●		●				
Oxford		●		●	●		●			●					●		●	●			
London		●		●	●		●			●							●	●			
Liverpool*		●		●			●			●	●						●	●	●	●	
Leeds (Volunteer)		●								●							●				
Boston (FIRST)		●				●	●					●	●				●	●			
Mansfield		●		●	●	●	●	●		●	●		●		●		●	●			
Utrecht		●		●	●	●	●	●		●	●		●	●			●				
Rhode Island		●		●	●	●	●	●		●	●		●	●	●		●				
Philadelphia (STAIR)		●		●						●			●				●	●	●	●	
Melbourne			●				●			●	●						●	●	●		●
Leeds (Psychiatry Nurse)			●							●		●		●			●				
Melbourne(SHIPS)			●														●	●	●		

Table 5.2: Subgrouping of Trials by Primary Intervention Emphasis
*Both intervention arms reported by the trialist as the same

Primary Patient outcomes

1. Subjective health status: Analysis of data for 3341 participants (14 interventions) did not suggest an overall benefit from Stroke Liaison Worker (as before). The subgroup providing education and information provision (two interventions) as the dominant emphasis of the service showed a positive subgroup result (SMD -0.24, 95% CI -0.44 to -0.04, p=0.02). Similarly the group providing liaison as the dominant emphasis (one intervention) suggested a benefit in the treatment group (SMD -0.24, 95% CI -0.47 to -0.01, p=0.04). There was no benefit seen for the larger subgroup (11 interventions) whose dominant emphasis was on social support (SMD 0.00, 95% CI -0.07 to 0.08, p=0.94). Overall there was significant subgroup heterogeneity ($p<0.05$) suggesting that the contrast between social support and the other aspects of the Stroke Liaison role reflected a real difference in the intervention.

Patient Satisfaction Data

1. "Someone has really listened": Data were available for 915 participants from three interventions, but only one subgroup (social support). Results suggest a benefit from the Stroke Liaison Worker intervention (OR 1.58 in favour of treatment, 95% CI 1.14 to 2.19, p=0.006).

Carer Satisfaction Data

1. "I received all the information I needed about the nature and causes of the patient's illness": Results for this question were available from 459 carers in three interventions but only one subgroup (social support). Results favoured the treatment group (OR 1.72, 95% CI 1.04 to 2.85, p=0.03).

2. “Someone has really listened”: Data were available from 300 carers in two interventions, but again only one subgroup (social support). Results favoured the intervention group (OR 2.56, 95% CI 1.52 to 4.31, p=0.0004).

3. “I have not felt neglected”: Results were available from two interventions (306 carers) in one subgroup (social support). These suggested a significant benefit in favour of the intervention group (OR 2.62, 95% CI 1.44 to 4.77, p=0.002).

4. “I have received enough information about recovery and rehabilitation”: Results were only available for one subgroup (social support), three trials with 457 carers. Results demonstrate significantly improved satisfaction in favour of the treatment group (OR 1.98, 95% CI 1.25 to 3.14, p=0.004).

Table 5.3: Subgroup Analysis : Emphasis of Stroke Liaison Worker Intervention

	N in analysis	*Analysis*	*Total [95% CI]*	*Subgroup Heterogeneity (Chi^2)*	*Subgroup Results*		
					Education and Information Provision	**Social Support**	**Liaison**
Primary Outcomes for Patients							
Subjective Health Status	3345	SMD	-0.05 (-0.11, 0.02), p=0.18	**<0.05**	**-0.24 (-0.44, -0.04), p=0.02#**	0.00 (-0.07, 0.08), p=0.94†	**-0.24 (-0.47, -0.01), p=0.04**
Extended Activities of Daily Living	3254	SMD	0.04 (-0.03, 0.11), p=0.22	>0.05	0.12 (-0.18, 0.41), p=0.44	0.06 (-0.01, 0.14), p=0.10	-0.23 (-0.48, 0.02), p=0.08†
Secondary Outcomes for Patients							
Death	4183	OR	0.87 (0.72, 1.06), p=0.17	>0.05	0.89 (0.31, 2.56), p=0.82	0.91 (0.73, 1.13), p=0.39	0.70 (0.43, 1.15), p=0.16
Place of Residence (Institutionalisation)	1146	OR	0.83 (0.51, 1.36), p=0.46	>0.05	NA	0.80 (0.51, 1.36), p=0.46	NA
Activities of Daily Living	3457	SMD	-0.02 (-0.09, 0.05), p=0.55	>0.05	0.19 (-0.11, 0.49), p=0.21	-0.01 (-0.08, 0.06), p=0.79	**-0.25 (-0.47, -0.02), p=0.03†**
Dependence (Barthel score ≤19)	2898	OR	0.90 (0.76, 1.06), p=0.20	>0.05	**0.37 (0.15, 0.93), p=0.03**	0.89 (0.75, 1.06), p=0.21	1.34 (0.77, 2.31), p=0.30†
Depression	2945	SMD	-0.05 (-0.12, 0.02), p=0.17	>0.05	-0.22 (-0.44, 0.01), p=0.06	-0.01 (-0.09, 0.07), p=0.78	-0.24 (-0.49, 0.02), p=0.07
Anxiety	1200	SMD	-0.20 (-0.66, 0.26), p=0.39	NA	NA	-0.20 (-0.66, 0.26), p=0.39	NA
Participation	860	SMD	-0.04 (-0.17, 0.10), p=0.59	NA	NA	-0.04 (-0.17, 0.10), p=0.59	NA
Primary Outcome for Carers							
Subjective Health Status	1915	SMD	0.04 (-0.05, 0.13), p=0.33†	>0.05	-0.41 (-0.88, 0.05), p=0.08	0.06 (-0.03, 0.16), p=0.20†	0.05 (-0.21, 0.31), p=0.72†
Secondary Outcome for Carers							
Extended Activities of Daily Living	752	SMD	-0.13 (-0.28, 0.01), p=0.07†	NA	NA	-0.13 (-0.28, 0.01), p=0.07†	NA
Caregiver Mental Health	1767	SMD	-0.02 (-0.12, 0.07), p=0.62	>0.05	NA	-0.02 (-0.12, 0.08), p=0.69	-0.05 (-0.36, 0.25), p=0.73

Subgroup analysis stratified by the emphasis of the Stroke Liaison Worker intervention
Results shown in boxes indicate statistically significant results. Significant subgroup Chi^2 results indicate significant subgroup interaction.
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group.)
#Intra-group heterogeneity present, SMD = Standardised Mean Difference, OR = Odds Ratio

Profession of Stroke Liaison Worker

The term "Stroke Liaison Worker" describes a role that spans different professions including Nursing, Psychology, Social Work, other Allied health professions or the voluntary sector. It could be argued that differing levels of knowledge and skill rather than attitude alone may differentiate between otherwise, externally comparable roles. This knowledge or skills may influence patient education and information provision, or provide more focused patient and carer counselling. For this reason dividing the results by professional grouping seems a legitimate method of analysing the overall results.

Trialists were asked to provide information on the professional background of the Stroke Liaison Worker evaluated in each trial where this was not clear from published data. The professions were grouped into four distinct subgroups: Nurse, Psychologist, Social Worker and a final grouping of Generic Health Care Worker or Volunteer. This last subgroup included trials where the SLW was from an Allied Health Profession, the voluntary sector or (in the case of some trials with more than one worker) no specific background but had been trained in the SLW role.

Results are presented in Table 5.4. Results are discussed here where there was a significant subgroup or subgroup interaction.

Secondary Patient Outcomes

1. Mental Health (Depression): Overall analysis from 15 interventions (2949 participants) as we have seen suggests a non-significant trend towards the Stroke Liaison Worker intervention being beneficial. In one subgroup (nurse) this effect becomes significant (SMD -0.20, 95%

CI -0.34 to -0.05, p=0.007). Subgroup heterogeneity was present with the Chi^2 heterogeneity $p<0.05$ suggesting a real subgroup interaction.

Patient Satisfaction Data

The most relevant satisfaction results are listed here.

1. "The staff attended well to my personal needs": Data were available for 1668 participants across 6 interventions in all four subgroups. Overall, the results for this question did not show any significant results, however the nurse subgroup showed a significant effect suggesting less satisfaction in the Stroke Liaison Worker group (OR controls 0.30, 95% CI 0.10 to 0.87, p=0.03). There was significant subgroup heterogeneity ($p<0.05$) suggesting a significant subgroup interaction.

Carer Satisfaction Data

1. "I know who to contact": 305 Carers in two subgroups (Social Worker and Generic Health Care Worker or Volunteer) did not demonstrate any overall significant improvement in satisfaction for this question (OR 1.24, 95% CI 0.69 to 2.20, p=0.01) however one subgroup (Social Worker) did report a significant improvement in satisfaction (OR 2.53, 95% CI 1.09 to 5.87, p=0.03) in the intervention group. The other subgroup (Generic Health Care Worker or Volunteer) suggested a trend in favour of an improvement in control group satisfaction (OR 0.56, 95% CI 0.69 to 2.20, p=0.19). As a result there was a significant subgroup effect (test for heterogeneity $p<0.05$).

Table 5.4: Subgroup Analysis: Profession of Stroke Liaison Worker

	N in analysis	*Analysis*	*Total [95% CI]*	*Subgroup Heterogeneity (Chi^2)*	*Subgroup Results*			
					Nurse	**Psychologist**	**Social Worker**	**Generic Health Care Worker or Volunteer**
Primary Outcomes for Patients								
Subjective Health Status	3343	SMD	-0.05 (-0.11, 0.02), p=0.18	>0.05	-0.07 (-0.19, 0.05), p=0.24	-0.10 (-0.23, 0.03), p=0.12	0.11 (-0.09, 0.31), p=0.29†	-0.03 (-0.15, 0.10), p=0.70
Extended Activities of Daily Living	3254	SMD	0.04 (-0.03, 0.11), p=0.22	>0.05	0.07 (-0.07, 0.20), p=0.33	-0.06 (-0.19, 0.07), p=0.38†	0.13 (-0.07, 0.33), p=0.21	0.08 (-0.04, 0.20), p=0.20
Secondary Outcomes for Patients								
Death	4179	OR	0.87 (0.72, 1.06), p=0.17	>0.05	1.14 (0.66, 1.95), p=0.64†	0.74 (0.50, 1.10), p=0.14	0.66 (0.41, 1.08), p=0.10	0.97 (0.73, 1.29), p=0.83†
Place of Residence (Institutionalisation)	1122	OR	0.83 (0.51, 1.36), p=0.46	>0.05	1.00 (0.34, 2.94), p=1.00	0.64 (0.29, 1.40), p=0.26	0.94 (0.12, 7.08), p=0.95	1.00 (0.42, 2.39), p=0.99
Activities of Daily Living	3457	SMD	-0.02 (-0.09, 0.05), p=0.55	>0.05	0.07 (-0.06, 0.20), p=0.32	-0.08 (-0.21, 0.04), p=0.20†	0.06 (-0.12, 0.24), p=0.50	-0.08 (-0.20, 0.04), p=0.21†
Dependence (Barthel ≤19)	2898	OR	0.90 (0.76, 1.06), p=0.20	>0.05	0.72 (0.52, 1.01), p=0.06	0.90 (0.64, 1.27), p=0.56	0.94 (0.65, 1.34), p=0.72	1.03 (0.77, 1.39), p=0.83†
Depression	2943	SMD	-0.05 (-0.12, 0.02), p=0.17	>0.05	**-0.20 (-0.34, -0.05), p=0.007**	-0.04 (-0.17, 0.10), p=0.60	0.11 (-0.11, 0.32), p=0.33†	-0.01 (-0.13, 0.12), p=0.92
Anxiety	1200	SMD	-0.20 (-0.66, 0.26), p=0.39	>0.05	-0.38 (-1.18, 0.42), p=0.35	NA	-0.52 (-1.33, 0.29), p=0.21	0.28 (-0.51, 1.06), p=0.49†
Participation	860	SMD	-0.04 (-0.17, 0.10), p=0.59	>0.05	NA	NA	0.02 (-0.19, 0.22), p=0.88	-0.08 (-0.25, 0.10), p=0.41†
Primary Outcome for Carers								
Subjective Health Status	1915	SMD	0.04 (-0.05, 0.13), p=0.33†	>0.05	0.05 (-0.12, .22), p=0.56†	0.05 (-0.15, 0.25), p=0.61†	-0.09 (-0.37, 0.19), p=0.51	0.07 (-0.07, 0.21), p=0.32†
Secondary Outcome for Carers								
Extended Activities of Daily Living	752	SMD	-0.13 (-0.28, 0.01), p=0.07†	>0.05	-0.04 (-0.40, 0.32), p=0.84†	-0.11 (-0.45, 0.23), p=0.52	**-0.34 (-0.64, -0.03), p=0.03†**	-0.07 (-0.28, 0.15), p=0.54
Caregiver Mental Health	1767	SMD	-0.02 (-0.12, 0.07), p=0.62	>0.05	0.00 (-0.20, 0.20), p=0.99	-0.08 (-0.29, 0.12), p=0.41	-0.03 (-0.28, 0.22), p=0.80	0.00 (-0.15, 0.14), p=0.97

Subgroup analysis stratified by the profession of the Stroke Liaison Worker
Results shown in boxes indicate statistically significant results. Significant subgroup Chi^2 results indicate significant subgroup interaction.
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group.) SMD = Standardised Mean Difference, OR = Odds Ratio

Patient Characteristics - Subgroup analysis

Patient Age

Patient data were dichotomised where possible into two subgroups - under 65s and 65 or older. It was postulated that younger patients may have differing or greater psychosocial problems to older patients, and may respond differently to the intervention. The results are shown in Table 5.5. Results are described here where a significant subgroup exists along with a significant subgroup interaction. Results for the outcome of depression are significant overall, however as with other subgroups, the data analysed here is only available from datasets that have adequate individual patient data and does not represent the overall dataset. For this reason, these results are not discussed here.

Secondary Patient Outcomes

1. Activities of Daily Living (ADL): Results for ADL were available for 2424 participants dichotomised by age from 11 interventions (9 trials). Analysis by patient age (<65 or >65) revealed one positive subgroup for the outcome of activities of daily living in favour of the younger treatment group (n=706, SMD 0.15, 95% CI 0.00 to 0.30, p=0.05). The older age group had a non-significant result in favour of the control group (SMD -0.04, 95% CI -0.14 to 0.05, p=0.38). Chi^2 Tests for heterogeneity were significant (<0.05) suggesting a significant subgroup interaction.

Table 5.5: Subgroup Analysis; Patient Age

	N in analysis‡	*Analysis*	*Total [95% CI]*	*Subgroup heterogeneity (Chi^2)*	*Subgroup Results*	
			Overall		**Under 65**	**Over 65**
Primary Outcomes for Patients						
Subjective Health Status	2503	SMD	-0.06 (-0.14, 0.01), p=0.11	>0.05	-0.09 (-0.23, 0.05), p=0.20	-0.05 (-0.15, 0.04), p=0.29
Extended Activities of Daily Living	2122	SMD	0.08 (0.00, 0.17), p=0.06	>0.05	0.15 (-0.03, 0.32), p=0.10	0.06 (-0.04, 0.16), p=0.21
Secondary Outcomes for Patients						
Death	2856	OR	0.88 (0.69, 1.12), p=0.29	>0.05	0.60 (0.26, 1.39), p=0.23	0.91 (0.70, 1.18), p=0.47
Place of Residence (Institutionalisation)	1227	OR	1.12 (0.76, 1.65), p=0.56†	>0.05	0.75 (0.23, 2.43), p=0.63	1.18 (0.78, 1.78), p=0.43†
Activities of Daily Living	2424	SMD	0.01 (-0.07, 0.09), p=0.76	**<0.05**	**0.15 (0.00, 0.30), p=0.05**	-0.04 (-0.14, 0.05), p=0.38†
Dependence (Barthel ≤19)	2150	OR	0.91 (0.75, 1.11), p=0.36	>0.05	0.80 (0.56, 1.14), p=0.21	0.97 (0.77, 1.22), p=0.78
Depression	2384	SMD	**-0.08 (-0.16, 0.00), p=0.05**	>0.05	-0.12 (-0.26, 0.03), p=0.11	-0.06 (-0.16, 0.04), p=0.21
Anxiety	868	SMD	0.09 (-0.84, 1.02), p=0.85†	>0.05	0.09 (-0.84, 1.02), p=0.85†	0.03 (-0.67, 0.74), p=0.92†
Primary Outcome for Carers						
Subjective Health Status	1483	SMD	-0.01 (-0.11, 0.09), p=0.87	>0.05	0.06 (-0.12, 0.24), p=0.53†	-0.04 (-0.16, 0.08), p=0.53)
Secondary Outcome for Carers						
Extended Activities of Daily Living	316	SMD	0.00 (-0.22, 0.22), p=0.99	>0.05	0.20 (-0.33, 0.73), p=0.47	-0.04 (-0.29, 0.20), p=0.72†
Caregiver Mental Health	1051	SMD	-0.03 (-0.15, 0.09), p=0.65	>0.05	0.10 (-0.15, 0.34), p=0.43†	-0.07 (-0.21, 0.07), p=0.33

Subgroup analysis stratified by patient age (Under 65, 65 or older).
Results shown in boxes indicate statistically significant results. Significant subgroup Chi^2 results indicate significant subgroup interaction.
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group.)
#Intra-group heterogeneity present
SMD = Standardised Mean Difference, OR = Odds Ratio

Patient Sex

Data were dichotomised on the basis of sex. It seemed reasonable to explore this sub grouping as men and women may respond to differently to an intervention with a significant psychological and social component. It should be noted that for analysis of carer data, these are analysed according to the sex of the patient and may not reflect the sex of the carer. For instance a carer may well be a daughter looking after a mother or a wife looking after a husband. Data on carer sex was inadequate across the trials to analyse according to carer sex. Results are presented in Table 5.6. No significant subgroups or significant subgroup interaction was observed. As before results for the outcome of depression are positive, but do not represent the totality of data and should be treated with caution.

Table 5.6: Subgroup Analysis: Patient Sex

	N in analysis‡	*Analysis*	*Total [95% CI]*	*Subgroup Heterogeneity (Chi^2)*	*Subgroup Results*	
			Overall		**Male**	**Female**
Primary Outcomes for Patients						
Subjective Health Status	2491	SMD	-0.05 (-0.13, 0.03), p=0.20	>0.05	0.00 (-0.11, 0.10), p=0.93	-0.11 (-0.22, 0.01), p=0.08
Extended Activities of Daily Living	2118	SMD	0.03 (-0.06, 0.11), p=0.52	>0.05	0.05 (-0.6, 0.17), p=0.36	0.00 (-0.13, 0.12), p=0.96
Secondary Outcomes for Patients						
Death	2658	OR	0.88 (0.69, 1.13), p=0.32	>0.05	1.06 (0.75, 1.52), p=0.73†	0.75 (0.54, 1.05), p=0.09
Place of Residence (Institutionalisation)	1055	OR	1.05 (0.68, 1.61), p=0.82†	>0.05	1.41 (0.68, 2.90), p=0.36†	0.90 (0.53, 1.53), p=0.69
Activities of Daily Living	2425	SMD	0.00 (-0.08, 0.08), p=0.91	>0.05	0.04 (-0.07, 0.15), p=0.51	-0.05 (-0.17, 0.07), p=0.38†
Dependence (Barthel ≤19)	2363	OR	0.88 (0.73, 1.06), p=0.17	>0.05	0.94 (0.74, 1.21), p=0.64	0.80 (0.60, 1.06), p=0.13
Depression	2325	SMD	**-0.08 (-0.17, 0.00), p=0.05**	>0.05	-0.07 (-0.18, 0.04), p=0.23	-0.10 (-0.23, 0.02), p=0.10
Anxiety	869	SMD	-0.01 (-0.56, 0.55), p=0.99	>0.05	0.02 (-0.75, 0.80), p=0.96†	-0.03 (-0.84, 0.77), p=0.93
Primary Outcome for Carers						
Subjective Health Status	1483	SMD	-0.01 (-0.11, 0.10), p=0.89	>0.05	0.06 (-0.08, 0.20), p=0.39†	-0.10 (-0.25, 0.06), p=0.23
Secondary Outcome for Carers						
Extended Activities of Daily Living	316	SMD	0.02 (-0.20, 0.24), p=0.86	>0.05	0.07 (-0.22, 0.37), p=0.62	-0.05 (-0.39, 0.29), p=0.76†
Caregiver Mental Health	1051	SMD	-0.04 (-0.17, 0.08), p=0.49	>0.05	0.03 (-0.13, 0.19), p=0.73†	-0.15 (-0.34, 0.05), p=0.13

Subgroup analysis stratified by patient sex.
Results shown in boxes indicate statistically significant results. Significant subgroup Chi^2 results indicate significant subgroup interaction.
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group)
#Intra-group heterogeneity present
SMD = Standardised Mean Difference, OR = Odds Ratio

Presence of a Carer

It is theoretically possible that patients without identified carer support might be at higher risk of (as we have discussed in Chapter One). It therefore follows that this subgroup might benefit the most from social support aspects of the intervention. Within the trials there was varied involvement of carers. (See Table 5.7). Some trials (Rhode Island, Adelaide) specifically recruited only patients who had an identified primary caregiver. Other studies did not include or record caregiver involvement at all (Glasgow). Clearly these trials do not allow us to test the hypothesis that the presence or absence of an identified primary caregiver results in different responses to the Stroke Liaison Worker intervention. For this reason, these trials have been excluded from this subgroup analysis.

