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Evaluation of Community Rehabilitation Service Delivery in Long-Term Neurological Conditions

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The authors would like to note that there are some formatting issues with this report which, despite extensive efforts by both the authors and the editorial team, were not possible to resolve.

Criteria for inclusion
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Glossary of terms/abbreviations

BCN – Basic Care Needs

BI – Barthel Index

CIQ – Community Integration Questionnaire

CRT – Community Rehabilitation Team

CSRI – Client Service Receipt Inventory

ERG – External reference group

HRG – Healthcare Resource Group

ICD-10 – International Classification of Disease Version 10

ICP – Integrated Care Planning

LSNRC – London Specialised Neuro-Rehabilitation Consortium

LTNC – Long-Term Neurological Condition

NIHR – National Institute for Health Research

NHS – National Health Service

NIS – Neurological Impairment Scale

NPCNA – Northwick Park Care Needs Assessment

NPCS – Needs and Provision Complexity Scale

NPDS – Northwick Park Dependency Scale

NPDS-P – NPDS Physical subscale

NPDS-CB – NPDS Cognitive/Behavioural subscale

NSF – National Service Framework

PbR – Payment by Results

PCT – Primary Care Trust

QIPP - Quality, Innovation, Productivity and Prevention

QR – Quality Requirement

R&D – Research and Development

SDO – Service Delivery & Organisation

SNN – Special Nursing Needs

UKROC – United Kingdom Rehabilitation Outcome Collaboration

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Recruiting Centres

We are most grateful to the clinical teams within the nine recruiting centres who recruited patients, and to Ifan Jones of the Stroke Network Team at the Wolfson Rehabilitation Centre who also assisted with recruitment.

The Principal Investigators within each centre were:

Northwick Park: Dr Andrew Thu (Consultant)

Maudsley: Dr Simon Fleminger (Consultant)

Edgware: Ana Bajo (Psychologist)

Blackheath: Tanya Hodnett (Manager)

Homerton: Dr Clarence Liu (Consultant)

Queens Square: Dr Diane Playford (Consultant)

Putney: Dr Sophie Duport (Research Manager)

King's: Dr Julian Harriss (Consultant)

Wolfson: Dr Pradeep Deshpande (Consultant)

Co-Applicants

The following co-applicants helped to develop the study proposal

Barbara Howe – Commissioning lead for specialist neurological services at the time of the application

Daniel Sims – Finance officer, King's College London

Irene Higginson – Head of Department of Palliative Care, Policy and Rehabilitation, King's College London

Members of the research team

Helena Morris – Research coordinator

Sasha Wade - Research coordinator

Bernadette Khoshaba - Research coordinator

Christine O'Connell - Research assistant

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Ralph Crook – Data entry

Ali Price - Research assistant

Jo Clark - Administrative support

Natalie Campbell - Administrative support

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Contributions of authors

Richard J. Siegert (Professor of Psychology and Rehabilitation) analysed recruitment data, the longitudinal cohort study data, evaluated the psychometric properties of the Needs and Provision Complexity Scale, and contributed towards writing the report.

Lynne Turner-Stokes (Professor of Rehabilitation) analysed the level and type of services patients received in the community, the extent to which needs were met and contributed towards writing the report.

Paul McCrone (Professor of Health Economics) analysed the differential costs and costs outcomes of models of community neuro-rehabilitation and contributed towards writing the report.

Diana Jackson (Senior Research Fellow, Health Services Research) analysed referral patterns for community rehabilitation services, findings from the survey of community rehabilitation teams and contributed towards writing the report.

Paul Bassett (Medical Statistician) carried out statistical analyses of service data.

Diane Playford (Senior Lecturer and Honorary Consultant Neurologist) was an active member of the LTNC study steering group providing oversight throughout.

Simon Fleminger (Consultant Neuropsychiatrist) was an active member of the LTNC study steering group providing oversight throughout.

Project Steering Group

The project steering group consisted of the applicants, members of the research team and principal investigators for each site. The group met on average quarterly and were key in guiding progress.

Public and Patient Involvement

The impetus for this study came from users themselves in the preparation of the NSF for Long Term Conditions, when they highlighted the gap between hospital care and rehabilitation and care in the community - and called for research in this area. User and carer involvement was integral to the planning and execution of the programme through our established patient and carer groups, and national voluntary organisations.

