ResearchSummary

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Continuity of care in stroke and its relation to outcomes

Continuity of care has been considered a desirable principle in the delivery of health care for many years but its definition has proved elusive (Starfield, 1980). Moreover the meaning of continuity of care to the users of services, particularly those with chronic, long-term conditions is not fully understood. The nature of stroke means it is an important condition in which to consider continuity of care.
Improvements in acute stroke care have helped more people to survive the initial event, but while mortality has been reduced, this has only served to highlight the fact that stroke is a major cause of disability. Half of the survivors of the initial stroke event (about one third of all acute strokes) are left with some degree of disability, ranging from moderate to severe. The assessment of continuity of care is therefore of relevance in this condition to determine its impact on outcomes for stroke survivors.

This research summary, based on research led by Professor Allan House at University of Leeds, commissioned by the NIHR Service Delivery and Organisation Programme (SDO), discusses the scope and structure of existing stroke services from the point of view of the patients who use them and the staff who work in them. (Hill *et al*, 2008). It will be of interest to anyone involved in delivering primary, secondary or social care services to people with stroke-related conditions, researchers with an academic interest, and interested members of the public.

Key findings

- Continuity of care is a professional and organisational-centred concept, which focuses on the provision of statutory services, and which is recognised by health care staff but not recognised in the same way by patients.
- It is unclear what aspects of continuity can be generalised from one disorder to another, and currently accepted models of continuity of care do not transfer to the type of care or services received by stroke survivors.
- Current ideas of continuity privilege certain factors as invariably important such as relational continuity (seeing the same person) in primary care; managerial continuity in acute care and informational continuity in areas like mental health where the emphasis is on care planning not consultant led care.
- Patients cannot distinguish the overall process of care, or appraise it, but they can give their perception of the outcome of care.
- Patients can relate incidences from their experiences of care and identify gaps in the care they receive but, even when questioned explicitly about the process of care, they do not recognise the mechanisms and systems of care, and do not understand the relevance of how these events impact on their care overall.
- In relation to measurement from the patient's perspective, continuity is intimately linked to related concepts such as quality of care and patient satisfaction.

Background

Stroke is a complicated, heterogeneous condition with acute onset but complex and enduring sequelae. Improvements in acute stroke care have helped more people to survive the initial event, but while mortality has been reduced, this has only served to highlight the fact that stroke is a major cause of disability. It is also increasing in incidence as a consequence of the growing population of elderly people. This creates particular challenges for continuity of care as patients may present with multiple co-morbidities and social issues arising from isolation in old age. Declining cognitive and physical function can also impact on stroke care. Furthermore, stroke is an acute event of sudden onset and is treated in the initial stages as a medical emergency, thereafter the focus and objectives of treatment are aimed at improving function and secondary prevention rather than the suppression of symptoms. Thus it is more often the case that multiple agencies are involved in stroke care than might be so in other conditions, with the exception of mental health and some palliative care, and stroke is therefore an important condition in which to consider continuity of care.

Aims of the study:

- To study the experience of stroke care from the patient's perspective and develop a description of patients' views and understanding of continuity in their care;
- To develop methods of quantifying continuity of stroke care (or modify and adapt existing methods) to produce both a patient-centred measure and a service record-based measure, that reflected where possible the patient's view of continuity of care;
- To apply quantitative assessments of continuity of care in a cohort of stroke patients in order to examine its impact on functional and psycho-social outcomes for survivors;
- To seek professionals' views on the aspects of service organisation that are relevant in determining continuity of care.

Participants

The study was carried out in two large acute hospital NHS trusts in the North of England. It aimed to be as inclusive as possible and cover a range of stroke severities therefore only patients with transient ischemic attack, subarachnoid haemorrhage or severe cognitive deficits were excluded. Health and social care professionals were contacted according to the nature of their role in stroke care or community care.

Study design

A review of the literature provided a theoretical framework for the study based on the Canadian Health Services Research Foundation three-element model of continuity of care: managerial, informational and relational continuity (Reid, 2002). A mixed-methods approach was then used in a series of inter-linked studies which were conducted in a cross-sectional design in order to explore the process of stroke care with patients during the year following an acute stroke event. Qualitative studies of process are important for developing an understanding of stroke care in order to establish what works not only for patients but also for formal and informal caregivers, why it works, and how care processes are perceived by them. Dowswell *et al* identified the need for more qualitative research in stroke. (Dowswell *et al*, 2000).

