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Information provision for stroke survivors and their carers (Review)

Crocker TF, Brown L, Lam N, Wray F, Knapp P, Forster A

Crocker TF, Brown L, Lam N, Wray F, Knapp P, Forster A.
Information provision for stroke survivors and their carers.
Cochrane Database of Systematic Reviews 2021, Issue 11. Art. No.: CD001919.
DOI: 10.1002/14651858.CD001919.pub4.

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TABLE OF CONTENTS

[Intervention Review]

Information provision for stroke survivors and their carers

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Editorial group: Cochrane Stroke Group.
Publication status and date: New search for studies and content updated (conclusions changed), published in Issue 11, 2021.

Citation: Crocker TF, Brown L, Lam N, Wray F, Knapp P, Forster A. Information provision for stroke survivors and their carers. *Cochrane Database of Systematic Reviews* 2021, Issue 11. Art. No.: CD001919. DOI: 10.1002/14651858.CD001919.pub4.

ABSTRACT

Background

A stroke is a sudden loss of brain function caused by lack of blood supply. Stroke can lead to death or physical and cognitive impairment and can have long lasting psychological and social implications. Research shows that stroke survivors and their families are dissatisfied with the information provided and have a poor understanding of stroke and associated issues.

Objectives

The primary objective is to assess the effects of active or passive information provision for stroke survivors (people with a clinical diagnosis of stroke or transient ischaemic attack (TIA)) or their identified carers. The primary outcomes are knowledge about stroke and stroke services, and anxiety.

Search methods

We updated our searches of the Cochrane Stroke Group Specialised Register on 28 September 2020 and for the following databases to May/June 2019: the Cochrane Central Register of Controlled Trials (CENTRAL; 2019, Issue 5) and the Cochrane Database of Systematic Reviews (CDSR; 2019, Issue 5) in the Cochrane Library (searched 31 May 2019), MEDLINE Ovid (searched 2005 to May week 4, 2019), Embase Ovid (searched 2005 to 29 May 2019), CINAHL EBSCO (searched 2005 to 6 June 2019), and five others. We searched seven study registers and checked reference lists of reviews.

Selection criteria

Randomised trials involving stroke survivors, their identified carers or both, where an information intervention was compared with standard care, or where information and another therapy were compared with the other therapy alone, or where the comparison was between active and passive information provision without other differences in treatment.

Data collection and analysis

Two review authors independently assessed trial eligibility and risk of bias, and extracted data. We categorised interventions as either active information provision or passive information provision: active information provision included active participation with subsequent opportunities for clarification and reinforcement; passive information provision provided no systematic follow-up or reinforcement procedure. We stratified analyses by this categorisation. We used GRADE methods to assess the overall certainty of the evidence.

Main results

We have added 12 new studies in this update. This review now includes 33 studies involving 5255 stroke-survivor and 3134 carer participants. Twenty-two trials evaluated active information provision interventions and 11 trials evaluated passive information provision interventions. Most trials were at high risk of bias due to lack of blinding of participants, personnel, and outcome assessors where outcomes

were self-reported. Fewer than half of studies were at low risk of bias regarding random sequence generation, concealment of allocation, incomplete outcome data or selective reporting. The following estimates have low certainty, based on the quality of evidence, unless stated otherwise.

Accounting for certainty and size of effect, analyses suggested that for stroke survivors, active information provision may improve stroke-related knowledge (standardised mean difference (SMD) 0.41, 95% confidence interval (CI) 0.17 to 0.65; 3 studies, 275 participants), may reduce cases of anxiety and depression slightly (anxiety risk ratio (RR) 0.85, 95% CI 0.68 to 1.06; 5 studies, 1132 participants; depression RR 0.83, 95% CI 0.68 to 1.01; 6 studies, 1315 participants), may reduce Hospital Anxiety and Depression Scale (HADS) anxiety score slightly, (mean difference (MD) -0.73, 95% CI -1.10 to -0.36; 6 studies, 1171 participants), probably reduces HADS depression score slightly (MD (rescaled from SMD) -0.8, 95% CI -1.27 to -0.34; 8 studies, 1405 participants; moderate-certainty evidence), and may improve each domain of the World Health Organization Quality of Life assessment short-form (WHOQOL-BREF) (physical, MD 11.5, 95% CI 7.81 to 15.27; psychological, MD 11.8, 95% CI 7.29 to 16.29; social, MD 5.8, 95% CI 0.84 to 10.84; environment, MD 7.0, 95% CI 3.00 to 10.94; 1 study, 60 participants). No studies evaluated positive mental well-being.

For carers, active information provision may reduce HADS anxiety and depression scores slightly (MD for anxiety -0.40, 95% CI -1.51 to 0.70; 3 studies, 921 participants; MD for depression -0.30, 95% CI -1.53 to 0.92; 3 studies, 924 participants), may result in little to no difference in positive mental well-being assessed with Bradley's well-being questionnaire (MD -0.18, 95% CI -1.34 to 0.98; 1 study, 91 participants) and may result in little to no difference in quality of life assessed with a 0 to 100 visual analogue scale (MD 1.22, 95% CI -7.65 to 10.09; 1 study, 91 participants). The evidence is very uncertain (very low certainty) for the effects of active information provision on carers' stroke-related knowledge, and cases of anxiety and depression.

For stroke survivors, passive information provision may slightly increase HADS anxiety and depression scores (MD for anxiety 0.67, 95% CI -0.37 to 1.71; MD for depression 0.39, 95% CI -0.61 to 1.38; 3 studies, 227 participants) and the evidence is very uncertain for the effects on stroke-related knowledge, quality of life, and cases of anxiety and depression. For carers, the evidence is very uncertain for the effects of passive information provision on stroke-related knowledge, and HADS anxiety and depression scores. No studies of passive information provision measured carer quality of life, or stroke-survivor or carer positive mental well-being.

Authors' conclusions

Active information provision may improve stroke-survivor knowledge and quality of life, and may reduce anxiety and depression. However, the reductions in anxiety and depression scores were small and may not be important. In contrast, providing information passively may slightly worsen stroke-survivor anxiety and depression scores, although again the importance of this is unclear. Evidence relating to carers and to other outcomes of passive information provision is generally very uncertain. Although the best way to provide information is still unclear, the evidence is better for strategies that actively involve stroke survivors and carers and include planned follow-up for clarification and reinforcement.

PLAIN LANGUAGE SUMMARY

Providing information to stroke survivors and their carers

What was the review about?

We reviewed the evidence about the effects of providing information to people after stroke. These were people who have had a stroke or mini-stroke (transient ischaemic attack (TIA)), or their carers, such as friends and family. We mainly looked at the effect on their knowledge of stroke and stroke care, their mood and their quality of life.

Background

A stroke is a sudden loss of brain function caused by lack of blood supply. Stroke can lead to death or physical and mental problems. It can have a major effect on the person's life and those around them.

Stroke survivors and their carers often say they have not been given enough facts about stroke. They often do not feel ready for life after leaving hospital. Some people say they were overwhelmed. The information was not explained to them or was given at the wrong time. Information may help people to manage their health better and adjust to life after stroke.

We wanted to know whether it was better or worse to be given extra information. We also wanted to know if the way information was provided matters.

Study characteristics

We found 33 studies involving 5255 stroke survivors and 3134 carers. In 11 studies, information was provided passively as a leaflet, DVD, medical history or personalised booklet. In 22 studies, information was provided actively, often combining ways such as talks, demonstrations, meetings and phone calls.

Key results

For stroke survivors, providing information actively may improve knowledge of stroke and stroke care. It may slightly reduce anxiety and depression, but this may not be noticeable. It may also improve quality of life. The evidence was less clear for providing information passively. However, it may slightly worsen anxiety and depression. Again, this may not be by a noticeable amount. For carers the evidence is very uncertain or absent.

Confidence in the evidence

We generally had low or very low confidence in the evidence. We were moderately confident that the depressive symptoms of stroke survivors were slightly reduced by active information provision. Our confidence was often limited by the following factors.

- The people in the studies knew if they were giving or receiving more information than usual. This may have affected what they did or how they said they felt.
- Too few people had been studied.
- The results were not precise, so they could show either benefit or harm.
- The results of individual studies did not agree with each other enough.

How up-to-date is this review?

We searched for studies in May and June 2019 and searched one source again in September 2020. The studies were published between 1987 and 2019.

Summary of findings 1. Active information provision compared to control for stroke survivors

Active information provision compared to control for stroke survivors

Patient or population: stroke survivors
Setting: all settings
Intervention: active information provision
Comparison: control

Outcomes	Anticipated absolute effects* (95% CI)		Relative effect (95% CI)	No of participants (studies)	Certainty of the evidence (GRADE)	Comments
	Without active information provision	With active information provision				
Knowledge of stroke and stroke services		SMD 0.41 higher (0.17 higher to 0.65 higher)	-	275 (3 RCTs)	⊕⊕⊖⊖ LOW[a,b]	Active information provision may slightly or moderately increase stroke-survivor knowledge of stroke and stroke services.
Anxiety (cases)	205 per 1000	175 per 1000 (140 to 218)	RR 0.85 (0.68 to 1.06)	1132 (5 RCTs)	⊕⊕⊖⊖ LOW[a,c]	Active information provision may slightly reduce cases of stroke-survivor anxiety.
Anxiety symptoms (HADS-A score) assessed with: anxiety subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21	The mean anxiety score was 6.52[d]	MD 0.73 lower (1.1 lower to 0.36 lower)	-	1171 (6 RCTs)	⊕⊕⊖⊖ LOW[a,e]	Active information provision may slightly reduce symptoms of anxiety for stroke survivors.[f]
Depression (cases)	241 per 1000	200 per 1000 (164 to 243)	RR 0.83 (0.68 to 1.01)	1315 (6 RCTs)	⊕⊕⊖⊖ LOW[a,c]	Active information provision may slightly reduce cases of stroke-survivor depression.
Depressive symptoms (HADS-D score) assessed with: depression subscale of the Hospital Anxiety and Depression Scale	The mean depression score was 6.58[d]	MD 0.8 lower (1.27 lower to 0.34 lower) Rescaled from: SMD 0.19 lower	-	1405 (8 RCTs)	⊕⊕⊕⊖ MODERATE[a]	Active information provision probably slightly reduces symptoms of depression for stroke survivors.[f]

Scale from: 0 to 21		(0.3 lower to 0.08 lower)[g]				
Positive mental well-being	-	-	-	-	-	We did not find any studies that looked at the effect of active information provision on stroke-survivor positive mental well-being.
Quality of life (QOL) assessed with: WHO-QOL-BREF (World Health Organization Quality of Life assessment short-form). Each domain from: 0 to 100	Domain mean differences were as follows: Physical, MD 11.5 higher (7.81 higher to 15.27 higher); Psychological, MD 11.8 higher (7.29 higher to 16.29 higher); Social, MD 5.8 higher (0.84 higher to 10.84 higher); Environment, MD 7.0 higher (3.00 higher to 10.94 higher).	-	60 (1 RCT)	⊕⊕⊖⊖ LOW[b,h]	Active information provision may improve physical, psychological, social and environment domains of stroke-survivor QOL, but we are uncertain as this is based on one small study with substantial risk of bias.

*__The risk in the intervention group__ (and its 95% confidence interval) is based on the assumed risk in the comparison group and the relative effect of the intervention (and its 95% CI).

CI: confidence interval; **SMD:** standardised mean difference; **RCT:** randomised controlled trial; **RR:** risk ratio; **MD:** mean difference.

GRADE Working Group grades of evidence
High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.
Moderate certainty: we are moderately confident in the effect estimate. The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low certainty: our confidence in the effect estimate is limited. The true effect may be substantially different from the estimate of the effect.
Very low certainty: we have very little confidence in the effect estimate. The true effect is likely to be substantially different from the estimate of effect.

[a]Potential limitations, because of lack of blinding in all studies (performance bias and detection bias), which are likely to lower confidence in the estimate of effect. Certainty downgraded by one level for serious risk of bias.
[b]Total number of participants is unlikely to meet the optimal information size. Confidence interval does not include no effect. Certainty downgraded by one level for serious imprecision.
[c]Total events and total participants are unlikely to meet the optimal information size. Confidence interval includes significant benefit (25% risk reduction) and no effect. Certainty downgraded by one level for imprecision as problems, though serious, are marginal.
[d]Pooled between stroke survivors in control groups of all trials (i.e. active information vs control and passive information vs control) reporting the HADS.
[e]All CIs overlap but Kalra 2004 and Forster 2013 only just overlap and these studies contribute most to the meta-analysis, with Kalra 2004 estimating greatest effect of all studies. Point estimates of the studies favour both intervention and control (Eames 2013 and Frank 2000). I^2 statistic suggests moderate heterogeneity (49%). Certainty downgraded by one level for serious inconsistency.

[f]Judging the clinical meaningfulness of the estimated effect was not straightforward, as there are no internationally agreed standards. The estimate for the average participant is less than a single point change, which would be a small change in one symptom. However, this may translate into a change that is meaningful for some participants in the population who may have greater than average benefit.
[g]Rescaled using the pooled SD of control groups at final follow-up of all trials reporting the HADS where available.
[h]Single study with largely unclear risk of bias. Certainty downgraded by one level for serious risk of bias.

Summary of findings 2. Active information provision compared to control for stroke carers

Active information provision compared to control for stroke carers

Patient or population: stroke carers
Setting: all settings
Intervention: active information provision
Comparison: control

Outcomes	Anticipated absolute effects* (95% CI)		Relative effect (95% CI)	No of participants (studies)	Certainty of the evidence (GRADE)	Comments
	Without active information provision	With active information provision				
Knowledge of stroke and stroke services	-	SMD 0.68 higher (0.03 lower to 1.39 higher)	-	356 (4 RCTs)	⊕⊖⊖⊖ VERY LOW[a,b,c]	Active information provision may increase/have little to no effect on carer knowledge of stroke and stroke services but the evidence is very uncertain.
Anxiety (cases)	176 per 1000	169 per 1000 (125 to 225)	RR 0.96 (0.71 to 1.28)	790 (3 RCTs)	⊕⊖⊖⊖ VERY LOW[a,d]	We are uncertain whether active information provision reduces or increases cases of carer anxiety.
Anxiety symptoms (HADS-A score) assessed with: anxiety subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21	The mean anxiety score was 6.26[e]	MD 0.4 lower (1.51 lower to 0.7 higher)	-	921 (3 RCTs)	⊕⊕⊖⊖ LOW[a,f]	Active information provision may slightly reduce symptoms of anxiety for carers.[g]
Depression (cases)	87 per 1000	85 per 1000 (56 to 130)	RR 0.98 (0.64 to 1.50)	843 (3 RCTs)	⊕⊖⊖⊖ VERY LOW[a,d]	We are uncertain whether active information provision reduces or increases cases of carer depression.

Depressive symptoms (HADS-D score) assessed with: depression subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21	The mean depression score was 4.59[e]	MD 0.3 lower (1.53 lower to 0.92 higher)	-	924 (3 RCTs)	⊕⊕⊖⊖ LOW[a,h]	Active information provision may slightly reduce symptoms of depression for carers.[g]
Positive mental well-being assessed with: positive well-being subscale of Bradley's well-being questionnaire Scale from: 0 to 12	The mean positive mental well-being score was 8.53	MD 0.18 lower (1.34 lower to 0.98 higher)	-	91 (1 RCT)	⊕⊕⊖⊖ LOW[a,i]	Active information provision may have little to no effect on carer positive mental well-being.
Quality of life (QOL) assessed with: visual analogue scale Scale from: 0 to 100	The mean quality of life score was 66.78	MD 1.22 higher (7.65 lower to 10.09 higher)	-	91 (1 RCT)	⊕⊕⊖⊖ LOW[a,i]	Active information provision may have little to no effect on carer quality of life.

*__The risk in the intervention group__ (and its 95% confidence interval) is based on the assumed risk in the comparison group and the relative effect of the intervention (and its 95% CI).

CI: confidence interval; **SMD:** standardised mean difference; **RCT:** randomised controlled trial; **RR:** risk ratio; **MD:** mean difference.

GRADE Working Group grades of evidence
High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.
Moderate certainty: we are moderately confident in the effect estimate. The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low certainty: our confidence in the effect estimate is limited. The true effect may be substantially different from the estimate of the effect.
Very low certainty: we have very little confidence in the effect estimate. The true effect is likely to be substantially different from the estimate of effect.

[a]Potential limitations, because of lack of blinding in all studies (performance bias and detection bias), which are likely to lower confidence in the estimate of effect. Certainty downgraded by one level for serious risk of bias.
[b]Confidence interval of Evans 1988, which contributes 25%, does not overlap with others. I^2 statistic suggests substantial heterogeneity. Certainty downgraded by one level for serious inconsistency.
[c]Confidence interval of pooled effect includes no effect and substantial benefit. Total number of participants may meet the optimal information size. Certainty downgraded by one level for serious imprecision.
[d]Confidence interval of pooled estimate includes substantial benefit and substantial harm (relative risk reduction and relative risk increase greater than 25%). Total numbers of events and participants are unlikely to meet the optimal information size. Certainty downgraded by two levels for very serious imprecision.
[e]Pooled between carers in control groups of all trials (i.e. active information vs control and passive information vs control) reporting the HADS.
[f]Point estimates favour intervention and control, but confidence intervals overlap. I^2 statistic suggests substantial heterogeneity. Certainty downgraded by one level for serious inconsistency.

[g]Judging the clinical meaningfulness of the estimated effect was not straightforward, as there are no internationally agreed standards. The estimate for the average participant is less than a single point change, which would be a small change in one symptom. However, this may translate into a change that is meaningful for some participants in the population who may have greater than average benefit.
[h]Quite wide variance in point estimates, favouring intervention and control, with CI of Kalra 2004 not overlapping the other two studies. I^2 statistic suggests substantial heterogeneity. Certainty downgraded by one level for serious inconsistency.
[i]Total participant number is unlikely to meet the optimal information size. Confidence interval does not include substantial harm or substantial benefit. Certainty downgraded by one level for serious imprecision.

Summary of findings 3. Passive information provision compared to control for stroke survivors

Passive information provision compared to control for stroke survivors

Patient or population: stroke survivors
Setting: all settings
Intervention: passive information provision
Comparison: control

Outcomes	Anticipated absolute effects* (95% CI)		Relative effect (95% CI)	No of participants (studies)	Certainty of the evidence (GRADE)	Comments
	Without passive information provision	With passive information provision				
Knowledge of stroke and stroke services	-	SMD 0.23 higher (0.23 lower to 0.69 higher)	-	270 (3 RCTs)	⊕⊖⊖⊖ VERY LOW[a,b,c]	Passive information provision may increase/have little to no effect on stroke-survivor knowledge of stroke and stroke services but the evidence is very uncertain.
Anxiety (cases)	119 per 1000	184 per 1000 (98 to 343)	RR 1.54 (0.82 to 2.88)	227 (3 RCTs)	⊕⊖⊖⊖ VERY LOW[a,d]	Passive information provision may increase/have little to no effect on cases of stroke-survivor anxiety but the evidence is very uncertain.
Anxiety symptoms (HADS-A) assessed with: anxiety subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21	The mean anxiety score was 6.52[e]	MD 0.67 higher (0.37 lower to 1.71 higher)	-	227 (3 RCTs)	⊕⊕⊖⊖ LOW[a,f]	Passive information provision may slightly increase symptoms of anxiety for stroke survivors.[g]

Depression (cases)	256 per 1000	286 per 1000 (215 to 384)	RR 1.12 (0.84 to 1.50)	361 (5 RCTs)	⊕⊖⊖⊖ VERY LOW[d,h]	Passive information provision may increase/have little to no effect on cases of stroke-survivor depression but the evidence is very uncertain.
Depressive symptoms (HADS-D) assessed with: depression subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21	The mean depression score was 6.58[e]	MD 0.39 higher (0.61 lower to 1.38 higher)	-	227 (3 RCTs)	⊕⊕⊖⊖ LOW[a,f]	Passive information provision may slightly increase symptoms of depression for stroke survivors.[g]
Positive mental well-being	-	-	-	-	-	No studies were found that looked at the effect of passive information provision on stroke-survivor positive mental well-being.
Quality of life (COOP: QOL) assessed with: quality of life chart of the Dartmouth Primary Care Cooperative Functional Assessment Charts Scale from: 1 to 5, lower scores are better	The mean quality of life score was 2.20	MD 0.04 higher (0.45 lower to 0.53 higher)	-	198 (2 RCTs)	⊕⊖⊖⊖ VERY LOW[b,i,j]	We are uncertain whether passive information provision reduces or increases stroke-survivor quality of life.

*__The risk in the intervention group__ (and its 95% confidence interval) is based on the assumed risk in the comparison group and the relative effect of the intervention (and its 95% CI).

CI: confidence interval; **SMD:** standardised mean difference; **RCT:** randomised controlled trial; **RR:** risk ratio; **MD:** mean difference.

GRADE Working Group grades of evidence
High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.
Moderate certainty: we are moderately confident in the effect estimate. The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low certainty: our confidence in the effect estimate is limited. The true effect may be substantially different from the estimate of the effect.
Very low certainty: we have very little confidence in the effect estimate. The true effect is likely to be substantially different from the estimate of effect.

[a]Potential limitations, because of lack of blinding in all studies (performance bias and detection bias), as well as concerns about missing data, which are likely to lower confidence in the estimate of effect. Certainty downgraded by one level for serious risk of bias.
[b]Confidence intervals overlap but point estimates are divergent. I^2 statistic suggests substantial heterogeneity. Certainty downgraded by one level for serious inconsistency.

[c]Confidence interval of pooled estimate includes no effect and appreciable benefit (effect size ≥ 0.5). Total participants may not meet the optimal information size. Certainty downgraded by one level for serious imprecision.
[d]Confidence interval of pooled estimate includes no effect and substantial harm, and almost includes substantial benefit (relative risk reduction and relative risk increase greater than 25%). Total number of events and participants are unlikely to meet the optimal information size. Certainty downgraded by two levels for very serious imprecision.
[e]Pooled between stroke survivors in control groups of all trials (i.e. active information vs control and passive information vs control) reporting the HADS.
[f]Total participants unlikely to meet the optimal information size. Certainty downgraded by one level for serious imprecision.
[g]Judging the clinical meaningfulness of the estimated effect was not straightforward, as there are no internationally agreed standards. The estimate for the average participant is less than a single point change, which would be a small change in one symptom. However, this may translate into a change that is meaningful for some participants in the population who may have greater than average harm.
[h]Lack of blinding in all studies (performance bias and detection bias), as well as substantial missing data (attrition bias) from studies making greatest contributions and concerns about allocation concealment, which are likely to seriously alter the estimate of effect. Certainty downgraded by two levels for very serious risk of bias.
[i]Potential limitations, because of lack of blinding in all studies (performance bias and detection bias), which are likely to lower confidence in the estimate of effect. Certainty downgraded by one level for serious risk of bias.
[j]Confidence interval of pooled estimate includes no effect and substantial harm, and almost includes substantial benefit (effect size ≥ 0.5). Total participants may not meet the optimal information size. Certainty downgraded by one level for serious imprecision.

Summary of findings 4. Passive information provision compared to control for stroke carers

Passive information provision compared to control for stroke carers

Patient or population: stroke carers
Setting: all settings
Intervention: passive information provision
Comparison: control

Outcomes	Anticipated absolute effects* (95% CI)		Relative effect (95% CI)	No of participants (studies)	Certainty of the evidence (GRADE)	Comments
	Without passive information provision	With passive information provision				
Knowledge of stroke and stroke services	-	SMD 0.28 higher (0.42 lower to 0.97 higher)	-	33 (1 RCT)	⊕⊖⊖⊖ VERY LOW[a,b]	Passive information provision may increase/have little to no effect on carer knowledge of stroke and stroke services but the evidence is very uncertain.
Anxiety (cases) - not measured	-	-	-	-	-	We did not find any studies that looked at the effect of passive information provision on cases of carer anxiety.
Anxiety symptoms (HADS-A score)	The mean anxiety score was 6.26[c]	MD 0.3 lower (3.25 lower to 2.65 higher)	-	40 (1 RCT)	⊕⊖⊖⊖ VERY LOW[a,d]	We are uncertain whether passive information provision reduces or increases symptoms of anxiety for carers.

assessed with: anxiety subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21						
Depression (cases) - not measured	-	-	-	-	-	We did not find any studies that looked at the effect of passive information provision on cases of carer depression.
Depressive symptoms (HADS-D score) assessed with: depression subscale of the Hospital Anxiety and Depression Scale Scale from: 0 to 21	The mean depression score was 4.59[c]	MD 0.7 higher (1.93 lower to 3.33 higher)	-	40 (1 RCT)	⊕⊝⊝⊝ VERY LOW[a,e]	We are uncertain whether passive information provision reduces or increases symptoms of depression for carers.
Positive mental well-being	-	-	-	-	-	We did not find any studies that looked at the effect of passive information provision on carer positive mental well-being.
Quality of life - not measured	-	-	-	-	-	We did not find any studies that looked at the effect of passive information provision on carer quality of life.

*__The risk in the intervention group__ (and its 95% confidence interval) is based on the assumed risk in the comparison group and the relative effect of the intervention (and its 95% CI).

CI: confidence interval; **SMD:** standardised mean difference; **RCT:** randomised controlled trial; **RR:** risk ratio; **MD:** mean difference.

GRADE Working Group grades of evidence
High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.
Moderate certainty: we are moderately confident in the effect estimate. The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low certainty: our confidence in the effect estimate is limited. The true effect may be substantially different from the estimate of the effect.
Very low certainty: we have very little confidence in the effect estimate. The true effect is likely to be substantially different from the estimate of effect.

[a]Only one study with substantial risk of bias. Certainty downgraded by one level for risk of bias.
[b]Confidence interval of pooled estimate includes no effect and substantial benefit, and almost includes substantial harm (effect size ± 0.5). Total number of participants are very unlikely to meet the optimal information size. Certainty downgraded by two levels for very serious imprecision.
[c]Pooled between carers in control groups of all trials (i.e. active information vs control and passive information vs control) reporting the HADS.
[d]Confidence interval of pooled estimate includes no effect, substantial benefit, and substantial harm (effect size ± 0.5). Total number of participants are very unlikely to meet the optimal information size. Certainty downgraded by two levels for very serious imprecision.

[e]Confidence interval of pooled estimate includes no effect and substantial harm, and almost includes substantial benefit (effect size ± 0.5). Total number of participants are very unlikely to meet the optimal information size. Certainty downgraded by two levels for very serious imprecision.

Summary of findings 5. Active compared to passive information provision for stroke survivors and their carers

Active compared to passive information provision for stroke survivors and their carers

Patient or population: stroke survivors and their carers
Setting: all settings
Intervention: active information provision
Comparison: passive information provision

Outcomes	Anticipated absolute effects* (95% CI)		Relative effect (95% CI)	No of participants (studies)	Certainty of the evidence (GRADE)	Comments
	With passive information provision	With active information provision				
All outcomes - not measured	-	-	-	-	-	We did not find any studies that compared active to passive information provision.

***The risk in the intervention group** (and its 95% confidence interval) is based on the assumed risk in the comparison group and the relative effect of the intervention (and its 95% CI).

CI: confidence interval

GRADE Working Group grades of evidence
High certainty: we are very confident that the true effect lies close to that of the estimate of the effect.
Moderate certainty: we are moderately confident in the effect estimate. The true effect is likely to be close to the estimate of the effect, but there is a possibility that it is substantially different.
Low certainty: our confidence in the effect estimate is limited. The true effect may be substantially different from the estimate of the effect.
Very low certainty: we have very little confidence in the effect estimate. The true effect is likely to be substantially different from the estimate of effect.

BACKGROUND

Description of the condition

A stroke is a sudden loss of brain function caused by lack of blood supply, defined by the World Health Organization as "rapidly developing clinical signs of focal (or global) disturbance of cerebral function, lasting more than 24 hours or leading to death, with no apparent cause other than vascular origin" (Aho 1980). A transient ischaemic attack (TIA) is a brief reversible episode of focal, non-convulsive ischaemic dysfunction of the brain with a duration of less than 24 hours (Adams 1998). Throughout this review we refer to people who have experienced a stroke or TIA collectively as 'stroke survivors', unless we are only referring to people who have experienced a TIA. Stroke can lead to death or physical and cognitive impairment (McKevitt 2011; Mukherjee 2011); it can also have long-lasting psychological and social implications (Knapp 2000).

Stroke is the third largest cause of loss of years of healthy life worldwide (GBD 2017 DALYs and HALE collaborators 2018; Murray 2012). Despite advances in prevention, 13.7 million people have a first stroke annually worldwide (GBD 2016 stroke collaborators 2019). Approximately five million people are left permanently disabled due to stroke each year, placing a considerable burden on family and community (Feigin 2014). In 2016, there were 80 million survivors of stroke (GBD 2016 stroke collaborators 2019).

Research suggests that survivors' understanding of stroke, its consequences and the support available, remains poor. Many stroke survivors have poor understanding of the risk factors for stroke, their risk of further strokes and the symptoms of stroke (Parappilly 2019; Saengsuwan 2019). This means they are unlikely to reduce their stroke risk or seek emergency care in case of a stroke. Systematic reviews have identified multiple and diverse unmet informational and educational needs reported by stroke survivors and their carers (Camak 2015; Hafsteinsdottir 2011; Luker 2017). In a survey of community dwelling adults who had a stroke between one and five years earlier, over half reported wanting more information about their stroke (McKevitt 2011).

Stroke survivors and carers routinely report dissatisfaction about the volume, content, delivery and timing of information provision, and a 'need' for relevant and usable information (Abrahamson 2019; Pindus 2018). Wilson 1981 reasoned that what is referred to as an information need is a desire to obtain information, because the person believes it can satisfy a human (e.g. physiological, affective, cognitive) need. Because the causes, sequelae and consequences of stroke are complex and highly variable, the specific needs which information may satisfy will be different for each stroke survivor and their carers. Moreover, these needs change over the poststroke trajectory (Abrahamson 2019; Burton 2021).

Description of the intervention

The intervention is the provision of information for stroke survivors or their informal carers, or both, following a stroke or TIA. The provision of appropriate, accurate, timely information and advice about stroke has been recommended as a key component of service provision (Heart and Stroke Foundation of Canada 2016; RCP 2016; Stroke Foundation Australia 2021). Patients should have information and data on all aspects of health care, to empower them to share in decisions about their care and access appropriate services (Department of Health 2010; NHS England 2019). Information should be tailored to an individual's requirements and provided in a variety of formats (Department of Health 2007; Eames 2011), taking into account their stroke-specific impairment and personal situation (RCP 2016). In a UK study, carers of stroke survivors reported that whilst leaflets were available, they were not always appropriate to the situation (Mackenzie 2007). A survey by primary care trusts in England, of the information provided to stroke survivors, reported that the majority provided good information. However, only 40% contained information relevant to local services. Furthermore, the size, content and organisation of the information varied extensively (Care Quality Commission 2011). Information provided verbally by professionals may tend to be overoptimistic to maintain hope and engagement with rehabilitation, and may provide insufficient information to prepare people for living with disability or an impending death (Burton 2021; Kendall 2018).

There is a wide range of nationally and locally produced, electronic and paper-based materials such as fact sheets, leaflets, booklets, web pages, videos and audio recordings available for stroke survivors and carers. The intervention may also be provided through face-to-face communication including family meetings, lectures or teaching sessions. Whilst the content of the intervention may vary, it is likely to contain at least one of the following components: information about the causes and nature of stroke; management and recovery from the effects of stroke; prevention or reducing the risk of future strokes; information on resources or services.

How the intervention might work

If stroke survivors and carers are to be active in their decision making and management of the long-term effects of stroke, appropriate information delivered in a timely and effective format is necessary. Information is considered necessary to recognise and act upon symptoms, manage disease exacerbation, access effective treatments and medicines, and produce better outcomes (Department of Health 2001; Department of Health 2010). Furthermore, inadequate provision of information has implications for compliance with secondary prevention and psycho-social outcomes for stroke survivors and carers (O'Mahony 1997). Evidence from non-stroke populations suggests providing written information improves adherence to hospital after-care regimens (Firth 1991; Gibbs 1989), and may assist with self-care (Coulter 1998), which may indirectly produce beneficial outcomes.

Information provision may occur in a very passive manner, such as leaving leaflets in a communal area or publishing online. In this case, the stroke survivor or carer may have to recognise the information need and seek the information deliberately ('active search'), come across it while seeking other information ('passive search') or incidentally ('passive attention') (Robson 2013). Alternatively, information provision may occur in a very active manner, with the provider communicating with the intended user to establish what information needs they have, adapting the provision to make it relevant and usable, and ensuring the needs have been met.

Provided information may be ignored or assessed, used or dismissed, used later or provided to another person (Robson 2013). Information may be provided to change behaviour (for example

lifestyle modification) or to change the perceived experience of life after stroke. This may be directly through relevant information, or by providing information about further sources of support. Information that is used is likely to operate through a variety of mechanisms, such as changing knowledge, beliefs, attitudes, and generating or moderating risk and reward sentiments. Aphasia, cognitive difficulties and low health literacy are likely to be significant barriers to understanding provided information for many stroke survivors (Easton 2010; Rose 2009).

Because of the variety of mechanisms through which information provision may work, we outline some examples here.

Information about the consequences of stroke may help stroke survivors and carers to cope by enabling them to make comparisons with others and feel comparatively fortunate. It may also enable stroke survivors and carers to recognise 'hidden' consequences of stroke such as fatigue and emotionalism, prompting them to seek support or treatment, or may help them to understand and accept the circumstances of their life after stroke. Information about social security entitlements, employment and disability discrimination legislation and third sector support may help stroke survivors and carers to access finance and thus ameliorate financial concerns, as well as reducing disruption to family life and enabling engagement in meaningful activities.

However, information provision may be ignored or even produce negative consequences. For example, information may overwhelm the recipient if it seems too much to process, particularly in the context of a turbulent life event (Cameron 2013). Alternatively, information about the consequences of stroke or likelihood of recurrence may cause fear or concern, or a sense of comparative misfortune, perhaps leading to a state of anxiety or depression (Visvanathan 2019). Somewhat incongruously, raising a person's sense of threat may be an intermediate outcome that an information provider intends if they wish to change behaviours they consider risky (Deyhoul 2018; Eames 2013). These examples demonstrate that even if intended outcomes such as lifestyle modification are produced, unintended consequences may also occur.

Why it is important to do this review

Information provision is a recommended component of care across the stroke pathway, including in the acute stroke unit, during early supported discharge, during rehabilitation, and in longer-term management and secondary prevention (Intercollegiate Stroke Working Party 2016). Dissatisfaction with, and a lack of, information provision remain routinely reported following stroke (Abrahamson 2019). Due to the potential for unintended consequences and cost implications, it is important that the effects of information provision on a range of outcomes are robustly evaluated. This review has the potential to lead to the development of more effective information provision strategies and to highlight which outcomes might be affected by such interventions.

OBJECTIVES

Primary objective

- To assess the effects of active or passive information provision for stroke survivors or their identified carers. The primary outcomes for both stroke survivors and carers are knowledge about stroke and stroke services, and anxiety.

Secondary objectives

- To assess the effects of active or passive information provision for stroke survivors on the secondary outcomes of depression, psychological distress, positive mental well-being, quality of life, activities of daily living, social activities, perceived health status, satisfaction with information, self-efficacy, locus of control, recurrent stroke and death.
- To present the effects of active or passive information provision for stroke survivors on modification of health-related behaviours.
- To assess the effects of active or passive information provision for stroke carers on the secondary outcomes of depression, psychological distress, positive mental well-being, burden, quality of life, social activities, perceived health status, satisfaction with information, self-efficacy and locus of control.
- To present the effects of active or passive information provision on cost to health and social services.
- To compare the effects of active information provision versus passive information provision for stroke survivors or their identified carers on the outcomes of interest.

METHODS

Criteria for considering studies for this review

Types of studies

We included randomised controlled trials (RCTs) where an information intervention was compared with standard care or where information combined with another therapy was compared with the other therapy alone. We included trials where individuals or clusters (e.g. stroke units) were randomised. We also included cross-over RCTs, limited to the results from the first phase to avoid carry-over effects.

Types of participants

We included studies of people with a clinical diagnosis of stroke or TIA – who we collectively refer to as 'stroke survivors' – their identified carers, or both. Although we refer to 'stroke survivors' for simplicity, if results had only related to people with a TIA we would have made this clear. However, none did. We did not apply any age limit; however this should be considered in future updates.

Types of interventions

The intervention of interest was information provided with the intention of improving the outcome of stroke survivors, their carers or both. We excluded trials in which information provision was only one component of a more complex rehabilitation intervention, for example family support worker trials (Dennis 1997; Ellis 2005; Forster 1996; Lincoln 2003; Mant 2000), which are assessed in a separate Cochrane Review (Ellis 2010), or self-management strategies (Damush 2016; Olaiya 2016), which are assessed in another Cochrane Review (Fryer 2016). Through discussion, we agreed to exclude interventions which involve reminders to perform health behaviours (rather than reminders to engage with information) and interventions which involve monitoring and reporting of factors such as blood glucose or blood pressure.

We allocated interventions to one of two categories: active information provision or passive information provision. We classified an intervention as active if, following the provision

of the information, there was a purposeful attempt to allow the participant to assimilate the information and a subsequent agreed plan for clarification and consolidation or reinforcement. We classified an intervention as passive if the information was provided on a single occasion with no subsequent systematic follow-up or reinforcement procedure. We made this classification to inform future research and help service planners when committing resources.

Types of outcome measures

Information provision is designed to produce a broad range of effects, and not all interventions are intended to affect the same outcomes. We decided that information provision was primarily intended to improve stroke survivors' or carers' knowledge. We also thought that stroke survivors' or carers' anxiety was a domain that may be adversely as well as positively affected. Therefore, we used the following primary and secondary outcome measures to assess the effectiveness of information provision.

Primary outcomes (stroke survivors)

- Knowledge about stroke, stroke services or both (typically assessed with the ordinal score from a multi-item questionnaire; see also 'Outcomes measured' in Included studies).
- Anxiety (e.g. Generalized Anxiety Disorder 7-item scale (GAD-7; Spitzer 2006), Hospital Anxiety and Depression Scale (HADS) anxiety subscale (HADS-A; Zigmond 1983)).

Secondary outcomes (stroke survivors)

- Depression (e.g. Patient Health Questionnaire 9-item depression module (PHQ-9; Kroenke 2001), HADS depression subscale (HADS-D; Zigmond 1983)).
- Positive mental well-being (e.g. Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; Tennant 2007)).
- Quality of life (e.g. Satisfaction with Life Scale (SWLS), World Health Organization Quality of Life assessment short-form (WHOQOL-BREF; Skevington 2004)).
- Satisfaction with information (e.g. Pound Scale (Pound 1994); see also 'Outcomes measured' in Included studies).
- Psychological distress (e.g. General Health Questionnaire-28 (GHQ-28; Goldberg 1979)).
- Self-efficacy (e.g. Stroke Self-Efficacy Questionnaire (Jones 2008)).
- Locus of control (e.g. Recovery Locus of Control Scale (RLOC; Partridge 1989)).
- Modification of health-related behaviours (e.g. Miller's Health Behaviour Scale (Miller 1983)).
- Independence in activities of daily living (ADL) (e.g. Barthel Index (Mahoney 1965)).
- Social activities (e.g. Frenchay Activities Index (FAI; Holbrook 1983)).
- Perceived health status (e.g. Medical Outcomes Study 36-item short-form health survey (SF-36; Ware 1992), Nottingham Health Profile (NHP; Hunt 1980), EuroQol 5 dimensions instrument (EQ-5D; Brooks 1996)).
- Recurrent stroke.
- Death.

Primary outcomes (carers)

- Knowledge about stroke, stroke services or both.
- Anxiety (e.g. GAD-7, HADS-A).

Secondary outcomes (carers)

- Depression (e.g. PHQ-9, HADS-D).
- Positive mental well-being (e.g. WEMWBS).
- Quality of life (e.g. SWLS, WHOQOL-BREF).
- Satisfaction with information (e.g. Pound Scale; Pound 1993).
- Psychological distress (e.g. GHQ-28).
- Burden (e.g. Caregiver Burden Scale (Elmståhl 1996), Caregiver Strain Index (Robinson 1983)).
- Self-efficacy (e.g. Revised Scale for Caregiving Self-Efficacy (Steffen 2002)).
- Locus of control (e.g. RLOC).
- Social activities (e.g. FAI).
- Perceived health status (e.g. SF-36, NHP, EQ-5D).

Resource outcomes

- Cost to health and social services.

Selection of measures

Perceived health status measures are often referred to as health-related quality of life measures, and there are disagreements over such definitions. We categorised measures as health status where they primarily measured overall health or dimensions of health such as functioning, mood, and pain. By contrast, we categorised measures as quality of life where they primarily asked individuals to evaluate how contented they are with life overall or dimensions of their life.

Where a measure such as the HADS provides subscales relating to depression and anxiety, or can be totalled to provide an overall indication of psychological distress, we used the separate depression and anxiety subscales to contribute to meta-analyses and did not incorporate the totalled results in meta-analyses of the psychological distress outcome.

We excluded bespoke metrics without evidence of evaluation of measurement properties, or metrics where significant problems with their use are recognised, such as totalling the subscales of the SF-36 (Anagnostopoulos 2005; Lins 2016). We only included broad measures of each domain. For example, for perceived health status, single whole measures such as EQ-5D utility or NHP total scores, or broad measures such as the Physical and Mental Component Summaries (PCS & MCS) of the Short-Form family would be included, but not all eight scales of the SF-36 (see below). Information provision interventions seek to change a wide variety of health-related behaviours and consequently studies may include measures that target these specific behaviours. We planned to systematically extract and tabulate measures and outcome data relating to health-related behaviours from respective studies. We did not plan any analysis of these data. Similarly, we planned to systematically extract and tabulate resource outcomes but not to analyse these data.

SF-36

The SF-36 includes 36 items, 35 of which form eight scales, from which the summary PCS and MCS can be formed. As described

above, for the SF-36 we used the PCS and MCS as measures of health status. If these were not reported but the General Health scale was, we used this as a measure of health status. Additionally, we used the Mental Health scale as a measure of psychological distress. We treated all versions of the SF-36 as equivalent.

Dartmouth Primary Care Cooperative (COOP) charts

The Dartmouth Primary Care Cooperative (COOP) charts measure health status, using single items per dimension with no total score (Nelson 1990). We treated the quality of life item as a measure of quality of life, the overall health item as a measure of health status, and the feelings item as a measure of psychological distress. We did not incorporate the daily activities item as a measure of independence in ADL as we judged it a measure of disability.

Stroke Impact Scale

The Stroke Impact Scale measures stroke-specific health status in nine scales, four of which can be combined in a composite physical score (Duncan 1999). We used this composite physical score and the percentage recovery from stroke from a visual analogue scale as measures of health status. Additionally, we used the emotions subscale as a measure of psychological distress.

Search methods for identification of studies

We aimed to identify all relevant RCTs regardless of language or publication status (published, unpublished, in press, or in progress).

Electronic searches

For this update, S Dalton, University of Leeds Information Specialist, revised all of our search strategies in line with current Cochrane Stroke Group (CSG) practices and in consultation with the authors. They were peer reviewed by J Cheyne, CSG Information Specialist. We updated our search terms by adding new terms to increase sensitivity following testing and on the advice of the CSG Information Specialist. Because we added new terms, we extended our searches back to 2005. Details of the previous search strategies are available in Forster 2012 (last searched in June 2012).

D Andre, University of Leeds Information Specialist, S Dalton and J Cheyne searched the following databases using the updated strategies. Searches were conducted up to 6 June 2019 except for the Cochrane Stroke Group Specialised Register, which was searched on 28 September 2020:

- Cochrane Stroke Group Specialised Register (searched 28 September 2020);
- Cochrane Central Register of Controlled Trials (CENTRAL) and the Cochrane Database of Systematic Reviews (CDSR; 2019, Issue 5) in the Cochrane Library (searched 31 May 2019; Appendix 1);
- MEDLINE Ovid (2005 to May week 4 2019; Appendix 2);
- Embase and Embase Classic Ovid (2005 to 29 May 2019; Appendix 3);
- CINAHL EBSCO (Cumulative Index to Nursing and Allied Health Literature; 2005 to 6 June 2019; Appendix 4);
- PsycINFO Ovid (2005 to May week 3 2019; Appendix 5);
- Web of Science SCI-E and SSCI Clarivate (Science Citation Index Expanded and Social Sciences Citation Index; 2005 to 6 June 2019; Appendix 6);
- ASSIA Proquest (Applied Social Sciences Index and Abstracts; 2012 to 31 May 2019; Appendix 7);
- Dissertations & Theses A&I Proquest (2012 to 31 May 2019; Appendix 8).

We used EndNote 2019 to deduplicate search results between databases and against the results of our previous searches.

Searching other resources

To identify further trials and reports, we searched the following ongoing trials and research registers (Appendix 9):

- ISRCTN Registry (www.isrctn.com; searched 5 June 2019);
- US National Institutes of Health RePORT Expenditures and Results system (RePORTER; projectreporter.nih.gov; searched 5 June 2019);
- Internet Stroke Center Stroke Trials Registry (www.strokecenter.org/trials/; searched 5 June 2019);
- National Rehabilitation Information Center (NARIC) REHABDATA database (naric.com/?q=en/SearchRehabdata; 2012 to 5 June 2019);
- NARIC NIDILRR Program Directory database (National Institute on Disability, Independent Living, and Rehabilitation Research; naric.com/?q=en/ProgramDatabase; 2012 to 5 June 2019);
- World Health Organization International Clinical Trials Registry Platform (WHO ICTRP; trialsearch.who.int; searched 5 June 2019); and
- US National Library of Medicine ClinicalTrials.Gov study registry (www.clinicaltrials.gov; searched 5 June 2019).

We searched included studies' lists of relevant reviews. We searched for reports about studies we had previously identified as ongoing or awaiting classification and reassessed their status. Because of the comprehensive nature of the electronic search and earlier searches, we did not contact authors of previous publications on information provision for this update. We did not perform a separate search for adverse effects of information provision. We considered adverse effects described in included studies only. We shall not update our searches of the Internet Stroke Center Stroke Trials Registry in the future as this resource is no longer active.

Data collection and analysis

Selection of studies

Two review authors independently assessed the titles and abstracts of records from the electronic searches and excluded obviously irrelevant studies. We obtained the full text of the remaining studies and at least two review authors assessed these against the review inclusion criteria to determine their eligibility. The review authors resolved disagreements by discussion with other members of the review team. Studies that were excluded following discussion at this stage were listed in the Characteristics of excluded studies table along with the reason for exclusion.

Data extraction and management

At least two review authors scrutinised all the eligible trials to grade methodological quality, participant selection, the intervention, outcome measures used, and length of follow-up. Two review authors extracted data independently using piloted data extraction

forms, and compared agreement. They resolved disagreement through group consensus. Where necessary, we contacted study authors for additional information and data.

Assessment of risk of bias in included studies

We assessed the methodological quality of selected studies using the tool for assessing risk of bias as described in section 8 of the *Cochrane Handbook for Systematic Reviews of Interventions* (Higgins 2011). We scored each of the following domains as 'high risk of bias', 'low risk of bias', or 'unclear risk of bias' and reported them in the risk of bias tables.

- Random sequence generation (selection bias).
- Allocation concealment (selection bias).
- Blinding of participants and personnel (performance bias).
- Blinding of outcome assessment (detection bias).
- Incomplete outcome data (attrition bias).
- Selective reporting (reporting bias).
- Other possible bias.

We produced a risk of bias summary figure to illustrate our judgement for each potential bias in each included study.

Measures of treatment effect

We compared studies based on end-of-study results. For continuous outcomes we used the mean difference (MD) where the analysis included one outcome measure or the standardised mean difference (SMD) where studies presented different measures. We treated ordinal values as if they were continuous variables. We combined dichotomous data using the risk ratio (RR), or the Peto odds ratio if there was a very low event rate in at least one of the studies.

Transformation of median data to mean data

Where studies reported medians and interquartile ranges we used the quantile method of Wan 2014 to derive means and standard deviations.

Transformation of reported data to standardised mean difference

For individually randomised trials we calculated Hedges' g using RevMan. For cluster-randomised trials that reported the standard error on the difference between means we used the equations of White 2005 to calculate the standard deviation, and used this in the equations of Walwyn 2017 to calculate the unbiased SMD estimator.

Satisfaction with information

For satisfaction-with-information outcomes we used the risk of the non-event, i.e. the risk of non-satisfaction, as this is the less likely state and more intuitive as an expression of risk.

Anxiety, depression and psychological distress

For the outcomes of anxiety, depression and psychological distress, we used dichotomous and continuous data. We dichotomised the Center for Epidemiological Studies Depression scale (CES-D), HADS subscale scores, the Geriatric Depression Scale (GDS) scores and GHQ scores using the recommended cut-off points (Table 1). For continuous data in these domains, lower scores are better, e.g. reduced anxiety, depression or distress. Dichotomised data may provide more clinically meaningful results as it relates to 'cases' of depression, anxiety and distress. However, it has been argued that collapsing ordinal stroke trial data in this way can result in a loss of discrimination between groups such that significant treatment effects are missed (OAST 2007).

Unit of analysis issues

Where cluster-randomised studies presented an estimate of effect that properly accounted for the cluster design and was suitable for inclusion in our analysis, we used this estimate. Where this was not the case, we assumed that the intracluster correlation coefficient (ICC) was the same as for other studies included in the review for that outcome. We calculated an average ICC for the outcome and corrected the values for each unadjusted study by the design effect (see Higgins 2019 and 'Transformation of reported data to standardised mean difference' above). Where the ICC for an outcome was not available from the other included studies we attempted to find an appropriate estimate from external databases (e.g. Elley 2005; Health Services Research Unit 2004; Ukoumunne 1999). Additionally, where both an estimate of effect that properly accounted for the cluster design was available but not in our preferred form for analysis (e.g. odds ratio) as well as unadjusted results for our preferred form of analysis (e.g. RR), we corrected the unadjusted results as above and used these in our preferred analysis (RR in our example), and conducted a sensitivity analysis using the estimate of effect that properly accounted for the cluster design (OR in our example). Where no appropriate ICC estimate was available, we presented unadjusted results.

In this review, Forster 2013 was the only study to report ICC estimates or cluster-adjusted results. We did not identify appropriate ICC estimates for other domains. We reported the ICCs used in this review in Table 2. We have only reported in Effects of interventions when the results of a cluster-randomised study were unadjusted or we adjusted them.

Dealing with missing data

If data were missing, we performed an available case analysis. The proportion of participants in each study arm who did not provide data is shown in the Data and analyses section.

Assessment of heterogeneity

We tested for the presence of heterogeneity between the trials using the I^2 statistic. We planned to investigate heterogeneity using the approach detailed below in Subgroup analysis and investigation of heterogeneity.

Assessment of reporting biases

It was not possible to detect reporting bias by the method of assessment of funnel plots as there were insufficient studies included in the meta-analyses.

Data synthesis

We grouped all results regarding effects of the interventions by comparison (active information provision versus control, passive information provision versus control, active versus passive information provision). We further grouped outcomes by effects on stroke survivors, effects on carers and effects on resources, as specified in Types of outcome measures. We undertook meta-analyses where feasible and appropriate using RevMan Web

(Review Manager Web 2021). For other outcomes, we have presented a narrative summary. A summary of the data is provided in the Data and analyses section. Previously, we did not conduct carer anxiety or depression meta-analyses. We have included them in this update for consistency with the stroke-survivor meta-analyses. These analyses primarily used the subscales of the HADS; therefore, where we had separate data, we excluded total HADS scores from the psychological distress meta-analysis, in a change from previous versions of this review.

Subgroup analysis and investigation of heterogeneity

For all outcomes, we used a fixed-effect model if we detected no substantial heterogeneity (I^2 < 50%). Where there was substantial heterogeneity (I^2 ≥ 50%) we presented the main meta-analysis using a random-effects model and reported the fixed-effect model as a sensitivity analysis. Where there was substantial heterogeneity and 10 or more studies contributed to the meta-analysis, we planned to subgroup the analysis according to time elapsed since stroke in the studies (acute (less than six weeks), subacute (six weeks to eight months) and chronic (more than eight months)). Often, this precise information was not available and so we made judgements based on factors such as when stroke survivors were discharged. If this process led to each subgroup having no substantial heterogeneity (I^2 < 50%), we planned to present subgrouped data using a fixed-effect model. If this process failed to resolve heterogeneity (I^2 ≥ 50% in at least one subgroup), we planned to not subgroup the studies. In practice, none of our analyses had sufficient studies to conduct subgroup analyses.

Sensitivity analysis

We conducted sensitivity analyses when results were from cluster-randomised trials, excluding these trials (see also, Unit of analysis issues). When we were concerned about the accuracy of reported data (e.g. uncertainty over which measure of variance was reported), we conducted sensitivity analyses excluding the trial and treating the data differently (e.g. employing different measures of variance), explaining this treatment in the results section. When we conducted SMD meta-analyses we conducted a sensitivity analysis using a mean difference meta-analysis if the majority of participants reported data on a common scale.

Summary of findings and assessment of the certainty of the evidence

Two authors used the GRADE approach to assess the degree of confidence in the estimates of effect for stroke survivors and carers separately for the following outcomes (Guyatt 2008).

- Knowledge of stroke and stroke services
- Anxiety
  - Anxiety (cases)
  - Anxiety symptoms (continuous)
- Depression
  - depression (cases)
  - depressive symptoms (continuous)
- Positive mental well-being
- Quality of life

Many of the included domains were measured with tools with differing constructs that are inappropriate to analyse together. This means we could not include all results in a single meta-analysis and they may be presented in our results as multiple meta-analyses, single study results or a combination of both. In order to facilitate construction of the summary of findings table, we selected the analysis with the largest sample size for each outcome listed above. Where this was a single study that did not present an estimate of effect we calculated one using RevMan Web (Review Manager Web 2021), but have presented these data in tables rather than as forest plots.

For each effect measure, the GRADE approach for randomised controlled trials considers how serious were the risk of bias, inconsistency of results, indirectness of evidence and imprecision of results, as well as the probability of publication bias, producing an overall rating of high, moderate, low or very low certainty of evidence. We used GRADEpro GDT 2021 (GRADEprofiler Guideline Development Tool) to construct summary of findings tables for our prespecified comparisons. We used wordings to summarise our findings based on Lasserson 2020 and Ryan 2016.

For effect sizes expressed as SMD we took 0.01 to be a very small effect, 0.2 to be a small effect, 0.5 to be a moderate effect, 0.8 to be a large effect, 1.2 to be a very large effect and 2.0 to be a huge effect, based on 'rules of thumb' (Cohen 1988; Sawilowsky 2009). The 'rules of thumb' are defined as point values, e.g. small = 0.2, which we have conservatively taken as the lower bounds for the category intervals (bins) such that we would consider an SMD of 0.49 to be small, for example (Crocker 2019; see Table 3). Where we calculated an SMD for an outcome from data including a familiar measure we rescaled the result to present it in these terms, using the pooled standard deviation at final follow-up of the control groups of all studies that presented that measure.

RESULTS

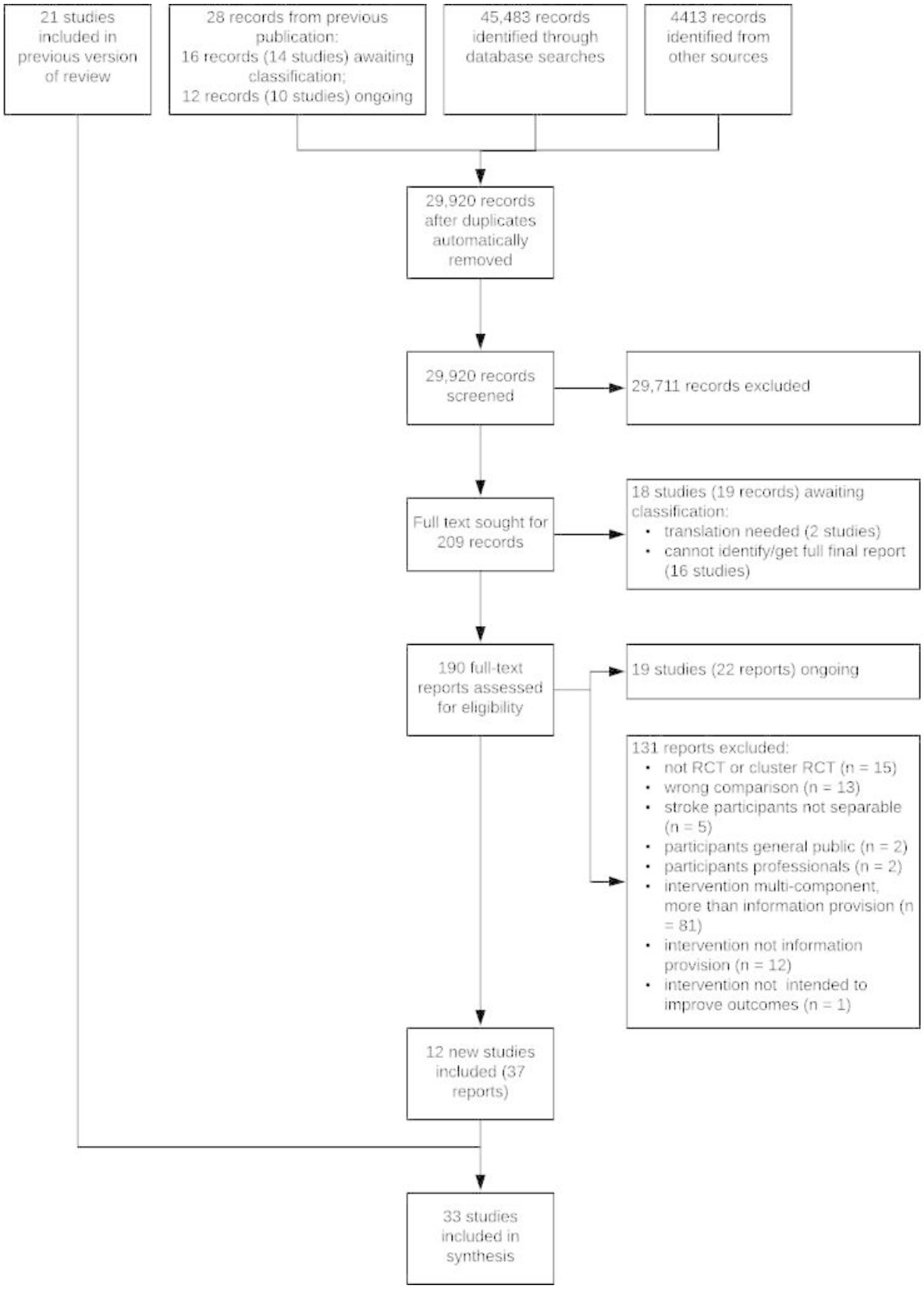
Description of studies

Results of the search

The results of our searches are detailed in a PRISMA diagram (Figure 1). For this update, our electronic searches retrieved 45,483 records. The previous review (Forster 2012) had 12 records ongoing and 16 records awaiting classification. Our searches of other resources produced 4413 additional references. We removed 20,004 references which were identified as duplicates. We therefore evaluated a total of 29,920 records, of which we excluded 29,711 on the basis of title and abstract. From the remaining records we included 12 new studies in the review, detailed in 37 reports (Boden-Albala 2015; Deyhoul 2018; Dharmakulaseelan 2019; Eames 2013; Forster 2013; Hekmatpou 2019; Jones 2018; Kamal 2016; Karimi 2018; Kim 2013; Kuo 2015; Mudzi 2012). We categorised 19 studies (22 reports) that may be eligible as ongoing (ACTRN12618002050235; Amooba 2018; Appalasamy 2018; ChiCTR-IIC-17011458; CN-01155247; Coombes 2018; CTRI/2017/07/009014; CTRI/2017/08/009267; CTRI/2017/09/009600; CTRI/2018/11/016312; Day 2018; IRCT20180419039362N1; NCT02398409; NCT02569099; NCT02769871; RBR-3n4tzc; Sureshkumar 2018; Tisel 2018; UMIN000030651); further information is in the Characteristics of ongoing studies table. We excluded 131 full-text reports (see Figure 1 for details). We categorised 19 records (18 studies) as awaiting classification, either because we could not get/identify a final report (Andrea 2003; Bhatia 2015; Bodin 2011; Bonita 1995; Heier 2002; Jian 1998; JPRN-UMIN000016716; Madarshahian

2018; Mendyk 2018; NCT02140619; NCT02140658; NCT02834273; Piano 2010; Tuncay 2006; Young 2007) or because we have not been able to organise their translation (Choi 2006; Kim 2011; Sun 2011); available details for these studies are provided in the Characteristics of studies awaiting classification table. For the results of searches prior to this update, please see the previous versions of the review (Forster 2001; Forster 2012; Smith 2008).