The quality of recording of caregiver presence and proximity of involvement with the patient was variable. Two trials reported carer relationship (Oxford, Utrecht). Other trials did not collect this data. To adequately analyse these trials, I hypothesised that the presence of carer data recorded by trialists formed a proxy for the clear identification of a caregiver. This proxy has its limitations, as the proximity and level of involvement of a caregiver with a patient may vary considerably and not be sensitively measured by this dichotomisation. Nevertheless it could be postulated that a closely involved carer is more likely to be contactable and therefore available for simple data collection. Data were therefore dichotomised according to whether a carer was identified (Oxford, Utrecht) or whether carer outcome data was collected. Results are presented here for these two subgroups. Clearly there can be no comparison of carer outcomes for this subgroup analysis. Results are presented in Table 5.8. No significant subgroup or subgroup interaction was observed.

Table 5.7: Trial Involvement of Carers

Trial			
	No Carer	Carer included	Carer necessary
Melbourne	●		
Glasgow	●		
Edinburgh		●	
Bradford		●	
Oxford		●	
Leeds		●	
Nottingham		●	
Utrecht		●	
Sheffield		●	
Melbourne (SHIPS)		●	
London		●	
Liverpool		●	
Adelaide			●
Philadelphia			●
Boston			●
Rhode Island			●

Classification of trials by their involvement of carers.

Table 5.8: Subgroup Analysis: Presence or Absence of Main Carer

	N in analysis‡	*Analysis*	*Total [95% CI]*	*Subgroup Heterogeneity (Chi^2)*	*Subgroup Results*	
			Overall		**Carer present**	**Carer absent**
Primary Outcomes for Patients						
Subjective Health Status	2296	SMD	-0.05 (-0.13, 0.03), p=0.26	>0.05	-0.08 (-0.18, 0.02), p=0.14	0.01 (-0.13, 0.16), p=0.88†
Extended Activities of Daily Living	2145	SMD	0.04 (-0.04, 0.13), p=0.34	>0.05	0.06 (-0.05, 0.17), p=0.32	0.02 (-0.11, 0.15), p=0.77
Secondary Outcomes for Patients						
Death	1965	OR	0.99 (0.75, 1.31), p=0.95	>0.05	1.05 (0.56, 1.98), p=0.88†	0.98 (0.71, 1.34), p=0.88
Place of Residence (Institutionalisation)	637	OR	1.45 (0.91, 2.32), p=0.12†	>0.05	1.36 (0.68, 2.69), p=0.39†	1.55 (0.82, 2.92), p=0.18†
Activities of Daily Living	2673	SMD	-0.05 (-0.13, 0.03), p=0.21	>0.05	-0.04 (-0.13, 0.06), p=0.43	-0.07 (-0.20, 0.06), p=0.29
Dependence (Barthel ≤19)	2889	OR	0.89 (0.75, 1.05), p=0.18	>0.05	0.86 (0.68, 1.08), p=0.19	0.93 (0.72, 1.19), p=0.57
Depression	2223	SMD	-0.08 (-0.16, 0.01), p=0.08	>0.05	-0.10 (-0.20, 0.00), p=0.06	-0.03 (-0.17, 0.11), p=0.69
Anxiety	1127	SMD	0.08 (-0.43, 0.58), p=0.76†	>0.05	0.06 (-0.57, 0.68), p=0.86†	0.12 (-0.74, 0.98), p=0.78†

Subgroup analysis by presence of a carer.
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group.)
SMD = Standardised Mean Difference, OR = Odds Ratio
.

Patient Functional Status

It has been assumed in most trials that the intervention of a Stroke Liaison Worker should be applied to all patients regardless of their level of disability or functional dependence. Data from one trial (Bradford) has previously suggested that patients with mild to moderate disability (as measured by - Barthel Index 15 - 19) make the most gains from Stroke Liaison Worker input. It was decided therefore to evaluate this question by functional status according to Barthel measurement. Patients were divided according to their Barthel index at recruitment (which usually equated to their Barthel at discharge from hospital). They were divided into three subgroups: Barthel 20 (independent), Barthel 15-19 (Mild to moderately dependent) and Barthel <15 (dependent).

Barthel indices at recruitment varied across the trials as might be expected and are illustrated in Figure 5.51. Recruitment appeared highest in the more independent groups as might be expected for a trial evaluating psychosocial interventions in a population returning to the community. Interestingly the patient population appears to trichotomise relatively equally. (Figures 5.52, 5.53)

Results are shown in Table 5.9. Where a significant subgroup effect was seen in conjunction with a significant subgroup interaction, the results are discussed here.

Patient Secondary Outcomes

1. Dependence (Barthel ≤19): Data were analysed for 2494 participants in 12 interventions of 10 trials. The subgroup Barthel 15-19 had a significant reduction in dependence (OR 0.60, 95% CI 0.44 to 0.83, p=0.002). This effect size would equate to 10 less dependent patients (95% CI 17 less to 4 less) for every 100 patients with mild to moderate disability that were seen by the Stroke Liaison Worker. Significant subgroup heterogeneity existed suggesting that this subgroup was responding differently to the intervention than the others (Chi^2 <0.05).

The other subgroups did not show a significant effect of the Stroke Liaison Worker intervention however (Barthel <15 OR 1.21, 95% CI 0.87 to 1.68, p=0.26; Barthel 20 OR 1.01, 95% CI 0.71 to 1.44, p=0.94). (Figure 5.52).

2. Death or Dependence: It was decided after analysis of dependence data to look at this combined outcome. The concern was that there might appear to be a reduction in dependence at the expense of increased mortality. Data were combined using the same dependence data. Overall data for this new outcome did not show a significant benefit from the Stroke Liaison Worker for a reduction in Death or Dependence (OR 0.87, 95% CI 0.73 to 1.04, p=0.12). A significant subgroup effect was again seen (Barthel 15-19) as well as subgroup heterogeneity suggesting that this group responded differently to the Stroke Liaison Worker input. (OR 0.62, 95% CI 0.47 0.83, p=0.001). This risk difference equates to 11 less dead or dependent patients (95% CI 17 less to 4 less) as a result of Stroke Liaison Worker input for the group with mild to moderate disability. Results for the other subgroups were not significant (Barthel <15 OR 1.06, 95% CI 0.79 to 1.40, p=0.71; Barthel 20 OR 1.10, 95% CI 0.75 to 1.59, p=0.63; Chi^2 <0.05). (Figure 5.53).

Figure 5.51: Barthel Index at Recruitment

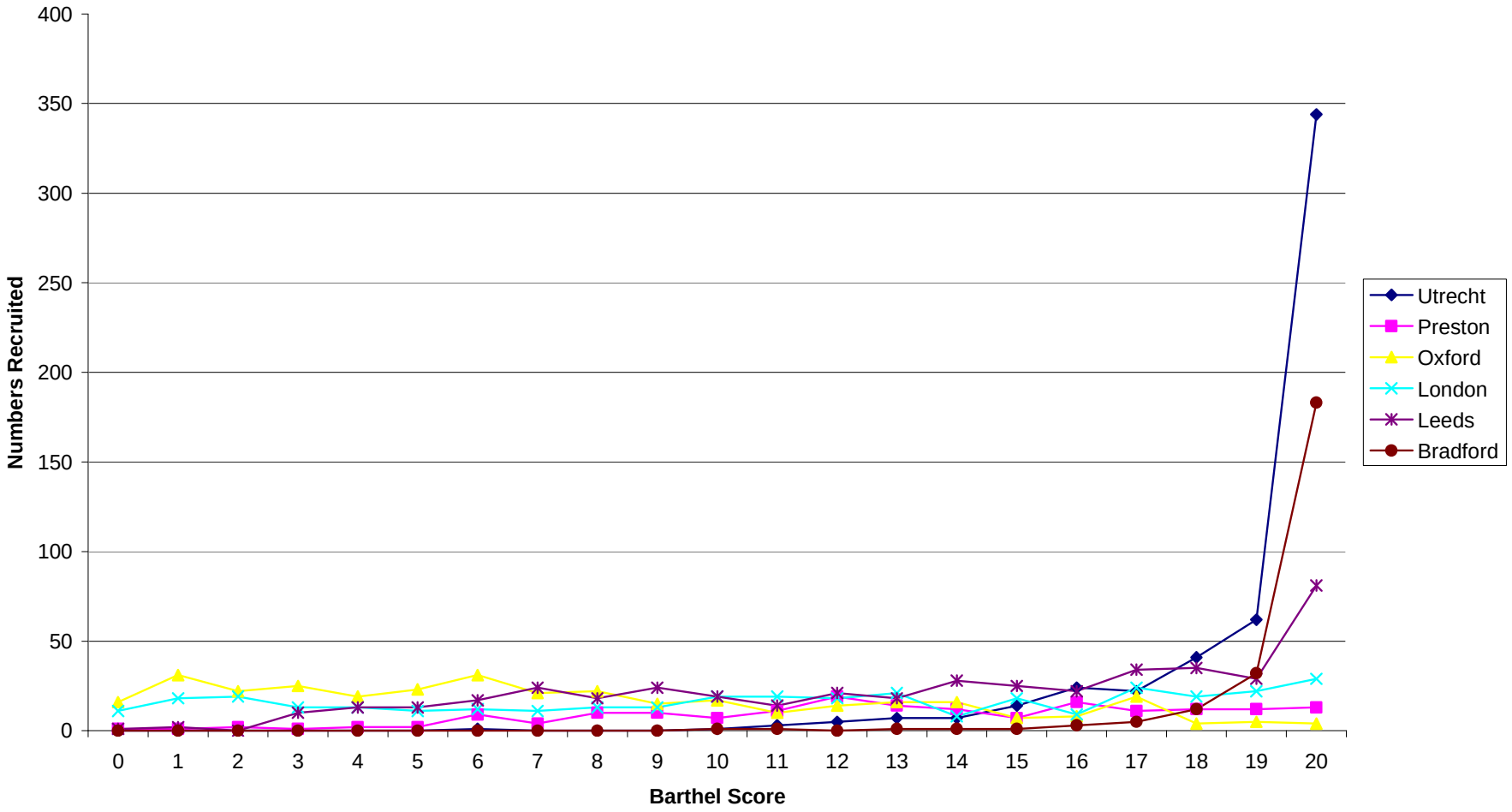


Table 5.9: Subgroup Analysis; Patient Dependency

	N in analysis‡	Analysis	Total [95% CI]	Subgroup Heterogeneity (Chi^2)	Subgroup Results		
			Overall		Barthel <15	Barthel 15-19	Barthel 20
Primary Outcomes for Patients							
Subjective Health Status	**2268**	**SMD**	**-0.03 (-0.11, 0.05), p=0.46**	**>0.05**	**-0.06 (-0.19, 0.07), p=0.35#**	**-0.11 (-0.27, 0.04), p=0.16**	**0.09 (-0.06, 0.24), p=0.26†**
Extended Activities of Daily Living	**2138**	**SMD**	**-0.02 (-0.10, 0.07), p=0.69†**	**>0.05**	**-0.01 (-0.13, 0.11), p=0.83†**	**0.02 (-0.13, 0.18), p=0.78**	**-0.09 (-0.28, 0.10), p=0.38†**
Secondary Outcomes for Patients							
Death	**2801**	**OR**	**0.85 (0.66, 1.09), p=0.20**	**>0.05**	**0.82 (0.61, 1.10), p=0.18**	**0.68 (0.39, 1.18), p=0.17**	**2.26 (0.88, 5.81), p=0.09†**
Place of Residence (Institutionalisation)	**1198**	**OR**	**1.17 (0.79, 1.74), p=0.44†**	**>0.05**	**1.27 (0.80, 2.00), p=0.31†**	**1.04 (0.45, 2.43), p=0.93†**	**0.16 (0.00, 4.87), p=0.29**
Activities of Daily Living	**2540**	**SMD**	**0.00 (-0.08, 0.08), p=1.00**	**>0.05**	**-0.07 (-0.19, 0.05), p=0.27†**	**0.09 (-0.06, 0.23), p=0.25**	**0.01 (-0.14, 0.16), p=0.88**
Dependence (Barthel ≤19)	**2494**	**OR**	**0.89 (0.74, 1.08), p=0.25**	<0.05	**1.21 (0.87, 1.68), p=0.26†**	0.60 (0.44, 0.83), p=0.002	**1.01 (0.71, 1.44), p=0.94**
Death or Dependence	**2225**	**OR**	**0.91 (0.74, 1.12), p=0.37**	<0.05	**1.45 (0.99, 2.11), p=0.06†**	0.55 (0.39, 0.78), p=0.0008	**1.02 (0.71, 1.45), p=0.93**
Depression	**2205**	**SMD**	**-0.07 (-0.15, 0.02), p=0.11**	**>0.05**	**-0.10 (-0.23, 0.02), p=0.11**	**-0.03 (-0.18, 0.13), p=0.73**	**-0.06 (-0.23, 0.11), p=0.48**
Anxiety	**826**	**SMD**	**0.07 (-0.53, 0.66), p=0.83†**	**>0.05**	**0.59 (-0.50, 1.69), p=0.29†**	**0.37 (-0.79, 1.52), p=0.53†**	**-0.47 (-1.36, 0.42], p=0.30**
Primary Outcome for Carers							
Subjective Health Status	**1509**	**SMD**	**0.01 (-0.10, 0.11), p=0.90**	**>0.05**	**0.10 (-0.06, 0.26), p=0.24†**	**-0.07 (-0.26, 0.12), p=0.47**	**-0.04 (-0.23, 0.15), p=0.67**
Secondary Outcome for Carers							
Extended Activities of Daily Living	**495**	**SMD**	**-0.01 (-0.19, 0.16), p=0.89**	**>0.05**	**-0.02 (-0.25, 0.21), p=0.87**	**0.03 (-0.37, 0.43), p=0.87†**	**-0.04 (-0.42, 0.34), p=0.85**
Caregiver Mental Health	**1387**	**SMD**	**-0.02 (-0.13, 0.09), p=0.71**	**>0.05**	**0.00 (-0.17, 0.17), p=0.97**	**-0.13 (-0.33, 0.07), p=0.20**	**0.05 (-0.14, 0.24), p=0.62†**

Subgroup analysis stratified by baseline Barthel index (Barthel <15, Barthel 15-19, or 20).
Results shown in boxes indicate statistically significant results. Significant subgroup Chi^2 results indicate significant subgroup interaction.
Unless otherwise stated the direction of effect favours the treatment group. (†Direction of effect favours control group.)
#Intra-group heterogeneity present, SMD = Standardised Mean Difference, OR = Odds Ratio

Figure 5.52: Patient Dependence

Review: [illegible]
Comparison: 05 Stroke Liaison Workers Versus Usual Care - Patient Functional Status
Outcome: 17 Barthel Dependency

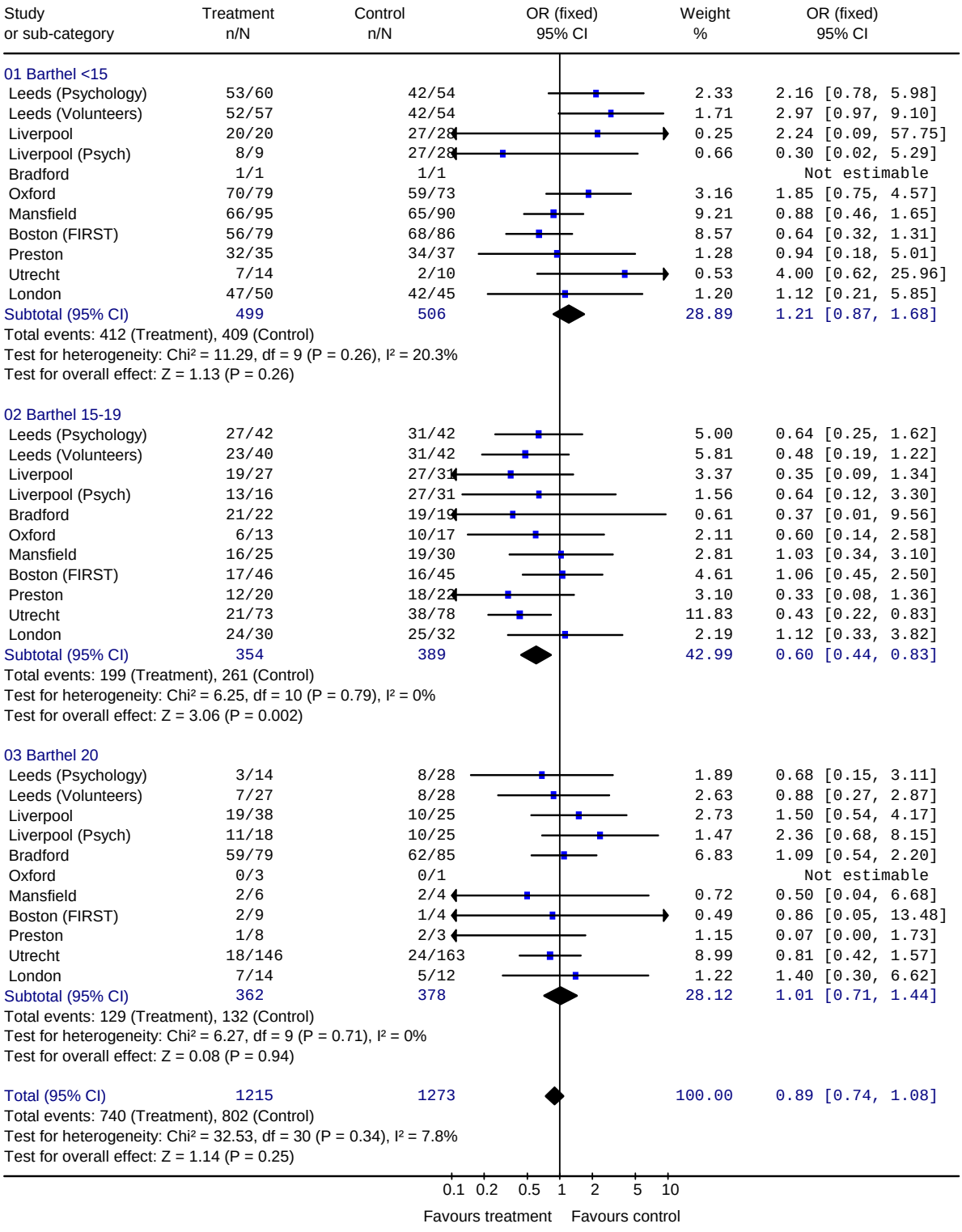
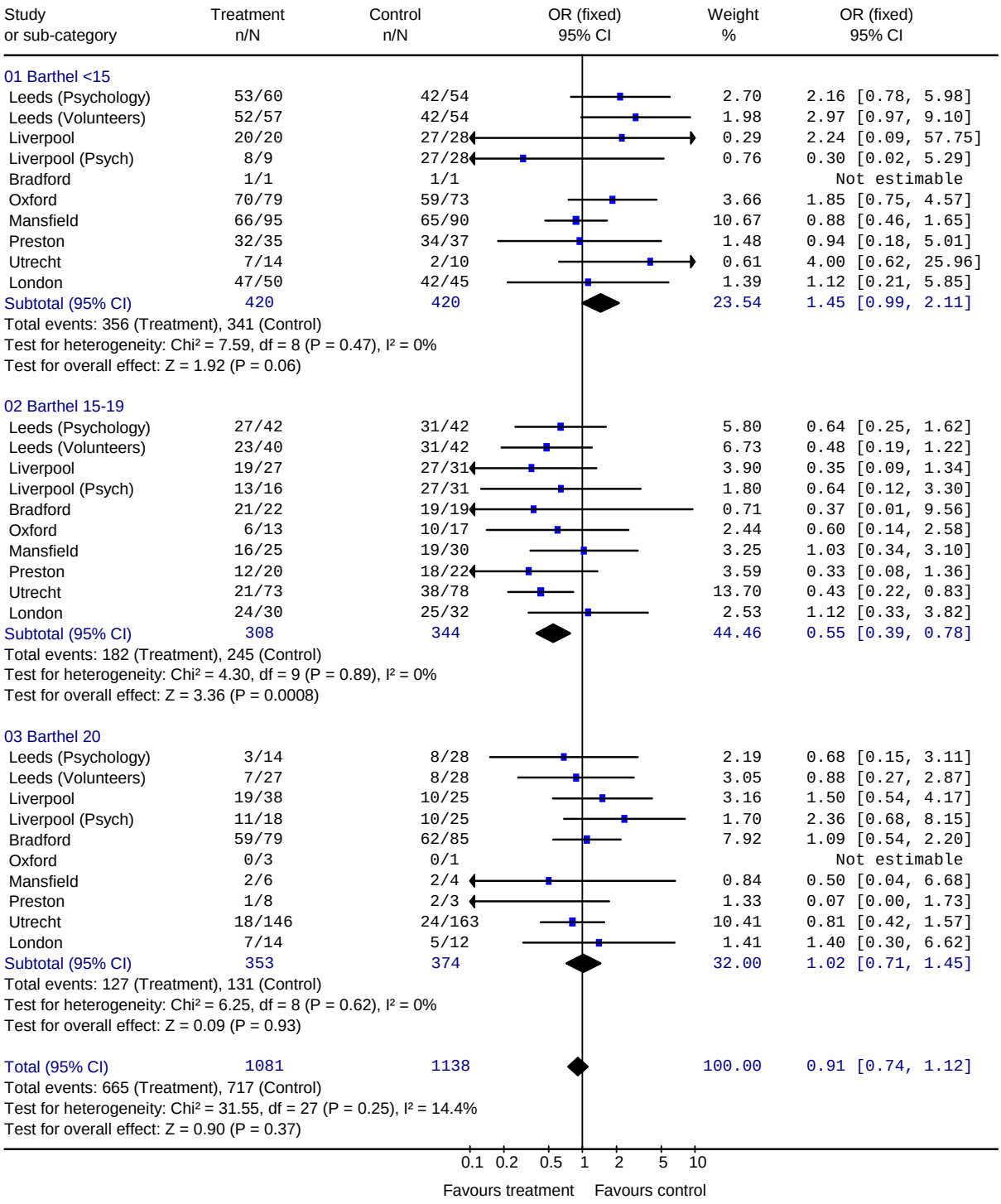


