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Continuity of care: Findings of a conceptual review and synthesis of the NIHR SDO programme of research

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Issues around continuity of care run through health and social policy. A programme of research studies, begun in 2001, explored what continuity of care actually means, what service users and carers want in the way of continuity of care, what influences their experience, and any outcomes produced. A report in 2007 reviewed interim outputs from the programme, when some of the research studies were still running. Our study builds on, extends and completes that review.

Key findings

- Patients generally talked about their preferences and experiences of care and treatment using language other than 'continuity'. Their behaviour, influenced by personal, family and cultural beliefs and choices, interacted with service provision and sometimes influenced outcomes.
- We found evidence about carers' own preferences and needs mainly in studies on cancer and severe mental illness. Carers valued good relationships with professionals; recognition of their contribution to patient care, and acknowledgment of their own needs for support.
- In most of the studies health and social care professionals saw continuity of care as a relationship between an individual professional and a service user. Sharing information was important, as was working together effectively.
- We found mixed progress in measuring continuity of care. One measure seemed to offer potential for development for other long-term conditions.
- The research studies used and interpreted in different ways a model of continuity of care proposed by Freeman and colleagues (2001). The model was based on the principle that continuity should be viewed from patients' and carers' perspectives. Our analysis showed how examining the concept of continuity from various discrete perspectives led to new understanding. This was that continuity is an experience that is co-constructed, arising from the interactions between patients, carers and professionals.

Background

Despite a focus on the importance of continuity of care within health and social care, it has been hard to change practice to achieve what service users appear to want. One problem is confusion about what continuity of care actually means.

A programme of research on continuity of care, funded by NIHR SDO, ran between 2001 and 2008. This included a scoping study (Freeman *et al*, 2001) and a series of primary and secondary research projects. Each project explored the meaning and experience of continuity of care from patient, carer and professional perspectives across a range of conditions and services (see Table 1 for details).

Within this programme, Freeman and colleagues (2001, 2002) outlined a conceptual framework for defining continuity of care, and conducted an interim review of the outputs of the programme (2007), while some of the research projects were still running. Our final synthesis extended and completed the review, aiming to:

- identify influences on the experience and delivery of continuity of care
- identify outcomes of continuity of care
- compare research instruments designed to measure continuity of care
- confirm or refine Freeman's conceptual model of continuity of care.

Table 1: SDO Continuity of Care Research Programme Projects

Lead researcher/s, year of final report	Patient group/topic	Type of study
Baker, 2006	Primary care	Primary
Burns / Catty, 2007	Mental health (2 linked studies)	Primary
Gulliford, 2006	Type 2 diabetes	Primary
Hardy, 2005	Organisational and professional boundaries (learning disabilities and stroke)	Primary
Hill, 2008	Stroke	Primary
King, 2006 & 2008	Cancer (2 linked studies)	Primary
Forbes, 2001	Transition from children's to adult care for young people with chronic illness or disability	Review
Freeman, 2002	Severe mental illness	Review
Humphrey, 2002	NHS human resources management (maternity care, primary care, mental health and cancer care)	Review

Findings

Patients' experiences of continuity of care

Patients generally did not use the term 'continuity', but talked about preferences and experiences of care and treatment using other language. Issues that were important centred around their relationships with professionals and service providers; access to services; their understanding of their condition and treatment; the exchange of information; co-ordination of their care; what happened to them during transitions in settings and services (for example, going home from hospital); their personal agency, and their identity as a whole person.

Patients' own behaviour, based on personal and cultural choices and beliefs, and sometimes family influences, interacted with service provision and delivery. This sometimes influenced outcomes. What might be considered 'discontinuities' in care were sometimes perceived positively or actively pursued. For example, some patients wanted a change in personnel or an alternative strategy.

Patients' experiences were influenced by their individual characteristics and circumstances, the trajectories of their illness, the schedules of care and treatment, and the way services were structured and administered. Their journeys through the health system were often complex and did not correspond with linear care pathways. There was some evidence that groups who found it particularly hard to obtain the kind of care they wanted included people not in paid work, those in non-white ethnic groups and people who were socially isolated.

The experience of carers

We found limitations in the research studies in relation to carers' experiences. Carers were defined and recruited in different ways in the studies and some research directed at carers was very small scale. It was not always possible to separate findings about carers' own experiences from their perceptions of patients' experiences.

We found the strongest evidence about carers' own preferences and needs in the cancer study and the severe mental illness study, with some supporting evidence in other studies.