Figure 1. Study flow diagram for this update



Included studies

This review includes 33 completed trials with 5255 stroke-survivor and 3134 carer participants (Banet 1997; Boden-Albala 2015; Chinchai 2010; Chiu 2008; Deyhoul 2018; Dharmakulaseelan 2019; Downes 1993; Draper 2007; Eames 2013; Ellis 2005; Evans 1988; Forster 2013; Frank 2000; Hekmatpou 2019; Hoffmann 2007; Johnson 2000; Johnston 2007; Jones 2018; Kalra 2004; Kamal 2016; Karimi 2018; Kim 2013; Kuo 2015; Larson 2005; Lomer 1987; Lowe 2007; Maasland 2007; Mant 1998; Mudzi 2012; O'Connell 2009; Pain 1990; Rodgers 1999; Smith 2004). A summary of the key characteristics of included studies is provided in Table 4.

Design

Chinchai 2010 and Forster 2013 were cluster-randomised controlled trials; the other studies were individually randomised.

Setting

Twelve of the included trials were conducted in the UK (Downes 1993; Ellis 2005; Forster 2013; Frank 2000; Johnston 2007; Kalra 2004; Lomer 1987; Lowe 2007; Mant 1998; Pain 1990; Rodgers 1999; Smith 2004), four in Australia (Draper 2007; Eames 2013; Hoffmann 2007; O'Connell 2009), four in the USA (Banet 1997; Boden-Albala 2015; Evans 1988; Johnson 2000), three in Iran (Deyhoul 2018; Hekmatpou 2019; Karimi 2018), two in Taiwan (Chiu 2008; Kuo 2015), one in Canada (Dharmakulaseelan 2019), one in the Netherlands (Maasland 2007), one in New Zealand (Jones 2018), one in Pakistan (Kamal 2016), one in South Africa (Mudzi 2012), one in South Korea (Kim 2013), one in Sweden (Larson 2005), and one in Thailand (Chinchai 2010).

Participants

Fourteen trials only included stroke survivors (Banet 1997; Boden-Albala 2015; Chiu 2008; Eames 2013; Ellis 2005; Dharmakulaseelan 2019; Frank 2000; Hoffmann 2007; Johnson 2000; Kim 2013; Lowe 2007; Maasland 2007; O'Connell 2009; Pain 1990). In 10 trials the intervention only involved the carer or spouse (Deyhoul 2018; Draper 2007; Evans 1988; Forster 2013; Hekmatpou 2019; Kalra 2004; Karimi 2018; Kuo 2015; Larson 2005; Mudzi 2012), although only two of these did not measure any stroke-survivor-specific outcomes (Hekmatpou 2019; Larson 2005). In the remaining nine trials the intervention involved the stroke survivor and carer (Chinchai 2010; Downes 1993; Johnston 2007; Jones 2018; Kamal 2016; Lomer 1987; Mant 1998; Rodgers 1999; Smith 2004). Six trials explicitly included people who had experienced a TIA (Boden-Albala 2015; Dharmakulaseelan 2019; Ellis 2005; Hoffmann 2007; Kuo 2015; Maasland 2007).

Age

The average age of stroke survivors in the studies ranged from a mean of 53 years old in Mudzi 2012 to 76 years old in Kalra 2004 (median) and Kuo 2015 (mean). In 11 studies the mean age of stroke survivors was less than 65 years old (Boden-Albala 2015; Chinchai 2010; Eames 2013; Evans 1988; Frank 2000; Johnson 2000; Jones 2018; Kamal 2016; Karimi 2018; Maasland 2007; Mudzi 2012). In eight studies the mean age of stroke survivors was 65 to 69 years old (Chiu 2008; Deyhoul 2018; Dharmakulaseelan 2019; Draper 2007; Ellis 2005; Hoffmann 2007; Johnston 2007; Kim 2013). Downes 1993 reported that 90% of stroke survivors were over 60 years old and Pain 1990 reported that two thirds of stroke survivors were over 65 years old. In nine studies the mean age was 70 years or older (Forster 2013; Kalra 2004; Kuo 2015; Larson 2005; Lowe 2007; Mant 1998; O'Connell 2009; Rodgers 1999; Smith 2004). Three trials did not report stroke-survivor age (Banet 1997; Hekmatpou 2019; Lomer 1987).

Fourteen trials reported carer age (Deyhoul 2018; Downes 1993; Draper 2007; Eames 2013; Evans 1988; Hekmatpou 2019; Kamal 2016; Karimi 2018; Kim 2013; Kuo 2015; Larson 2005; Mudzi 2012; Rodgers 1999; Smith 2004). Carers were younger than the stroke survivors in each study and by more than twenty years in Deyhoul 2018, Kamal 2016, Karimi 2018 and Kuo 2015.

Gender

Most included studies had similar proportions of men and women stroke survivors (40% to 60%: Banet 1997; Boden-Albala 2015; Chinchai 2010; Chiu 2008; Deyhoul 2018; Downes 1993; Eames 2013; Ellis 2005; Forster 2013; Frank 2000; Hoffmann 2007; Johnson 2000; Kalra 2004; Karimi 2018; Kuo 2015; Lowe 2007; Maasland 2007; Mudzi 2012; O'Connell 2009; Rodgers 1999; Smith 2004). The stroke survivors in the remaining studies were predominantly men (60% to 80%: Dharmakulaseelan 2019; Johnston 2007; Jones 2018; Kamal 2016; Kim 2013; Mant 1998; Pain 1990), with 94.5% of stroke survivors in Evans 1988 being men. Two studies that included stroke survivors did not provide details of their gender (Draper 2007; Lomer 1987).

In most studies that reported carer gender, more than 60% of carers were women (Deyhoul 2018; Downes 1993; Evans 1988; Forster 2013; Hekmatpou 2019; Johnston 2007; Karimi 2018; Kuo 2015; Larson 2005; Mudzi 2012; Rodgers 1999), the greatest proportion being 90.6% in Evans 1988. There were similar proportions of men and women carers in three studies (40% to 60%: Chinchai 2010; Jones 2018; Smith 2004), while 63.9% of carers were men in Eames 2013. Seven studies that included carers did not report details of their gender (Draper 2007; Kalra 2004; Kamal 2016; Kim 2013; Lomer 1987; Mant 1998; Pain 1990).

Communication and cognition

Most studies explicitly excluded stroke survivors based on cognition or communication, such as having aphasia, lack of fluency in particular languages, cognitive impairment or lacking capacity to consent (Banet 1997; Boden-Albala 2015; Chinchai 2010; Deyhoul 2018; Dharmakulaseelan 2019; Eames 2013; Ellis 2005; Frank 2000; Hoffmann 2007; Johnson 2000; Johnston 2007; Jones 2018; Kamal 2016; Kim 2013; Lomer 1987; Lowe 2007; Maasland 2007; Mant 1998; O'Connell 2009; Smith 2004); other studies may not have made provision for participation by people lacking capacity to consent. Draper 2007 was unusual in requiring stroke survivors to have significant communication problems (the intervention involved their carers only).

Physical functioning

Nine studies had eligibility criteria regarding physical function of stroke survivors. Four studies excluded stroke survivors with severe disability or motor impairment (Chinchai 2010; Jones 2018; Kamal 2016; Maasland 2007), two of which also excluded stroke survivors with no or few functional limitations (Chinchai 2010; Jones 2018). Four other studies only included stroke survivors with some degree of disability (Deyhoul 2018; Downes 1993; Kalra 2004; Kuo 2015); in three of these the intervention involved their carers only (Deyhoul 2018; Kalra 2004; Kuo 2015). One study excluded participants whose

physical impairment would restrict their ability to comply with the study protocol (Dharmakulaseelan 2019).

Other requirements

Other notable requirements for inclusion included presence of vascular risk factors (Ellis 2005; Kamal 2016), dysphagia (Kuo 2015), sleep complaints (Dharmakulaseelan 2019), absence of bedsores and moderate to severe risk of developing them (Karimi 2018), access to equipment such as a Digital Versatile Disc (DVD) player (Boden-Albala 2015; Jones 2018; Kim 2013), living locally (Hoffmann 2007; Jones 2018; Kamal 2016; Karimi 2018; Mant 1998; Rodgers 1999), regular attendance at an outpatient clinic for the past 12 months (Chiu 2008), or a minimum length of hospital stay (Deyhoul 2018; Forster 2013; Jones 2018; Lomer 1987; Pain 1990; Rodgers 1999).

Interventions

Two of the included trials evaluated two interventions in addition to a standard care control (Downes 1993; Evans 1988): the two interventions in Evans 1988 were education and counselling, while Downes 1993 evaluated information provision alone and information provision plus counselling. In both cases, we have excluded the data about the arms including counselling and have only reported two arms for each included study, in each case comparing an information provision intervention with a control condition.

Category

In 22 studies the intervention was active (Boden-Albala 2015; Chinchai 2010; Chiu 2008; Deyhoul 2018; Draper 2007; Eames 2013; Ellis 2005; Evans 1988; Forster 2013; Frank 2000; Hekmatpou 2019; Johnson 2000; Johnston 2007; Kalra 2004; Kamal 2016; Karimi 2018; Kim 2013; Kuo 2015; Larson 2005; Mudzi 2012; Rodgers 1999; Smith 2004); in the remaining 11 studies the intervention was passive (Banet 1997; Dharmakulaseelan 2019; Downes 1993; Hoffmann 2007; Jones 2018; Lomer 1987; Lowe 2007; Maasland 2007; Mant 1998; O'Connell 2009; Pain 1990). We had considered that one of the studies exhibited features of both categories and sought further information from the lead author (Lowe 2007). Following discussion we agreed that it should be categorised as passive because information was only provided on one occasion, with no subsequent opportunity for clarification and consolidation or reinforcement. No studies compared active and passive approaches.

Content and administration

Active interventions

In five trials the intervention consisted of a programme of lectures providing information about stroke and available services with an opportunity to ask questions (Deyhoul 2018; Evans 1988; Johnson 2000; Larson 2005; Rodgers 1999). The four-week course evaluated by Johnson 2000 additionally emphasised the importance of self-esteem and coping strategies. Participants in the trial by Larson 2005 were also able to contact the stroke specialist nurse between sessions for extra information and support. The intervention in Kamal 2016 was similar to these except that the lectures were videos, with subsequent discussion and opportunity to ask questions.

Eleven studies evaluated a multi-component intervention (Draper 2007; Eames 2013; Ellis 2005; Forster 2013; Frank 2000; Hekmatpou 2019; Kalra 2004; Karimi 2018; Kuo 2015; Mudzi 2012; Smith 2004). In Frank 2000 the intervention consisted of a recovery plan, an interactive workbook and a weekly phone call from the researcher. Carers in Kalra 2004 and Forster 2013 received instruction on a range of topics plus demonstration and feedback on manual caring techniques. Stroke survivors and carers in Smith 2004 were provided with an information manual supported by fortnightly prearranged review meetings with their multidisciplinary team. In Ellis 2005 the stroke survivors in the intervention group received a monthly review by a stroke nurse specialist, specially selected relevant written information, and personalised records detailing their individual risk factors and recommended risk factor targets. In Draper 2007 the programme for carers of aphasic stroke survivors included communication strategies, relaxation and stress management. In Mudzi 2012 carers were given information on stroke-related problems and their prevention, and demonstration and feedback about caring and assistance. In Eames 2013 the intervention consisted of online written information, with face-to-face and telephone-based support. Carers in Kuo 2015 received instruction, demonstration and feedback specifically on oral care. Carers in Karimi 2018 received face-to-face training and a pamphlet. Carers in Hekmatpou 2019 received face-to-face training in hospital, a home visit, telephone support and a booklet.

In Johnston 2007, participants received a workbook which provided information about stroke, quizzes, task materials and an audio relaxation tape. In Chiu 2008 the intervention consisted of information delivered by a pharmacist over a course of six sessions. In Chinchai 2010 the intervention consisted of lectures delivered to carers with weekly follow-up reinforcement at home by health service volunteers. In Kim 2013 the intervention consisted of a website with lectures and automated quizzes. In Boden-Albala 2015 the intervention consisted of presentations, video, role-playing and the generic information provided to all participants, focused on recognition of recurrent stroke and rapid presentation to an emergency department.

Passive interventions

In five studies participants were provided with generic information. Three studies provided information in booklets and leaflets (Downes 1993; Lomer 1987; Mant 1998), and one study in a DVD (Jones 2018). Dharmakulaseelan 2019 provided participants with a leaflet and a five-minute animated slide-show.

In six studies the information was tailored to the individual (Banet 1997; Hoffmann 2007; Lowe 2007; Maasland 2007; O'Connell 2009; Pain 1990). In Banet 1997 participants in the intervention group were given a copy of their medical history, clinical résumés, test results and leaflets. In Hoffmann 2007 and Pain 1990 participants were provided with individualised booklets. In Lowe 2007 the intervention comprised personalised information presented by a research registrar who explained its contents and addressed any additional concerns. In Maasland 2007 information was delivered via an individualised multimedia computer programme. In O'Connell 2009 the intervention group were given a patient-held record that included telephone numbers, generic stroke information and fact sheets relevant to their specific stroke-related problems.

Further details of the interventions are provided in the Characteristics of included studies table.

Timing and location

The intervention began prior to discharge from hospital in 18 studies, which we categorised as acute (Banet 1997; Boden-Albala 2015; Deyhoul 2018; Eames 2013; Evans 1988; Forster 2013; Hekmatpou 2019; Hoffmann 2007; Kalra 2004; Kamal 2016; Karimi 2018; Lomer 1987; Lowe 2007; Mant 1998; Mudzi 2012; O'Connell 2009; Rodgers 1999; Smith 2004). In the remaining studies the intervention was implemented at varying times postdischarge. We categorised the following as subacute: soon after discharge (Downes 1993; Pain 1990); within three weeks of discharge (Johnston 2007); within three months of stroke (Ellis 2005; Maasland 2007); a mean of 76 days after stroke onset (Larson 2005); and within 12 months of stroke (Draper 2007; Kim 2013). We categorised the following as chronic: after 12 months since stroke (Chiu 2008); six months to three years after stroke (Johnson 2000); within 18 months of stroke (Chinchai 2010); within two years of stroke (Frank 2000); and within three years of stroke (Jones 2018). One study took place an unspecified time after stroke (Kuo 2015). When meta-analyses were statistically heterogeneous, we planned to subgroup the analysis according to time elapsed since stroke (see Assessment of heterogeneity).

Outcomes measured

The studies measured a range of outcomes, which are detailed in the Characteristics of included studies table. While many of this review's outcomes of interest are measured across health conditions or in relation to many stroke interventions with widely recognised instruments, satisfaction with information and assessment of knowledge about stroke and stroke services are particularly pertinent to the scope of this review. Here we describe the instruments used in the included studies to assess these outcomes and how we handled them.

Assessment of knowledge about stroke and stroke services

Twelve studies evaluated general aspects of stroke-survivor or carer knowledge regarding stroke and stroke services, such as definition, risk factors, effects and appropriate or available care. All but one used different questionnaires, most of which had been specifically developed for the study. The 29-item stroke knowledge survey used in Boden-Albala 2015 was previously used in a survey for the National Stroke Association (Gallup Organization 1996). The Stroke Care Information Test (range 0 to 36) used in Evans 1988 had been validated (Evans 1985). In the study by Hoffmann 2007, the 25-item Knowledge of Stroke questionnaire developed for the study was based partly on a previously validated measure (Sullivan 2004). The content validity and test-retest reliability of this instrument were assessed prior to the commencement of the study. The same 25-item Knowledge of Stroke questionnaire was used in Eames 2013 as well as evaluations of unprompted recall of stroke-related risk factors, both personally relevant and in general, and prompted recognition of 13 risk factors from the National Stroke Foundation's checklist. The questionnaire used in Lowe 2007 was developed from professionals' ideas of what stroke survivors should be aware of concerning secondary prevention of stroke and was piloted with 58 stroke survivors. In Maasland 2007 the questionnaire was developed and validated in 42 partners of people who have experienced a TIA. The 26-item knowledge of stroke scale used in Rodgers 1999 and the 17-item knowledge of stroke and services questionnaire used in Smith 2004 were based on instruments used in other studies (Drummond 1996; Mant 1998; Wellwood 1994), and the content of the specific educational programme under evaluation. None of the questionnaires in the remaining four studies appeared to have been validated (Kamal 2016; Lomer 1987; Mant 1998; Pain 1990), so we did not incorporate these into our analyses.

Satisfaction with information

Nine trials evaluated stroke-survivor satisfaction with information received (Eames 2013; Ellis 2005; Hoffmann 2007; Johnston 2007; Kamal 2016; Lowe 2007; Mant 1998; Rodgers 1999; Smith 2004). The Pound Scale measures satisfaction with stroke services for survivors (Pound 1994) or carers (Pound 1993), and includes two questions that we considered to be particularly relevant to the review: (1) satisfaction with the information received about the causes and nature of stroke; and (2) satisfaction with the information received about allowances and services. Five trials included these two questions (Ellis 2005; Lowe 2007; Mant 1998; Rodgers 1999; Smith 2004), either by administering the Pound Scale, a modified version of that scale or a bespoke questionnaire. We performed a meta-analysis for those two questions. Four trials did not contribute data to the meta-analysis (Eames 2013; Hoffmann 2007; Johnston 2007; Kamal 2016). Eames 2013 measured stroke-survivor satisfaction with information received using a bespoke questionnaire with 10-point Likert scales for the topics of medical information, practical information, service and benefits, and prevention information. Hoffmann 2007 used a bespoke questionnaire to measure satisfaction with content and presentation of written information. Johnston 2007 assessed satisfaction with both treatment and advice using a 0 to 10 scale applied in a previous study (Morrison 2000). However, the study presented a combined score, so we have not included these data. Kamal 2016 did not present results for this outcome.

Six trials evaluated carer satisfaction (Eames 2013; Kalra 2004; Mant 1998; Pain 1990; Rodgers 1999; Smith 2004). Of these, three trials measured carer satisfaction using the Pound Scale (Pound 1993) or a modified version of this scale (Mant 1998; Rodgers 1999; Smith 2004). We performed meta-analyses for two questions considered to be of most relevance to the review: 1) satisfaction with the information received about recovery and rehabilitation; and 2) satisfaction with the information received about allowances and services. The remaining studies evaluated aspects of carer satisfaction using bespoke questionnaires (Eames 2013; Kalra 2004; Pain 1990); we have not included these in the analyses.

Excluded studies

We have excluded 117 studies that may, on the surface, appear to meet the inclusion criteria, but do not; individual reasons for exclusion are provided in the Characteristics of excluded studies table. Fifty-two of these studies were excluded in this update, with the other studies excluded in previous versions of the review. We excluded 87 studies because the information/education was part of a multiple component, complex rehabilitation intervention (see the Characteristics of excluded studies table). We excluded six studies because information provision was not the evaluated intervention (Hackett 2013; Lincoln 2003; Lo 2018; Mant 2000; Spassova 2016; Towle 1989). Four studies included participants with conditions other than stroke and the data about stroke participants were not available separately (Brotons 2011; Dongbo 2003; NCT01062243; Sanguinetti 1987). Three studies included motivational interviewing (Adie 2010; Byers 2010; Green 2007). In two studies the intervention recipients were clinicians (Ab

Malik 2017; Lynch 2016). One study used a non-random allocation procedure (Sit 2007). We excluded the remaining 14 studies as they had the wrong kind of comparison (ACTRN12618001066279; Ballard 2013; Feld-Glazman 2012; Gorman 2015; Hirano 2012; Johnson 2018; Jones 2009; Lorenc 1992; NCT02591511; Neubert 2011; Ostwald 2014; Saal 2015; Skidmore 2008; Tielemans 2015).

Risk of bias in included studies

Details of risk of bias judgements for individual studies are provided in the risk of bias tables in Characteristics of included studies and summarised in Figure 2. Here we summarise the risk in different domains of bias across the included studies.

Figure 2. Risk of bias summary

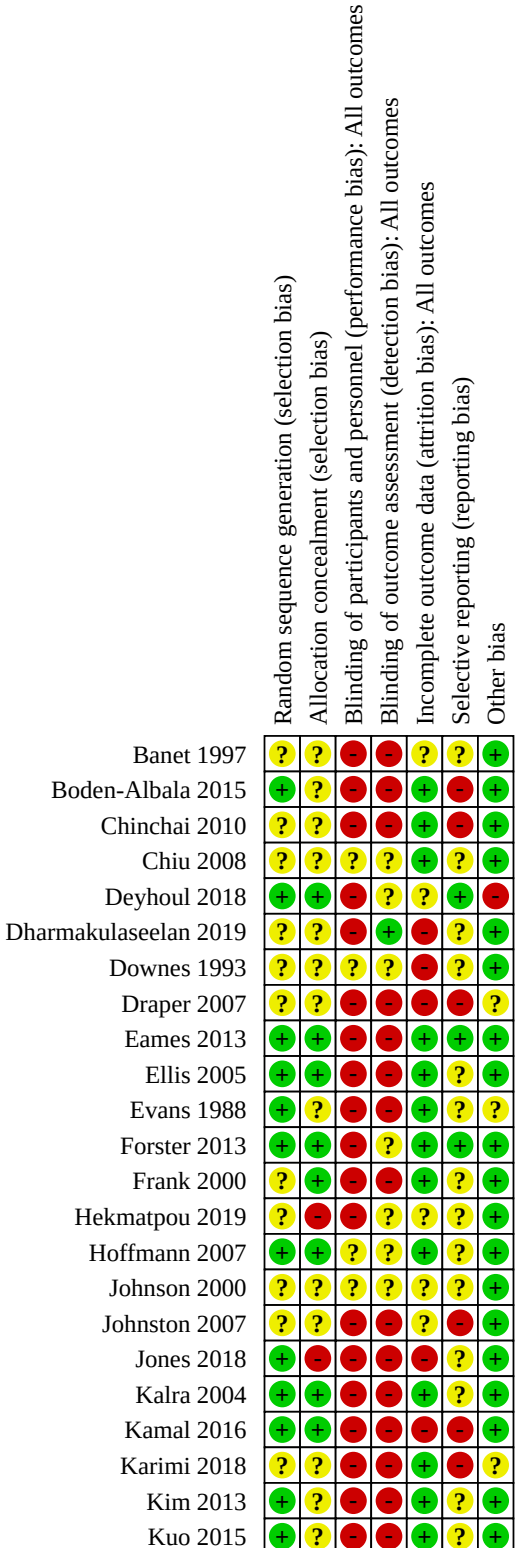
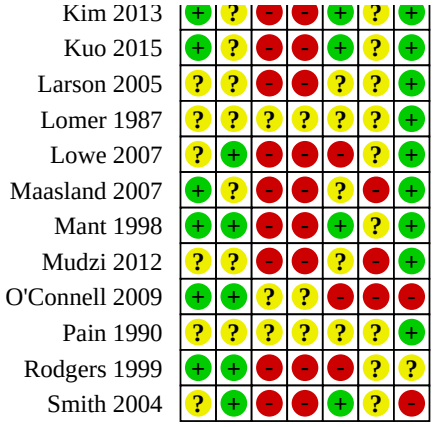


Figure 2. (Continued)



Allocation

We judged the method of random sequence generation to have a low risk of bias in 16 trials (Boden-Albala 2015; Deyhoul 2018; Eames 2013; Ellis 2005; Evans 1988; Forster 2013; Hoffmann 2007; Jones 2018; Kalra 2004; Kamal 2016; Kim 2013; Kuo 2015; Maasland 2007; Mant 1998; O'Connell 2009; Rodgers 1999), and to be unclear or not reported in 17 trials (Banet 1997; Chinchai 2010; Chiu 2008; Dharmakulaseelan 2019; Downes 1993; Draper 2007; Frank 2000; Hekmatpou 2019; Johnson 2000; Johnston 2007; Karimi 2018; Larson 2005; Lomer 1987; Lowe 2007; Mudzi 2012; Pain 1990; Smith 2004). Allocation was concealed in 13 trials (Deyhoul 2018; Eames 2013; Ellis 2005; Forster 2013; Frank 2000; Hoffmann 2007; Kalra 2004; Kamal 2016; Lowe 2007; Mant 1998; O'Connell 2009; Rodgers 1999; Smith 2004). We judged the risk due to allocation concealment unclear in 18 studies as methods of allocation concealment were unreported (Banet 1997; Boden-Albala 2015; Chinchai 2010; Chiu 2008; Dharmakulaseelan 2019; Downes 1993; Draper 2007; Evans 1988; Johnson 2000; Johnston 2007; Karimi 2018; Kim 2013; Kuo 2015; Larson 2005; Lomer 1987; Maasland 2007; Mudzi 2012; Pain 1990); Larson 2005 reported that the sequence could not be predicted but did not report the method used. Allocation was judged predictable (high risk) in two studies (Hekmatpou 2019; Jones 2018). Hekmatpou 2019 used small, unvaried block sizes and prior allocation was known by the recruiting researcher, making future allocation quite predictable. We judged that Jones 2018 used pure minimisation with an open list of previous allocations making future allocations entirely predictable.

Blinding

Blinding of both participants and personnel was not a feature in any of the trials, or blinding was unclear. In many cases, it would have been impossible to blind the personnel delivering the intervention as their explanation of the information was an important ingredient. Blinding of participants can also be challenging when the control condition is usual care. Blinding of outcome assessors was reported in 18 trials (Boden-Albala 2015; Chinchai 2010; Dharmakulaseelan 2019; Downes 1993; Eames 2013; Ellis 2005; Forster 2013; Hoffmann 2007; Johnston 2007; Kalra 2004; Kamal 2016; Kim 2013; Kuo 2015; Mant 1998; O'Connell 2009; Pain 1990; Rodgers 1999; Smith 2004). However, in most studies we judged risk of detection bias as unclear (Chiu 2008; Deyhoul 2018; Downes 1993; Forster 2013; Hekmatpou 2019; Hoffmann 2007; Johnson 2000; Lomer 1987; O'Connell 2009; Pain 1990) or high (Banet 1997; Boden-Albala 2015; Chinchai 2010; Draper 2007; Eames 2013; Ellis 2005; Evans 1988; Frank 2000; Johnston 2007; Jones 2018; Kalra 2004; Kamal 2016; Karimi 2018; Kim 2013; Kuo 2015; Larson 2005; Lowe 2007; Maasland 2007; Mant 1998; Mudzi 2012; Rodgers 1999; Smith 2004), typically because self-reported measures were completed by unblinded participants. Although participants were unblinded, we judged risk of detection bias to be low in Dharmakulaseelan 2019 as it seemed unlikely responses to a questionnaire on knowledge of sleep apnoea would be biased by knowledge of allocation; however, the reported outcomes were not specified for inclusion in our review.

Incomplete outcome data

We judged 15 studies to be at low risk of attrition bias (Boden-Albala 2015; Chinchai 2010; Chiu 2008; Eames 2013; Ellis 2005; Evans 1988; Forster 2013; Frank 2000; Hoffmann 2007; Kalra 2004; Karimi 2018; Kim 2013; Kuo 2015; Mant 1998; Smith 2004), where losses to follow-up were sufficiently small and balanced in numbers and reasons across groups. Eight studies were at high risk of attrition bias: in Downes 1993 almost two thirds of participants were not included in the final analysis; in Dharmakulaseelan 2019 there were imbalances in drop out which may have related to the intervention and reasons for losses were not provided; in Draper 2007 40% of control group participants were lost; in Jones 2018 there were substantial imbalances that may have related to the intervention; in Kamal 2016 there was approximately two-thirds missing data for some outcomes and reasons for losses were not provided; in Lowe 2007 there were large differences in losses between groups; in O'Connell 2009 one-third were lost to follow-up, with more lost in the intervention group and reasons for losses not being reported; and in Rodgers 1999 almost half of SF-36 outcomes were missing and approximately 40% of carers were lost to follow-up. The remaining 10 studies provided insufficient information to judge risk of attrition bias (Banet 1997; Deyhoul 2018; Hekmatpou 2019; Johnson 2000; Johnston 2007; Larson 2005; Lomer 1987; Maasland 2007; Mudzi 2012; Pain 1990).

Selective reporting

Three studies were judged at low risk of reporting bias (Deyhoul 2018; Eames 2013; Forster 2013). Nine studies were judged at high

risk of reporting bias (Boden-Albala 2015; Chinchai 2010; Draper 2007; Johnston 2007; Kamal 2016; Karimi 2018; Maasland 2007; Mudzi 2012; O'Connell 2009), usually because they did not present data on prespecified outcomes. We did not obtain protocols for older studies. As a result, it is unclear if selective reporting contributed to bias in most studies.

Other potential sources of bias

The intervention in Deyhoul 2018 appeared to be halved in dose (contact time) between protocol and the results publication, potentially resulting in a performance bias towards no effect. In Draper 2007, collection of baseline data occurred after randomisation (although participants were still blinded at that point). In Evans 1988, imbalance in reported baseline conditions (marital status and number in household) may mean the choice of minimisation factors (by which allocation occurred) was incomplete. In Karimi 2018, substantial inconsistencies between the trial register record and results publication meant we were uncertain about what occurred and whether reported results were true. In O'Connell 2009, the trial was terminated early as it was reported that numerous participants could not remember receiving the information (a sample size of 240 was the initial target; however, the trial was stopped when 66 participants were recruited). In the trial undertaken by Rodgers 1999, only 51 stroke survivors (42%) of those randomised attended three or more out of the six outpatient sessions provided. In Smith 2004, contamination between the two groups of stroke survivors was suspected because of unavoidable contact on the ward during the inpatient period.

Effects of interventions

See: **Summary of findings 1** Active information provision compared to control for stroke survivors; **Summary of findings 2** Active information provision compared to control for stroke carers; **Summary of findings 3** Passive information provision compared to control for stroke survivors; **Summary of findings 4** Passive information provision compared to control for stroke carers; **Summary of findings 5** Active compared to passive information provision for stroke survivors and their carers

Results are reported separately for comparisons of active or passive information provision with control, and for stroke survivors and carers. As there were no studies comparing active and passive information provision, we have not reported any results for these planned comparisons. Resource outcomes are also presented separately. A summary of the data are provided in the Data and analyses table.

Active information provision

Stroke-survivor outcomes

Knowledge of stroke and stroke services

Stroke-survivor knowledge was assessed in four studies of active information provision (Boden-Albala 2015; Eames 2013; Rodgers 1999; Smith 2004). For details of how knowledge was measured please see 'Outcomes measured' in Included studies. We pooled results from three studies in a standardised mean difference (SMD) meta-analysis (Eames 2013; Rodgers 1999; Smith 2004). Knowledge of stroke and stroke services in the active information provision group was better on average by a small amount (SMD 0.41, 95% confidence interval (CI) 0.17 to 0.65; I^2 = 0%; 275 participants; low certainty evidence; Analysis 1.1; Summary of findings 1). The confidence interval ranged from a very small effect to a moderate effect in favour of the active information provision group. No one scale contributed the majority of data so we did not perform a mean difference (MD) sensitivity analysis. Boden-Albala 2015 did not present suitable data for inclusion but did present results showing slightly greater odds of stroke knowledge proficiency among the active information provision group (odds ratio (OR) 1.21, 95% CI 0.87 to 1.67); however, the wide confidence intervals include no difference (Analysis 1.2).

Anxiety

Seven trials of active information provision measured stroke-survivor anxiety, all of which used the anxiety subscale of the Hospital Anxiety and Depression Scale (HADS-A) (Eames 2013; Forster 2013; Frank 2000; Johnston 2007; Kalra 2004; Rodgers 1999; Smith 2004). We did not include Johnston 2007 in the meta-analysis as we were unable to obtain suitable data; the only available postintervention result was a total HADS score (psychological distress: combined anxiety and depression, see below).

We included five studies with data from 1132 participants in the dichotomous analysis (Eames 2013; Forster 2013; Kalra 2004; Rodgers 1999; Smith 2004). Because the intracluster correlation coefficient (ICC) was 0 we could not adjust the results of Forster 2013 for clustering. The pooled risk ratio (RR) of anxiety was 0.85 (95% CI 0.68 to 1.06; I^2 = 5%; low certainty evidence; Analysis 1.3; Summary of findings 1), favouring the active information provision group but including the chance of no difference between groups. There was little evidence of heterogeneity. A sensitivity analysis using an odds ratio adjusted for clustering and baseline data from Forster 2013 produced similar results (OR 0.80, 95% CI 0.61 to 1.05; Analysis 1.4). Further sensitivity analyses excluding this cluster-randomised trial also produced similar results (not shown).

We included six trials with data from 1171 participants in the mean difference meta-analysis (Eames 2013; Forster 2013; Frank 2000; Kalra 2004; Rodgers 1999; Smith 2004). The pooled result for all trials showed a slightly lower mean HADS-A score in the active information provision group and a narrow confidence interval that excluded no difference between groups (MD -0.73, 95% CI -1.10 to -0.36; I^2 = 49%; low certainty evidence; Analysis 1.5; Summary of findings 1). A sensitivity analysis excluding the Forster 2013 cluster-randomised trial made a small shift in the estimate favouring the active information provision group and reduced heterogeneity (MD -1.01, 95% CI -1.48 to -0.55; I^2 = 27%; 559 participants; not shown). Johnston 2007 reported no significant difference between intervention and control at baseline (P > 0.05) and no significant effects postintervention (data and P value not reported; Analysis 1.6).

Depression

Nine studies of active information provision measured stroke-survivor depression: seven trials used the depression subscale of the HADS (HADS-D) (Eames 2013; Forster 2013; Frank 2000; Johnston 2007; Kalra 2004; Rodgers 1999; Smith 2004), Ellis 2005 used the Geriatric Depression Scale (short form) (Sheikh 1986) and Johnson 2000 used the Beck Depression Inventory (Gallagher 1982). We did not include the Johnston 2007 study in either meta-analysis as we were unable to obtain suitable data (see psychological distress, below).

We included six studies with data from 1315 participants in the dichotomous analysis (Eames 2013; Ellis 2005; Forster 2013; Kalra 2004; Rodgers 1999; Smith 2004). We adjusted the results of Forster 2013 for clustering. The pooled RR of depression was 0.83 (95% CI 0.68 to 1.01; I^2 = 0%; low certainty evidence; Analysis 1.7; Summary of findings 1), favouring the active information provision group but including the chance of no difference between groups. There was no evidence of heterogeneity. A sensitivity analysis using an odds ratio adjusted for clustering and baseline data from Forster 2013 produced similar results (OR 0.71, 95% CI 0.54 to 0.92; Analysis 1.8), although in this case the confidence interval excludes no difference between groups. Further sensitivity analyses excluding this cluster-randomised trial produced similar results with confidence intervals that included no difference between groups (not shown).

We included eight studies with data from 1405 participants in the SMD meta-analysis (Eames 2013; Ellis 2005; Forster 2013; Frank 2000; Johnson 2000; Kalra 2004; Rodgers 1999; Smith 2004). The pooled results showed a lower average depression score in the active information provision group by a very small amount with a narrow confidence interval that excluded no difference between groups (SMD -0.19, 95% CI -0.30 to -0.08; I^2 = 40%; moderate certainty evidence; Analysis 1.9; Summary of findings 1). Sensitivity analyses, one excluding the cluster-randomised trial of Forster 2013 and one mean difference meta-analysis using the HADS-D (six studies), produced similar results (MD -0.58, 95% CI -0.96 to -0.21; 1173 participants; not shown).

Positive mental well-being

No studies of active information provision evaluated this outcome.

Quality of life

Only one study with 60 participants measured quality of life (Chinchai 2010). Chinchai 2010 measured subscales of the Thai version of the World Health Organization Quality of Life assessment short-form (WHOQOL-BREF Thai; Sakthong 2007) and reported results unadjusted for clustering effects, which we used. We transformed the reported results to a standard 0 to 100 scale. For each of the four subscales, the active information provision group had greater quality of life on average, with quite wide confidence intervals that excluded no difference between groups (low certainty evidence; Analysis 1.10; Summary of findings 1). Domain mean differences were as follows: physical (MD 11.5, 95% CI 7.81 to 15.27); psychological (MD 11.8, 95% CI 7.29 to 16.29); social (MD 5.8, 95% CI 0.84 to 10.84); environment (MD 7.0, 95% CI 3.00 to 10.94).

Satisfaction with information

Satisfaction with the information received about the causes and nature of stroke

Three studies of active information provision with data from 398 participants contributed to the meta-analysis (Ellis 2005; Rodgers 1999; Smith 2004). Compared to the control group, the intervention group had a substantially lower risk of being unsatisfied with the information received about the causes and nature of stroke, and the confidence interval excluded equal risk between groups (RR (non-event) 0.56, 95% CI 0.38 to 0.84; I^2 = 36%; Analysis 1.11).

Satisfaction with the information received about allowances and services

Three studies of active information provision with data from 395 participants contributed to the meta-analysis (Ellis 2005; Rodgers 1999; Smith 2004). Compared to the control group, the intervention group had a slightly lower risk of being unsatisfied with the information received about allowances and services, but the confidence interval included the chance of a slightly higher risk (RR (non-event) 0.82, 95% CI 0.59 to 1.14; I^2 = 27%; Analysis 1.12).

Psychological distress

Four studies measured psychological distress; Hekmatpou 2019 and Rodgers 1999 reported the mental health subscale of the SF-36, Forster 2013 reported the emotions subscale of the Stroke Impact Scale (SIS; Duncan 1999), and Johnston 2007 reported the total score from the HADS. We used the negative of SF-36 and SIS scores in the SMD meta-analysis, so that greater scores indicated greater psychological distress. For Hekmatpou 2019, we assumed the data were mean and standard error, rather than standard deviation and mean as they were labelled. We made this assumption because the second figure would be infeasibly small for an SF-36 subscale mean (while the first figure would be typical) and would be infeasibly small for an SF-36 subscale standard deviation. As explained in Data synthesis, we did not use the HADS total score for studies where we had separate anxiety and depression scores as these are analysed above. We were unable to conduct a dichotomous meta-analysis.

We included all four studies in an SMD meta-analysis with 982 participants. Psychological distress was greater by a very small amount in the active information provision group, although the small confidence interval included no difference between groups (SMD -0.01, 95% CI -0.14 to 0.11; I^2 = 0%; Analysis 1.13). There was no evidence of excess statistical heterogeneity. Sensitivity analyses that used the data as reported by Hekmatpou 2019 because we had assumed they were not correctly labelled and excluding that study produced very similar results (not shown). A sensitivity analysis excluding the cluster-randomised trial of Forster 2013 produced similar results, although with the average favouring the control group (SMD 0.09, 95% CI -0.12 to 0.29; 364 participants). The majority of participants reported data on the SIS emotions subscale (for which higher scores indicate less psychological distress), which was analysed by Forster 2013 with similar results (MD 1.4, 95% CI -1.3 to 4.2; 603 participants), with the average favouring the intervention group.

Self-efficacy

Three studies measured stroke-survivor self-efficacy (Deyhoul 2018; Eames 2013; Frank 2000), although only Frank 2000 reported data we could include. Deyhoul 2018 did not report results; Eames 2013 used a bespoke measure.

The mean difference in the Perceived Health Competence Scale (Smith 1995) in Frank 2000 favoured the intervention group but was not statistically significant in this small study (Analysis 1.14).

Locus of control

Four studies measured locus of control (Deyhoul 2018; Frank 2000; Johnston 2007; Kim 2013). Deyhoul 2018 used the Multidimensional Health Locus of Control scale (Wallston 1978), but did not report results. Frank 2000 and Johnston 2007 used

the Recovery Locus of Control Scale (RLOC; Partridge 1989). Kim 2013 used The Mastery Scale (Pearlin 1978). We included the three studies that reported results in an SMD meta-analysis with data from 231 participants.

On average, locus of control was greater in the intervention group by a very small amount, but the confidence interval ranged from a very small benefit to the control group to a small benefit to the intervention group (SMD 0.09, 95% CI -0.17 to 0.35; I^2 = 26%; Analysis 1.15). The majority of participants reported data on the RLOC; a sensitivity analysis using just these results produced very similar results (MD 0.06, 95% CI -1.28 to 1.40; 197 participants).

Modification of health-related behaviours

Eight studies evaluated measures related to this outcome (Boden-Albala 2015; Chiu 2008; Eames 2013; Ellis 2005; Kamal 2016; Kim 2013; Kuo 2015; Rodgers 1999). Results are tabulated in Analysis 1.16. Boden-Albala 2015 measured time taken to present to the emergency department for first suspected recurrent stroke; the effect estimate favoured the control group, but was not statistically significant. Chiu 2008 measured satisfactory management of blood pressure, glucose and lipids; they reported a statistically significant difference (P < 0.001) favouring the intervention group for management of blood pressure but not for management of glucose or lipids. Eames 2013 reported a small difference in stroke-risk-related behaviours favouring the control group that was not statistically significant. Ellis 2005 reported that their initial (planned) analysis produced a statistically significant reduction in systolic blood pressure in the intervention group compared with the control group (P value not reported). However, when the analysis was repeated with adjustment for baseline blood pressure, the difference was not significant (P = 0.126). There were no statistically significant changes in other major modifiable risk factors: systolic and diastolic blood pressure; reported smoking rate; cholesterol; random blood glucose; or glycated haemoglobin. Kamal 2016 reported a ratio favouring the intervention group for all measures (medication adherence, systolic and diastolic blood pressure, blood sugar and blood cholesterol) but no significant differences. Kim 2013 reported a ratio favouring the intervention group for full medication adherence but no significant difference. Kuo 2015 reported significantly better oral care in the intervention group. Rodgers 1999 reported no significant difference in the numbers of stroke survivors who stopped smoking after the stroke (intervention 9/25, control 3/17, P = 0.44).

Independence in activities of daily living

Eight studies of active information provision measured independence in activities of daily living (ADL) using the Barthel Index (Deyhoul 2018; Draper 2007; Forster 2013; Johnston 2007; Kalra 2004; Kamal 2016; Mudzi 2012; Smith 2004). Draper 2007 did not report follow-up data, so we could not include this study in the meta-analysis. We could not include the studies by Kalra 2004 and Kamal 2016 in the meta-analysis as they reported dichotomised/trichotomised data only. Deyhoul 2018 reported the Barthel Index on the 0 to 100 scale, which we transformed to 0 to 20 for comparability with other results. Johnston 2007 reported transformed scores (higher scores equalled greater dependence) which appeared to be from the 0 to 20 scale, so we subtracted them from 20 to make them comparable. We also noticed that the reported SDs were unusually small, and substantially smaller than those at baseline, so we assumed they were standard errors and performed sensitivity analyses.

We included five studies with data from 1178 participants in a mean difference meta-analysis (Deyhoul 2018; Forster 2013; Johnston 2007; Mudzi 2012; Smith 2004). The Barthel Index (0 to 20) was slightly greater in the active information provision group (on average by 0.45) although the confidence interval included no difference between groups (95% CI -0.01 to 0.91; I^2 = 0%; Analysis 1.17). There was no evidence of heterogeneity. Sensitivity analyses modifying the estimate for Johnston 2007 by substituting the baseline standard deviations and using the SDs as reported did not substantially alter the MD or CI. Excluding Johnston 2007 also made little impact on the MD or CI, except that the CI excluded no difference between groups (MD 0.48, 95% CI 0.01 to 0.96; 4 studies; 1020 participants). A further sensitivity analysis excluding the Forster 2013 cluster-randomised trial slightly increased the average difference in favour of the active information provision group and also excluded no difference between groups (MD 0.71, 95% CI 0.05 to 1.38; 4 studies, 500 participants) (sensitivity analyses not shown).

There were no statistically significant differences between the intervention and control groups in Kalra 2004 or Kamal 2016 (Analysis 1.18).

Social activities

Four studies of active information provision evaluated social activities: two used the Frenchay activities index (FAI, Holbrook 1983) (Kalra 2004; Smith 2004) and two used the Nottingham extended activities of daily living scale (NEADL; Nouri 1987), scored 0 to 66 in Forster 2013 and scored 0 to 22 in Rodgers 1999. We pooled the results of these trials in an SMD meta-analysis with data from 1175 participants. On average, social activities were a very small amount greater in the active information provision group, with a narrow confidence interval encompassing very small benefit to either the active information provision or control group (SMD 0.03, 95% CI -0.09 to 0.15; I^2 = 0%; Analysis 1.19). There was no evidence of heterogeneity. A sensitivity analysis excluding the Forster 2013 cluster-randomised trial produced similar results (not shown). The majority of participants reported data on the NEADL 0 to 66 scale analysed by Forster 2013 (not directly transformable to the 0 to 22 scale) with similar results (MD 0.5, 95% CI -2.2 to 3.2; 631 participants).

Perceived health status

Eight studies measured health status and compared active information provision with a control (Ellis 2005; Eames 2013; Forster 2013; Frank 2000; Hekmatpou 2019; Kalra 2004; Mudzi 2012; Rodgers 1999).

Three trials administered the EuroQol 5 dimensions instrument (EQ-5D; EuroQol Group 1990) (Ellis 2005; Forster 2013; Mudzi 2012), but only Forster 2013 reported the index value. The EQ-5D index value was, on average, 0.03 greater in the active information provision group, although the confidence interval included no difference between groups (95% CI -0.02 to 0.08; 598 participants; Analysis 1.20). Ellis 2005 found no significant difference between the intervention and control group (Analysis 1.20). Mudzi 2012 only reported means.

Ellis 2005 and Kalra 2004 reported the EuroQol Visual Analogue Scale (EQ-VAS), which we included in a meta-analysis. The EQ-VAS was greater in the active information provision group, on average by 4.31 points, although the confidence interval included no difference between groups (95% CI -0.11 to 8.73; I^2 = 0%; 416 participants; Analysis 1.21). There was no excess heterogeneity.

Frank 2000 measured the Functional Limitations Profile (FLP; Patrick 1989). The FLP favoured the active information provision group (on average by -2.86), although the confidence interval was wide and included no difference between groups (95% CI -16.62 to 10.90; 39 participants; Analysis 1.20).

Eames 2013 measured the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39), and found no mean difference between the groups (MD 0.00, 95% CI -0.34 to 0.34; 66 participants; Analysis 1.20).

Two studies measured the general health subscale of the SF-36 (Hekmatpou 2019; Rodgers 1999), although Hekmatpou 2019 only reported results for the intervention group so we were unable to pool the studies. Rodgers 1999 reported a slightly lower average SF-36 general health score among intervention participants, although the confidence interval was wide and included no difference between groups (MD -1.80, 95% CI -9.56 to 5.96; 168 participants; Analysis 1.22).

Forster 2013 reported the physical function composite domain and recovery subscale of the SIS. On average, results favoured the intervention group although the confidence intervals were wide and included no difference between groups (Analysis 1.20).

Recurrent stroke

Two studies recorded recurrent stroke (Boden-Albala 2015; Karimi 2018). However, only one study with 1193 participants presented results (Boden-Albala 2015). In Boden-Albala 2015 there was an increased risk of having a first recurrent stroke, TIA or stroke mimic in the active information provision group, although the confidence interval also included the chance of a reduced risk of stroke for this group (RR 1.22, 95% CI 0.96 to 1.55; Analysis 1.23). This increase was not driven by stroke mimics, according to the authors.

Death

Mortality data were available for 2460 participants from eight studies (Ellis 2005; Evans 1988; Forster 2013; Johnston 2007; Kalra 2004; Kamal 2016; Rodgers 1999; Smith 2004). Boden-Albala 2015 did not present data separately for the two groups, so we could not include this in the meta-analysis. Ellis 2005, which included 205 participants, reported no deaths in either arm so the analysis incorporates data from 2355 participants from seven studies. Forster 2013 reported results unadjusted for clustering effects, and we used these data. The odds of death within the study period were lower in the active information provision group, although the confidence interval included equal risk between groups (Peto OR 0.91, 95% CI 0.70 to 1.19; I^2 = 0%; Analysis 1.24). A sensitivity analysis excluding the Forster 2013 cluster-randomised trial produced similar results, although slightly more in favour of the active information provision group (not shown).

Carer outcomes

Knowledge of stroke and stroke services

Five trials of active information provision assessed carer knowledge (Eames 2013; Evans 1988; Kamal 2016; Rodgers 1999; Smith 2004). We pooled results of four trials with data from 356 participants in a standardised mean difference random-effects meta-analysis (Eames 2013; Evans 1988; Rodgers 1999; Smith 2004). Knowledge of stroke and stroke services in the active information provision group was moderately better on average (SMD 0.68, 95% CI -0.03 to 1.39; I^2 = 90%; very low certainty evidence; Analysis 2.1; Summary of findings 2). There was substantial heterogeneity and the confidence interval ranged from a very small effect in favour of the control group to a very large effect in favour of the active information provision group. In the fixed-effect meta-analysis the CI was narrower, ranging from a moderate to large effect in favour of the active information provision group (SMD 0.76, 95% CI 0.54 to 0.99; not shown). The estimate of Evans 1988 was notably larger than other studies, its CI not overlapping with that of the fixed-effect meta-analysis, which may relate to the bespoke outcome measures used in the studies or differences in usual care related to the different ages or countries of the studies. No one scale contributed the majority of data so we did not perform a mean difference sensitivity analysis.

Anxiety

Four studies measured this outcome using the anxiety subscale of the HADS (Eames 2013; Forster 2013; Johnston 2007; Kalra 2004). Johnston 2007 presented insufficient data to include in a meta-analysis. The dichotomous analysis included three studies with data from 921 participants (Eames 2013; Forster 2013; Kalra 2004). We adjusted the results of Forster 2013 for clustering. The estimate for the pooled RR of anxiety was very imprecise (RR 0.96, 95% CI 0.71 to 1.28; I^2 = 29%; very low certainty evidence; Analysis 2.2; Summary of findings 2). A sensitivity analysis using an odds ratio adjusted for clustering and baseline data from Forster 2013 produced similar results (OR 0.98, 95% CI 0.64 to 1.51; Analysis 2.3). In a sensitivity analysis excluding the Forster 2013 cluster-randomised trial the RR favoured the control group, although the confidence interval was even wider and still included no difference between groups as there were few cases in the remaining trials (RR 1.58, 95% CI 0.67 to 3.72; 324 participants; not shown).

We included three studies with data from 921 participants in the mean difference (HADS-A) random-effects meta-analysis (Eames 2013; Forster 2013; Kalra 2004). The pooled results showed little difference in HADS anxiety score between groups (MD -0.40, 95% CI -1.51 to 0.70; I^2 = 78%; low certainty evidence; Analysis 2.4; Summary of findings 2). There was substantial excess heterogeneity. In the fixed-effect meta-analysis the MD was larger and the CI was narrower (MD -0.78, 95% CI -1.20 to -0.37; not shown). A sensitivity analysis excluding the Forster 2013 cluster-randomised trial from the random-effects meta-analysis produced similar results with wider confidence intervals (not shown).

Depression

Four studies measured this outcome using the depression subscale of the HADS (Eames 2013; Forster 2013; Johnston 2007; Kalra 2004). Johnston 2007 presented insufficient data to include in a meta-analysis.

Three studies with data from 924 participants were included in the dichotomous analysis (Eames 2013; Forster 2013; Kalra 2004). We adjusted the results of Forster 2013 for clustering. The estimate for the pooled RR of depression was very imprecise (RR 0.98, 95% CI 0.64 to 1.50; I^2 = 0%; very low certainty evidence; Analysis 2.5; Summary of findings 2). A sensitivity analysis using an odds ratio adjusted for clustering and baseline data from Forster 2013 produced similar results (OR 0.86, 95% CI 0.52 to 1.44; Analysis 2.6). In a sensitivity analysis excluding the Forster 2013 cluster-randomised trial the RR favoured the control group, although the CI was very wide and still included no difference between groups as there were few cases in the remaining trials (RR 1.63, 95% CI 0.28 to 9.42; 326 participants; not shown).

We included three studies with data from 924 participants in the mean difference (HADS-D) random-effects meta-analysis (Eames 2013; Forster 2013; Kalra 2004). The pooled results showed little difference in HADS depression score between groups (MD -0.30, 95% CI -1.53 to 0.92; I^2 = 86%; low certainty evidence; Analysis 2.7; Summary of findings 2). There was substantial excess heterogeneity. In the fixed-effect meta-analysis the MD was larger and the CI was narrower (MD -0.69, 95% CI -1.08 to -0.31; not shown). A sensitivity analysis excluding the cluster-randomised trial by Forster 2013 produced similar results with wider confidence intervals (not shown).

Positive mental well-being

Larson 2005 measured this using the positive well-being subscale of Bradley's well-being questionnaire (W-BQ 12; Pouwer 2000). There was little difference between intervention and control groups across the range of the confidence interval (MD -0.18, 95% CI -1.34 to 0.98; 91 participants; low certainty evidence; Analysis 2.8; Summary of findings 2).

Quality of life

Larson 2005 measured quality of life using a visual analogue scale anchored at worst and best possible quality of life (0 to 100). The confidence interval was wide and differences between the intervention and the control group were not statistically significant at any time point, with the mean difference at final follow-up being 1.22 (95% CI -7.65 to 10.09; 91 participants; low certainty evidence; Analysis 2.9; Summary of findings 2).

Satisfaction with information

Satisfaction with the information received about recovery and rehabilitation

Data were available for 165 of 273 carers from two studies (Rodgers 1999; Smith 2004). Compared to the control group, the active information provision group had a lower risk of being unsatisfied with the information received about recovery and rehabilitation, although the confidence interval included the chance of a slightly higher risk (RR (non-event) 0.66, 95% CI 0.39 to 1.10; I^2 = 0%; Analysis 2.10).

Satisfaction with the information received about allowances and services

Data were available for 167 of 273 carers from two studies (Rodgers 1999; Smith 2004). Compared to the control group, the intervention group had a lower risk of being unsatisfied with the information received about allowances and services, although the confidence interval included the chance of a slightly higher risk (RR (non-event) 0.72, 95% CI 0.45 to 1.16; I^2 = 37%; Analysis 2.11).

Psychological distress

Psychological distress in carers was measured by Draper 2007 and Smith 2004 using the General Health Questionnaire (GHQ)-28 (Goldberg 1979), and by Rodgers 1999 using the GHQ-30 (Goldberg 1979). We converted scale data to dichotomous data using published cutoffs (Table 1). Rodgers 1999 also measured psychological distress using the mental health subscale of the SF-36 and we did not have scale data for the GHQ from this study so we used the negative of the SF-36 scores in the continuous analysis. Suitable data were not available to include Draper 2007 in the dichotomous meta-analysis.

Two studies with data from 176 carers were included in the dichotomous meta-analysis (Rodgers 1999; Smith 2004). The pooled results showed a marginally greater risk of psychological distress in the active information provision group (RR 1.07, 95% CI 0.83 to 1.38; I^2 = 19%; Analysis 2.12), although the confidence interval was quite wide and included no difference between groups.

We included three studies with 211 carers in an SMD meta-analysis (Draper 2007; Rodgers 1999; Smith 2004). The pooled results showed no difference between the groups on average, with the confidence interval including a small difference in favour of either group (SMD 0.00, 95% CI -0.27 to 0.28; I^2 = 0%; Analysis 2.13). The majority of data came from the GHQ-28. In a sensitivity analysis excluding Rodgers 1999, the pooled GHQ-28 favoured the intervention group on average, although the confidence interval included no difference between groups (MD -1.16, 95% CI -3.79 to 1.46; 105 participants; I^2 = 0%).

Burden

The concept of burden has an important history in studies of carers but has no agreed definition and is often used interchangeably with stress and strain. On face value, we considered the following measures to have sufficient similarity to each other to group together. Eight studies evaluated this outcome: Eames 2013 and Mudzi 2012 used the Caregiver Strain Index (Robinson 1983), Forster 2013 and Kalra 2004 used the Caregiver Burden Scale (Elmståhl 1996), Hekmatpou 2019 and Karimi 2018 used the Zarit Burden interview (Zarit 1985), Deyhoul 2018 used the Caregiver Burden Inventory (Novak 1989), and Draper 2007 used the Relatives' Stress Scale (RSS; Greene 1982).

We conducted an SMD random-effects meta-analysis including five studies with data from 1099 participants (Deyhoul 2018; Eames 2013; Forster 2013; Hekmatpou 2019; Kalra 2004). Carers in the active information provision group had moderately lower burden on average, with the confidence interval ranging from a very large to very small reduction in burden (SMD -0.74, 95% CI -1.44 to -0.03; I^2 = 96%; Analysis 2.14). There was substantial excess heterogeneity. In the fixed-effect meta-analysis there was a small to moderate reduction in burden (SMD -0.44, 95% CI -0.58 to -0.31; not shown). The estimate of Hekmatpou 2019 was notably larger than the other studies; the estimate of Kalra 2004 was also notably large. Reasons for these differences are unclear. A sensitivity analysis excluding the cluster-randomised trial by Forster 2013 produced similar results (not shown). The majority of data came from the Caregiver Burden Scale. In a sensitivity analysis, the result was

similarly heterogeneous and had a very wide confidence interval that included no difference between groups using the random-effects model (MD -4.00, 95% CI -13.80 to 5.80; 856 participants; I^2 = 96%; not shown).