The external reference panel for the LTNC dataset included both individual users/carers and representatives of user organisations led by Nicola Russell

of the MS Trust. We continued to liaise with those groups throughout the planning and development stages of this programme. Patient involvement was harnessed in terms of the research process, and particularly in the drafting and layout of questionnaires, and of the on-line survey, to make these as applicable and user-friendly as possible.

Our questionnaires evolved from those developed in the course of our earlier research into experiences of carers of people with LTNCs in the community. Members of our established Project Advisory Panel for that research comprised six carers and four representatives of voluntary organisations for people with LTNCs (Headway, Encephalitis Society, MS Society, Motor Neurone Disease Association), who were instrumental in influencing the design and content of the original questionnaire study at three-monthly meetings.

During the pilot phase of this study we took extensive feedback from participants regarding the nature and content of the questionnaires, which influenced their further development.

Community rehabilitation services

We are most grateful to those community services that completed the questionnaires describing their services.

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Ethics

Approval for the study was granted by Bromley Research Ethics Committee (Ref no: 09/H0805/25) and subsequently R&D centres of the seven participating NHS trusts. The remaining two recruiting centres were in the independent sector - approval for recruitment was obtained through their internal clinical and research governance processes.

CLRN Registration

The study was registered with the Comprehensive Local Research Network ID number 7503

Project Funding

This project was funded by the National Institute for Health Research Service Delivery and Organisation programme (project number 08/1809/235).

Executive Summary

Background

The National Service Framework (NSF) for Long-Term Neurological Conditions (LTNCs) emphasises the need to place patients and families at the centre of service provision, and promotes integrated community-based services focussed on a person-centred model of service delivery.

A previous report funded by the NIHR SDO programme (Gladman 2007) demonstrated that community services for LTNCs were fragmented or missing. Particular gaps were highlighted in services for people with cognitive deficits and/or challenging behaviours.

Given the life-long nature of LTNC, it is critical to be able to identify and track patients via longitudinal data collection. The NSF for LTNC Expert Reference Panel therefore recommended the development of: (a) a LTNC register to identify patients with complex needs and (b) a dataset to support long-term follow-up by monitoring their changing needs over time and the support services they receive.

The register and dataset have the potential to provide benchmarking of service provision and 'practice-based evidence' for the effectiveness of interventions on a national scale. But before data can be collected in routine clinical practice, the data collection tools must be made fit for purpose. Further, to gather prospective information on service costs and cost benefits, we need simple and practical tools to collate these data.

Aims

1. To pilot the use of an LTNC register and its associated tools as a means to identify and monitor patients with LTNC who have unmet needs.
2. To describe the needs of this group for on-going community based rehabilitation and support.
3. To identify any unmet needs and determine which variables predict the level of rehabilitation services received.
4. To examine the relationship between provision of rehabilitation and outcomes with respect to disability and community integration.
5. To examine the health economic aspects of met and unmet health and social care needs.
6. To identify the differential cost and cost-outcomes of different models of community neurorehabilitation/support services.

Methods

The research had five components:

1. A rapid literature review of evidence on best models of integrated service provision for LTNCs in the community.
2. Piloting and feasibility testing of the LTNC register, including:
3. Development and testing of a manageable set of tools/questionnaires to support data collection for the register, both by clinicians and patients and/or their proxies.
4. Evaluation of a new tool - the Needs and Provision Complexity Scale (NPCS) - as a simple practical instrument for evaluating met and unmet needs.
5. A longitudinal cohort study using postal survey questionnaires to follow up consecutive patients discharged over a 12-month period from the nine specialised (Level 1) rehabilitation units within the London region.

The following were measured:

- neurological impairments
- physical, cognitive and behavioural disability
- needs for and provision of health and social services (including community rehabilitation)
- community integration and participation
- perceived carer burden
- client satisfaction

The extent to which needs for health and social care were met was compared with outcome.

Health economic modelling:

Information on health and social care services used in the past six months, and care hours from family carers, allowed costs of current care to be estimated by combining the service use information with appropriate unit cost data.

Cost estimates of providing unmet community rehabilitation needs were made using the same unit cost data. Multivariate regression analyses were conducted to identify predictors of (a) current costs (b) potential costs if services were provided to meet needs.

To assess the development of integrated services locally during implementation of the NSF, we mapped community rehabilitation and support services that patients were referred to, and surveyed services offered by clinical teams and perceived barriers to services and service utilisation.