Figure 5.53: Patient Death or Dependence

Review: Stroke liaison workers for stroke patients and carers
Comparison: 05 Stroke Liaison Workers Versus Usual Care - Patient Functional Status
Outcome: 07 Death or Dependence



Discussion

Individual data meta-analysis confers considerable advantage in unpacking the potential benefits or harms of an intervention. At a statistical level, it is less likely to overestimate the effect of an intervention, but also gives narrower confidence intervals, reducing the chance of missing a real benefit or harm (313). They permit a greater understanding of the studies involved, which is vital where the interventions and trials are complex, as in this case. Additionally they allow greater flexibility in exploring subgroups (313). This is important in this case as little is understood regarding the underlying mechanism of potential benefit for Stroke Liaison Workers and therefore it is hard to identify which intervention characteristics are most important and additionally which patient subgroup if any are most likely to benefit. However individual patient data meta-analysis is considerably more complex.

Meta-analysis is secondary analysis of research where ethics approval has already been obtained. Despite that however, some trialists did run into difficulties in sharing their data. Two studies (Boston, Adelaide) described having to have permission to share their data with a third party. In one case (Adelaide), the ethics committee would not give permission to share anonymised individual patient data with the collaborative group. Instead, data for subgroup analysis were provided in aggregate form on request from the lead author. In one case (Boston) awaiting approval from the data review board took approximately one year and represented considerable delay for the review process.

It is important to state that in the planning of this analysis, the lack of a theoretical or pathophysiological rationale for Stroke Liaison Workers affected the selection of appropriate primary outcome measures. Given that this is a broad or comprehensive intervention for a wide range of problems, it was unclear from the published trials (76;167;170;297) which outcome might be expected to be impacted most. As a result, the published trials evaluated different primary outcome measures from activities of daily

living (101), satisfaction (296;297), subjective health status (170;295) and extended activities of daily living (70) or none at all (76). For this reason, two primary outcome measures were chosen, as it was argued that if the Stroke Liaison Workers aim was to return patients to normal roles that this might be measured in activities and perceived health. It remains a relevant potential criticism that we chose the wrong outcome measure to evaluate effectiveness and that Stroke Liaison Workers might have an unanticipated impact in an entirely different domain.

The intervention of a Stroke Liaison Worker did not affect the primary outcomes of subjective health status or extended activities of daily living. The implication is that patients who were seen by the Stroke Liaison Worker did not feel their health or quality of life to be better than controls, and they were not more independent. There are two potential explanations for failing to demonstrate an impact. The first concerns the intervention itself. The second concerns matters of methodology.

The criticism of the intervention might appropriately be that it is poorly focused and too broad or diffuse to impact a single, specific outcome. Because these interventions were developed on a practical and intuitive basis, as has already been said, they lack a clear underlying mechanism of action. This development of services to meet a wide range of problems post stroke may have been too ambitious and as a consequence poorly focused. The provision of information and education is a real need with a wider evidence base than in this review alone (133). The impact of information might reasonably be expected to be measured in satisfaction first, rather than in behaviour change (as we have seen from Chapters One and Two). Liaison as a service offered for patients may be difficult to measure and is perhaps poorly addressed in the Stroke Liaison Worker trials. It might be reasonable to expect that liaison between the patient and community services or health services might be measured in resource use. Unfortunately we were unable to assess resource use in this review due to a lack of standardised measures. In addition the meaning of increased resource use must be evaluated. It is unclear whether increased uptake of

community services for instance means increased access and enhanced resources, or conversely an increasing dependence. Similarly in a health care context, it would be difficult to tell from crude data whether increased use of medical and therapy resources meant an attitude of active and self motivated health care or simply increasing ill health. Social support, whilst being potentially hardest to define, may in fact be the one outcome that has the most measures of effectiveness. Many of these outcomes are surrogates (e.g. measures of mental health, self efficacy, satisfaction, participation) and poorly correlated with what is a diffuse and poorly defined entity. Some trials have tried to be more specific about social support and have included counselling as part of the intervention (101;257). Whilst it might be expected that this would more directly impact some measures (e.g. depression, anxiety etc.) it has not been so clear in either the trials or the review process.

It has been assumed that all patients have information needs and share many of the psychological and social problems post stroke. Similarly it has been assumed that the intervention should be targeted at all patients regardless of age, sex or stroke severity. This assumption does not adequately take into consideration differences in risk between patients in terms of (for example) the onset of post stroke depression, social isolation, anxiety etc. Patient subgroup analysis was only possible for those identifiers that allow division of patients into groups (e.g. age, sex, Barthel at recruitment etc.). These patient descriptors may not adequately correlate with the risks of a poor outcome (e.g. age and depression) and therefore may not subdivide patient subgroups according to meaningful groups. Despite these shortfalls, and because of the existing limitations with the data the subgroup analysis by age, sex, Barthel and the presence of a carer seems a robust and plausible exploration of the data.

Only one study (Melbourne) recruited patients more than six months after stroke. Data for this study were only obtained from published data for limited numbers of outcomes. For this reason subgroup analysis for this description was felt to be unhelpful.

Subgroup analysis within the review process highlights some interesting areas of differences that may be important and may identify important aspects of either the intervention or the target population. It is recognised in observational studies and trials that multiple analyses carry the risk of false positive results. This risk should be lessened in meta-analysis, nevertheless it still remains a risk with multiple subgroup analyses. For this reason we have only considered subgroup results where there is both a significant subgroup effect and a significant subgroup interaction.

Analysis of the intervention effect by emphasis of the intervention highlights some differences between the intervention types that may be important. In the analysis of subjective health status for instance, two subgroups (education and information provision as well as liaison) were significant in favour of the intervention, whilst one subgroup (social support) was non significant. Importantly, the subgroups varied in size, with the education and information provision subgroup containing two studies, and the Liaison group containing only one. The social support group contained 10 interventions from eight trials. The differences between the groups could be potentially accounted for by "regression to the mean" where the larger subgroup has more neutral results. Heterogeneity tests were positive, suggesting that a subgroup interaction exists and that the subgroups are behaving differently for this outcome. There is a risk of over interpreting subgroup data and given the overall non-significant result for Stroke Liaison Workers we cannot necessarily conclude that any one subgroup is effective. Despite this it is possible to conclude that interventions with a strong emphasis on social support are less effective at impacting subjective health status.

Analysis of the same data by the profession of the Stroke Liaison Worker reveals a few interesting findings. Patients whose Stroke Liaison Worker was a nurse by professional background appear to have a significant reduction in depression score when compared to controls. This effect also differed significantly from the other subgroups suggesting that the

intervention, when delivered by a nurse, differed in nature from interventions delivered by other professions.

If the intervention itself is does not appear to be effective for all patients, it is reasonable to explore patient subgroups to establish which groups of patients (if any) benefit, and which do not. Analysis by age suggested differences between the two subgroups in how they responded to the Stroke Liaison Worker in the area of ADL. Younger patients appeared to benefit in improvement in ADL score in the group reviewed by the Stroke Liaison Worker. In addition, heterogeneity tests were positive suggesting that the younger (<65) and older (≥65) patients respond differently to the intervention of a Stroke Liaison Worker. It is not possible to say whether these differences relate to differences in the way the Stroke Liaison Workers treated patients who were younger, or more probably because there are important differences in the patient group examined.

Analysis of data by the presence or absence of a carer could be criticized for our choice of a surrogate for carer involvement. The absence of data for a primary carer does not mean the absence of a good caregiving network. This may be a reason that no significant differences were found between the two subgroups. Equally, the impact of a Stroke Liaison Worker's social support on the effects of social isolation may be small. Arguably, several short visits from a Stroke Liaison Worker may not be enough to mitigate against the risks of social isolation, depression and mortality that appear to be associated with reduced social support. In an exploration of the difference between those who have a carer and those who do not, we compared the mortality of patients who had a carer with those who did not. Treatment and control groups were combined for each subgroup. Results were striking, with patients who had an identified carer having a 90% reduction in mortality compared with those who did not have an identified carer (OR 0.10, 95% CI 0.07 to 0.15, p<0.00001). These results must be treated with caution for a number of reasons. Firstly, because heterogeneity tests were strongly positive (p<0.00001), largely due to one

trial (Oxford) that had a disproportionate difference in mortality in favour of those with carers. Removal of this study from the analysis still results in an overall positive effect, but without the heterogeneity (OR 0.21, 95% CI 0.14 to 0.31, $p<0.00001$, Chi^2 heterogeneity $p>0.05$). Secondly, and most importantly, this research methodology is not appropriate for exploring the relationship between risk and outcome in cohorts of patients. Thirdly, the effect size is greater than that previously identified in the literature (37-39;52). Fourthly, patients enrolled in this study are not necessarily representative of the wider stroke population. Patients may have been randomised who were considered isolated or at high risk. Additionally, as we have already said the absence of data for a carer does not directly equate with reduced or absent social support. We have assumed it to be suggestive, but cannot infer more than this. Patients without carer data may have been more dependent and therefore not directly comparable to patients who had carer data. It may be that this relationship between the presence of a strong carer relationship and mortality should be explored further in carefully designed cohort studies. Key to the design of these studies must be some robust description or measure of the degree of social support.

The final patient subgrouping is the functional status of the patient at recruitment. This subgrouping was suggested by one of the trials (Bradford (167)) as identifying patients who would benefit most. This trial had suggested that patients with mild-moderate dependence (Barthel 15-19) benefited most. For this reason, we have used the same definitions of dependence. It is plausible that patients with severe dependence may make minimal gains with information provision. Similarly patients who are dependent may already have established connections with services (such as carers, social work, primary care etc.) and may have little to gain from liaison input. Alternatively, you might expect that caregivers of patients who are dependent would need the most support and might be the most satisfied. By contrast, independent patients might be expected to have the least risk of depression or morbidity, and the least to gain from social

support or liaison. The finding of a reduction in dependence (or an increase in the number who were independent in ADL) was in some respects surprising. The intervention was primarily a psycho-social one and was not expected to impact physical outcomes. As has already been said, there was concern that the reduction in dependence could be at the expense of an increase in mortality. For this reason a post hoc analysis of a combined outcome of death or dependency was considered necessary in order to rule out this concern. This result was also considered surprising. The effect size of this reduction in death or dependence is considerable equating to 11 fewer dead or dependent patients for every 100 patients treated. The mechanism of this effect is not clear. It is interesting to note that the review of Early Supported Discharge after stroke also found that patients with mild to moderate disability (Barthel 10-20) made the most gains with Early Supported Discharge resulting in reductions in death or disability (223). It is interesting to postulate whether the improvement seen in this group reflects the impact of the Stroke Liaison Worker per se (as opposed to any other form of rehabilitation intervention) or whether it reflects the sensitivity of this particular patient group to rehabilitation and to potential gains in independence. None of the studies in the Stroke Liaison Worker review appears to have had input from an Early Supported Discharge service. There may be potential benefit from further research exploring the rehabilitation potential of this patient subgroup and the most appropriate design of rehabilitation interventions.

Data for the outcome of satisfaction appear to provide the only overall statistically significant results for the intervention. Patients responded significantly to only one question: “Someone has really listened”. This response would potentially fit well with the social support intentions of the intervention. It is interesting to note however that there are a number of patient responses that show a trend towards significance in favour of the control group (“I have been treated with kindness and respect”, “I was able to talk to the staff about any problems I had” and “I am satisfied with outpatient services”). There may be more than one explanation for these

findings (although in the absence of statistical significance we must be cautious about drawing conclusions). One possible explanation is that in simple terms patients were as satisfied with the intervention as those who did not receive it. One additional potential explanation reflects the complexity of using satisfaction as an outcome measure. Satisfaction, it might be argued, is based in part on a participant's expectations. If expectations are low, participants may express high satisfaction with what is delivered. If expectations are raised for example by a Stroke Liaison Worker educating patients on the importance of treatment and investigation, it might be expected that patients become less satisfied with service provision (e.g. outpatient services). In addition, it is recognised that satisfaction questionnaires have a ceiling effect and that they may not be sensitive to discriminate between groups if overall satisfaction is high.

Interestingly, carers appear to express satisfaction more frequently than patients. The responses that reach significance appear to be related to the nature of the intervention and are therefore plausible. For example the response - "I have received enough information about recovery and rehabilitation" and the response "I have received all the information I needed about the causes of the patient's illness" would plausibly fit with the education and information provision aspects of the intervention. Similarly, the response "Someone has really listened" would fit with the social support aspects of the intervention and the response "I have not felt neglected" would fit with the liaison aspects of the service. In some cases however the positive results are drawn from only two studies studying approximately 300 carers. The results, although statistically significant are not robust, and the addition of as few as 10 positive responses to the control group could result in a change to a non-significant result ("Someone has really listened").

Group details

The Stroke Liaison Workers Collaboration are (in study alphabetical order): Michael Clark (Adelaide), Martha Fay, Thomas Glass (Boston - FIRST), Anne Forster (Bradford), Martin Dennis, Suzanne O'Rourke (Edinburgh), Graham Ellis, Peter Langhorne (Glasgow), Allan House (Leeds), Michael Leathley, Anil.Sharma, Caroline Watkins (Liverpool), Kate Tilling, Catherine Coshall, Charles Wolfe (London), Nadina Lincoln (Mansfield), Judith Frayne (Melbourne – SHIPS), Jonathan Mant (Oxford), Arthur Gershkoff (Philadelphia - STAIR), Chris Burton (Preston), Ivan Miller, Duane Bishop (Rhode Island), Han Boter, Thora Hafsteinsdottir (Utrecht).

Table 5.10: Study Characteristics - Adelaide

Trial Location	**Adelaide**
Study methodology	Randomised controlled trial.
Randomisation	Centralised randomisation procedure.
Recruitment	Stroke patients and carers recruited from a stroke rehabilitation unit in Adelaide within two weeks of stroke onset (n=62 patients and 62 carers).
Exclusion criteria	Exclusion criteria: severe communication problems, poor English language, cognitive impairment and ongoing care or rehabilitation needs.
Inclusion criteria	Inclusion criteria: Confirmed stroke, co-resident with spouse and returning to the community.
Patient characteristics	Mean age 71 (SD 9) controls, 73 (SD 9) experiment, approximately 60% male.
Intervention	The intervention comprised an information package and three visits from a Social Worker trained in family counselling techniques. Visits lasted on average one hour. Final visits were conducted at five months.
Comparison	Control group patients and their spouses did not receive the information pack or the visits from the Social Worker.
Outcome assessment	Follow up was at six months, conducted by a research nurse independent of the interventions. No blinding is described. Patient outcomes assessed were: Subjective health status (SF-36); extended activities of daily living (Adelaide activities profile); Activities of daily living (Barthel); Mood (Geriatric Depression Score, Hospital Anxiety and Depression Scale - Anxiety component); McMaster Family Assessment Device Global Function Scale- Mastery Scale).
Carers	Involvement of a spouse was compulsory for entry into the study. Carer outcomes were: Subjective health status (SF36; McMaster Family Assessment Device Global Functioning Scale).
Allocation concealment	A=adequate*
Data	Aggregated data was available on request.
Publication status	Published

*Cochrane criteria

Table 5.11: Study Characteristics - Boston

Trial Location	**Boston (FIRST)**
Study methodology	Randomised controlled trial.
Randomisation	Centralised randomisation by computer generated random numbers and remote, telephone allocation.
Recruitment	Stroke patients recruited from inpatient stroke unit care within 30 days of event.
Exclusion criteria	Exclusion criteria: age less than 45; resident out with area; terminally ill; severe communication problems; cognitive impairment; poor English language; institutional care; social isolation.
Inclusion criteria	Inclusion criteria: Confirmed stroke of mild or moderate severity; competent to consent.
Patient characteristics	(n=291, Mean age 70, Male 49%)
Intervention	Intervention: The intervention was provided by a clinical psychologist or a social worker who were formally trained. The emphasis of the intervention was on recruiting families and naturally occurring social networks rather than formal or community-care based services. 15 Intervention visits were made according to protocol (approximately 90 minutes in duration).
Comparison	Control: The control group received usual care (not defined).
Outcome assessment	Outcome assessment was conducted at 3 and 6 months by a blinded outcome assessor. Patient outcome measures: These included Activities of daily living (Barthel, Instrumental activities of daily living); Dependency (Physical performance test); Mood (Centre for Epidemiological Studies Depression Scale CESD); Cognition (A cognitive summary score); Perceived health status (Self-rated health and quality of life).
Carers	Involvement of a carer was not compulsory.
Allocation concealment	A=adequate*
Data	Individual patient data obtained.
Publication status	Published

*Cochrane criteria

Table 5.12: Study Characteristics - Bradford

Trial Location	**Bradford**
Study methodology	Randomised controlled trial.
Randomisation	Allocation by random number tables and carried out by assistant not connected to study.
Recruitment	Patients were obtained from hospital and primary care within six weeks of stroke (n=240).
Exclusion criteria	Exclusion criteria: Cognitive impairment; poor prognosis or placement in institutional care.
Inclusion criteria	Inclusion criteria: Acute stroke with some disability; aged over 60 and able to give informed consent.
Patient characteristics	Mean age 73 (SD 7), Male 53%.
Intervention	Intervention: The intervention was delivered by senior nurses who visited 7 times according to a protocol and provided information, advice and support.
Comparison	Control: The control group received no visits.
Outcome assessment	The outcomes were assessed at 3, 6 and 12 months. No blinding was attempted. Patient outcomes: Extended activities of daily living (Nottingham extended ADL); Activities of daily living (Barthel); Dependency (Functional ambulatory category); Subjective health status (Nottingham health profile).
Carers	Involvement of a carer was not compulsory. Carer outcomes: Mental health and Subjective health status (GHQ28); Extended activities of daily living (Frenchay activities index).
Allocation concealment	A=adequate*
Data	Individual patient data obtained
Publication status	Published