Results for the other studies are tabulated in Analysis 2.15. Mudzi 2012 dichotomised data and presented an odds ratio substantially favouring the intervention group that appeared to be statistically significant, although it is unclear whether the reported CI was at the 95% level. In Draper 2007 there was insufficient information reported to compare RSS scores between the intervention and waiting-list control groups. Karimi 2018 did not present results.

Self-efficacy

No studies of active information provision evaluated this outcome.

Locus of control

No studies of active information provision evaluated this outcome.

Social activities

Three studies of active information provision evaluated carers' social activities (Draper 2007; Forster 2013; Kalra 2004). Draper 2007 did not report data suitable for inclusion in analyses. Forster 2013 and Kalra 2004 measured carers' social activities using the FAI, which we pooled in a meta-analysis including data from 865 participants. On average, social activities were lower in the active information provision group, with the confidence interval including greater social activities for the active information provision group (MD -0.40, 95% CI -1.16 to 0.37; I^2 = 0%; Analysis 2.16). There was no evidence of excess heterogeneity. A sensitivity analysis excluding the Forster 2013 cluster-randomised trial produced similar results with no mean difference between groups (not shown).

Perceived health status

Six studies measured carer health status and compared active information provision with a control (Forster 2013; Johnston 2007; Kalra 2004; Larson 2005; Mudzi 2012; Rodgers 1999). Forster 2013 reported results adjusted for clustering.

Three studies administered the EQ-5D, only one of which reported the index value (Forster 2013); Forster 2013 and Kalra 2004 reported quality-adjusted life years (QALYs) for the year poststroke, Mudzi 2012 only described trends. Because QALYs were reported by two studies we used these in a meta-analysis with 768 participants; we did not analyse the EQ-5D index as the QALY data are partly derived from it. On average, there was no difference in QALYs, a narrow confidence interval and no excess heterogeneity (MD 0.00, 95% CI -0.01 to 0.02; I^2 = 0%; Analysis 2.17). A sensitivity analysis excluding the cluster-randomised trial by Forster 2013 produced similar results, although the MD slightly favoured the intervention group (MD 0.01, 95% CI -0.02 to 0.04; 232 participants; not shown).

Two studies reported the EQ-VAS (Kalra 2004; Larson 2005), which we pooled in a meta-analysis including data from 323 participants. There was substantial excess heterogeneity (I^2 = 91%) so we conducted a random-effects meta-analysis. On average, carers in the intervention group reported a slightly better health status although there was a very wide confidence interval that may include substantial benefit and harm (MD 3.52, 95% CI -9.83 to 16.87; Analysis 2.18). In the fixed-effect meta-analysis the MD was larger and the CI was narrower (MD 6.91, 95% CI 3.51 to 10.31; not shown). The confidence intervals of the two studies did not overlap, which may be due to the time poststroke of the studies.

In Rodgers 1999 there was a wide confidence interval and no statistically significant difference between carers in the intervention and control groups, as measured by the general health subscale of the SF-36 (Analysis 2.19). Johnston 2007 measured the physical function subscale of the SF-36 for carers but did not report results.

Resource outcomes

Cost to health and social services

Only two studies evaluated resource use, both of which evaluated the same intervention (Forster 2013; Kalra 2004; Analysis 3.1). In Forster 2013, total health and social care costs over one year for stroke survivors and for carers were greater in the intervention arm, but not significantly so. In Kalra 2004, total health and social care costs over one year for stroke survivors whose carers received training (intervention) were significantly lower. The cost differences were largely due to differences in length of hospital stay.

Passive information provision

Stroke-survivor outcomes

Knowledge of stroke and stroke services

Six studies of passive information provision assessed stroke-survivor knowledge (Hoffmann 2007; Lomer 1987; Lowe 2007; Maasland 2007; Mant 1998; Pain 1990). We were able to pool results of three studies in a standardised mean difference random-effects meta-analysis (Hoffmann 2007; Lowe 2007; Maasland 2007); the other three studies used unvalidated instruments. Knowledge of stroke and stroke services in the passive information group was better on average by a small amount (SMD 0.23, 95% CI -0.23 to 0.69; 270 participants; I^2 = 70%; very low certainty evidence; Analysis 4.1; Summary of findings 3). There was substantial heterogeneity and the confidence interval ranged from a small effect in favour of the control group to a moderate effect in favour of the passive information provision group. The fixed-effect meta-analysis produced similar results with a slightly narrower confidence interval (not shown).

Anxiety

Three studies of passive information provision measured anxiety in 227 stroke survivors; all three studies used the anxiety subscale of the HADS (Downes 1993; Hoffmann 2007; Mant 1998). Sufficient data were available to include these studies in both dichotomous and continuous analyses.

The estimate for the pooled RR of anxiety was very imprecise (RR 1.54, 95% CI 0.82 to 2.88; I^2 = 0%; very low certainty evidence; Analysis 4.2; Summary of findings 3), with no evidence of heterogeneity.

The pooled mean difference showed a higher mean HADS-A score in the passive information group (MD 0.67, 95% CI -0.37 to 1.71; I^2 = 0%; low certainty evidence; Analysis 4.3; Summary of findings 3), with no evidence of heterogeneity.

Depression

Five trials of passive information provision measured stroke-survivor depression; three trials used the depression subscale

of the HADS (Downes 1993; Hoffmann 2007; Mant 1998), Jones 2018 used the Center for Epidemiological Studies Depression scale (CES-D; Radloff 1977) and Lowe 2007 used the Yale single question (Mahoney 1994).

We included five studies with data from 361 participants in the dichotomous analysis (Downes 1993; Hoffmann 2007; Jones 2018; Lowe 2007; Mant 1998). The estimate for the pooled RR of depression was very imprecise (RR 1.12, 95% CI 0.84 to 1.50; I^2 = 27%; very low certainty evidence; Analysis 4.4; Summary of findings 3), with little evidence of excess heterogeneity.

We included three studies with data from 227 participants in the mean difference (HADS depression) meta-analysis (Downes 1993; Hoffmann 2007; Mant 1998). The pooled results showed a higher mean HADS depression score in the passive information group (MD 0.39, 95% CI -0.61 to 1.38; I^2 = 0%; low certainty evidence; Analysis 4.5; Summary of findings 3), with no evidence of excess heterogeneity.

Positive mental well-being

No trials of passive information provision evaluated this outcome.

Quality of life

Two studies of passive information provision measured quality of life using the quality of life subscale of the Dartmouth Primary Care Cooperative (COOP) charts (Nelson 1990) (Hoffmann 2007; Mant 1998), which we included in a random-effects meta-analysis with 198 participants. Higher scores on the COOP charts are associated with worse outcomes. On average, stroke survivors in the intervention group had a slightly higher quality of life score, although there was a wide confidence interval that may include substantial benefit and harm (MD 0.04, 95% CI -0.45 to 0.53; I^2 = 70%; very low certainty evidence; Analysis 4.6; Summary of findings 3). There was substantial excess heterogeneity. The fixed-effect meta-analysis produced similar results but with a narrower confidence interval (not shown).

Satisfaction with information

Satisfaction with the information received about the causes and nature of stroke

Two trials with data from 143 stroke survivors contributed to the meta-analysis (Lowe 2007; Mant 1998). Compared to the control group, the intervention group had a lower risk of being unsatisfied with the information received about the causes and nature of stroke, but the confidence interval included the chance of equal risks (RR (non-event) 0.63, 95% CI 0.34 to 1.18; I^2 = 0%; Analysis 4.7). There was no evidence of heterogeneity.

Satisfaction with the information received about allowances and services

One trial with data from 57 stroke survivors presented data for this outcome (Mant 1998). Compared to the control group, the intervention group had a higher risk of being unsatisfied with the information received about allowances and services, but the confidence interval was very wide, including substantially lower risk (RR (non-event) 1.76, 95% CI 0.61 to 5.05; Analysis 4.8).

Psychological distress

Three studies of passive information provision measured psychological distress: Hoffmann 2007 and Mant 1998 used the feelings subscale of the COOP charts and O'Connell 2009 used the emotions subscale of the SIS. We took the negative value of the SIS scores so that greater scores indicate greater distress. Hoffmann 2007 presented results as mean change from baseline, so to include the study in an SMD meta-analysis we added the change scores to the mean baseline scores for each group and used the baseline standard deviation for each group. We were unable to conduct a dichotomous meta-analysis.

We included these studies in an SMD meta-analysis with 264 participants. On average, stroke survivors in the intervention group had a very small amount more psychological distress, although the confidence interval included a very small amount less psychological distress for this group (SMD 0.15, 95% CI -0.09 to 0.39; I^2 = 15%; Analysis 4.9). In a sensitivity analysis using the change score and baseline SD presented by Hoffmann 2007 the pooled results were very similar. In a further sensitivity analysis excluding Hoffmann 2007, on average the intervention group had a small amount more psychological distress than the control group, although the confidence interval still included no difference between groups (SMD 0.31, 95% CI -0.04 to 0.66; 2 studies; 131 participants). The majority of data came from the COOP feelings chart, for which there were similar results (MD 0.13, 95% CI -0.22 to 0.48; I^2 = 0%; 2 studies; 198 participants) in a sensitivity analysis that excluded O'Connell 2009.

Self-efficacy

Hoffmann 2007 and Jones 2018 evaluated stroke-survivor self-efficacy, but we were unable to assess any results. Hoffmann 2007 used an instrument with no overall scale, only six subscales; Jones 2018 did not report results.

Locus of control

No trials of passive information provision evaluated this outcome.

Modification of health-related behaviours

Three trials evaluated this outcome (Banet 1997; Lowe 2007; Maasland 2007) (Analysis 4.10). The Banet 1997 trial reported no statistically significant difference in scores for diet or medication between the group who received their medical records and the group that received information leaflets only, although did not report the actual results. In Lowe 2007, there were no statistically significant differences in blood pressure between the intervention group and control groups. In Maasland 2007, those who regularly used tobacco or alcohol reduced these behaviours more in the intervention group, but differences were not significant. There was a decrease in systolic and diastolic blood pressure in the intervention and control group but no significant difference between the groups. Stroke survivors in neither group reduced their weight. Serum cholesterol dropped significantly in both the intervention and the control group, with no differences between the groups.

Independence in activities of daily living

Two trials of passive information provision measured independence in ADL using the Barthel Index (Mant 1998; Pain 1990). Pain 1990 reported the Barthel Index on the 0 to 100 scale, which we transformed to 0 to 20 for comparability with other results. We included data from 100 participants from these two trials in a mean difference meta-analysis. The Barthel Index (0 to 20) was slightly lower in the passive information provision group, on

average by -0.8 (95% CI -2.83 to 1.23; I^2 = 0%; Analysis 4.11). There was no evidence of heterogeneity.

Social activities

One trial evaluated the effect of passive information provision on social activities using the Frenchay Activities Index (Holbrook 1983). Pain 1990 reported no significant difference in social activities between the intervention and control groups (Analysis 4.12).

Perceived health status

Three studies of passive information provision evaluated the effect on perceived health status. Two used the overall health subscale of the COOP charts (Hoffmann 2007; Mant 1998), and one used the recovery subscale of the SIS (Duncan 1999) (O'Connell 2009). We pooled the results from the COOP charts; we did not conduct an SMD meta-analysis as we considered the two subscales to be distinct constructs within the health status domain.

On average, overall health measured using the COOP charts was slightly better in the passive information provision group, although the confidence interval included slightly better overall health in the control group (MD -0.13, 95% CI -0.45 to 0.19; 198 participants; I^2 = 0%; Analysis 4.13) (lower scores indicate better overall health).

O'Connell 2009 found no significant difference between the intervention and control group, as measured by the recovery subscale of the SIS (Analysis 4.14).

Recurrent stroke

No studies of passive information provision evaluated this outcome.

Death

Mortality data were available for 331 participants from three studies of passive information provision (Hoffmann 2007; Lowe 2007; Mant 1998). The odds of death within the study period were lower in the passive information provision group, although the confidence interval was very wide, including substantially higher odds of death (Peto OR 0.80, 95% CI 0.34 to 1.86; I^2 = 0%; Analysis 4.15).

Carer outcomes

Knowledge of stroke and stroke services

One trial of passive information provision provided usable data (Mant 1998). The estimate of the effect on carer knowledge was very imprecise (SMD 0.28, 95% CI -0.42 to 0.97; 33 participants; very low certainty evidence; Analysis 5.1; Summary of findings 4).

Two small trials did not contribute data to the meta-analysis (Lomer 1987; Pain 1990) due to the use of outcome measures which did not have evidence of adequate reliability and validity.

Anxiety

In Downes 1993, the estimate of the effect on carer anxiety as measured by the HADS was very imprecise (MD -0.3, 95% CI -3.25 to 2.65; 40 participants; very low certainty evidence; Analysis 5.2; Summary of findings 4).

Depression

In Downes 1993, the estimate of the effect on carer depression as measured by the HADS was very imprecise (MD 0.7, 95% CI -1.93 to 3.33; 40 participants; very low certainty evidence; Analysis 5.3; Summary of findings 4). Jones 2018 did not present data for the carer CES-D.

Positive mental well-being

No trials of passive information provision evaluated this outcome.

Quality of life

No trials of passive information provision evaluated this outcome.

Satisfaction with information

Carer satisfaction with the information received about recovery and rehabilitation

No trials of passive information provision evaluated this outcome.

Carer satisfaction with the information received about allowances and services

Only one study with 47 participants contributed data (Mant 1998). Compared to the control group, the intervention group had a higher risk of being unsatisfied with the information received about allowances and services, although confidence intervals were very wide (RR (non-event) 1.48, 95% CI 0.52 to 4.24). (Analysis 5.4).

Psychological distress

One study of passive information evaluated this outcome using the mental health subscale of the SF-36 (Mant 1998). There was no significant difference between the intervention and control group (Analysis 5.5).

Burden

Jones 2018 and Mant 1998 evaluated carer burden using the Caregiver Strain Index. In Mant 1998 there was no statistically significant evidence of an effect of passive information on carer burden. Jones 2018 did not present data (Analysis 5.6).

Self-efficacy

No trials of passive information provision evaluated this outcome.

Locus of control

No trials of passive information provision evaluated this outcome.

Social activities

No trials of passive information provision evaluated this outcome.

Perceived health status

One study of passive information provision evaluated this outcome using the SF-36 general health subscale (Mant 1998). Differences between the groups were not statistically significant, but there were very few participants in either group (Analysis 5.7).

Resource outcomes

Cost to health and social services

No trials of passive information provision evaluated this outcome.

Active versus passive information provision

No trials compared active and passive information provision.

DISCUSSION

Summary of main results

We found evidence that the addition of active information provision to usual care may slightly improve some important stroke-survivor outcomes (Summary of findings 1), but the evidence is generally very uncertain for effects on carers (Summary of findings 2), or the effects of passive information provision (Summary of findings 3; Summary of findings 4). We included evidence from 33 trials overall: 22 trials with 4401 stroke-survivor and 2852 carer participants compared active information provision to usual care; and 11 trials with 854 stroke-survivor and 282 carer participants compared passive information provision to usual care. No trials compared active and passive information provision (Summary of findings 5). The evidence from most studies was at sufficiently high risk of bias to affect the interpretation of results.

Active information provision

Evidence from three trials suggested active information provision may increase stroke-survivor knowledge of stroke and stroke services slightly or moderately. Evidence from five trials suggested active information provision may slightly reduce cases of stroke-survivor anxiety, although the confidence interval included no effect and a reduction of cases by almost one third. However, evidence from the same trials plus one small trial suggested active information provision may slightly reduce stroke-survivor anxiety symptoms, although it is unclear if this amount of change would be clinically meaningful. Evidence from six trials suggested active information provision may slightly reduce cases of stroke-survivor depression, although again the confidence interval included no effect and a reduction of cases by almost one third. However, evidence from the same trials suggested active information provision probably reduces stroke-survivor depressive symptoms slightly, although it is unclear if this amount of change would be clinically meaningful. No studies reported the effect on positive mental well-being. Evidence from one small study suggested active information provision may improve the four quality of life domains measured by the WHOQOL-BREF: physical, psychological, social and environment. There was some evidence that active information provision may improve satisfaction with information, and may have a very small effect on stroke survivors' independence in activities of daily living. However, there was some evidence of little to no effect on their level of psychological distress or social activities, while results were inconclusive regarding self-efficacy, locus of control, health status, risk of recurrent stroke and death. The limited evidence of little to no effect on survivors' psychological distress is a further reason for caution regarding any effects on anxiety and depression.

For carers, the effect of active information provision was very uncertain for knowledge, cases of anxiety and cases of depression. Active information provision may slightly reduce carer symptoms of anxiety and depression (three trials). Active information provision may result in little to no effect on positive mental well-being or quality of life (one trial), or on social activities (two trials). Results were inconclusive regarding satisfaction with information, cases and levels of psychological distress, burden and health status. No studies reported the effect on self-efficacy or locus of control.

Passive information provision

Passive information provision may slightly increase stroke-survivor symptoms of anxiety and depression (three trials). The effect of passive information provision was very uncertain for stroke survivors' knowledge, cases of anxiety, cases of depression and quality of life. No studies reported the effect on positive mental well-being. Passive information provision may slightly increase stroke-survivor levels of psychological distress. The effect of passive information provision was very uncertain for stroke-survivor satisfaction with information, independence in activities of daily living, social activities, health status, or death. There was no evidence regarding self-efficacy, locus of control or risk of stroke recurrence.

For carers, the effect of passive information provision was very uncertain for knowledge, and symptoms of anxiety and depression. There was no evidence regarding carer cases of anxiety, cases of depression, positive mental well-being or quality of life. The effect was very uncertain for satisfaction with information, psychological distress, burden and health status. There was no evidence regarding the effects of passive information provision on carer self-efficacy, locus of control or social activities.

Active versus passive information provision

There was no direct evidence comparing active and passive information provision. Observation of the indirect comparison via usual care, which must be interpreted with caution, suggests there may be a divergence of effect on stroke-survivor symptoms of anxiety and depression. Active information provision may slightly improve these symptoms while passive information provision may slightly worsen them. Further caution is warranted as the evidence for each direct comparison is of low certainty (moderate certainty for the effect of active information provision on depressive symptoms).

Overall completeness and applicability of evidence

There was extensive variation in the content and delivery format of the interventions. This appears to reflect the diversity of interventions provided within clinical practice. Whilst there were some data to address the primary outcomes and the majority of secondary outcomes for this review, few studies contributed to each outcome comparison. Of the main outcomes, data were particularly limited regarding quality of life and positive mental well-being. Overall, evidence was more limited for passive information provision, and no studies directly compared active information provision with passive information provision.

Our evaluation of the effect of passive or active information provision on the outcome of stroke-related knowledge was limited by a lack of a consistently-used measure. Knowledge of stroke and stroke services was assessed in 12 of the 33 studies reviewed (Boden-Albala 2015; Eames 2013; Evans 1988; Hoffmann 2007; Kamal 2016; Lomer 1987; Lowe 2007; Maasland 2007; Mant 1998; Pain 1990; Rodgers 1999; Smith 2004), but as each study within each comparison had used a different questionnaire, combining the results in a meta-analysis was problematic. Our initial intention was to perform a meta-analysis using dichotomised data (knowledge improved or not improved). However, this was not feasible as in some trials knowledge was measured on one occasion only. We therefore combined the data using the SMD wherein the MDs in outcome between the groups being studied are standardised to

account for differences in scoring methods. A disadvantage with this method is that interpretation of the clinical relevance of the treatment effect is difficult as estimated effect sizes serve only as a qualitative measure of the strength of evidence against the null hypothesis (de Beurs 1999). The results should therefore be treated with some caution. In addition, there was limited information about the reliability of the majority of bespoke questionnaires used to measure knowledge.

We were uncertain whether the size of the point-estimates of effects on anxiety and depressive symptoms were clinically meaningful, due to a lack of internationally agreed standards. The estimates were less than a single point change for the average participant. This suggests that some individual participants reported a single point change, which would be a small change in one symptom, while others reported no change. We judged the point-estimates to indicate small changes that may be important to some, but not all, participants.

Few studies included participants with aphasia and cognitive problems. This substantially limits the applicability of the results given that around a third of stroke survivors experience aphasia (Engelter 2006; Laska 2001), and even more experience cognitive impairment (Jokinen 2015; Liao 2020).

Current practice on information provision after stroke varies nationally and internationally. Our review identified studies from twelve countries. Therefore, confidence in the international applicability of findings remains limited, but is improved in this updated review. Notable additions include three studies in Iran (Deyhoul 2018; Hekmatpou 2019; Karimi 2018), one in New Zealand (Jones 2018), one in Pakistan (Kamal 2016), one in South Africa (Mudzi 2012), and one in South Korea (Kim 2013).

Certainty of the evidence

We did not have high confidence in the estimate of effect for any of the outcomes that we formally evaluated with GRADE. We had moderate confidence in only one outcome (stroke-survivor depressive symptoms after active information provision), and generally low or very low confidence in the evidence (see Summary of findings 1; Summary of findings 2; Summary of findings 3; Summary of findings 4). Risk of bias was a serious limitation in the evidence for all outcomes (very serious limitation for one outcome). There was usually concern relating to performance bias due to the difficulties of blinding participants and personnel when the intervention is information provision, and consequent concerns for detection bias when unblinded participants self-reported outcomes. For some outcomes we were seriously concerned about attrition bias. Imprecision was often a serious or very serious limitation in the evidence because the pooled sample size was insufficient, or because the confidence interval included no effect and substantial benefit/harm, or both. Sometimes there were problems with inconsistency in the evidence, where individual study confidence intervals did not overlap, or only did so marginally, and statistical heterogeneity was substantial. Given the diversity of interventions, timing and settings this inconsistency is not surprising, but still limits our confidence in the applicability of the estimates.

Potential biases in the review process

Our search strategy was comprehensive and as we were able to identify a number of unpublished studies, publication bias is unlikely.

Our eligibility criteria regarding the intervention were sometimes difficult to apply. Distinguishing interventions solely consisting of information provision from interventions incorporating other components, such as emotional support or reminders, was sometimes challenging. It was also difficult to distinguish information provision from psychoeducation or paper-based self-management interventions, for example. Making these judgements was often hampered by the reporting of interventions, as well as the lack of a definitive boundary between such intervention types. Two people undertook study selection and data collection, with a third person or consensus meeting used to resolve differences. Attempts to obtain additional data were often successful, though not always, but usually this related to a small proportion of the participants included in an analysis. As a result, we are confident of limited bias relating to our selection of studies and handling of data.

As acknowledged elsewhere there was substantial heterogeneity in the interventions, timing and settings for studies. This did not often result in statistical heterogeneity. To some extent, the clinical heterogeneity was addressed by categorising interventions as active or passive. Our subgrouping strategy did not resolve statistical heterogeneity as there were no analyses with ten or more studies .

The interventions in this review had a variety of aims, including: improving aspects of recovery; reducing carer burden; changing health behaviours to prevent recurrence; and improving speed of presentation to an emergency department in the case of recurrence. This variety may reflect an important limitation in the review process. Because of the risk of information overload, it is not clear that the effects of different information provision interventions at the same time will be additive; indeed, if not managed appropriately, they may negatively interact.

Usual care will almost always involve some information provision, however ad-hoc and informal. This base level of information provided to both arms is likely to interact with the experimental intervention. Therefore, the comparisons may be better conceptualised as always being between two types of information provision. Moreover, the experimental intervention is likely to interact with other contextual factors, such as available services and social norms. However, given the lack of information typically provided about usual care and context in randomised controlled trials, it may be difficult to investigate such differences through a systematic review of intervention effectiveness .

Alternative approaches to synthesis, such as a network meta-analysis or realist synthesis, may be more appropriate given the variation between most studies.

Agreements and disagreements with other studies or reviews

A Cochrane Review of self management programmes for people with stroke found generally low quality evidence of possible small effects, similar to the findings for active information provision in this review (Fryer 2016). A Cochrane Review of stroke liaison workers for stroke survivors and carers using individual

participant data found evidence that there were probably no effects on important outcomes, except among stroke survivors with mild to moderate disability (Ellis 2010). The lack of individual participant data in this review reduces the power available for such comparisons. The lack of effect evident for stroke liaison workers for most types of participants is a reason to be cautious about the plausible effects of information provision.

In other conditions, evidence of the effects of information provision is varied. In multiple sclerosis it probably increases disease-related knowledge (Köpke 2018). This finding, which is stronger than in this review, may relate to the use of narrative synthesis in that review. Similarly, for people with diabetic kidney disease, education programmes probably improve participants' knowledge of diabetes and some self-management behaviours (Li 2011). The large effect seen in this population may relate to the more specific set of knowledge needed by comparison with stroke. Similar findings to this review were found for adults with asthma, for whom information may improve symptoms and knowledge, but did not appear to improve health outcomes (Gibson 2002). A systematic review of education for adults with rheumatoid arthritis showed a small effect on depression (Riemsma 2003). A meta-analysis of patient teaching strategies showed that the greatest effect size was associated with reinforcement, independent study, and the use of multiple strategies (Theis 1995). Given the substantial differences between these conditions and stroke, caution should be taken; the transferability of findings to stroke is likely to be limited.

Future direction

While reports of information 'needs' are ubiquitous, there is insufficient understanding of the ways in which stroke survivors expect to benefit from information. This means it is unclear which types of outcomes should be evaluated and what effects could be considered successful. Reflecting the diversity of aims related to the interventions, studies often measured different sets of outcomes, meaning our analyses typically include only a small subsample. This highlights the importance of a core outcome set relevant to information provision after stroke.

The relatively small effects identified in this review suggest more effective information provision strategies after stroke need to be developed. The results of the review suggest that a strategy based on an active, rather than passive, provision should be adopted. This is perhaps unsurprising as stroke is a complex condition with wide-ranging effects and probably requires a more comprehensive approach to promote recovery than can be achieved by the provision of passive information alone. The specific attributes of the active information provision (i.e. involving recipients, planned follow-up or reinforcement), which resulted in modest beneficial effects on some outcomes, requires further investigation. There may also be situations where information provision is not the appropriate response to a person's need, for example because the information does not exist. Therefore, adjuncts to information provision should also be considered. Future work should focus on the further development of a generalisable intervention suitable for the vast majority of stroke survivors that could be robustly evaluated in a large multicentre study.

AUTHORS' CONCLUSIONS

Implications for practice

Adding active information provision to usual care may slightly improve some important stroke-survivor outcomes, but effects are generally very uncertain for carers, or in the case of passive information provision. Actively providing information may improve knowledge of stroke and stroke services, increase some aspects of stroke-survivor satisfaction, slightly reduce cases and symptoms of anxiety and depression in stroke survivors, and improve quality of life. Providing information passively may have a slightly negative effect on survivor anxiety and depression. The effects of providing information on other stroke-survivor and carer outcomes is generally uncertain. Although the best way to provide information is still not clear, the results of this review suggest that strategies that actively involve stroke survivors and carers and include planned follow-up for clarification and reinforcement should be used in routine practice, and favoured over passive approaches.

Implications for research

Future work should focus on the further development of a generalisable intervention which could be robustly evaluated in a large multicentre study. The evaluation of interventions is currently limited by the lack of a widely recognised measure of stroke-related knowledge. Attention should be given to the design, development and evaluation of a stroke-related knowledge questionnaire. Further consideration should be given to the most appropriate outcome domains for this type of intervention, in particular whether they reflect the expectations and aspirations of stroke survivors and their carers. Information provision for people with aphasia and cognitive impairment also requires further attention.

ACKNOWLEDGEMENTS

Northern and Yorkshire NHS Executive Research and Development Directorate funded the original review. This publication presents independent research funded by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Numbers RP-PG-0606-1128 and RP-PG-0611-20010). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care. We would like to thank the authors who provided additional information and data: H Rodgers, H Pain, R Evans, J Mant, L Lorenc, J Johnson, V Morrison, L Kalra, R Hartke, IW Miller, S Jian, D Lowe, T Hoffmann, L Kalra, G Ellis, Dongbo Fu, E Maasland, B Draper, B O'Connell, M Johnston, K Jones, AF Abdul Aziz, A Kamal, B Lapergue, WH Hou, S Eames and P Vasli. We also wish to thank Deirdre Andre and Sally Dalton (University of Leeds), and Josh Cheyne (Cochrane Stroke Group), who undertook the search strategies, and Sadia Ahmed, Alex Benham, Caroline Brundle, Andre Etchebarne, Eleanor Grant, Ruth Illingworth and Seline Ozer for assisting with reviewing the papers. We are also grateful for the ongoing support of Hazel Fraser from the Cochrane Stroke Group.

John Young was previously an author of this review, who contributed to its conception, design and funding proposal. John Wright is a previous author who assisted in designing the review and writing the research proposal. He also provided methodological expertise. Previous authors John Wright, John

Young, Allan House and Jane Smith all contributed to refining the original protocol. Jane Smith contributed to co-ordinating the first update of the review. Previous author Mark Perry contributed to developing the initial protocol for this update.

We are pleased to acknowledge the peer review provided by consumers, including from Mbaka Fon Nji.

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* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Banet 1997

Study characteristics	
Methods	Participants who met all criteria and volunteered to participate were randomly assigned to treatment group; no further details given. No stated blind outcome assessment 6 participants lost to follow-up; no report of differential losses between groups 6-month follow-up
Participants	St Louis, Mo, USA 58 first-time stroke patients: number allocated to intervention or control not given No details of age Sex: women N = 28 Inclusion criteria: aged 18 years or older, first-time stroke, medically stable, competent to give informed consent, ready for hospital discharge Exclusion criteria: aphasia or motor impairments that hindered ability to complete forms unless neurologist believed it did not interfere with giving consent and had a carer who could help complete forms, or could dictate answer to investigator. N = 52 for final follow-up
Interventions	Treatment: passive. Copy of medical history, clinical resumes, notes on outpatient visits, x-ray, scan reports and pertinent laboratory results. Also received patient education packet containing leaflets on stroke care, stroke team, tests and procedures, community resources, defining terms, facts about stroke, how stroke affects behaviour and recovering from stroke. Focus: stroke survivor Setting: hospital Administration: unclear who gave record Encouraged to maintain records by incorporating updated information by taking them to all appointments with physicians and all trips during the study 1 contact, length unknown Patients ready for discharge Control: given patient education packet containing leaflets on stroke care, stroke team, tests and procedures, community resources, defining terms, facts about stroke, how stroke affects behaviour and recovering from stroke

Banet 1997 *(Continued)*

Outcomes	• Intention to modify health-related behaviours and compliance: Miller's Health Intention Scale and Miller's Health Behaviour Scale (stroke survivor; baseline and 6 months) **Not included in this review (not a prespecified outcome of interest)** • Glasgow Outcome Scale (stroke survivor; baseline and 6 months) • Global Outcome (stroke survivor; baseline and 6 months)
Details of funding sources	Supported by a grant from the Missouri Affiliate of the American Heart Association
Notes	Validity assessment: use of inappropriate statistical tests

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	The procedure for generating a random sequence was not reported.
Allocation concealment (selection bias)	Unclear risk	Reported that stroke survivors were randomly assigned but method not described.
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants or personnel but as no intervention provided for the control group, group assignment would have been apparent.
Blinding of outcome assessment (detection bias) All outcomes	High risk	It was not reported if outcome assessments were blinded, however, participants self-reporting outcomes would have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Quote: "One volunteer died, and five provided incomplete data. Thus data from 52 subjects [were] available for analysis." Although losses were relatively small, it was not reported which groups they were from.
Selective reporting (reporting bias)	Unclear risk	Quote: "Subjects reported their intentions to modify health-related behaviours by completing the diet, smoking, and medication sub-scales of Miller's Health Intention Scale." Quote: "Because so few subjects smoked, this was not included as a variable in the analysis." Comment: note that this question was typically answered (i.e. data were not generally missing), but only 7 smoked at the time of their stroke
Other bias	Low risk	No other obvious sources of bias

Boden-Albala 2015

Study characteristics

Methods	Stratified RCT 30 losses to follow-up Follow-up at 30 days, 1 year, then annually for 5 years

Boden-Albala 2015 *(Continued)*

Participants	USA 1193 participants: multi-ethnic stroke/transient ischaemic attack survivors Age mean: 63 (SD = 15) 50% women Inclusion criteria: ischaemic stroke or TIA diagnosis, over 18 years of age, living in a household with a telephone, participants were either an English or Spanish speaker. Exclusion criteria: unable to give informed consent, discharged to long-term nursing care, had severe aphasia limiting comprehension, had a prestroke dementia history or end-stage disease resulting in probable mortality ≤ 1 year
Interventions	Intervention: active. Interactive intervention with enhanced education for stroke survivors to facilitate the early recognition of stroke warning signs, and increase the speed with which stroke survivors present to the emergency department after stroke onset. 2 sessions delivered by 2 health educators using Powerpoint presentation, narrative video, role-playing techniques, standardised packet of preparedness focused education materials Control: participants in both groups received a standardised packet of preparedness focused education materials.
Outcomes	• Knowledge about stroke: Stroke Knowledge Survey (29 items; dichotomised < 23 vs ≥ 23) • Recurrent strokes • Modification of health related behaviours: time from first symptoms to ED arrival (reported or elicited based on responses to a sequence of questions) **Not included in this review (not a prespecified outcome of interest)** • Preparedness capacity (3 items; dichotomised < 100% vs 100%) • Hospitalisations/Recurrent TIAs/stroke mimics **Not included in this review (insufficient information provided)** • Deaths
Details of funding sources	National Institute of Health National Institute of Neurological Disorders and Stroke (NINDS) through the Specialized Programs of Translational Research in Acute Stroke (SPOTRIAS) Network, P50 NS049060 P. 3, and the Robert Wood Johnson Health and Society Scholars Pilot Funds.
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer programme used to generate the sequence. Quote: "patients are randomized, using a computer generated randomization program, into usual care or intervention group"
Allocation concealment (selection bias)	Unclear risk	Methods of allocation concealment are not described.
Blinding of participants and personnel (performance bias) All outcomes	High risk	The participants were aware of the allocated intervention as the educational handouts given to both groups were provided prior to randomisation. Therefore, their performance in the trial may be influenced by this knowledge.

Boden-Albala 2015 *(Continued)*

Blinding of outcome assessment (detection bias) All outcomes	High risk	Stroke knowledge and preparedness capacity are self-reported outcome measures. Although the assessors were blinded to the intervention status, the information provided by the participants may be influenced by their awareness of their allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Dropouts reported and reasons given. ITT analysis used. 19/601 (3.2%) participants in intervention group, and 11/592 (1.9%) of the standard care group did not complete the trial. The reasons and number of incomplete follow-ups are unlikely to affect the overall results.
Selective reporting (reporting bias)	High risk	Death was a prespecified outcome, but numbers per group were not reported, only as total and lack of statistical significance.
Other bias	Low risk	Appears to be free of other risks of bias.

Chinchai 2010

Study characteristics	
Methods	Cluster-RCT No participants lost to follow-up
Participants	Chiang Mai, Thailand Six subdistricts were clusters of 10 stroke survivors and their carers each. Two subdistricts were randomly selected from each of 3 randomly selected districts. Ten eligible stroke survivors randomly selected in each subdistrict from those available. 60 stroke survivors and their primary carers (N = 60) Stroke survivors: intervention N = 30; control N = 30 Carers: intervention N = 30; control N = 30 Age range of stroke survivors intervention (years): < 40 N = 9; 40 to 59 N = 8; 60 to 69 N = 9; 70 to 79 N = 7 Age range of stroke survivors control (years): < 40 N = 4; 40 to 59 N = 8; 60 to 69 N = 5; 70 to 79 N = 13 Sex of stroke survivors (men): intervention 60%; control 53% Age range of carers intervention (years): < 40 N = 2; 40 to 59 N = 8; 60 to 69 N = 11; 70 to 79 N = 9 Age range of carers control (years): < 40 N = 5; 40 to 59 N = 12; 60 to 69 N = 6; 70 to 79 N = 7 Sex of carers (men): intervention 47%; control 53% Inclusion criteria for stroke survivors: discharged from hospital < 18 months, physical function recovery level 2 to 4 classified by Brunnstorm; communication (verbal, non-verbal), no complications (e.g. bedsores, pain, fever during data collection), willingness to participate in the study Inclusion criteria for carers: primary carer (family member or relative), not previously attended the home health care and stroke rehabilitation programme, minimum 8 hours a day caring, willingness to participate in the study Exclusion criteria: not reported
Interventions	Intervention: active. Education programme for carers with follow-up reinforcement. Included lectures and active practice of activities of daily living and written information in guidebooks. Intervention

Chinchai 2010 *(Continued)*

	started within 18 months of patient stroke. Carers attended a 1-day, 7-hour education session on 3 consecutive weeks and received weekly visits for reinforcement by health service volunteers Focus: patient and carer Setting: primary healthcare unit Administration: occupational therapists with a minimum of 2 years experience Control: usual care information from health stations located in the community
Outcomes	• Quality of Life: WHOQOL-BREF-THAI (stroke survivor; 7 days pre-intervention and 2 months post intervention)
Details of funding sources	National Research Council of Thailand
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	The procedure for generating a random sequence was not reported.
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	Although not specifically reported, control participants received usual care, therefore the (lack of) intervention would have been obvious
Blinding of outcome assessment (detection bias) All outcomes	High risk	Research assistants blind to group assignment performed assessments. However, participants self-reporting outcomes would have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	No dropouts or exclusions
Selective reporting (reporting bias)	High risk	When describing the WHOQOL-BREF the authors report the individual items for overall health and overall QOL, as well as a total score (the summation of all items). However these were not presented in the results
Other bias	Low risk	No other obvious sources of bias

Chiu 2008

Study characteristics

Methods	RCT by simple random sampling. Stroke survivors were stratified by age (over 65 or not) and sex 4 stroke survivors from the control group and 2 stroke survivors from the intervention group lost to follow-up
Participants	Kaohsiung, Taiwan

Chiu 2008 *(Continued)*

	160 stroke survivors (intervention N = 80, control N = 80) Mean age of stroke survivors: intervention 66 years; control 65 years Sex of stroke survivors (men): 50% Inclusion criteria: stroke out-patients who had visited clinics regularly after stroke (> 12 months) Exclusion criteria: enrolled in other studies, terminal illness, no consent
Interventions	Intervention: active. Consultation (drug effects, lifestyle modification, benefits of therapies, importance of compliance, verification of drug interaction and reminder of adverse events). Focus: stroke survivors Setting: unclear Administration: intervention delivered by pharmacist over 6 x 1-hour sessions over a 6-month period Control: no information reported

Outcomes	• Modification of health related behaviours: compliance with treatment/rehabilitation (stroke survivor; before and after study [during clinic visits, not scheduled])
	  ○ Management of hypertension: BP < 140/90 mmHg
	  ○ Management of lipids: low-density lipoprotein (LDL) cholesterol < 100 mg/dL or, if LDL was not available, total cholesterol (TC) < 160 mg/dL.
	  ○ Management of glucose: glycosylated haemoglobin A1c (HbA1c) < 7% or, if HbA1c not available, FBG < 126 mg/dL

Details of funding sources	Investigator initiated with reporting of no conflicts of interest or financial support
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Described as simple random sampling but method of sequence generation not reported
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No information reported
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No information reported
Incomplete outcome data (attrition bias) All outcomes	Low risk	Small number lost to follow-up (2 from intervention and 4 from the control)
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious signs of bias

Deyhoul 2018

Study characteristics	
Methods	RCT. The report states that "intention-to-treat analysis" was considered. However, not all randomised participants were included in the results reported. It appears those not included were either readmitted to hospital or died. 28 dyads lost to follow-up
Participants	Iran Pairs of stroke survivors and their family carers Number of participants assessed not reported 118 dyads randomised (236 participants assigned): control n = 60 dyads, intervention n = 58 dyads Mean age (SD) of stroke survivors: 67.0 (11.5) years; carers: 40.8 (11.3) years Gender. stroke survivors: women = 37 (41%), men = 53 (59%); carers: women = 58 (64%); men = 32 (36%) Stroke-survivor inclusion criteria: minimum of four days length of stay at the departments of neurology; disability degree of 3, 4 or 5 in accordance with the standard Rankin scale; educability; age 45 years and up; definitive diagnosis of stroke; continuous family care delivery Family carer inclusion criteria: lack of a history of care delivery for chronically ill patients; lack of academic instruction in medical sciences; age over 18; ability to complete questionnaires and make phone calls Exclusion criteria: postdischarge readmission; demise before final evaluation; changing family carers
Interventions	Treatment: active. Education/instructional intervention to help carers "understand the significance of disease threats and complications, adopt a positive attitude toward disease prevention, and have adequate motivation to participate" i.e. increase perceived threat Focus: carer Setting: classroom in the ward Administration: 4 x 1-hour sessions on 4 consecutive days of face-to-face (PowerPoint) educational slides presentation, practical illustrations, question and ask sessions by the principal investigator during hospital stay Control: usual care

Outcomes	• ADL: Barthel Index
	• Caregiver burden: Caregiver Burden Inventory
	
	Not included in this review (not a prespecified outcome of interest)
	
	• Researcher-developed questionnaire to measure the carers' "perceived threat" of the stroke survivor's dependence on personal help.
	  ○ Perceived Sensitivity, i.e., family carers' mental understanding of the stroke survivor's dependency risk in ADLs.
	  ○ Perceived Intensity, i.e., family carers' mental understanding of the extent of damage induced by stroke survivor's dependency on family carer in ADLs.
	• Rosenberg Self-Esteem Scale
	
	Not included in this review (insufficient information provided)
	
	• General Self Efficacy-10

Deyhoul 2018 *(Continued)*

	• Multidimensional Health Locus of Control scale.
Details of funding sources	Faculty of Nursing and Midwifery, Shahid Beheshti University of Medical Sciences
Notes	Request for additional data made 20 August 2019

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Coin flipping used as the random approach to generate sequence Quote: "The subjects were randomly assigned to either of the intervention and control groups through coin flipping."
Allocation concealment (selection bias)	Low risk	Comment: No information provided about method of allocation concealment. Coin toss probably conducted at time of allocation and therefore could not be known in advance. Restricted randomisation but probably insufficient to cause substantial risk of bias. Quote: "Because there were sample dropouts, sampling continued until the desired number for each group was achieved. For example, if the coin toss indicated that a participant should enter a group that had met the required sample size, the person would not be enrolled in the study. The coin toss would continue until a person was assigned to the group that required more participants. This process continued until the required number of participants was reached in each group."
Blinding of participants and personnel (performance bias) All outcomes	High risk	According to the trial record, the trial was single-blinded. It appears that the personnel was not blind, because there was only one researcher (ND) who performed the experiments and delivered the intervention sessions to the intervention group. However, attempts appear to have been made to blind participants. Quote: "To prevent contamination of the participants in the intervention group, after each participant was assigned to the appropriate group, the next participant was not selected until the previous patient had been discharged."
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	The outcomes were self-reported by participants. Attempts were made to blind participants but some may have realised their allocation based on the nature of the intervention and usual care.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Specific reasons for loss of participants in each group not given (approximately a quarter of all participants). The account of this differs between and within publications. 13/58 pairs in intervention group, and 15/60 pairs in control group are not included in the reported results. Quote: "A total of 15 and 12 subjects were respectively eliminated from the control and intervention groups based on the exclusion criteria." One more pair from the intervention group was not included in the analyses but not accounted for. Quote: "A total of 24 dyads from both groups were excluded because of death, stroke, and rehospitalization, while 4 dyads were excluded because of a lack of adequate participation."
Selective reporting (reporting bias)	Low risk	Trial record suggests there should be other outcome measures reported such as General Self Efficacy-10, Rosenberg Self-Esteem Scale and Multidimensional

Deyhoul 2018 *(Continued)*

		Health Locus of Control scale. However, outcomes of relevance to this review have been reported.
Other bias	High risk	According to the IRCT trial record, the intervention consisted of 4 sessions of two hours and in 4 consecutive days. However, in the reports, the length of the sessions was reported to be one hour. No explanation is provided for the change. The contact time between the researcher and carers was cut to half which might have altered the intervention effectiveness.

Dharmakulaseelan 2019

Study characteristics	
Methods	RCT comparing passive information provision to usual care 4 participants lost to follow-up in control arm (reasons not reported); 2 participants withdrew after randomisation but before baseline assessment (allocation to intervention or control arm unclear) 6-month follow-up
Participants	50 stroke survivors attending a hospital clinic; intervention (n = 25), control (n = 25). Completed final follow-up n = 44 Mean age of participants: 68.9 (SD: 11.5) Men: 30 (62.5%); women: 18 (37.5%) Inclusion criteria: people who had sustained a stroke or TIA and were experiencing sleep complaints Exclusion criteria: significant physical or cognitive impairment that would restrict their ability to comply with the study protocol, aphasia, inability to communicate in English, facial/bulbar weakness, life expectancy of less than 6 months (which was the duration of the study)
Interventions	Intervention: passive. Educational pamphlet and 5-minute animated slide-show Control: usual care
Outcomes	**Not included in this review (not a prespecified outcome of interest)** • Knowledge of obstructive sleep apnoea • Epworth Sleepiness Scale • Functional Outcomes of Sleep Questionnaire • Adherence to CPAP (of those using CPAP): at least 4 hours/night or 28 hours/week • Ease of use of educational materials (intervention group only)
Details of funding sources	Work was supported by a grant from the Sunnybrook Education Advisory Council and Education Research Unit, as well as summer student awards from the Comprehensive Research Experience for Medical Students (CREMS) program at the University of Toronto and the Hurvitz Brain Sciences Research Program at the Sunnybrook Research Institute
Notes	

Risk of bias		
Bias	**Authors' judgement**	**Support for judgement**

Dharmakulaseelan 2019 *(Continued)*

Random sequence generation (selection bias)	Unclear risk	Unclear sequence generation method, although appears to have been restricted as appears to have 25 randomised to each arm, although this is also unclear. Quote: "Recruited patients were randomized 1:1 to either the intervention group (educational materials) or the control group (usual care)."
Allocation concealment (selection bias)	Unclear risk	No information on allocation concealment
Blinding of participants and personnel (performance bias) All outcomes	High risk	One group of participants randomised to no additional intervention, so allocation likely to have been apparent to participants. Personnel were reported to be blinded.
Blinding of outcome assessment (detection bias) All outcomes	Low risk	Although the participants were unblinded, it is unlikely answers on knowledge of OSA were skewed substantially by awareness of allocation. Researcher collecting the data was reported to be blinded
Incomplete outcome data (attrition bias) All outcomes	High risk	Substantial losses to follow-up (probably 6/25 (24%) although precise value unclear) in control arm only. No reasons given
Selective reporting (reporting bias)	Unclear risk	No protocol available
Other bias	Low risk	No other risks of bias identified

Downes 1993

Study characteristics	
Methods	3-arm trial: control, information provision, and counselling plus information provision. Only data relating to the information provision and control arms are reported in this review. Allocation by random number sequence; no other details given Blinded outcome assessment Number lost to follow-up unclear; no report of differential losses between groups 6-month follow-up
Participants	Birmingham, UK Stroke survivors and carers (couples): number initially recruited to control and information groups unknown (105 couples recruited to the 3-group trial) Information provided for N = 18 control group, N = 22 information group who completed 6-month assessment Age of stroke survivors: < 60 years: control 11%; information 9% 60-69 years: control 28%; information 32% 70-79 years: control 44%; information 45% 80-89 years: control 17%; information 14% Age of carers: < 60 years: control 44%; information 36%

Downes 1993 *(Continued)*

	60-69 years: control 22%; information 27% 70-79 years: control 28%; information 36% 80-89 years: control 6%; information 0% stroke-survivor gender (women): control 55%; information 45% Carer gender (women): control 72%; information 73% Inclusion criteria: stroke survivors living at home with their informal carers, recent stroke (not necessarily first) causing increase on modified Rankin Disability Scale and poststroke Rankin score of 2 to 5 Exclusion criteria: none stated
Interventions	Treatment: passive. Information pack designed for study containing information about physical, cognitive and emotional effects of stroke, carer well being and local services Focus: stroke survivor and carer Setting: home Administration: single visit by nurse counsellor who demonstrated how to access relevant information and answered questions. 1 x 1-hour visit at least 2 weeks after discharge but exact time unknown Control: usual care, no intervention
Outcomes	Anxiety and Depression: HADS (stroke survivor and carer; baseline and 6 months)
Details of funding sources	Stroke Association (UK)
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Quote: "they were allocated by a random number sequence generation." However, method not described
Allocation concealment (selection bias)	Unclear risk	No information reported
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No evidence of blinding of participants or personnel
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Assesment was carried out by a research assistant who was blind to group allocation, However, participants self-reporting outcomes may have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	High risk	105 couples originally recruited in to the study but only 62 completed and were in the final analysis. Unclear how many from each group
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias
Other bias	Low risk	Appears free from other sources of bias

Draper 2007

Study characteristics	
Methods	Allocation by random selection of names by blinded investigator Postal outcome assessment 8 carers lost to follow-up
Participants	Sydney, Australia 39 carers of aphasic stroke survivors recruited from rehabilitation services of 3 public hospitals: treatment N = 19; control N = 20 Completed final follow-up: N = 31 Mean age carer: treatment 64 years; control 60 years Mean age of stroke survivor: treatment 69 years; control 68 years Gender of carer: not reported Gender of stroke survivor: not reported Inclusion criteria: stroke survivor has significant communication problem determined by assessment with the Western Aphasia Battery, stroke survivor is up to 12 months post stroke, stroke survivor is cared for at home, carer is able to speak and understand sufficient English to complete the programme and the questionnaires
Interventions	Treatment: active. Education programme covering the impact of stroke, managing the resulting life changes, communication strategies, relaxation and stress management, managing emotions, accessing community services and relapse prevention strategies. At the end of course the carers were encouraged to remain in contact as a self-help group. Focus: carer Setting: held in outpatient area of hospital rehabilitation department Administration: 4 x 1-weekly group session, each session 2 hours, numbers in each group varied from 6 to 11, sessions run by a speech pathologist and social worker, clinical psychologist included for 1 session Control: usual care, waiting-list control commenced the treatment after a delay of 3 months
Outcomes	Psychological distress: GHQ (carer; 4 weeks and 3 months) **Not included in this review (insufficient information provided)** Carer • Caregiver burden: Relatives' Stress Scale (4 weeks and 3 months) • Communication strategies: bespoke questionnaire (4 weeks and 3 months) • Attitudes towards care-giving: The Caring for Relatives Questionnaire (4 weeks and 3 months) • Self-rated health: self-rating scale, higher scores indicating poorer health (4 weeks and 3 months) • Social/recreational activities: Measure of Social and Recreational Activities (baseline, 4 weeks and 3 months) • Social support: Social Support Questionnaire (baseline, 4 weeks and 3 months) • Participation and satisfaction with social and recreational activities: adapted Quality of Life Questionnaire (baseline, 4 weeks and 3 months) Stroke survivor

Draper 2007 *(Continued)*

- ADL: BI (baseline, 4 weeks and 3 months)
- IADL: FAI (baseline, 4 weeks and 3 months)
- Carer perception of behaviour and mood disturbance: Behaviour and Mood Disturbance Questionnaire (baseline, 4 weeks and 3 months)

Details of funding sources	Unfunded
Notes	Shortfall in recruitment: recruited 39/60 required

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Reported as random but specific method not reported
Allocation concealment (selection bias)	Unclear risk	Reported as concealed but specific method for concealment not reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	Quote: ''Caregivers did not know which group they were in when the baseline measures were completed, however this blinding could not be subsequently maintained.''
Blinding of outcome assessment (detection bias) All outcomes	High risk	There was no external outcome assessor. However, participants self-reporting outcomes were aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	High risk	Control group lost 40% of participants
Selective reporting (reporting bias)	High risk	Sufficient data for most measures not reported in results
Other bias	Unclear risk	Baseline data collected after randomisation

Eames 2013

Study characteristics

Methods	RCT, using computer-generated random numbers. Random sequence transcribed into sequential envelopes by person uninvolved in the study. Paired stroke-survivor/carer dyads allocated together. Outcome assessment blinded ITT approach stated for analysis 11 stroke survivors (6 treatment, 5 control) and 8 carers (2 treatment and 6 control) lost to follow-up 3-month follow-up
Participants	2 public tertiary stroke units in Brisbane, Australia 77 stroke survivors nearing discharge: treatment N = 37; control N = 40. Completed final follow-up: N = 66 61 carers: treatment N = 30; control N=31. Completed final follow-up: N = 53

Eames 2013 *(Continued)*

	Mean age of participants: treatment 55 years; control 61 years Male participants: treatment 45.1%; control 46.3% REALM grade ≥ 9th: treatment 65.7%; control 64.5% Ischaemic stroke: treatment 72.5%; control 86.1% First time stroke: treatment 67.5%; control 83.8% Carers were usually the stroke survivors' partners (64.5% treatment and 70% control) but also the stroke survivors' children (29% treatment and 23.3% control). The remaining few were siblings/other. Inclusion: having, or being a carer for someone with, a current diagnosis of stroke (first or later); community dwelling pre-stroke with no plans for residential care post discharge; contactable by phone and sufficient language and cognition to participate
Interventions	Treatment: active. Education and support package in addition to usual care. Usual care is described below. The education and support package comprised an online written information booklet, verbal reinforcement of information up to 3 x pre-discharge, telephone contact up to 3 x postdischarge, and a number that participants could call to ask questions. The written booklet contained 34 topics from which participants could choose, and the level of information required could be varied. Face-to-face sessions (by bedside or private room) were also given pre-discharge. Intervention providers used the Health Belief Model to inform interactions with participants. Intervention providers were not HCPs at the unit. Stroke-survivor/carer dyads could be instructed together or separately, as desired. Control: usual care comprised standard stroke unit care from the medical, nursing and AHP teams, with some unstructured verbal education and advice.
Outcomes	• Knowledge about stroke: 25 item Knowledge of Stroke Questionnaire (stroke survivor and carer; 3 months) • Modification of health-related behaviours: stroke risk-related behaviours (stroke survivor; 3 months) • Anxiety and Depression: (14-item HADS) (stroke survivor and carer; 3 months) • Perceived health status: SAQOL-39 (stroke survivor; 3 months) • Caregiver burden: Caregiver Strain Index (carer; 3 months) • Satisfaction with information: medical, practical, prevention, service and benefits; Likert scale (stroke survivor and carer; 3 months) **Not included in this review (not a prespecified outcome of interest)** • Unprompted recall of risk factors, personal and general (stroke survivor; 3 months) • Prompted recognition of 13 personal risk factors (stroke survivor; 3 months) • Perception of importance of information received (Likert scale) (stroke survivor and carer; 3 months) • Perception of being informed (Likert scale) (stroke survivor and carer; 3 months) • Reported readiness to change stroke risk-related behaviours (3 months) **Not included in this review (bespoke outcome)** • Self-efficacy (9-item instrument based on Lorig's Self-efficacy to Perform Self-Management Behaviour measures for chronic disease) (stroke survivor and carer; 3 months)
Details of funding sources	This research received no specific grant from any funding agency in the public, commercial or not-for-profit sectors. At the time of the study, the lead author (S Eames) was in receipt of an Australian Post-Graduate Award scholarship, funding full-time doctoral research conducted at The University of Queensland. T Hoffmann is supported by a National Health and Medical Research Council of Australia/Primary Health Care Research Evaluation and Development Career Development Fellowship (number: 1033038) with funding provided by the Australian Department of Health and Ageing.
Notes	

Eames 2013 *(Continued)*

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer–generated random sequence generation Quote: "Concealed random allocation was achieved via sequentially numbered envelopes containing computer-generated random numbers prepared by a person not involved in the study."
Allocation concealment (selection bias)	Low risk	Sequentially numbered, opaque, sealed envelopes used to conceal allocation. Quote: "The randomization schedule was prepared using a computer-generated random numbers table, and concealed allocation was achieved by using sealed opaque envelopes that were prepared by a person not affiliated with the study."
Blinding of participants and personnel (performance bias) All outcomes	High risk	Blinding of HCPs and participants not possible; treatment group had greater quantity of care (usual care plus intervention) compared to control (usual care only). Quote: "Control group participants received standard stroke unit care (medical, nursing and allied-health assessment and treatment, which included the provision of unstructured informal verbal education and advice from various members of the treating team). Structured stroke education or support groups were not offered at either site during the time of this study, and nor were written materials routinely provided. Participants in the intervention group received the education and support package in addition to standard care."
Blinding of outcome assessment (detection bias) All outcomes	High risk	The outcome measures are subjective self-report assessments, even though the assessors are blind to allocation. The data and information provided by the participants can be influenced by the knowledge of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Losses to follow-up balanced in numbers and reasons across groups. The overall attrition rate is 13.8%.
Selective reporting (reporting bias)	Low risk	All outcomes in protocol covered.
Other bias	Low risk	None identified

Ellis 2005

Study characteristics	
Methods	Random allocation using a computer-generated random sequence concealed in sequentially-numbered opaque sealed envelopes. Blinded outcome assessment Stated intention-to-treat analysis 13 stroke survivors (6 treatment, 7 control) lost to follow-up 5-month follow-up
Participants	Glasgow, UK

Ellis 2005 *(Continued)*

	205 stroke survivors at stroke clinic or geriatric day hospital: treatment N = 100; control N = 105; completed final follow-up N = 192 Mean age of stroke survivors: treatment 64 years; control 66 years Gender of stroke survivors: men: treatment 54%, control 50% Inclusion criteria: clinical diagnosis of stroke, TIA or amaurosis fugax commencing in the previous 3 months; 1 or more risk factors from raised BP, history of concurrent smoking, high cholesterol, diabetes (regardless of their risk factor control) Exclusion criteria: cognitive impairment (defined as AMT < 5 on screening)
Interventions	Treatment: active. Monthly review with Stroke Nurse Specialist for 3 months at which individual given advice on lifestyle changes, the importance of medication compliance and relevance to secondary prevention Focus: stroke survivor Setting: outpatient consultation Administration: reviewed by Stroke Nurse Specialist in consultation lasting approximately 30 minutes. Lifestyle issues including diet, exercise or increased activity and medical services discussed in depth and tailored to the stroke survivor's circumstances and functional abilities. Verbal information backed up by written information selected by Stroke Nurse Specialist as relevant to the individual stroke survivor. Personalised patient-held records, detailing their risk factors and the recommended risk factor targets given to the stroke survivor and updated at each visit (considered a key part of intervention). Stroke survivors given opportunity to bring up other subjects as appropriate. If risk factor (e.g. BP) deemed to be at unacceptable level, stroke survivors encouraged to consult their General Practitioner with that information. Control: usual care including generic risk factor advice from medical staff as well as the Stroke Nurse Specialist
Outcomes	• Depression: GDS • Perceived health status: EQ-5D • Modification of health related behaviours: compliance with treatment (proportion of participants whose risk factors were “on target”) • Satisfaction with information about allowances and services: satisfaction with stroke services • Death
Details of funding sources	This study was funded by a grant from the Chief Scientist Office, Scotland. Boehringer Ingelheim contributed towards the printing of the individualised patient records. G Ellis, J Rodger and C McAlpine have received reimbursement for attendance at educational meetings from Boehringer Ingelheim. P Langhorne has received similar expenses from Boehringer Ingelheim, Sanofi and Pfizer.
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "eligible patients were randomly allocated to treatment or control groups using a computer-generated random sequence concealed in sequentially numbered opaque sealed envelopes." Quote: "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."

