Developing primary care services for stroke survivors: the Improving Primary Care After Stroke (IPCAS) research programme

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Primary conflicts of interest: Vicki Johnson declares that she is employed by the University Hospitals of Leicester NHS Trust within the Leicester Diabetes Centre (LDC), which receives not-for-profit income for DESMOND, a suite of self-management programmes for which LDC holds the Intellectual Property Rights. UHL also receives various grants to pay staff within LDC to carry out and implement various studies and self-management programmes. The Intellectual Property for MLAS is held by the University of Leicester on behalf of UHL. Jonathan Mant declares that he is a NIHR Senior Investigator, a subpanel chair for NIHR Programmes for Applied Health Research and a member of the NIHR CTU Standing Advisory Committee.

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Scientific summary

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Scientific summary

Background

There is evidence that stroke survivors and their carers have longer-term needs that are not well addressed by current services. This shortfall might be met by extending access to specialist services or enhancing generalist primary care services. This programme of research focuses on the latter approach.

Objectives

1. Develop a primary care-based model to optimise postdischarge longer-term care:
    - Understand perspectives of stroke survivors and carers on experiences of health and care services since discharge from specialist services.
    - Explore roles of specialist and primary care services for stroke aftercare and avenues of communication between specialist and primary care.
    - Consider poststroke checklists for primary care.
    - Establish criteria for rereferral from primary care to specialist care.
    - Agree the components of the primary care model.
    - Pilot the primary care model.
2. Develop a 'Managing Life After Stroke' (MLAS) programme (including self-management) for people with stroke.
3. Evaluate the effectiveness and cost-effectiveness of these interventions.

Methods

The primary care model was informed by:

A systematic review and meta-ethnography of the literature

We recorded themes identified by authors of the included studies and grouped these into issues relating to continuity of care, access to services, information and quality of communication. We then developed our own overarching explanation of why stroke survivors and caregivers had the experiences that they did.

Qualitative interviews with patients and carers

Semistructured interviews were carried out with 22 stroke survivors and their caregivers (n = 14), recruited from general practice stroke registers. Interviews were audio-recorded, transcribed and analysed using a framework approach.

Focus groups with healthcare professionals and patients

Six focus groups were run involving healthcare professionals (HCPs) from primary care and from six NHS acute trusts in the East of England and East Midlands in order to better understand communication processes between generalists and specialists with regard to stroke care.

Focus groups were carried out to explore the use of checklists to support management of healthcare needs of people with stroke in primary care. Focus groups with HCPs and with patients and their carers were held separately.

Modified Research And Development Corporation Appropriateness Consensus Study

The purpose of this study was to understand when referrals to specialist services are appropriate from the perspective of HCPs. Fictional scenarios were devised covering all the areas of need that had been identified in our work on checklists. In the first round, panellists representing both secondary and primary care were asked to rate online the appropriateness of referral decisions in these scenarios. In the second round, the panellists met face to face to discuss each referral decision.

Scoping review

The aim was to give an overview of interventions delivered in the community that were effective at addressing long-term outcomes after stroke. We conducted a systematic search to identify reviews of randomised controlled trials (RCTs), reviews of observational studies, and single trials published in the last 5 years.

Pilot study

A 6-month single arm (i.e. no control group) feasibility study was carried out in a single practice in Cambridgeshire.

The Managing Life After Stroke programme

The MLAS programme was informed by a literature review; a consultation phase with a multidisciplinary healthcare professional group and stroke survivors; an iterative phase in two cycles and a feasibility study.

The evaluation phase involved three components:

Cluster randomised controlled trial

Forty-six general practices were randomised to usual care or the new model of care. Participants were people with stroke on the practice stroke registers. The coprimary outcomes were two subscales (emotion and participation) of the stroke impact scale. Follow-up was by postal questionnaire at 6 and 12 months.

Process evaluation

A mixed-methods design was used to assess fidelity of design, training, delivery and engagement. Methods included questionnaires sent to practices (to ascertain 'usual care'); video-recording and audio-recording of training sessions of staff; direct observations; and interviews with staff and participants.

Cost-effectiveness analysis

The evaluation takes a 'within-trial' approach and assesses only those costs and benefits that fall within the first 12 months following the evaluation. Costs were measured from the perspective of the UK NHS. Resources to implement the intervention were costed using a micro-costing approach that took into account the time spent by healthcare staff on training and intervention delivery. Health service use was assessed through patient questionnaires and primary care electronic health records. Quality-adjusted life-years (QALYs) were estimated from the EuroQol-5 Dimension, five level questionnaire (EQ-5D-5L) questionnaire. We calculated incremental cost-effectiveness ratios to represent the incremental cost required to obtain one additional QALY when moving from usual care to the new intervention.

Results

A systematic review and meta-ethnography of the literature

Key themes were lack of proactive follow-up; premature withdrawal of services; lack of support in specific areas; lack of information about local services and realistic timescales for recovery; and poor communication both between patients and HCPs and between different HCPs. Our overarching

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narrative was of marginalisation of stroke survivors and caregivers by the healthcare system, characterised by passivity of both patients and health services and fluidity of needs.