*Cochrane criteria

Table 5.13: Study Characteristics - Edinburgh

Trial Location	**Edinburgh**
Study methodology	Randomised controlled trial.
Randomisation	Allocation by remote computer generated random numbers.
Recruitment	Patients were recruited from both inpatient and outpatient settings within 30 days of stroke onset. Patient blinding was achieved through a process of delayed consent.
Exclusion criteria	
Inclusion criteria	
Patient characteristics	Number recruited = 417, mean age 68 (SD13), 50% male
Intervention	Intervention: The intervention was delivered by a social worker, who contacted patients on average four times to provide social support, counselling and to identify unmet needs requiring services.
Comparison	Control: Control patients received usual care which did not include contact with the stroke family care worker until after final follow up had been completed at six months.
Outcome assessment	Outcomes were recorded by a research psychologist blinded to treatment allocation at six months. Patient outcomes: Extended activities of daily living (Frenchay activities index FAI); Activities of daily living (Barthel), Dependency (Oxford handicap scale); Mental \Health (GHQ30, Hospital Anxiety and Depression Scale, Mental adjustment to stroke scale, medical coping modes questionnaire); Satisfaction (Pound satisfaction scale).
Carers	Involvement of a carer was not compulsory. Carer outcomes: Subjective health status (Caregiver hassles scale); Extended activities of daily living (Frenchay activities index, social adjustment scale); mental health (GHQ28); Satisfaction (Pound satisfaction scale).
Allocation concealment	A=adequate*
Data	Individual patient data was obtained for most outcomes.
Publication status	Published

*Cochrane criteria

Table 5.14: Study Characteristics - Glasgow

Trial Location	**Glasgow**
Study methodology	Randomised Controlled Trial.
Randomisation	Allocation by remote random number generation and sequentially numbered opaque envelopes.
Recruitment	Patients were recruited on discharge from outpatient clinics and rehabilitation facilities.
Exclusion criteria	Exclusion: Major illness; cognitive impairment; severe communication disorder.
Inclusion criteria	Inclusion criteria: Clinical diagnosis of stroke or TIA; presence of at least one modifiable risk factor; able to give informed consent.
Patient characteristics	Number = 205, mean age = 65 (SD 9), male = 51%
Intervention	Intervention: Intervention patients received three appointments (30 minutes each) with a nurse to discuss lifestyle, risk factors and recovery from stroke. In addition patients were given written information specific to them regarding risk factor targets etc.
Comparison	Control: Control patients received one meeting with the stroke nurse to discuss risk factors prior to recruitment.
Outcome assessment	Outcomes were assessed at 5 months by a research nurse blinded to treatment allocation. Outcomes: Cumulative risk factor control; individual risk factor control; Subjective health status (Euroqol); mood (Geriatric Depression Scale) and satisfaction (Pound satisfaction scale).
Carers	Carers were not involved in this study.
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.15: Study Characteristics - Leeds

Trial Location	**Leeds**
Study methodology	Randomised controlled trial.
Randomisation	Remote random number sequence generation and telephone allocation.
Recruitment	Patients were identified from admissions to hospital (n=450). Consent was obtained after randomisation. Patients were blinded to other treatment or control arms.
Exclusion criteria	Exclusion criteria: Subarachnoid haemorrhage; too ill; poor communication; poor English language ability; cognitive impairment; serious concurrent illness.
Inclusion criteria	Inclusion criteria: First or recurrent stroke, local to area and able to give consent.
Patient characteristics	Mean age was 71 (SD 12), 54% male.
Intervention	The trial tested two separate interventions and one control group. Psychology Intervention: The psychology arm of this trial was delivered by Psychiatric Nurses who aimed to improve patient's problem solving skills by working with patients at fortnightly visits. The Pyschiatric Nurses were supervised fortnightly by a Senior Psychiatrist. Volunteer Intervention: Volunteers were recruited through local charities and self help groups. All attended a training session on the consequences of stroke.
Comparison	Control: Patients in the control group received usual care, although this was not standardised.
Outcome assessment	Outcomes were measured at 6 and 12 months by an outcome assessor blinded to patient allocation.
Carers	Involvement of a carer was not compulsory.
Allocation concealment	A=adequate*
Data	Individual patient data obtained from trialists.
Publication status	This study is published in abstract form only.

*Cochrane criteria

Table 5.16: Study Characteristics - Liverpool

Trial Location	**Liverpool**
Study methodology	Randomised controlled trial.
Randomisation	Allocation by remote computer generated random numbers and telephone randomisation.
Recruitment	Participants were recruited at discharge from hospital following admission with stroke to a larger multi centre study (Life after Stroke).
Exclusion criteria	
Inclusion criteria	
Patient characteristics	
Intervention	Three separate interventions were evaluated singly or in combination for this study. They include the evaluation of a Stroke Family Support Worker (Social Intervention), a Psychologist (Psych) and an Occupational Therapist (Physical). Only the social and psychological arms of this study have been used for analysis, where these were conducted alone and in comparison to the control group. Social Intervention: This involved the input of a Stroke Family Support Worker to provide verbal and written information, informal counselling and social support as well as liaison with other services. On average the SFSW made 4 contacts per patient by telephone or visit. Psychology Intervention: The intervention was delivered by a Psychology Assistant, working under the supervision of an experienced Clinical Psychologist. It included assessing a patient's mental and emotional state and delivering cognitive behavioural therapy for the patient as well as problem solving for the whole family. On average the psychologists made 10 visits per patient.
Comparison	Control group: The control group received usual care which did not include the Family Support Worker, Psychologist or the Occupational Therapist.
Outcome assessment	Outcomes were assessed at 12 months.
Carers	Involvement of a carer was not compulsory.
Allocation concealment	A=adequate*
Data	Individual patient data obtained.
Publication status	This study remains unpublished at this time.

*Cochrane criteria

Table 5.17: Study Characteristics - London

Trial Location	**London**
Study methodology	Randomised controlled trial.
Randomisation	Allocation by fax to remote centre with computer generated random number table.
Recruitment	Participants were recruited from admissions to hospital with first-in-a-lifetime stroke (n=340).
Exclusion criteria	Exclusion criteria: Unable to consent due to poor prognosis, cognitive impairment or poor communication and where assent was not available.
Inclusion criteria	Inclusion criteria: First stroke and resident in local area.
Patient characteristics	Mean age was 78 (SD 10), 42% male.
Intervention	Intervention: A Stroke Association Family Support Organiser, offering emotional support, information and liaison to services and voluntary agencies. They made contact, primarily through visits on average 15 times.
Comparison	Control: The control group received no input from the Family Support Organiser but could receive usual care including other agency involvement.
Outcome assessment	Outcomes were evaluated at 12 months by a blinded outcome assessor. Patient outcomes: Extended Activities of Daily Living (Frenchay Activities Index); Death; Residence; Activities of daily living (Barthel); Mood (Hospital Anxiety and Depression Scale); Participation (Reintegration to Normal Living Index); Satisfaction (Pound Satisfaction Scale); Hope and Acceptance scale.
Carers	Involvement of a carer was not compulsory. Carer outcomes: Subjective Health Status (Caregiver Strain Index); Extended activities of daily living (Reintegration to normal living index); Mental health (Hospital anxiety and depression scale); Hope and acceptance.
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.18: Study Characteristics - Mansfield

Trial Location	**Mansfield**
Study methodology	Randomised controlled trial.
Randomisation	Telephone allocation from remote, computer generated list of random numbers.
Recruitment	Patients admitted to hospital with an acute stroke (n=250).
Exclusion criteria	Exclusion criteria: Unconscious on admission; Institutional care; Severe disability; Resident outwith local area.
Inclusion criteria	Inclusion criteria: Confirmed stroke within 4 weeks of onset.
Patient characteristics	Mean age 69 (SD 11), 54% male.
Intervention	Intervention: A Psychologist with training by the Stroke Association as a Family Support Organiser delivered an information pack, and identified unmet information needs, concerns and emotional needs. In addition they acted as liaison to the stroke team. The FSO visited on average twice with additional telephone liaison. The intervention was provided for up to 9 months.
Comparison	Control: Control group patients received no contact from the Family Support Organiser.
Outcome assessment	Outcomes were recorded at 4 months and 9 months by an independent assessor who was blinded to treatment allocation. Patient outcomes: Subjective health status (GHQ12); Extended activities of daily living (Nottingham extended ADL); Activities of daily living (Barthel); Mental health (GHQ12); Satisfaction (Modified Pound satisfaction scale).
Carers	Involvement of a carer was not compulsory. Carer outcomes: Subjective health status (Carer strain index); Mental health (GHQ12); Extended activities of daily living (Nottingham extended ADL).
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.19: Study Characteristics - Melbourne

Trial Location	**Melbourne**
Study methodology	Randomised controlled trial.
Randomisation	Methods of allocation and randomisation are not defined.
Recruitment	Patients were recruited from a previous population incidence study, two years after the onset of stroke. (N=213).
Exclusion criteria	
Inclusion criteria	Stroke (patients were recruited from a previous population incidence study).
Patient characteristics	
Intervention	Intervention: This was provided by a social worker who provided liaison with health and community services and social support. On average seven visits to a clients home were carried out.
Comparison	Control: The control group had no social work input.
Outcome assessment	Outcomes were recorded at one year. No attempt was made at blinding outcome assessment. Patient Outcomes: Death; Days in Institutional care, local, undefined measures of activities of daily living and dependency.
Carers	
Allocation concealment	B=unclear*
Data	Published data only. No successful contact could be made with the authors.
Publication status	Published

*Cochrane criteria

Table 5.20: Study Characteristics – Melbourne (SHIPS)

Trial Location	**Melbourne (SHIPS)**
Study methodology	Randomised controlled trial.
Randomisation	No information was available on methods of randomisation or allocation concealment.
Recruitment	Patients were recruited from hospital (n=96).
Exclusion criteria	
Inclusion criteria	
Patient characteristics	
Intervention	Intervention: Regular visits and phone calls from a nurse who provides support, education and liaison to patients and carers.
Comparison	Control: Patients and caregivers in the control group received no home visits until after the end of the nine month trial follow up.
Outcome assessment	Patient outcomes: Subjective health status (Assessment of quality of life scores); Activities of daily living (Barthel); Dependency (Modified Rankin score); health service usage.
Carers	Carer involvement does not appear to have been compulsory.
Allocation concealment	B=unclear*
Data	
Publication status	This study finished early due to funding shortages. No individual patient data was available. This data remains unpublished.

*Cochrane criteria

Table 5.21: Study Characteristics - Oxford

Trial Location	**Oxford**
Study methodology	Randomised controlled trial.
Randomisation	Allocation by telephone randomisation to remote individual; with sequentially numbered opaque envelopes.
Recruitment	Patients were recruited from hospital presenting within six weeks of stroke.
Exclusion criteria	Exclusion criteria: Institutional care, dominant medical problems or severe illness.
Inclusion criteria	Inclusion criteria: Confirmed stroke aged 18 or over local in area and with close family carer.
Patient characteristics	(n=323, mean age = 74 (SD 13), 52% male).
Intervention	Intervention: Patients assigned to the intervention group were visited by the Family Support Organiser (trained by the Stroke Association) who provided written and verbal information and advice, support and liaison with services. On average, patients received 2 visits and three telephone contacts.
Comparison	Control: The control group did not receive any input from the Family Support Organiser.
Outcome assessment	Outcomes were assessed at six months by a researcher blinded to treatment allocation. Patient outcomes: Subjective health status (Dartmouth CO-OP chart); Death; Place of residence; Activities of daily living (Barthel, Rivermead mobility index); Dependency (London handicap scale); Mental health (Hospital anxiety and depression scale); Satisfaction (Local satisfaction scale).
Carers	Carer outcomes: Subjective health status (Carer strain index, SF36); Extended activities of daily living (Frenchay activities index); Mental health (GHQ28); Satisfaction.
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.22: Study Characteristics – Philadelphia (STAIR)

Trial Location	**Philadelphia (STAIR)**
Study methodology	Randomised controlled trial.
Randomisation	Randomisation by random number table but allocation concealment unclear.
Recruitment	Patients were recruited from in-patient wards within 3 months of stroke onset.
Exclusion criteria	Exclusion criteria: Severe co-morbidity; cognitive impairment; communication problems; institutional care.
Inclusion criteria	Inclusion criteria: Aged over 65; recent stroke; returning to community; caregiver identified; able to give informed consent.
Patient characteristics	n=55, 52% Male
Intervention	Intervention: Patients were assigned a case manager who visited monthly and telephoned weekly. They provided access to information, identified psychosocial stresses and provided liaison to community or hospital resources.
Comparison	Control: The control group did not receive visits from the case manager or input from the multi-disciplinary team.Outcomes were recorded at 12 months by a researcher blinded to treatment allocation.
Outcome assessment	Patient outcomes: Extended activities of daily living (Frenchay activities index, Social Functioning Examination, Older American Resources and Services Scales-Social Resources (OARS-SR)); Activities of daily living (FIM, OARS-ADL, OARS-Physical health, SFE, FAI); OARS-Economic resources.
Carers	Carer involvement was necessary for the study. Carer outcomes: Subjective health status (Questionnaire on resources and stress (QRS)); Mental health (Centre for epidemiological studies-depression scale (CESD)).
Allocation concealment	B=unclear*
Data	Some aggregated data were available in addition to the paper, but not individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.23: Study Characteristics - Preston

Trial Location	**Preston**
Study methodology	Randomised controlled trial.
Randomisation	Allocation by telephone to remote centre with concealed random number sequence.
Recruitment	Patients with a clinical diagnosis of stroke were recruited from admission to hospital.
Exclusion criteria	Exclusion criteria: Depression prior to stroke, cognitive impairment, poor prognosis, substance addiction.
Inclusion criteria	Inclusion criteria: clinical diagnosis of stroke.
Patient characteristics	(n=176), mean age =75 (SD 10), 52% male.
Intervention	Intervention: Patients were visited by a stroke nurse who visited on average 3 times over 2 months and provided information and advice, emotional support and liaison with services.
Comparison	Control: The control group received inpatient case management and multidisciplinary rehabilitation, but no home visits on discharge.
Outcome assessment	Outcomes were recorded at 3 and 12 months by a researcher blinded to treatment allocation. Patient outcomes: Subjective health status (Nottingham health profile); Extended activities of daily living (Frenchay activities index); Activities of daily living (Barthel); Mental health (Beck depression inventory).
Carers	Involvement of a carer was not compulsory. Carer outcomes; Subjective health status (Carer strain index).
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.24: Study Characteristics – Rhode Island

Trial Location	**Rhode Island**
Study methodology	Randomised controlled trial.
Randomisation	There was no information on the method of randomisation or allocation concealment.
Recruitment	Patients and carers were recruited in hospital following stroke.
Exclusion criteria	Exclusion criteria: Subarachnoid haemorrhage; Institutional care; no caregiver.
Inclusion criteria	Inclusion criteria: Age over 35 with confirmed stroke, competent to consent and caregiver present.
Patient characteristics	Number = 215, mean age 65(SD 13), 55% male.
Intervention	Intervention: Patients received on average 13 telephone calls (lasting 15-20 minutes) from the stroke liaison worker who provided education, social and emotional support and counselling.
Comparison	Control group: Control group patients were allocated to usual care.
Outcome assessment	Outcomes were recorded at 3, 6, 12 and 18 months by staff blinded to treatment assignment. Patient outcomes: Subjective health status (SF36); Extended activities of daily living (Frenchay activities index, FIM); mental health (Geriatric depression scale); Family function (Family assessment device).
Carers	Involvement of a carer was compulsory. Carer outcomes: Subjective health status (Caregiver strain index, SF36); Mental health (CES-D).
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	This trial is unpublished at present.

*Cochrane criteria

Table 5.25: Study Characteristics – Utrecht (HESTIA)

Trial Location	**Utrecht (HESTIA)**
Study methodology	Randomised controlled trial.
Randomisation	Randomisation was performed by telephone to a remote centre. Patient blinding was achieved by a process of delayed consent.
Recruitment	Patients were recruited from 12 hospitals prior to discharge following a first-in-a-lifetime stroke.
Exclusion criteria	Exclusion criteria: Recurrent stroke; age under 18; poor prognosis; severe dependency; lives out with area; institutional care.
Inclusion criteria	Inclusion criteria: Age 18 or over with first ever stroke, resident in area with no or only mild dependency, discharged to community and expected to live more than one year.
Patient characteristics	n=536, mean age 63 (SD 15), 49% male.
Intervention	Intervention: Senior nurses made three telephone contacts and visited the patient in their homes. They provided information, support and liaison to primary care.
Comparison	Control group: The control group received the same in-patient care but were not contacted on discharge.
Outcome assessment	Outcomes were recorded at six months by postal questionnaire and telephone interview by an assessor blinded to treatment allocation. Patient outcomes: Subjective health status (SF36); Activities of daily living (Barthel); Dependency (Modified rankin scale); Mental health (Hospital anxiety and depression scale); Use of services; satisfaction (Satisfaction-With-Stroke-Care questionnaire SASC 19).
Carers	Involvement of a carer was not compulsory. Carer outcomes: Subjective health status (Carer strain index); Extended activities of daily living (Social support list - discrepancies (SSL-D)); Mental health (Sense of competence questionnaire (SCQ)).
Allocation concealment	A=adequate*
Data	Individual patient data.
Publication status	Published

*Cochrane criteria

Table 5.26: Primary Patient Outcomes

Primary Outcomes		
Study	**Subjective Health Status**	**EADL**
Adelaide	SF36 - physical health	Adelaide Activities Profile (cumulative)
Boston (FIRST)		Instrumental Activities of Daily Living
Bradford	Nottingham Health Profile	Frenchay Activities Index
Edinburgh	GHQ30	Frenchay Activities Index
Glasgow	EuroQOL	
Leeds	GHQ	Frenchay Activities Index
Liverpool	GHQ12	Nottingham Extended ADL
London		Reintegration to normal living
Mansfield	GHQ12	Nottingham Extended ADL
Melbourne		Local tool
Melbourne (SHIPS)	AQOL	Barthel
Oxford	COOP	Frenchay Activities Index
Philadelphia (STAIR)		Frenchay Activities Index
Preston	Nottingham Health Profile	Frenchay Activities Index
Rhode Island	SF36 (general health subsection)	Frenchay Activities Index
Utrecht	SF36 (general health subsection)	Barthel

Analysis plan with outcomes for each trial in the categories for the review process.