> ***"While a great deal has been written about stroke recovery, there has been relatively little theoretical work examining the process from the point of view of patients and caregivers."***
> **Dowswell *et al*, 2000**

As a starting point for this study qualitative methods were used to obtain empirical evidence about the meaning of continuity of care from 42 people with stroke. This enabled the development of a method of evaluating continuity of care, and subsequent phases of the study, to be firmly grounded in the patient's perspective. Information about the process of care was also extracted from medical records and hospital and community care notes to produce a record-based measure.

A range of assessments of both physical and psychological functioning were undertaken during the period shortly after admission, and at regular intervals up to one year after the initial stroke event. Data on demographic and other variable social and life-style factors were also collected from patients. These assessments were used to determine whether there was an association with continuity of care and to examine its impact on outcomes of care for stroke patients.

Practical findings

Patient experiences of care

Currently accepted models of continuity of care did not readily transfer to the type of care or the services received by stroke survivors although the narratives did reveal implicit aspects of continuity within them. Patients could, either directly or indirectly, identify gaps in care and comment on the quality of the individual elements of care they had received, and expressed feelings of satisfaction or dissatisfaction with them. However, they could not distinguish the overall process of care, or make an appraisal of it other than to give their perception of its outcome.

Continuity in the management and organisation of care

Managerial continuity is regarded as important in chronic or complex diseases like stroke. Ideally, therefore, it involves a coordinated approach to care using shared protocols and cooperative planning to facilitate the delivery of care in a complementary and timely manner. However an appreciation of a formal, 'managed' view of health care was not readily elicited from the lay respondents in this study, and very few of the stroke patients interviewed could talk objectively about aspects of their care in these terms unless they had some special knowledge or insight. Notwithstanding the ability of the participating patients to describe their care, it became evident as the study progressed that few, if any, had more than a vague idea about the mechanisms and processes that contribute to care. There was no overall concept of care as managed or organised in a systematic way other than a rather vague overarching idea of the consultant *"being in charge"*.

When specifically asked what they thought about the way care was organised their responses were often ambivalent.

> ***"...Well yes – and, but as I say whether they're working together basically as a team I don't know, you know and to be honest I don't, I don't really care because what they're doing for me individually is working, or it has been..."***
>
> **Patient**

Continuity in relationships

Conversations with patients and carers revealed that inter-personal relationships with health care staff were clearly important to them. Nevertheless, they had difficulty identifying the individuals involved in their care, and did not easily recognise the different roles of hospital or community staff. From the patients' perspective, most professionals in hospital were divided into two broad categories: nurses and doctors. The nature of stroke and the acute hospital environment inevitably played a role as this patient describes:

> ***"I don't know there was so many backwards and forwards that I think the only one that I really think and talked to me was (Doctor's name) then and I think that was when they decided that they were going to take me to (Another hospital) then. But it's a bit hard trying to remember (of course) you know and the thing is as well there was so many people coming and going in the end you didn't who was what there. I mean it was nice that they come and say this is doctor so and so. But it's too quick."***
>
> **Patient**

Continuity in information

Information was the theme which patients recognised most readily, and could interpret in relation to their care. It had links to relationships with staff, and patients often mentioned people who were *"good at telling you things"* or *"had time to talk"*. Discussions with General Practitioners after discharge were also frequently mentioned, and by and large it was evident that patients found their GP to be a source of information and support after their stroke. GPs were often individually described as *"a good communicator"*.

How information was passed between health care agencies, and the initiators of information transfer were much less clear, both in hospital and in the community.

> ***"I mean, like I say doctor didn't come to see, you know they say when you come out of hospital your doctor will come and see you when they get this letter, we'll fax them and that, but I mean, practice nurse came so... I suppose he must have passed it on".***
>
> **Patient**

Positive and negative views of continuity

When patients were asked whether they thought their care had been 'well joined up' or 'coordinated', seventeen patients were able to make an assessment of this aspect of their care. Eight out of the seventeen expressed positive perceptions of the coordination of their care. Nine seemed doubtful about the degree of coordination that existed in health care, although most felt that things 'worked' despite this.

The remainder of the interviewees said that they didn't know or couldn't say how joined up or coordinated their care had been, or they were equivocal. The carers (n = 5) who contributed to an assessment of continuity presented a different, and sometimes contradictory, perspective. More negative views of continuity were expressed by the carers of stroke patients than by the patients themselves.

Case-note reviews

The medical and community care records of participants in the qualitative study were reviewed, and the number of health care professionals involved in the care of each patient assessed. It was found that the process of stroke care could not be determined simply by quantifying input from care-givers. This was due not only to the complex nature of stroke but also to the confounding factors which arose from the dependency or physical status (stroke and non-stroke related) of the patients, as well as to the quality of entries in the care records.