Qualitative interviews with patients and carers

Patients talked about many different needs, including physical (e.g. fatigue), psychological (e.g. fear of another stroke; loss of confidence) and informational (e.g. feeling unprepared; lack of prognosis). They noted a lack of continuity and advance planning from health services. Caregivers added the impact on themselves, such as the loss of the physical/emotional side of a relationship. General practice was the first point of contact with health services to raise any of these needs.

Focus groups with healthcare professionals and patients

Roles of generalist and specialist overlapped, but they tended to work in silos. Referral decision-making was associated with quality of communication, which was variable. Barriers to communication included different information technology systems, different technical languages and lack of knowledge of roles.

Both HCPs and patients were supportive of the idea of using a checklist, though healthcare professionals emphasised the importance of having a pathway to address identified needs. Some needs were added to the 11 in the published checklist that was used as a starting point.

Modified Research And Development Corporation Appropriateness Consensus Study

For most referral decisions (59 out of 69, 86%), there was agreement as to whether or not referral was indicated. Lack of consensus tended to be where it was questioned if specialist input would lead to patient benefit. This lack of consensus was not related to professional background.

Scoping review

Rehabilitation and physiotherapy interventions to address activities of daily living were most common. Cognitive problems, fatigue and specific mental health outcomes were not addressed.

Pilot study

Out of 48 stroke survivors invited, 13 (27%) took part. All attended a stroke review with a practice nurse. Action plans were generated for 10 (77%) patients.

The Improving Primary Care After Stroke (IPCAS) model

The final model included five elements: a structured review; a direct point of contact (DPoC); improving communication between primary and secondary care; local service mapping; and training of primary care professionals.

Managing Life After Stroke development work

The feasibility study involved 17 stroke survivors and 7 carers in three courses. Fifteen (88%) patients completed the course and 5 (71%) carers. Fourteen of 15 (93%) participants who completed a follow-up questionnaire said they would recommend the course to someone else.

The final MLAS self-management programme for people with stroke comprised an initial individual session, four weekly group-based sessions and a final individual session.

Cluster randomised controlled trial

One thousand and forty patients with a mean age of 70.6, 63% male, were recruited from 46 general practices (range per practice: 8–36). Median time since last stroke was 5 years. Primary outcome data were available for 76% of those still alive at 12 months. There was a 0.64 [97.5% confidence interval (CI) −1.7 to +2.8] improvement in the emotion outcome in the intervention arm compared to the control arm and a 1.3 (97.5% CI −2.0 to +4.6) increase in the participation outcome in the intervention arm compared to control. There was no evidence of effect of the intervention on short form Stroke Impact

Scale, quality of life (QoL) (EQ-5D-5L), well-being ICEpop CAPability measure for Adults, Southampton Stroke Self-Management questionnaire or Health Literacy Questionnaire (HLQ). One hundred and seventy (43%) patients in the intervention arm identified fatigue as a need. Mobility (153, 39%), mood (130, 33%) and cognition (128, 33%) were the next most commonly identified needs.

Process evaluation

With regard to the different components of IPCAS, delivery of the structured review had the most uptake, with 421 (81%) of 522 participants receiving a review and action plans being generated. These included follow-up appointments (29%), referrals (25%) and provision of advice (45%). Only 139 patients attended an MLAS course, but those who did appeared to value it. Practice staff perceived that a lot of effort was put into setting up the DPoC service, but this was hardly used. The local directory of services had variable take-ups by HCPs. It did not prove possible to support improved communication between primary and secondary care as originally intended. Instead, we needed to rely on videos of specialist staff explaining what they did and how to access their service. Training fidelity was high.

Cost-effectiveness analysis

There was a non-significant mean QALY difference of 0.013 (95% CI −0.024 to 0.048) in favour of the intervention. The intervention was associated with an incremental cost to the NHS of £267.07 per person. This equated to an incremental cost per QALY of £20,863.

Conclusions

Implications for health care

1. We found no evidence that structured stroke reviews offered in primary care to all stroke survivors in the community are effective at addressing stroke-related needs. Such reviews should perhaps therefore be time-limited after stroke and only continued in selected patients.
2. The 15-item checklist that we developed is perceived to be useful and practicable in primary care.
3. Greater attention needs to be paid to services that can address the prevalent long-term needs of stroke survivors, namely fatigue, low mood and cognitive issues.
4. From the evidence in the wider literature, self-management programmes have a role in improving QoL of stroke survivors in the community. Our findings suggest that such programmes are likely to be of greatest value if offered early after discharge from hospital.

Research recommendations

1. Research to inform who should be offered poststroke assessment of needs in the community in the longer term (after 6 months).
2. Development and evaluation of interventions to address fatigue, low mood and cognitive problems in people with stroke in the community.

Study registrations

This study is registered as PROSPERO 2015 CRD42015026602.

Trial registration

This trial is registered as ISRCTNCT03353519.

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