Table 5.27: Table of Secondary Outcomes

Secondary Outcomes											
Study	**Death**	**Place of Residence**	**ADL**	**Dependency**	**Mental Health - Generic**	**Mental Health - Depression**	**Mental Health - Anxiety**	**Knowledge about stroke**	**Use of Services**	**Participation**	**Other**
Adelaide			Barthel		GDS	GDS	HADS anx				
Boston (FIRST)			Barthel	Physical Performance	Recovery Efficacy	Recovery Efficacy				Received Social Support	
Bradford	Yes		Barthel	Functional Ambulatory Category							
Edinburgh	Yes	Yes	Barthel	Modified Rankin	HADS cumulative	HADS dep	HADS anx		Yes	RLOC	SAS
Glasgow	Yes				GDS	GDS			Yes		
Leeds	Yes		Barthel		GHQ	GHQ					
Liverpool			Barthel		GHQ12	GHQ12			Yes		
London			Barthel		HADS cumulative	HADS dep	HADS anx			RNLI	
Mansfield			Barthel					Local			
Melbourne			Local	Local					Yes		
Melbourne (SHIPS)			Barthel								
Oxford	Yes	Yes	Barthel	London Handicap Scale	HADS cumulative	HADS dep	HADS anx	Local	Yes	London Handicap Scale	
Philadelphia (STAIR)			FIM						Yes	FAI	
Preston	Yes	Yes	Barthel		Beck Depression Inventory	Beck Depression Inventory					
Rhode Island					GDS	GDS					
Utrecht	Yes		Barthel	Modified Rankin	HADS cumulative	HADS dep	HADS anx		Yes		

Analysis plan with outcomes for each trial in the categories for the review process

Table 5.28: Table of Outcomes for Carers

Carer Outcomes - Analysis Plan	Primary Outcomes	Secondary Outcomes	
Study	**Subjective Health Status**	**EADL**	**Mental Health**
Adelaide	SF36 (physical health)		SF-36 mental health
Boston (FIRST)	Caregiver Burden		
Bradford	GHQ28	Frenchay Activities Index	GHQ28
Edinburgh	Caregiver Hassles Scale	Frenchay Activities Index from published medians	GHQ28
Glasgow			
Leeds	Carer Strain Index		GHQ28
Liverpool	Carer Strain Index		GHQ12
London	Carer Strain Index		HADS
Mansfield	Carer Strain Index		GHQ12
Melbourne			
Melbourne (SHIPS)	Carer Strain Index		
Oxford	Carer Strain Index	Frenchay Activities Index	GHQ28
Philadelphia (STAIR)	Questionnaire and Resources		CES-D
Preston	Carer Strain Index		
Rhode Island	Carer Strain Index	Frenchay Activities Index	CES-D
Utrecht	Carer Strain Index		Sense of Competence

Analysis plan with outcomes for each trial in the categories for the review process

Table 5.29: Identifying Relevant Satisfaction Questions

Satisfaction questions	Edinburgh*	Glasgow*	Leeds*	London*	Mansfield†	Oxford†	Utrecht†
I have been treated with kindness and respect by staff at the hospital	●	●	●			●	●
The staff attended well to my personal needs whilst in hospital	●	●	●			●	●
I was able to talk to the staff about any problems I might have had	●	●	●			●	●
I have received all the information I want about the causes and nature of my illness	●	●	●	●	●	●	●
The doctors have done everything they can to make me well again	●	●	●			●	●
I am happy with the amount of recovery I have made	●	●	●			●	●
I am satisfied with the type of treatment the therapists have given me	●		●			●	●
I have had enough therapy	●					●	●
I was given all the information I needed about allowances or services I might need after leaving hospital	●	●	●	●	●	●	●
Things were well prepared for my return home	●		●			●	●
I get all the support I need from services such as meals on wheels, home help etc.	●		●	●		●	●
I am satisfied with the outpatient services provided by the hospital	●	●	●				●
I am satisfied with the practical help I have received since I left hospital	●						●
I have received enough information about recovery and rehabilitation after stroke	●			●	●		●
Somebody has really listened and understood my needs and problems since I left hospital	●	●	●	●			●
I have felt neglected since I left hospital	●			●			●
I have had enough emotional support since I left hospital	●	●	●		●		●
I have received enough special equipment	●			●			●
I know who to contact if I have problems relating to my stroke	●	●		●			●
I think the ambulance service is reliable	●		●				
I am satisfied with the amount of contact I have had with the hospital since I have attended		●				●	
reducing the risk				●	●		
I am satisfied with the service I have received from my GP			●				
I am satisfied that my family were encouraged to be involved in my care			●				
I was given enough information about voluntary organisations			●				
overall satisfaction				●			
hospital services summary score						●	
community services summary score						●	

*High score indicates dissatisfaction, †High score indicates satisfactions

Chapter Six:

Identifying Stroke Liaison Roles in Scotland

Introduction

As we have seen from Chapter 5, the evidence for Stroke Liaison Workers is at the very least complicated and without a clear, simple message. Despite this lack of clear evidence, Stroke Liaison Worker roles have multiplied throughout the United Kingdom including Scotland. Many of these posts are paid for by charities such as the Stroke Association in England and Chest Heart and Stroke, Scotland (CHSS). To some degree this may have been driven in the charity sector by a perception that mainstream NHS services are failing to provide for patients and carers felt needs simply because evidence and cost effectiveness cannot be easily demonstrated for these services. In that respect satisfaction described by patients and carers may be felt to be adequate grounding for the provision of such services.

Some services are part of mainstream NHS provision, but guidance on the roll out of services is limited (12;332). It would appear that in the absence of a clear evidence basis or mechanism of effect for SLW-like interventions that roles and posts have proliferated (stroke nurse website). What unites or separates these roles currently is a definition by title or terminology without a standardised or agreed definition of job plans for these posts (i.e. who does what in what way to whom, when and where). It is apparent at national forums (National Stroke Forum) where these roles are discussed that important differences emerge in the provision of input to patients and carers.

Additionally in personal communication with Stroke Liaison Workers and on presentation of the evidence in scientific communications to conferences

(333) it is apparent that despite potentially disappointing results, that individual Stroke Liaison Workers have a high degree of confidence in the effectiveness of their work.

It is therefore legitimate to consider exploring two central questions in mapping the existing evidence to current health service practice.

1. Firstly, can current Liaison Roles be quantified and evaluated in Scotland? Do they bear any comparison to the interventions described in the research or have the roles and services evolved to make current evidence invalid for current services?

2. Secondly, what are the beliefs of those who carry out these roles regarding the effectiveness of their work and its applicability to some or all patients.

Answering these questions requires both quantitative data and semi-qualitative data.

No central register exists within the NHS Scotland to locate and contact these health workers. In addition, because many of the services have evolved from local needs and local contexts, it was apparent that some degree of description and classification would be required in order to identify comparable roles independent of titles and superficial descriptives. The Scottish Stroke Nurses Forum (SSNF) was established in 2003 to provide a forum for the professional development and promotion of high quality nursing standards and education amongst nursing professionals in Scotland. It is currently the most comprehensive network of nursing clinicians and researchers in Scotland and as such provides a forum to contact and evaluate role development across Scotland.

Methods

Questionnaire Development

No single definition of a Stroke Liaison Worker exists and no single job description or profession has been defined by services nationally or locally. For this reason identifying and evaluating these roles proves difficult. In practice, a number of screening questions are likely to be required to identify individuals who work with patients after stroke providing liaison, social support and information. A questionnaire was developed to map existing services in Scotland and mirror the roles described in the Stroke Liaison Workers literature. These questionnaires asked for information under a series of domains including geographic, employment (profession and grade), and the scope of the individuals work (e.g. inpatients only, outpatients etc).

SSNF members who identified that they worked with patients in the community after a stroke were asked a series of further questions. These related to the areas of a Stroke Liaison role as identified in the review process. Specific questions were asked of the type of social support, liaison and information provision provided by each respondent. Respondents were asked to categorise their approach to the individual patient (i.e. proactive and structured or reactive and flexible) and their type of interaction with the patient or carer (Focussed or Comprehensive). Definitions were given for each of these terms (see Table 5.1, Appendix J) and respondents were asked to prioritise their responses according to which was their most common method of approach. Care was taken to avoid pejorative terminology that might influence respondents. Those respondents who were identified by screening questions to be in relevant roles were asked their personal belief of whether their role was effective for all or only some of their clients. Additional questions allowed respondents to record free text

where they felt important. Additional questions were asked of respondents regarding the three commonest problems they dealt with day to day.

Questionnaires were piloted with staff members known to the author to work in this type of post. Following this minor modifications were made to the questionnaire to clarify definitions etc. The questionnaires were then sent to all 209 members of the Scottish Stroke Nurses Forum. In response to the initial mailing, 89 questionnaires were returned. A second mailing was therefore carried out, prompting a further 21 responses.

From all the responses, only initial demographic data were retained for this analysis. Respondents who were identified through the screening question to be dealing with the relevant patient and carer group were analysed separately. Their results are presented here.

Results

In total 110 questionnaires were returned (52.6%), of which 58 met the screening criteria for a Stroke Liaison Worker role.

The regional distribution of respondents is shown in Figure 6.1.

Quantitative data

All respondents who identified themselves as potential Stroke Liaison Workers were from the nursing profession. Most were from senior nursing grades; 35% (n=20) grade F, 28% (n=16) grade G and 16% (n=9) grade H, with the majority (59%, n=34) working with both in-patients and outpatients, implying an immediate role in discharge liaison. Responders were asked who they dealt with. All 58 respondents identified that they dealt with patients, with 97% (57) dealing additionally with carers and families.

Respondents were then asked to identify which aspects of stroke liaison they were involved in (education and information provision, liaison, social support), with 90% identifying themselves as delivering all three roles.

Respondents were then asked to identify within these general areas, which specific areas of information provision they provided, or what form of social and psychological support they provided and with whom they regularly liaised.

These questions had been developed by the author and used within the review process described in Chapter Five to try and classify the specific types of intervention delivered.

In general terms, response rates were very high to all questions, with most nurses responding to nearly all areas (Table 6.1).

The Stroke Liaison Worker approach is illustrated in Table 6.2. Respondents were asked to identify their primary mode of approach or interaction with a patient or carer. A number of respondents scored both approaches as equal, hence the overlap of statistics.

Visits were primarily conducted in the community in the patients homes (80%), with some liaison contacts additionally being made by telephone (81%) or at visit to the hospital (e.g. at outpatient clinics – 48%).

Respondents were asked if they believed their role to be effective. 62% (36 respondents) believed that their role was effective for all their patients. 22% (13) suggested that their role in their opinion benefited most patients, whilst 14% (8) believed that it benefited only some.

Qualitative data

Responses to the questions regarding the three commonest problems dealt with by Stroke Liaison Workers were reviewed. I looked for common threads or themes that might group the responses together. The four dominant themes identified were:

a) Psychological or emotional issues,

b) Informational or educational issues,

c) Practical or service related needs and

d) Medical or physical needs.

Other issues including problems relating to service provision and staffing issues were grouped under "other responses".

A count of the frequency of problems in these five themes was conducted, illustrating that the commonest theme was psychological or emotional needs (103 responses) followed by informational and educational needs (30 responses), practical or service needs (23 responses) and medical or physical (20 responses). 13 responses were listed that did not relate to patient care or support.

Psychological or emotional needs

Responses in this category illustrate a number of separate themes. These include psychological adjustment to the effects of stroke.

> "Helping patients and relatives deal with the life changing events of stroke."

> "Patient, carer/relative not coming to terms with stroke and its effect."

"Life changes"

Nurses also identified anxiety and depression as a frequent theme:

"Patient/carer depression and anxiety"

"Depression"

"Fear of re-stroke"

"Anxiety (especially re recurrence)"

A number of other issues and themes were also identified as important:

"Communication problems - social isolation"

"Loneliness"

"Physiological issues"

"Motivation"

"Change in family dynamics"

Informational or educational needs

Respondents identified a number of issues as having an educational or informational basis. These include behaviour modification and lifestyle factors related to reducing risk factors:

"How to change lifestyle e.g. smoking cessation, exercise and diet"

"Secondary prevention e.g. medication compliance and understanding"

"Management of risk factors - especially smoking"

Other informational needs were more general:

"Lack of understanding of stroke and recovery"

"Patients not understanding all the aspects of stroke"

"Educating other family members"

Specific information needs were also identified in relation to driving and returning to work.

Practical or service needs

A number of responses indicated a variety of needs relating to support or rehabilitation services in the community and problems where nurses were clearly being required to provide liaison:

"Benefits advice"

"Problems communicating with GP, social work etc."

"Lack of support for patients from AHPs in community"

"Advice re local support services"

Financial issues relating to benefits was the most frequent single issue identified.

Medical or Physical needs

These included issues in relation to physical rehabilitation:

"Patients not carrying over their functional level in the home setting and physical regression"

"Communication/swallowing"

Physical needs:

"Fatigue"

"Bowel and bladder problems"

"Pressure area problems"

"B/P control"

And issues in relation to specific treatments and treatment modification:

"Medication problems - e.g. dosage, how long"

"Side effects of stroke or medication"

Discussion

Overall, 53% of respondents identified themselves as potentially fitting the category of Stroke Liaison Worker. The screening question appears to correctly identify the nurses who provide the key aspects of Stroke Liaison Workers.

Overall, results from the nurses who responded are broadly similar. Most respondents report that they are offering all three of liaison, education and information provision and social support. Specifically nearly all respondents offer a broad range of information and education. In addition, the nurses employ a range of methods of social support to patients and their families, with the general exception of formal counselling methods. Most respondents have a comprehensive role in liaison between the patients and other services. One of the limitations of this patient survey might be its lack of definition of the specific differences for example between; informal

emotional support, informal counselling and formal counselling. The questions were listed as though to illustrate a continuum of different methods of support, and despite the lack of a formal definition, the response rate was high, and broadly similar, suggesting that despite this limitation, nurses appeared to respond in a consistent way.

Attempts to specifically define the intervention prove challenging when trying to compare it to the established literature in this area. Asking respondents to identify their primary mode of approach (reactive or proactive) proved difficult with a number of respondents rating both approaches as of equal frequency. There is a risk that the way in which the question is constructed implies that one approach sounds more positive (e.g. pro-active) and another pejorative (reactive). Attempts were made to avoid negative language where possible. This question attempted to dichotomise interventions to mirror some of the trials in the literature that were either reactive (76) or proactive (297). Additional dichotomisation was attempted to identify trials that focussed on a specific problem or defined area (e.g. risk factor control or mood and emotional health) (279;298) or attempted to be comprehensive and cover a broad range of areas (32). These differences become important if evidence suggests that a particular method of working as well as role proves to be effective.

One further area of potential difficulty relates to the team associations that the Stroke Liaison Nurses have. Traditionally Stroke Liaison Nurses have had a more independent role, operating between primary and secondary care and tending not to be a part of a multidisciplinary team. Attempting to map existing Scottish roles to therapy teams was not clearly distinguished by the questionnaire. Respondents identified that they were related to a hospital stroke team (35, 60%), as part of community support teams (12, 21%) or other service structures (9, 16%). Further questions about the nature of the team structure and the frequency of team meetings and multidisciplinary discussion could have highlighted the degree to which Stroke Liaison Nurses were integrated to or independent from multidisciplinary teams.

Scottish nurses who responded to this survey to identify Stroke Liaison Worker roles appear to offer a service comparable to each other in terms of the intervention delivered. Minor differences appear in relation to the approach taken by Stroke Nurses and their interaction with patients. The roles performed by the nurses appear to compare with those in the original trials. Overall, Scottish Stroke Nurses appear to offer a multifaceted service with a high level of confidence that it is effective; that is, that in some way their role meets needs that would not otherwise be met. The themes identified by the Stroke Nurses appear to be broadly consistent with the existing literature and primarily identify psychological and emotional issues as the dominant ones.

Figure 6.1: Region of Stroke Liaison Workers

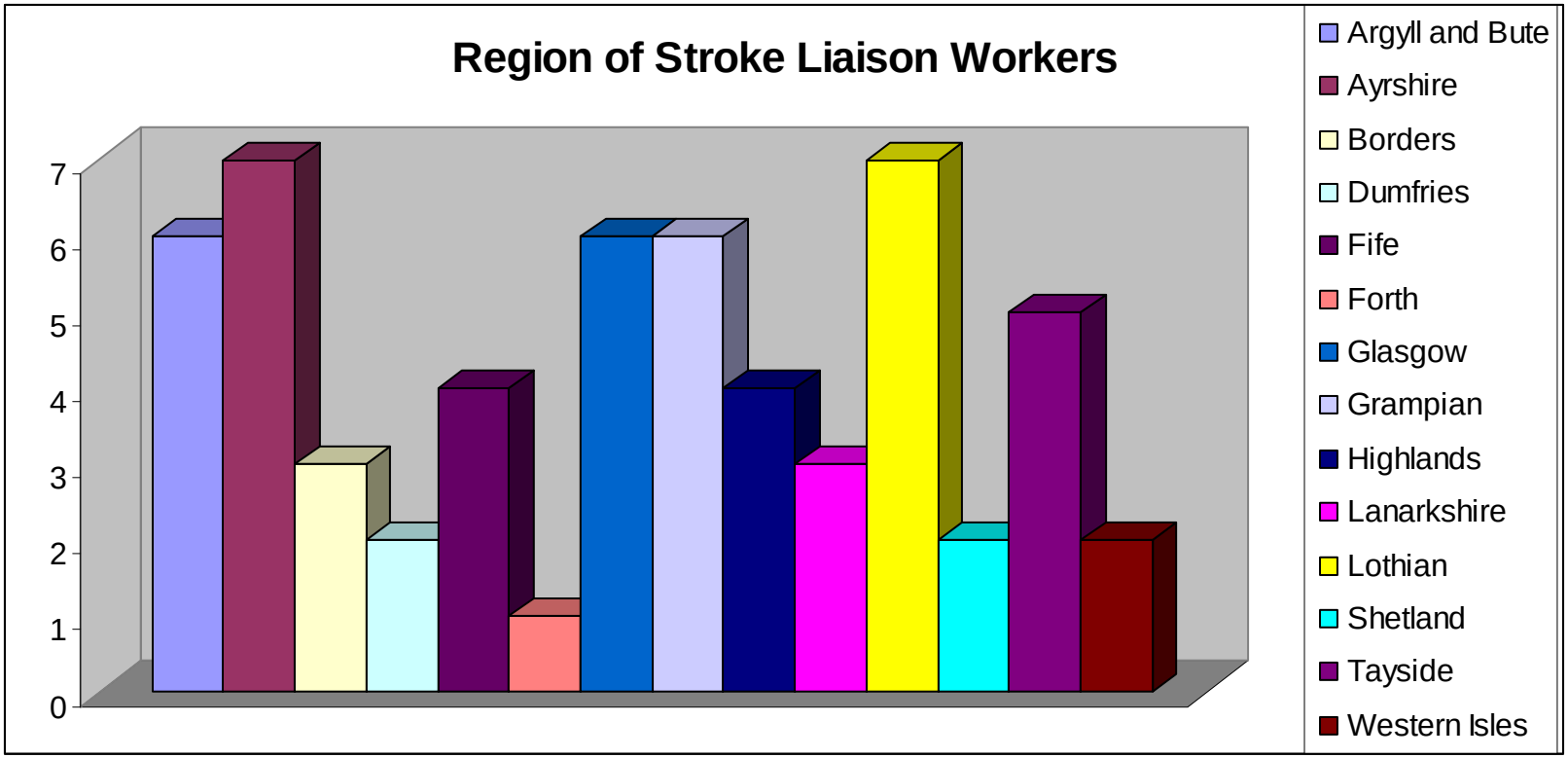


Table 6.1: Specific Interventions Provided by Scottish Stroke Liaison Workers

Specific help	**Yes n=58 (%)**
Information Provision and Education	
Stroke Information (general)	56 (97)
Risk Factors	57 (98)
Stroke consequences and complications	52 (90)
Stroke services and benefits	50 (86)
Stroke treatments and therapies	51 (88)
Social Support	
Informal emotional	56 (97)
Informal counselling	54 (93)
Formal counselling	6 (10)
Family support and problem solving	56 (97)
Individual problem solving	55 (95)
Organising other social support	53 (91)
Liaison	
…with patient	57 (98)
…with community services	54 (93)
…with primary care	54 (93)
…with secondary care	52 (90)

Table 6.2: Scottish Stroke Liaison Workers Primary Approach

Stroke Liaison Approach and Interaction	**Primary (%) n=58**
Stroke Liaison Approach	
Pro-active and Structured	30 (52)
"I tend to seek out to meet or talk with everyone. I tend to bring up subjects even when not brought up by the patient (or carer), or I work through a list of potential problem areas."	
Reactive and Flexible	33 (57)
"I respond to patients needs and adjust my workload or discussions around the problems that they bring up. The amount of time or follow-up will depend on need."	
Stroke Liaison Workers interaction	
Focussed	12 (21)
"I am quite specific about which areas we talk about (e.g. my role is to talk about risk factors or to talk about psychological problems etc.)"	
Comprehensive	49 (85)
"I cover a broad range of subjects and provide broad support for different aspects of living with stroke"	

Results show the proportion of respondents who identified an approach as their *primary* approach or interaction with a patient. In some cases, despite being asked to choose only one approach, respondents identified both approaches as equal.

Chapter Seven

Conclusions and Recommendations

We have seen from the existing literature that there is a strong association between specific problems post stroke (e.g. social isolation, depression etc.) and poorer outcomes for both patients and their carers (e.g. mortality, depression etc.) It seems legitimate therefore to explore specific interventions that might be seen to buffer these post stroke problems and limit their consequences. The context therefore exists for trials of (for example) information provision and social or psychological support.

In Chapter Two, we evaluated the short term outcomes from a brief intervention of education, information provision and liaison. We hypothesised that a better informed and better supported stroke patient might take more active control of their risk factors and be more satisfied with their care. This intervention did not appear to improve overall risk factor control despite modest effects on systolic blood pressure. Patients did appear to describe improved satisfaction with some aspects of their care. The evaluation in Chapter Three of the longer term benefits was limited by the significant drop out rate of both the intervention and control group subjects. Either for this reason, or because the effects of the intervention were limited, there was no evidence of benefit from the intervention described in Chapter Two at over three years later. One interesting observation was the relatively high persistence with secondary prevention therapy in both groups. One potential confounding factor in the intervening period between Chapters Two and Three is the development of a local primary care initiative for Chronic Disease Management. This is a programme that seeks to regularly review patients with Stroke, Ischaemic Heart Disease and Diabetes and aim to modify or improve their risk factors.