Ellis 2005 *(Continued)*

		Comment: errors in sequence generation could have subverted randomisation but as the issue only affected three of 205 participants we judged the risk of bias to be low.
Allocation concealment (selection bias)	Low risk	Randomly allocated to treatment or control groups using a computer-generated random sequence concealed in sequentially-numbered opaque sealed envelopes.
Blinding of participants and personnel (performance bias) All outcomes	High risk	Single blinded trial with blinded assessment so presume unblinded participants or personnel.
Blinding of outcome assessment (detection bias) All outcomes	High risk	Quote: "Outcomes were recorded at 5 months by an independent blinded assessor." However, participants self-reporting outcomes probably aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Low numbers lost to follow-up and similar across groups
Selective reporting (reporting bias)	Unclear risk	All outcomes specified in the methods were reported in the results. However, study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Evans 1988

Study characteristics	
Methods	3-arm trial: education, counselling, and control. Only data relating to the education and control arms are reported in this review. Allocation by method of Taves (minimisation) Blinded outcome assessment 13 stroke survivors and carers (6 treatment, 7 control) lost to follow-up 6-month and 1-year follow-up
Participants	Seattle, WA, USA 140 stroke survivors and carers (majority couples) recruited: treatment N = 70; control N = 70; completed final follow-up: N = 127 Mean age of stroke survivors: treatment 63 years; control 62 years Sex of stroke survivors (men): treatment 95%; control 94% Inclusion criteria: all people on inpatient wards from any referring service, hospitalised primarily for stroke, living with primary carer Exclusion criteria: none stated
Interventions	Treatment: active. 2 classes: 1) lecture and video 'Living with stroke', followed specific outline of information developed by psychiatrists, included basic information about the consequences of stroke; and 2) explanation of treatment unique to the family's situation and questions

Evans 1988 *(Continued)*

	Focus: carer Setting: hospital Administration: occupational therapist (class 1), social worker (class 2). 2 x 1-hour classes during third week of stroke; second class within 3 working days of the first Control: routine care
Outcomes	• Knowledge about stroke: Stroke Care Information Test (carer; 6 months and 1 year) • Death (stroke survivor) **Not included in this review (not a prespecified outcome of interest)** • Family function: Family Assessment Device (6 months and 1 year) • Stroke survivor adjustment: Personal Adjustment and Role Skills (stroke survivor; 6 months and 1 year) • Use of social resources: ESCROW profile (6 months and 1 year)
Details of funding sources	Veterans Administration Health Services Research and Development Grant IIR 85-033
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "Patients were randomly assigned to conditions after minimizing the differences for variates known to predict stroke recovery: mood, self-care ability (Barthel Index), mental status, age, and location of the lesion. The method of Taves was used."
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported.
Blinding of participants and personnel (performance bias) All outcomes	High risk	No information reported. However, as no alternative intervention for control groups, blinding of participants not possible.
Blinding of outcome assessment (detection bias) All outcomes	High risk	No report of blinded assessment. However, participants self-reporting outcomes would have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Small numbers lost to follow-up with similar reasons reported.
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias.
Other bias	Unclear risk	Imbalance in reported baseline conditions (marital status and number in household) may mean choice of minimisation factors was incomplete.

Forster 2013

Study characteristics

Forster 2013 *(Continued)*

Methods	Cluster-RCT using centralised block randomisation by cluster, stratified for geographical region and quality of care. Centres were recruited prior to allocation. Stroke-survivor and carer recruiters were not part of the clinical team. Selection bias was monitored for throughout. Outcome assessment blinded. ICC data provided. ITT approach stated for analysis. 0 clusters lost to follow-up. 290 stroke survivors (145 treatment, 145 control) and 279 carers (145 treatment and 134 control) lost to follow-up. 12-month follow-up
Participants	36 stroke units in UK 928 stroke survivors: treatment N = 450; control N = 478. Completed final follow-up: N = 638 928 carers: treatment N = 450; control N = 578. Completed final follow-up: N = 609 Mean age of stroke survivors: treatment 71 years; control 71 years Male stroke survivors: treatment 57%; control 55% Barthel score post stroke: treatment 12.2; control 12.6% Mean age of carers: treatment 61 years; control 61 years Male carers: treatment 21%; control 22% Left school at or before age 16: treatment: 70%; control 71% Clusters were included if: 1) 4 out of 5 criteria to define a stroke unit were present, 2) substantial number in unit had stroke, 3) staff able to deliver the London Stroke Carers Training Course (LSCTC), and 4) most stroke survivors were discharged to a permanent place of residence. Inclusion: patient with primary diagnosis of new stroke (ischaemic or haemorrhagic, and first or recurrent), medically stable and liable to be discharged home, and had a carer Exclusion: patient needing palliative care, discharge planned within 1 week to the stroke unit, or previously registered with the trial
Interventions	Treatment: active. In addition to usual care, the LSCTC was provided to carers. The LSCTC is a structured educational programme for carers, comprising 6 mandatory components and 6 non-mandatory components. Intervention manual used. Examples of components are: what a stroke is, knowing the survivor-specific problems associated with stroke such as swallowing or mobility problems, knowledge of how to manage and provide support for personal activities. The education was provided flexibly to the carer while stroke survivor was an in-patient, with a follow-through (telephone or in-person) session after discharge. Training on implementation of the LSCTC was provided to key staff on each of the 36 units. Control: usual care based on National Guidelines
Outcomes	• Caregiver burden: Caregiver Burden Scale (CBS) (carer; 6 and 12 months) • Anxiety and depression: HADS (stroke survivor and carer; 6 and 12 months) • Perceived health status: EQ-5D (stroke survivor and carer; 6 and 12 months) • Perceived health status: Stroke Impact Scale (SIS) (stroke survivor; 6 and 12 months) • ADL: BI (stroke survivor; 6 and 12 months) • Social activities (stroke survivor): Nottingham Extended Activities of Daily Living (NEADL) scale (6 and 12 months)

Forster 2013 *(Continued)*

- Social activities (carer): Frenchay Activities Index (FAI) (6 and 12 months)
- Death (stroke survivor and carer; 6 and 12 months)
- Resource outcomes: Cost-effectiveness-resource use measured via Client Service Receipt Inventory (CSRI) (stroke survivor and carer; 6 and 12 months)

Not included in this review (not a prespecified outcome of interest)

- Carer preparation (carer; 6 months)
- Hospitalisation/readmission and institutionalisation (stroke survivor and carer; 6 and 12 months)

Details of funding sources	Funded by the Medical Research Council (MRC) and managed by the National Institute for Health Research (NIHR; project number 09/800/10) on behalf of the MRC-NIHR partnership
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	The randomisation sequence was computer-generated.
Allocation concealment (selection bias)	Low risk	Allocation was performed centrally. Quote: "Cluster randomisation of the 36 eligible SRUs was performed centrally at the Clinical Trials Research Unit (CTRU). SRUs were randomised on a 1:1 basis to either the intervention or the control group."
Blinding of participants and personnel (performance bias) All outcomes	High risk	The healthcare staff providing the intervention were aware of the treatment allocation Quote: "The LSCTC intervention required delivery by the whole multidisciplinary ward team (MDT). If randomization was at the level of individual patients, the MDT would have to operate two approaches (usual care and the LSCTC) with an associated high risk of between-group contamination as it is not possible to blind members of the MDT, it is likely that the new care process would have been extended to patients in the usual care group."
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Assessor blinding. However, participants self-reporting outcomes may have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Groups very similar for number and reason of loss to follow-up, despite substantial losses. 321/930 (34.5%) participants were not available for the final analyses. Sensitivity analyses were conducted, which estimate that the unavailable data were unlikely to affect the reported outcomes. Quote: "A sensitivity analysis including patients who had died was undertaken and assumed that these patients had a NEADL score of 0. This sensitivity analysis showed results similar to the primary analysis…"
Selective reporting (reporting bias)	Low risk	No statistical comparison for death, hospital admission and institutionalisation, but this was decided pre-hoc in protocol.
Other bias	Low risk	Clustering accounted for by presentation of the adjusted ICC for 2 key outcomes.

Frank 2000

Study characteristics	
Methods	Randomisation using independently prepared envelopes Outcome assessment not blinded 2 stroke survivors (1 treatment, 1 control) lost to follow-up 1 month follow-up
Participants	Fife, UK 41 stroke survivors: treatment N = 20; control N = 21; completed final follow-up: N = 39 Mean age of stroke survivor: treatment 64 years; control 64 years Sex of stroke survivor: men: treatment 53%; control 50% Inclusion criteria: stroke within 24 months of recruitment, fluent in English, not aphasic, not cognitively impaired Exclusion criteria: none stated
Interventions	Treatment: active. Workbook designed to increase perceptions of control by giving information, enhancing coping resources and rehearsing planning and problem-solving skills. Recovery plan developed with researcher. Weekly phone call (over 3-week period). First part of workbook dealt largely with information about stroke, causes, management, and recovery. Additional sections of relevance to the individual available (e.g. on diet, smoking). Second part introduced methods of coping and relaxation tape and instructions for use Focus: stroke survivor Setting: stroke survivor's home Administration: workbook introduced in 2 parts: part 1 introduced following baseline assessment; stroke survivor asked to work through the sections, answering quizzes and deciding which additional sections were relevant to them; part 2 introduced 1 week later along with relaxation tape and instructions for use. Requests for additional parts of the workbook met. A recovery plan consisting of a daily task with records made as joint exercise between researcher, stroke survivor and carer. Over next 3 weeks stroke survivor and carer worked independently on workbook and received weekly telephone call from researcher to enquire about progress and give opportunity to ask questions Control: waiting-list control group received the workbook once the study was complete
Outcomes	• Anxiety and depression: HADS (1 month) • Perceived health status: Functional Limitations Profile (1 month) • Self-efficacy: Perceived Health Competence Scale (1 month) • Locus of control: Recovery Locus of Control Scale (1 month)
Details of funding sources	Due to resourcing constraints, all data collection and the workbook administration were done by G Frank during a 7-month period while studying for a doctorate.
Notes	Validity assessment: No stated intention-to-treat analysis

Risk of bias		
Bias	**Authors' judgement**	**Support for judgement**

Frank 2000 *(Continued)*

Random sequence generation (selection bias)	Unclear risk	Method of randomisation not reported
Allocation concealment (selection bias)	Low risk	Used an enveloped prepared independently of the interviewer
Blinding of participants and personnel (performance bias) All outcomes	High risk	No mention of blinding; treatment group received a workbook and control group received nothing until end of trial – would have been obvious which group they were in
Blinding of outcome assessment (detection bias) All outcomes	High risk	The intervention and assessment were undertaken by the same individual
Incomplete outcome data (attrition bias) All outcomes	Low risk	2 of 41 lost to follow-up, 1 from each group, both unavailable
Selective reporting (reporting bias)	Unclear risk	All outcome measures specified in methods were reported. However, study protocol not available so cannot assess reporting bias
Other bias	Low risk	No other obvious sources of bias

Hekmatpou 2019

Study characteristics	
Methods	RCT Number of participants included in results analysis and any attrition were not reported. Follow-up at 1 month after intervention
Participants	Iran 100 carers who were family members of stroke survivors: 50 treatment, 50 control Age: 46.8 years women: N = 63; men: N = 37 Inclusion criteria: desire of the carer to participate in the research; carer being a family member (father, mother, sister, …); carer providing care for a stroke survivor for at least 6 hours a day for at least 1 month; age of the carer being > 18 years; and the presence of all or some of the stroke complications which the carer has faced in previous month. These complications were like sensory impairment, movement, swallowing, speech impairment, vision, and urinary and faeces discharge problems in the stroke survivor. The exclusion criteria were the unwillingness to continue and the death of the stroke survivor or the carer.
Interventions	Treatment: active. Education. Face-to-face training and provision of information booklet consisting of 30 pages of illustrated nursing interventions for stroke survivors. Follow-up telephone calls at 3-day intervals and home visits. At home visits the trainer responded to all related nursing intervention questions and the carer conducted supervised practice. Focus: carer Setting: both hospital, and carer and stroke survivor's home

Hekmatpou 2019 *(Continued)*

	Administration: 6 sessions (2 face-to-face, 2 telephone call, 2 home visit) 1 month after stroke. Unclear duration, time gaps between most sessions not known. Conducted by researcher (student of Master of Science in Nursing). Control: usual care
Outcomes	Carer outcomes: • Caregiver burden: Zarit Burden of Care questionnaire • Perceived health status: SF-36
Details of funding sources	Not reported
Notes	Attempted to clarify contents of intervention by email to dr_hekmat@arakmu.ac.ir, which bounced, and hekmatpou@yahoo.com, no response at time of publication.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	There is insufficient information regarding the random component in the sequence generation process, specifically, how the blocks were sorted. Quote: "they were randomly assigned to two groups of intervention (A) and control (B) using randomized blocking method. First, the blocks with four parts (AABB, ABAB, ABBA, BBAA, BABA, BAAB, and so on) were designed. Then these blocks were randomly sorted and the individuals were assigned to two groups according to A and B. This continued until the sample size was completed."
Allocation concealment (selection bias)	High risk	Methods of allocation concealment were not described. Small, unvaried block size (n = 4) with prior allocations known to the researcher mean future allocations were predictable in approximately half of cases, being deterministically known in approximately a third of cases.
Blinding of participants and personnel (performance bias) All outcomes	High risk	The research personnel who delivered the intervention knew the treatment allocation. It is unclear whether the participants were aware of their treatment allocation.
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	All the outcome measures were self-reported by the participants. It is unclear whether the participants were aware of the treatment allocation.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Numbers not reported.
Selective reporting (reporting bias)	Unclear risk	The protocol and trial register record were not available.
Other bias	Low risk	Appears to be free of other risks of bias.

Hoffmann 2007

Study characteristics

Methods	Randomisation using predetermined computer-generated randomisation sequence.

Hoffmann 2007 *(Continued)*

	Balanced block design where randomisation occurred in blocks of 4. Blinded outcome assessment Stated ITT analysis 5 stroke survivors (3 treatment, 2 control) lost to follow-up 3-month follow-up
Participants	Brisbane, Australia 138 stroke survivors: treatment N = 69; control N = 69. Completed final follow-up N = 133 Mean age of stroke survivors: treatment 67 years; control 69 years Sex of stroke survivors men: treatment 64%; control 46% Inclusion criteria: diagnosed stroke or TIA, medically stable, reported English-proficiency level, corrected hearing and vision and communication status adequate to participate in an interview and complete assessment tasks, no reported or observable dementia, living within 50 km of the hospital Exclusion criteria: none stated
Interventions	Treatment: passive. Computer-generated tailored written information, customised according to stroke survivors' informational needs. 34 topics available covering such issues as: how stroke occurs, risk factors, understanding and managing the effects of stroke, reducing stroke risk, treatment and rehabilitation and managing after discharge. Focus: stroke survivors Setting: stroke unit Administration: within 1 day of baseline interview the research nurse completed the 'what you need to know about stroke' checklist with the stroke survivor. Further information given as needed about the scope and content in each of the available topics. Once the checklist completed, the research nurse entered topic selections, desired version of each topic (detailed, shortened) and desired font size into the database. Then generated and printed an individualised booklet and placed into a ring-binder folder. Stroke survivor's name written on booklet and given to the stroke survivor. Control: within 1 day of the baseline interview, provided by research nurse with a copy of the Stroke Association of Queensland fact sheet.
Outcomes	• Knowledge about stroke: adapted Stroke Knowledge Questionnaire (3 months) • Anxiety and depression: HADS (3 months) • Quality of Life and perceived health status: COOP charts (3 months) • Self-Efficacy to Perform Self-Management Behaviours Scale (3 months) **Not included in this review (not a prespecified outcome of interest)** • Self-report of reading information provided, satisfaction with the content and satisfaction with the presentation (3 months) • Desire for additional information
Details of funding sources	Funded by the Medical Benefits Fund (MBF) of Australia. The sponsor played no role in the trial's design, data collection, analysis, or interpretation.
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement

Hoffmann 2007 *(Continued)*

Random sequence generation (selection bias)	Low risk	Quote: "…database randomly assigned the patient to either the intervention or control group."
Allocation concealment (selection bias)	Low risk	Quote: "One of the database tables contained a predetermined computer generated randomisation sequence, thus ensuring concealed allocation."
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No report of blinding of participants and may not have been obvious to participants which group they were in as both received written information. However, remains unclear
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Quote: "An outcome assessor who was blind to patients' group allocation, conducted baseline interviews while the patient was in hospital, and follow-up interviews 3 months after discharge." However, participants self-reporting outcomes may have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Low number of losses to follow-up and numbers balanced across groups, with similar reasons.
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Johnson 2000

Study characteristics	
Methods	Matched pairs design based on baseline scores on outcome measures, age, sex and side of stroke. Random assignment within each pair by tossing a coin. Not blind outcome assessment All participants reassessed 1 week after intervention group completed a 4-week course. No losses to follow-up
Participants	Minneapolis, USA 41 stroke survivors identified from hospital-based register Treatment N = 21; control N = 20. Completed final follow-up N = 41 Mean age: treatment 64.2 years; control 63.9 years Sex of stroke survivors: men: treatment 38%; control 50% Inclusion criteria: > 18 years of age, English speaking, community dwelling, stroke 6 months to 3 years earlier, gave informed consent
Interventions	Treatment: active. 8 x 2-hour structured educational classes over a 4-week period. Content included facts on stroke, living with disability, exploring spiritual wellness. Control group offered the intervention after the end of the evaluation.
Outcomes	• Depression: Beck Depression Inventory **Not included in this review (not a prespecified outcome of interest)**

Johnson 2000 *(Continued)*

- Self-reported sense of hope: Herth Hope Scale (Farran 1995)
- Self-reported ways of coping: Ways of Coping - Cardiovascular Accident scale

Details of funding sources	American Heart Association
Notes	Match pairs design then randomisation by toss of a coin, not concealed. Unpaired participant assigned to the treatment group.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Reported that one member of each pair was randomly assigned to either the treatment or control group but method not reported.
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported.
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No report of blinding of participants and personnel. Control group received usual care (compared with structured education course) so may have been obvious they were not receiving an intervention.
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	No report of blinded outcome assessment.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Unclear if outcomes were reported for all participants.
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias.

Johnston 2007

Study characteristics

Methods	RCT. A statistician prepared 2 separate randomisations for stroke survivors with carers who also agreed to participate (carer-patient subgroup) and for carers partnered with a stroke survivor who could not participate because of cognitive and communication impairments (carer-only subgroup). Blinded outcome assessment Reported ITT analysis 45 stroke survivors (29 intervention, 16 control) and 42 carers (total across intervention and control groups) lost to follow-up 6-month follow-up
Participants	Dundee, Scotland 203 acute stroke survivors and 172 carers

Johnston 2007 *(Continued)*

	Stroke survivors: intervention N = 103; control N = 100 Carers: intervention N = 82; control N = 90 Mean age of stroke survivors: intervention 69 years; control 69 years Sex of stroke survivors (men): intervention 61%; control 61% Mean age of carers: intervention 63 years; control 61 years Carer sex (men): 35% (across intervention and control groups) Inclusion criteria. Stroke survivor: fluent in English; discharged from hospital following stroke. Carers identified by the stroke survivor as the person most involved in their care Exclusion criteria: not reported
Interventions	Intervention: active. Postdischarge workbook intervention delivered by a workbook implementer over a 5-week period. The workbook provided information about stroke and recovery; guidance on coping skills; and self-management instruction. Task materials (e.g. goal setting), diary sheets and an audio relaxation cassette tape that described simple body relaxation and breathing exercises. Intervention included 2 home visits and 2 telephone contacts. Intervention started within 3 weeks (approximately) of hospital discharge Focus: stroke survivor and carer Setting: home Administration: work book implementer Control: usual care
Outcomes	• Anxiety and depression: HADS (stroke survivor; 8 weeks postintervention and 6 months after baseline) • ADL: BI (stroke survivor; 8 weeks postintervention and 6 months after baseline) • Locus of control: Recovery Locus of Control Scale (completed by the stroke survivor and by the carer on behalf of the stroke survivor at 8 weeks) • Death (stroke survivor; 8 weeks postintervention and 6 months after baseline) **Not included in this review (not a prespecified outcome of interest)** • Observer Assessed Disability (stroke survivor; 8 weeks postintervention and 6 months after baseline) **Not included in this review (insufficient information provided)** • Anxiety and depression: HADS (carer; 8 weeks postintervention and 6 months after baseline) • Physical functioning scale of SF-36 (carer; 8 weeks postintervention) • Satisfaction with treatment and advice (stroke survivor; 8 weeks postintervention and 6 months after baseline)
Details of funding sources	Scottish Executive Chief Scientist Office (Grant No. K/CR1/1/7)
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Insufficient information reported

Johnston 2007 *(Continued)*

Allocation concealment (selection bias)	Unclear risk	Insufficient information reported
Blinding of participants and personnel (performance bias) All outcomes	High risk	Stroke survivors asked not to disclose group allocation though potentially broken. Participants would have been aware they were receiving the intervention.
Blinding of outcome assessment (detection bias) All outcomes	High risk	Research assistants blind to the process. However, participants self-reporting outcomes may have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	More losses to follow-up in the intervention group (29 out of 103) compared with the control group (16 out of 100). 42 carers lost (only reported across groups)
Selective reporting (reporting bias)	High risk	Observer Assessed Disability (OAD) not reported at baseline. Hospital and Anxiety Depression Scale (HADS) subscales reported for anxiety and depression at baseline but combined post intervention.
Other bias	Low risk	No other obvious signs of bias

Jones 2018

Study characteristics	
Methods	RCT with individuals allocated by minimisation with 2-month follow-up Multi-country study Blinded collection of outcomes Only stroke survivors with baseline and follow-up data were included in analysis. Probably analysed as assigned but not explicit (though states all received intervention as assigned so probably irrelevant). No mention of other exclusions 12 stroke survivors lost to follow-up at 2 months
Participants	Community-living adults up to three years post stroke with moderate to severe disability and their nominated informal carers From New Zealand, Australia, Nigeria, India, UK, Canada, USA, Egypt Number assessed not reported 68 stroke survivors randomised: treatment N = 34, control N = 34 (after randomisation, 2 from control group excluded due to not meeting criteria for Rankin Scale score) 41 nominated carers: treatment N = 16, control N = 25 Mean age of stroke survivors (SD) 63.5 (12.47) years Men: 47 (71.2%), women: 19 (28.8%) Educated beyond formal schooling: N = 34 (52%) Participant characteristics seemed reasonably comparable between groups but baseline data for outcome measures was not reported.

Jones 2018 *(Continued)*

	Inclusion criteria: age 16 years or above, clinically diagnosed with stroke within the last 3 years with a moderate-to-severe level of disability (defined as a Rankin Scale score of 2 to 4), discharged to own home, availability of a DVD player, carer: survivors of stroke asked to nominate a carer (the main person who assists with their care in the home environment) to be invited to participate in the study. Exclusion criteria: inability to communicate with the researchers (including non-fluent English), history of disabling stroke (prestroke modified Rankin Scale score 3 to 5), discharged home within 24 hours of hospital admission, living outside the study area, admission to hospital from a residential care facility/rest home, unable to provide informed consent, participation in another clinical trial, history of alcohol or drug abuse, history of serious mental illness (including severe depression)
Interventions	Treatment: passive. Instructional and educational DVD focusing on various aspects of caring for the stroke survivor at home. "Educational components included understanding stroke and coping with stroke aftermath. Instructional topics comprised a range of rehabilitation exercises (i.e. hand massage, relaxation, breathing exercises) and early care and hygiene techniques (i.e. changing sheets, feeding, bathing and dressing). Most of the information is presented by role models, including stroke survivors (across a range of age groups, European, Asian and ethnic minority groups) and their informal carers." Focus: both stroke survivors and carers. Setting: to be watched in the stroke survivor's home. Administration: DVD provided in person or by post. 6 segments in the DVD to be watched over 6 weeks. The average duration of each of the sessions was approximately 20 minutes (total DVD running time: 129 minutes). Control: usual care
Outcomes	Stroke survivor: • Depression: CES-D • Psychological distress: GHQ-28 • Perceived health status: EQ-5D – 5-level (each dimension analysed separately) **Not included in this review (not a prespecified outcome of interest)** • Disability: mRS **Outcomes not reported in this review (insufficient information provided)** Stroke survivor: • Recurrent stroke • Daily Living Self-Efficacy Scale Carer: • Depression: CES-D • Caregiver Strain Index
Details of funding sources	New Zealand Stroke Education Charitable Trust Moleac Pte Ltd Georgia Physical Therapy Education and Research Committee National Institute for Stroke & Applied Neurosciences, AUT University, New Zealand
Notes	
Risk of bias	

Jones 2018 *(Continued)*

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Comment: Online programme used to generate "random" sequence by minimisation. Quote: "The use of a free online randomization program, MinimPy, known as MUI Online Minimization (see [rct.mui.ac.ir/qminim]), ensures that each site can randomize participants in a consistent and timely fashion. Group distribution is stratified by age (<65 and 65+), gender, and stroke severity (Rankin Scale score 2 or 3-4). A 1:1 ratio and a minimization method will ensure maximum balance between treatment arms and the elimination of selection bias."
Allocation concealment (selection bias)	High risk	Comment: It appears that pure minimisation was used (despite mention of block randomisation in the quote below) and that research assistants who had collected baseline data performed the allocation (not an independent person) using a system with open display of current participants. Therefore, the next allocation would have been foreseeable, depending on research assistant understanding. Quote: "Following the collection of baseline data, a research assistant at each site randomized each patient to the intervention or control group. Randomization was conducted using a free on-line computer-generated block randomization sequence balanced for age (<65; 65+), gender and stroke severity (modified Rankin Scale) score of 2 versus 3–4." The cited on-line sequence generator is: Saghaei M and Saghaei S. Implementation of an open-source customizable minimization program for allocation of patients to parallel groups in clinical trials. J Biomed Sci Eng 2011; 4: 734–739.
Blinding of participants and personnel (performance bias) All outcomes	High risk	Open-label trial, only outcome assessors were blinded. The participants were not blinded to allocation, thus their performance might be influenced by the knowledge of allocation.
Blinding of outcome assessment (detection bias) All outcomes	High risk	The participants were not blinded to allocation, thus their self-reported outcomes might be influenced by the knowledge of allocation.
Incomplete outcome data (attrition bias) All outcomes	High risk	Comment: 11 (32%) stroke survivors in the intervention group did not complete the trial, thus not included in the endpoint results. Comparing to the control group in which only 1 stroke survivor did not complete the trial, there was an imbalance. The authors suggested that this might be attributable to the requirements and content of the intervention. Quote: "Loss to follow-up in the intervention group was 32% (n = 11) of patients [...] This result may have been due to an imbalance in the time commitment required across the two study groups, and/or a lack of relevance of some intervention content, as noted by some patients and/or carers."
Selective reporting (reporting bias)	Unclear risk	Some of the data needed for this review was provided on request. Of concern, Daily Living Self-Efficacy Scale was the primary outcome measure in the trial register but not reported and without reason. Additionally, the carer outcomes were not reported and without reason.
Other bias	Low risk	No other sources of bias identified

Kalra 2004

Study characteristics	
Methods	Block randomisation procedures, each block included 10 participants. Allocation schedule prepared in advance using computer-generated random numbers. Allocation codes held in central office remote from study environment. Blinded outcome assessment Stated ITT analysis 32 stroke survivors and carers lost to follow-up: treatment N = 17; control N = 15 12-month follow-up
Participants	London, UK 300 stroke survivors and carers: treatment N = 151; control N = 149. Completed final follow-up: N = 268 Median age of stroke survivors: treatment N = 76 years ; control N = 76 years Sex of stroke survivors (men): treatment 57%; control 50% Inclusion criteria: stroke survivor - independent in daily living activities before the stroke, medically and neurologically stable at time of baseline assessments, expected to return home with residual disability; carer - no notable disability (Rankin score 0 to 2), willing and able to provide support after discharge Exclusion criteria: none stated
Interventions	Treatment: active. Conventional care plus 3 to 5 sessions of 30 to 45 minutes comprising instruction by appropriate professional on common stroke-related problems and their prevention, management of pressure areas and prevention of bed sores, continence, nutrition, positioning, gait facilitation, advice on benefits and services. Hands-on training in lifting and handling techniques, facilitation of mobility and transfers, continence, assistance with personal activities of daily living and communication, tailored to the needs of the individual stroke survivor Focus: carers Setting: stroke rehabilitation unit Administration: training started when stroke survivor's rehabilitation needs stabilised and discharge contemplated. Carer competencies assessed at the end of training. Follow-through session conducted by hospital team at home to adapt skills learnt to home environment. Control: conventional care consisting of information on stroke and its consequences, prevention and management options; involvement in goal setting for rehabilitation and discharge planning; encouragement to attend nursing and therapy activities to learn about stroke survivor's abilities and informal instruction on facilitating mobility and activities of daily living tasks; advice on community services, benefits, and allowances including contact information for voluntary support services for carers
Outcomes	• Anxiety and depression: HADS (stroke survivor and carer; 3 and 12 months) • ADL: BI (stroke survivor; 3 and 12 months) • Social activities: FAI (stroke survivor and carer; 3 and 12 months) • Perceived health status: EQ-VAS (stroke survivor and carer; 3 and 12 months) • Death (stroke survivor; 3 and 12 months) • Caregiver burden: Caregiver Burden Scale (carer; 3 and 12 months) Resource outcomes • Health and social care costs (12 months)

Kalra 2004 *(Continued)*

- Informal care costs (12 months)
- Quality adjusted life years in carers (over 1 year)

Not included in this review (not a prespecified outcome of interest)

- Disability: mRS (stroke survivor; 3 and 12 months)
- Institutionalisation (stroke survivor; 3 and 12 months)

Details of funding sources	NHS R&D Executive's Primary Secondary Interface Priority Programme (Project No: F-4/1997)
Notes	Validity assessment: possibility of limited generalisability (setting was largely middle-class suburban area) Reference to Caregiver Burden Scale is incorrectly presented as Caregiver Strain Index

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated randomisation
Allocation concealment (selection bias)	Low risk	Quote: "Allocation codes were held in a central office remote from the study environment"
Blinding of participants and personnel (performance bias) All outcomes	High risk	Participants were aware of training received
Blinding of outcome assessment (detection bias) All outcomes	High risk	Reported that an observer who did not participate in allocation or management of stroke survivors assessed outcome. However, participants self-reporting outcomes may have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Some missing data. However, numbers and reasons for missing data relatively balanced across groups.
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Kamal 2016

Study characteristics

Methods	Randomised control, outcome assessor blinded, parallel group, single centre superiority trial Stated ITT analysis 32 "lost to follow-up" at 12 months, but missing data for many more
Participants	Karachi, Pakistan Adult stroke survivors having first ever stroke within the past 6 weeks and mild to moderate disability, and their carers.

Kamal 2016 *(Continued)*

	Sample size: 310 stroke-survivor and carer dyads: 155 intervention, 155 control Inclusion criteria: adult men and women; 18 years of age or older; resident of Karachi and planning to live in Karachi until the follow-up period; able to understand Urdu (language of the videos); admitted with first ever stroke (ischaemic or haemorrhagic stroke); mRS ≤ 4 (mild to moderate stroke); have at least one vascular risk factor that requires medical intervention; consenting to participate in the study and follow-up, both stroke survivor and carer; have a stable surrogate carer at home who is responsible for appointments, follow-ups, overall care, e.g. wife, daughters, daughter-in-law, husband; stroke is medically stable and participant is likely to return to the community after the in-hospital stay. Exclusion criteria: stroke survivor: actively treated strokes, e.g. decompressive surgeries, carotid endarterectomy (CEA), in-hospital sepsis, ventilator complications, as these were considered to preclude return to community settings; serious aphasia, visual hemi-neglect, short-term memory loss precluding understanding, visualisation or retention of the video material (will be measured through the NIH Stroke Scale performed by trained physicians; those having a score of greater than 4 due to aphasia alone will be excluded); iatrogenic stroke, i.e. stroke due to non-atherosclerotic vascular disease and rare causes, e.g. carotid dissections, gunshot wounds to the neck, post coronary artery bypass grafting (CABG); serious concurrent medical illnesses, like cancer, renal failure, acute liver disease in past 6 months (that precludes the use of statins), chronic liver disease that excludes the use of stroke preventive medications, or require non-standardized therapy; use of any off-label, non-guideline medications which, due to stroke survivors' unique co-morbidities, interfere with medication compliance to antihypertensives, statins, antiplatelet agents and diabetes control. carer: serious aphasia, visual hemi-neglect, short-term memory loss, dementia precluding understanding, visualisation or retention of the video material (will be measured through the NIH Stroke Scale performed by trained physicians; those having a score of greater than 4 due to aphasia alone will be excluded, dementia status will be assessed by the Mini-Mental State Examination). stroke survivor & caregiver dyad continue post-stroke care in a nursing assisted, professional or hospital setting and do not return to the community after discharge. 400 assessed. 50 excluded, 40 declined, 310 randomised. Stroke survivor mean (SD) age: 60.2 (13.2) years
Interventions	Intervention: active. Movies4Stroke software installed on their electronic device allow them to receive, view and repeat 5-minute videos on stroke-related topics. Topics are information for carers and skills; emergency preparedness; adherence to medications; stroke prevention Focus: both patients and carers Setting: ward, home, clinic Administration: 4 sessions over 3 months. Each video viewed first in hospital with discussion, questions and answers immediately after to ensure understanding. First session at admission provides training, installation of app and first video. Second set of videos at time of discharge, third set at one month postdischarge follow-up, fourth set at three months postdischarge follow-up. Participants in the intervention group were sent twice weekly messages as a reminder to watch the movies at home. Control: usual care. Usual care consisted of verbal instructions and information booklets regarding diet, need for rehabilitation, possible complications and medication use. These were delivered by a multidisciplinary team of a neuro-physician, stroke nurse, dietitian and physiotherapist. Additionally, a discharge co-ordinator recapped skills learnt in hospital prior to discharge and a stroke helpline was provided.
Outcomes	• ADL: Barthel Index • Modification of health-related behaviours: medication adherence (Morisky Medication Adherence Scale), blood pressure control, blood sugar control, blood cholesterol control • Death: total mortality (calculated from available data)

Kamal 2016 *(Continued)*

Not included in this review (bespoke measure)

- Carer knowledge (stroke risk factors, stroke rehabilitation and medications)

Not included in this review (insufficient information provided)

- Satisfaction with intervention (intervention participants only)
- Readmission with stroke-related complications

Not included in this review (not a prespecified outcome of interest)

- Stroke-related mortality
- NIHSS
- Disability: mRS

Details of funding sources	University Research Council (URC), Aga Khan University, Project ID: 132001MED Adeel Khoja is a neurovascular research fellow whose mentored research practicum training is currently being funded by Award Number D43TW008660 from the Fogarty International Center and the National Institute of Neurologic Disorders and Stroke (NIH) and involves ascertainment of outcomes in this study. The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.
Notes	Author directed us to preprint location (preprints.jmir.org/preprint/12113) but this was not available due to a technical error. We identified the preprint on ResearchGate.

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated sequence generated by CTU staff Quote: "A computer generated randomization list was used to randomize subjects to the control group or the intervention group. The randomization center was at a secure computer in the Clinical Trials Unit and the randomization list was generated by CTU staff not involved in recruitment, outcome ascertainment or any aspect of the study."
Allocation concealment (selection bias)	Low risk	Central allocation with sealed opaque envelopes kept locked away. Some risk due to use of block randomisation but minimal with block size of 10. Quote: "Randomization list was centralized and thus not predictable. No one from the research team had any access to randomization list, randomization envelopes, block size or code. It was made sure that envelopes were sealed, opaque and it was impossible to view the sequence even if held against bright sunlight. Randomization list and opaque envelopes containing the randomization sequence were always kept inside the premises of Clinical Trials Unit (CTU) under lock and key." Quote: "Block randomization technique with a fixed block size of ten was used."
Blinding of participants and personnel (performance bias) All outcomes	High risk	Participants were not blinded to allocation.
Blinding of outcome assessment (detection bias) All outcomes	High risk	Blinded outcome assessment stated. However, functional outcomes, Morisky Medication Adherence scale, knowledge questionnaire, and level of satisfac-

Kamal 2016 *(Continued)*

		tion were reported by the participants or carers, who were not blinded to the treatment allocation.
Incomplete outcome data (attrition bias) All outcomes	High risk	Although losses to follow-up reported at approximately 10% (32/310), there is approximately two-thirds missing data for many measures at 12 months e.g. blood pressure: n = 106, HbA1C: n = 95; LDL: n = 96. Losses are less substantial for NIHSS, mRS and BI (n = 248) and similar between groups but are not explained.
Selective reporting (reporting bias)	High risk	Carer knowledge, satisfaction and readmission with stroke-related complications (outcomes of interest in the review) were not reported. Quote: "A number of predefined secondary outcomes were included in this study; we report here mortality and functional disability at 12 months."
Other bias	Low risk	Appears to be free of other risks of bias

Karimi 2018

Study characteristics	
Methods	RCT No attrition at end of trial and no report of changing group. Absence from training was a reported exclusion criterion
Participants	Stroke survivors discharged from hospital, and their main family carers Iran 70 dyads: 35 intervention, 35 control Age: stroke survivors: 61.97 years (SD ~ 10.5); family carers: 38.14 years (SD ~ 11) Gender: stroke survivors: 52.9% women, 47.1% men; carers: 65.7% women, 34.3% men Stroke survivor inclusion criteria: absence of any signs suggesting bedsore or skin disorders in the stroke survivor at the beginning of this study; being a resident of Zahedan, age of 45 to 75 years old; bedsore risk score ≤ 14 (being moderately or severely at risk of bedsore, according to Braden scale) Stroke survivor exclusion (exit) criteria: rehospitalisation of the stroke survivor during the study, death of the stroke survivor during the study, having suspicious ulcers or any skin disease, (additional criteria in trial register record) to take the stroke survivor to the care centres Family carer inclusion criteria: age of above 18 years, having a carer that provided care for a longer time compared to other carers, being literate (ability of writing and reading), (additional criteria in trial register record) The absence of other family members, the maintenance of a mental illness or elderly in the family Family carer exclusion (exit) criteria: absence of more than 1 session of training sessions, (additional criteria in trial register record) the occurrence of any burden stress incident for the carer during the study
Interventions	Treatment: active. Educational: covering stroke, risk factors, problems caused by stroke, how bedsores develop, recognising different types of bedsore and methods for their prevention. Provided in addition to usual care. Focus: main family carer Setting: 1 session in hospital at time of discharge, 2 sessions at home

Karimi 2018 *(Continued)*

	Administration: pamphlet and 3 x face-to-face sessions over 3 weeks Control: usual care. The routine training provided on the ward.
Outcomes	**Not included in this review (insufficient information provided)** • Zarit's Care Load Questionnaire • Recurrent stroke **Not included in this review (not a prespecified outcome of interest)** • 4-point scale of bedsore proposed by the National Pressure Ulcer Advisory Panel • Braden's Wound Burden Risk Evaluation Score
Details of funding sources	Zahedan University of Medical Sciences
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Comment: The procedures described in the trial register and published results are different, with insufficient detail to determine whether either procedure would have produced a random sequence. Quote: "red cards (intervention) and control cards (prefixes) will be pre-numbered and randomly ordered. Then, with the choice and gradual entry of patients and carers to study, each of the above-mentioned cards will determine the allocation of the group" – from trial register Quote: "Coloured cards, including red (intervention) and blue (control), including 70 in total (35 of each card) were randomly placed inside a box and given to the family carers. Then, everyone picked a coloured card randomly from inside the box. Eventually, this procedure was continued without substituting the card until completion of the coloured cards." – from published results
Allocation concealment (selection bias)	Unclear risk	Insufficient information to permit judgement.
Blinding of participants and personnel (performance bias) All outcomes	High risk	According to the trial record, there was no blinding in the trial. The participants were likely to know which allocation they received because of the type of intervention in the intervention group and comparison to usual care.
Blinding of outcome assessment (detection bias) All outcomes	High risk	The participants were not blinded to allocation, thus their self-reported outcomes might be influenced by the knowledge of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Reported no attrition.
Selective reporting (reporting bias)	High risk	Main outcome variables registered in trial record are "prevent bed sores and attendant care burden". The primary outcome measurements are Zarit's Care Load Questionnaire, and Barden Wound Burden Risk Evaluation score (Barden pressure ulcer risk assessment). Secondary outcomes are recurrent stroke. However, only incidence of bedsore during the trial was reported.

Karimi 2018 *(Continued)*

		This report was adapted from the MSc thesis of the first author, which is not available. Therefore, insufficient information is available to determine whether the results about carer burden and recurrent stroke were reported elsewhere, e.g. in the original thesis.
Other bias	Unclear risk	There are substantial inconsistencies between the trial register record and report, e.g. inclusion and exclusion criteria, randomisation details; and within the report, e.g. information of carers' gender does not added up to the total, number of participants completed the trial was stated as 17 but was apparently 70 (it also states no attrition and numbers reported for bedsore incidence total 70). Due to these inconsistencies, it is unclear what actually happened in the trial; and the reasons for the differences between the information in the trial record and the report, or whether the different details were simply mistakes in reporting.

Kim 2013

Study characteristics	
Methods	Randomised controlled pilot trial, using computer-generated random numbers. No report concerning who carried out the random allocation, and no report of use of sealed envelopes. Paired stroke-survivor/carer dyads allocated together. Outcome assessment may be blinded as carried out by an RA who did not give intervention, but unclear as blinding not specifically reported. ITT approach stated for analysis 2 stroke survivors (1 treatment, 1 control) and 6 carers (2 treatment, 4 control) lost to follow-up 3-month follow-up
Participants	Neurology clinic in South Korea 36 stroke survivors: treatment N = 18; control N = 18. Completed final follow-up: N = 34 36 carers: treatment N = 18; control N = 18. Completed final follow-up: N = 30 Mean age of stroke survivors: treatment 67 years; control 64 years Mean age of carer participants: treatment 49.8 years; control 53 years Male participants: treatment 72.5%; control 55.6% MMSE-K: treatment 27.2 control 26.6 NIHSS: treatment: 1.1; control 0.5 K-MBI: treatment: 85.2; control 91.7 Hypertension: treatment 55.6%; control 72.2% Diabetes: treatment 22%; control 22% Carers were usually the stroke survivors' partners (66.7% treatment and 77.8% control) but also the stroke survivors' children (22.2% treatment and 22.2%% control). The remaining 2 were hired helps. All lived with the stroke survivor. Inclusion: clinical diagnosis of ischaemic stroke in past 12 months and had visited a clinic for treatment; normal cognition; living at home; internet access and access to a usable computer; carer on-site who also volunteered to participate

Kim 2013 *(Continued)*

Interventions	Treatment: active. Internet-based video lectures and automated quizzes. Areas covered included importance of stroke recurrence, stroke and exercise, exercise and falls prevention, medication adherence and surgery, nutrition management, smoking and drinking, control and prevention of hypertension/diabetes, control of emotions and formation of family intimacy. A research assistant provided telephone technical support for using the Internet. A guidebook for using the service was also provided. Lectures lasted 15 to 20 minutes and were given by a physician, PT or professor of nursing. Sessions were meant to be done weekly over the 9 weeks. Quizzes were given at the end of each session. Control: usual care
Outcomes	• Modification of health related behaviours: medication adherence; regular exercise; smoking; alcohol, salty food, fruit and vegetable consumption (stroke survivor; 3 months) • Risk factors: triglyceride and total cholesterol levels (stroke survivor; 3 months) • Locus of control: The Mastery Scale (stroke survivor; 3 months) **Not included in this review (not a prespecified outcome of interest)** • The Health Motivation Scale (3 months)
Details of funding sources	Basic Science Research Program through the National Research Foundation of Korea (NRF) funded by the Ministry of Education, Science and Technology [20110003345]
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Sequence generated by computer random number generator. Quote: "After screening and baseline testing, the participants were randomly assigned to an experimental or control group in a 1:1 ratio, using a computer-generated random code."
Allocation concealment (selection bias)	Unclear risk	Insufficient information available about method of allocation concealment. Quote: "After screening and baseline testing, the participants were randomly assigned to an experimental or control group in a 1:1 ratio, using a computer-generated random code. Baseline evaluations were performed during appointments at the stroke clinic. The researcher introduced the web-based program to the intervention group after allocation."
Blinding of participants and personnel (performance bias) All outcomes	High risk	No blinding of HCPs and participants was possible. Greater attention and time spent with intervention group.
Blinding of outcome assessment (detection bias) All outcomes	High risk	Most of the outcomes were self-reported, including participant's health behaviours and psychological characteristics, and carer mastery among carers. The information reported may have been influenced by the knowledge of allocated intervention. The research assistant was blinded but the participants were not. Quote: "As a research assistant provided Internet technical support by telephone to the intervention group, blinding of the participants and researchers was not possible. However, the face-to-face interviews with stroke patients and the telephone interviews with primary caregivers at baseline and the 3-month follow-up were conducted by a research assistant (not the researcher who delivered the intervention)."

Kim 2013 *(Continued)*

Incomplete outcome data (attrition bias) All outcomes	Low risk	Attrition rates seem low, i.e. 2/36 (5%) stroke survivors, and 6/36 (16.7%) carers. The reasons for not completing the trial were unlikely to be related to the true outcome. Therefore, these were are unlikely to affect the estimated effects. Quote: "Although 36 patients were randomized to each group, two participants were lost to follow-up as a result of poor health (n = 1) and refusal to complete the follow-up assessment (n = 1). In the intervention group, two primary caregivers were lost to follow-up because they were too busy; in the control group, four primary caregivers declined to complete the follow-up evaluation for the same reason (n = 1), because of lack of interest (n = 1) and illness (n = 2). Sixteen primary caregivers in the intervention group and 14 primary caregivers in the control group completed the program..."
Selective reporting (reporting bias)	Unclear risk	No protocol found
Other bias	Low risk	None identified

Kuo 2015

Study characteristics	
Methods	RCT 1 month (during intervention period) and 2 months (postintervention) follow-up
Participants	From Taiwan 100 stroke survivors and their family carers: intervention N = 50; control N = 50. Completed final follow-up N = 94 Age mean (SD): stroke survivors 76 (12) years; carers 53 (14) years Gender: stroke survivors 43% women; carers 63% women Stroke survivors were eligible if they had experienced an ICD-9 diagnosis ranging from 430 to 438, had a Barthel Index score less than 60, and had dysphagia. Stroke survivors were excluded if they were diagnosed with a pulmonary infection, had a diagnosis of oral or tongue pathology, or had used antimicrobial mouthwash in the past 3 months. Family carers were eligible if their family member was. The family carers who were unable to open their stroke survivor's mouth were also not eligible for this study; this is because stroke survivors with unstable conditions will increase intervention risk. Each family carer was actively caring for their stroke survivor for at least 8 hours per day and was able to communicate in Mandarin or Taiwanese.
Interventions	Treatment: active. Education: home-based oral care training programme Face-to-face education/presentation/discussion for carer by trained home healthcare nurse including: oral care overview, discussion of basic oral care procedures and risks, providing oral care products, demonstration by nurse, return demonstration by carer, record sheets as a reminder Control: routine care
Outcomes	Knowledge of Oral Care (carer) Attitude towards Oral care (carer) Self-efficacy of Oral Care (carer)

Kuo 2015 *(Continued)*

	Behaviour of Oral Care (carer) Tongue coating: Winkel Tongue Coating Index (stroke survivor) Plaque: Dental Plaque Index (stroke survivor) Symptoms of respiratory infection (stroke survivor)
Details of funding sources	No external funding
Notes	The 44-item Knowledge of Oral Care questionnaire was primarily based on an existing measure (Frenkel 2002) with additional items generated from a literature review. Content validity and internal consistency of the questionnaire were assessed within the study (Kuo 2015).

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "a computer-generated random number table was used to prepare the allocation schedule"
Allocation concealment (selection bias)	Unclear risk	Details of allocation concealment were not provided.
Blinding of participants and personnel (performance bias) All outcomes	High risk	Quote: "Single-blind" – assumed that single-blind means that the personnel are not blinded to allocation and can not be as the intervention group received the HOCP and the control group did not.
Blinding of outcome assessment (detection bias) All outcomes	High risk	Attempted to reduce observer bias by using observers not involved in treatment assignments or patient care. However, participants could not be blinded to their allocation therefore self-report outcomes were at high risk of detection bias.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Incomplete outcome data were appropriately reported. 2/50 were excluded from analysis in the first intervention follow-up for the intervention group and 0/48 were lost to second intervention follow-up for the intervention group. 0/50 were excluded from analysis in the first intervention follow-up for the control group and 4/50 were excluded from analysis in the second intervention follow-up for the control group. 5/6 of the exclusions were a result of death and 1/6 refused to participate. No imbalance between groups.
Selective reporting (reporting bias)	Unclear risk	No protocol found.
Other bias	Low risk	Appears to be free of other risks of bias.

Larson 2005

Study characteristics

Methods	Randomisation performed by authors using blocks of 20 participants, where 10 would be allocated to each arm of the trial and the sequence could not be predicted. Outcome assessment by self-rated questionnaires. 9 carers (4 treatment, 5 control) lost to follow-up. 6-month and 1-year follow-up

Larson 2005 *(Continued)*

Participants	Stockholm, Sweden 100 spouses of stroke survivors: treatment N = 50; control N = 50. Completed final follow-up: N = 91 Mean (SD) age of spouse: treatment 68 (10) years; control 67 (10) years Mean (SD) age of stroke survivor: treatment 72 (10) years; control 70 (10) years Sex of spouse (women): treatment 76%; control 84% Inclusion criteria: spouse of stroke survivor (defined as person living in the same household as the stroke survivor) Exclusion criteria: not possible to obtain information from the spouse or if stroke survivor not able to return home after hospitalisation
Interventions	Treatment: active. Support and education programme led by stroke specialist nurses and group discussion with issues raised by participants. Topics included: the nature of stroke, treatment and recovery, psychological and social effects, how to prevent recurrence. Participants able to call the stroke specialist nurse between sessions to get extra information or support Focus: spouse of stroke survivor Setting: hospital Administration: groups of 10, attended 6 times in 6 months. Session commenced with lecture on 1 of the topics for 20 to 30 minutes, followed by group discussion Control: regular information during hospitalisation and also at discharge. Possibility of attending 1 open session of 1.5 hours by a stroke physician on the ward (only 3 control participants chose this option)
Outcomes	• Mental well-being: Bradley's well-being questionnaire (6 and 12 months) • Quality of life: General Quality of Life visual analogue scale (6 and 12 months) • Perceived health status: EQ-VAS (6 and 12 months) **Not included in this review (not a prespecified outcome of interest)** • Life Situation Among Spouses after the Stroke event (6 and 12 months)
Details of funding sources	Not reported
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Randomly assigned to intervention or control group but method of sequence generation not reported.
Allocation concealment (selection bias)	Unclear risk	Reported that sequence could not be predicted but method of allocation concealment not reported.
Blinding of participants and personnel (performance bias) All outcomes	High risk	No placebo intervention for control group
Blinding of outcome assessment (detection bias)	High risk	No report of blinding. However, participants self-reporting outcomes would have been aware of allocation.

Larson 2005 *(Continued)*

All outcomes		
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Losses to follow-up low (10% control and ~2% treatment) but reasons not provided.
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported in the results. However, study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Lomer 1987

Study characteristics	
Methods	Stroke survivors randomly selected to receive leaflets, no further details given No stated blind outcome assessment No reported losses to follow-up 1-week follow-up
Participants	Southampton, UK Numbers unclear; report states that 73 stroke incidents were assessed. Appears 48 stroke survivors' and 44 carers' (19 of the 48 stroke survivors plus 25 carers of stroke survivors who were unable to complete questionnaire) knowledge was assessed across 73 (48 + 25) incidents No participant characteristics reported Inclusion criteria: admission to medical or geriatric wards of the 2 major teaching hospitals in Southampton, clinical diagnosis of stroke Exclusion criteria: discharge within 7 days of admission, severe illness, aphasia or dysphasia that prevents response to interview, lack of awareness that have had a stroke
Interventions	Treatment: passive. 12-page leaflet prepared for study personalised with name, sections on basic pathologies of stroke, predisposing factors, treatment, recovery, facilities available in the community, and financial benefits available Focus: stroke survivor and relative Setting: hospital Administration: presented to stroke survivor by a medical student with no explanation other than the leaflet may be interesting for them and their relatives to read. 1 contact, length of time unknown, between 1 and 2 weeks after admission Control: usual care, no leaflet
Outcomes	**Not included in this review (bespoke measure)** • Knowledge about stroke (1 week)
Details of funding sources	Not mentioned
Notes	Validity assessment: comparability of treatment and control groups unknown as no reporting of participant characteristics

Lomer 1987 *(Continued)*

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of randomisation not reported.
Allocation concealment (selection bias)	Unclear risk	Method for allocation concealment not reported.
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	No placebo intervention for control group. However, participants did not appear to be informed of the study when they were provided with the leaflet and staff were not informed who received the leaflet. However, blinding may have been broken.
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Unclear if blinded outcome assessment was undertaken.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	A number of exclusions and unclear at which time point in the study
Selective reporting (reporting bias)	Unclear risk	All outcomes described. However, study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Lowe 2007

Study characteristics	
Methods	Randomised using sealed opaque envelopes in blocks of 10 and 1 to 1 ratio. Envelopes prepared by independent researcher Blinded outcome assessment Stated ITT analysis 16 stroke survivors (6 treatment, 10 control) lost to follow-up 3-month and 6-month follow-up
Participants	Liverpool, UK 100 stroke survivors: treatment N = 50; control N = 50. Completed final follow-up: N = 84 Median age of stroke survivor: treatment 68 years; control 73 years Sex of stroke survivor (women): treatment 42%; control 38% Inclusion criteria: confirmed stroke, all ages, either sex, stroke survivors who were discharged home and who could complete a questionnaire, or who had a named carer who could do so Exclusion criteria: pre-existing cognitive impairment, discharged to institutionalised care, discharged home but unable to self-complete questionnaire and no named carer

Lowe 2007 *(Continued)*

Interventions	Treatment: passive. CareFile (A5 size laminated 29 page booklet). Includes general information about stroke as well as information personal to the stroke survivor, secondary prevention measures, and personal goals aimed at reducing risk of further stroke. Also contains useful telephone numbers for all stroke-related services and local support agencies. Design allows for removal of pages not relevant to the individual. Sections included for members of the multi-disciplinary team to complete summaries of stroke survivor's achievements and future rehabilitation goals. Also provided with advice from therapists and offered leaflets from Chest, Heart and Stroke Association Focus: stroke survivor Setting: hospital ward Administration: interview arranged between researcher and stroke survivor when discharge date in place. Carer also invited to attend. The CareFile and its contents explained by the research registrar and any additional concerns or issues addressed in discussion lasting approximately 15 to 20 minutes. Stroke survivors advised to take the CareFile with them to all General Practitioner and clinic appointments Control: received the usual stroke information leaflets provided by the stroke unit and follow-up in stroke review clinic
Outcomes	• Knowledge about stroke: Stroke Knowledge Questionnaire (3 and 6 months) • Depression: Yale Screening question for depression (3 and 6 months) • Satisfaction with information given (3 and 6 months) • Modification of health related behaviours: Blood pressure (3 and 6 months) **Not included in this review (not a prespecified outcome of interest)** • Disability: mRS (3 and 6 months)
Details of funding sources	£5000 research grant from Bristol Myers Squibb
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Reported that eligible stroke survivors were randomised but method not reported
Allocation concealment (selection bias)	Low risk	Reported to have used sealed opaque envelopes
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants or personnel
Blinding of outcome assessment (detection bias) All outcomes	High risk	Outcome assessors do not appear to have been blinded – Quote: "those in the intervention group were asked if they had brought the CareFile to the Review Clinic and if they found it useful"
Incomplete outcome data (attrition bias) All outcomes	High risk	Almost twice as many lost to follow-up in the control group (10/50) compared with the intervention group (6/50)
Selective reporting (reporting bias)	Unclear risk	Study protocol not available so cannot assess reporting bias

Lowe 2007 *(Continued)*

Other bias	Low risk	No other obvious sources of bias

Maasland 2007

Study characteristics	
Methods	Random allocation in blocks of 10 using computer-generated random numbers. Size of blocks unknown to investigators at time of trial Blinded outcome assessment ITT analysis 7 stroke survivors lost to follow-up plus 1 withdrawn (results not reported) as breached inclusion criteria. Differential losses between the groups unclear Follow-up at 1 and 12 weeks
Participants	Rotterdam, Netherlands 65 service users at TIA/minor stroke clinic: treatment N = 33; control N = 32. Completed final follow-up: N = 58 (results reported for 57) Mean age of stroke survivors: treatment 65 years; control 63 years Sex of stroke survivors (men): treatment 57%; control 63% Inclusion criteria: 18 years or older, TIA or minor Ischaemic stroke within last 3 months, speak/write Dutch fluently, modified Rankin score < 4 Exclusion criteria: professionally engaged in cardio-vascular health education, aphasia, dementia, visual impairment to a degree that would interfere with health education delivery
Interventions	Treatment: passive. Discussion of test results and standard education by physician plus IMCP comprising of modules containing lay information for each of 8 modifiable risks. All modules highly structured and contained combinations of slides shows, background voice and personal address Focus: stroke survivor Setting: outpatient clinic Administration: after consultation with physician shown IMCP. Given brief introduction. 1 of 2 versions used according to age and educational level: general introduction of their personal diagnosis, explanation of the used or prescribed medications, then each stroke survivor shown 4 risk factor modules, or if has less than 4 risk factors general information about frequent vascular risk factor, printed summary of the information Control: discussion of test results and standard health education
Outcomes	• Knowledge about stroke: at 1 (primary) and 12 weeks (secondary) post intervention • Modification of health related behaviours: Changes in cholesterol level, weight, cigarette, and alcohol consumption and physical activity (12 weeks) **Not included in this review (not a prespecified outcome of interest)** • Disability: mRS (12 weeks)
Details of funding sources	Revolving Fund of the Erasmus Medical Center

Maasland 2007 *(Continued)*

Notes

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Quote: "Treatment allocation was random, and based on computer-generated random numbers."
Allocation concealment (selection bias)	Unclear risk	Method of allocation concealment not reported.
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants or personnel and no placebo intervention provided.
Blinding of outcome assessment (detection bias) All outcomes	High risk	No report of blinded assessment. However, participants self-reporting outcomes would have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Eight of the 65 participants were lost in total and unclear which groups they were lost from.
Selective reporting (reporting bias)	High risk	Blood pressure was not a prespecified outcome but has been reported.
Other bias	Low risk	No other obvious sources of bias

Mant 1998

Study characteristics

Methods	Randomisation performed by telephone in computer-generated blocks of 10 using sequentially-numbered opaque envelopes Blinded outcome assessment Stated ITT analysis 22 stroke survivors (11 treatment, 11 control) and 7 carers (4 treatment, 3 control) lost to follow-up 6-month follow-up
Participants	Oxford, UK 93 stroke survivors: treatment N = 48; control N = 45. Completed final follow-up: N = 71 56 carers of these stroke survivors: treatment N = 32; control N = 24. Completed final follow-up: N = 49 Mean age of stroke survivors: treatment 70 years; control 76 years Sex of stroke survivors (men): treatment 65%; control 65% Inclusion criteria: Oxfordshire resident, admission to any Oxford hospital, stroke within past month (could be recurrent)

Mant 1998 *(Continued)*

	Exclusion criteria: identified over 1 month after stroke, death within 1 month of admission or considered likely to occur prior to follow-up, taking part in another trial involving follow-up interview, dysphasic with no close informal carer, stroke not the major medical problem, admitted from a nursing home, subdural, subarachnoid haemorrhage when no accompanying intracerebral haemorrhage, TIA
Interventions	Treatment: passive. A collection of 8 leaflets published by the Stroke Association assembled in an A5 folder covering what a stroke is, effects, cause, problems that might be experienced and how they might be dealt with. An introductory leaflet was specially prepared plus leaflets giving local and national contact names and addresses of support groups and services Focus: stroke survivor and closest informal carer if available Setting: home Administration: pack addressed to both stroke survivor and carer (where applicable). No contact at delivery. Sent to home address 1 week after randomisation (4 to 5 weeks after stroke). Pack left with stroke survivor and carer for 6 months Control: received nothing
Outcomes	• Anxiety and depression: HADS (stroke survivor; 6 months) • Burden: Caregiver Strain Index (carer; 6 months) • Perceived health status: Dartmouth COOP Chart (stroke survivor; 6 months) • Perceived health status: SF-36 (carer; 6 months) • Satisfaction with information and care received (stroke survivor and carer; 6 months) • ADL: BI (stroke survivor; 6 months) **Not included in this review (bespoke measure)** • Knowledge about stroke (stroke survivor and carer; 6 months) **Not included in this review (not a prespecified outcome of interest)** • Participation: London Handicap Scale (stroke survivor; 6 months) • Service use (stroke survivor; 6 months)
Details of funding sources	Stroke Association (UK) The Stroke Register was supported by a grant from the Anglia & Oxford Regional Health Authority
Notes	Validity assessment: treatment and control groups not balanced in respect of age

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated random sequence generation
Allocation concealment (selection bias)	Low risk	Sequentially numbered opaque envelopes
Blinding of participants and personnel (performance bias) All outcomes	High risk	No intervention provided for the control group. As a result a high risk of bias
Blinding of outcome assessment (detection bias) All outcomes	High risk	Quote: "While in theory the interviewer was blinded to the treatment allocation, in practice she guessed the correct status of the patients more often than might be expected by chance."