Evaluating a patient perceived continuity measure

The literature review identified a questionnaire, the Patient Perceived Continuity questionnaire, which had been developed in a family care setting in the USA (Chao, 1988). This was given to a sample of stroke survivors living at home a year or more after their acute stroke event. A total of 178 completed questionnaires were obtained representing 54% of the total eligible survey population.

The results showed that the Chao measure was not particularly sensitive to those factors that might be expected to drive care patterns, for example respondent differences in age, gender or level of dependency. Only those outcomes assessed by the mental health dimensions of the instruments used in the cohort study showed any association with the Chao scores.

Quantifying continuity

Two new measures of care were designed and tested as part of this study. A checklist evaluated care recorded in formal health and social care records using the phases and transitions in stroke care as markers of continuity. This measure was tested in a full case note review of a sample of 126 patients. Using this method it was difficult to separate an evaluation of continuity in the process of care from the input and intensity of care. The scores largely reflected the physical status of the patient and their level of disability. Patient perceived continuity was measured using structured interviews conducted directly with the same cohort of stroke patients. Care assessed in this way showed a strong association with mood and psycho-social wellbeing.

A confirmatory factor analysis showed that the two new measures were in fact measuring two distinct constructs: 'disability' and 'perceived care', which were separate and uncorrelated. Latent variables were derived as part of this process in order to represent the underlying constructs and used to describe their association with the demographic features of the sample, and to examine effects on outcomes for patients.

The disability construct measured in this study was slightly higher (worse) for female stroke patients than for males, although the male group had more outliers. There was however only a very slight association between worse disability and age, which was heavily influenced by two younger outliers in the data. A similar pattern was found for the perceived care construct. Lower (worse) median scores for the perceived care construct were associated with female gender, and there was no association between age and the perceived care construct.

The impact of care on outcomes for patients

The structural equation model used in the confirmatory factor analysis had shown that baseline mood contributed to the latent constructs perceived care and disability. This was explored further by using them as predictors of mood at one year after stroke. The results showed that worse emotional outcomes were associated with poorer perceptions of care, and to a lesser extent with higher levels of disability. Worse physical rehabilitation outcomes were associated with higher levels of disability, which is unsurprising given that the severity of the stroke and its consequent disabling effects will usually be good predictors of the level of residual disability that the patient will experience – only in rare cases do patients make a full recovery from a severe, initial disabling stroke event. Poorer perceptions of care were also implicated to a lesser extent. Determining causality however was not straightforward in this evaluation since emerging poor outcomes may have resulted in perceptions of poor care, in which mood was an important mediating variable. Alternatively it is possible that patients were able to identify aspects of their care that genuinely made a difference to them.

'Achieved care' could thus be measured by including contributions from components of the physical, psychological and cognitive status of the patient in addition to the two measures of care. The results showed that the chances of a less successful outcome for rehabilitation went up as disability increased and ratings of perceived care decreased. However, patient mood states and short-comings in services alone did not affect care, and examples were also found of cases where patient choice or behaviour were the primary factors influencing the care that they received.

Understanding how care is delivered

In the final strand of research health care professionals described the patterns, modes, content and impact of their interactions and communication. Focus groups and individual interviews were conducted with clinical care staff, community care providers, voluntary sector workers and health care managers in hospital, primary care and community settings to examine the ways in which stroke care professionals and community care staff work with patients.

What emerged was an account of communication networks that, when peopled with people and patients, amounted to a description of care delivered through care networks. Patterns of care were identified in the study that indicated that care networks exist in stroke services, which while not structurally explicit were evident from their activities and functionality.

> ***"We are all based together in the same room... So virtually everyday we are meeting to do a handover every morning... We have on going discussion if there's any problems... we all work together, which is very useful because we problem solve together and we overlap in many ways... we go out and do joint visits with the Physio and the OT and look at problems together, and ways of working together."***
> **Senior Nurse, Intermediate Care Team**

The findings suggested that it was the connectedness of individuals within these networks rather than the longevity or predictability of individual relationships that delivered good care.

In terms of stroke care, continuity may be more easily understood in the context of a network of care. Patients and carers in this model would form an integral part, with individuals accessing different parts of the network according to their needs or circumstances. In this study it was not possible to define the characteristics of a high quality network but access to knowledge and the sharing of skills and expertise are clearly important factors. Network models offer a mechanism for coordinating care through the sharing of knowledge and collaborative working which are vital to deliver diversity in care.