It is possible to postulate that this may have had an effect on both intervention and control groups.

The results in Chapters Two and Three could represent a Type II statistical error. Whilst larger scale studies may address this uncertainty, meta-analysis of similar studies can enable meaningful conclusions to be drawn from the existing literature. In order to establish what randomised controlled trials existed in this area of stroke research and to assess their combinability, we needed to develop a descriptive framework that would allow comparability. In the absence of an underpinning science, intervention characteristics for comparison must be based on external descriptors such as those discussed in Chapters Four and Five. To a great extent, this is because the Phase One modelling described in the MRC framework (page 67) has not been carried out. This limits our understanding of the intervention aims and effects to external factors. Nevertheless randomised trials currently exist evaluating a comparable group of interventions and therefore meta-analysis of these trials was warranted despite these limitations. The process of identifying the current evidence for possible comparability highlighted an emerging group of interventions that have developed in recent years with the sole purpose of addressing the needs of carers. This emerging group of trials merits further evaluation, but this is beyond the scope of this thesis.

In attempting to combine appropriate randomised controlled trials for meta-analysis we sought to add to the external descriptives of Chapter Four additional information gleaned directly from the trialists. We hoped that this would improve our accuracy in understanding the interventions and ensure if they could be appropriately combined and sub-grouped. In many respects, given that little was known about how these interventions might work, our analysis could be described as exploratory. For this reason, the wide range of outcome measures is appropriate. Despite this broad approach, no clear evidence of effectiveness for the current model of Stroke

Liaison Workers appears to emerge. Interesting and potentially important themes do exist however.

Stroke Liaison Worker interventions result in greater satisfaction with certain aspects of service provision (such as information provision and liaison) but do not appear to result in changes to patient subjective health status, extended ADL or carer subjective health. Subgroup analysis suggests that patients with mild to moderate dependence in activities of daily living may benefit with reductions in dependence as well as improved independent survival.

It would appear that this complex intervention with its broad intentions does not result in significant benefits when applied to all patients and carers.

Further research in this area may not be warranted on the existing model of Stroke Liaison Worker - that is a multidimensional intervention delivered to all patients and carers. Further work to explore alternative interventions however is urgently needed. This research and evaluation must include where possible, more detailed modelling (or phase one) work and take into account the themes emerging from this thesis. In essence it must consider:

- Being more focussed on a specific problem or impairment
    - E.g. depression
- Or focussing on a specific sub-group of patients
    - E.g. mild to moderately dependent patients
    - Carers
- Or working in combination with existing proven interventions

- E.g. Early supported discharge teams (Since the development of these trials Early Supported Discharge services have become more widespread and we do not as yet know the potential interaction between these two interventions.)

What does appear to emerge as a clear message is that Stroke Liaison Worker roles as they currently exist do not have an adequate evidence base to justify their continued support. Despite this, as we have seen from Chapter Six, there is a widespread belief in their effectiveness and current roles in Scotland appear to map well to the models of Stroke Liaison Workers that were evaluated in the trials. The research and stroke community needs to consider the significance of this evidence and its implications for practice.

Publications and Presentations

Publications

Ellis G, Mant J, Langhorne P, Dennis M, Winner S. Stroke liaison workers for stroke patients and carers. (Protocol) The Cochrane Database of Systematic Reviews 2004, Issue 4.

Ellis G, Rodger J, McAlpine C, Langhorne P. The Impact of Stroke Nurse Specialist input on Risk Factor Modification: A Randomised Controlled Trial. Age & Ageing 2005; 34(4): 389-92

Abstract Publications

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McManus JA, Craig A, Ellis G, McAlpine C, Langhorne P. 3 Years on: - Does behaviour modification affect post stroke risk factor control? Cerebrovascular Diseases 2006; 21(suppl 4): 92

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Ellis G, Smith L. N. Stroke liaison worker services in Scotland. International Journal of Stroke 2006; Volume 1, Supp 1: p62

Presentations

European Stroke Congress (Brussels, Belgium). May 2006 Stroke Liaison Workers Meta-analysis – Results by Intervention Type. Poster

European Stroke Congress (Bologna, Italy). Spring 2005 Stroke Liaison Workers. Poster

International Stroke Association (San Diego, USA). Spring 2004 Patient Centred Education Lowers Blood Pressure. Poster

Fifth National Stroke Nursing Conference: Stroke Care Rehabilitation and Long-term Support (Harrogate, Uk) September 2005 Stroke Liaison Workers Invited Speaker

British Geriatrics Society (Harrogate, UK) Autumn 2003 The Impact of a Stroke Nurse Specialist on Risk Factor Modification in a TIA Clinic: A Randomised Controlled Trial. Platform Presentation

Scottish Stroke Collaboration (Glasgow, Scotland) Autumn 2004 Stroke Family Care Workers. Invited Speaker

BGS – Scottish Branch (Ayr, Scotland) Autumn 2003 The Impact of a Stroke Nurse Specialist on Risk Factor Modification in a TIA clinic: A Randomised Controlled Trial. Platform Presentation

Appendices

Appendix A: Initial Consent and Patient Questionnaire

Enrolment Data-set	Page 1

Please fill in the white boxes.

Date:

1.

Demographics	Enrolment Number			
	Name:			
	Address:			
	Post Code:			
	Unit Number:			
	D.O.B.			
	Sex	Male		1
		Female		2

2.

Diagnosis		Tick	Coding
	TIA		1
	CVA		2
	Cerebrovascular Disease		3
	Other		4

PLEASE FILL IN

3.

Risk Factors		Tick	Coding	CURRENT RISK			
	Smoking		1	No per day:			
	Hypertension		2	Current BP	Sys	Dia	
	NIDDM / IDDM / IGT		3	Current / Most recent		RBG	HbA1c
	Previous TIA		4				
	Previous CVA		5				
	AF		6	On Warfarin?		Yes:	No:
	High Cholesterol		7	Level:			
	Alcohol Excess		8	Units per week:			
	Obesity		9				
	IHD		10				
	PVD		11				
	Other		12	(Specify)			

INFORMATION SHEET	**Page 2**

Patient Number:

Patient's Name: Date of Birth: Post Code:

THE IMPACT OF A STROKE NURSE SPECIALIST ON RISK FACTOR MODIFICATION IN A TIA CLINIC: A RANDOMISED, CONTROLLED TRIAL

You are being invited to enrol in a study that we are currently conducting in our "TIA" clinic.
This study forms part of research we are conducting into the effects of advice we give to our patients who are at risk of a stroke.

We hope to find out whether different kinds of approach to advice-giving can make a difference to our patients in terms of their health, understanding of their illness and satisfaction.

As part of the study patients will be randomly allocated to two different groups. One group will receive monthly appointments with our specialist stroke nurse. The other group will not receive these appointments. You will already have been allocated to one of these groups. We are unable to influence which group you will have been allocated to. All patients will be seen in four months time when they will be given a further questionnaire, have their blood pressure measured and blood tests taken. Many of these blood tests and blood pressure measurements may have been necessary as part of your normal care. For a few patients however, these tests will be purely for the purposes of research.

Research in medicine helps us to discover new or better ways of helping patients like yourself, and your participation would be greatly appreciated. Participation in the study may be of little or no benefit to you, but the results may help other patients in the future.

If you do agree to take part in the research project, your own General Practitioner will be told and will be given details about any care which you are to receive.

Consent Form	Page 3

Patient's Name: Date of Birth: Post Code:

Please place your initials in the boxes provided to indicate that you understand the statements that are being made.

The Doctor or Sister named below has
explained the study to me.

I know that I can withdraw from the study
at any time without having to give a reason.

I know that should I withdraw, this will not
in any way affect my care.

I consent to take part in this study.

Patients Name:
Address:
Signature:
Date:
Doctor/Sisters Name:
Signature:
Date:

Questionnaire	**Page 4**

Patient's Name:
Date of Birth:
Postcode:

We would like to know some information about your quality of life at the beginning of our study.

1. Quality of life

Please tick the box which you think best describes your current state of health.

Mobility

1. No problems in walking about
2. Some problems in walking about
3. Confined to bed

Self-care

1. No problems with self-care
2. Some problems washing or dressing self
3. Unable to wash or dress self

Usual Activities

1. No problems with performing usual activities
(E.g. work, study, leisure, family etc.)
2. Some problems with performing usual activities
3. Unable to perform usual activities

Pain/Discomfort

1. No pain or discomfort
2. Moderate pain or discomfort
3. Extreme pain or discomfort

Anxiety/Depression

1. Not anxious or depressed
2. Moderately anxious or depressed
3. Extremely anxious or depressed

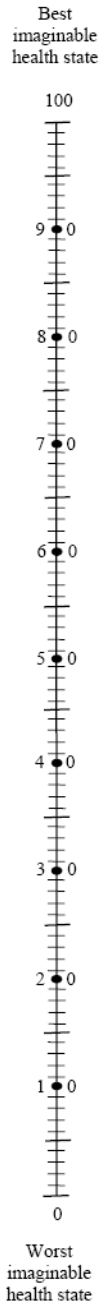
Questionnaire **Page 5**

Patient's Name:
Date of Birth:
Postcode:

To help people say how good or bad a health state is, we have drawn a scale (rather like a thermometer) on which the best state you can imagine is marked 100 and the worst state you can imagine is marked 0.

We would like you to indicate on this scale how good or bad your own health is today, in your opinion. Please do this by drawing a line from the box below to whichever point on the scale indicates how good or bad your health state is today.

Your own health state today



Appendix B: Concluding Data-set and Patient Questionnaire

Concluding Data-set	Page 1

Date:

1.

Demographics	Enrolment Number						Patient Phone No:
	Name:						GP:
	Address:						
	Post Code:						
	Unit Number:						
	D.O.B.						
	Sex		Male		1		
			Female		2		

2.

Diagnosis		Tick	Coding
	TIA		1
	CVA		2
	Cerebrovascular Disease		3
	Other		4

3.

Risk Factors		Tick	Coding	CURRENT RISK			
	Smoking		1	No per day:			
	Hypertension		2	Current BP	Sys	Dia	
	NIDDM / IDDM / IGT		3	Current / Most recent		RBG	HbA1c
	Previous TIA		4				
	Previous CVA		5				
	AF		6	On Warfarin?		Yes:	No:
	High Cholesterol		7	Level:			
	Alcohol Excess		8	Units per week:			
	Obesity		9	Weight:		Height:	
	IHD		10				
	PVD		11				
	Other		12	(Specify)			

4.

	Questionnaire completed?		Bloods taken where indicated?	
	Blood Pressure Recorded?		Results available?	

5.

Clinical Data				
	Further event not leading to admission?			
	Cause?			
	Admission to Hospital since enrolment?			
	Diagnosis?			
	Death?			
	Cause?			
	Other event?			
	Details:			
	Key	TIA=1	CVA=2	Other=3 (Please specify)

Questionnaire	**Page 2**

Patient's Name:
Date of Birth:
Postcode:

Now that you have completed your period in the study we would like to know some information about your quality of life, medications, mood and satisfaction with the service you have received.

2. Quality of life

Please tick the box which you think best describes your current state of health.

Mobility

4. No problems in walking about
5. Some problems in walking about
6. Confined to bed

Self-care

4. No problems with self-care
5. Some problems washing or dressing self
6. Unable to wash or dress self

Usual Activities

4. No problems with performing usual activities
(E.g. work, study, leisure, family etc.)
5. Some problems with performing usual activities
6. Unable to perform usual activities

Pain/Discomfort

4. No pain or discomfort
5. Moderate pain or discomfort
6. Extreme pain or discomfort

Anxiety/Depression

4. Not anxious or depressed
5. Moderately anxious or depressed
6. Extremely anxious or depressed

Questionnaire	**Page 3**

Patient's Name:
Date of Birth:
Post Code:

2. Your satisfaction with the service you have received

Please tick the box which best describes how you feel about the statements below:

	Strongly Agree	Agree	Disagree	Strongly Disagree
I have been treated with kindness and respect by staff at the hospital.				
The staff attended well to my needs when I was at the hospital.				
I was able to talk to the staff about any problems I might have had.				
I have received all the information I want about the causes and nature of my illness.				
The doctors have done everything they can to make me well again.				
I am satisfied with the outpatient services provided by the hospital.				
I have received enough information about my risk factors for stroke.				
Somebody has really listened and understood my needs and problems since I attended the hospital.				
I am satisfied with the amount of contact I have had with the hospital since I have attended.				
I have had enough emotional support since I attended the hospital.				
I know who to contact if I have problems relating to my TIA/stroke.				
I am happy with the amount of recovery I have made.				
I was given all the information I needed about the allowances or services I might need.				

Questionnaire	**Page 4**

Patient's Name:
Date of Birth:
Post Code:

3. Your medications

Please list in the boxes below all the medications you are taking and how frequently.

E.g. Medicine	E.g. 1 tablet	E.g. 2x per day

4. Your mood

Please answer the following questions by circling either YES or NO.

1. Are you basically satisfied with your life? YES / NO
2. Have you dropped many of your activities and interests? YES / NO
3. Do you feel that your life is empty? YES / NO
4. Do you often get bored? YES / NO
5. Are you in good spirits most of the time? YES / NO
6. Are you afraid that something bad is going to happen to you? YES / NO
7. Do you feel happy most of the time? YES / NO
8. Do you often feel helpless? YES / NO
9. Do you prefer to stay at home rather than going out and doing new things? YES / NO
10. Do you feel you have more problems with memory than most? YES / NO
11. Do you think it is wonderful to be alive now? YES / NO
12. Do you feel pretty worthless the way you are now? YES / NO
13. Do you feel full of energy? YES / NO
14. Do you feel your situation is hopeless? YES / NO
15. Do you think most people are better off than you are? YES / NO

Appendix C: Concluding Letter to GP after Final Follow-up

Date:

Dear Doctor,

Your patient _____has been enrolled in a trial of health education in secondary TIA / Stroke prevention.

They have now finished follow up. Their results are shown below along with our recommended targets.

Modifiable Risk Factor	**Result**	**Our Recommendation**
Blood Pressure		<140/85
Cholesterol		<5.0
Blood Sugar HbA1c		Random Blood Glucose <8 HbA1c <7.5
Smoking		Cessation

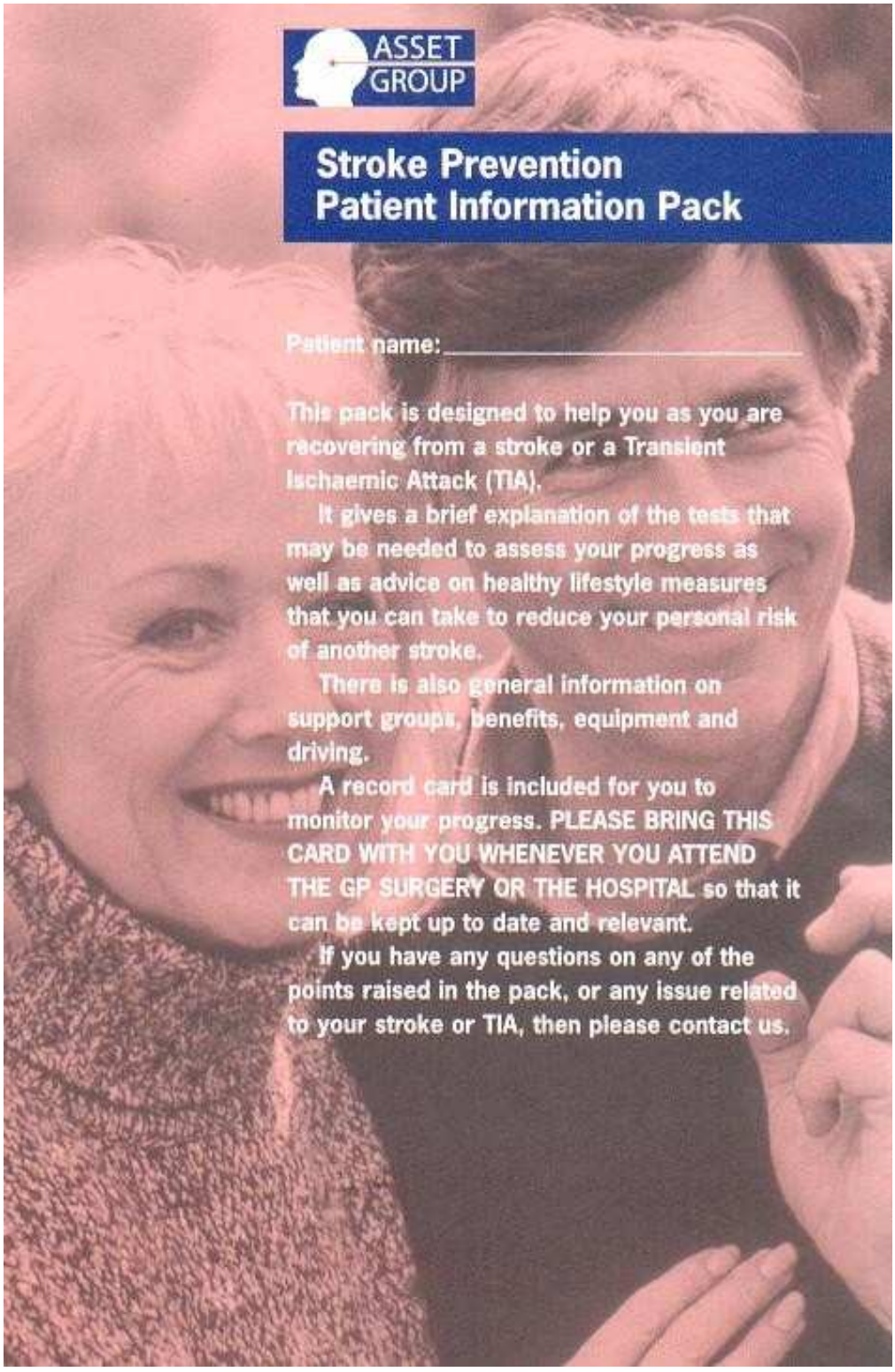
As a secondary preventative measure we would recommend that their risk factors are reduced to within these levels.

If you have any questions regarding their treatment or the trial I will be happy to try and answer these, as will the trial supervisor, Dr McAlpine.

Yours Sincerely,

Graham Ellis

Appendix D: Example of Patient Held Record



Background:

Name: _____ DOB 10/04/38

Diagnosis TIA Date of diagnosis MAY 02

1. HBP
2. DM
3. ANGINA

GP _____ Hospital Consultant _____

Surgery Address _____ Hospital Address _____

_____ _____

Number _____ Hospital number _____

Initial Assessment	Date	Results	Action
Pulse(regular/irregular - AF ?)			
BP			
Cholesterol	12/05/02	6·0	
Thyroid Function			
Blood glucose	12/05/02	12·0	MEDICATION↑
Plasma viscosity/ESR			
CT scan			
Carotid Duplex Scan	17/05/02	NORMAL FLOW	
Echocardiogram			
Alcohol intake	12/05/02	40 UNITS/WK	
Smoking-cigarette no.	12/05/02	25 CPD	
Exercise	12/05/02	WALK DOG DAILY	
Weight	12/05/02	75kg	
Height	12/05/02	5ft 8	
BMI	12/05/02		
General Medication			
Antiplatelet Therapy-specify		ASPIRIN	
		PERSANTIN	

AF = Atrial Fibrillation - a measure of heart rhythm.
BP = Blood pressure.
CT Scan = Computerised Tomography - see the test section.
BMI = Body Mass Index - a measure of weight and height.
ESR = Erythrocyte Sedimentation Rate - see the test section.

