PB-PG-0407-13228 – NIHR Research for Patient Benefit Programme – Final report

Project title: Identifying the long-term needs of stroke survivors and modeling implications for innovative services

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Plain language summary

Background

Stroke has long term consequences for many people. Until now, there has been very little research into the long-term problems faced by people who have had a stroke and how best to address needs in the long term.

Aim

To investigate the long term consequences of stroke (1 year onwards) from the perspectives of patients and professionals to develop an innovative strategy to meet long term needs.

Findings

- South London Stroke Register (SLSR) outcome data from 3373 patients show that between 20% and 30% of stroke survivors overall have a poor range of outcomes up to 10 years after stroke. These outcomes serve as objective estimates of need (Wolfe et al, in press).
- Data from 35 qualitative interviews with stroke survivors (plus 14 informal carers) indicated a range of unmet needs relating to health, everyday living (eg. home help), lack of social participation, transport, finances and information (eg. recovery and secondary stroke prevention)
- Data from qualitative interviews with 31 professionals (eg. community therapists, voluntary sector professionals) identified significant gaps in services relating to psychological/ emotional support, group activity, vocational rehabilitation services and a regular assessment of patients' needs.

Pilot intervention

- Consultations with four established groups of stroke survivors and a group of professionals working with stroke survivors in the local community drew together the findings in relation to the existing literature to design an intervention. This was called Stroke Annual Review (StAR).
- StAR was based on a model of 'group reviews' as a novel, cost-effective method of addressing the multiple needs identified drawing on theoretical principles relating to the Drop-in Group Medical Appointment model, a team approach to patient management developed in the US involving peer learning (gaining knowledge through experience and observation of an equal) (Noffsinger, 1999).
- StAR was a one day event at an accessible local venue delivered by 17 professionals, attended by 16 patients and 2 informal carers (spouses) recruited from the SLSR.

- 3 group sessions (Recovery and wellbeing after stroke; Everyday living and physical activity; Healthy Living*)* consisted of a 10 minute presentation by a professional followed by 20 minutes discussion where participants asked questions and raised issues important to them, with the opportunity for a private consultation after.
- Information was provided on stalls run by different organisations and professionals in the form of written information on tables and display boards and verbal information and advice.

Feasibility study

The following methods were used to evaluate StAR;

- Participant Satisfaction questionnaire.
- Questionnaire measuring participants' health related quality of life 4-8 weeks after StAR
- Interviews with a subsample of 8 participants and 1 carer 4-8 weeks after StAR to investigate acceptability and feasibility.
- Group interview with 11 professionals delivering StAR 4-8 weeks after StAR to investigate acceptability and feasibility.
- Basic cost data (venue, catering, transport).

Key findings

- 88-94% of participants reported that each of the three group sessions were helpful or very helpful, indicating a high level of satisfaction and all participants interviewed reported that they would attend StAR if it were to be held again, suggesting that the StAR model is acceptable to participants.
- Peer learning and information provision were particularly valued by participants but some wanted more information about emotional problems, return to work/ study, self-help and more written information.
- Professionals reported that this model is not suitable for participants with severe disability and aphasia.
- Professionals reported StAR would be feasible, acceptable and more cost-effective if delivered by a core group of 3-4 professionals.

Implications

- A future StAR should aim to address the gaps in information identified and provide written summaries of group sessions.
- StAR should be aimed at patients who are not fully recovered after 1 year, without severe disability and aphasia.
- Further testing of StAR should evaluate the model delivered by a core group of professionals.
- Further work is required to develop a reliable system of identifying potential participants. Lists of stroke participants held by General Practices are one possible source.

Keywords
Stroke, needs, long term, pilot feasibility study

Summary of research findings

Background

Stroke is the leading cause of adult physical disability with a significant proportion of survivors being left with ongoing physical, social and psychological needs which can persist for many years. However, the perspectives of patients, their carers and health care professionals have not been systematically canvassed. There is little evidence of how best to address needs in the long term.

Aim

This study investigates the long term consequences of stroke (one year and beyond), and identify from the perspectives of both service users and professionals long term needs. The data from this research phase has been used collaboratively by service users, providers and researchers to develop and pilot test an innovative strategy to meet long term needs.

Objectives

1. To identify the long-term needs (one-year onwards post-stroke) of stroke survivors using standardised measures of clinical, psychological and social consequences in a population sample.

2. To identify stroke survivors' and carers' own perceptions of long term needs, strategies to meet these and identification of needs that remain unmet

3. To identify perceptions of long term needs after stroke held by health and care professionals and voluntary sector providers and views of the extent to which current services/interventions meet need.

4. To use findings to develop the building blocks of a novel intervention iteratively refined through focus group work with service providers, stroke survivors/carers and commissioners.

5. To conduct a pilot study of the intervention to assess feasibility and user acceptability, finalise trial components and protocol for a definitive RCT.

Objective 1

Methods

Data were collected from the population-based South London Stroke Register, a prospective population-based register documenting all first in a lifetime strokes since 1995 in a multi-ethnic inner city population. The outcomes assessed are reported as estimates of need. Estimates were stratified by age, gender, and ethnicity, and age-adjusted using the standard European population. Plots of outcome estimates over time were constructed to examine temporal trends and sociodemographic differences.