Results

An appropriate set of tools was developed for inclusion in the LTNC register. Of those asked, 96% of patients were willing to be registered, but only about one-third responded consistently to questionnaires.

The data provided support for the utility of the Needs and Provision Complexity Scale (NPCS) as a brief and practical tool for assessing complex needs among a group with significant physical and cognitive impairments. Two-thirds of the group required medical support and assistance with personal care; over 90% required on-going community rehabilitation.

The NPCS also provides a simple, reliable and scale-able tool for measuring met and unmet needs for health and social care. At six months post discharge, it demonstrated significant gaps between needs and service provision, especially regarding on-going community rehabilitation, equipment and social support. By contrast, needs for medical and nursing care were relatively well met. Provision of support for personal care above the level of predicted need suggested a deterioration of independence for some patients after discharge from in-patient rehabilitation, possibly due to the failure to meet their needs for rehabilitation and social support.

We found no evidence that demographic variables (age, gender, marital status, education, diagnosis) predicted how much rehabilitation/support people received after discharge from hospital. The best single predictor was dependency for basic care needs which accounted for 33% of variance in total NPCS score. Motor and cognitive impairment improved the predictive ability of the model to 40%. Similarly, we found no evidence that people with cognitive behavioural problems were likely to receive less rehabilitation - cognitive behavioural needs predicting 22% of the NPCS score. Whether disability is physical or cognitive, more disabled patients receive greater levels of health and social services. Clinical teams, however, reported insufficient staff and resources to support patients with complex needs – especially in vocational rehabilitation.

The relationship between levels of rehabilitation received after discharge and outcomes (dependency, community integration and perceived carer burden) was explored. We hypothesised that outcomes would be better when needs for rehabilitation and support were well-met. In fact we demonstrated the opposite relationship. The overall level of health and social services received was a strong negative predictor of community integration at six months and a positive predictor of dependency and perceived carer burden. At first sight it seems surprising that having one’s needs for healthcare and rehabilitation met is associated with poorer outcomes. However, at a practical level this is logical. Rehabilitation is a goal-oriented process, and therapy interventions will normally be withdrawn once goals have been met. Given the scarcity of community rehabilitation services it makes clinical sense for therapy teams to focus their efforts on patients with the greatest needs for support.

The average cost of formal care across the sample was £10,486 in the first six months. When informal care costs were included, the mean cost rose to £28,352. In-patient care accounted for 46% of total costs. Over half of the patients received care from family/friends, which accounted for 62% of total costs. During the second six-month period, use of many health and social care services reduced. Total formal care costs fell to an average of £6,824, but reliance on informal care increased – so that by 12-months it accounted for 75% of total costs. Total mean costs had reduced slightly to £25,803.

Over the whole 12-month follow-up period, significant predictors of total cost were cognitive and motor problems, and being in the physical, hidden or mixed dependency groups compared to being independent. This model could explain 35% of variation.

Costs-analysis of met and unmet needs demonstrated a relative under spend on rehabilitation, social care and equipment at 6 months, compared with predicted needs, and an overspend on personal care and accommodation. Applying the costing algorithm within the NPCS suggests that appropriate investment in rehabilitation and support services could potentially save on average over £10,000 per person per year of over expenditure on personal care and accommodation – although admittedly families and informal carers currently bear the brunt of the extra costs.

Conclusions

Our findings suggest that a register in the form tested here would be used and appreciated by at least a third of patients. However, postal/telephone follow-up is labour intensive, and may not capture some of the most vulnerable patients. Integrated care planning reviews should normally involve face-to-face meetings with patients and/or carers and this may offer an appropriate route to data collection for the register.

While community-based services provided specialist multi-disciplinary care, some were under-staffed, and others felt under pressure to increase throughput of patients at the expense of providing high quality holistic services in the longer term, especially for patients with complex needs.

The NPCS forms a simple practical tool to capture met and unmet needs and so assist clinical teams to identify and address any gaps in service provision at either an individual or population level.

Failure to meet needs for rehabilitation, social support and equipment provision in this sample was demonstrably associated with increased requirements for personal care. The burden of caring for people with LTNCs fell largely on their families and this burden increased over time

This study was confined to the London region for pragmatic reasons. Further work is now required to match provision to need in other parts of the country and to provide more detailed analysis of the costs and cost-benefits of meeting unmet needs, so to determine future priorities for investment in service development.