Monitoring

	Blood pressure	Smoking* (no per day)	BMI* (W/H²)	Alcohol* (units per week)	Daily activity*	Cholesterol (mmol/l)	Blood glucose (mmol/l)	Change in drug therapy (inc dose)	Comments and/or changes	Next review date
Personal targets	<140/85	0	<26	<21	'D'	<5·0	RBG <8			
Date										
12/05/02	150/85	25		40	'B'	6·0	12·0	HYPOGLYCAEMICS REVIEWED		12/06/02
12/06/02	145/80	15		21	'B'		8·5(BM)			15/07/02

NB In each section marked* the following key can be applied:

'A' - if not interested in changing
'B' - if thinking about changing
'C' - if ready to change
'D' - if making changes

Appendix E: Examples of Literature Given to Patients

Appendix F: The Impact of Stroke Nurse Specialist Input on Risk Factor Modification: A Randomised Controlled Trial – Age & Ageing

The impact of stroke nurse specialist input on risk factor modification: a randomised controlled trial

SIR—Interventions with an educational or counselling component have been reported to be effective in a variety of patient groups to encourage smoking cessation [1], lower blood pressure (BP) [2, 3], achieve modest reductions in cholesterol [4], and promote weight loss [5]. Evaluation of the impact of education on physical outcomes is lacking in stroke disease, despite evidence that inadequate provision of information may adversely affect compliance with secondary prevention and psychosocial outcomes [6].

We describe a single-blind randomised controlled trial of health education and counselling for patients with stroke or transient ischaemic attack (TIA), and its effects on risk factors, satisfaction, mood and perceived health status.

Methods

We recruited ambulant patients identified from a TIA clinic or a geriatric medical day hospital (where patients discharged with a diagnosis of stroke were attending for ongoing rehabilitation), in a UK teaching hospital.

Patients were eligible for inclusion if they had a clinical diagnosis of stroke, TIA or amaurosis fugax commencing in the previous 3 months. They had to have one or more of the following risk factors: high BP, a history of current smoking, high cholesterol and/or diabetes (regardless of their risk factor control). Patients with cognitive impairment (defined as an AMT <5 on screening) were excluded from involvement [7].

After collecting baseline data, and written consent, eligible patients were randomly allocated to treatment or control groups using a computer-generated random sequence concealed in sequentially numbered opaque sealed envelopes.

Patients randomised to the control group received usual care, which included generic risk factor advice from medical staff as well as the Stroke Nurse Specialist (SNS), given within the outpatient context. This service was standard to the control group and the intervention group prior to enrolment within the study. Following enrolment, control patients were discharged back to the care of their general practitioner and had no further input from the SNS.

Treatment group patients were offered additional input from the SNS, who reviewed them at monthly intervals for approximately 3 months. These reviews were conducted within the hospital premises as an outpatient consultation. Patients were interviewed and given individual advice on lifestyle changes, the importance of medication compliance and its relevance to secondary prevention. Issues of lifestyle including diet, exercise or increased activity, and interaction with medical services were discussed in depth and tailored to the patient's circumstances and functional abilities. All verbal information was backed up by written information that was selected by the SNS as relevant to the individual patient. Personalised patient-held records were also given to patients, detailing their risk factors, and the recommended risk factor targets. This record was updated at each visit, and was considered a key part of the intervention. The SNS did not attempt to contact the patient's general practitioner (GP) or hospital specialist in order to influence prescribing. Where a risk factor (e.g. BP) was deemed to be at unacceptable levels, patients were encouraged to consult their GPs with that information. Additional open questions gave patients the opportunity to bring up other subjects as the patient felt appropriate. The average consultation length was approximately 30 minutes.

GPs of both treatment and control group patients were informed of the study by letter, and of the form of intervention. At the end of the study, a letter summarising the patient's risk factors as well as our recommended risk factor targets was sent to the GPs of all the patients (treatment and control groups).

Outcomes were recorded at 5 months by an independent blinded assessor. The primary outcome of interest was the proportion of patients whose risk factors were 'on target', defined as the number of patients whose major modifiable risk factors were within the recommended treatment range according to the contemporary national and local treatment guidelines including BP (<140/85 mmHg), reported cigarette consumption (complete cessation), random blood glucose (<8.0 mmol/l) and HbA1c (<7.5%), and total cholesterol (<5.0 mmol/l). Secondary outcome measures included survival, the EuroQol perceived health status [8], Geriatric Depression Score [9] and a stroke services satisfaction questionnaire [10].

Power calculations were based on a case note survey of 51 consecutive patients attending the TIA clinic. The average number of risk factors per patient was 2.9 and only 20% had achieved complete risk factor control by the time of discharge. Eighty-nine patients per group would be needed to show an increase in the proportion of patients whose risk factors were 'on target' from 25 to 50%.

Local ethical approval was obtained for the study.

Data were entered by the principal investigator and analysed on an intention-to-treat basis using SPSS version 10.0.

Results

From an initial screening of 1,804 patients, 205 patients were recruited at their concluding visit to the stroke clinic or geriatric medical day hospital. Three patients were entered twice in error, each time to the treatment group. These subjects were analysed on their initial data only and subsequent data were excluded from the analysis. One patient in the control group was later found to be ineligible based on information unavailable at the time of enrolment. This patient has been included on an intention-to-treat basis. For additional information please see Appendix 1 in the supplementary data on the journal website (www.ageing.oupjournals.org). Baseline characteristics demonstrate the similarity of the two groups at randomisation (Table 1).

The main results are summarised in Table 2. Initial (planned) analysis of individual risk factors appeared to demonstrate a statistically significant reduction in systolic BP in the treatment group compared to the control group. In view of baseline differences in BP between the two groups, we performed analysis using a general linear model

Table 1. Summary of baseline characteristics

		Intervention group $n=100$ (%)	Control $n=105$ (%)	P value
Age		64.3 (62.4–66.1)	65.8 (64.0–67.5)	0.25
Sex (male)		54 (54%)	52 (50%)	0.68
Diagnosis				
TIA		29 (29%)	27 (26%)	0.18
Stroke		61 (61%)	68 (65%)	0.18
Multi-infarct disease		2 (2%)	4 (4%)	0.16
Amaurosis fugax		4 (4%)	4 (4%)	0.21
Transient global amnesia		2 (2%)	0 (0%)	0.13
Retinal artery occlusion (embolic)		2 (2%)	2 (2%)	0.36
Modifiable risk factors				
Smoker		36 (36%)	42 (40%)	0.55
Number of cigarettes per day		13 (9.4–16.7)	13 (9.7–16.3)	0.99
Hypertensive		66 (66%)	77 (73%)	0.26
Systolic BP (mmHg)		156.2 (150.7–161.7)	151.1 (145.6–156.6)	0.19
Diastolic BP (mmHg)		83.4 (79.7–87.1)	80.0 (76.8–83.2)	0.18
Diabetic		25 (25%)	26 (25%)	0.97
Random blood glucose (mmol/l)		10.73 (8.63–12.83)	9.94 (8.26–11.62)	0.57
HbA1C (%)		7.54 (6.47–8.61)	7.89 (7.26–8.52)	0.58
Hypercholesterolaemia		79 (79%)	79 (75%)	0.52
Total cholesterol (mmol/l)		5.8 (5.49–6.11)	5.7 (5.46–5.94)	0.66
Other risk factors				
Previous TIA		18 (18%)	11 (11%)	0.12
Previous stroke		12 (12%)	23 (22%)	0.06
Atrial fibrillation		2 (2%)	4 (4%)	0.45
Number of modifiable risk factors	1	22 (22%)	26 (25%)	0.64
	2	49 (49%)	42 (40%)	0.20
	3	29 (29%)	34 (32%)	0.60
	4	0 (0%)	3 (3%)	0.09

Data are presented as the mean (95% confidence intervals) or number (%).
Comparisons are made using the chi-squared test or Mann–Whitney U test.

(Ancova) to adjust for baseline BP. This suggested the result could not be fully explained by regression to the mean. However, repeating the analysis with adjustment for baseline BP indicated that the difference between groups in systolic BP drop was less marked (−7.8 mmHg, 95% CI −13.1 to −2.6 versus −2.2 mmHg, CI −7.1 to 2.7, $P=0.126$).

Changes in diastolic BP, reported smoking number, cholesterol, random blood glucose and HbA1c did not reach statistical significance.

There was no significant difference between the groups on the EuroQol or Geriatric Depression Score.

On the stroke service satisfaction questionnaire there were some significant differences between the groups. Patients in the treatment group were more likely to express satisfaction that they had been able to talk to someone ($P=0.027$), and that they knew who to contact if they needed to ($P=0.034$). They also expressed greater satisfaction with the information they had received, both about the causes of stroke ($P=0.022$) and about their risk factors ($P=0.010$). For additional information please see Appendix 2 in the supplementary data.

Discussion

It appears that nurse specialist-led education with tailored risk factor advice and patient-held documentation was well tolerated. However, the intervention did not result in significant improvements in risk factor control. This may reflect underpowering of the trial as the risk factor control in the control group was better than anticipated from pilot studies and in comparison to other trial evidence [11–13]. The lack of statistical significance for the reduction in systolic BP when adjusted for baseline BP is likely to represent underpowering.

Patients in the intervention group were statistically more likely to express satisfaction that they had been able to talk to someone about the problems they were having and that they knew who to contact should they have further problems relating to their stroke or TIA. Intervention group patients were also more satisfied with the amount of information they received, and expressed satisfaction that they felt they had someone they could contact with regard to their stroke disease.

Key points

- This stroke nurse specialist advice and counselling improved patients' satisfaction that they were able to talk to a member of staff and knew who to contact if they had a problem.
- Patients were more satisfied that they had received adequate information about their risk factors and the nature and causes of their disease.
- This intervention did not change overall risk factor control, but may be effective in lowering systolic BP.

Table 2. Summary of results

Outcome	Intervention group $n = 94$	Control $n = 98$	P value
'All relevant risk factors controlled'	45 (46.4%)	41 (41.7%)	0.34
Individual risk factors			
Hypertension			
Change in systolic BP (mmHg)	−9.3 (−15.0 to −3.5)	−1.0 (−6.3 to 4.3)	0.039
Change in diastolic BP (mmHg)	−2.1 (−5.7 to 1.5)	−1.2 (−4.5 to 4.5)	0.71
Smoking			
Change in number of cigarettes per day	−1.6 (−5.1 to 1.8)	−0.4 (−3.7 to 2.8)	0.61
Diabetes			
Change in random blood glucose (mmol/l)	0.92 (−1.39 to 3.23)	0.89 (−2.09 to 3.87)	0.99
Change in HbA1C (%)	−0.25 (−0.57 to 0.08)	−0.78 (−1.50 to 0.05)	0.20
Hypercholesterolaemia			
Total cholesterol (mmol/l)	−0.96 (−1.20 to 0.71)	−0.87 (−1.14 to 0.61)	0.63
Quality of life (EuroQol)			
Percentage with a deterioration in QOL[a] (score increase of ≥1)			
Mobility	11 (12%)	17 (17%)	0.27
Self-care	8 (9%)	16 (16%)	0.10
Usual activities	14 (15%)	22 (22%)	0.18
Pain	18 (19%)	25 (26%)	0.29
Anxiety and depression	17 (18%)	25 (26%)	0.21
Percentage change (visual analogue scale)[b]	3.5 (−0.9 to 7.9)	1 (−3.3 to 5.3)	0.43
Geriatric Depression Score[c]	4.3 (3.6–4.9)	5.1 (4.4–5.7)	0.11

[a]Positive scores indicate worse functioning.
[b]Positive scores for change in visual analogue scale indicate improvement.
[c]Positive scores indicate worse function.
Data are presented as the mean (95% confidence intervals) or number (%).
Comparisons are made using the chi-squared test or Mann–Whitney U test.

Acknowledgements

G.E. was responsible for the study design, patient recruitment, data entry and analysis and writing. J.R. reviewed patients in the intervention and control groups. C.M. provided clinical supervision and advice. P.L. provided advice on trial design, data analysis and writing. We would like to thank the patients who participated in this study for their co-operation.

Funding

This study was funded by a grant from the Chief Scientists Office, Scotland. We would also like to thank Boehringer Ingelheim who contributed towards the printing of the individualised patient records. G.E., J.R. and C.M. have received reimbursement for attendance at educational meetings from Boehringer Ingelheim. P.L. has received similar expenses from Boehringer Ingelheim, Sanofi and Pfizer.

GRAHAM ELLIS[1]*, JAN RODGER[2], CHRISTINE MCALPINE[3], PETER LANGHORNE[1]
[1]*Academic Section of Geriatric Medicine, 3rd Floor, Centre Block, Glasgow Royal Infirmary, Glasgow G4 0SF, UK*
Fax: (+44) 0141 211 4944
Email: g.ellis@clinmed.gla.ac.uk
[2]*Geriatric Day Hospital, Stobhill Hospital, 133 Balornock Road, Glasgow G21 3UW, UK*
[3]*Medicine for the Elderly, Stobhill Hospital, 133 Balornock Road, Glasgow G21 3UW, UK*
**To whom correspondence should be addressed*

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doi:10.1093/ageing/afi075

Non-valvular atrial fibrillation and cognitive function—baseline results of a longitudinal cohort study

SIR—Risk factors for cerebrovascular disease increase the risk of dementia and cognitive decline [1]. Non-valvular atrial fibrillation (NVAF) is an established risk factor for thromboembolism and stroke [2], which is significantly reduced by antithrombotic therapy [3]. Small cross-sectional studies report associations between NVAF, silent cerebral infarction and cognitive impairment [4–10], but there has been no longitudinal work in this area except for one small, highly selective comparison of cognition before and after coronary artery bypass grafting [11]. Given the high prevalence of NVAF in older people [12], we wished to determine whether NVAF is a preventable cause for cognitive decline in a prospective, longitudinal, community-based cohort study. Here we report baseline data comparing detailed neuropsychological testing of NVAF patients and controls, and assessing the effect of antithrombotic therapy.

Methods

Participants in NVAF and controls in sinus rhythm, recruited from general practice and aged over 60 years, underwent a home visit composed of a validated battery of neuropsychological tests [13]: a health questionnaire; a health status questionnaire (the SF-36 [14]); a physical examination; an ECG and blood tests. Cases and controls were analysed as subgroups according to antithrombotic therapy (aspirin/warfarin/neither).

Neuropsychological tests

The neuropsychological test battery included measures of selective/divided/sustained attention, short- and long-term verbal and non-verbal memory, information processing and premorbid intelligence.

Confounding factors

We incorporated all key confounders (age, duration of atrial fibrillation, coronary heart disease, diabetes, hypertension, cholesterol, health status (SF-36), congestive heart failure and education) into a multivariate model (Analysis of Covariance, ANCOVA) as covariates and found almost no effect of confounders on the neuropsychological tests, with only age showing borderline significance. Extensive additional analysis demonstrated no effect of confounders on the relationship between NVAF and cognitive function, regardless of use of antithrombotic therapy. Therefore we adjusted for age only.

Please see Appendices 1, 2 and 3 in the supplementary data on the journal website (www.ageing.oupjournals.org) for more details of methods, analyses, confounders and neuropsychological tests.

Results

After baseline interview, 362 participants were included (Table 1). There was no evidence of significant response bias, and cases and controls were comparable in most respects. Please see Appendix 4 in the supplementary data for full details of recruitment, response bias and characteristics of the cohort.

Baseline cognitive function tests (Table 2)

There were no significant differences ($P > 0.05$) in the means of the neuropsychological tests between cases and controls for the majority of sub-tests after adjustment for age, except for one item, 'time taken to perform the telephone task', where cases performed less well ($P = 0.003$ adjusted for age).

Subgroup analysis

Cases and controls were analysed as subgroups and the means of the test scores compared (cases on aspirin ($n = 62$), warfarin ($n = 80$) or neither ($n = 32$), and controls on aspirin ($n = 52$) or neither ($n = 136$)). The small sample size in cases who were in the 'neither warfarin nor aspirin' subgroup limits the interpretation of the results for this subgroup.

Initially significant differences between subgroups for the variables logical memory delayed, Rey figure copy, PASAT-4 seconds, telephone task number and digit span, were no longer significant when age was used as a covariate, with the exception of 'telephone task time taken' with aspirin cases performing significantly worse (118.43 seconds) than aspirin controls (90.25 seconds, $P = 0.004$).

Discussion

This is the largest cross-sectional study comparing cognitive function in older people with NVAF to those in sinus rhythm and adds considerably to previous cross-sectional data.

Context of existing research

The results presented here contrast with the findings of previous research addressing the association between NVAF and cognitive decline, including our pilot study in the North of England [13], as we found no difference at baseline between patients with NVAF and controls. Furthermore, there was no clear difference between patients on different forms of antithrombotic therapy.

Appendix G: Meta-Analysis Trial Grid

Stroke Liaison Workers Collaborative Review

Trial Details		
Contacts Trialists		
Year		
Place		
Trial Name		

Participants				
Population from which patient selected				
Carers involved?				
Inclusion criteria				
Exclusion Criteria				
Numbers	Patient (Treatment)		Patient (Control)	
	Carer (Treatment)		Carer (Control)	

Methods
Method of generating random sequence?
Method of treatment allocation and allocation concealment?
Intention to treat analysis?
Blinding *(e.g. patient/healthcare staff/outcome assessor/follow up/single/ double/none)*
Time from stroke onset to enrolment
Length of follow-up

Intervention	
Please indicate which ***one*** of the following domains you consider the most key in your intervention.	
Education and Information Provision	
Social and Family Support	
Liaison	

We have attempted as far as possible to classify the interventions to allow grouping or comparisons. Please indicate which descriptions you feel most fit your trial intervention. *(You may select as many boxes as you feel appropriate.)*	
Education and Information Provision	
Stroke (general)	
Stroke risk factors or preventing another stroke	
Stroke consequences and complications	
Stroke services and available benefits	
Stroke treatment and therapies	
Other *(please give details)*	
Social and Family Support	
Informal and emotional support	
Informal counselling	
Formal counselling	
Family support/problem solving	
Individual support and problem solving	
Organising of other social support	
Other *(please give details)*	
Liaison	
With patient/carer	
With community services	
With primary care	
With secondary care	
Other *(please give details)*	

Mean number of visits/contacts?	
Visits:	
Phone calls:	

Background of Stroke Liaison Worker
Please describe the professional background of the Stroke Liaison Worker(s)
Did the Stroke Liaison Worker receive any formal training?
Any other information you feel relevant regarding the intervention?

Outcome Measures	
The following is a list of the main outcome measures of the review. Please indicate which measure you used for each domain, listing them in the order of priority.	
Patients	
Primary Outcomes	
Subjective Health Status	
Extended activities of daily living	
Secondary Outcomes	
death	Yes / No
place of residence	Yes / No
activities of daily living	
dependency	
mental health (including anxiety and depression)	
knowledge about stroke	
use of services	
satisfaction with services	
participation	
other	

Carers	
Primary Outcomes	
Subjective Health Status (including measures of carer strain)	
Secondary Outcomes	
Extended activities of daily living	
mental health	
knowledge about stroke	
satisfaction with services	

Data	
I am happy to have my relevant individual patient data used as specified	
I am unhappy to have my relevant individual patient data used as specified	
I am happy to have some of my data used with the following qualifications:	
NB. If you have used a local outcome questionnaire or instrument, which is not widely available (e.g. satisfaction questionnaire) It would be very helpful if you were able to forward one to me.	
Data format *(e.g. software)*	
Please also note if the data labels on your database are not obviously apparent, a copy or note of the field labels would be very helpful.	

Contact details	
I require assistance with travel:	
I require accommodation:	
I am most easily contacted at/by: *(please note email is our preferred method of contact)*	Phone Email Mobile Fax
My most up to date email is:	

Appendix H: Minutes of Stroke Liaison Workers Collaborative Meeting

Minutes of Stroke Liaison Workers Collaboration

Royal College of Physicians and Surgeons of Glasgow
4th March 2005

Present: J Mant, M Dennis, S O'Rourke, V Miller, N Lincoln, A Forster, C Burton, A Sharma, G Ellis, P Langhorne

Apologies: T Hafsteinsdottir, M Clark, J Frayne, and D Bishop

Absent: T Glass, D Christie, and G Goldberg

Presentations:

Introduction to protocol (Jonathan Mant)

Literature Search and Taxonomy of Interventions (Graham Ellis)

There was some brief discussion around the changes in the protocol and the exclusion of carer only interventions as well as the appropriate inclusion of TIA patients.

Discussion around taxonomy and subgroup classification:

The model proposed by GE was discussed.
With the breadth of interventions, and in some cases the flexibility required in a particular context, these classifications were felt to be somewhat arbitrary.
It also became clear that apparently similar trials had a reasonable degree of variation.
A further model was proposed, based on whether the intervention was responding to individual problems and needs, whether it was relatively fixed and systematic in its approach or whether it was theory driven and focussed in a particular area.