Mant 1998 *(Continued)*

		Correct guessing may indicate blinding was unsuccessful or that the outcome assessor was noticing real differences between participants. However, participants self-reporting outcomes would have been aware of allocation
Incomplete outcome data (attrition bias) All outcomes	Low risk	Losses to follow-up balanced in numbers and reasons across groups.
Selective reporting (reporting bias)	Unclear risk	All measures described in the methods were reported in the results. However, study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Mudzi 2012

Study characteristics	
Methods	RCT, but no description of how this was done. Allocation described as concealed, but no report concerning who carried out the random allocation, and no report of use of sealed envelopes. Paired stroke-survivor/carer dyads allocated together. Outcome assessment not reported to be blinded. ITT approach stated for analysis. Unknown numbers lost to follow-up. 3, 6, and 12 months follow-up
Participants	Hospital in South Africa 200 stroke survivors: treatment N = 100; control N = 100. Completed final follow-up: not reported 200 carers: treatment N = 100; control N = 100. Completed final follow-up: not reported Mean age of male/female stroke survivors: 52/54 (no group data) Mean age of male/female carers: 43/37 (no group data) 78% of sample with < Grade 11 of education Relationship of carers to stroke survivors not reported. Inclusion: first time ischaemic stroke; carer also volunteered to participate
Interventions	Treatment: active. Usual care plus all carers received hands-on training in lifting and handling techniques; back care; facilitation of mobility and transfers; continence; assistance with ADLs; and communication. Information on stroke-related problems and their prevention; and management/prevention of pressure sores, continence, positioning, gait facilitation and sexuality. Given as a 45 minute training session just before discharge home; geared to the individual needs of the stroke survivor. Control: usual care
Outcomes	• ADL: BI (stroke survivor; 3, 6 and 12 months) • Carer burden: Caregiver Strain Index (CSI) (carer; 3, 6 and 12 months) **Not included in this review (insufficient information)** • Perceived health status: EQ-5D (stroke survivor and carer; 3, 6 and 12 months) **Not included in this review (not a prespecified outcome of interest)**

Mudzi 2012 *(Continued)*

- Rivermead Mobility Index (RMI) (stroke survivor; 3, 6 and 12 months)

Details of funding sources	University of the Witwatersrand Medical Research Council of South Africa
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Insufficient information about sequence generation process available. The baseline characteristics of the two groups were not provided, which could indicate any imbalance.
Allocation concealment (selection bias)	Unclear risk	Allocation concealment was claimed but no details were given of the method used. Quote: "The allocation into groups and training of the informal carers was done with blinding of the researcher."
Blinding of participants and personnel (performance bias) All outcomes	High risk	No blinding of HCPs and participants was possible. Greater attention and time spent with intervention group.
Blinding of outcome assessment (detection bias) All outcomes	High risk	Barthel Index and Rivermead mobility Index are self-reported assessments, answered by the participants or carers. Their knowledge of the intervention allocations may influence the outcomes.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Attrition not reported
Selective reporting (reporting bias)	High risk	Protocol not found, however, sufficient details of Caregiver Strain Index and EQ-5D not presented.
Other bias	Low risk	None identified

O'Connell 2009

Study characteristics

Methods	RCT utilising computer-generated randomised sequence Blinded outcome assessment 27 stroke survivors (18 intervention, 9 control) lost to follow-up
Participants	Melbourne, Australia 93 stroke survivors (intervention N = 46; control N = 47) Age mean (range): 73 years (32.1 to 91.3) 33 men and 33 women completed second post intervention follow-up (sex details not reported at baseline)

O'Connell 2009 *(Continued)*

	Inclusion criteria: > 18 years, able to be discharged home, English proficiency, adequate communication for interview, corrected vision and hearing, no evidence of severe cognitive impairment Exclusion criteria: none reported
Interventions	Intervention: passive. Patient held-record (PHR) which included contact details, questions for health professionals, notes on care, useful phone numbers, brochures from the national stroke foundation and fact sheets relating to specific problems associated with their stroke, level of disability and symptoms (movement and balance, swallowing difficulties, continence, driving and vision, mood changes, pain, sexuality, speech and communication). In addition, usual discharge information (health summary sheet listing medication) Focus: stroke survivor Setting: hospital prior to discharge Administration: trained health care researcher Control: usual discharge information (health summary sheet listing medication)
Outcomes	• Perceived health status: Stroke Impact Scale (4 weeks and 4 months post intervention) **Not included in this review (not a prespecified outcome of interest)** • PHR evaluation questionnaire (unclear when administered)
Details of funding sources	Medical Benefits Fund of Australia Limited MBF Research Awards R Buchbinder supported in part by an Australian National Health and Medical Research Council Practitioner Fellowship
Notes	

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated randomisation procedure
Allocation concealment (selection bias)	Low risk	Computer-generated randomisation procedure. External researcher held randomisation codes
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Insufficient information provided
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Whilst it was reported that the outcome assessor was blinded, one of the measures appeared to be given to the intervention group only which would have compromised assessor blinding (not explained how this was overcome). As a result unclear
Incomplete outcome data (attrition bias) All outcomes	High risk	One-third lost to follow-up. More lost in the intervention group and reasons for losses not reported
Selective reporting (reporting bias)	High risk	Protocol unavailable so cannot determine if all outcomes have been reported. No pre-intervention data reported

O'Connell 2009 *(Continued)*

Other bias	High risk	This trial was terminated early as a number of the intervention participants were unable to recall receiving the information

Pain 1990

Study characteristics	
Methods	Computer-generated randomised allocation. Stratified for side of cerebrovascular accident Blinded outcome assessment 6 stroke survivors (2 treatment, 4 control) lost to follow-up 3-month follow-up
Participants	Southampton, UK 36 stroke survivors and carers (couples): treatment N = 21; control N = 15. Completed final follow-up: N = 30 Age of stroke survivors: number < 65 years: treatment N = 8; control N = 4; number > 65 years: treatment N = 13, control N = 11 Sex of stroke survivors (men): treatment N = 16; control N = 9 Inclusion criteria: admission to hospital with a CVA as defined by WHO, discharge home after a minimum period of treatment of 10 days to live with a relative or carer, agreement to participate in the study Exclusion criteria: none stated
Interventions	Treatment: Passive. Individualised booklet containing information on persisting symptoms, current aims of rehabilitation, instructions concerning ADLs, description of exercises provided, pertinent photos, useful local and national addresses and contacts. Also provided with advice from therapists and offered leaflets from Chest, Heart and Stroke Association Focus: both stroke survivor and carer Setting: home Administration: no contact at delivery. Sent within 7 days of discharge (> 17 days poststroke) by research therapist to home address Control: provided with advice from therapists and offered leaflets from Chest, Heart and Stroke Association
Outcomes	• ADL: BI (stroke survivor; 3 months) • Social activities: modified FAI (stroke survivor; 3 months) **Not included in this review (bespoke measure)** • Knowledge of stroke (carer; 3 months) • Satisfaction with information received (carer; 3 months)
Details of funding sources	Grants from the Wessex Medical School Trust and the Social Services Department of Hampshire County Council
Notes	Validity assessment: unequal numbers in treatment and control, participants in the treatment group had higher levels of impairment and comorbidity

Pain 1990 *(Continued)*

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of random sequence generation not reported
Allocation concealment (selection bias)	Unclear risk	No information provided
Blinding of participants and personnel (performance bias) All outcomes	Unclear risk	Therapists were not informed which stroke survivors were to receive the booklets. No report of blinding of participants, both groups were provided with advice and offered leaflets in hospital, only treatment group received booklets after discharge – may not have been obvious which group they were in.
Blinding of outcome assessment (detection bias) All outcomes	Unclear risk	Social services occupational therapists who were blind to the trial and control groupings undertook the interviews. However, participants self-reporting outcomes may have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Unclear risk	Slightly more losses to follow-up in intervention group (4/21) than control group (2/15); reasons only given for group as a whole so cannot determine if reasons were similar between groups.
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported in the results. However, study protocol not available so cannot assess reporting bias.
Other bias	Low risk	No other obvious sources of bias

Rodgers 1999

Study characteristics	
Methods	Randomisation by a centralised telephone service. Randomised by computer initially in blocks of 8, stratified by presence of informal carer and incontinence of urine at 24 hours post stroke Blinded outcome assessment Stated intention-to-treat analysis 50 stroke survivors (31 treatment, 19 control) and 70 carers (42 treatment, 28 control) lost to follow-up 6-month follow-up
Participants	North Tyneside, UK 204 stroke survivors: treatment N = 121; control N = 83. Completed final follow-up: N = 154 176 informal carers of these stroke survivors: treatment N = 107; control N = 69. Completed final follow-up: N = 106 Median age of stroke survivors: treatment 74 years, control 76 years Sex of stroke survivors (men): treatment 49%; control 46% Inclusion criteria: confirmed diagnosis of stroke, medically stable, normally resident in North Tyneside, not in residential home prior to admission, still in hospital within 48 hours of admission Exclusion criteria: none stated

Rodgers 1999 *(Continued)*

Interventions	Treatment: active. 7 group sessions (1 during inpatient stay and 6 outpatient) covering the experience and nature of stroke, the role of physiotherapy and occupational therapy, psychological effects, caring, communication and swallowing problems, reducing risk. Leaflet with telephone number of stroke help line, Stroke Association, day hospital and stroke units Focus: both stroke survivor and informal carer Setting: stroke unit and day hospital Administration: a rolling programme held 7 times during course of study. Presentation by speaker at each session followed by questions and discussion. Opportunity to ask questions at beginning or end of session. Inpatient session 1 x 1 hour, 6 x 1 hour outpatient sessions over 6-week period Control: usual care. All given a basic 2-sided leaflet about North Tyneside stroke service plus staff prompted to provide information about stroke on day of admission and at regular intervals throughout stay. Record of communication and Stroke Association literature available. Given details of telephone hotline run by the stroke service prior to discharge
Outcomes	• Knowledge about stroke (stroke survivor and carer; 6 months) • Anxiety and depression: HADS (stroke survivor; 6 months) • Psychological distress: GHQ (carer; 6 months) • Perceived health status: SF-36 (stroke survivor and carer; 6 months) • Satisfaction with hospital services and discharge (stroke survivor and carer; 6 months) • Social activities: NEADL (stroke survivor; 6 months) • Death (stroke survivor; 6 months) **Not included in this review (not a prespecified outcome of interest)** • Disability: Oxford Handicap Scale (stroke survivor; 6 months) • Service use (stroke survivor and carer; 6 months)
Details of funding sources	Northern and Yorkshire Regional Health Authority National Health Service Research and Development Directorate
Notes	Validity assessment: large losses to follow-up

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Low risk	Computer-generated random number sequence
Allocation concealment (selection bias)	Low risk	Central telephone service used
Blinding of participants and personnel (performance bias) All outcomes	High risk	No placebo intervention for the control group
Blinding of outcome assessment (detection bias) All outcomes	High risk	Quote: "interviewed in their own homes at 6 months after stroke by a researcher who was blinded to the randomisation group." However, participants self-reporting outcomes would have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	High risk	Non-attenders and attenders included in analysis as is appropriate. Approximately 25% lost to follow-up with relatively similar numbers and reasons across groups. However, due to dysphasia or cognitive problems the primary outcome (SF-36) could not be completed by another 37 stroke survivors (24%)

Rodgers 1999 *(Continued)*

		meaning almost half of these outcomes were missing. Also, approximately 40% of carers were lost to follow-up.
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported. However, study protocol not available so cannot assess reporting bias.
Other bias	Unclear risk	Only 51 stroke survivors (42%) of those randomised attended 3 or more of the 6 outpatient sessions

Smith 2004

Study characteristics	
Methods	Stroke survivors randomly allocated using random length restricted permuted blocks (block lengths of 2, 4, and 6). Randomisation carried out by independent research assistant by using sealed, numbered, opaque envelopes kept in a locked separate location. Stratified by Barthel Index scores of 0 to 4, 5 to 9, 10 to 14, 15 to 19, presence of aphasia, and presence of a carer Blinded outcome assessment Stated ITT analysis 37 stroke survivors (15 treatment, 22 control) and 21 carers (9 treatment, 12 control) lost to follow-up 3- and 6-month follow-up
Participants	Bradford, UK 170 stroke survivors: treatment N = 84; control N = 86. Completed final follow-up: N = 133 97 carers of these patients: treatment N = 49; control N = 48. Completed final follow-up: N = 76 Median age of stroke survivors: treatment 75 years; control 74 years Sex of stroke survivors (women): treatment N = 46%; control N = 52% Inclusion criteria: all stroke survivors admitted to the stroke rehabilitation unit with a confirmed diagnosis of stroke Exclusion criteria: stroke survivors with receptive aphasia, cognitive impairment or who did not understand English and did not have a carer
Interventions	Treatment: active. Provided with the Stroke Recovery Programme, a specifically devised manual containing information about causation and consequences of stroke, recovery, financial benefits, relevant services, and a specific section for carers. Also invited to attend specifically convened meetings with members of their multidisciplinary team (doctor, nurse, physiotherapist, occupational therapist). The intention of the meeting was to provide background information about stroke, discuss stroke survivor's progress, answer specific questions, and develop shared rehabilitation goals Focus: stroke survivor but when they had receptive aphasia, cognitive impairment or did not understand English the carer was the main focus. Setting: stroke unit Administration: Stroke Recovery Programme given by stroke unit staff following randomisation. Meetings scheduled to last approximately 20 minutes held in the ward dayroom fortnightly for duration of stroke unit stay. Guidelines developed for use by rehabilitation teams to ensure coverage of the of the key topics included in the Stroke Recovery Programme and record of matters discussed completed following each meeting. Agreed goals recorded in the manual and retained by the stroke survivor.

Smith 2004 *(Continued)*

	Control: received usual practice. A folder of information about stroke causation, consequences and recovery previously devised by ward staff and stroke association leaflets were available.
Outcomes	• Knowledge about stroke (stroke survivor or carer; 3 and 6 months) • ADL: BI (stroke survivor; 3 and 6 months) • Social activities: FAI (stroke survivor; 3 and 6 months) • Anxiety and depression: HADS (stroke survivor; 3 and 6 months) • Psychological distress: GHQ-28 (carer; 3 and 6 months) • Satisfaction with information (stroke survivor and carer; 3 and 6 months) **Not included in this review (not a prespecified outcome of interest)** • Participation: LHS (stroke survivor; 3 and 6 months) • Use of services and receipt of benefits (stroke survivor; 6 months)
Details of funding sources	Northern and Yorkshire Region Research and Development
Notes	Validity assessment: losses to follow-up 22%

Risk of bias

Bias	Authors' judgement	Support for judgement
Random sequence generation (selection bias)	Unclear risk	Method of sequence generation not reported
Allocation concealment (selection bias)	Low risk	Quote: "Concealed randomisation was achieved using sealed, numbered, opaque envelopes kept in a locked separate location by an independent research assistant who carried out the randomisation and conveyed patient allocation information to the stroke unit co-ordinator."
Blinding of participants and personnel (performance bias) All outcomes	High risk	No report of blinding of participants and groupings probably obvious-treatment group attended meetings, control group received usual care
Blinding of outcome assessment (detection bias) All outcomes	High risk	Stroke survivors and carers were followed up by a research nurse who was blind to group allocation. However, participants self-reporting outcomes would have been aware of allocation.
Incomplete outcome data (attrition bias) All outcomes	Low risk	Approximately 22% lost to follow-up with similar reasons and proportions across groups
Selective reporting (reporting bias)	Unclear risk	All outcomes described in the methods reported in the results. However, study protocol not available so cannot assess reporting bias.
Other bias	High risk	Quote: "unavoidable contact and associated intervention contamination between the two groups of patients and relatives during the inpatient period"

- ADL: activities of daily living
- AHP: allied health professional
- AMT: Abbreviated Mental Test
- BI: Barthel Index
- BP: blood pressure
- CES-D: Center for Epidemiological Studies Depression scale

- CPAP: continuous positive airway pressure
- CTU: clinical trials unit
- CVA: cerebrovascular accident
- ED: emergency department
- EQ-5D: EuroQol 5-Dimension health status instrument
- EQ-VAS: EuroQol Visual Analogue Scale health assessment
- ESCROW: Environment, Social interaction, Cluster of family members, Resources, Outlook, Work/school/retirement status
- FAI: Frenchay Activities Index
- FBG: fasting blood glucose
- GDS: Geriatric Depression Scale
- GHQ: General Health Questionnaire
- HADS: Hospital Anxiety and Depression Scale
- HbA1C: glycosylated haemoglobin A1c
- HCP: health care professional
- IADL: instrumental activities of daily living
- ICD-9: International Classification of Diseases, 9th revision
- IMCP: individualised multimedia computer programme
- IRCT: Iranian Registry of Clinical Trials
- ITT: intention to treat
- K-MBI: Korean version of the modified Barthel Index
- LDL: low-density lipoprotein
- LHS: London Handicap Scale
- MMSE-K: Mini-Mental State Exam - Korean version
- mRS: Modified Rankin Scale
- N: sample size
- NIHSS: National Institutes of Health Stroke Scale
- OSA: obstructive sleep apnoea
- PHR: Patient-held record
- QOL: quality of life
- RCT: randomised controlled trial
- REALM: Rapid Estimate of Adult Literacy in Medicine
- SAQOL-39g: Stroke and Aphasia Quality of Life Scale-39 Generic
- SF-36: 36-item Short-Form health survey
- TIA: transient ischaemic attack
- WHO: World Health Organization
- WHOQOL-BREF-THAI: Thai version of the WHO Quality of Life short-form instrument

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Aben 2012	The information/education provision was part of a more complex rehabilitation intervention: includes goal setting and psycho-education.
Ab Malik 2017	Participants were healthcare workers.
ACTRN12618001066279	Ineligible comparison (differences in approach to training)
Adie 2010	The intervention included motivational interviewing.
Allen 2009	The information/education provision was part of a more complex rehabilitation intervention.

Study	Reason for exclusion
Andersen 2002	The information/education provision was part of a more complex rehabilitation intervention.
ATTEND 2017	The information/education provision was part of a more complex rehabilitation intervention.
Bacchini 2011	The information/education provision was part of a more complex rehabilitation intervention.
Bakas 2008	The information/education provision was part of a more complex rehabilitation intervention.
Bakas 2015	The information/education provision was part of a more complex rehabilitation intervention.
Ballard 2013	Ineligible comparison (two information interventions). Seems likely intervention recipients did not receive "usual care".
Battersby 2009	The information/education provision was part of a more complex rehabilitation intervention.
Bishop 2014	The information/education provision was part of a more complex rehabilitation intervention.
Blanton 2019	The information/education provision was part of a more complex rehabilitation intervention (included behavioural contract and diary).
Boden-Albala 2019	The information/education provision was part of a more complex rehabilitation intervention (social support and reminders).
Boehme 2018	The information/education provision was part of a more complex rehabilitation intervention (included adjustment of medication).
Boter 2004	The information/education provision was part of a more complex rehabilitation intervention.
Boysen 2009	The information/education provision was part of a more complex rehabilitation intervention.
Brotons 2011	The trial included participants with conditions other than stroke and the data were not available separately.
Burton 2005	The information/education provision was part of a more complex rehabilitation intervention.
Byers 2010	The intervention included motivational interviewing.
Cameron 2015	The information/education provision was part of a more complex rehabilitation intervention.
Chaiyawat 2009	The information/education provision was part of a more complex rehabilitation intervention.
Chang 2000	The information/education provision was part of a more complex rehabilitation intervention.
Chang 2011	The information/education provision was part of a more complex rehabilitation intervention.
Cheng 2011	The information/education provision was part of a more complex rehabilitation intervention.
Cheng 2015	The information/education provision was part of a more complex rehabilitation intervention focusing on equipping caregivers with problem-solving skills.
Christie 1984	The information/education provision was part of a more complex rehabilitation intervention.
Chumbler 2011	The information/education provision was part of a more complex rehabilitation intervention.
Claiborne 2006	The information/education provision was part of a more complex rehabilitation intervention.

Study	Reason for exclusion
Clark 2003	The information/education provision was part of a more complex rehabilitation intervention.
Clarke 2011	The information/education provision was part of a more complex rehabilitation intervention.
Damush 2011	The information/education provision was part of a more complex rehabilitation intervention.
Damush 2016	The information/education provision was part of a more complex rehabilitation intervention.
Dennis 1997	The information/education provision was part of a more complex rehabilitation intervention.
Desrosiers 2007	The information/education provision was part of a more complex rehabilitation intervention.
Dongbo 2003	Study included both stroke and non-stroke patients and data not available separately.
Dromerick 2011	The information/education provision was part of a more complex rehabilitation intervention.
Ertel 2007	The information/education provision was part of a more complex rehabilitation intervention.
Faulkner 2011	The information/education provision was part of a more complex rehabilitation intervention (exercise plus education).
Faulkner 2017	The information/education provision was part of a more complex rehabilitation intervention (exercise plus education).
Feld-Glazman 2012	The comparison was education vs education plus motivational interviewing – so education effects cancel, motivational interviewing is the experimental condition.
Forster 1996	The information/education provision was part of a more complex rehabilitation intervention.
Friedland 1992	The information/education provision was part of a more complex rehabilitation intervention.
Fukuoka 2015	The information/education provision was part of a more complex rehabilitation intervention (self-management).
Gillham 2010	The information/education provision was part of a more complex rehabilitation intervention.
Glass 2004	The information/education provision was part of a more complex rehabilitation intervention.
Goldberg 1997	The information/education provision was part of a more complex rehabilitation intervention.
Gorman 2015	Ineligible comparison (two information interventions). Comparison was “interactive stroke education booklet compared to a printed packet of stroke information”.
Grant 2002	The information/education provision was part of a more complex rehabilitation intervention.
Grasel 2006	The information/education provision was part of a more complex rehabilitation intervention.
Graven 2008	The information/education provision was part of a more complex rehabilitation intervention.
Green 2007	The intervention included motivational interviewing.
Habibzadeh 2007	The information/education was part of a more complex rehabilitation intervention. Non-random
Hackett 2013	The intervention was not information provision.

Study	Reason for exclusion
Harari 2004	The information/education provision was part of a more complex rehabilitation intervention specifically targeted at improving bowel function.
Harrington 2010	The information/education provision was part of a more complex rehabilitation intervention.
Hartke 2003	The information/education provision was part of a more complex rehabilitation intervention.
Harwood 2012	The information/education provision was part of a more complex rehabilitation intervention.
Heron 2017	The information/education provision was part of a more complex rehabilitation intervention (self-management).
Hirano 2012	Physical training only
Hochstenbach 1999	The information/education was part of a more complex rehabilitation intervention.
Hoffmann 2015	The information/education provision was part of a more complex rehabilitation intervention.
Holzemer 2011	The information/education provision was part of a more complex rehabilitation intervention.
Johnson 2018	Ineligible comparison (education vs education + test awareness)
Jones 2009	The information/education provision was part of a more complex rehabilitation intervention. No control group
Jones 2016	The information/education provision was part of a more complex rehabilitation intervention.
Kamal 2018	The information/education provision was part of a more complex rehabilitation intervention. Intervention included sending regular reminders to the participants to enhance medication adherence.
Kendall 2007	The information/education provision was part of a more complex rehabilitation intervention.
Kronish 2014	The information/education provision was part of a more complex rehabilitation intervention.
Lawal 2018	The information/education provision was part of a more complex rehabilitation intervention: self-management program enhanced by community-based education.
Leathley 2003	The information/education provision was part of a more complex rehabilitation intervention.
Lincoln 2003	Information provision was not the intervention evaluated. The experimental condition was a support organiser.
Linn 1979	The information/education provision was part of a more complex intervention specifically targeted at management of medication.
Lo 2018	Information provision was not the intervention evaluated.
Lorenc 1992	The study lacked a suitable control.
Lynch 2016	Participants were clinicians.
Mackay-Lyons 2010	The information/education provision was part of a more complex rehabilitation intervention.

Study	Reason for exclusion
Mant 2000	Information provision was not the intervention evaluated. The experimental condition was a support worker.
Mayo 2015	The information/education provision was part of a more complex rehabilitation intervention.
McKinney 1999	The information/education provision was part of a more complex intervention focused on providing feedback of cognitive assessment to stroke survivors' carers and members of the multidisciplinary team.
Merchán-Baeza 2015	The information/education provision was part of a more complex rehabilitation intervention (including assessments and reminders).
Napolitan 1999	The information/education provision was part of a more complex rehabilitation intervention.
NCT00431821	The information/education provision was part of a more complex rehabilitation intervention.
NCT01062243	Included participants with conditions other than stroke.
NCT01693341	The information/education provision was part of a more complex rehabilitation intervention.
NCT02591511	Ineligible comparison: active comparator
NCT03034330	The information/education provision was part of a more complex rehabilitation intervention (including family reorganisation).
NCT03708835	The information/education provision was part of a more complex rehabilitation intervention (care-coordination).
NCT03861494	The information/education provision was part of a more complex rehabilitation intervention (self-management).
Neubert 2011	No usual care group
Nguyen 2011	The information/education provision was part of a more complex rehabilitation intervention.
Nir 2006	The information/education provision was part of a more complex rehabilitation intervention.
Nour 2002	The information/education provision was part of a more complex rehabilitation intervention.
O'Carroll 2010	The information/education provision was part of a more complex rehabilitation intervention (psycho-education).
Olaiya 2016	The information/education provision was part of a more complex rehabilitation intervention.
Ostwald 2014	Ineligible comparison: both groups had education and intervention group had additional home-based intervention, so education cancels.
Pierce 2009	The information/education provision was part of a more complex rehabilitation intervention.
Printz-Feddersen 1990	The information/education was part of a more complex rehabilitation intervention. Non-random
Redfern 2008	The information/education provision was part of a more complex rehabilitation intervention.

Study	Reason for exclusion
Rimmer 2000	The information/education provision was part of a more complex rehabilitation intervention, which included classes in fitness and nutrition.
Rochette 2013	The information/education provision was part of a more complex rehabilitation intervention.
Saal 2015	Both groups had education and intervention group had additional home-based intervention, so education cancels.
Sabariego 2013	The information/education provision was part of a more complex rehabilitation intervention. The intervention primarily involved group-based problem solving.
Sahebalzamani 2009	The information/education provision was part of a more complex rehabilitation intervention.
Sajatovic 2018	The information/education provision was part of a more complex rehabilitation intervention (self-management).
Sanguinetti 1987	The focus of the paper was head injury. The data for stroke survivors were not reported separately.
Shyu 2008	The information/education provision was part of a more complex rehabilitation intervention.
Sit 2007	Although the allocation procedure was described as random it was deterministic, being based on alternation. Quote: "Subject allocation was randomized by time slot. Subjects were allocated to the intervention group in the first, third and fifth recruitment exercises. Subjects in the second, fourth and sixth recruitment exercises were allocated to the control group."
Skidmore 2008	No control group
Spassova 2016	Information provision was not the intervention evaluated. The intervention involved monitoring and feedback.
Tielemans 2015	The comparison was education vs self-management. This is not a prespecified comparison and there is an existing Cochrane Review for self-management after stroke.
Tilling 2005	The information/education provision was part of a more complex rehabilitation intervention.
Towle 1989	Information provision was not the intervention evaluated. The experimental condition was a support worker.
Winkens 2009	The information/education provision was part of a more complex intervention (psycho-education).
Wolf 2017	The information/education provision was part of a more complex rehabilitation intervention (chronic disease self-management programme).
Yu 2019	The information/education provision was part of a more complex rehabilitation intervention (includes counselling).

Characteristics of studies awaiting classification *[ordered by study ID]*

Andrea 2003

Methods	Not known
Participants	"Hemiplegic patients"
Interventions	"Self-care educational program"
Outcomes	Not known
Notes	Unable to get reference or contact details. Nor have the Cochrane self management programmes for quality of life in people with stroke review team been able to (Fryer 2016).

Bhatia 2015

Methods	Unclear methods of allocation
Participants	"56 caregivers of stroke patients admitted in neurology wards were allocated into an intervention group (n = 27) and a control group (n = 29)."
Interventions	"The intervention group received an individualized structured teaching program on 'prevention of secondary complications after stroke' which consisted of three sessions each of 30 minutes duration. Subjects in control group received routine care and education."
Outcomes	Knowledge and skills of the carers on day 4 in both the groups Patient complications within 10 days
Notes	Required additional information from the authors regarding the study design but no information was gained after at least one contact and 2 weeks' wait. Email sent to rohitbhatia71@yahoo.com.

Bodin 2011

Methods	Controlled trial
Participants	Stroke survivors
Interventions	The InfoCom booklet contains general information about aphasia, verbal and non-verbal communications skills.
Outcomes	Assessment of language deficiency (Montreal-Toulouse-1986) and communication skills (Test Lillois de Communication-TLC and Protocole Toulousain d'Evaluation de la Communication au sein du Couple Aphasique- PTECCA).
Notes	

Bonita 1995

Methods	Not known
Participants	Not known

Bonita 1995 *(Continued)*

Interventions	Not known
Outcomes	Not known
Notes	No information found

Choi 2006

Methods	Not known
Participants	Primary carers of stroke survivors
Interventions	Education classes delivered by a researcher
Outcomes	Knowledge
Notes	Article only available in Korean. Translation required.

Heier 2002

Methods	Not known
Participants	Carers of stroke survivors
Interventions	Psychoeducative intervention
Outcomes	Not known
Notes	Cannot get reference

Jian 1998

Methods	Not known
Participants	15 stroke survivors with stroke after discharge aged 50 to 69 (7 intervention, 8 control)
Interventions	Group education course aimed at eliminating knowledge deficit, promoting healthy behaviour and providing proper physical exercise for rehabilitation.
Outcomes	Not known
Notes	Abstract only, not enough information about methods, intervention or outcomes

JPRN-UMIN000016716

Methods	Parallel cluster-RCT. Assessors blinded. Participants and personnel unblinded.

JPRN-UMIN000016716 *(Continued)*

Participants	Inclusion criteria: minimum age 40 years, stroke survivor "admitted to Rehabilitation Hospital, has received the rehabilitation of normal", consent provided Exclusion criteria: communication is not possible due to severe cognitive impairment, transfer by means of a stretcher, "cannot run or have awareness and understanding about the preventive measures", hospitalised for less than one month
Interventions	Education rehabilitation program about the risk of falls and physical activity plus usual rehabilitation vs usual rehabilitation
Outcomes	Rate of inpatients falling during intervention period and postintervention period Changes of falls self-efficacy scale and FIM during hospitalisation
Notes	Trial record only. Insufficient information. Attempts to contact author unsuccessful.

Kim 2011

Methods	Controlled trial
Participants	Stroke survivors and family
Interventions	A web-based secondary stroke prevention education program
Outcomes	Knowledge and health behaviour compliance
Notes	Full article in Korean only. Translation needed. Allocation probably non-random but unclear.

Madarshahian 2018

Methods	RCT
Participants	50 stroke survivors from a neurology and stroke clinic aged over 50 with a stroke over one year ago (and their family members)
Interventions	Family support instruction: key family members taught according to their educational needs in small groups
Outcomes	Morisky Medication Adherence Scale, Social support questionnaire, Mini-Mental Status Examination
Notes	Abstract only. Insuffiicient information on nature of intervention

Mendyk 2018

Methods	RCT
Participants	French stroke survivors
Interventions	Optimised follow-up. In addition to usual care, telephone interview to answer questions, explain lifestyle recommendations, monitoring procedures and signs of an intercurrent event. Telephone

Mendyk 2018 *(Continued)*

	interviews monthly for the first 6 months, two-monthly for the second 6 months and quarterly in the second year Usual care: 2 x 1-hour face-to-face sessions to explain lifestyle recommendations, treatments prescribed and monitoring procedures (blood pressure and blood sugars). Medical consultations at 6, 12, and 24 months
Outcomes	Blood pressure, glycosolated hemoglobin, total cholesterol, LDL cholesterol, HDL cholesterol, triglycerides, anticoagulant treatment monitoring, 8-item Morisky scale, mortality, stroke or myocardial infarction, adverse events from medications, Rankin score, MoCA, EQ-5D, service contacts
Notes	Protocol only

NCT02140619

Methods	Open label, multicentre study. Trial registry entry describes the study as randomised allocation but also states patients from 24 hospitals received intervention while patients from 6 other hospitals received usual care. Title describes it as a prospective cohort study. Unclear if it is a cluster-RCT.
Participants	Beijing, China 3111 participants Inclusion criteria: adult participants (men or women ≥ 18 years), acute ischaemic stroke occurred within 14 days of symptoms onset, signed informed consent, has a cell phone and has the ability to receive and view messages Exclusion criteria: non-cerebrovascular events or haemorrhagic stroke; serious heart, liver, kidney dysfunction or coagulation disorders; circumstances that may affect the follow-up such as disturbance of consciousness, severe depression or other mental disorders, aphasia; modified Rankin Scale score at discharge ≥ 3; those who are participating in other clinical trials; those who can not guarantee completion of 1 year follow-up after enrolment
Interventions	The intervention group receive health education manuals and Digital Video Disc (DVD) during hospitalisation and regular health education text message during 1 year after discharge vs usual care.
Outcomes	Outcomes at 3, 6, and 12 months Proportion of stroke survivors taking antiplatelet drugs Proportion of stroke survivors taking statins Recurrence of ischaemic stroke Death Non-fatal myocardial infarction Non-fatal hemorrhagic stroke Severe disabilities (modified Rankin Scale ≥ 4)
Notes	Trial registry entry only, unclear if an appropriate study design. Appears near-identical to NCT02140658 except for sample size. Attempts to contact author unsuccessful.

NCT02140658

Methods	Allocation described as randomised, yet title describes it as a prospective cohort study.
Participants	Beijing, China 1500 participants

NCT02140658 *(Continued)*

	Inclusion criteria: adult participants (men or women ≥ 18 years), acute ischaemic stroke occurred within 14 days of symptoms onset; blood low density lipoprotein (LDL) ≧ 100 mg/dl (2.59 mmol/L), prescribed statins at discharge, signed informed consent, have a cell phone and have the ability to receive and view messages Exclusion criteria: non-cerebrovascular events or haemorrhagic stroke; have serious heart, liver, kidney dysfunction or coagulation disorders; have circumstances that may affect the follow-up such as disturbance of consciousness, severe depression or other mental disorders, aphasia; modified Rankin Scale score at discharge ≥ 3, patients with severe vision or vision field impairment which may affect patients to read message in cell phone; those who are participating in other clinical trials; those who can not guarantee the completion of 6 months' follow-up after enrolment
Interventions	The intervention group receive health education manuals and Digital Video Disc (DVD) during hospitalisation and regular health education text message during 1 year after discharge vs usual care.
Outcomes	Outcomes at 3, 6, and 12 months Statins persistence and adherence Recurrence of ischaemic stroke Death Non-fatal myocardial infarction Non-fatal hemorrhagic stroke Severe disabilities (modified Rankin Scale ≥ 4)
Notes	Trial registry entry only. Appears near-identical to NCT02140619 except for sample size. Attempts to contact author unsuccessful.

NCT02834273

Methods	A prospective, randomised, open-label controlled clinical trial
Participants	Inclusion criteria: older than 18 years, diagnosis of ischaemic stroke, back home or shorter rehabilitation, affiliated to a social security scheme, consented to participate in writing Exclusion criteria: cognitive disorders, vigilance, aphasia; institutionalised
Interventions	Experimental: stroke education workshops during hospital stay to improve understanding of the symptoms, risk factors and what to do following stroke vs usual care
Outcomes	Stroke knowledge: EPIC [unknown expansion] score measuring knowledge of stroke risk factors, alert symptoms and what to do (3 months) The following at 12 months: • Blood pressure • LDL-C • Body Mass Index • Smoking intoxication • Recurrent stroke • Compliance to treatments
Notes	Trial registry entry only. Attempts to contact author unsuccessful.

Piano 2010

Methods	A prospective, randomised, open-label controlled clinical trial
Participants	Stroke survivors
Interventions	Video-based stroke education programme Standard nurse education
Outcomes	Stroke knowledge
Notes	Abstract only. Unclear if participants who get video presentation also get standard nurse education or whether this is a comparison of two information provision interventions.

Sun 2011

Methods	RCT
Participants	70 stroke survivors
Interventions	Personalised health education
Outcomes	Hamilton Anxiety Scale (HAS) to assess anxiety status, Barthel Index and Life Satisfaction Index to assess the life satisfaction of stroke survivors
Notes	Translation needed

Tuncay 2006

Methods	Not known
Participants	Patients with a new diagnosis of cerebrovascular disease
Interventions	A self-care educational brochure
Outcomes	Barthel ADL
Notes	Cannot determine if participants are stroke survivors. Authors contacted, no reply.

Young 2007

Methods	Not known
Participants	Adult stroke survivors with a monophasic disabling neurological condition admitted to a neurological rehabilitation unit
Interventions	Group education session and video
Outcomes	Self-efficacy Mood Confidence and recovery Goals achieved variance Participation in therapy

Young 2007 *(Continued)*

	Practice with nursing staff
Notes	No results found

ADL: activities of daily living
FIM: Functional Independence Measure
LDL-C: low-density lipoprotein cholesterol
MoCA: Montreal Cognitive Assessment
RCT: randomised controlled trial

Characteristics of ongoing studies *[ordered by study ID]*

ACTRN12618002050235

Study name	Would knowing your risk for getting stroke make you change your lifestyle? [Influence of stroke riskometer on making lifestyle changes among urban dwelling Malaysian stroke caregivers: a pilot randomised controlled trial]
Methods	RCT with blinded analysis
Participants	Adult stroke carers in Kuala Lumpur, Malaysia.
Interventions	Stroke Riskometer application which can be downloaded for free via iOS and Google Play. The app contains 20 questions specifically designed to assess participants' modifiable and non-modifiable risk factors and videos advising on risk reduction. The application is available in English and Bahasa Malaysia version.
Outcomes	Risk of stroke among stroke carers at 5 and 10 years in percentage using Stroke Riskometer Lifestyle changes of stroke carers as measured by Life's Simple 7 questionnaire
Starting date	1 January 2019
Contact information	Dr Aznida Firzah Binti Abdul Aziz: draznida@ppukm.ukm.edu.my
Notes	

Amooba 2018

Study name	Delivering poststroke education in Ghana; a feasibility randomised controlled trial (RCT) with qualitative evaluation
Methods	RCT with qualitative evaluation
Participants	Stroke survivors and their family carers in Ghana
Interventions	Poststroke educational intervention Usual care
Outcomes	Not known
Starting date	Not known
Contact information	Not known

Amooba 2018 *(Continued)*

Notes	

Appalasamy 2018

Study name	MyStrokeStory
Methods	RCT
Participants	200 stroke survivors in Malaysia
Interventions	Video narratives about stroke with average Flesch-Kincaid reading grade of 6 viewed at baseline, 3 and 6 months, in addition to standard care Standard patient education care including advice, SMS appointment reminders, pamphlets about stroke effects and prevention, self-monitoring calendar, a general helpline
Outcomes	Medication understanding and use self-efficacy (MUSE); stroke knowledge test (SKT); Brief Illness Perception Questionnaire (BIPQ); Likert scale of the belief about medicine questionnaire; control of stroke risk factors; SF-36
Starting date	19 March 2018
Contact information	Ms Jamunarani Appalasamy School of Medicine and Health Sciences, Monash University, Jalan Lagoon Selatan, Bandar Sunway, 47500 Subang Jaya, Selangor, Malaysia Phone: +60123253775 Email: jhamunaa2@gmail.com
Notes	

ChiCTR-IIC-17011458

Study name	A study to evaluate the effectiveness of structured education on discharge in Department of Medicine and Therapeutics, Prince of Wales Hospital
Methods	RCT with block randomisation
Participants	Sample size: 450 Inclusion criteria: patients of the Department of M&T wards; patients' main carers if patients cannot communicate; patients who have the principle diagnose of the following disease: congestive heart failure, chronic obstructive pulmonary disease, diabetes mellitus, renal failure and stroke; aged between 18 and 85 years (inclusive); Chinese in ethnicity Exclusion criteria: patients who are unconscious and critically ill; clinically unstable psychiatric illnesses; speak non-Cantonese dialect or different language or had conditions that prevented effective communications e.g. patients who are deaf, mute, have dysphagia or cognitive impairment; live in nursing home with supervised treatment
Interventions	Structured education including 1) provide education pamphlets, information sheet of their specific disease. 2) ward nurses adopt a simple discharge reminder to guide discharge Usual care
Outcomes	Patient knowledge of the specific diseases, patients' and nurses' satisfaction, readmission rate

ChiCTR-IIC-17011458 *(Continued)*

Starting date	Not known
Contact information	Applicant: Heung Wan Cheung Telephone: +852 55696142 Email: chw331@ha.org.hk Address: Cardiac Care Unit, ward 10C, Prince of Wales Hospital, Shatin, Hong Kong Study leader: Yee Man Rebecca Wong Telephone: +852 94075291 Email: wongymr@ha.org.hk Address: Diabetes & Endocrine Centre, ward 3L, Prince of Wales Hospital, Shatin, Hong Kong
Notes	

CN-01155247

Study name	A stepped-wedge cluster-RCT for evaluating an intervention for stroke survivors: tailored education in addition to physiotherapist treatment
Methods	A stepped-wedge cluster design will be used, with the duration of the trial being 50 weeks. The randomisation occurs before the start of the trial. All clusters start the trial in a control phase with no intervention being delivered at any site, then sequentially cross over from the control group to the intervention group, until all sites are receiving the intervention. Outcomes are measured on the study participants in all clusters at every time period, hence measurement of outcomes takes place at each step in the wedge; each cluster provides data points in the control and intervention conditions allowing each site to act as its own control
Participants	320 participants 18 years to 70 years old. The study participants had all been hospitalised in 8 regional hospitals of Andalusian Health Service with acute cerebral stroke, were clinically stable, presented an ischaemic or haemorrhagic aetiology and clinical symptoms of hemiplegia, were selected to receive physiotherapy in hospitalisation, were assisted by a carer, had an adequate understanding of Spanish, and had given their written informed consent.
Interventions	Educational advice plus physiotherapist treatment
Outcomes	Primary outcome measure • Canadian Neurological Scale (CNS): time frame: 8 weeks, measures neurological status of stroke Secondary outcome measures • Trunk Control Test (TCT): time frame: 8 weeks, scores trunk control • Motricity index (MI) of the lower and upper limbs: time frame: 8 weeks, measures upper and lower limb strength • Barthel Index (BI): time frame: 8 weeks, scores ability to perform ADL • Stroke Impact Scale-16 (SIS-16): time frame: 8 weeks, measures the deficits and physical limitations provoked by stroke (ADL, mobility and hand function) • Modified Rankin Scale (mRS): time frame: 8 weeks, to score disability • Multidimensional Scale of Perceived Social Support (MSPSS): time frame: 8 weeks
Starting date	Expected to be June 2016
Contact information	Prof Dr Antonio I Cuesta-Vargas Departamento de Psiquiatría y Fisioterapia, Facultad de Ciencias de la Salud Universidad de Málaga

CN-01155247 *(Continued)*

	Av/ Arquitecto Peñalosa s/n (Teatinos Campus Expansion) 29009 Málaga (Spain) acuesta@uma.es Tlf:0034951 952 852
Notes	Estimated study completion date: February 2018 Email sent 1 August 2018 requesting further information

Coombes 2018

Study name	Use of a patient-centred educational exchange (PCEE) to improve patient's self-management of medicines after a stroke: a randomised controlled trial study protocol
Methods	RCT
Participants	Sample size: 200 Inclusion criteria: aged 18+ years, principle diagnosis of stroke or TIA, planned to be discharged home Exclusion criteria: MSQ score < 10, unable to provide consent, planned rehabilitation greater than one month
Interventions	"Both [groups] will receive usual care. In addition to usual care participants in the intervention group will receive two sessions of a [patient-centred educational exchange (PCEE)], one before discharge and one by telephone at least 10 days after discharge. These sessions will be conducted by a clinical pharmacist who attends weekly multidisciplinary MSU meetings." PCEE involves "identifying patients perceptions' and beliefs' then using these to personalise educational messages and to engage patients in a conversation".
Outcomes	Medications adherence; perception of stroke; beliefs about medications; medication-related adverse events; blood pressure; cholesterol; stroke or myocardial infarction; EQ-5D; cost-utility.
Starting date	21 December 2015
Contact information	Judith Ann Coombes judith@pharmacy.uq.edu.au
Notes	

CTRI/2017/07/009014

Study name	A study to evaluate the effect of a technology driven educational intervention for management of disabilities following stroke in India [A randomized controlled trial to evaluate the effectiveness of the 'Care for Stroke' intervention in India, a smartphone-enabled, carer-supported,educational intervention for management of disabilities following stroke]
Methods	RCT
Participants	320 stroke survivors Inclusion criteria: recent diagnosis of first-ever stroke as defined by the WHO (within 3 to 6 weeks prior to recruitment); all kinds of stroke severity (score 1 to 42, according to NIH stroke scale); stroke survivor medically stable (reaching a point in medical treatment where life-threatening

CTRI/2017/07/009014 *(Continued)*

	problems following stroke have been brought under control); poststroke functional stat us of the stroke survivor: requiring assistance of at least one person to perform daily activities such as transfers, self-care and mobility (scoring less than the maximum score obtainable in one or more components of the Barthel Index); stroke survivor residing with a primary carer (family member) at home Exclusion criteria: severe cognitive difficulties (scoring > 1 in Orientation, Executive function, Inattention and Language components of the NIH Stroke Scale for cognition); severe communication problem (scoring > 1 in Dysarthria and Best Language component of the NIH Stroke Scale); severe comorbidities (severe psychiatric illness, hearing loss, vision loss); stroke survivor functionally dependent because of other pre-existing conditions (fracture, dementia); stroke survivor without a primary carer; stroke survivor unwilling/unable to adhere to the study protocol; did not meet the training requirements regarding operation of a smartphone
Interventions	The 'Care for Stroke' intervention will be delivered through a smartphone and it will include information about stroke and the ways to manage poststroke disabilities. The intervention includes 2 to 3 minutes of several videos in vernacular language organised in 5 sections. The sections are information about stroke, home-based exercises, functional skills training, activities of daily living, and assistive devices. The intervention will also have an option for the stroke survivor or the identified carer to contact the intervention co-ordination centre for any support Standard post stroke rehabilitation
Outcomes	Modified Rankin Scale; modified Barthel Index; modified Caregiver Strain Index; WHOQOL-BREF; use of health care and rehabilitation services
Starting date	1 September 2017
Contact information	Assistant Professor Sureshkumar Kamalakannan Email: suresh.kumar@iiphh.org Telephone: 04049006023 Address: Epidemiology Department South Asia Centre for Disability and Inclusive Development Research, Hyderabad, Andhra Pradesh, 500033, India
Notes	

CTRI/2017/08/009267

Study name	Medical Application-based Post Stroke care Strategy (MAPSS)
Methods	RCT
Participants	400 stroke survivors and their carers Inclusion criteria: all stroke survivors ≥ 18 years of age; recent (< 1 month) acute ischaemic/haemorrhagic/undifferentiated stroke; stroke survivors with significant residual disability (requiring help from another person for everyday activities)/bedridden (mRS > 3); the carers are willing and able to provide care to the stroke survivors after discharge; the carers / stroke survivors must have a smartphone/ tablet with internet facility and should be competent as well as willing to use an app as a health care tool (For Phase Ib (Pilot phase) and Phase II); expected to survive to discharge from hospital with a reasonable expectation of 6 month survival (i.e. not palliative, no evidence of widespread cancer, etc); stroke survivors/carers who will provide informed written consent Exclusion criteria: stroke survivors with no carer or hired carer or illiterate carer, carer who is not competent enough to use MAPSS as per the investigators judgement (For Phase Ib (Pilot phase) and Phase II); stroke survivors who localised in poor network connectivity area (For Phase Ib (Pilot phase) and Phase II)

CTRI/2017/08/009267 *(Continued)*

Interventions	MAPSS, the medical application based post stroke care strategy using smartphone/tablet incorporating all the procedures including stroke education, warfarin education, skin care, prevention and management of bedsores, positioning technique, nasogastric feeding, active and passive exercises, post stroke rehabilitation, stroke nursing care, physiotherapy etc. The medical application will be bilingual (in 'Hindi and English'). Advanced functions of the app will be used for training and follow-up e.g. SMS, reminder, e-mails etc Routine care and booklet provided to all participants.
Outcomes	Development of bed-sores in astroke survivor with mRS 3 at discharge from the hospital with in first 3 months; development of other complications e.g. aspiration pneumonia, catheter-related UTIs, contracture frozen shoulder, DVT; Caregiver Stress Index (CSI) score; quality of life of stroke survivors; modified Rankin Scale; number of hospital visits; skills, knowledge and practice; ADL score
Starting date	11 July 2018
Contact information	Ashok Kumar (PhD scholar) Telephone: 9855012233 Email: ajangir_27@yahoo.in Prof Dheeraj Khurana Email: dherajk@yahoo.com Address: Department of neurology Postgraduate Institute of Medical Education and Research (PGIMER), Chandigarh, Chandigarh, 160012, India
Notes	

CTRI/2017/09/009600

Study name	Secondary prevention by structured semi-interactive stroke prevention package in India (SPRINT - INDIA)
Methods	RCT
Participants	5830 stroke survivors Inclusion criteria: first ever ischaemic stroke or intracerebral haemorrhage; between 1 and 3 months of stroke symptom onset; computed tomography/magnetic resonance imaging shows recent stroke (infarct, haemorrhage, or both); able to read and complete simple tasks suggested in the stroke work-book if having aphasia or is illiterate, a carer is available to read for the stroke survivor and complete the reading/work-book tasks for the stroke survivor; able to read and possess a working personal mobile cellular device. In case of stroke survivors who are not able to read or do not have a personal mobile cellular device or unable to use it, a carer is available all times who is able to use mobile cellular devices and read to the stroke survivor; able to watch health education videos on a video player on cellular device or any other video player available to the stroke survivor; able to come for follow-up visits for at least 1 year; able to provide signed informed consent Exclusion criteria: Modified Rankin scale score > 4 at the time of enrolment; limited Internet or mobile accessibility due to travel; having active malignancies needing intensive therapy; terminal illness with an anticipated lifespan of less than 1 year; heart failure and admitted more than twice in last six months; current psychiatric illness with loss of insight and suicide attempts; cerebral venous sinus thrombosis, aneurysmal subarachnoid haemorrhage, isolated central nervous system vasculitis and systemic vasculitis
Interventions	Structured semi-interactive stroke prevention package including stroke survivor workbook, short messaging services and health education videos for a period of 1-year in addition to standard of care as per current guidelines

CTRI/2017/09/009600 *(Continued)*

	Standard care only
Outcomes	Composite endpoint of recurrent stroke, high-risk transient ischaemic attack, acute coronary syndrome, and death; blood pressure (mmHg); fasting blood glucose (mg/dl); LDL cholesterol (mg/dl); triglycerides (mg/dl); smoking cessation (No/total %); alcohol cessation; body mass index; physical activity MET (min/week); medication adherence; modified Rankin scale (mRS)
Starting date	2 October 2017
Contact information	Dr Jeyaraj D Pandian Phone: 9915784750 Email: jeyarajpandian@hotmail.com Dr Mahesh P Kate Phone: 9878807951 Email: maheshpkate@gmail.com Address: Department of Neurology, Christian Medical College and Hospital, Ludhiana, Punjab, 141008, India.
Notes	

CTRI/2018/11/016312

Study name	A clinical trial to evaluate the role of education to care givers in reducing complications and improving outcomes of hospitalised stroke patients [Evaluating the role of structured education to care givers in reducing complications in hospitalised stroke patients and improving their outcomes - a cluster-randomized trial]
Methods	Phase 3 cluster-randomised trial
Participants	Sample size = 164 Inclusion criteria: "Any carer more than 18 years to a patient more than 18 years with acute stroke and with mRS 4-5 at the time of enrolment and admitted to neurology wards NS-4 and NS-5 in AIIMS, Cardiothoracic and Neurosciences center within 24 hours of admission is eligible for enrolment". Exclusion criteria: "1. Care givers who are not willing to give informed consent, and those not willing to be attending the patient for at least 8 hours a day will be excluded. 2. Care givers who are paid attendants and those care givers to patients having baseline complications which are being measured in the outcomes will also be excluded. 3. Care givers whose patients have a total stay in the hospital less than 5 days will be excluded from the study."
Interventions	Structured education to carers: audiovisual interactive session lasting about 1 hour teaching carers about stroke, its complications and the means to prevent recurrence Standard care
Outcomes	Incidence of in-hospital complications; mortality; modified Rankin Scale score
Starting date	23 November 2018
Contact information	Pedapati Radhakrishna Email: radhakrishna.p15@gmail.com Telephone: 9751077065 Address: Room number 702, Neurology Office, Department of Neurology, CN centre, AIIMS, Ansari Nagar, New Delhi. Delhi 110029, India

CTRI/2018/11/016312 *(Continued)*

	Dr Rohit Bhatia, Professor Email: rohitbhatia71@yahoo.com Telephone: 9891267417 Address: Room Number 702, Neurology Office, Department of Neurology, CN centre, AIIMS, Ansari Nagar, New Delhi. Delhi 110029, India
Notes	

Day 2018

Study name	Nursing home care intervention post stroke (SHARE)
Methods	RCT
Participants	48 family carers of stroke survivors
Interventions	Systematic follow-up by nurses who will perform 3 home visits over a period of 1 month, in addition to usual care Usual care
Outcomes	Primary outcomes: burden and quality of life of the carer Secondary outcomes: functional capacity and readmissions of the stroke survivors; the use of health services of the stroke survivors and their family carers
Starting date	May 2016
Contact information	Lisiane Manganelli Girardi Paskulin Email: 00009812@ufrgs.br Address: Nursing School, Nursing Graduate Program, Universidade Federal do Rio Grande do Sul (UFRGS), São Manoel Street, 963, Rio Branco, Porto Alegre 90620110, Rio Grande do Sul, Brazil.
Notes	

IRCT20180419039362N1

Study name	The effect of training on self-efficacy and self-esteem in stroke patients [The effect of educating skills on using mobility assistive devices on self-esteem and self-efficacy of patients with stroke]
Methods	RCT
Participants	Stroke survivors Sample size: 68 Inclusion criteria: diagnosis of stroke by a neurologist; passed 48 hours from the onset of stroke (acute stage be passed); having muscle force of 3.5 or 4.5; stroke survivor's age should be less than 70 years old; willingness to participate in this study Exclusion criteria: having verbal and visual cognitive impairment, previous dementia, global aphasia or any visual impairment; having any underlying disease that can cause motor dysfunction; history of previous stroke

IRCT20180419039362N1 *(Continued)*

Interventions	Intervention: educations about how to use mobility assistive devices (walker and walking stick), in addition to usual care Usual care
Outcomes	Sherer's Self Efficacy Questionnaire; Rosenberg's Self Esteem Questionnaire
Starting date	22 May 2018
Contact information	Bakhtiar Peikfalak Phone: +98 38 3333 5982 Email: ba.peikfalak@uswr.ac.ir
Notes	

NCT02398409

Study name	ANSWERS-VA
Methods	RCT with outcome assessor blinding
Participants	USA Carers of veterans with stroke or traumatic brain injury (TBI) Sample size: 330 Inclusion criteria: informal carer of a family member or friend (Veteran) with a stroke or TBI; carer must express need or concerns in providing care; plans to be providing care for 1 year or longer; access to telephone; willingness to participate in 9 call from a nurse and 5 data collection calls at designated time points; veteran's stroke must be within past 3 years; veteran's TBI must be since 11 September 2001 Exclusion criteria: carer or survivor age < 18 years; carer denies that survivor has had a stroke or a TBI; carer does not consider him or herself a carer, stating that the survivor is not impaired or is the same as before the stroke or TBI; carer has low task difficulty (OCBS task difficulty score < 16); carer communication difficulties (e.g. hearing loss); carer not fluent in the English language; carer with serious medical illness limiting ability to participate; carer refuses to sign a HIPAA authorisation allowing the VA to store personal health information (PHI) in a location outside the VA; survivor residing in a nursing home or long-term care facility; survivor or carer has a terminal illness (e.g. cancer, end of life condition with decreased life expectancy, renal failure requiring dialysis); survivor or carer history of hospitalisation for alcohol or drug abuse; survivor or carer history of Alzheimer's, dementia, suicidal tendencies, severe untreated depression or manic depressive disorder, or schizophrenia; survivor or carer pregnancy; survivor or carer is a prisoner or on house arrest; survivor had a TIA (rather than a haemorrhagic or ischaemic stroke); survivor had a stroke more than 3 years ago
Interventions	ANSWERS - Acquiring New Skills While Enhancing Remaining Strengths: 8 week telephone intervention with nurse case manager versus usual care (8 week telephone usual care with education with nurse case manager)
Outcomes	At 12 weeks, 6 months, and 1 year: Depressive symptoms: PHQ-9 Oberst Caregiving Burden Scale Cost-effectiveness using an incremental cost-effectiveness ratio Optimism: Life Orientation Test-Revised Scale Threat appraisal: Appraisal of Caregiving Scale: Threat Subscale

NCT02398409 *(Continued)*

Starting date	3 November 2014
Contact information	Principal Investigator: Virginia (Ginger) S. Wilder, PhD MSN RN; Richard L. Roudebush VA Medical Center, Indianapolis, IN, United States, 46202-2884
Notes	

NCT02569099

Study name	Effects of training caregivers on the outcomes of stroke survivors and caregivers in Zimbabwe [A randomised controlled study to compare the effects of standardised care plus conventional care versus conventional care only on the outcomes of stroke survivors (HIV+ and HIV-) and their family caregivers in Harare and Chitungwiza]
Methods	RCT
Participants	Stroke survivors and their family carers Inclusion criteria: first ever confirmed clinical diagnosis of stroke. All persons diagnosed with stroke and who are 18 years and above will be recruited; the stroke patients are likely to return home with residual disability; both males and females are eligible and should be residing in Harare and Chitungwiza communities during the period of study; stroke survivors must have a family carer; HIV status may or may not be known; caregiver is willing and able to provide support after discharge; fulfils the research definition of a family caregiver Exclusion criteria: persons with other diagnoses of neurological origin and a previous neurological disorder and orthopedic conditions that hamper treatment are not eligible to participate; persons with a history of psychiatric illness will be excluded
Interventions	Intervention: carers are trained on caring for relative who has survived a stroke once only for one hour using a developed curriculum, plus usual care Usual care
Outcomes	EQ-5D; Caregiver Strain Index; FIM; community reintegration of stroke survivors
Starting date	October 2014
Contact information	Farayi Kaseke, Masters University of Zimbabwe
Notes	

NCT02769871

Study name	NICE: NeuroImaging In Cessation Education
Methods	RCT Blinding of participant, investigator, outcomes assessor
Participants	Stroke survivors who are active smokers
Interventions	Intervention: participants are shown images of head CT or brain MRI of their stroke and it is described. Participants are given a paper copy showing the slice with the largest volume of stroke.