Key findings

Outcome data from 3373 patients indicated that at 1 year post-stroke 11% had moderate/severe disability (Barthel index), 36% were inactive (Frenchay Activities Index), 36% were anxious and 23% were depressed (Hospital Anxiety and Depression scale) and 18% had cognitive impairment (Mini Mental State Examination and Abbreviated Mental Test). These outcomes remained relatively stable from 1-10 years. Between 20% and 30% of stroke survivors overall have a poor range of outcomes up to 10 years after stroke. These outcomes serve as objective estimates of need (Wolfe et al, in press)..

Objective 2

Methods

Qualitative interviews with patients and informal carers recruited from the SLSR were conducted to identify unmet needs. Patients were purposively selected to gain a sample that reflected different time points after stroke and a range of ages, ethnic groups, levels of disability, living arrangement and equal numbers of male and females. The interviews were based on a topic guide developed in relation to the literature and in consultation with the Stroke Research Patients and Family Group (SRPFG) run by the Stroke Research Team at King's College London (KCL). Interviews were recorded, transcribed verbatim and analysed using QSR NVivo software to manage the data. A coding scheme was developed drawing on the World Health Organisation's International Classification of Functioning, Disability and Health (ICF) (WHO, 2001).

Key findings

Data from 35 qualitative interviews with stroke survivors (plus 14 informal carers) 1-11 years post stroke indicated that as stroke survivors adapted to their circumstances, expectations changed. Some reported no unmet needs or had developed their own management strategies and mobilised existing resources, mainly social support networks. However others reported a range of unmet needs. These related to health, everyday living (eg. home help, home adaptations), lack of social participation leading to social isolation, housing (eg. unsuitable for those with disability), transport (eg. lack of access), financial needs (ie. additional expenses incurred, difficulty accessing benefits) and the need for information, advice and reassurance from health professionals about physical and cognitive recovery and secondary prevention.

Objective 3

Methods

Qualitative individual and group interviews with health and social care professionals who work with stroke survivors in the community were carried out to identify unmet needs and gaps in services. Interviews were recorded, transcribed verbatim and analysed thematically using QSR NVivo software to manage the data.

Key findings

Data from interviews with 31 service providers (eg. community therapists, GP, voluntary sector professionals) largely reflected the findings from the patient and carer interviews. The service providers identified significant gaps in services relating to psychological/ emotional support, group activity, vocational rehabilitation services and a review service.

Objective 4

Consultations with four established groups of stroke survivors and a group of professionals working with stroke survivors in the local community (including community rehabilitation team managers, stroke consultants and senior staff from the Stroke Association) drew together the findings in relation to the existing literature to design an intervention.

An intervention was designed based on a model of 'group reviews' as a novel, cost-effective method of addressing the multiple needs identified, many not within the scope of current health and social care provision. This intervention draws on theoretical principles relating to the Drop-in Group Medical Appointment model (DIGMA), a team approach to patient management developed in the US involving peer learning (defined as gaining knowledge through experience and observation of an equal) (Noffsinger, 1999). There is some RCT evidence that group appointments result in increased patient and provider satisfaction (Beck et al, 1997; Levine et al, 2010, Scott et al 2004), improvements in standards of care, better coordination of care (Clancy et al, 2003) and a reduction in hospital admissions and visits to emergency departments (Beck et al 1997; Coleman et al 2001, Scott et al, 2004). There is mixed evidence regarding reductions in cost of care (Beck et al, 1997; Levine, et al 2010).

Description of the Stroke Annual Review (StAR) pilot intervention

17 professionals from Southwark and Lambeth participated in delivering StAR held at an accessible local venue on 10th December 2010 at 10am-2pm.

Project team members and other research staff greeted stroke patients on arrival and assisted them in registration. Each patient was provided with an information pack containing the information booklet and a satisfaction questionnaire. On each pack was a label showing a unique patient number (SLSR ID number) that was used by the professionals when recording any actions taken as a result of a one-to-one discussion with patients (see below).

Following the DIGMA model, but tailored to the UK and local context, group sessions addressing different domains of need, identified based on the interviews with stroke survivors, were led by professionals. Each session consisted of a 10 minute presentation followed by 20 minutes discussion where participants were invited to ask questions or raise issues important to them. Participants were invited to attend as many sessions as they feel necessary. If participants wished to discuss any in private with professionals the use of private side rooms was available.

Group sessions

1. *Recovery and wellbeing after stroke*
    - Led by a stroke consultant
    - Information on recovery and emotional wellbeing after stroke, including anxiety and depression.

2. *Everyday living and physical activity*
    - Led by an occupational therapist and physiotherapist
    - Information on exercise and function accessing home adaptations and home aids.

3. *Healthy Living*
    - Led by a stroke nurse and dietician
    - Information on healthy eating, secondary prevention advice, medication management and continence.