These categories would be as follows:

1. Proactive and Structured
    a. Preston
    b. Bradford
    c. Utrecht
    d. Rhode Island
2. Reactive and Flexible
    a. Edinburgh
    b. Adelaide
    c. Oxford
    d. London
    e. Liverpool
    f. Nottingham
    g. Melbourne
    h. Melbourne (SHIPS)

3. Proactive and Focused
    a. Glasgow
    b. Leeds (Volunteer)
    c. Leeds (Psychiatric Nurse)
    d. Boston (FIRST)
    e. Philadelphia

Other sub-groupings were discussed:

Service related

1. According to what intervention or services the control group received
2. In-patient versus outpatient (never admitted)
3. Related to outcome of question (e.g. Psychological to mental health outcomes)
4. Prior stroke unit admission versus none

These were in addition to the previously stated suggestions:

5. Intervention characteristics
6. Prior profession of Stroke Liaison Worker (and specialist versus non specialist)
7. Direct versus remote services
8. Early Versus Late (Cumulative add in analysis were suggested to reflect range)
9. Intensity (Cumulative add in?)
10. Duration (Cumulative add in?)

Patient related

1. First Versus Recurrent stroke
2. Admitted Versus Never Admitted
3. TIAs Versus Stroke
4. Prior depression

These were in addition to previously stated suggestions:

5. Prior functional / Baseline functional status
6. Age
7. Sex
8. Carer (or first degree relative?) Versus None (3 Groups – first degree, other support, none?)

Outcome measures

Discussion continued around dichotomisation/continuous data comparisons.
The possibility of individual patient dichotomisation was discussed, although the pragmatics of this seemed challenging.
Discussion continued on the theme of the satisfaction outcomes and whether these be grouped or taken individually. In addition there was discussion around the use of relevant satisfaction outcomes to appropriate intervention.
Additional comment was made on the worth of giving mention to the inclusion of qualitative data in the review.
The possibility of combining similar and comparable outcomes was discussed.

Publication and Authorship issues

Data Ownership

There was some discussion around the use of data from unpublished trials.
It was reiterated that the rights to ownership and use of this data were with the individual trialists or group and that we did not intend to jeopardise individual trial publication. For this reason (where timescales are important), it was decided that at the point of completion of data analysis, the use of the relevant data would be discussed with the individuals or groups concerned. Where this presents a problem, that data would be excluded if requested. For reasons of efficiency and practicality it was requested that data be submitted for analysis now, but on the agreement that its public release not be permitted until further discussions take place with the trialists affected.

Group Authorship

It was agreed that where the journals permitted, a group name would be used for the primary publication, with recognition of the contribution of individual authors.
Where further subsequent papers of additional analysis were involved, the authorship would be represented by a statement such as:
Y, Y and Z on behalf of the Stroke Liaison Workers collaboration.

The meeting was concluded with thanks expressed to all for their co-operation and helpfulness.

Sweepstake:

Nadina	Caregiver strain
Peter	Satisfaction with services
	Caregiver strain index
Chris	Satisfaction with Services
	Caregiver Strain index
Anne	Caregiver satisfaction
Anil	Satisfaction with services
Martin	Caregiver satisfaction
Jonathan	Caregiver satisfaction with knowledge
Van	Satisfaction with services
Suzanne	Patient satisfaction with liaison

Appendix I: Cochrane Protocol

Stroke liaison workers for stroke patients and carers (Protocol)

Ellis G, Mant J, Langhorne P, Dennis M, Winner S

This is a reprint of a Cochrane protocol, prepared and maintained by The Cochrane Collaboration and published in *The Cochrane Library* 2005, Issue 2

http://www.thecochranelibrary.com

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Stroke liaison workers for stroke patients and carers (Protocol)

Ellis G, Mant J, Langhorne P, Dennis M, Winner S

This record should be cited as:
Ellis G, Mant J, Langhorne P, Dennis M, Winner S. Stroke liaison workers for stroke patients and carers. (Protocol) *The Cochrane Database of Systematic Reviews* 2004, Issue 4. Art. No.: CD005066. DOI: 10.1002/14651858.CD005066.

This version first published online: 18 October 2004 in Issue 4, 2004.
Date of most recent substantive amendment: 10 August 2004

ABSTRACT

This is the protocol for a review and there is no abstract. The objectives are as follows:
To determine the efficacy of stroke liaison workers for patients with stroke and their carers in returning to normal roles, as measured by improving social activities, participation, and mental health.

BACKGROUND

Stroke is a major cause of disability and handicap, with an incidence of 3 to 5 per 1000 in people aged 45 to 84 (Sudlow 1997). The majority of people survive their stroke, but a third to a half remain functionally dependent after one year (Bamford 1990; Taub 1994). This is associated with significant psycho-social problems for both patients and their carers, which may also occur independent of physical disability (Dennis 1998; Kotila 1998; Scholte 1998). The burden of such problems may increase as a result of demographic change and reductions in age-specific stroke case fatality (Barker 1997; Bonita 1993).

A number of different approaches have been evaluated to try to lessen these psycho-social problems. These include provision of therapy (Wade 1992a; Walker 1999), information leaflets (Mant 1998), antidepressants (Palomaki 1999), counselling, education (Evans 1988; Rogers 1999), and social support (Friedland 1992). While some studies did find positive effects of these interventions, none were found to have a significant impact on psychological outcomes or quality of life, though this may have been due to type II statistical error.

Support following discharge from hospital, information about stroke and available resources, and practical help have been identified by patients and carers as services that they would value (Greveson 1991). A stroke liaison worker can be defined as someone whose aim is to return patients and their carers to normal roles. Typically they provide emotional and social support and information to stroke patients and their families and liaise with services with the aim of improving aspects of participation and quality of life for patients with stroke and/or their carers (Lilley 2003). This multi-faceted role distinguishes stroke liaison workers from therapists whose aim is to treat a single problem such as improving activities (rehabilitation) or knowledge (information provision). A stroke liaison worker may be a health or social care professional, or be from the voluntary sector. Such services have been evaluated under a range of different names, such as 'social work' (Christie 1984; Towle 1989), 'specialist nurse support' (Forster 1996), 'stroke family care worker' (Dennis 1997), and 'stroke family support organiser' (Mant 1999). For the purposes of this review, such services have been grouped under the generic title of 'stroke liaison worker'. There has been one descriptive review of published trials of 'support workers' within the context of a broader review of non-drug strategies aimed at reducing psycho-social problems after stroke (Knapp 2000). No meta-analysis of these studies has yet been attempted.

OBJECTIVES

To determine the efficacy of stroke liaison workers for patients with stroke and their carers in returning to normal roles, as measured by improving social activities, participation, and mental health.

CRITERIA FOR CONSIDERING STUDIES FOR THIS REVIEW

Types of studies

Randomised controlled trials comparing allocation to stroke liaison worker with normal care or alternative service.

Types of participants

Survivors of acute stroke and/or their closest informal carer. A clinical definition of stroke will be used: rapidly developing clinical symptoms and/or signs of focal, and at times global loss of cerebral function (Bamford 1988). Studies that have included TIA patients will not be excluded since TIA is part of the same disease spectrum and patients with TIAs, while seldom having reduced activities, may have reduced participation and a high level of anxiety regarding stroke recurrence (van Veenendaal 1996). Participants must be adult (aged 16 or over). Trials that address carer needs alone (and do not include patients) will not be considered.

Types of intervention

Referral to a stroke liaison worker. Such a worker would typically provide a multi-faceted service including more than one of: education and information provision; social support; and liaison with other services (OSST 1999). Often this intervention is provided from the point of patient discharge from hospital. Trials assessing workers of any professional background will be relevant, and might include health or social care professionals or volunteers. Studies where the intervention was judged to be single faceted would be excluded. This distinction is to separate the stroke liaison worker interventions from trials of (for example) information provision alone (Forster 2001). Similarly, trials of therapist-delivered physical rehabilitation or psychological interventions on their own would be excluded. The control group will receive usual care.

Types of outcome measures

Outcomes for Patients

Primary: Subjective Health Status (e.g. GHQ12, SF36, EuroQol); Extended activities of daily living (including social activities e.g. Nottingham EADL, Frenchay AI).

Secondary: death; place of residence; activities of daily living; dependency; mental health (including anxiety and depression); knowledge about stroke; use of services; satisfaction with services; participation.

Outcomes for Carers

Primary: Subjective Health Status (including measures of carer strain).

Secondary: Extended activities of daily living; mental health; knowledge about stroke, satisfaction with services.

SEARCH STRATEGY FOR IDENTIFICATION OF STUDIES

See: Stroke Group search strategy

Relevant trials will be identified in the Cochrane Stroke Group's trials register. The register will be searched for trials that relate to psychological therapy, counselling, social support, therapists, service provision, support workers, carer training, or information giving.

In addition we will search the following bibliographic databases: Cochrane Central Register of Controlled Trials (latest issue); MEDLINE (from 1966); EMBASE (from 1980); CINAHL (from 1982); ASSIA (Applied Social Science Index and Abstracts, from 1987); PsychINFO (from 1967); and Social Science Citation Index (from 1956). The search strategy for MEDLINE is shown below. This will be adapted for the other databases.

1. stress, psychological/
2. psychosocial$.tw.
3. social adjustment/
4. adaptation, psychological/
5. activities of daily living/
6. exp interpersonal relations/
7. morale/
8. (cope or coping).tw.
9. patient satisfaction/
10. exp emotions/
11. ((psychological or social) and (problem$ or difficult$)).tw.
12. exp social isolation/
13. emotion$.tw.
14. stress/
15. knowledge, attitudes, practice/
16. exp motivation/
17. quality of life/
18. anxiety/
19. caregivers/
20. life change events/
21. depression/
22. life style/
23. social behavior/
24. mental health/
25. knowledge/
26. psychomotor performance/
27. exp family relations/
28. or/1-27
29. patient care management/
30. continuity of patient care/
31. needs assessment/
32. rehabilitation nursing/
33. home nursing/
34. "referral and consultation"/
35. social support/

36. exp professional-patient relations/
37. ((patient$ or carer or caregiver$ or famil$) adj10 support$).tw.
38. patient education/
39. exp social work/
40. community health services/
41. (home or in-home or home-based).tw.
42. health services for the aged/
43. ((patient$ or carer or caregiver$ or famil$) adj10 information$).tw.
44. family health/
45. family care$.tw.
46. outreach.tw.
47. advice.tw.
48. counseling/
49. counsel?ing.tw.
50. nursing assessment/
51. aftercare/
52. volunteer$.tw.
53. exp rehabilitation/
54. communit$.tw.
55. empathy/
56. visitor$.tw.
57. patient-centered care/
58. health education/
59. interview, psychological/
60. exp patient care planning/
61. domiciliary.tw.
62. (liaison or link or contact).tw.
63. Home care services/
64. ambulatory care/
65. or/29-64
66. exp cerebrovascular disorders/
67. (stroke$ or cva$ or cerebrovascular or cerebral vascular or post-stroke or transient isch$ or TIA).tw.
68. (cerebral or cerebellar or brain$ or vertebrobasilar).tw.
69. (infarct$ or isch?emi$ or thrombo$ or emboli$ or apoplexy).tw.
70. 68 and 69
71. (cerebral or brain or subarachnoid).tw.
72. (haemorrhage or hemorrhage or haematoma or hematoma or bleed$ or aneurysm).tw.
73. 71 and 72
74. hemiplegia/ or exp aphasia/ or hemianopsia/
75. (aphasi$ or dysphasi$ or hemianop$ or hemipleg$ or hemipar$).tw.
76. 66 or 67 or 70 or 73 or 74 or 75
77. 28 and 65 and 76
78. limit 77 to human

In order to identify further published and unpublished studies, a citation search will be carried out using the Web of Science Citation Indices, the reference lists of identified relevant trials will be checked, and authors of relevant papers contacted. Relevant conference proceedings will be reviewed, trials registers will be searched, and contact will be made with investigators in this area of stroke services trials.

METHODS OF THE REVIEW

Selection of studies

Two independent reviewers (GE & PL) will screen titles and abstracts of papers identified from the searches of the Cochrane Stroke Group's trials register and the other bibliographic databases. Papers that clearly do not meet the inclusion criteria will be excluded at this stage, and the reason recorded. A full text copy of all possibly relevant papers will be obtained, and two independent reviewers (GE & PL) will assess these according to pre-defined inclusion criteria. Where there is disagreement, SW and MD will moderate.

Data extraction

Data extraction will be performed using a pre-designed data abstraction form on all studies that fulfil the inclusion criteria. This will be carried out independently by two reviewers (GE & PL), and will include data on design characteristics, the study population, the intervention, outcome measures used, and length of follow up. Classification of the intervention will include which facets (e.g. information giving and education; social support; liaison) the workers were involved with. Authors will be contacted for clarification/ additional data where necessary. Where there are disagreements, these will be resolved by moderators (SW, JM & MD).

Assessment of quality

Eligible trials will not be given a quality score (Juni 1999). Nevertheless, the trials will be coded with regard to quality of randomisation procedure, method of consent, concealment of treatment allocation, blinding of patients and carers, blinding of outcome assessor, and handling of withdrawals and drop-outs.

Analysis

Outcome measures will be classified according to which domain they are assessing (activities of daily living; extended activities of daily living; participation; dependency; mental health; subjective health status; knowledge about stroke; use of services; satisfaction with services). Most of the scales used are likely to be ordinal. Where appropriate, these will be converted to dichotomous data, using pre-determined cut-off points. For some measures, such as the Hospital Anxiety & Depression Scale and the General Health Questionnaire-28, these cut-off points have already been defined (O'Rourke 1998; Wade 1992b). For the remainder, clinically relevant cut-off points will be specified. Results will be presented separately for patients and carers for each domain of outcome. Where it is possible to dichotomise the data, then odds ratios and 95% confidence intervals will be calculated for each study.

If the same measures have been used in different studies, then a chi-square test for heterogeneity will be performed. If this is non-significant (i.e. $p > 0.05$), then a weighted treatment effect using a fixed effect model will be calculated across trials using the Cochrane statistical package RevMan Analyses. If there is significant heterogeneity, the individual study characteristics will be explored to try to identify the source of the heterogeneity, and meta-analysis will be performed (if appropriate) using both fixed-effect and random-effects models to see how much of the estimate of treatment effect varies with the two different models. No meta-analysis will be performed where grossly differing outcome measures preclude combination. Where it is not possible to dichotomise the data, the effects on outcome will be summarised in terms of direction of effect (in favour of intervention or control), and the size of the effect (in terms of standardised mean differences). The latter may allow some additional meta-analysis.

If meta-analysis proves possible, then a sensitivity analysis will be performed on the basis of methodological quality.

The results will also be presented stratified by timing of referral to stroke liaison worker (less than six months after stroke; more than six months after stroke) and type of intervention (liaison; education and information provision; social support).

ACKNOWLEDGEMENTS

We would like to thank Brenda Thomas of the Cochrane Stroke Group for developing the specialised search strategy.

POTENTIAL CONFLICT OF INTEREST

Martin Dennis (Edinburgh Stroke Family Care Worker Trial), Jonathan Mant and Simon Winner (Oxford Family Support Organiser trial), Graham Ellis and Peter Langhorne (Glasgow, unpublished) were involved in studies likely to be relevant to the review.

SOURCES OF SUPPORT

External sources of support

- No sources of support supplied

Internal sources of support

- No sources of support supplied

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**Indicates the major publication for the study*

COVER SHEET

Title	Stroke liaison workers for stroke patients and carers
Authors	Ellis G, Mant J, Langhorne P, Dennis M, Winner S
Contribution of author(s)	Information not supplied by author
Issue protocol first published	2005/1
Review first published	/

Date of most recent amendment	17 September 2004
Date of most recent SUBSTANTIVE amendment	10 August 2004
What's New	Information not supplied by author
Date new studies sought but none found	Information not supplied by author
Date new studies found but not yet included/excluded	Information not supplied by author
Date new studies found and included/excluded	Information not supplied by author
Date authors' conclusions section amended	Information not supplied by author
Contact address	Dr Graham Ellis Clinical Research Fellow Academic Department of Geriatric Medicine Glasgow Royal Infirmary Castle Street Glasgow G4 0SF UK Telephone: 0141 211 4000 E-mail: g.ellis@clinmed.gla.ac.uk
Cochrane Library number	CD005066
Editorial group	Cochrane Stroke Group
Editorial group code	HM-STROKE

Appendix J: Scottish Stroke Nurse Questionnaire

Stroke Liaison Worker Questionnaire

My region is:

Argyll and Clyde		Grampian	
Ayrshire and Arran		Highlands	
Borders		Lanarkshire	
Dumfries and Galloway		Lothian	
Fife		Shetland	
Forth Valley		Tayside	
Glasgow		Western Isles	
Other (please specify below)		Orkney	

I am a:

Nurse		Health Visitor	
Volunteer		Social Work	
AHP (please specify)			
Other (please specify)			

Grade:	

I work with:

Inpatients only	
Inpatients and outpatients (including ward discharges)	
Only outpatients (including ward discharges)	
Not applicable (e.g. no patient contact)	

If your answer above is “inpatients only”, or “not applicable” jump to page 4 “Questions for everyone”

We are particularly interested in these three areas and in how your role might include these aspects of care. We would like you to try and identify which are most relevant to your work. *(Tick **ALL** that apply to you)*

My role with patients/carers in the community is:

Liaison (This may mean referring the patient on to appropriate clinicians, or simply acting as a point of contact.)	
Social Support (This can be anything from simple support to offering advice about family problems or more in depth counselling.)	
Education and Information Provision (This could mean anything from giving leaflets to taking seminars with patients and carers or counselling about lifestyle and risk factors.)	

We would like to explore a little more, aspects of your practice with patients or carers. Which of the following apply to your work? If you wish to add comments at the end, please do so.
*(Please tick **ALL** that apply)*

I provide:

Education and Information provision in the following areas:	
Stroke (general information)	
Stroke risk factors or preventing another stroke	
Stroke consequences and complications	
Stroke services and benefits	
Stroke treatments and therapies	
Other	
Social Support of the following kinds:	
Informal emotional support	
Informal counselling	
Formal counselling (e.g. as a trained counsellor using established techniques)	
Family support / problem solving	
Individual support / problem solving	
Organising of other social support	
Other	
Liaison:	
With patient / carer	
With community services	
With primary care	
With secondary care	
Other	
Other comments	

My approach is:

We would like you to put a **1** *in the box that best describes what approach you would use most of the time. If you sometimes use the other approach, put a* **2** *in the other box. If you rarely or never use the other approach, leave it blank.*

Pro-active and Structured I tend to seek out to meet or talk with everyone. I tend to bring up subjects even when not brought up by the patient (or carer), or I work through a list of potential problem areas.	
Reactive and Flexible I respond to patients needs and adjust my workload or discussions around the problems that they bring up. The amount of time or follow-up will depend on need.	

My interaction and discussions with patients are:

We would like you to put a **1** *in the box that best describes what approach you would use most of the time. If you sometimes use the other approach, put a* **2** *in the other box. If you rarely or never use the other approach, leave it blank.*

Focussed I am quite specific about which areas we talk about (e.g. my role is to talk about risk factors or to talk about psychological problems etc.)	
Comprehensive I cover a broad range of subjects and provide broad support for different aspects of living with stroke.	

My involvement with patients is by:

Tick ***ALL that*** *apply to your work*

Visit to their home	
Phone	
They come to me at hospital	
Other (please specify)	

Colleagues:

Tick ***ONLY ONE*** *description that sounds closest to your work*

I work in a community support team (such as community rehabilitation or discharge support)	
I am a member of the hospital stroke team, but not a member of a community team as above.	
Other	

I deal with:

Tick ***ALL*** *that apply to your work*

Informal Carers	
Patients	
Families	
Other (specify)	

Does it work?

Tick ***ONLY ONE***

I believe my work has a positive impact on all the patients/carers I see	
I am uncertain if all patients/carers benefit from my work but think that most will	
I am convinced that some patients benefit from my work.	
I am not sure if my role is beneficial	

Questions for everyone

I think the following are the most important aspects of my work:

I believe I am most likely to have a beneficial impact on the following people:

The commonest three problems I deal with are:

1_____

2_____

3_____

Comments on your role:

Other Comments:

If you are willing to be interviewed on your role in stroke care, please contact Louise Craig by phone (0141 330 5645) or email (lec5t@clinmed.gla.ac.uk) of by providing contact details below.

Name: Contact details:

Thank you for your time in completing this questionnaire.

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