NCT02769871 *(Continued)*

	Participants are also shown images of "normal" brains and of those that have had recurrent strokes due to smoking. Participants advised to stop smoking to avoid further damage. Active comparator: Standardised smoking cessation counselling (provided to both arms)
Outcomes	Cessation of smoking Number of cigarettes per day
Starting date	January 2017
Contact information	Hardik Amin MD Yale University
Notes	

RBR-3n4tzc

Study name	Effectiveness of educational primer for caregivers of stroke patients [Effect of educational primer for caregivers of stroke victims: randomized controlled trial]
Methods	Single-blind RCT
Participants	Carers of stroke survivors Planned sample size: 180 (90 intervention, 90 control) Inclusion criteria: age greater than or equal to 18 years; be accompanying the stroke survivor during the period of hospitalisation; be one of the main carers of the stroke survivor after discharge; and have at least one telephone contact for the researcher to contact to carry out the other phases of the research Exclusion criteria: carers who present some mental impossibility to understand interventions and those who cannot read and write; cases of discontinuity will be considered: telephone change after follow-up, failure to answer telephone calls after three attempts at different days and times, carer whose cell phone is out of area or disconnected for more than 10 attempts to connect in days and schedules and no longer be the carer of the stroke survivor; the stroke survivor or carer who died in the course of the research will be considered a loss
Interventions	Intervention group: will be submitted to an intervention using an educational primer about what is stroke, its nuances and the main care after hospital discharge in the theory of basic human needs Control group: will be submitted to the guidelines in the unit of the hospital in which they are
Outcomes	knowledge, practice and attitude
Starting date	31 October 2018
Contact information	Ariane Alves Barros Address: Rua José Meneleu, 123 casa A, Fortaleza / Brazil. 60714-040 Telephone: (85) 98834-3804 E-mail: arianealvesbarros@hotmail.com Affiliation: Universidade Estadual do Ceará - UECE
Notes	

Sureshkumar 2018

Study name	Protocol for a randomised controlled trial to evaluate the effectiveness of the 'Care for Stroke' intervention in India: a smartphone-enabled, carer-supported, educational intervention for management of disabilities following stroke
Methods	RCT. Outcome-assessor blinded
Participants	India Stroke survivors Planned sample size: 320 Inclusion criteria: adults (aged ≥18 years); recent diagnosis of first ever stroke as defined by the WHO; stroke survivor medically stable; poststroke functional status of the stroke survivor: requiring assistance of at least one person to perform daily activities such as transfers, self-care and mobility (i.e. scoring less than the maximum score obtainable in one or more components of the Barthel Index); stroke survivor residing with a primary carer (family member) at home Exclusion criteria: severe cognitive difficulties (scoring > 1 in orientation, executive function, inattention and language components of the NIH Stroke Scale for cognition); severe communication problem (scoring > 1 in dysarthria and best language component of the NIH Stroke Scale); stroke survivor functionally dependent because of other pre-existing conditions (e.g. amputation, fracture and dementia); stroke survivor without a primary carer; stroke survivor unwilling/unable to adhere to the study protocol; stroke survivors who did not meet the training requirements regarding operation of a smartphone. This criterion was deliberately placed just to make sure that there is no dropout after the recruitment. It was based on the observations from previous piloting.
Interventions	'Care for Stroke' intervention: "delivered through a smartphone and it will include information about stroke and the ways to manage poststroke disabilities. The intervention includes 2 to 3 min of 60 videos in vernacular language organised in five sections. The sections are: (1) information about stroke, (2) home-based exercises, (3) functional skills training, (4) activities of daily living, and (5) assistive devices. The intervention will be self-directed, with participants seeking information in the different categories as they require. The intervention will also have an option for the stroke survivor or the identified carer to contact the intervention provider for any technical support in accessing the intervention through smartphone." Versus standard poststroke rehabilitation
Outcomes	Dependence in daily activities: mRS Modified Barthel Index Modified Caregiver Strain Index Quality of Life: WHOQOL–BREF Use of healthcare and rehabilitation services Direct costs of healthcare and rehabilitation Indirect costs
Starting date	September 2017
Contact information	Sureshkumar Kamalakannan Public Health Foundation of India Indian Institute of Public Health, Epidemiology Department South Asia Centre for Disability and Inclusive Development Research, Hyderabad, Andhra Pradesh, 500033 India Phone: 04049006023 Email: suresh.kumar@iiphh.org
Notes	

Tisel 2018

Study name	Clinics as classrooms: assessing patient knowledge and satisfaction following stroke video education
Methods	Randomised trial
Participants	Stroke survivors coming for routine hospital follow-up
Interventions	Stroke education video versus standard care
Outcomes	Knowledge Satisfaction
Starting date	Not known
Contact information	Not known
Notes	

UMIN000030651

Study name	Effects of an educational program for getting the behavior of home blood pressure measurement in stroke patients: evaluation by a randomised-controlled trial
Methods	RCT. No blinding Randomisation by central allocation
Participants	Target sample size = 48 Age 55 to 75 Inclusion criteria: stroke patient; modified Rankin Scale score 0 to 3; plan of discharged home Exclusion criteria: severely handicapped; modified Rankin Scale score 4 to 5; with dementia; terminally ill
Interventions	One face-to-face session 4 times of telephone support In addition to usual care: Standard treatment To be given a textbook and a self-management handbook To rent a sphygmomanometer
Outcomes	Rate of home blood pressure measurement; recurrent stroke rate; mortality; weight; BMI; blood pressure
Starting date	4 January 2018
Contact information	Shingo Kishita Address 1-2 Ajinadai-Higashi Hatsukaichi-shi Hiroshima Tel 0829-20-2800 Email sk11169@jrchcn.ac.jp
Notes	

AHA: American Heart Association
CPRS: Computerised Patient Record System
CT: Computed Tomography
FIM: Functional Independence Measure
HIPAA: Health Insurance Portability and Accountability Act
MARS: Medication Adherence Report Scale
MET: metabolic equivalent of task
MRI: Magnetic Resonance Imaging
mRS: modified Rankin Scale
OCBS: Oberst Caregiving Burden Scale
PHQ-9: Patient Health Questionnaire 9-item depression module
RCT: randomised controlled trial
TIA: transient ischaemic attack
VA: Veterans Affairs
WHOQOL-BREF: World Health Organization Quality of Life assessment short-form

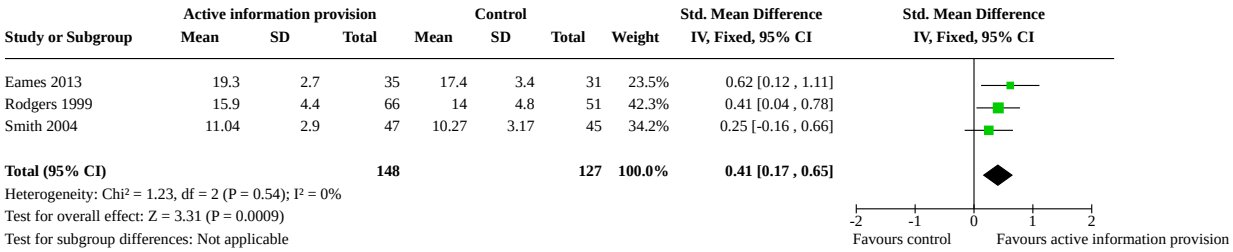
DATA AND ANALYSES

Comparison 1. Active information provision vs control for stroke survivors

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1.1 Stroke-survivor knowledge of stroke and stroke services (SMD)	3	275	Std. Mean Difference (IV, Fixed, 95% CI)	0.41 [0.17, 0.65]
1.2 Stroke-survivor knowledge of stroke and stroke services: summary of results	1		Other data	No numeric data
1.3 Stroke-survivor anxiety (dichotomised data)	5	1132	Risk Ratio (M-H, Fixed, 95% CI)	0.85 [0.68, 1.06]
1.4 Sensitivity analysis. Stroke-survivor anxiety (dichotomised data)	5	1132	Odds Ratio (IV, Fixed, 95% CI)	0.80 [0.61, 1.05]
1.5 Stroke-survivor anxiety (HADS-A)	6	1171	Mean Difference (IV, Fixed, 95% CI)	-0.73 [-1.10, -0.36]
1.6 Stroke-survivor anxiety: summary of results	1		Other data	No numeric data
1.7 Stroke-survivor depression (dichotomised data)	6	1315	Risk Ratio (M-H, Fixed, 95% CI)	0.83 [0.68, 1.01]
1.8 Sensitivity analysis. Stroke-survivor depression (dichotomised data)	6	1325	Odds Ratio (IV, Fixed, 95% CI)	0.71 [0.54, 0.92]
1.9 Stroke-survivor depression (SMD)	8	1405	Std. Mean Difference (IV, Fixed, 95% CI)	-0.19 [-0.30, -0.08]
1.10 Stroke-survivor QOL (WHOQOL-BREF): summary of results	1		Other data	No numeric data
1.11 Stroke-survivor satisfaction with information on causes and nature of stroke (dichotomised data)	3	398	Risk Ratio (M-H, Fixed, 95% CI)	0.56 [0.38, 0.84]

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
1.12 Stroke-survivor satisfaction with information about allowances and services (dichotomised data)	3	395	Risk Ratio (M-H, Fixed, 95% CI)	0.82 [0.59, 1.14]
1.13 Stroke-survivor psychological distress (SMD)	4	982	Std. Mean Difference (IV, Fixed, 95% CI)	-0.01 [-0.14, 0.11]
1.14 Stroke-survivor self-efficacy: summary of results	1		Other data	No numeric data
1.15 Stroke-survivor locus of control (SMD)	3	231	Std. Mean Difference (IV, Fixed, 95% CI)	0.09 [-0.17, 0.35]
1.16 Stroke-survivor modification of health related behaviours: summary of results	8		Other data	No numeric data
1.17 Stroke-survivor activities of daily living (Barthel Index, 0-20)	5	1178	Mean Difference (IV, Fixed, 95% CI)	0.45 [-0.01, 0.91]
1.18 Stroke-survivor independence in activities of daily living: summary of results	2		Other data	No numeric data
1.19 Stroke-survivor social activities (SMD)	4	1175	Std. Mean Difference (IV, Fixed, 95% CI)	0.03 [-0.09, 0.15]
1.20 Stroke-survivor perceived health status: summary of results	5		Other data	No numeric data
1.21 Stroke-survivor perceived health status (EQ-VAS)	2	416	Mean Difference (IV, Fixed, 95% CI)	4.31 [-0.11, 8.73]
1.22 Stroke-survivor perceived health status (SF-36)	2	168	Mean Difference (IV, Fixed, 95% CI)	-1.80 [-9.56, 5.96]
1.23 Stroke-survivor recurrent stroke: summary of results	1		Other data	No numeric data
1.24 Stroke-survivor deaths	8	2460	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.91 [0.70, 1.19]

Analysis 1.1. Comparison 1: Active information provision vs control for stroke survivors, Outcome 1: Stroke-survivor knowledge of stroke and stroke services (SMD)



Analysis 1.2. Comparison 1: Active information provision vs control for stroke survivors, Outcome 2: Stroke-survivor knowledge of stroke and stroke services: summary of results

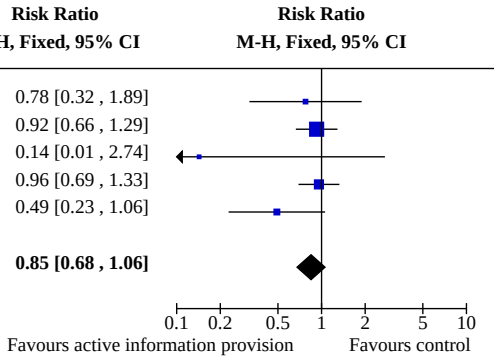
Stroke-survivor knowledge of stroke and stroke services: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Boden-Albala 2015	30 days, 1 year, then annually for 5 years	Enhanced education for stroke survivors to facilitate the early recognition of stroke warning signs plus a standardised packet of preparedness focused education materials versus a standardised packet of preparedness focused education materials	Stroke Knowledge Survey (29 items; dichotomised < 23 vs ≥ 23) at 12 months (last available data)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 582/601, control 581/592 OR 1.21 (95% CI 0.87 to 1.67)	

Analysis 1.3. Comparison 1: Active information provision vs control for stroke survivors, Outcome 3: Stroke-survivor anxiety (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Eames 2013	7	35	8	31	7.1%	0.78 [0.32 , 1.89]
Forster 2013 (1)	53	294	62	318	49.9%	0.92 [0.66 , 1.29]
Kalra 2004	0	122	3	122	2.9%	0.14 [0.01 , 2.74]
Rodgers 1999	36	66	29	51	27.4%	0.96 [0.69 , 1.33]
Smith 2004	8	50	14	43	12.6%	0.49 [0.23 , 1.06]
Total (95% CI)		**567**		**565**	**100.0%**	**0.85 [0.68 , 1.06]**
Total events:	104		116			

Heterogeneity: Chi² = 4.21, df = 4 (P = 0.38); I² = 5%
Test for overall effect: Z = 1.48 (P = 0.14)
Test for subgroup differences: Not applicable

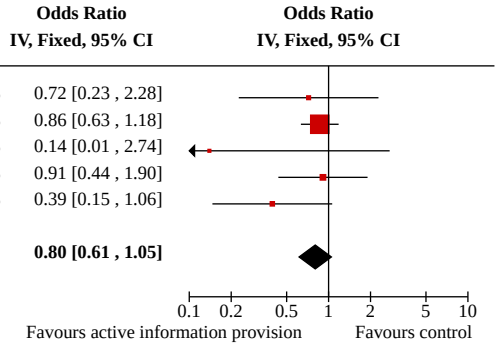


Footnotes
(1) Used ICC = 0.000, design effect = 1.00

Analysis 1.4. Comparison 1: Active information provision vs control for stroke survivors, Outcome 4: Sensitivity analysis. Stroke-survivor anxiety (dichotomised data)

Study or Subgroup	log[OR]	SE	Active information provision Total	Control Total	Weight	Odds Ratio IV, Fixed, 95% CI
Eames 2013	-0.33	0.589	35	31	5.4%	0.72 [0.23 , 2.28]
Forster 2013 (1)	-0.146	0.159	294	318	73.4%	0.86 [0.63 , 1.18]
Kalra 2004	-1.97	1.52	122	122	0.8%	0.14 [0.01 , 2.74]
Rodgers 1999	-0.093	0.376	66	51	13.1%	0.91 [0.44 , 1.90]
Smith 2004	-0.93	0.505	50	43	7.3%	0.39 [0.15 , 1.06]
Total (95% CI)			**567**	**565**	**100.0%**	**0.80 [0.61 , 1.05]**

Heterogeneity: Chi² = 3.67, df = 4 (P = 0.45); I² = 0%
Test for overall effect: Z = 1.62 (P = 0.11)
Test for subgroup differences: Not applicable

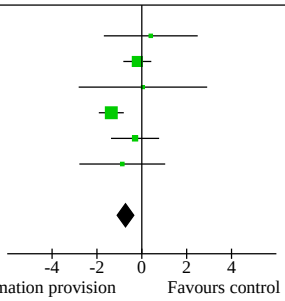


Footnotes
(1) Adjusted results from logistic regression with clustering

Analysis 1.5. Comparison 1: Active information provision vs control for stroke survivors, Outcome 5: Stroke-survivor anxiety (HADS-A)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Fixed, 95% CI
Eames 2013	6.8	4	35	6.4	4.6	31	3.1%	0.40 [-1.69 , 2.49]
Forster 2013	6.4	3.94	294	6.6	3.92	318	35.3%	-0.20 [-0.82 , 0.42]
Frank 2000	7.1	5	19	7.05	4.05	20	1.7%	0.05 [-2.81 , 2.91]
Kalra 2004	3.39	1.96	122	4.75	2.45	122	44.2%	-1.36 [-1.92 , -0.80]
Rodgers 1999	11	3.1	66	11.3	2.8	51	11.9%	-0.30 [-1.37 , 0.77]
Smith 2004	6.78	3.62	50	7.65	5.45	43	3.7%	-0.87 [-2.78 , 1.04]
Total (95% CI)			**586**			**585**	**100.0%**	**-0.73 [-1.10 , -0.36]**

Heterogeneity: Chi² = 9.74, df = 5 (P = 0.08); I² = 49%
Test for overall effect: Z = 3.85 (P = 0.0001)
Test for subgroup differences: Not applicable



Analysis 1.6. Comparison 1: Active information provision vs control for stroke survivors, Outcome 6: Stroke-survivor anxiety: summary of results

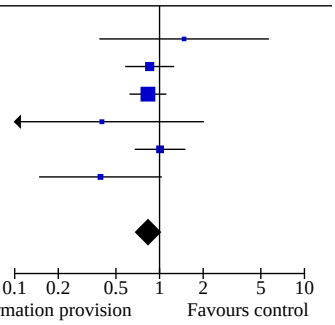
Stroke-survivor anxiety: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Johnston 2007	8 weeks (postintervention) and 6 months from baseline	Postdischarge workbook intervention including information and audio relaxation tape versus usual care	Hospital Anxiety and Depression Scale (HADS): anxiety subscale	HADS anxiety: baseline: no significant difference between intervention and control (P > 0.05); postintervention: no significant difference between intervention and control (P > 0.05); (data and P value not reported).	

Analysis 1.7. Comparison 1: Active information provision vs control for stroke survivors, Outcome 7: Stroke-survivor depression (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Eames 2013	5	35	3	31	2.0%	1.48 [0.38 , 5.68]
Ellis 2005 (1)	30	93	37	98	22.7%	0.85 [0.58 , 1.26]
Forster 2013 (2)	61	289	80	315	48.3%	0.83 [0.62 , 1.11]
Kalra 2004	2	122	5	122	3.2%	0.40 [0.08 , 2.02]
Rodgers 1999	30	66	23	51	16.4%	1.01 [0.67 , 1.51]
Smith 2004	5	50	11	43	7.5%	0.39 [0.15 , 1.04]
Total (95% CI)		**655**		**660**	**100.0%**	**0.83 [0.68 , 1.01]**
Total events:	133		159			

Heterogeneity: Chi² = 4.68, df = 5 (P = 0.46); I² = 0%
Test for overall effect: Z = 1.85 (P = 0.06)
Test for subgroup differences: Not applicable



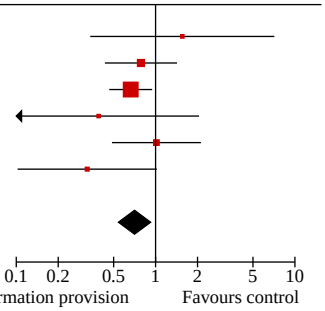
Footnotes

(1) We previously used cutoff > 10 with 5 intervention cases and 10 control cases.
(2) Used ICC = 0.001, design effect = 1.02

Analysis 1.8. Comparison 1: Active information provision vs control for stroke survivors, Outcome 8: Sensitivity analysis. Stroke-survivor depression (dichotomised data)

Study or Subgroup	log[OR]	SE	Active information provision Total	Control Total	Weight	Odds Ratio IV, Fixed, 95% CI
Eames 2013	0.442	0.776	35	31	3.1%	1.56 [0.34 , 7.12]
Ellis 2005	-0.242	0.304	93	98	19.9%	0.79 [0.43 , 1.42]
Forster 2013 (1)	-0.411	0.181	294	320	56.1%	0.66 [0.46 , 0.95]
Kalra 2004	-0.942	0.847	122	122	2.6%	0.39 [0.07 , 2.05]
Rodgers 1999	0.014	0.375	66	51	13.1%	1.01 [0.49 , 2.11]
Smith 2004	-1.13	0.587	50	43	5.3%	0.32 [0.10 , 1.02]
Total (95% CI)			**660**	**665**	**100.0%**	**0.71 [0.54 , 0.92]**

Heterogeneity: Chi² = 4.48, df = 5 (P = 0.48); I² = 0%
Test for overall effect: Z = 2.57 (P = 0.01)
Test for subgroup differences: Not applicable

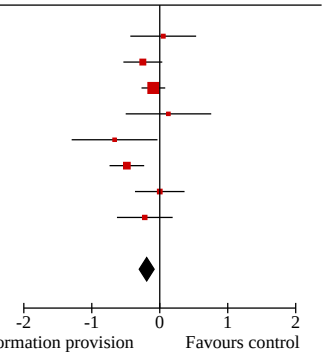


Footnotes
(1) Adjusted results from logistic regression with clustering

Analysis 1.9. Comparison 1: Active information provision vs control for stroke survivors, Outcome 9: Stroke-survivor depression (SMD)

Study or Subgroup	SMD	SE	Active information provision Total	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Eames 2013	0.051	0.247	35	31	5.1%	0.05 [-0.43 , 0.54]
Ellis 2005	-0.249	0.146	93	98	14.7%	-0.25 [-0.54 , 0.04]
Forster 2013	-0.094	0.089	294	320	39.5%	-0.09 [-0.27 , 0.08]
Frank 2000	0.128	0.321	19	20	3.0%	0.13 [-0.50 , 0.76]
Johnson 2000	-0.665	0.322	21	20	3.0%	-0.67 [-1.30 , -0.03]
Kalra 2004	-0.484	0.13	122	122	18.5%	-0.48 [-0.74 , -0.23]
Rodgers 1999	0	0.186	66	51	9.0%	0.00 [-0.36 , 0.36]
Smith 2004	-0.22	0.209	50	43	7.2%	-0.22 [-0.63 , 0.19]
Total (95% CI)			**700**	**705**	**100.0%**	**-0.19 [-0.30 , -0.08]**

Heterogeneity: Chi² = 11.61, df = 7 (P = 0.11); I² = 40%
Test for overall effect: Z = 3.44 (P = 0.0006)
Test for subgroup differences: Not applicable



Analysis 1.10. Comparison 1: Active information provision vs control for stroke survivors, Outcome 10: Stroke-survivor QOL (WHOQOL-BREF): summary of results

Stroke-survivor QOL (WHOQOL-BREF): summary of results

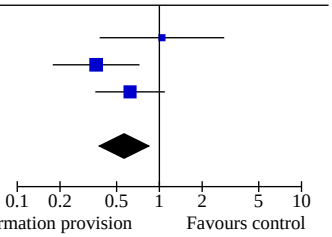
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Chinchai 2010	2 months	Education programme including follow-up visits versus usual care information from health stations in the community	Thai version of the WHO Quality of Life assessment short-form (WHOQOL-BREF Thai)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 30/30, control 30/30. WHOQOL-BREF Thai physical subscale (2 months) Mean score: intervention 59.75 (SD 7.96), control 48.21 (SD 6.75) Mean difference: 11.54 (95% CI 7.81 to 15.27) WHOQOL-BREF Thai psychological subscale (2 months)	

Mean score: intervention 62.08 (SD 7.83), control 50.29 (SD 9.83)
Mean difference: 11.79 (95% CI 7.29 to 16.29)
WHOQOL-BREF Thai social subscale (2 months)
Mean score: intervention 46.67 (SD 7.43), control 40.83 (SD 11.83)
Mean difference: 5.84 (95% CI 0.84 to 10.84)
WHOQOL-BREF Thai environment subscale (2 months)
Mean score: 55.94 (SD 6.97), control 48.97 (SD 8.63)
Mean difference: 6.97 (95% CI 3.00 to 10.94)

Analysis 1.11. Comparison 1: Active information provision vs control for stroke survivors, Outcome 11: Stroke-survivor satisfaction with information on causes and nature of stroke (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio (Non-event) M-H, Fixed, 95% CI
Ellis 2005	87	94	91	98	14.0%	1.04 [0.38 , 2.86]
Rodgers 1999	57	66	31	50	44.2%	0.36 [0.18 , 0.72]
Smith 2004	33	46	24	44	41.8%	0.62 [0.35 , 1.09]
Total (95% CI)		**206**		**192**	**100.0%**	**0.56 [0.38 , 0.84]**
Total events:	177		146			

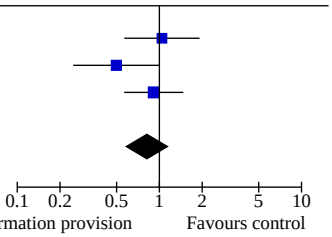
Heterogeneity: Chi² = 3.13, df = 2 (P = 0.21); I² = 36%
Test for overall effect: Z = 2.81 (P = 0.005)
Test for subgroup differences: Not applicable



Analysis 1.12. Comparison 1: Active information provision vs control for stroke survivors, Outcome 12: Stroke-survivor satisfaction with information about allowances and services (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio (Non-event) M-H, Fixed, 95% CI
Ellis 2005	77	94	81	98	30.6%	1.04 [0.57 , 1.92]
Rodgers 1999	54	64	35	51	32.8%	0.50 [0.25 , 1.00]
Smith 2004	27	46	23	42	36.6%	0.91 [0.57 , 1.47]
Total (95% CI)		**204**		**191**	**100.0%**	**0.82 [0.59 , 1.14]**
Total events:	158		139			

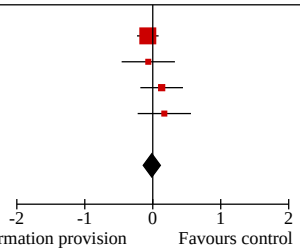
Heterogeneity: Chi² = 2.75, df = 2 (P = 0.25); I² = 27%
Test for overall effect: Z = 1.19 (P = 0.23)
Test for subgroup differences: Not applicable



Analysis 1.13. Comparison 1: Active information provision vs control for stroke survivors, Outcome 13: Stroke-survivor psychological distress (SMD)

Study or Subgroup	SMD	SE	Active information provision Total	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Forster 2013	-0.073	0.081	296	322	63.1%	-0.07 [-0.23 , 0.09]
Hekmatpou 2019 (1)	-0.066	0.2	50	50	10.4%	-0.07 [-0.46 , 0.33]
Johnston 2007	0.131	0.16	74	84	16.2%	0.13 [-0.18 , 0.44]
Rodgers 1999	0.17	0.2	65	41	10.4%	0.17 [-0.22 , 0.56]
Total (95% CI)			**485**	**497**	**100.0%**	**-0.01 [-0.14 , 0.11]**

Heterogeneity: Chi² = 2.27, df = 3 (P = 0.52); I² = 0%
Test for overall effect: Z = 0.22 (P = 0.83)
Test for subgroup differences: Not applicable



Footnotes

(1) We assumed the data were mean and standard error, rather than standard deviation and mean as they were labelled.

Analysis 1.14. Comparison 1: Active information provision vs control for stroke survivors, Outcome 14: Stroke-survivor self-efficacy: summary of results

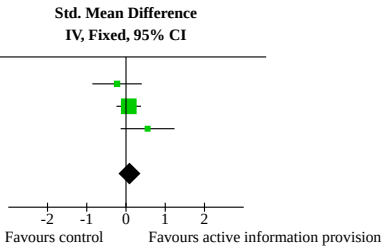
Stroke-survivor self-efficacy: summary of results

Study	Follow up	Comparison	Outcome measure	Results	Notes
Frank 2000	1 month	Workbook and development of recovery plan versus waiting list control	Perceived Health Competence Scale. Higher scores indicate greater self-efficacy	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 19/20, control 20/21. Mean (SD) Intervention: 29.21 (5.97) Control: 26.95 (5.49) F(group x time) < 1, P > 0.05	Baseline imbalance of 1.25 favouring the intervention group.

Analysis 1.15. Comparison 1: Active information provision vs control for stroke survivors, Outcome 15: Stroke-survivor locus of control (SMD)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Frank 2000	36.42	5.56	19	37.55	4.08	20	16.9%	-0.23 [-0.86 , 0.40]
Johnston 2007	35.87	4.31	74	35.53	5.21	84	68.8%	0.07 [-0.24 , 0.38]
Kim 2013	19.8	3.7	17	17.6	4.1	17	14.3%	0.55 [-0.14 , 1.24]
Total (95% CI)			**110**			**121**	**100.0%**	**0.09 [-0.17 , 0.35]**

Heterogeneity: Chi² = 2.72, df = 2 (P = 0.26); I² = 26%
Test for overall effect: Z = 0.67 (P = 0.50)
Test for subgroup differences: Not applicable



Analysis 1.16. Comparison 1: Active information provision vs control for stroke survivors, Outcome 16: Stroke-survivor modification of health related behaviours: summary of results

Stroke-survivor modification of health related behaviours: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Boden-Albala 2015	5 years	Interactive stroke preparedness package to encourage prompt recognition of stroke symptoms and presen-	Proportion of subjects presenting/not within 3 hours of symptom onset	601 participants were randomised to intervention, 592 to control. 124 first recurrent stroke symptoms in in-	

		tation at emergency department versus control group (received educational materials also given to the experimental group)		tervention, 100 in control. Overall, among the intervention group, 40% arrived within 3 hours compared with 46% of the control group (no significant difference). For the whole randomised sample, there were no significant differences in the odds of arriving within 3 hours or of the odds of not arriving within 3 hours.
Chiu 2008	6 month intervention; follow-up during clinic visits, not scheduled	Pharmacist lead intervention providing information on drug effects, lifestyle modification, benefits of therapies, importance of compliance, drug interactions and adverse events versus control group (no information reported)	Proportion of subjects with satisfactory management of modifiable risk factors: Blood pressure (BP) (defined as < 140/90 mmHg) Lipids (defined as low-density lipoprotein (LDL) cholesterol < 100 mg/dL or, if LDL was not available, total cholesterol (TC) < 160 mg/dL) Glucose (defined as glycosylated haemoglobin A1c (HbA1c) < 7% or, if HbA1c not available, fasting blood glucose (FBG) < 126 mg/dL. When HbA1c or FBG were not available, random postprandial blood glucose < 200 mg/dL was used to define adequate control.	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 78/80, control 76/80 There was a statistically significant difference (P < 0.001) between the groups for management of BP. After the intervention, 65/78 (83.3%) of the intervention group and 33/76 (43.4%) of the control group had satisfactory management of BP. No statistically significant difference between the intervention and control groups for management of lipids or glucose. After the intervention, 21/53 (39.6%) of the intervention group and 13/49 (26.5%) of the control group had satisfactory management of lipids. After the intervention, 12/34 (53.5%) of the intervention group and 15/33 (45.5%) of the control group had satisfactory management of glucose.
Eames 2013	3 months	Education and support package including online materials, verbal and telephone support in addition to usual care versus usual care	Stroke survivor performance of stroke risk-related behaviours (0 to 10, 10 is ideal)	At follow-up there was no statistically significant difference between treatment: Mean (SD) = 8.1 (1.3) (n = 35); and control 8.6 (1.3) (n = 31)
Ellis 2005	5 months	Generic risk factor advice and stroke nurse specialist review and written advice versus generic risk factor advice	Modifiable risk factors within the recommended treatment range according to the contemporary national and local treatment guidelines: blood pressure (< 140/85 mmHg), cigarette consumption (complete cessation), Random blood glucose (< 80 mmol/l), HbA1c (< 7.5%), Total cholesterol (< 5.0 mmol/l)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 94/100, control 98/105 Mean (95% confidence intervals) or number (%) 5 months: intervention n = 94, control n = 98 All relevant risk factors controlled: intervention 45 (46.4%), control 41 (41.7%) Individual risk factors: • hypertension, change in systolic BP (mmHg): intervention -9.3 (-15.0

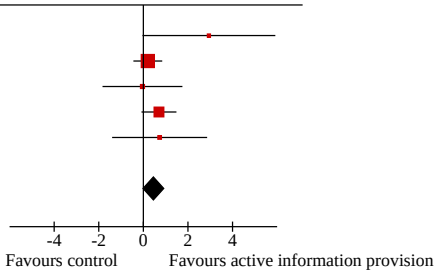
				to -3.5), control -1.0 (-6.3 to 4.3) • hypertension, change in diastolic BP (mmHg): intervention -2.1 (-5.7 to 1.5), control -1.2 (-4.5 to 4.5) • smoking, change in number of cigarettes per day: intervention -1.6 (-5.1 to 1.8), control -0.4 (-3.7 to 2.8) • diabetes, change in random blood glucose (mmol/l): intervention 0.92 (-1.39 to 3.23), control 0.89 (-2.09 to 3.87) • diabetes, change in HbA1C (%):intervention -0.25 (-0.57 to 0.08), control -0.78 (-1.50 to 0.05) • hypercholesterolaemia, total cholesterol (mmol/l): intervention -0.96 (-1.20 to 0.71), control -0.87 (-1.14 to 0.61)	
Kamal 2016	12 months	Videos on phone, verbal information and booklets versus verbal information and booklets only.	Morisky Medication Adherence Scale (MMAS) Risk factor modification: blood pressure (SBP, DBP) blood sugar (HbA1c) blood cholesterol (LDL)	Number of participants in group at outset of the trial: intervention 155, control 155. Number in category MMAS low/medium/high adherence: intervention 11/17/99, control 12/23/80 SBP </≥ 125 mmHg: intervention 18/36, control 11/41 DBP </≥ 85 mmHg: intervention 44/10, control 37/15 HbA1c </≥ 7%: intervention 36/19, control 30/10 LDL </≥ 100 mg/dl: intervention 36/15, control 30/15	
Kim 2013	3 months	Internet-based video lectures and quizzes versus usual care	Full medication adherence at follow-up	At follow-up, 15/18 had full medication adherence in the active info group and 11/18 had full medication adherence in the control group.	There were baseline differences in medication adherence (intervention 10/18, control 14/18) but these favoured the control group, so this does not threaten validity of the follow-up result, which favours the intervention group.
Kuo 2015	2 months	Home-based oral care training programme for carers versus routine care	Behaviour of Oral Care (BOC, 0 to 52) including time, frequency, content, technique and products used for oral care. Assessed by a research assistant via record sheets and observation.	At follow-up, the mean (SD) BOC for the intervention group 45.4 (9.20) was statistically significantly greater than for the control group 24.22 (8.73).	Baseline scores were similar, 15.3 (7.94) and 16.4 (7.7). Data were from 48 of 50 intervention participants and 46 of 50 control participants.
Rodgers 1999	6 months	Education programme versus usual care	Lifestyle and risk factor modifications: smoking, BP, and medication	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 66/121, control 51/83 Smoking:	Smoking: present smoking P = 0.44 Smoked six months ago: P = 0.61 BP checked since leaving hospital: P = 0.74 Medication:

	present smoker: intervention 14 (21%), control 14 (28%) smoked 6 months ago: intervention 25 (38%), control 17 (33%) BP, checked since leaving hospital: intervention 61 (92%), control 48 (94%) Medication aspirin: intervention 36 (62%), control 31 (72%) dipyridamole: intervention 2 (3%), control 2 (5%) warfarin: intervention 10 (17%), control 6 (14%)	aspirin: P = 0.29, dipyridamole: P = 0.66, warfarin: P = 0.76

Analysis 1.17. Comparison 1: Active information provision vs control for stroke survivors, Outcome 17: Stroke-survivor activities of daily living (Barthel Index, 0-20)

Study or Subgroup	MD	SE	Experimental Total	Control Total	Weight	Mean Difference IV, Fixed, 95% CI
Deyhoul 2018	2.94	1.52	45	45	2.4%	2.94 [-0.04 , 5.92]
Forster 2013	0.2	0.33	330	348	51.3%	0.20 [-0.45 , 0.85]
Johnston 2007 (1)	-0.04	0.914	74	84	6.7%	-0.04 [-1.83 , 1.75]
Mudzi 2012	0.7	0.4	66	53	34.9%	0.70 [-0.08 , 1.48]
Smith 2004	0.73	1.087	69	64	4.7%	0.73 [-1.40 , 2.86]
Total (95% CI)			**584**	**594**	**100.0%**	**0.45 [-0.01 , 0.91]**

Heterogeneity: Chi² = 4.00, df = 4 (P = 0.41); I² = 0%
Test for overall effect: Z = 1.90 (P = 0.06)
Test for subgroup differences: Not applicable



Footnotes

(1) Reported SD is unfeasibly small and substantially smaller than given in the baseline table, so interpreted as SE.

Analysis 1.18. Comparison 1: Active information provision vs control for stroke survivors, Outcome 18: Stroke-survivor independence in activities of daily living: summary of results

Stroke-survivor independence in activities of daily living: summary of results

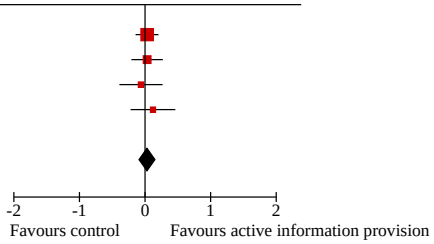
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Kalra 2004	3 and 12 months	Education sessions + hands on training versus conventional care	Barthel Index (BI) (0 to 20)	Number of participants with BI data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 134/151, control 134/149 BI score > 18 3 months: intervention 77/141, control 52/140 12 months: intervention 93/134, control 75/134	
Kamal 2016	12 months	Videos on phone, verbal information and booklets versus verbal information and booklets only.	Barthel Index (BI)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 120/155, control 128/155. Number in category per group	Odds ratios between adjacent categories are presented by the authors but not reproduced here as they do not dichotomise the entire sample.

BI 95 to 100: intervention n = 87, control n = 71
BI 55 to 90: intervention n = 23, control n = 27
BI 0 to 50: intervention n = 18, control n = 22

Analysis 1.19. Comparison 1: Active information provision vs control for stroke survivors, Outcome 19: Stroke-survivor social activities (SMD)

Study or Subgroup	SMD	SE	Experimental Total	Control Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Forster 2013	0.03	0.089	301	330	48.2%	0.03 [-0.14 , 0.20]
Kalra 2004	0.032	0.122	134	133	25.7%	0.03 [-0.21 , 0.27]
Rodgers 1999	-0.062	0.168	84	61	13.5%	-0.06 [-0.39 , 0.27]
Smith 2004	0.121	0.174	68	64	12.6%	0.12 [-0.22 , 0.46]
Total (95% CI)			**587**	**588**	**100.0%**	**0.03 [-0.09 , 0.15]**

Heterogeneity: Chi² = 0.57, df = 3 (P = 0.90); I² = 0%
Test for overall effect: Z = 0.48 (P = 0.63)
Test for subgroup differences: Not applicable



Analysis 1.20. Comparison 1: Active information provision vs control for stroke survivors, Outcome 20: Stroke-survivor perceived health status: summary of results

Stroke-survivor perceived health status: summary of results

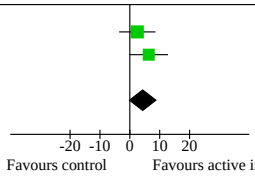
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Eames 2013	3 months	Education and support package including online materials, verbal and telephone support in addition to usual care versus usual care	The Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 31/37, control 35/40. SAQOL-39: Mean difference (MD) 0.00 (95% CI -0.34 to 0.34)	
Ellis 2005	5 months	Generic risk factor advice + stroke nurse specialist review and written advice versus generic risk factor advice	EuroQol 5 Dimension (EQ-5D)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 94/100, control 98/105. Number (%) with decrease in quality of life (score increase of 1 or more) Mobility: intervention 11 (12%), control 17(17%) Self-care: intervention 8 (9%), control 16 (16%) Usual activities: intervention 14 (15%), control 22 (22%) Pain: intervention 18 (19%), control 25 (26%) Anxiety and depression: intervention 17 (18%), control 25 (26%)	
Forster 2013	6 and 12 months	London Stroke Carers Training Course + usual care based on national guidelines versus usual care based on national guidelines	EQ-5D (Index value only) Stroke Impact Scale (SIS)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: in-	

				tervention 305/450, control 333/478. EQ-5D Index value at 12 months: MD 0.03 (95% CI -0.02 to 0.08) SIS Physical composite domain subscale at 12 months: MD 2.4 (95% CI -0.8 to 5.6) SIS Recovery subscale at 12 months: MD 0.8 (95% CI -3.1 to 4.6)
Frank 2000	1 month	Workbook versus wait list control	Functional Limitations Profile (FLP)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 19/20, control 20/21. FLP: MD -2.86 (95% CI -16.62 to 10.90).
Mudzi 2012	3, 6 and 12 months	Carer training session + usual care versus usual care	EQ-5D	Unknown number of participants lost to follow-up. Mean EQ-5D score at 12 months: intervention (68.8), control (67)

Analysis 1.21. Comparison 1: Active information provision vs control for stroke survivors, Outcome 21: Stroke-survivor perceived health status (EQ-VAS)

	Active information provision			Control				Mean Difference	Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**	**IV, Fixed, 95% CI**
Ellis 2005 (1)	3.5	21.48	94	1	21.45	98	52.9%	2.50 [-3.57 , 8.57]	
Kalra 2004	66.67	18.77	112	60.33	29.28	112	47.1%	6.34 [-0.10 , 12.78]	
Total (95% CI)			**206**			**210**	**100.0%**	**4.31 [-0.11 , 8.73]**	

Heterogeneity: Chi² = 0.72, df = 1 (P = 0.40); I² = 0%
Test for overall effect: Z = 1.91 (P = 0.06)
Test for subgroup differences: Not applicable

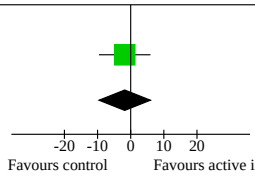


Footnotes
(1) Change from baseline

Analysis 1.22. Comparison 1: Active information provision vs control for stroke survivors, Outcome 22: Stroke-survivor perceived health status (SF-36)

	Active information provision			Control				Mean Difference	Mean Difference
Study or Subgroup	**Mean**	**SD**	**Total**	**Mean**	**SD**	**Total**	**Weight**	**IV, Fixed, 95% CI**	**IV, Fixed, 95% CI**
Hekmatpou 2019 (1)	56.2	59.8	50	0	0	1		Not estimable	
Rodgers 1999	47	19.8	66	48.8	22.3	51	100.0%	-1.80 [-9.56 , 5.96]	
Total (95% CI)			**116**			**52**	**100.0%**	**-1.80 [-9.56 , 5.96]**	

Heterogeneity: Not applicable
Test for overall effect: Z = 0.45 (P = 0.65)
Test for subgroup differences: Not applicable



Footnotes
(1) Data not presented by the authors for the control group. We assumed the data were mean and standard error, rather than standard deviation and mean as they were labelled.

Analysis 1.23. Comparison 1: Active information provision vs control for stroke survivors, Outcome 23: Stroke-survivor recurrent stroke: summary of results

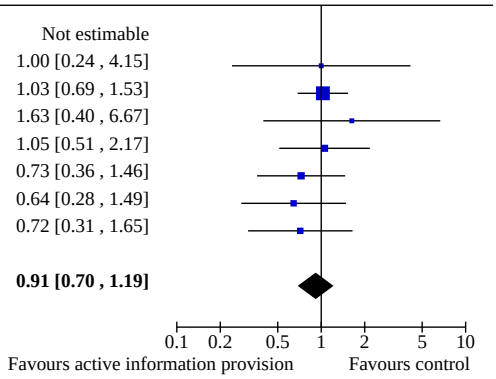
Stroke-survivor recurrent stroke: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Boden-Albala 2015	30 days, 1 year, then annually for 5 years	Enhanced education for stroke survivors to facilitate the early recognition of stroke warning signs plus a standardised packet of preparedness focused education materials versus a standardised packet of preparedness focused education materials	Recurrent strokes	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: 1163/1193 (insufficient information about loss to follow-up in intervention versus control arm). Recurrent stroke events (5 year follow-up): Intervention: 124/601, control: 100/592 Risk Ratio (5 year follow-up): RR 1.22 (95% CI 0.96 to 1.55)	

Analysis 1.24. Comparison 1: Active information provision vs control for stroke survivors, Outcome 24: Stroke-survivor deaths

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Peto Odds Ratio Peto, Fixed, 95% CI
Ellis 2005	0	100	0	105		Not estimable
Evans 1988	4	70	4	70	3.5%	1.00 [0.24 , 4.15]
Forster 2013	53	450	55	478	44.3%	1.03 [0.69 , 1.53]
Johnston 2007	5	103	3	100	3.6%	1.63 [0.40 , 6.67]
Kalra 2004	17	151	16	149	13.7%	1.05 [0.51 , 2.17]
Kamal 2016 (1)	15	155	20	155	14.5%	0.73 [0.36 , 1.46]
Rodgers 1999	13	121	13	83	10.2%	0.64 [0.28 , 1.49]
Smith 2004	11	84	15	86	10.3%	0.72 [0.31 , 1.65]
Total (95% CI)		**1234**		**1226**	**100.0%**	**0.91 [0.70 , 1.19]**
Total events:	118		126			

Heterogeneity: Chi² = 2.55, df = 6 (P = 0.86); I² = 0%
Test for overall effect: Z = 0.66 (P = 0.51)
Test for subgroup differences: Not applicable



Footnotes

(1) Stroke-related, non-stroke-related and in-hospital mortality were reported separately, but combined here.

Comparison 2. Active information provision vs control for stroke carers

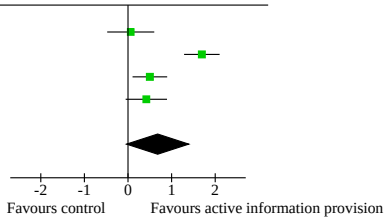
Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
2.1 Carer knowledge of stroke and stroke services (SMD)	4	356	Std. Mean Difference (IV, Random, 95% CI)	0.68 [-0.03, 1.39]
2.2 Carer anxiety (dichotomised data)	3	790	Risk Ratio (M-H, Fixed, 95% CI)	0.96 [0.71, 1.28]
2.3 Sensitivity analysis. Carer anxiety (dichotomised data)	3		Odds Ratio (IV, Fixed, 95% CI)	0.98 [0.64, 1.51]
2.4 Carer anxiety (HADS-A)	3	921	Mean Difference (IV, Random, 95% CI)	-0.40 [-1.51, 0.70]

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
2.5 Carer depression (dichotomised data)	3	843	Risk Ratio (M-H, Fixed, 95% CI)	0.98 [0.64, 1.50]
2.6 Sensitivity analysis. Carer depression (dichotomised data)	3		Odds Ratio (IV, Fixed, 95% CI)	0.86 [0.52, 1.44]
2.7 Carer depression (HADS-D)	3	924	Mean Difference (IV, Random, 95% CI)	-0.30 [-1.53, 0.92]
2.8 Carer positive mental well-being: summary of results	1		Other data	No numeric data
2.9 Carer quality of life: summary of results	1		Other data	No numeric data
2.10 Carer satisfaction with information about recovery and rehabilitation (dichotomised data)	2	165	Risk Ratio (M-H, Fixed, 95% CI)	0.66 [0.39, 1.10]
2.11 Carer satisfaction with information about allowances and services (dichotomised data)	2	167	Risk Ratio (M-H, Fixed, 95% CI)	0.72 [0.45, 1.16]
2.12 Carer psychological distress (dichotomised data)	2	176	Risk Ratio (M-H, Fixed, 95% CI)	1.07 [0.83, 1.38]
2.13 Carer psychological distress (SMD)	3	211	Std. Mean Difference (IV, Fixed, 95% CI)	0.00 [-0.27, 0.28]
2.14 Carer burden (SMD)	5	1099	Std. Mean Difference (IV, Random, 95% CI)	-0.74 [-1.44, -0.03]
2.15 Carer burden: summary of results	3		Other data	No numeric data
2.16 Carer social activities (FAI)	2	865	Mean Difference (IV, Fixed, 95% CI)	-0.40 [-1.16, 0.37]
2.17 Carer perceived health status (QALYs for year post-stroke)	2	768	Mean Difference (IV, Fixed, 95% CI)	0.00 [-0.01, 0.02]
2.18 Carer perceived health status (EQ-VAS)	2	323	Mean Difference (IV, Random, 95% CI)	3.52 [-9.83, 16.87]
2.19 Carer perceived health status (SF-36): summary of results	1		Other data	No numeric data

Analysis 2.1. Comparison 2: Active information provision vs control for stroke carers, Outcome 1: Carer knowledge of stroke and stroke services (SMD)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Random, 95% CI
Eames 2013	20.4	3.3	25	20.2	3	28	24.0%	0.06 [-0.48 , 0.60]
Evans 1988	23	5.5	64	14.2	4.8	63	25.5%	1.69 [1.29 , 2.10]
Rodgers 1999	16.9	4	65	14.8	4.4	41	25.6%	0.50 [0.10 , 0.90]
Smith 2004	12.44	2.46	36	11.38	2.53	34	24.8%	0.42 [-0.05 , 0.89]
Total (95% CI)			**190**			**166**	**100.0%**	**0.68 [-0.03 , 1.39]**

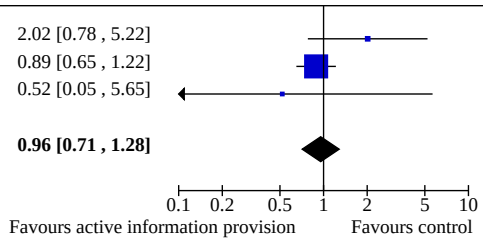
Heterogeneity: Tau² = 0.47; Chi² = 30.22, df = 3 (P < 0.00001); I² = 90%
Test for overall effect: Z = 1.87 (P = 0.06)
Test for subgroup differences: Not applicable



Analysis 2.2. Comparison 2: Active information provision vs control for stroke carers, Outcome 2: Carer anxiety (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Eames 2013	9	25	5	28	6.8%	2.02 [0.78 , 5.22]
Forster 2013 (1)	53	223	65	243	90.3%	0.89 [0.65 , 1.22]
Kalra 2004	1	133	2	138	2.8%	0.52 [0.05 , 5.65]
Total (95% CI)		**381**		**409**	**100.0%**	**0.96 [0.71 , 1.28]**
Total events:	63		72			

Heterogeneity: Chi² = 2.83, df = 2 (P = 0.24); I² = 29%
Test for overall effect: Z = 0.31 (P = 0.76)
Test for subgroup differences: Not applicable

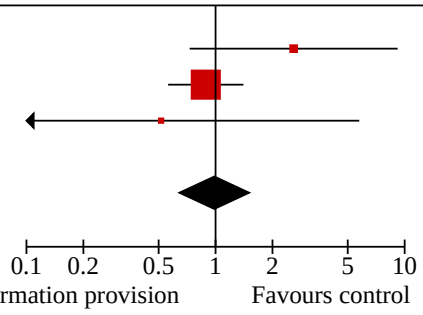


Footnotes
(1) Used ICC = 0.018, design effect = 1.28

Analysis 2.3. Comparison 2: Active information provision vs control for stroke carers, Outcome 3: Sensitivity analysis. Carer anxiety (dichotomised data)

Study or Subgroup	log[OR]	SE	Weight	Odds Ratio IV, Fixed, 95% CI
Eames 2013	0.951	0.646	11.2%	2.59 [0.73 , 9.18]
Forster 2013 (1)	-0.119	0.234	85.7%	0.89 [0.56 , 1.40]
Kalra 2004	-0.663	1.231	3.1%	0.52 [0.05 , 5.75]
Total (95% CI)			**100.0%**	**0.98 [0.64 , 1.51]**

Heterogeneity: Chi² = 2.71, df = 2 (P = 0.26); I² = 26%
Test for overall effect: Z = 0.07 (P = 0.94)
Test for subgroup differences: Not applicable

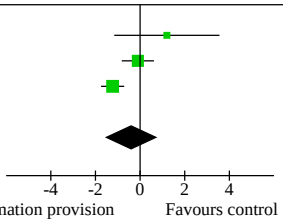


Footnotes
(1) Adjusted results from logistic regression with clustering

Analysis 2.4. Comparison 2: Active information provision vs control for stroke carers, Outcome 4: Carer anxiety (HADS-A)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Eames 2013	8.1	4.6	25	6.9	4.1	28	15.2%	1.20 [-1.16 , 3.56]
Forster 2013	6.9	4.397	286	7	4.59	311	40.6%	-0.10 [-0.82 , 0.62]
Kalra 2004	3.05	2.01	133	4.28	2.34	138	44.2%	-1.23 [-1.75 , -0.71]
Total (95% CI)			**444**			**477**	**100.0%**	**-0.40 [-1.51 , 0.70]**

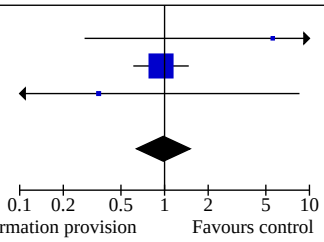
Heterogeneity: Tau² = 0.65; Chi² = 9.02, df = 2 (P = 0.01); I² = 78%
Test for overall effect: Z = 0.71 (P = 0.48)
Test for subgroup differences: Not applicable



Analysis 2.5. Comparison 2: Active information provision vs control for stroke carers, Outcome 5: Carer depression (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Eames 2013	2	25	0	28	1.3%	5.58 [0.28 , 110.89]
Forster 2013 (1)	32	247	37	270	94.8%	0.95 [0.61 , 1.47]
Kalra 2004	0	133	1	140	3.9%	0.35 [0.01 , 8.53]
Total (95% CI)		**405**		**438**	**100.0%**	**0.98 [0.64 , 1.50]**
Total events:	34		38			

Heterogeneity: Chi² = 1.72, df = 2 (P = 0.42); I² = 0%
Test for overall effect: Z = 0.09 (P = 0.93)
Test for subgroup differences: Not applicable

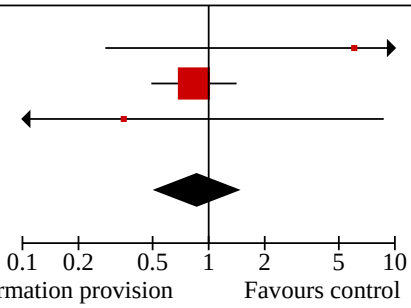


Footnotes
(1) used ICC = 0.010, design effect = 1.16

Analysis 2.6. Comparison 2: Active information provision vs control for stroke carers, Outcome 6: Sensitivity analysis. Carer depression (dichotomised data)

Study or Subgroup	log[OR]	SE	Weight	Odds Ratio IV, Fixed, 95% CI
Eames 2013	1.8	1.57	2.8%	6.05 [0.28 , 131.26]
Forster 2013 (1)	-0.182	0.269	94.7%	0.83 [0.49 , 1.41]
Kalra 2004	-1.05	1.64	2.5%	0.35 [0.01 , 8.71]
Total (95% CI)			**100.0%**	**0.86 [0.52 , 1.44]**

Heterogeneity: Chi² = 1.86, df = 2 (P = 0.39); I² = 0%
Test for overall effect: Z = 0.57 (P = 0.57)
Test for subgroup differences: Not applicable

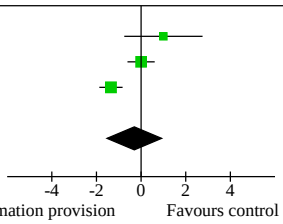


Footnotes
(1) Adjusted results from logistic regression with clustering

Analysis 2.7. Comparison 2: Active information provision vs control for stroke carers, Outcome 7: Carer depression (HADS-D)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Eames 2013	4.5	3.8	25	3.5	2.5	28	22.6%	1.00 [-0.75 , 2.75]
Forster 2013	5.2	3.72	286	5.2	3.89	312	38.2%	0.00 [-0.61 , 0.61]
Kalra 2004	2.05	1.91	133	3.4	2.46	140	39.2%	-1.35 [-1.87 , -0.83]
Total (95% CI)			**444**			**480**	**100.0%**	**-0.30 [-1.53 , 0.92]**

Heterogeneity: Tau² = 0.92; Chi² = 14.65, df = 2 (P = 0.0007); I² = 86%
Test for overall effect: Z = 0.49 (P = 0.63)
Test for subgroup differences: Not applicable



Analysis 2.8. Comparison 2: Active information provision vs control for stroke carers, Outcome 8: Carer positive mental well-being: summary of results

Carer positive mental well-being: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Larson 2005	6 months and 1 year	Education programme + support versus regular information and possibility of attending 1 open session	Bradley's well-being questionnaire (W-BQ 12): positive well-being subscale. Mean (SD)	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 46/50, control 45/50 Positive well-being: Before intervention: intervention 9.14 (2.55), control 8.90 (2.28) 6 months: intervention 8.52 (1.95), control 7.91 (2.46) 12 months: intervention 8.35 (3.03), control 8.53 (2.61); MD -0.18 (95% CI -1.34 to 0.98) P = 0.74	

Analysis 2.9. Comparison 2: Active information provision vs control for stroke carers, Outcome 9: Carer quality of life: summary of results