There was an opportunity for patients to have a one-one discussion with professionals after the group sessions. Private side rooms were available for this purpose. Professionals recorded information on any actions taken on a record sheet as a result of any one-one discussions with stroke patients (eg. referral, information on self-referral).

Information provision

Information was provided on stalls run by different organisations and professionals in the form of written information on tables and display boards and verbal information and advice. Participants had time available before, after and in between group sessions to visit these stalls.

Sample

Inclusion criteria:
- 12-24 months post stroke
- Able to communicate in English

Exclusion criteria:
- Living in a residential home

All eligible SLSR patients were contacted by letter with an invitation to attend StAR together with their informal carers, where appropriate. An information booklet was provided with details of the StAR and the group sessions taking place and a map of the location. The booklet also contained a list of possible issues/ needs experienced after stroke for patients to read and tick if they felt any were applicable to them so they can gain information and advice on these issues.

Patients were sent a reply slip to and a freepost envelope. A researcher contacted the patients by phone to give further details of the StAR event and to answer any questions. Transport was arranged for those who required it and reimbursement for travel was offered.
150 eligible SLSR patients were invited to participate in StAR
54 refused with the most common reason being ill health or disability.
16 patients attended and 2 wives/ carers of patients making a total of 18. This was 20% of those with whom we made contact.

Objective 5
A feasibility study of the pilot intervention was carried out using the following methods;
- satisfaction questionnaire completed by participants on the day.
- questionnaire measuring participants' health related quality of life 4-8 weeks after StAR based on the SF12.
- qualitative interviews with a subsample of 8 participants and 1 carer 4-8 weeks after StAR to investigate acceptability and feasibility and help identify appropriate patient focused outcomes for a future testing of the intervention.
- group interview with 11 service providers delivering the intervention 4-8 weeks after StAR to investigate acceptability and feasibility.
- Basic cost data regarding venue, catering, and transport.

Key findings
- 88-94% of participants reported that each of the three group sessions were helpful or very helpful, indicating a high level of satisfaction and all participants interviewed reported that they would attend StAR if it were to be held again, suggesting that the StAR model is acceptable to participants.
- Peer learning and information provision were particularly valued by participants but some wanted more information about depression and emotional problems; return to work and study; self-help; services in Southwark and those with memory problems wanted written informationsummarising the group sessions.

- Professionals (community therapists, Stroke Association Stroke Care Advisors, Stroke Consultant) took 10 referrals and provided 10 patients with information on how to self-refer. The most frequent form of action by professionals was to provide information with the most common topic being recovery after stroke, what a stroke is and secondary prevention.
- The majority of participants were without severe physical disability and aphasia.
- Professionals reported that this model is not suitable for participants with a higher level of disability and severe aphasia.
- Professionals reported StAR would be feasible, acceptable and more cost-effective, if delivered by a core group of 3-4 professionals.

Implications

- A future StAR should aim to address the gaps in information identified by participants and provide written summaries of the group sessions
- StAR should be aimed at those who are not fully recovered after one year, without severe disability and severe aphasia.
- A future StAR should evaluate the model delivered by a core group of 3-4 professionals.
- Further work is required to develop a reliable system of identifying potential participants. Lists of stroke participants held by General Practices are one possible source.

Patient and public involvement

The RfPB Programme is particularly keen to learn from the experiences of research teams regarding patient and public involvement (PPI) and contribution from PPI members involved in the research is encouraged when completing this form. Please provide comment on your experiences with PPI, any changes made and lessons drawn. Please include detail of PPI with dissemination and with trajectory into practice both in the project and beyond.
(Maximum 5,000 characters)

Patients have been involved from the outset of this study. Mr Dave Morrison, a stroke survivor, was a co-applicant on this study and regularly attended steering group meetings. We have developed the topic guide in consultation with patients and informal carers from the Stroke Research Patients Family Group (SRFPG), a service user research advisory group. We carried out consultations on the development of the pilot with four different local groups of stroke survivors; SRPFG, Connect (communication charity) women’s group, Lambeth and Southwark Stroke User Involvement Network, Time and Talents stroke club.
After developing a model of the pilot we then consulted again with the SRPFG regarding the name of the pilot. The name Stroke Annual Review (StAR) was suggested and agreed on by the group.

We also presented the findings from the evaluation of the pilot to the SRPFG to gain feedback from patients. Feedback was largely positive regarding the StAR model of group review but members identified the need to provide written summaries of group sessions for those with memory problems, supporting the findings from the participant interviews. There was also a discussion about the possibility of carrying of a group review within a General Practice setting.

Data sharing statement

See link [https://www.nihr.ac.uk/documents/nihr-position-on-the-sharing-of-research-data/12253] for the NIHR position of the sharing of research data. The NIHR strongly supports the sharing of data in the most appropriate way, to help deliver research that maximises benefits to patients and the wider public, the health and care system and which contributes to economic growth in the UK. All requests for data should be directed to the award holder and managed by the award holder.

Disclaimer

This project is funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-0407-13228). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

This project was carried out between 1 November 2008 and 31 October 2010. This final report has not been peer-reviewed. The report was examined by the Programme Director at the time of submission to assess completeness against the stated aims.