Conclusions

This study of continuity in stroke care led the researchers to conclude that continuity of care is a professional and organisational-centred concept, which focuses on the provision of statutory services, and which is recognised by health care staff but not recognised in the same way by patients. Current ideas of continuity tend to privilege certain factors as invariably important such as relational continuity (seeing the same person) in primary care; managerial continuity in acute care and informational continuity in areas like mental health were the emphasis is on care planning not consultant led care. It is unclear what aspects of continuity can be generalised from one disorder to another. In relation to measurement from the patient's perspective, while patient perceived care could be assessed, continuity is intimately linked to related concepts such as quality of care and patient satisfaction.

Future research

Research is needed:

- To determine the nature of the relationship between perceived care, mood and rehabilitation outcomes.
- To identify the characteristics of effective clinical care networks so that, as they are implemented for example in response to the UK National Stroke Strategy (Department of Health, 2007), they have most chance of being successful.
- To refine existing measures to develop simple to use measures of perceived care, of which continuity and coordination would be a component, as a means of assessing the patient-centeredness of stroke services.

Service delivery should emphasise:

- The need for both planned care pathway, especially early after stroke, and planned care networks, especially in longer-term care.
- The needs to integrate physical and psychological aspects of stroke rehabilitation and longer term care, given the importance of mood and perceptions of care in influencing rehabilitation outcomes.

About the study

This five year programme of NHS SDO work was integrated with a four-year longitudinal, observational cohort study funded by the Stroke Association, which sought to examine the effect of depressive symptoms on outcomes for patients in the year following an acute stroke. The SDO study of continuity of care recruited patient participants from two sources:

1. Stroke survivors identified and recruited from the local stroke database
2. Chronic stroke patients sequentially recruited from the cohort of patients participating in the Stroke Association funded study.

The Stroke Outcomes Study: Continuity of Care Programme

The programme comprised a series of inter-linked studies which followed on from a review of existing research.

Study 1: An exploratory qualitative study to investigate how stroke patients understand and experience continuity in their care.

Study 2: A review of hospital and community clinical care notes using a count of signatures to provide a measure of continuity of care.

Study 3: A pilot study of a published measure of continuity, identified from the literature, to establish the feasibility of using it as a measure of continuity of care in stroke.

Study 4a: A study extracting information recorded in the patients' full complement of clinical case notes using a checklist to measure continuity.

Study 4b: A patient-centred study measuring experienced continuity using a semi-structured interview, the content of which was based on the findings from Study 2 and Study 3.

Study 5: A qualitative study of communication between health professionals delivering care to patients with stroke.

Analysis

Social and demographic characteristics are described for patient participants for each of the separate studies that form the programme. Interviews are recorded in the qualitative studies with patients and health care professionals, and subsequently transcribed and analysed using framework analysis. The theoretical framework for the analysis derives from existing research by Freeman *et al* and the Canadian Health Services Research Foundation (CHSRF), (Freeman, 2000, Reid, 2002). Quantitative analyses are conducted on responses to the questionnaire used in Study 3 (Chao, 1988), and to data derived from the Snakes and Ladders checklist and the Patient Perceived Continuity Interview in Studies 4a and 4b. Univariate methods are used to assess the effects on functional and psychosocial outcome variables derived from the Stroke Association funded, longitudinal cohort study. Multivariate techniques are applied to examine the factor structure of the newly developed measures using structural equation modelling. The effects of the latent variables derived on outcomes are examined in the cohort by undertaking logistic and binary regression analyses.

Members of the research team

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Further information

The full report, this research summary and details of current SDO research in the field can be downloaded at: www.sdo.nihr.ac.uk

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Feedback

The SDO Programme welcomes your feedback on this research summary. To tell us your views, please complete our online survey, available at: www.sdo.nihr.ac.uk/researchsummaries.html

About the SDO Programme

The Service Delivery and Organisation Programme (SDO) is part of the National Institute for Health Research (NIHR). The NIHR SDO Programme is funded by the Department of Health.

The NIHR SDO Programme improves health outcomes for people by:

- commissioning research and producing research evidence that improves practice in relation to the organisation and delivery of health care; and
- building capacity to carry out research amongst those who manage, organise and deliver services and improve their understanding of research literature and how to use research evidence.

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Addendum

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The management of the Service Delivery and Organisation (SDO) programme has now transferred to the National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre (NETSCC) based at the University of Southampton. Prior to April 2009, NETSCC had no involvement in the commissioning or production of this document and therefore we may not be able to comment on the background or technical detail of this document. Should you have any queries please contact sdo@southampton.ac.uk.