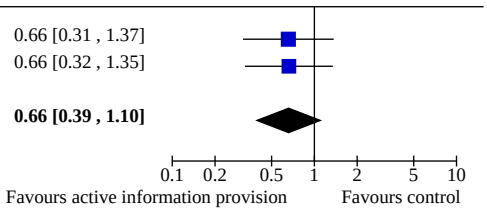
Carer quality of life: summary of results

Study	Follow -up	Comparison	Outcome measure	Results	Notes
Larson 2005	6 months and 1 year	Education programme + support versus regular information and possibility of attending 1 open session	General quality of life visual analogue scale	Number of participants with outcome data available at the end of scheduled follow up/number of participants in group at outset of the trial: intervention 46/50, control 45/50 Mean (SD) General quality of life visual analogue scale: Before intervention: intervention 60.08 (22.79), control 60.22 (22.57) 6 months: intervention 63.04 (22.35), control 63.87 (20.45) 1 year: intervention 68.00 (22.89), control 66.78 (20.22); MD 1.22 (95% CI -7.65 to 10.09)	

Analysis 2.10. Comparison 2: Active information provision vs control for stroke carers, Outcome 10: Carer satisfaction with information about recovery and rehabilitation (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio (Non-event) M-H, Fixed, 95% CI
Rodgers 1999	50	61	29	40	51.0%	0.66 [0.31 , 1.37]
Smith 2004	25	34	18	30	49.0%	0.66 [0.32 , 1.35]
Total (95% CI)		**95**		**70**	**100.0%**	**0.66 [0.39 , 1.10]**
Total events:	75		47			

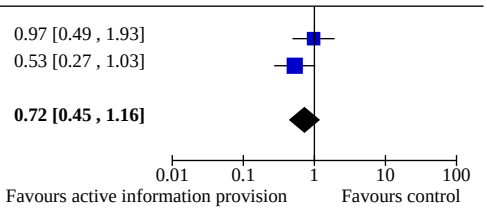
Heterogeneity: Chi² = 0.00, df = 1 (P = 0.99); I² = 0%
Test for overall effect: Z = 1.60 (P = 0.11)
Test for subgroup differences: Not applicable



Analysis 2.11. Comparison 2: Active information provision vs control for stroke carers, Outcome 11: Carer satisfaction with information about allowances and services (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio (Non-event) M-H, Fixed, 95% CI
Rodgers 1999	48	64	29	39	43.8%	0.97 [0.49 , 1.93]
Smith 2004	25	34	15	30	56.2%	0.53 [0.27 , 1.03]
Total (95% CI)		**98**		**69**	**100.0%**	**0.72 [0.45 , 1.16]**
Total events:	73		44			

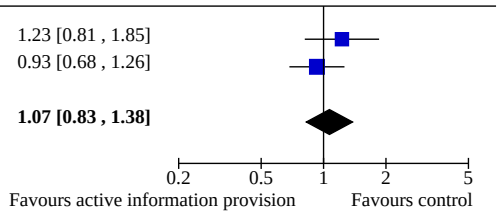
Heterogeneity: Chi² = 1.58, df = 1 (P = 0.21); I² = 37%
Test for overall effect: Z = 1.34 (P = 0.18)
Test for subgroup differences: Not applicable



Analysis 2.12. Comparison 2: Active information provision vs control for stroke carers, Outcome 12: Carer psychological distress (dichotomised data)

Study or Subgroup	Active information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Rodgers 1999	35	65	18	41	46.5%	1.23 [0.81 , 1.85]
Smith 2004	25	37	24	33	53.5%	0.93 [0.68 , 1.26]
Total (95% CI)		**102**		**74**	**100.0%**	**1.07 [0.83 , 1.38]**
Total events:	60		42			

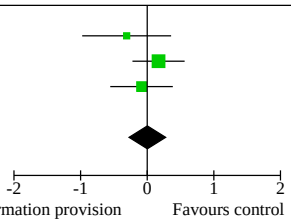
Heterogeneity: Chi² = 1.23, df = 1 (P = 0.27); I² = 19%
Test for overall effect: Z = 0.50 (P = 0.62)
Test for subgroup differences: Not applicable



Analysis 2.13. Comparison 2: Active information provision vs control for stroke carers, Outcome 13: Carer psychological distress (SMD)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Draper 2007	4.26	5.67	17	6.28	7.01	18	16.9%	-0.31 [-0.98 , 0.36]
Rodgers 1999	-66.6	20.5	65	-70.3	23.3	41	49.0%	0.17 [-0.22 , 0.56]
Smith 2004	8.68	7.38	37	9.3	6.94	33	34.1%	-0.09 [-0.55 , 0.38]
Total (95% CI)			**119**			**92**	**100.0%**	**0.00 [-0.27 , 0.28]**

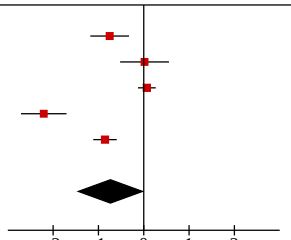
Heterogeneity: Chi² = 1.67, df = 2 (P = 0.43); I² = 0%
Test for overall effect: Z = 0.01 (P = 0.99)
Test for subgroup differences: Not applicable



Analysis 2.14. Comparison 2: Active information provision vs control for stroke carers, Outcome 14: Carer burden (SMD)

Study or Subgroup	SMD	SE	Active information provision Total	Control Total	Weight	Std. Mean Difference IV, Random, 95% CI
Deyhoul 2018	-0.752	0.218	45	45	19.8%	-0.75 [-1.18 , -0.32]
Eames 2013	0.017	0.275	25	28	19.0%	0.02 [-0.52 , 0.56]
Forster 2013	0.068	0.1	291	314	21.0%	0.07 [-0.13 , 0.26]
Hekmatpou 2019	-2.207	0.256	50	50	19.3%	-2.21 [-2.71 , -1.71]
Kalra 2004	-0.855	0.132	123	128	20.8%	-0.85 [-1.11 , -0.60]
Total (95% CI)			**534**	**565**	**100.0%**	**-0.74 [-1.44 , -0.03]**

Heterogeneity: Tau² = 0.61; Chi² = 88.14, df = 4 (P < 0.00001); I² = 95%
Test for overall effect: Z = 2.04 (P = 0.04)
Test for subgroup differences: Not applicable



Analysis 2.15. Comparison 2: Active information provision vs control for stroke carers, Outcome 15: Carer burden: summary of results

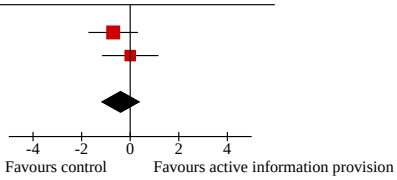
Carer burden: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Draper 2007	4 weeks and 3 months	Education programme versus usual care (waiting-list control)	Relatives' Stress Scale (RSS)	Number of participants with outcome data at final follow-up: intervention 17/19, waiting-list control 18/20. Insufficient information provided to compare RSS data between intervention and control group. No significant differences in pre to post-treatment scores for either the intervention or waiting-list control group (P > 0.05).	
Karimi 2018	3 months	Educational programme versus usual care	Zarit Burden Interview	Insufficient information provided	
Mudzi 2012	12 months	Individualised structured training on how to help the stroke survivor versus usual care	Caregiver Strain Index	Number of participants with outcome data available unclear. 100 in each group at outset of the trial. 43.1% were strained in the intervention group, 77.6% in the control group. OR: 0.29; CI 0.12 to 0.72 (unclear if this a 95% CI)	

Analysis 2.16. Comparison 2: Active information provision vs control for stroke carers, Outcome 16: Carer social activities (FAI)

Study or Subgroup	MD	SE	Active information provision Total	Control Total	Weight	Mean Difference IV, Fixed, 95% CI
Forster 2013	-0.7	0.52	286	313	56.6%	-0.70 [-1.72 , 0.32]
Kalra 2004	0	0.594	133	133	43.4%	0.00 [-1.16 , 1.16]
Total (95% CI)			**419**	**446**	**100.0%**	**-0.40 [-1.16 , 0.37]**

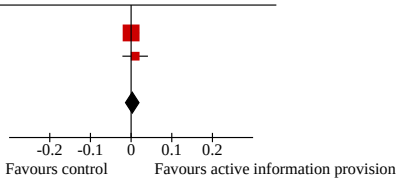
Heterogeneity: Chi² = 0.79, df = 1 (P = 0.38); I² = 0%
Test for overall effect: Z = 1.01 (P = 0.31)
Test for subgroup differences: Not applicable



Analysis 2.17. Comparison 2: Active information provision vs control for stroke carers, Outcome 17: Carer perceived health status (QALYs for year post-stroke)

Study or Subgroup	MD	SE	Active information provision Total	Control Total	Weight	Mean Difference IV, Fixed, 95% CI
Forster 2013	0	0.01	257	279	71.9%	0.00 [-0.02 , 0.02]
Kalra 2004	0.01	0.016	112	120	28.1%	0.01 [-0.02 , 0.04]
Total (95% CI)			**369**	**399**	**100.0%**	**0.00 [-0.01 , 0.02]**

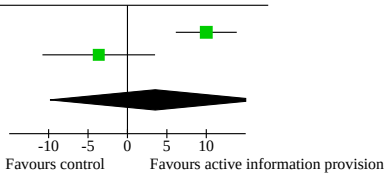
Heterogeneity: Chi² = 0.28, df = 1 (P = 0.60); I² = 0%
Test for overall effect: Z = 0.33 (P = 0.74)
Test for subgroup differences: Not applicable



Analysis 2.18. Comparison 2: Active information provision vs control for stroke carers, Outcome 18: Carer perceived health status (EQ-VAS)

Study or Subgroup	Active information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Kalra 2004	80	15.02	112	70	15	120	52.5%	10.00 [6.13 , 13.87]
Larson 2005	73.63	17.98	46	77.27	16.77	45	47.5%	-3.64 [-10.78 , 3.50]
Total (95% CI)			**158**			**165**	**100.0%**	**3.52 [-9.83 , 16.87]**

Heterogeneity: Tau² = 84.44; Chi² = 10.84, df = 1 (P = 0.0010); I² = 91%
Test for overall effect: Z = 0.52 (P = 0.60)
Test for subgroup differences: Not applicable



Analysis 2.19. Comparison 2: Active information provision vs control for stroke carers, Outcome 19: Carer perceived health status (SF-36): summary of results

Carer perceived health status (SF-36): summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Rodgers 1999	6 month	Group sessions covering the nature and experience of stroke versus usual care	SF-36	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 65/107, control 41/69. SF-36 general health subscale at 6 months Mean difference: 0.80 (95% CI -8.59 to 10.19)	

Comparison 3. Active information provision vs control: resource use

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
3.1 Cost to health and social services: summary of results	2		Other data	No numeric data

Analysis 3.1. Comparison 3: Active information provision vs control: resource use, Outcome 1: Cost to health and social services: summary of results

Cost to health and social services: summary of results

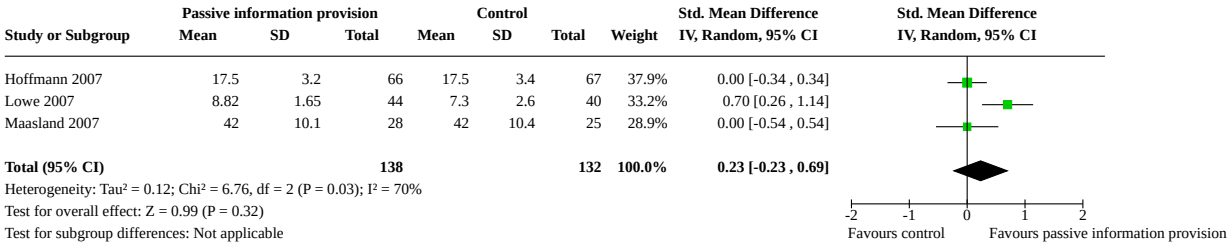
Study	Follow-up	Comparison	Outcome measure	Results	Notes
Forster 2013	12 months	Education versus usual care	Direct costs of the initial stroke admission Stroke survivor and carer health and social care costs and total societal costs, each including the cost of LSCTC development and training	Direct costs: treatment GBP 13127, control GBP 12471, adjusted mean difference (MD) GBP 1243, 95% CI −1533 to 4019, P = 0.380 Stroke survivor total health and social care costs: MD GBP 563, 95% CI −2986 to 4112, P = 0.756 Caregiver total health and social care costs: MD GBP 96, 95% CI -186 to 379, P = 0.505 Stroke survivor total societal costs: MD GBP 167, 95% CI −4163 to 4497, P = 0.940 Caregiver total societal costs: MD GBP -574, 95% CI −3112 to 1964, P = 0.658	
Kalra 2004	12 months	Education sessions + hands on training versus conventional care	Costs in first year after onset of stroke	Costs: total health and social care costs over one year significantly lower for intervention group, mean difference GBP 4043 (EUR 6072, USD 7249); 95% CI GBP -6544 to GBP -1595	

Comparison 4. Passive information provision vs control for stroke survivors

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
4.1 Stroke-survivor knowledge of stroke and stroke services (SMD)	3	270	Std. Mean Difference (IV, Random, 95% CI)	0.23 [-0.23, 0.69]
4.2 Stroke-survivor anxiety (dichotomised data)	3	227	Risk Ratio (M-H, Fixed, 95% CI)	1.54 [0.82, 2.88]
4.3 Stroke-survivor anxiety (HADS-A)	3	227	Mean Difference (IV, Fixed, 95% CI)	0.67 [-0.37, 1.71]
4.4 Stroke-survivor depression (dichotomised data)	5	361	Risk Ratio (M-H, Fixed, 95% CI)	1.12 [0.84, 1.50]

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
4.5 Stroke-survivor depression (HADS-D)	3	227	Mean Difference (IV, Fixed, 95% CI)	0.39 [-0.61, 1.38]
4.6 Stroke-survivor quality of life (COOP charts: quality of life)	2	198	Mean Difference (IV, Random, 95% CI)	0.04 [-0.45, 0.53]
4.7 Stroke-survivor satisfaction with information about the causes and nature of stroke	2	143	Risk Ratio (M-H, Fixed, 95% CI)	0.63 [0.34, 1.18]
4.8 Stroke-survivor satisfaction with information about allowances and services	1	57	Risk Ratio (M-H, Fixed, 95% CI)	1.76 [0.61, 5.05]
4.9 Stroke-survivor psychological distress (SMD)	3	264	Std. Mean Difference (IV, Fixed, 95% CI)	0.15 [-0.09, 0.39]
4.10 Stroke-survivor modification of health related behaviours: summary of results	3		Other data	No numeric data
4.11 Stroke-survivor independence in activities of daily living (Barthel Index, 0-20)	2	100	Mean Difference (IV, Fixed, 95% CI)	-0.80 [-2.83, 1.23]
4.12 Stroke-survivor social activities: summary of results	1		Other data	No numeric data
4.13 Stroke-survivor perceived health status (COOP charts: overall health)	2	198	Mean Difference (IV, Fixed, 95% CI)	-0.13 [-0.45, 0.19]
4.14 Stroke-survivor perceived health status (SIS): summary of results	1		Other data	No numeric data
4.15 Stroke-survivor deaths	3	331	Peto Odds Ratio (Peto, Fixed, 95% CI)	0.80 [0.34, 1.86]

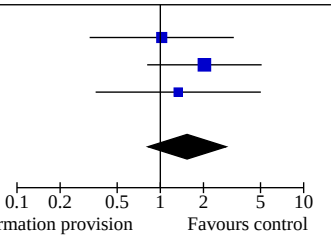
Analysis 4.1. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 1: Stroke-survivor knowledge of stroke and stroke services (SMD)



Analysis 4.2. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 2: Stroke-survivor anxiety (dichotomised data)

Study or Subgroup	Passive information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Downes 1993	5	22	4	18	32.1%	1.02 [0.32 , 3.26]
Hoffmann 2007	12	66	6	67	43.5%	2.03 [0.81 , 5.09]
Mant 1998	5	30	3	24	24.4%	1.33 [0.35 , 5.03]
Total (95% CI)		**118**		**109**	**100.0%**	**1.54 [0.82 , 2.88]**
Total events:	22		13			

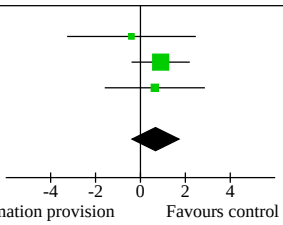
Heterogeneity: Chi² = 0.87, df = 2 (P = 0.65); I² = 0%
Test for overall effect: Z = 1.34 (P = 0.18)
Test for subgroup differences: Not applicable



Analysis 4.3. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 3: Stroke-survivor anxiety (HADS-A)

Study or Subgroup	Passive information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Fixed, 95% CI
Downes 1993	6.7	4.6	22	7.1	4.6	18	13.3%	-0.40 [-3.27 , 2.47]
Hoffmann 2007	6.3	4.1	66	5.4	3.5	67	64.8%	0.90 [-0.40 , 2.20]
Mant 1998	5.27	4.6	30	4.63	3.76	24	21.9%	0.64 [-1.59 , 2.87]
Total (95% CI)			**118**			**109**	**100.0%**	**0.67 [-0.37 , 1.71]**

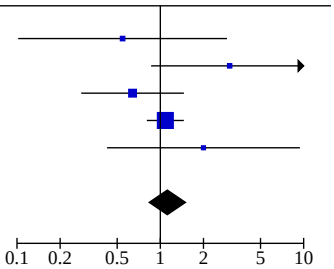
Heterogeneity: Chi² = 0.66, df = 2 (P = 0.72); I² = 0%
Test for overall effect: Z = 1.26 (P = 0.21)
Test for subgroup differences: Not applicable



Analysis 4.4. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 4: Stroke-survivor depression (dichotomised data)

Study or Subgroup	Passive information provision Events	Total	Control Events	Total	Weight	Risk Ratio M-H, Fixed, 95% CI
Downes 1993	2	22	3	18	7.2%	0.55 [0.10 , 2.92]
Hoffmann 2007	9	66	3	67	6.5%	3.05 [0.86 , 10.75]
Jones 2018	6	23	11	27	22.1%	0.64 [0.28 , 1.46]
Lowe 2007	31	44	26	40	59.4%	1.08 [0.81 , 1.46]
Mant 1998	5	30	2	24	4.8%	2.00 [0.42 , 9.42]
Total (95% CI)		**185**		**176**	**100.0%**	**1.12 [0.84 , 1.50]**
Total events:	53		45			

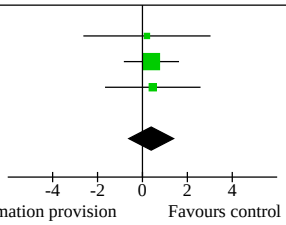
Heterogeneity: Chi² = 5.47, df = 4 (P = 0.24); I² = 27%
Test for overall effect: Z = 0.76 (P = 0.45)
Test for subgroup differences: Not applicable



Analysis 4.5. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 5: Stroke-survivor depression (HADS-D)

Study or Subgroup	Passive information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Fixed, 95% CI
Downes 1993	6.5	4.6	22	6.3	4.5	18	12.4%	0.20 [-2.63 , 3.03]
Hoffmann 2007	5.4	4.2	66	5	2.9	67	65.7%	0.40 [-0.83 , 1.63]
Mant 1998	5.63	4.89	30	5.17	3.02	24	21.9%	0.46 [-1.67 , 2.59]
Total (95% CI)			**118**			**109**	**100.0%**	**0.39 [-0.61 , 1.38]**

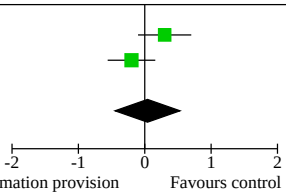
Heterogeneity: Chi² = 0.02, df = 2 (P = 0.99); I² = 0%
Test for overall effect: Z = 0.76 (P = 0.44)
Test for subgroup differences: Not applicable



Analysis 4.6. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 6: Stroke-survivor quality of life (COOP charts: quality of life)

Study or Subgroup	Passive information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Hoffmann 2007 (1)	-0.2	1.18	66	-0.5	1.18	67	48.3%	0.30 [-0.10 , 0.70]
Mant 1998	2.2	0.68	33	2.4	0.79	32	51.7%	-0.20 [-0.56 , 0.16]
Total (95% CI)			**99**			**99**	**100.0%**	**0.04 [-0.45 , 0.53]**

Heterogeneity: Tau² = 0.09; Chi² = 3.32, df = 1 (P = 0.07); I² = 70%
Test for overall effect: Z = 0.17 (P = 0.87)
Test for subgroup differences: Not applicable

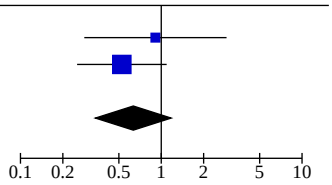


Footnotes
(1) Change from baseline

Analysis 4.7. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 7: Stroke-survivor satisfaction with information about the causes and nature of stroke

Study or Subgroup	Passive information provision Events	Total	Control Events	Total	Weight	Risk Ratio (Non-event) M-H, Fixed, 95% CI
Lowe 2007	39	44	35	40	28.1%	0.91 [0.28 , 2.91]
Mant 1998	25	33	14	26	71.9%	0.53 [0.25 , 1.09]
Total (95% CI)		**77**		**66**	**100.0%**	**0.63 [0.34 , 1.18]**
Total events:	64		49			

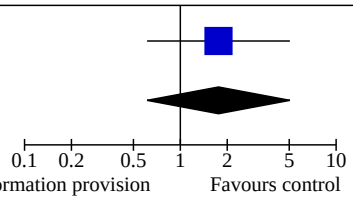
Heterogeneity: Chi² = 0.62, df = 1 (P = 0.43); I² = 0%
Test for overall effect: Z = 1.45 (P = 0.15)
Test for subgroup differences: Not applicable



Analysis 4.8. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 8: Stroke-survivor satisfaction with information about allowances and services

Study or Subgroup	Favours control Events	Total	Control Events	Total	Weight	Risk Ratio (Non-event) M-H, Fixed, 95% CI
Mant 1998	23	32	21	25	100.0%	1.76 [0.61 , 5.05]
Total (95% CI)		**32**		**25**	**100.0%**	**1.76 [0.61 , 5.05]**
Total events:	23		21			

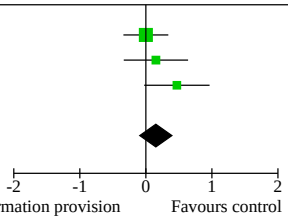
Heterogeneity: Not applicable
Test for overall effect: Z = 1.05 (P = 0.29)
Test for subgroup differences: Not applicable



Analysis 4.9. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 9: Stroke-survivor psychological distress (SMD)

Study or Subgroup	Passive information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Std. Mean Difference IV, Fixed, 95% CI
Hoffmann 2007 (1)	2.1	1.2	66	2.1	1.3	67	51.1%	0.00 [-0.34 , 0.34]
Mant 1998	2.4	1.41	33	2.2	1.17	32	24.9%	0.15 [-0.33 , 0.64]
O'Connell 2009	-76.88	17.42	28	-84.36	14.39	38	24.1%	0.47 [-0.03 , 0.96]
Total (95% CI)			**127**			**137**	**100.0%**	**0.15 [-0.09 , 0.39]**

Heterogeneity: Chi² = 2.35, df = 2 (P = 0.31); I² = 15%
Test for overall effect: Z = 1.22 (P = 0.22)
Test for subgroup differences: Not applicable



Footnotes
(1) Calculated mean at follow-up and baseline SD

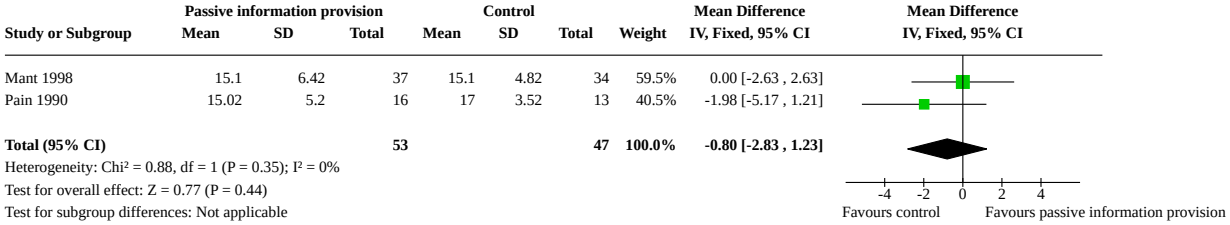
Analysis 4.10. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 10: Stroke-survivor modification of health related behaviours: summary of results

Stroke-survivor modification of health related behaviours: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Banet 1997	6 months	Education packet and shared medical record versus education packet only	Miller's Health Intention Scale Miller's Health Behaviour Scale 3 areas of compliance examined: smoking, diet and medication	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 24/number unclear, control 28/number unclear Smoking: no analysis done Follow-up variable comparisons between shared record and control groups: diet: F= 0.03, P = 0.85 medication: F=0.02, P = 0.87	
Lowe 2007	3 and 6 months	CareFile (29 page personalised information booklet) + discussion with research registrar versus usual information and follow up	Risk factor modification: blood pressure (SBP, DBP)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 44/50, control 40/50 Median (mmHg) (interquartile range)	

				Before intervention, SBP: intervention 137 (124 to 150), control 130 (116 to 149) Before intervention, DBP: intervention 77 (70 to 83), control 71 (65 to 80) 3 months, SBP: intervention 140 (130 to 160), control 140 (124 to 150) 3 months, DBP: intervention 80 (70 to 85), control 76 (70 to 82) 6 months, SBP: intervention 149 (130 to 159), control 138 (130 to 150) 6 months, DBP: intervention 80 (70 to 84), control 70 (70 to 80)
Maasland 2007	12 weeks	Health education + computer programme versus health education alone	Risk factor modification: Blood pressure (SBP, DBP), Serum cholesterol, Serum Triglyceride, Serum LDL, Body mass index, Number of cigarettes/smoker, Number of alcoholic drinks/drinker	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 30/33, control 27/32 Change from baseline to 12 weeks (intervention effect and 95% CI) SBP: intervention -8.4, control -6.9 (1.5 95% CI -7.7 to 10.8) DBP: intervention -5.4, control -6.2 (-0.8 (95% CI -6.1 to 4.5) serum cholesterol: intervention -1.1, control -1.6 (-0.5 95% CI -1.2 to 0.2) serum triglyceride: intervention -0.6, control -0.6 (0.0 95% CI -0.7 to 0.7) serum LDL: intervention -1.2, control -1.4 (-0.2 95% CI -1.0 to 0.5) body mass index: intervention 0.0, control 0.3 (0.3 95% CI -0.3 to 0.8) number of cigarettes/smoker: intervention -20.1, control -13.2 (6.9 95% CI -16.2 to 30.1) number of alcoholic drinks/drinker: intervention -0.8, control -0.6 (0.2 95% CI -0.6 to 1.0)

Analysis 4.11. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 11: Stroke-survivor independence in activities of daily living (Barthel Index, 0-20)



Analysis 4.12. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 12: Stroke-survivor social activities: summary of results

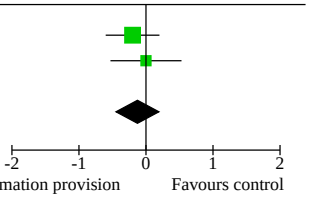
Stroke-survivor social activities: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Pain 1990	3 months	Individualised information booklet + advice and information versus advice and information	Frenchay Activities Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 16/21, control 13/15 Mean Score Discharge (baseline): intervention 21.4 (SD 10.6), control 23.8 (SD 7.5) 3 months: intervention 12.5 (SD 8.8), control 13.9 (SD 10.4)	

Analysis 4.13. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 13: Stroke-survivor perceived health status (COOP charts: overall health)

Study or Subgroup	Passive information provision Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Fixed, 95% CI
Hoffmann 2007 (1)	-0.35	1.18	66	-0.15	1.18	67	63.6%	-0.20 [-0.60 , 0.20]
Mant 1998	3.2	1.11	33	3.2	1.07	32	36.4%	0.00 [-0.53 , 0.53]
Total (95% CI)			**99**			**99**	**100.0%**	**-0.13 [-0.45 , 0.19]**

Heterogeneity: Chi² = 0.35, df = 1 (P = 0.56); I² = 0%
Test for overall effect: Z = 0.78 (P = 0.44)
Test for subgroup differences: Not applicable



Footnotes
(1) Change from baseline

Analysis 4.14. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 14: Stroke-survivor perceived health status (SIS): summary of results

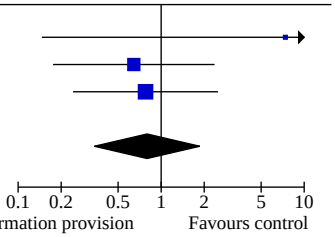
Stroke-survivor perceived health status (SIS): summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
O'Connell 2009	4 weeks and 4 months	Patient-held record of information plus usual discharge information versus usual discharge information	Stroke Impact Scale (SIS)	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 28/46, control 38/47. SIS recovery subscale (4 months): mean difference -6.29 (95% CI -17.77 to 5.19)	

Analysis 4.15. Comparison 4: Passive information provision vs control for stroke survivors, Outcome 15: Stroke-survivor deaths

Study or Subgroup	Passive information provision Events	Total	Control Events	Total	Weight	Peto Odds Ratio Peto, Fixed, 95% CI
Hoffmann 2007	1	69	0	69	4.7%	7.39 [0.15 , 372.38]
Lowe 2007	4	50	6	50	42.5%	0.64 [0.18 , 2.36]
Mant 1998	6	48	7	45	52.8%	0.78 [0.24 , 2.50]
Total (95% CI)		**167**		**164**	**100.0%**	**0.80 [0.34 , 1.86]**
Total events:	11		13			

Heterogeneity: Chi² = 1.34, df = 2 (P = 0.51); I² = 0%
Test for overall effect: Z = 0.52 (P = 0.60)
Test for subgroup differences: Not applicable



Comparison 5. Passive information provision vs control for stroke carers

Outcome or subgroup title	No. of studies	No. of participants	Statistical method	Effect size
5.1 Carer knowledge of stroke and stroke services: summary of results	1		Other data	No numeric data
5.2 Carer anxiety: summary of results	1		Other data	No numeric data
5.3 Carer depression: summary of results	2		Other data	No numeric data
5.4 Carer satisfaction with information about allowances and services: summary of results	1		Other data	No numeric data
5.5 Carer psychological distress (SF-36): summary of results	1		Other data	No numeric data
5.6 Carer burden: summary of results	2		Other data	No numeric data
5.7 Carer perceived health status (SF-36): summary of results	1		Other data	No numeric data

Analysis 5.1. Comparison 5: Passive information provision vs control for stroke carers, Outcome 1: Carer knowledge of stroke and stroke services: summary of results

Carer knowledge of stroke and stroke services: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Mant 1998	6 months	Information pack versus no intervention	Knowledge of stroke	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 19/32, control 14/24. Knowledge of stroke at 6 months: mean (standard deviation) Intervention: 8.42 (1.95) Control: 7.86 (2.03) Standardised mean difference: 0.28 (95% CI -0.42 to 0.97).	

Analysis 5.2. Comparison 5: Passive information provision vs control for stroke carers, Outcome 2: Carer anxiety: summary of results

Carer anxiety: summary of results

Study	Follow up	Comparison	Outcome measure	Results	Notes
Downes 1993	6 months	Information pack versus no intervention	anxiety subscale of the Hospital Anxiety and Depression Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 22/?35, control 18/?35 Mean score (SD) Baseline: intervention 8.3 (6.0), control 8.9 (3.8) 6 months: intervention 7.4 (5.0), control 7.7 (4.5); MD -0.3 (95% CI -3.25 to 2.65)	?: It is unclear how many participants were initially allocated to each arm. 105 participants were allocated to three arms. If allocation was equal this would equate to 35 participants in each of the arms (only two arms are included in this review).

Analysis 5.3. Comparison 5: Passive information provision vs control for stroke carers, Outcome 3: Carer depression: summary of results

Carer depression: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Downes 1993	6 months	Information pack versus no intervention	depression subscale of the Hospital Anxiety and Depression Scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 22/?35, control 18/?35 Mean (SD) Baseline: intervention 6.3 (4.0), control 5.4 (3.7) 6 months: intervention 5.8 (5.2), control 5.1 (3.2); MD 0.7 (95% CI -1.93 to 3.33)	?: It is unclear how many participants were initially allocated to each arm. 105 participants were allocated to three arms. If allocation was equal this would equate to 35 participants in each of the arms (only two arms are included in this review).
Jones 2018	2 months	Instructional and educational DVD versus usual care	Center for Epidemiologic Studies Depression Scale	Insufficient information provided	

Analysis 5.4. Comparison 5: Passive information provision vs control for stroke carers, Outcome 4: Carer satisfaction with information about allowances and services: summary of results

Carer satisfaction with information about allowances and services: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Mant 1998	6 months	Information pack versus no intervention	Single question about satisfaction with information about allowances and services from Pound scale	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 27/32, control 20/24. 19/27 participants in the passive information provision group and 16/20 participants in the control group were satisfied (answered yes). OR 0.6 (95% CI 0.2 to 1.6)	

				RR (non-satisfaction) 1.48 (95% CI 0.52 to 4.24).	

Analysis 5.5. Comparison 5: Passive information provision vs control for stroke carers, Outcome 5: Carer psychological distress (SF-36): summary of results

Carer psychological distress (SF-36): summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Mant 1998	6 month	Information pack versus no intervention	SF-36	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 28/32, control 21/24. SF-36 mental health subscale at 6 months Mean difference: 10.74 (95% CI -1.86 to 23.34)	

Analysis 5.6. Comparison 5: Passive information provision vs control for stroke carers, Outcome 6: Carer burden: summary of results

Carer burden: summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Jones 2018	2 months	Instructional and educational DVD versus usual care	Caregiver Strain Index	Insufficient information provided	
Mant 1998	6 months	Information pack versus no intervention	Caregiver Strain Index	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 27/32, control 19/24 Mean score: intervention 3.9 (SD 3.7), control 4.1 (SD 2.74)	

Analysis 5.7. Comparison 5: Passive information provision vs control for stroke carers, Outcome 7: Carer perceived health status (SF-36): summary of results

Carer perceived health status (SF-36): summary of results

Study	Follow-up	Comparison	Outcome measure	Results	Notes
Mant 1998	6 months	Information pack versus no intervention	SF-36	Number of participants with outcome data available at the end of scheduled follow-up/number of participants in group at outset of the trial: intervention 28/32, control 21/24. SF-36 general health subscale at 6 months Mean difference: -5.68 (95% CI -19.50 to 8.14)	

ADDITIONAL TABLES

Table 1. Mood scale cut-off scores for dichotomisation

Scale and reference	Non-disorder scores	Disorder (case) scores
Center for Epidemiological Studies Depression scale (CES-D) (Radloff 1977)	0 to 15	16 to 60
General Health Questionnaire-28 (Goldberg 1979)	0 to 4	5 to 28
General Health Questionnaire-30 (Goldberg 1988)	0 to 4	5 to 30
Geriatric Depression Scale (short form) (Sheikh 1986)	0 to 5	6 to 15
Hospital Anxiety and Depression Scale: anxiety (Zigmond 1983)	0 to 10	11 to 21
Hospital Anxiety and Depression Scale: depression (Zigmond 1983)	0 to 10	11 to 21

Table 2. Intracluster correlation coefficients (ICCs) used in this review

Participant	Outcome	Measure	ICC
Stroke survivor	Anxiety	HADS-A	0.000
Stroke survivor	Depression	HADS-D	0.001
Stroke survivor	Psychological distress	SIS emotions	0.000
Stroke survivor	Social activities	NEADL	0.015
Carer	Anxiety	HADS-A	0.018
Carer	Depression	HADS-D	0.010
Carer	Burden	CBS	0.032
Carer	Social activities	FAI	0.000

All ICCs were reported by Forster 2013 for ordinal scores.
CBS: Caregiver Burden Scale
FAI: Frenchay Activities Index
HADS-A: Hospital Anxiety and Depression Scale anxiety subscale
HADS-D: Hospital Anxiety and Depression Scale depression subscale
NEADL: Nottingham Extended Activities of Daily Living scale
SIS: Stroke Impact Scale

Table 3. Rules of thumb for standardised mean differences (SMDs)

Category	Lower boundary (g ≥)	Upper boundary (g <)
Very small	0.01	0.2
Small	0.2	0.5
Moderate	0.5	0.8

Table 3. Rules of thumb for standardised mean differences (SMDs) *(Continued)*

Large	0.8	1.2
Very large	1.2	2.0
Huge	2.0	-

Table 4. Summary of key characteristics of included studies

Study ID	Setting	Number of stroke survivors randomised	Number of carers randomised	Participant age (years): mean (SD)	Participant gender (% female)	Intervention category	Phase post-stroke (subgroups)
Banet 1997	USA	58	-	?	53.8%	Passive	Acute
Boden-Albala 2015	USA	1193	-	63 (15)	50%	Active	Acute
Chinchai 2010	Thailand	60	60	Details in Characteristics of included studies	Stroke survivors: 43.5% Carers: 50%	Active	Chronic
Chiu 2008	Taiwan	160	-	Intervention: 66 (SD ?) Control: 65 (SD ?)	50%	Active	Chronic
Deyhoul 2018	Iran	118	118	Stroke survivors: 67.0 (11.5) Carers: 40.8 (11.3)	Stroke survivors: 41% Carers: 64%	Active	Acute
Dharmakulaseelan 2019	Canada	50	-	68.9 (11.5)	37.5%	Passive	Chronic
Downes 1993	UK	105	105	Details in Characteristics of included studies	Stroke survivors: 49.5% Carers: 72.6%	Passive	Subacute
Draper 2007	Australia	-	39	Stroke survivors: 69 (10) Carers: 62 (13)	?	Active	Subacute
Eames 2013	Australia	77	61	Stroke survivors: 61 (15) Carers: 55 (13)	Stroke survivors: 43.9% Carers: 62.3%	Active	Acute
Ellis 2005	UK	205	-	65 (SD ?)	48%	Active	Subacute
Evans 1988	USA	140	140	Stroke survivors:	Stroke survivors: 5.5%	Active	Acute

Table 4. Summary of key characteristics of included studies *(Continued)*

				62.9 (9.9) Carers: 49.7 (15.2)	Carers: 90.6%		
Forster 2013	UK	928	928	Stroke survivors: 71.2 (12.5) Carers: 60.9 (14.3)	Stroke survivors: 44% Carers: 78.5%	Active	Acute
Frank 2000	UK	41	-	64 (13)	48.5%	Active	Chronic
Hekmatpou 2019	Iran	-	100	46.8 (SD ?)	63%	Active	Acute
Hoffmann 2007	Australia	138	-	68 (15)	45%	Passive	Acute
Johnson 2000	USA	41	-	64 (SD ?)	56%	Active	Chronic
Johnston 2007	UK	203	172	Stroke survivors: 69 (12) Carers: 62 (14)	Stroke survivors: 39% Carers: 65%	Active	Subacute
Jones 2018	Multi-country	68	41	Stroke survivors: 63.5 (12.47) Carers: ?	Stroke survivors: 28.8% Carers: 51.2%	Passive	Chronic
Kalra 2004	UK	300	300	? (Median age of stroke survivors: 76)	Stroke survivors: 46.5%	Active	Acute
Kamal 2016	Pakistan	155	155	Stroke survivors: 60.2 (13.2) Carers: 39.2 (12.9)	Stroke survivors: 32.6%	Active	Acute
Karimi 2018	Iran	70	70	Stroke survivors: 62.0 (10.5) Carers: 38.1 (11.1)	Stroke survivors: 52.9% Carers: 65.7%	Active	Acute
Kim 2013	South Korea	36	36	Stroke survivors: 65.7 (7.5) Carers: 53.6 (13.6)	Stroke survivors: 36% Carers: ?	Active	Subacute
Kuo 2015	Taiwan	100	100	Stroke survivors: 76 (12)	Stroke survivors: 43%	Active	?

Table 4. Summary of key characteristics of included studies *(Continued)*

				Carers: 53 (14)	Carers: 63%		
Larson 2005	Sweden	-	100	Intervention: 68 (10) Control: 67 (10)	80%	Active	Subacute
Lomer 1987	UK	48[a]	44[a]	?	?	Passive	Acute
Lowe 2007	UK	100	-	? (Median age: Intervention: 68 Control: 73)	40%	Passive	Acute
Maasland 2007	Netherlands	65	-	64 (12)	40%	Passive	Subacute
Mant 1998	UK	93	56	Stroke survivors: 73 (11)	Stroke survivors: 35% Carers: ?	Passive	Acute
Mudzi 2012	South Africa	200	200	Stroke survivors: 53 (11) Carers: 40 (14)	Stroke survivors: 56.5% Carers: 70%	Active	Acute
O'Connell 2009	Australia	97	-	73 (SD ?)	50%	Passive	Acute
Pain 1990	UK	36	36	?	Survivors: 30.6% Carers: ?	Passive	Subacute
Rodgers 1999	UK	204	176	Stroke survivors: ? (Median: Intervention: 74 Control: 76) Carers: ? (Median: Intervention: 58 Control: 60)	Stroke survivors: 52.5% Carers: 68.5%	Active	Acute
Smith 2004	UK	170	97	Stroke survivors: ? (Median: Intervention: 75 Control: 74)	Stroke survivors: 49% Carers: 57.7%	Active	Acute

Table 4. Summary of key characteristics of included studies *(Continued)*

							Carers: ? (Median: Intervention: 65 Control: 67)

? Insufficient information reported; SD: standard deviation

[a]Numbers unclear; report states that 73 stroke incidents were assessed. It appears that knowledge of 48 stroke survivors and 44 (19 + 25) carers (comprising 19 of the 48 stroke survivors' carers plus 25 carers of stroke survivors who did not complete the questionnaire) was assessed across 73 (48 + 25) incidents.

APPENDICES

Appendix 1. Cochrane search strategy

#1 MeSH descriptor: [Patient Education as Topic] this term only
#2 MeSH descriptor: [Consumer Health Information] explode all trees
#3 MeSH descriptor: [Access to Information] this term only
#4 MeSH descriptor: [Information Dissemination] this term only
#5 MeSH descriptor: [Health Education] this term only
#6 MeSH descriptor: [Health Promotion] this term only
#7 MeSH descriptor: [Health Knowledge, Attitudes, Practice] this term only
#8 MeSH descriptor: [Patient Medication Knowledge] this term only
#9 MeSH descriptor: [Counseling] this term only
#10 MeSH descriptor: [Patient Participation] explode all trees
#11 MeSH descriptor: [Patient Compliance] explode all trees
#12 MeSH descriptor: [Patient Satisfaction] explode all trees
#13 MeSH descriptor: [Telephone] this term only
#14 MeSH descriptor: [Cell Phone] explode all trees
#15 MeSH descriptor: [Pamphlets] this term only
#16 MeSH descriptor: [Patient Education Handout] this term only
#17 MeSH descriptor: [Books] this term only
#18 MeSH descriptor: [Manuals as Topic] this term only
#19 MeSH descriptor: [Teaching Materials] this term only
#20 MeSH descriptor: [Audiovisual Aids] this term only
#21 MeSH descriptor: [Computer-Assisted Instruction] this term only
#22 MeSH descriptor: [Multimedia] this term only
#23 MeSH descriptor: [Optical Storage Devices] explode all trees
#24 MeSH descriptor: [Tape Recording] this term only
#25 MeSH descriptor: [Mobile Applications] this term only
#26 MeSH descriptor: [Internet] explode all trees
#27 MeSH descriptor: [Electronic Mail] this term only
#28 MeSH descriptor: [Social Networking] this term only
#29 MeSH descriptor: [Health Communication] this term only
#30 MeSH descriptor: [Information Literacy] explode all trees
#31 MeSH descriptor: [Marketing of Health Services] this term only
#32 MeSH descriptor: [Caregivers] this term only and with qualifier(s): [education - ED]
#33 MeSH descriptor: [Communication Barriers] explode all trees
#34 MeSH descriptor: [Video Recording] explode all trees
#35 (patient* or inpatient* or outpatient* or consumer* or carer* or "care giver*" or caregiver* or family or families) near/5 (education* or information* or support* or knowledge or counsel* or lecture* or teach*):ti,ab,kw (Word variations have been searched)
#36 (patient* or inpatient* or outpatient* or carer* or "care giver*" or caregiver* or family or families) near/5 (book* or leaflet* or pack* or video* or tape* or phone* or telephone* or manual* or advice* or audiovisual or "audio visual"):ti,ab,kw (Word variations have been searched)
#37 (education* or information* or material* or resource*) near/5 (book* or leaflet* or pack* or video* or tape* or phone* or telephone* or manual* or advice* or audiovisual or "audio visual"):ti,ab,kw (Word variations have been searched)
#38 (education* or information*) near/5 (program* or intervention* or material* or resource* or provision or provid* or session* or consultation* or class or classes or discussion* or meeting*):ti,ab,kw (Word variations have been searched)
#39 patient near/5 (participat* or complian* or satisf*):ti,ab,kw (Word variations have been searched)
#40 (doctor* or nurse* or professional*) near/5 (patient* communicat* or inpatient* communicat* or outpatient* communicat* or carer* communicat* or care giver* communicat* or caregiver* communicat* or family communicat* or families communicat*)
#41 (remote* or distanc* or distant or audio or "audio-visual" or audiovisual or "audio visual" or telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or electronic or smartphone* or email or "e-mail" or "e mail") near/3 (consult* or communicat* or assess*):ti,ab,kw (Word variations have been searched)
#42 (((behav* near/3 chang*) or (problem* near/3 solv*) or (goal* near/3 setting) or (decision* near/3 mak*) or coping) near/5 (patient* or consumer* or client*)):ti,ab,kw (Word variations have been searched)
#43 ((patient* or consumer* or client*) near/5 (educat* or participat* or behaviour* or behavior* or compliance or centered)):ti,ab,kw (Word variations have been searched)
#44 (("self care" or "self-care" or "self manage*" or "self-manage*" or "self efficacy" or "self-efficacy" or "self monitor*" or "self-monitor*" or "self-help" or "self help") near/5 (device* or tool* or technolog*)):ti,ab,kw (Word variations have been searched)
#45 ((rehabilitation or therap* or treatment or communication or consultation) near/5 (telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or email)):ti,ab,kw (Word variations have been searched)

#46 ((cell* or smart* or mobile or android or internet or web) near/3 (comput* or device or app* or phone)):ti,ab,kw (Word variations have been searched)
#47 (smartphone or "text-messag*" or "text message" or (tablet near/3 (device* or comput*))):ti,ab,kw (Word variations have been searched)
#48 {or #1-#47}
#49 MeSH descriptor: [Cerebrovascular Disorders] this term only
#50 MeSH descriptor: [Basal Ganglia Cerebrovascular Disease] explode all trees
#51 MeSH descriptor: [Brain Ischemia] explode all trees
#52 MeSH descriptor: [Carotid Artery Diseases] explode all trees
#53 MeSH descriptor: [Cerebrovascular Trauma] explode all trees
#54 MeSH descriptor: [Intracranial Arterial Diseases] explode all trees
#55 MeSH descriptor: [Intracranial Arteriovenous Malformations] explode all trees
#56 MeSH descriptor: [Intracranial Embolism and Thrombosis] explode all trees
#57 MeSH descriptor: [Intracranial Hemorrhages] explode all trees
#58 MeSH descriptor: [Stroke] this term only
#59 MeSH descriptor: [Brain Infarction] explode all trees
#60 MeSH descriptor: [Stroke, Lacunar] this term only
#61 MeSH descriptor: [Vasospasm, Intracranial] this term only
#62 MeSH descriptor: [Vertebral Artery Dissection] this term only
#63 MeSH descriptor: [Hypoxia, Brain] explode all trees
#64 stroke* or "post stroke" or poststroke or "post-stroke" or apoplex* or "cerebral vasc*" or cerebrovasc* or cva or SAH:ti,ab,kw (Word variations have been searched)
#65 ((brain or cerebr* or cerebell* or vertebrobasil* or hemispher* or intracran* or intracerebral or infratentorial or supratentorial or "middle cerebr*" or mca* or "anterior circulation" or "basilar artery" or "vertebral artery") near/5 (ischemi* or ischaemi* or infarct* or thrombo* or emboli* or occlus* or hypoxi*)):ti,ab,kw (Word variations have been searched)
#66 ((brain* or cerebr* or cerebell* or intracerebral or intracran* or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli* or putaminal or putamen or posterior fossa or hemispher* or subarachnoid) near/5 (haemorrhag* or hemorrhag* or hematoma* or haematoma or bleed*)):ti,ab,kw (Word variations have been searched)
#67 MeSH descriptor: [Hemiplegia] explode all trees
#68 MeSH descriptor: [Paresis] explode all trees
#69 MeSH descriptor: [Aphasia] explode all trees
#70 MeSH descriptor: [Gait Disorders, Neurologic] explode all trees
#71 MeSH descriptor: [Hemianopsia] this term only
#72 (hempar* or hemipleg* or paresis or paretic or aphasi* or dysphasi* or hemianopsia or hemianopia or transient isch* or "isch?emic attack*" or TIA or TIAs):ti,ab,kw (Word variations have been searched)
#73 {or #49-#72}
#74 #48 and #73 with Cochrane Library publication date Between Jan 2005 and May 2019

Appendix 2. MEDLINE search strategy

1. patient education as topic/
2. exp consumer health information/
3. access to information/
4. information dissemination/
5. health education/
6. health promotion/
7. health knowledge, attitudes, practice/
8. patient medication knowledge/
9. counseling/
10. exp patient participation/
11. exp patient compliance/
12. exp patient satisfaction/
13. telephone/
14. exp Cell Phones/
15. pamphlets/
16. patient education handout/
17. books/
18. manuals as topic/
19. teaching materials/

20.audiovisual aids/
21.computer-assisted instruction/
22.multimedia/
23.exp optical storage devices/
24.exp Tape Recording/
25.Mobile Applications/
26.exp Internet/
27.Electronic Mail/
28.Social Networking/
29.Health Communication/
30.exp information literacy/
31."Marketing of Health Services"/
32.Caregivers/ed [Education]
33.exp communication barriers/
34.(((behav$ adj3 chang$) or (problem$ adj3 solv$) or (goal$ adj3 setting) or (decision$ adj3 mak$) or coping) adj5 (patient$ or consumer$ or client$)).tw.
35.((patient$ or inpatient$ or outpatient$ or consumer$ or carer$ or care giver$ or caregiver$ or family or families) adj5 (education$ or information$ or support$ or knowledge or counsel$ or lecture$ or teach$)).tw.
36.((patient$ or inpatient$ or outpatient$ or carer$ or care giver$ or caregiver$ or family or families) adj5 (book$ or leaflet$ or pack$ or video$ or tape$ or phone$ or telephone$ or manual$ or advice$ or audiovisual or audio visual)).tw.
37.((education$ or information$ or material$ or resource$) adj5 (book$ or leaflet$ or pack$ or video$ or tape$ or phone$ or telephone$ or manual$ or advice$ or audiovisual or audio visual)).tw.
38.((education$ or information$) adj5 (program$ or intervention$ or material$ or resource$ or provision or provid$ or session$ or consultation$ or class or classes or discussion$ or meeting$)).tw.
39.(patient adj5 (participat$ or complian$ or satisf$)).tw.
40.((doctor$ or nurse$ or professional$) adj5 (patient$ or inpatient$ or outpatient$ or carer$ or care giver$ or caregiver$ or family or families) adj5 communicat$).tw.
41.((remote$ or distanc$ or distant or audio or audio-visual or audiovisual or telephone$ or phone$ or video$ or internet$ or computer$ or sensor$ or modem or webcam or website$ or electronic or smartphone$ or email or e-mail) adj3 (consult$ or communicat$ or assess$)).tw.
42.((patient$ or consumer$ or client$) adj5 (educat$ or participat$ or behaviour$ or behavior$ or compliance or centered)).tw.
43.((self care or self-care or self manage* or self-manage* or self efficacy or self-efficacy or self monitor$ or self-monitor$ or self-help or self help) adj5 (device* or tool* or technolog*)).tw.
44.((rehabilitation or therap$ or treatment or communication or consultation) adj5 (telephone$ or phone$ or video$ or internet$ or computer$ or sensor$ or modem or webcam or website$ or email)).tw.
45.((cell$ or smart$ or mobile or android or internet or web) adj3 (comput$ or device or app$ or phone)).tw.
46.(smartphone or text-messag$ or (tablet adj3 (device$ or comput$))).tw.
47.or/1-46 [INFORMATION PROVISION]
48.cerebrovascular disorders/
49.exp basal ganglia cerebrovascular disease/
50.exp brain ischemia/
51.exp carotid artery diseases/
52.exp cerebrovascular trauma/
53.exp intracranial arterial diseases/
54.exp intracranial arteriovenous malformations/
55.exp "intracranial embolism and thrombosis"/
56.exp intracranial hemorrhages/
57.stroke/
58.exp brain infarction/
59.stroke, lacunar/
60.vasospasm, intracranial/
61.vertebral artery dissection/
62.exp hypoxia, brain/
63.(stroke$ or post stroke or poststroke or post-stroke or apoplex$ or cerebral vasc$ or cerebrovasc$ or cva or SAH).tw.

64. ((brain or cerebr$ or cerebell$ or vertebrobasil$ or hemispher$ or intracran$ or intracerebral or infratentorial or supratentorial or middle cerebr$ or mca$ or anterior circulation or basilar artery or vertebral artery) adj5 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$ or hypoxi$)).tw.
65. ((brain$ or cerebr$ or cerebell$ or intracerebral or intracran$ or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli$ or putaminal or putamen or posterior fossa or hemispher$ or subarachnoid) adj5 (h?emorrhag$ or h?ematoma$ or bleed$)).tw.
66. exp hemiplegia/
67. exp paresis/
68. exp aphasia/
69. exp gait disorders, neurologic/
70. hemianopsia/
71. (hempar$ or hemipleg$ or paresis or paretic or aphasi$ or dysphasi$ or hemianopsia or hemianopia or transient isch$ or isch?emic attack$ or TIA or TIAs).tw.
72. or/48-71 [cochrane stroke group stroke terms BT 17.06.14]
73. Randomized Controlled Trials as Topic/
74. random allocation/
75. Controlled Clinical Trials as Topic/
76. control groups/
77. clinical trials as topic/
78. double-blind method/
79. single-blind method/
80. Placebos/
81. placebo effect/
82. cross-over studies/
83. randomized controlled trial.pt.
84. controlled clinical trial.pt.
85. clinical trial.pt.
86. (random$ or RCT or RCTs).tw.
87. (controlled adj5 (trial$ or stud$)).tw.
88. (clinical$ adj5 trial$).tw.
89. ((control or treatment or experiment$ or intervention) adj5 (group$ or subject$ or patient$)).tw.
90. (quasi-random$ or quasi random$ or pseudo-random$ or pseudo random$).tw.
91. ((control or experiment$ or conservative) adj5 (treatment or therapy or procedure or manage$)).tw.
92. ((singl$ or doubl$ or tripl$ or trebl$) adj5 (blind$ or mask$)).tw.
93. (cross-over or cross over or crossover).tw.
94. (placebo$ or sham).tw.
95. trial.ti.
96. (assign$ or allocat$).tw.
97. controls.tw.
98. or/73-97 [RCT filter from BT cochrane stroke group 17.6.14]
99. 47 and 72 and 98 [INFO PROVISION AND STROKE AND RCT FILTER]
100. exp animals/ not humans.sh.
101. 99 not 100 [INFO PROVISION AND STROKE AND RCT FILTER AND HUMAN ONLY STUDIES]
102. limit 101 to yr="2005 -Current"

Appendix 3. EMBASE search strategy

1. patient education/
2. patient information/
3. consumer health information/
4. access to information/
5. information dissemination/
6. health education/
7. health promotion/

8. information service/
9. medical information/
10. attitude to health/
11. knowledge/
12. patient counseling/
13. counseling/
14. caregiver support/
15. caregiver burden/
16. patient participation/
17. patient attitude/
18. exp patient compliance/
19. patient preference/
20. patient satisfaction/
21. teaching/
22. information literacy/
23. telephone/
24. exp mobile phone/
25. exp telephone interview/
26. internet/
27. blogging/
28. mobile application/
29. social media/
30. text messaging/
31. social network/
32. e-mail/
33. publication/
34. book/
35. audiovisual equipment/
36. multimedia/
37. exp optical disk/
38. video disk/
39. videorecorder/
40. videotape/
41. videorecording/
42. ((patient$ or inpatient$ or outpatient$ or consumer$ or carer$ or care giver$ or caregiver$ or family or families) adj5 (education$ or information$ or support$ or knowledge or counsel$ or lecture$ or teach$)).tw.
43. ((patient$ or inpatient$ or outpatient$ or carer$ or care giver$ or caregiver$ or family or families) adj5 (book$ or leaflet$ or pack$ or video$ or tape$ or phone$ or telephone$ or manual$ or advice$ or audiovisual or audio visual)).tw.
44. ((education$ or information$ or material$ or resource$) adj5 (book$ or leaflet$ or pack$ or video$ or tape$ or phone$ or telephone$ or manual$ or advice$ or audiovisual or audio visual)).tw.
45. ((education$ or information$) adj5 (program$ or intervention$ or material$ or resource$ or provision or provid$ or session$ or consultation$ or class or classes or discussion$ or meeting$)).tw.
46. (patient adj5 (participat$ or complian$ or satisf$)).tw.
47. ((doctor$ or nurse$ or professional$) adj5 (patient$ or inpatient$ or outpatient$ or carer$ or care giver$ or caregiver$ or family or families) adj5 communicat$).tw.
48. ((remote$ or distanc$ or distant or audio or audio-visual or audiovisual or telephone$ or phone$ or video$ or internet$ or computer $ or sensor$ or modem or webcam or website$ or electronic or smartphone$ or email or e-mail) adj3 (consult$ or communicat$ or assess$)).tw.
49. (((behav$ adj3 chang$) or (problem$ adj3 solv$) or (goal$ adj3 setting) or (decision$ adj3 mak$) or coping) adj5 (patient$ or consumer $ or client$)).tw.
50. ((patient$ or consumer$ or client$) adj5 (educat$ or participat$ or behaviour$ or behavior$ or compliance or centered)).tw.
51. ((self care or self-care or self manage* or self-manage* or self efficacy or self-efficacy or self monitor$ or self-monitor$ or self-help or self help) adj5 (device* or tool* or technolog*)).tw.

52. ((rehabilitation or therap$ or treatment or communication or consultation) adj5 (telephone$ or phone$ or video$ or internet$ or computer$ or sensor$ or modem or webcam or website$ or email)).tw.
53. ((cell$ or smart$ or mobile or android or internet or web) adj3 (comput$ or device or app$ or phone)).tw.
54. (smartphone or text-messag$ or (tablet adj3 (device$ or comput$))).tw.
55. communication barrier/
56. or/1-55 [INFORMATION PROVISION]
57. stroke/
58. cerebrovascular disease/
59. exp basal ganglion hemorrhage/
60. exp brain hematoma/
61. exp brain hemorrhage/
62. exp brain infarction/
63. exp brain ischemia/
64. exp carotid artery disease/
65. cerebral artery disease/
66. exp cerebrovascular accident/
67. exp cerebrovascular malformation/
68. exp intracranial aneurysm/
69. exp occlusive cerebrovascular disease/
70. stroke patient/
71. stroke unit/
72. (stroke$ or post stroke or poststroke or post-stroke or apoplex$ or cerebral vasc$ or cerebrovasc$ or cva or SAH).tw.
73. ((brain or cerebr$ or cerebell$ or vertebrobasil$ or hemispher$ or intracran$ or intracerebral or infratentorial or supratentorial or middle cerebr$ or mca$ or anterior circulation or basilar artery or vertebral artery) adj5 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$ or hypoxi$)).tw.
74. ((brain$ or cerebr$ or cerebell$ or intracerebral or intracran$ or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli$ or putaminal or putamen or posterior fossa or hemispher$ or subarachnoid) adj5 (h?emorrhag$ or h?ematoma$ or bleed$)).tw.
75. hemiplegia/
76. hemiparesis/
77. paresis/
78. aphasia/
79. exp neurologic gait disorder/
80. hemianopia/
81. homonymous hemianopia/
82. (hempar$ or hemipleg$ or paresis or paretic or aphasi$ or dysphasi$ or hemianopsia or hemianopia or transient isch$ or isch?emic attack$ or TIA or TIAs).tw.
83. or/57-82 [stroke terms]
84. Randomized Controlled Trial/
85. "randomized controlled trial (topic)"/
86. Randomization/
87. Controlled clinical trial/
88. "controlled clinical trial (topic)"/
89. control group/
90. controlled study/
91. clinical trial/
92. "clinical trial (topic)"/
93. Crossover Procedure/
94. Double Blind Procedure/
95. Single Blind Procedure/
96. triple blind procedure/
97. placebo/
98. placebo effect/

99. (random$ or RCT or RCTs).tw.
100. (controlled adj5 (trial$ or stud$)).tw.
101. (clinical$ adj5 trial$).tw.
102. ((control or treatment or experiment$ or intervention) adj5 (group$ or subject$ or patient$)).tw.
103. (quasi-random$ or quasi random$ or pseudo-random$ or pseudo random$).tw.
104. ((control or experiment$ or conservative) adj5 (treatment or therapy or procedure or manage$)).tw.
105. ((singl$ or doubl$ or tripl$ or trebl$) adj5 (blind$ or mask$)).tw.
106. (cross-over or cross over or crossover).tw.
107. (placebo$ or sham).tw.
108. trial.ti.
109. (assign$ or allocat$).tw.
110. controls.tw.
111. or/84-110 [RCT filter]
112. 56 and 83 and 111 [INFO PROVISION AND STROKE AND RCT FILTER]
113. (exp animals/ or exp invertebrate/ or animal experiment/ or animal model/ or animal tissue/ or animal cell/ or nonhuman/) not (human/ or normal human/ or human cell/)
114. 112 not 113 [INFO PROVISION AND STROKE AND RCT FILTER AND HUMAN ONLY]
115. limit 114 to yr="2005-Current"

Appendix 4. CINAHL search strategy

S1	(MH "Patient Education")
S2	(MH "Consumer Health Information")
S3	(MH "Access to Information")
S4	(MH "Health Education")
S5	(MH "Health Promotion")
S6	(MH "Attitude to Health")
S7	(MH "Counseling")
S8	(MH "Consumer Participation")
S9	(MH "Patient Compliance")
S10	(MH "Patient Satisfaction")
S11	(MH "Telephone")
S12	(MH "Wireless Communications")
S13	(MH "Pamphlets")
S14	(MH "Books")
S15	(MH "Teaching Materials")
S16	(MH "Multimedia")
S17	(MH "Optical Disks")

(Continued)

S18	(MH "Audiorecording")
S19	(MH "Videorecording")
S20	TI (patient* N5 education* or patient N5 information* or patient* N5 support* or patient* N5 knowledge or patient* N5 counsel* or patient* N5 lecture* or patient* N5 teach* or inpatient* N5 education* or inpatient* N5 information* or inpatient* N5 support* or inpatient* N5 knowledge or inpatient* N5 counsel* or inpatient* N5 lecture* or inpatient* N5 teach* or outpatient* N5 education* or outpatient* N5 information* or outpatient* N5 support* or outpatient* N5 knowledge or outpatient* N5 counsel* or outpatient N5 lecture* or outpatient* N5 teach* or consumer* N5 education* or consumer* N5 information* or consumer* N5 support* or consumer* N5 knowledge or consumer* N5 counsel* or consumer* N5 lecture* or consumer* N5 teach* or carer* N5 education* or carer* N5 information* or carer* N5 support* or carer* N5 knowledge or carer* N5 counsel* or carer* N5 lecture* or carer* N5 teach* or care giver* N5 education* or care giver* N5 information* or care giver* N5 care giver* or care giver* N5 knowledge or care giver* N5 counsel* or care giver* N5 lecture* or care giver* N5 teach* or caregiver* N5 education* or caregiver* N5 information* or caregiver* N5 caregiver* or caregiver* N5 knowledge or caregiver* N5 counsel* or caregiver* N5 lecture* or caregiver* N5 teach* or family N5 education* or family N5 information* or family N5 family or family N5 knowledge or family N5 counsel* or family N5 lecture* or family N5 teach* or families N5 education* or families N5 information* or families N5 families or families N5 knowledge or families N5 counsel* or families N5 lecture*) OR AB (patient* N5 education* or patient N5 information* or patient* N5 support* or patient* N5 knowledge or patient* N5 counsel* or patient* N5 lecture* or patient* N5 teach* or inpatient* N5 education* or inpatient* N5 information* or inpatient* N5 support* or inpatient* N5 knowledge or inpatient* N5 counsel* or inpatient* N5 lecture* or inpatient* N5 teach* or outpatient* N5 education* or outpatient* N5 information* or outpatient* N5 support* or outpatient* N5 knowledge or outpatient* N5 counsel* or outpatient N5 lecture* or outpatient* N5 teach* or consumer* N5 education* or consumer* N5 information* or consumer* N5 support* or consumer* N5 knowledge or consumer* N5 counsel* or consumer* N5 lecture* or consumer* N5 teach* or carer* N5 education* or carer* N5 information* or carer* N5 support* or carer* N5 knowledge or carer* N5 counsel* or carer* N5 lecture* or carer* N5 teach* or care giver* N5 education* or care giver* N5 information* or care giver* N5 care giver* or care giver* N5 knowledge or care giver* N5 counsel* or care giver* N5 lecture* or care giver* N5 teach* or caregiver* N5 education* or caregiver* N5 information* or caregiver* N5 caregiver* or caregiver* N5 knowledge or caregiver* N5 counsel* or caregiver* N5 lecture* or caregiver* N5 teach* or family N5 education* or family N5 information* or family N5 family or family N5 knowledge or family N5 counsel* or family N5 lecture* or family N5 teach* or families N5 education* or families N5 information* or families N5 families or families N5 knowledge or families N5 counsel* or families N5 lecture*)
S21	TI (patient* N5 book* or inpatient* N5 book* or outpatient* N5 book* or carer* N5 book* or “care giver*” N5 book* or caregiver* N5 book* or family N5 book* or families N5 book* or patient* N5 leaflet* or inpatient* N5 leaflet* or outpatient* N5 leaflet* or carer* N5 leaflet* or “care giver*” N5 leaflet* or caregiver* N5 leaflet* or family N5 leaflet* or families N5 leaflet* orpatient* N5 pack* or inpatient* N5 pack* or outpatient* N5 pack* or carer* N5 pack* or “care giver*” N5 pack* or caregiver* N5 pack* or family N5 pack* or families N5 pack* or patient* N5 video* or inpatient* N5 video* or outpatient* N5 video* or carer* N5 video* or “care giver*” N5 video* or caregiver* N5 video* or family N5 video* or families N5 video* patient* N5 tape* or inpatient* N5 tape* or outpatient* N5 tape* or carer* N5 tape* or “care giver*” N5 tape* or caregiver* N5 tape* or family N5 tape* or families N5 tape* or patient* N5 phone* or inpatient* N5 phone* or outpatient* N5 phone* or carer* N5 phone* or “care giver*” N5 phone* or caregiver* N5 phone* or family N5 phone* or families N5 phone* orpatient* N5 telephone* or inpatient* N5 telephone* or outpatient* N5 telephone* or carer* N5 telephone* or “care giver*” N5 telephone* or caregiver* N5 telephone* or family N5 telephone* or families N5 telephone* or patient* N5 manual* or inpatient* N5 manual* or outpatient* N5 manual* or carer* N5 manual* or “care giver*” N5 manual* or caregiver* N5 manual* or family N5 manual* or families N5 manual* or patient* N5 audiovisual or inpatient* N5 audiovisual or outpatient* N5 audiovisual or carer* N5 audiovisual or “care giver*” N5 audiovisual or caregiver* N5 audiovisual or family N5 audiovisual or families N5 audiovisual or patient* N5 "audio visual" or inpatient* N5 "audio visual" or outpatient* N5 "audio visual" or carer* N5 "audio visual" or “care giver*” N5 "audio visual" or caregiver* N5 "audio visual" or family N5 "audio visual" or families N5 "audio visual" or patient* N5 book* or inpatient* N5 book* or outpatient* N5 book* or carer* N5 book* or “care giver*” N5 book* or caregiver* N5 book* or family N5 book* or families N5 book* or

(Continued)

patient* N5 leaflet* or inpatient* N5 leaflet* or outpatient* N5 leaflet* or carer* N5 leaflet* or "care giver*" N5 leaflet* or caregiver* N5 leaflet* or family N5 leaflet* or families N5 leaflet* orpatient* N5 pack* or inpatient* N5 pack* or outpatient* N5 pack* or carer* N5 pack* or "care giver*" N5 pack* or caregiver* N5 pack* or family N5 pack* or families N5 pack* or patient* N5 video* or inpatient* N5 video* or outpatient* N5 video* or carer* N5 video* or "care giver*" N5 video* or caregiver* N5 video* or family N5 video* or families N5 video* patient* N5 tape* or inpatient* N5 tape* or outpatient* N5 tape* or carer* N5 tape* or "care giver*" N5 tape* or caregiver* N5 tape* or family N5 tape* or families N5 tape* or patient* N5 phone* or inpatient* N5 phone* or outpatient* N5 phone* or carer* N5 phone* or "care giver*" N5 phone* or caregiver* N5 phone* or family N5 phone* or families N5 phone* orpatient* N5 telephone* or inpatient* N5 telephone* or outpatient* N5 telephone* or carer* N5 telephone* or "care giver*" N5 telephone* or caregiver* N5 telephone* or family N5 telephone* or families N5 telephone* or patient* N5 manual* or inpatient* N5 manual* or outpatient* N5 manual* or carer* N5 manual* or "care giver*" N5 manual* or caregiver* N5 manual* or family N5 manual* or families N5 manual* or patient* N5 audiovisual or inpatient* N5 audiovisual or outpatient* N5 audiovisual or carer* N5 audiovisual or "care giver*" N5 audiovisual or caregiver* N5 audiovisual or family N5 audiovisual or families N5 audiovisual or patient* N5 "audio visual" or inpatient* N5 "audio visual" or outpatient* N5 "audio visual" or carer* N5 "audio visual" or "care giver*" N5 "audio visual" or caregiver* N5 "audio visual" or family N5 "audio visual" or families N5 "audio visual") OR AB (patient* N5 book* or inpatient* N5 book* or outpatient* N5 book* or carer* N5 book* or "care giver*" N5 book* or caregiver* N5 book* or family N5 book* or families N5 book* or patient* N5 leaflet* or inpatient* N5 leaflet* or outpatient* N5 leaflet* or carer* N5 leaflet* or "care giver*" N5 leaflet* or caregiver* N5 leaflet* or family N5 leaflet* or families N5 leaflet* orpatient* N5 pack* or inpatient* N5 pack* or outpatient* N5 pack* or carer* N5 pack* or "care giver*" N5 pack* or caregiver* N5 pack* or family N5 pack* or families N5 pack* or patient* N5 video* or inpatient* N5 video* or outpatient* N5 video* or carer* N5 video* or "care giver*" N5 video* or caregiver* N5 video* or family N5 video* or families N5 video* patient* N5 tape* or inpatient* N5 tape* or outpatient* N5 tape* or carer* N5 tape* or "care giver*" N5 tape* or caregiver* N5 tape* or family N5 tape* or families N5 tape* or patient* N5 phone* or inpatient* N5 phone* or outpatient* N5 phone* or carer* N5 phone* or "care giver*" N5 phone* or caregiver* N5 phone* or family N5 phone* or families N5 phone* orpatient* N5 telephone* or inpatient* N5 telephone* or outpatient* N5 telephone* or carer* N5 telephone* or "care giver*" N5 telephone* or caregiver* N5 telephone* or family N5 telephone* or families N5 telephone* or patient* N5 manual* or inpatient* N5 manual* or outpatient* N5 manual* or carer* N5 manual* or "care giver*" N5 manual* or caregiver* N5 manual* or family N5 manual* or families N5 manual* or patient* N5 audiovisual or inpatient* N5 audiovisual or outpatient* N5 audiovisual or carer* N5 audiovisual or "care giver*" N5 audiovisual or caregiver* N5 audiovisual or family N5 audiovisual or families N5 audiovisual or patient* N5 "audio visual" or inpatient* N5 "audio visual" or outpatient* N5 "audio visual" or carer* N5 "audio visual" or "care giver*" N5 "audio visual" or caregiver* N5 "audio visual" or family N5 "audio visual" or families N5 "audio visual") OR AB (patient* N5 book* or inpatient* N5 book* or outpatient* N5 book* or carer* N5 book* or "care giver*" N5 book* or caregiver* N5 book* or family N5 book* or families N5 book* or patient* N5 leaflet* or inpatient* N5 leaflet* or outpatient* N5 leaflet* or carer* N5 leaflet* or "care giver*" N5 leaflet* or caregiver* N5 leaflet* or family N5 leaflet* or families N5 leaflet* orpatient* N5 pack* or inpatient* N5 pack* or outpatient* N5 pack* or carer* N5 pack* or "care giver*" N5 pack* or caregiver* N5 pack* or family N5 pack* or families N5 pack* or patient* N5 video* or inpatient* N5 video* or outpatient* N5 video* or carer* N5 video* or "care giver*" N5 video* or caregiver* N5 video* or family N5 video* or families N5 video* patient* N5 tape* or inpatient* N5 tape* or outpatient* N5 tape* or carer* N5 tape* or "care giver*" N5 tape* or caregiver* N5 tape* or family N5 tape* or families N5 tape* or patient* N5 phone* or inpatient* N5 phone* or outpatient* N5 phone* or carer* N5 phone* or "care giver*" N5 phone* or caregiver* N5 phone* or family N5 phone* or families N5 phone* orpatient* N5 telephone* or inpatient* N5 telephone* or outpatient* N5 telephone* or carer* N5 telephone* or "care giver*" N5 telephone* or caregiver* N5 telephone* or family N5 telephone* or families N5 telephone* or patient* N5 manual* or inpatient* N5 manual* or outpatient* N5 manual* or carer* N5 manual* or "care giver*" N5 manual* or caregiver* N5 manual* or family N5 manual* or families N5 manual* or patient* N5 audiovisual or inpatient* N5 audiovisual or outpatient* N5 audiovisual or carer* N5 audiovisual or "care giver*" N5 audiovisual or caregiver* N5 audiovisual or family N5 audiovisual or families N5 audiovisual or patient* N5 "audio visual" or inpatient* N5 "audio visual" or outpatient* N5 "audio visual" or carer* N5 "audio visual" or "care giver*" N5 "audio visual" or caregiver* N5 "audio visual" or family N5 "audio visual" or families N5 "audio visual")

(Continued)

S22	TI (education* N5 book* or education* N5 leaflet* or education* N5 pack* or education* N5 video* or education* N5 tape* or education* N5 phone* or education* N5 telephone* or education* N5 manual* or education* N5 advice* or education* N5 education* N5 “audiovisual” or education N5 “audio visual” or information* N5 book* or information* N5 leaflet* or information* N5 pack* or information* N5 video* or information* N5 tape* or information* N5 phone* or information* N5 telephone* or information* N5 manual* or information* N5 advice* or information* N5 information* N5 “audiovisual” or education N5 “audio visual” material* N5 book* or information* N5 leaflet* or material* N5 pack* or material* N5 video* or material* N5 tape* or material* N5 phone* or material* N5 telephone* or material* N5 manual* or material* N5 advice* or material* N5 “audiovisual” or material* N5 “audio visual”resource* N5 book* or information* N5 leaflet* or resource* N5 pack* or resource* N5 video* or resource* N5 tape* or resource* N5 phone* or resource* N5 telephone* or resource* N5 manual* or resource* N5 advice* or resource* N5 “audiovisual” or resource* N5 “audio visual”) OR AB (resource* N5 book* or information* N5 leaflet* or resource* N5 pack* or resource* N5 video* or resource* N5 tape* or resource* N5 phone* or resource* N5 telephone* or resource* N5 manual* or resource* N5 advice* or resource* N5 “audiovisual” or resource* N5 “audio visual”)
S23	TI (education* N5 program* or education* N5 intervention* or education* N5 material* or education* N5 resource* or education* N5 provision* or education* N5 provid* or education* N5 session* or education* N5 consultation* or education* N5 class or education* N5 classes or education* N5 discussion* or education* N5 meeting* or information* N5 program* or information* N5 intervention* or information* N5 material* or information* N5 resource* or information* N5 provision* or information* N5 provid* or information* N5 session* or information* N5 consultation* or information* N5 class or information* N5 classes or information* N5 discussion* or information* N5 meeting*) OR AB (education* N5 program* or education* N5 intervention* or education* N5 material* or education* N5 resource* or education* N5 provision* or education* N5 provid* or education* N5 session* or education* N5 consultation* or education* N5 class or education* N5 classes or education* N5 discussion* or education* N5 meeting* or information* N5 program* or information* N5 intervention* or information* N5 material* or information* N5 resource* or information* N5 provision* or information* N5 provid* or information* N5 session* or information* N5 consultation* or information* N5 class or information* N5 classes or information* N5 discussion* or information* N5 meeting*)
S24	TI (patient N5 participat* or patient N5 complian* or patient N5 satisf*) OR AB (patient N5 participat* or patient N5 complian* or patient N5 satisf*)
S25	TI (doctor* N5 patient* communicat* or doctor N5 inpatient* communicat* or doctor N5 outpatient* communicat* or doctor* N5 carer* communicat* or doctor N5 “care giver*” communicat* or doctor N5 caregiver* communicat* or doctor N5 family communicat* or doctor N5 families communicat* or nurse* N5 patient* communicat* or nurse* N5 inpatient* communicat* or nurse* N5 outpatient* communicat* or nurse* N5 carer* communicat* or nurse* N5 “care giver*” communicat* or nurse* N5 caregiver* communicat* or nurse* N5 family communicat* or nurse* N5 families communicat* or professional* N5 patient* communicat* or professional* N5 inpatient* communicat* or professional* N5 outpatient* communicat* or professional* N5 carer* communicat* or professional* N5 “care giver*” communicat* or professional* N5 caregiver* communicat* or professional* N5 family communicat* or professional* N5 families communicat*) OR AB (doctor* N5 patient* communicat* or doctor N5 inpatient* communicat* or doctor N5 outpatient* communicat* or doctor* N5 carer* communicat* or doctor N5 “care giver*” communicat* or doctor N5 caregiver* communicat* or doctor N5 family communicat* or doctor N5 families communicat* or nurse* N5 patient* communicat* or nurse* N5 inpatient* communicat* or nurse* N5 outpatient* communicat* or nurse* N5 carer* communicat* or nurse* N5 “care giver*” communicat* or nurse* N5 caregiver* communicat* or nurse* N5 family communicat* or nurse* N5 families communicat* or professional* N5 patient* communicat* or professional* N5 inpatient* communicat* or professional* N5 outpatient* communicat* or professional* N5 carer* communicat* or professional* N5 “care giver*” communicat* or professional* N5 caregiver* communicat* or professional* N5 family communicat* or professional* N5 families communicat*)
S26	TI (hempar* or hemipleg* or paresis or paretic or aphasi* or dysphasi* or hemianopsia or hemianopia or transient isch* or isch?emic attack* or TIA or TIAs) OR AB (hempar* or hemipleg* or

(Continued)

	paresis or paretic or aphasi* or dysphasi* or hemianopsia or hemianopia or transient isch* or isch? emic attack* or TIA or TIAs)
S27	(MH "Computer Assisted Instruction")
S28	(MH "Internet")
S29	(MH "Caregivers/ED") OR (MH "Caregiver Support") OR (MH "Caregiver Burden")
S30	TI ((remote* or distanc* or distant or audio or audio-visual or "audio visual*" or audiovisual or telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or electronic or smartphone* or email or e-mail or "e mail") N3 (consult* or communicat* or assess*)) OR AB ((remote* or distanc* or distant or audio or audio-visual or "audio visual*" or audiovisual or telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or electronic or smartphone* or email or e-mail or "e mail") N3 (consult* or communicat* or assess*))
S31	TI ((behav* N3 chang* or problem* N3 solv* or goal* N3 setting or decision* N3 mak* or coping) N5 (patient* or consumer* or client*)) OR AB ((behav* N3 chang* or problem* N3 solv* or goal* N3 setting or decision* N3 mak* or coping) N5 (patient* or consumer* or client*))
S32	((patient* or consumer* or client*) N5 (educat* or participat* or behaviour* or behavior* or compliance or centered)) OR ((patient* or consumer* or client*) N5 (educat* or participat* or behaviour* or behavior* or compliance or centered))
S33	TI (("self manage*" or "self-manage*" or "self efficacy" or "self-efficacy" or "self monitor*" or "self-monitor*" or "self-help" or "self help") N5 (device* or tool* or technolog*)) OR AB (("self manage*" or "self-manage*" or "self efficacy" or "self-efficacy" or "self monitor*" or "self-monitor*" or "self-help" or "self help") N5 (device* or tool* or technolog*))
S34	TI ((rehabilitation or therap* or treatment or communication or consultation) N5 (telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or email)) OR AB ((rehabilitation or therap* or treatment or communication or consultation) N5 (telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or email))
S35	TI ((cell* or smart* or mobile or android or internet or web) N3 (comput* or device or app* or phone)) OR AB ((cell* or smart* or mobile or android or internet or web) N3 (comput* or device or app* or phone))
S36	TI (smartphone or "text-messag*" or "text message") OR AB (smartphone or "text-messag*" or "text message")
S37	TI (tablet N3 (device* or comput*)) OR AB (tablet N3 (device* or comput*))
S38	(MH "Mobile Applications")
S39	(MH "Electronic Mail")
S40	(MH "Social Networking")
S41	(MH "Social Media")
S42	(MH "Cellular Phone")
S43	(MH "Smartphone")
S44	(MH "Text Messaging")

(Continued)

S45	(MH "Communication Barriers")
S46	(MH "Information Literacy+")
S47	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46
S48	(MH "Cerebrovascular Disorders")
S49	(MH "Basal Ganglia Cerebrovascular Disease+")
S50	(MH "Cerebral Ischemia+")
S51	(MH "Carotid Artery Diseases+")
S52	(MH "Intracranial Arterial Diseases+")
S53	(MH "Arteriovenous Malformations")
S54	(MH "Intracranial Embolism and Thrombosis+")
S55	(MH "Intracranial Hemorrhage+")
S56	(MH "Stroke")
S57	(MH "Stroke, Lacunar")
S58	(MH "Vertebral Artery Dissections")
S59	(MH "Hypoxia, Brain+")
S60	TI (stroke* or "post stroke" or poststroke or post-stroke or apoplex* or "cerebral vasc*" or cerebrovasc* or cva or SAH) OR AB (stroke* or "post stroke" or poststroke or post-stroke or apoplex* or "cerebral vasc*" or cerebrovasc* or cva or SAH)
S61	TI (brain N5 isch?emi* or brain N5 infarct* or brain N5 thrombo* or brain N5 emboli* or brain N5 occlus* or brain N5 hypoxi* or cerebr* N5 isch?emi* or cerebr* N5 infarct* or cerebr* N5 thrombo* or cerebr* N5 emboli* or cerebr* N5 occlus* or cerebr* N5 hypoxi* or cerebell* N5 isch?emi* or cerebell* N5 infarct* or cerebell* N5 thrombo* or cerebell* N5 emboli* or cerebell* N5 occlus* or cerebell* N5 hypoxi* or vertebrobasil* N5 isch?emi* or vertebrobasil* N5 infarct* or vertebrobasil* N5 thrombo* or vertebrobasil* N5 emboli* or vertebrobasil* N5 occlus* or vertebrobasil* N5 hypoxi* or hemispher* N5 isch?emi* or hemispher* N5 infarct* or hemispher* N5 thrombo* or hemispher* N5 emboli* or hemispher* N5 occlus* or hemispher* N5 hypoxi* or intracran* N5 isch?emi* or intracran* N5 infarct* or intracran* N5 thrombo* or intracran* N5 emboli* or intracran* N5 occlus* or intracran* N5 hypoxi* or intracerebral N5 isch?emi* or intracerebral N5 infarct* or intracerebral N5 thrombo* or intracerebral N5 emboli* or intracerebral N5 occlus* or intracerebral N5 hypoxi* or intracerebralor N5 isch?emi* or intracerebralor N5 infarct* or intracerebralor N5 thrombo* or intracerebralor N5 emboli* or intracerebralor N5 occlus* or intracerebralor N5 hypoxi* or infratentorial N5 isch?emi* or infratentorial N5 infarct* or infratentorial N5 thrombo* or infratentorial N5 emboli* or infratentorial N5 occlus* or infratentorial N5 hypoxi* or supratentorial N5 isch?emi* or supratentorial N5 infarct* or supratentorial N5 thrombo* or supratentorial N5 emboli* or supratentorial N5 occlus* or supratentorial N5 hypoxi* or “middle cerebr*” N5 isch?emi* or “middle cerebr*” N5 infarct* or “middle cerebr*” N5 thrombo* or “middle cerebr*” N5 emboli* or “middle cerebr*” N5 occlus* or “middle cerebr*” N5 hypoxi* or mca* N5 isch?emi* or mca* N5 infarct* or mca* N5 thrombo* or mca* N5 emboli* or mca* N5 occlus* or mca* N5 hypoxi* or “anterior circulation” N5 isch?emi* or “anterior circulation” N5 infarct* or “anterior circulation” N5 thrombo* or “ante-

(Continued)

	rior circulation" N5 emboli* or "anterior circulation" N5 occlus* or "anterior circulation" N5 hypoxi* or "basilar artery" N5 isch?emi* or "basilar artery" N5 infarct* or "basilar artery" N5 thrombo* or "basilar artery" N5 emboli* or "basilar artery" N5 occlus* or "basilar artery" N5 hypoxi* or "vertebral artery" N5 isch?emi* or "vertebral artery" N5 infarct* or "vertebral artery" N5 thrombo* or "vertebral artery" N5 emboli* or "vertebral artery" N5 occlus* or "vertebral artery" N5 hypoxi*) OR AB (brain N5 isch?emi* or brain N5 infarct* or brain N5 thrombo* or brain N5 emboli* or brain N5 occlus* or brain N5 hypoxi* or cerebr* N5 isch?emi* or cerebr* N5 infarct* or cerebr* N5 thrombo* or cerebr* N5 emboli* or cerebr* N5 occlus* or cerebr* N5 hypoxi* or cerebell* N5 isch?emi* or cerebell* N5 infarct* or cerebell* N5 thrombo* or cerebell* N5 emboli* or cerebell* N5 occlus* or cerebell* N5 hypoxi* or vertebrobasil* N5 isch?emi* or vertebrobasil* N5 infarct* or vertebrobasil* N5 thrombo* or vertebrobasil* N5 emboli* or vertebrobasil* N5 occlus* or vertebrobasil* N5 hypoxi* or hemispher* N5 isch?emi* or hemispher* N5 infarct* or hemispher* N5 thrombo* or hemispher* N5 emboli* or hemispher* N5 occlus* or hemispher* N5 hypoxi* or intracran* N5 isch?emi* or intracran* N5 infarct* or intracran* N5 thrombo* or intracran* N5 emboli* or intracran* N5 occlus* or intracran* N5 hypoxi* or intracerebral N5 isch?emi* or intracerebral N5 infarct* or intracerebral N5 thrombo* or intracerebral N5 emboli* or intracerebral N5 occlus* or intracerebral N5 hypoxi* or intracerebralor N5 isch?emi* or intracerebralor N5 infarct* or intracerebralor N5 thrombo* or intracerebralor N5 emboli* or intracerebralor N5 occlus* or intracerebralor N5 hypoxi* or infratentorial N5 isch?emi* or infratentorial N5 infarct* or infratentorial N5 thrombo* or infratentorial N5 emboli* or infratentorial N5 occlus* or infratentorial N5 hypoxi* or supratentorial N5 isch?emi* or supratentorial N5 infarct* or supratentorial N5 thrombo* or supratentorial N5 emboli* or supratentorial N5 occlus* or supratentorial N5 hypoxi* or "middle cerebr*" N5 isch?emi* or "middle cerebr*" N5 infarct* or "middle cerebr*" N5 thrombo* or "middle cerebr*" N5 emboli* or "middle cerebr*" N5 occlus* or "middle cerebr*" N5 hypoxi* or mca* N5 isch?emi* or mca* N5 infarct* or mca* N5 thrombo* or mca* N5 emboli* or mca* N5 occlus* or mca* N5 hypoxi* or "anterior circulation" N5 isch?emi* or "anterior circulation" N5 infarct* or "anterior circulation" N5 thrombo* or "anterior circulation" N5 emboli* or "anterior circulation" N5 occlus* or "anterior circulation" N5 hypoxi* or "basilar artery" N5 isch?emi* or "basilar artery" N5 infarct* or "basilar artery" N5 thrombo* or "basilar artery" N5 emboli* or "basilar artery" N5 occlus* or "basilar artery" N5 hypoxi* or "vertebral artery" N5 isch?emi* or "vertebral artery" N5 infarct* or "vertebral artery" N5 thrombo* or "vertebral artery" N5 emboli* or "vertebral artery" N5 occlus* or "vertebral artery" N5 hypoxi*)
S62	TI (brain* N5 h?emorrhag* or cerebr* N5 h?emorrhag* or cerebell* N5 h?emorrhag* or intracerebral N5 h?emorrhag* or intracran* N5 h?emorrhag* or parenchymal N5 h?emorrhag* or intraparenchymal N5 h?emorrhag* or intraventricular N5 h?emorrhag* or infratentorial N5 h?emorrhag* or supratentorial N5 h?emorrhag* or basal gangli* N5 h?emorrhag* or putaminal N5 h?emorrhag* or putamen N5 h?emorrhag* or posterior fossa N5 h?emorrhag* or hemispher* N5 h?emorrhag* or subarachnoid N5 h?emorrhag* or brain* N5 h?ematoma* or cerebr* N5 h?ematoma* or cerebell* N5 h?ematoma* or intracerebral N5 h?ematoma* or intracran* N5 h?ematoma* or parenchymal N5 h?ematoma* or intraparenchymal N5 h?ematoma* or intraventricular N5 h?ematoma* or infratentorial N5 h?ematoma* or supratentorial N5 h?ematoma* or basal gangli* N5 h?ematoma* or putaminal N5 h?ematoma* or putamen N5 h?ematoma* or posterior fossa N5 h?ematoma* or hemispher* N5 h?ematoma* or subarachnoid N5 h?ematoma* or brain* N5 bleed*or cerebr* N5 bleed*or cerebell* N5 bleed*or intracerebral N5 bleed*or intracran* N5 bleed* or parenchymal N5 bleed*or intraparenchymal N5 bleed*or intraventricular N5 bleed* or infratentorial N5 bleed*or supratentorial N5 bleed*or basal gangli* N5 bleed*or putaminal N5 bleed*or putamen N5 bleed*or posterior fossa N5 bleed*or hemispher* N5 bleed*or subarachnoid N5 bleed*) OR AB (brain* N5 h?emorrhag* or cerebr* N5 h?emorrhag* or cerebell* N5 h?emorrhag* or intracerebral N5 h?emorrhag* or intracran* N5 h?emorrhag* or parenchymal N5 h?emorrhag* or intraparenchymal N5 h?emorrhag* or intraventricular N5 h?emorrhag* or infratentorial N5 h?emorrhag* or supratentorial N5 h?emorrhag* or basal gangli* N5 h?emorrhag* or putaminal N5 h?emorrhag* or putamen N5 h?emorrhag* or posterior fossa N5 h?emorrhag* or hemispher* N5 h?emorrhag* or subarachnoid N5 h?emorrhag* or brain* N5 h?ematoma* or cerebr* N5 h?ematoma* or cerebell* N5 h?ematoma* or intracerebral N5 h?ematoma* or intracran* N5 h?ematoma* or parenchymal N5 h?ematoma* or intraparenchymal N5 h?ematoma* or intraventricular N5 h?ematoma* or infratentorial N5 h?ematoma* or supratentorial N5 h?ematoma* or basal gangli* N5 h?ematoma* or putaminal N5 h?ematoma* or putamen N5 h?ematoma* or posterior fossa N5 h?ematoma* or hemispher* N5 h?ematoma* or subarachnoid N5 h?ematoma* or brain* N5 bleed*or cerebr* N5 bleed*or cerebell* N5 bleed*or intracerebral N5 bleed*or intracran* N5 bleed* or parenchymal N5 bleed*or intraparenchymal N5 bleed*or intraventricular N5 bleed* or infratentorial N5 bleed*or supratentorial N5 bleed*or basal gangli* N5 bleed*or putaminal N5

(Continued)

	bleed*or putamen N5 bleed*or posterior fossa N5 bleed*or hemispher* N5 bleed*or subarachnoid N5 bleed*)
S63	(MH "Hemiplegia")
S64	(MH "Aphasia+")
S65	(MH "Gait Disorders, Neurologic+")
S66	TI (hempar* or hemipleg* or paresis or paretic or aphasi* or dysphasi* or hemianopsia or hemianopia or transient isch* or isch?emic attack* or TIA or TIAs) OR AB (hempar* or hemipleg* or paresis or paretic or aphasi* or dysphasi* or hemianopsia or hemianopia or transient isch* or isch?emic attack* or TIA or TIAs)
S67	S48 OR S49 OR S50 OR S51 OR S52 OR S53 OR S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64 OR S65 OR S66
S68	(MM "Randomized Controlled Trials") OR (MM "Clinical Trials")
S69	TX "randomized controlled trial*"
S70	TX "controlled clinical trial*"
S71	TX "randomised controlled trial*"
S72	AB (randomised or randomized)
S73	AB placebo*
S74	AB "drug therapy"
S75	AB randomly
S76	AB trial#
S77	AB group#
S78	S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77
S79	S47 AND S67 AND S78: Limiters - Published Date: 20050101-20190531

Appendix 5. PsycINFO search strategy

1. Client Education/
2. Information Dissemination/
3. Health Education/
4. Health Promotion/
5. health knowledge/
6. counseling/
7. rehabilitation counseling/
8. Client Participation/
9. Treatment Compliance/
10. Client Satisfaction/
11. telephone systems/ or cellular phones/
12. caregiver burden/

13.instructional media/
14.Books/
15.Educational Audiovisual Aids/
16.Multimedia/
17.Tape Recorders/
18.Videotapes/
19.exp internet/
20.printed communications media/
21.internet/
22.electronic learning/
23.websites/
24.social media/
25.television/
26.online social networks/
27.social networks/
28.computer assisted instruction/
29.exp mobile devices/
30.programmed instruction/
31.computer mediated communication/
32.blog/
33.virtual classrooms/
34.written communication/
35.verbal communication/
36.educational programs/
37.exp teaching/
38.education/
39.exp verbal comprehension/
40.comprehension/
41.consumer$ health information.tw.
42.access to information.tw.
43.information literacy/
44.((patient$ or inpatient$ or outpatient$ or consumer$ or carer$ or care giver$ or caregiver$ or family or families) adj5 (education$ or information$ or support$ or knowledge or counsel$ or lecture$ or teach$)).tw.
45.((patient$ or inpatient$ or outpatient$ or carer$ or care giver$ or caregiver$ or family or families) adj5 (book$ or leaflet$ or pack$ or video$ or tape$ or phone$ or telephone$ or manual$ or advice$ or audiovisual or audio visual)).tw.
46.((education$ or information$ or material$ or resource$) adj5 (book$ or leaflet$ or pack$ or video$ or tape$ or phone$ or telephone$ or manual$ or advice$ or audiovisual or audio visual)).tw.
47.((education$ or information$) adj5 (program$ or intervention$ or material$ or resource$ or provision or provid$ or session$ or consultation$ or class or classes or discussion$ or meeting$)).tw.
48.(patient adj5 (participat$ or complian$ or satisf$)).tw.
49.((doctor$ or nurse$ or professional$) adj5 (patient$ or inpatient$ or outpatient$ or carer$ or care giver$ or caregiver$ or family or families) adj5 communicat$).tw.
50.((remote$ or distanc$ or distant or audio or audio-visual or audiovisual or telephone$ or phone$ or video$ or internet$ or computer $ or sensor$ or modem or webcam or website$ or electronic or smartphone$ or email or e-mail) adj3 (consult$ or communicat$ or assess$)).tw.
51.(((behav$ adj3 chang$) or (problem$ adj3 solv$) or (goal$ adj3 setting) or (decision$ adj3 mak$) or coping) adj5 (patient$ or consumer $ or client$)).tw.
52.((patient$ or consumer$ or client$) adj5 (educat$ or participat$ or behaviour$ or behavior$ or compliance or centered)).tw.
53.((self care or self-care or self manage* or self-manage* or self efficacy or self-efficacy or self monitor$ or self-monitor$ or self-help or self help) adj5 (device* or tool* or technolog*)).tw.
54.((rehabilitation or therap$ or treatment or communication or consultation) adj5 (telephone$ or phone$ or video$ or internet$ or computer$ or sensor$ or modem or webcam or website$ or email)).tw.
55.((cell$ or smart$ or mobile or android or internet or web) adj3 (comput$ or device or app$ or phone)).tw.
56.(smartphone or text-messag$ or (tablet adj3 (device$ or comput$))).tw.

57.or/1-56 [INFORMATION PROVISION]
58.Cerebrovascular Disorders/
59.exp Cerebral Ischemia/
60.Carotid Arteries/
61.exp Cerebrovascular Accidents/
62.Cerebral Hemorrhage/
63.(stroke$ or post stroke or poststroke or post-stroke or apoplex$ or cerebral vasc$ or cerebrovasc$ or cva or SAH).tw.
64.((brain or cerebr$ or cerebell$ or vertebrobasil$ or hemispher$ or intracran$ or intracerebral or infratentorial or supratentorial or middle cerebr$ or mca$ or anterior circulation or basilar artery or vertebral artery) adj5 (isch?emi$ or infarct$ or thrombo$ or emboli$ or occlus$ or hypoxi$)).tw.
65.((brain$ or cerebr$ or cerebell$ or intracerebral or intracran$ or parenchymal or intraparenchymal or intraventricular or infratentorial or supratentorial or basal gangli$ or putaminal or putamen or posterior fossa or hemispher$ or subarachnoid) adj5 (h?emorrhag$ or h?ematoma$ or bleed$)).tw.
66.hemiplegia/
67.exp aphasia/
68.Hemianopia/
69.(hempar$ or hemipleg$ or paresis or paretic or aphasi$ or dysphasi$ or hemianopsia or hemianopia or transient isch$ or isch?emic attack$ or TIA or TIAs).tw.
70.or/58-69 [stroke terms]
71.Treatment Effectiveness Evaluation/
72.exp Treatment Outcomes/
73.Psychotherapeutic Outcomes/
74.PLACEBO/
75.exp Followup Studies/
76.placebo*.tw.
77.random*.tw.
78.comparative stud*.tw.
79.(clinical adj3 trial*).tw.
80.(research adj3 design).tw.
81.(evaluat* adj3 stud*).tw.
82.(prospectiv* adj3 stud*).tw.
83.((singl* or doubl*or trebl* or tripl*) adj3 (blind* or mask*)).tw.
84.control*.tw.
85.or/71-84 [RCT FILTER]
86.57 and 70 and 85 [INFO PROVISION AND STROKE AND RCT FILTER]
87.limit 86 to yr="2005 -Current"

Appendix 6. Web of Science search strategy

# 1	TOPIC: ((stroke* or post stroke or poststroke or post-stroke or apoplex* or cerebral vasc* or cerebrovasc* or cva or SAH))
# 2	TOPIC: ((empar* or hemipleg* or paresis or paretic or aphasi* or dysphasi* or hemianopsia or hemianopia or transient isch* or isch?emic attack* or TIA or TIAs))
# 3	TOPIC: (("patient* education" or "patient* information" or "patient* support" or "patient* knowledge" or "patient* counsel*" or "patient* lecture*" or "patient* teach*" or "care* education" or "care* information" or "care* support" or "care* knowledge" or "care* counsel*" or "care* lecture*" or "care* teach*" or"famil* education" or "famil* information" or "famil* support" or "famil* knowledge" or "famil* counsel*" or "famil* lecture*" or "famil* teach*"))
# 4	TOPIC: (book* or leaflet* or pack* or video* or tape* or phone* or telephone* or manual* or advice* or audiovisual or "audio visual")

(Continued)

# 5	TS=("education* program*" or "education* intervention*" or "education* material*" or "education* resource*" or "education* provision*" or "education* provid*" or "education* session*" or "education* consultation*" or "education* class*" or "education* discussion*" or "education* meeting*" or "information program*" or "information intervention*" or "information material*" or "information resource*" or "information provision*" or "information provid*" or "information session*" or “information consulation*" or "information class*" or "information discussion*" or "information meeting*")
# 6	TOPIC: (("patient participat*" or "patient complian*" or "patient satisf*"))
# 7	TOPIC: ("access to information" or "information dissemination" or "patient medication knowledge")
# 8	TOPIC: (doctor* NEAR/5 "patient communicat*" or nurse* NEAR/5 "patient communicat*" or professional* NEAR/5 "patient* communicat*" or doctor* NEAR/5 "care* communicat*" or nurse* NEAR/5 "care* communicat*" or professional* NEAR/5 "care* communicat*" or doctor* NEAR/5 "famil* communicat*" or nurse* Near/5 "famil* communicat*" or professional Near/5 "famil* communicat*")
# 9	TOPIC: ((remote* or distanc* or distant or audio or audio-visual or "audio visual*" or audiovisual or telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or electronic or smartphone* or email or e-mail or "e mail") NEAR/3 (consult* or communicat* or assess*))
# 10	TOPIC: ((behav* NEAR/3 chang* or problem* NEAR/3 solv* or goal* NEAR/3 setting or decision* NEAR/3 mak* or coping) NEAR/5 (patient* or consumer* or client*))
# 11	TOPIC: ((patient* or consumer* or client*) NEAR/5 (educat* or participat* or behaviour* or behavior* or compliance or centered))
# 12	TOPIC: (("self manage*" or "self-manage*" or "self efficacy" or "self-efficacy" or "self monitor*" or "self-monitor*" or "self-help" or "self help") NEAR/5 (device* or tool* or technolog*))
# 13	TOPIC: ((rehabilitation or therap* or treatment or communication or consultation) NEAR/5 (telephone* or phone* or video* or internet* or computer* or sensor* or modem or webcam or website* or email))
# 14	TOPIC: ((cell* or smart* or mobile or android or internet or web) NEAR/3 (comput* or device or app* or phone))
# 15	TOPIC: (smartphone or "text-messag*" or "text message")
# 16	TOPIC: (tablet NEAR/3 (device* or comput*))
# 17	TOPIC: ((random* or rct))
# 18	#2 OR #1
# 19	#16 OR #15 OR #14 OR #13 OR #12 OR #11 OR #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3
# 20	#19 AND #18 AND #17

Appendix 7. ASSIA search strategy

- ALL(
  - (stroke* OR post stroke OR poststroke OR post-stroke OR apoplex* OR cerebral vasc* OR cerebrovasc* OR cva OR SAH)
  - OR (hempar* OR hemipleg* OR paresis OR paretic OR aphasi* OR dysphasi* OR hemianopsia OR hemianopia OR transient isch* OR isch?emic attack* OR TIA OR TIAs))
- AND ALL(
  - (patient* NEAR/5 education* OR patient NEAR/5 information* OR patient* NEAR/5 support* OR patient* NEAR/5 knowledge OR patient* NEAR/5 counsel* OR patient* NEAR/5 lecture* OR patient* NEAR/5 teach*)
  - OR (inpatient* NEAR/5 education* OR inpatient* NEAR/5 information* OR inpatient* NEAR/5 support* OR inpatient* NEAR/5 knowledge OR inpatient* NEAR/5 counsel* OR inpatient* NEAR/5 lecture* OR inpatient* NEAR/5 teach*)
  - OR (outpatient* NEAR/5 education* OR outpatient* NEAR/5 information* OR outpatient* NEAR/5 support* OR outpatient* NEAR/5 knowledge OR outpatient* NEAR/5 counsel* OR outpatient NEAR/5 lecture* OR outpatient* NEAR/5 teach*)
  - OR (consumer* NEAR/5 education* OR consumer* NEAR/5 information* OR consumer* NEAR/5 support* OR consumer* NEAR/5 knowledge OR consumer* NEAR/5 counsel* OR consumer* NEAR/5 lecture* OR consumer* NEAR/5 teach*)
  - OR (carer* NEAR/5 education* OR carer* NEAR/5 information* OR carer* NEAR/5 support* OR carer* NEAR/5 knowledge OR carer* NEAR/5 counsel* OR carer* NEAR/5 lecture* OR carer* NEAR/5 teach*))
- AND ALL(rct OR random*)

Appendix 8. Dissertations and Theses A&I search strategy

- ALL(
  - (stroke* OR post stroke OR poststroke OR post-stroke OR apoplex* OR cerebral vasc* OR cerebrovasc* OR cva OR SAH)
  - OR (hempar* OR hemipleg* OR paresis OR paretic OR aphasi* OR dysphasi* OR hemianopsia OR hemianopia OR transient isch* OR isch?emic attack* OR TIA OR TIAs))
- AND ALL(
  - (patient* NEAR/5 education* OR patient NEAR/5 information* OR patient* NEAR/5 support* OR patient* NEAR/5 knowledge OR patient* NEAR/5 counsel* OR patient* NEAR/5 lecture* OR patient* NEAR/5 teach*)
  - OR (inpatient* NEAR/5 education* OR inpatient* NEAR/5 information* OR inpatient* NEAR/5 support* OR inpatient* NEAR/5 knowledge OR inpatient* NEAR/5 counsel* OR inpatient* NEAR/5 lecture* OR inpatient* NEAR/5 teach*)
  - OR (outpatient* NEAR/5 education* OR outpatient* NEAR/5 information* OR outpatient* NEAR/5 support* OR outpatient* NEAR/5 knowledge OR outpatient* NEAR/5 counsel* OR outpatient NEAR/5 lecture* OR outpatient* NEAR/5 teach*)
  - OR (consumer* NEAR/5 education* OR consumer* NEAR/5 information* OR consumer* NEAR/5 support* OR consumer* NEAR/5 knowledge OR consumer* NEAR/5 counsel* OR consumer* NEAR/5 lecture* OR consumer* NEAR/5 teach*)
  - OR (carer* NEAR/5 education* OR carer* NEAR/5 information* OR carer* NEAR/5 support* OR carer* NEAR/5 knowledge OR carer* NEAR/5 counsel* OR carer* NEAR/5 lecture* OR carer* NEAR/5 teach*))
- AND ALL(rct OR random*)

Appendix 9. Ongoing trials and research registers search strategy

ISRCTN Registry

Only terms stroke and information were searched

RePORTER

Text Search: stroke AND information (and);

Search in: Projects

Limit to: Project Abstracts; Project Title; Project Terms;

AdminIC: All;

Fiscal Year: Active Projects

Internet Stroke Center Stroke Trials Registry

Separate searches conducted for interventions using the terms education, knowledge, satisfaction and communication

NARIC: REHABDATA and NIDILRR

Separate searches conducted for:

Stroke Education

Stroke Information

WHO ICTRP

Title: (Information OR educat* OR teach* OR instruction OR learning OR communicat* OR carer OR caregiver)

Condition: (stroke OR cerebrovascular OR cerebral)

ClinicalTrials.Gov

Condition or disease: Stroke

Other terms: Information OR education OR instruction OR caregiver

Study type: All studies

Study results: All studies

WHAT'S NEW

Date	Event	Description
28 September 2020	New citation required and conclusions have changed	The addition of new studies, use of GRADE and separation of active and passive information provision have broadened the outcomes for which we concluded there may be a slight improvement with active information provision, and contrasted that effect more clearly between active and passive information provision.
28 September 2020	New search has been performed	This review update has added 12 new studies (Boden-Albala 2015; Deyhoul 2018; Dharmakulaseelan 2019; Eames 2013; Forster 2013; Hekmatpou 2019; Jones 2018; Kamal 2016; Karimi 2018; Kim 2013; Kuo 2015; Mudzi 2012). The review now includes 33 studies involving 5255 stroke-survivor and 3134 carer participants, more than doubling participant numbers. Outcomes of interest have been made more specific and changed (see Differences between protocol and review). Additional methods for handling data from cluster trials and transforming data for inclusion in meta-analyses have been added, as well as new methods for investigating heterogeneity and conducting sensitivity analyses (see Differences between protocol and review). Additional meta-analyses have been conducted. Active and passive information provision have been separated as different comparisons (they were previously treated as subgroups). Analyses of stroke-survivor and carer results have been placed in separate comparisons for clarity (they were always analysed separately). Certainty of evidence has been assessed using GRADE, and summary of findings tables have been added. The review title and text have been amended to change 'stroke patients' to 'stroke survivors' and 'caregivers' to 'carers'.

HISTORY

Protocol first published: Issue 1, 2000
Review first published: Issue 3, 2001

Date	Event	Description
18 July 2012	New citation required but conclusions have not changed	The results and the conclusions for this update are the same as for the previous version of the review.
30 December 2011	New search has been performed	This review update has added four new trials (Johnston 2007; Chiu 2008; O'Connell 2009; Chinchai 2010).The review now includes 21 trials involving 2289 patient and 1290 carer participants. Additional data have been added for analysis for the patient outcome for death.
12 May 2008	Amended	Converted to new review format. Additional text added to the 'Acknowledgements' section and a new 'External sources of support' included.

CONTRIBUTIONS OF AUTHORS

Anne Forster conceived and designed the review and wrote the research proposal to obtain funding for the original review and this update.

Peter Knapp and Anne Forster contributed to refining the original protocol. Anne Forster contributed to co-ordinating the first update of the review. Anne Forster and Lesley Brown co-ordinated the review of papers, data extraction, obtaining additional information and writing of the second update.

Tom Crocker and Anne Forster contributed to the revised protocol for this update, co-ordinated the review of papers, data extraction, obtaining additional information and writing of this third update. Natalie Lam contributed to data extraction and the summary of findings tables. Faye Wray contributed to data extraction and writing of this third update.

DECLARATIONS OF INTEREST

Thomas F Crocker

- Grants and contracts: Development and evaluation of strategies to provide longer-term health and social care for stroke survivors and their carers, RP-PG-0611-20010, National Institute for Health Research (paid to institution).

Lesley Brown

- Grants and contracts: contributed to the protocol for 'Development and evaluation of strategies to provide longer-term health and social care for stroke survivors and their carers', National Institute for Health Research (NIHR) under its Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-0611-20010) (paid to Bradford Teaching Hospitals NHS Foundation Trust).

Natalie Lam: none known.

Faye Wray: none known.

Peter Knapp: none known.

Anne Forster

- Grants and contracts: undertaken many research projects which include components of information provision for people after stroke, Department of Health; Stroke Association; NIHR (paid to institution).
- Published opinions in medical journals, the public press, broadcast and social media relevant to the interventions in the work: Reported research and commented on information provision for people after stroke, University of Leeds and Bradford Teaching Hospitals NHS Foundation Trust (www.journalslibrary.nihr.ac.uk/pgfar/pgfar02060/#/abstract).
- Any affiliation to an organisation (including not-for-profit) that has a declared opinion or position on the topic: undertake review activities, liaise regarding research, Stroke Association.
- Declaring involvement in eligible studies:
  - Smith J, Forster A, Young J. A randomized trial to evaluate an education programme for patients and caregivers after stroke. Clinical Rehabilitation 2004;18(7):726-36. Funding: Northern and Yorkshire Region Research and Development UK

- Forster A, Dickerson J, Young J, Patel A, Kalra L, Nixon J; the TRACS Trial Collaboration. A structured training programme for caregivers of inpatients after stroke (TRACS): a cluster-randomised controlled trial and cost-effectiveness analysis. Lancet 2013;382(9910):2069-76. [DOI: 10.1016/ S0140-6736(13)61603-7] [PMID: 24054816]. Funding: Medical Research Council (MRC) UK

SOURCES OF SUPPORT

Internal sources

- R&D Levy Funding, UK
- Bradford Teaching Hospitals NHS Foundation Trust, UK

External sources

- NHS Executive Northern and Yorkshire R&D, UK
- National Institute for Health Research, UK

  Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-0606-1128). Development and evaluation of tools and an intervention to improve patient- and carer-centred outcomes in Longer-Term Stroke care and exploration of adjustment post stroke: the LoTS care research programme.
- National Institute for Health Research, UK

  Programme Grants for Applied Research Programme (Grant Reference Number RP-PG-0611-20010). Development and evaluation of strategies to provide longer-term health and social care for stroke survivors and their carers (LoTS-2-Care).

DIFFERENCES BETWEEN PROTOCOL AND REVIEW

Since the previous version of the review was published, and prior to new searches being conducted, a revised protocol was agreed with the editorial board of the CSG. These changes were as follows. The search strategy was updated (details in Search methods for identification of studies). We stratified comparisons by whether information provision was active or passive (previously this was examined through subgrouping). We also proposed to compare active and passive information provision directly for the first time, although we found no studies to enable this comparison. We sought to conduct meta-analyses where possible. We used the risk ratio instead of the odds ratio as the effect measure for dichotomous outcomes where possible and where there was not a very low event rate. We added a new subgrouping strategy to investigate heterogeneity based on time since stroke.

In addition to these agreed changes, we have made our exclusion of self-management, reminders or monitoring interventions explicit. We have also added methods for handling cluster-randomised trials, adopting the approach used in another Cochrane Review (Crocker 2013). We have added summary of findings tables and methods to assess the quality of the evidence, adopting standard Cochrane approaches.

We made a post-hoc decision to add a new secondary outcome of recurrent stroke, prompted by its measurement in two studies (Boden-Albala 2015; Karimi 2018), and based on its importance, relevance to the review and association with existing outcomes, in particular modification of health-related behaviours and mortality.

We added meta-analyses of quality of life, additional kinds of knowledge, health status, and recurrent stroke. For carers, we added a meta-analysis of the HADS anxiety subscale, as well as dichotomous anxiety and depression scores, for consistency with our handling of stroke-survivor outcomes. Therefore, we have removed the HADS total score (reported by Downes 1993 and Kalra 2004) from the dichotomous carer psychological distress meta-analysis, leaving the GHQ (reported by Rodgers 1999 and Smith 2004). We have changed the cutoff used for the Geriatric Depression Scale short form (Sheikh 1986) from > 10 to > 5 points (see Table 1), based on the suggestions of Marc 2008 and Yesavage 2019. This changed the number of cases of depression in the study by Ellis 2005 in Analysis 1.7.

Following submission of our update to Cochrane Stroke, we were asked to make further changes to our methods. These changes are detailed below.

We have reworded the objectives to be more explicit about the comparisons and outcomes of interest.

We have changed the outcomes of interest, explicitly separating stroke-survivor and carer outcomes and refining the specification of outcomes, further detailed below.

We have changed the umbrella outcome of mood to specific outcomes of interest: anxiety, depression, psychological distress, positive mental well-being, self-efficacy and locus of control for stroke survivors and carers, and additionally burden for carers. It had always been the intention for the review to capture a range of mood-related outcomes, but this allows us to be more precise about those we consider particularly important in this context. As a result we have changed our co-primary outcomes from knowledge and mood to knowledge and anxiety for stroke survivors and carers, choosing anxiety because it was a domain that may be adversely as well as positively affected. Having been more explicit about the outcomes of interest, we have removed some results that were present in previous versions of the review but no longer listed as being of interest: the Herth Hope Scale and Ways of Coping-Cardiovascular Accident Scale reported by

Johnson 2000, and the Life Situation Among Spouses after the Stroke event (Larson 2005b), reported by Larson 2005. For Larson 2005, which reported results from Bradley's well-being questionnaire, we have also changed from using the general well-being score to the positive well-being score, as this better fits the positive well-being construct.

In an effort to make the review more digestible, we have removed the outcomes of participation; hospital admissions, service contacts or health professional contacts; and institutionalisation. We have been explicit that we will not analyse results related to modification of health-related behaviour and cost. We have removed disability measures from our analyses of independence in activities of daily living to provide greater conceptual clarity (Stroke Impact Scale: daily activities; Glasgow Outcome Scale; modified Rankin Scale). We have also explicitly excluded measures without adequate evidence of reliability and validity, which was somewhat ad-hoc in previous versions of the review. This means some results relating to knowledge have been removed from this version, as well as the Global Outcome Scale reported by Banet 1997. We have changed our handling of health status measures, explicitly including only summary measures of health status under this outcome, incorporating subscales into other outcomes where appropriate and excluding subscales that are not prespecified. This means we now have results grouped together for the outcomes of quality of life and psychological distress that were previously separated out as subscales of different instruments. We have also removed the results relating to the daily activities subscale of the Stroke Impact Scale reported by O'Connell 2009, and other results from data tables.

Following these changes, we have also reordered our outcomes to present critical outcomes first and additional important outcomes in themed groups to improve the presentation of results.

We have added further meta-analyses and preferred the SMD approach where there are results for a consistent construct but using multiple scales, to include as many studies in the analyses as possible. We have also added methods for handling the inclusion of cluster-randomised trials in SMD meta-analyses. We have added methods to transform median data to mean data and used these to increase the number of studies included in analyses. We have removed all forest plots of single studies.

We previously planned to conduct our subgrouping strategy regardless of the number of studies in an analysis but have altered our approach to only conduct these when there were at least 10 studies. In practice this removed all subgroup analyses from the report.

INDEX TERMS

Medical Subject Headings (MeSH)

Caregivers [*psychology]; Depression [*rehabilitation]; Health Knowledge, Attitudes, Practice; Health Services Accessibility; Ischemic Attack, Transient [*psychology]; Patient Education as Topic [*methods] [standards]; Randomized Controlled Trials as Topic; Stroke [*psychology]

MeSH check words

Humans