Carers valued good relationships with professionals. Those who had key roles in practical care, such as giving medication, wanted to understand the patient's condition and treatment. Carers wanted recognition of their own role. Those supporting people with severe mental illness particularly wanted professional recognition of and response to their own assessments of crisis situations. Some carers also wanted acknowledgment of their own needs for support, and timely provision of help. They mentioned here support for their own emotional responses, and support in dealing with the impact of the illness of the person cared for. However, the needs of patients and carers were not always the same, and sometimes conflicted.

Views of professionals

Health and social care professionals tended to see continuity of care as a personal relationship between a professional and a service user. From their perspective, a relationship with the patient's family or carer was not a critical component of continuity. They valued information sharing, through both formal and informal systems, and proximity with other health professionals.

However, working together effectively was not just a matter of location and contact. Trust and understanding of other professionals had important parts to play, and could be enhanced through strong leadership and supportive management.

Professionals rarely mentioned enabling service users' personal agency as contributing to continuity of care. They did believe that wider policy and resource issues affected the chance of delivering continuity, which sometimes pushed continuity down the scale of priorities when services were organised.

Measures of continuity of care

Several projects in the SDO programme developed measures of continuity of care, for service users, carers and professionals and then used these as part of their research. We reviewed both the measures and the findings they generated. The results suggested that different service user groups have different priorities in relation to aspects of continuity. For people with severe mental illness, service responsiveness to the needs of an individual over time (flexibility) and not having to deal with frequent staff changes (longitudinal continuity) are important aspects. Among people who have suffered a stroke, flexibility is most prominent. For people with cancer, flexibility and continuity across geographical or organisational boundaries and health-care teams are key issues. By contrast, for people with type 2 diabetes, establishing and maintaining a satisfactory relationship between staff and service user (relational continuity) seem most important. However, service users recognised all types of continuity to some degree, underlining the overall general applicability of the Freeman model.

Different approaches within the studies to developing valid and reliable measures meant it was difficult to assess whether continuity of care (or different types of continuity) led to different outcomes.

The measure developed for people with diabetes (the simplest of all those developed) seemed to offer most potential for future development and extension to groups of people with other long-term conditions.

The concept of continuity of care

The scoping report (Freeman *et al*, 2001) provided a conceptual framework for the subsequent research projects. In that report, and in an early project elaborating the Freeman model (Freeman *et al*, 2002), continuity of care was defined as something *experienced* by patients and their carers. It was also represented as a complex, *multi-dimensional* concept, and seen as an *outcome* as well as a *process* of care. Hence, there was emphasis on the need to measure both patients' experiences of continuity using these different dimensions, and the difference continuity makes to their health outcomes as well as satisfaction with care.

The studies used and interpreted Freeman's model in different ways. As outlined above, most expanded knowledge of patients' experiences of continuity, but fewer explored carers' perspectives, and some considered professional perspectives. Several added to existing understanding of the dimensions in the model, or identified new ones. Exploring the different perspectives and dimensions reported in the studies, our review suggests that continuity is *co-constructed*, arising from the interactions between patients, carers and professionals. Seeing continuity in this way helps to move from the initial outlook of the Freeman model, which focused on *perspectives* of individuals, towards a new paradigm of achieving continuity of care through *partnerships.*

Implications

Our review shows how a change of culture will be necessary for continuity of care to be the general experience. Understanding continuity as *co-constructed* by professionals and service users, rather than something *delivered* to service users, requires adjustments to professional training, professional identity and a shift in the way service users see themselves and their role in health systems.

There is not, and unlikely ever to be, a single way of achieving continuity. The components of the model originally developed by Freeman and colleagues in 2001 remain valid as a framework for understanding continuity. Differences between characteristics of service users such as health condition, age, family and household circumstances and ethnicity give different weights to the various components, and these may vary over time. People who are vulnerable and most likely to experience poorer continuity of care include those with rapidly deteriorating conditions and those whose condition fluctuates considerably. However, there is much to be gained, when considering service user needs and what can be achieved, from thinking about the ways in which continuity is co-constructed through the interaction of service users, carers and professionals and how this can be facilitated, rather than focussing on one perspective or another.

Methods of review

We identified and read the reports from all the core research projects, subsequent publications from the projects, and other key reports and publications that were part of, or influential on, the overall continuity of care programme. Material from the studies was extracted into spreadsheets and handled by developing a thematic framework, and displaying and interrogating data. Themes within the framework for analysis included: design and purpose of the studies; use of models of continuity of care; conceptual issues and innovations; patients', carers' and professionals' separate preferences and experiences; outcomes and delivery.

Qualitative methods were used throughout. A new approach to synthesising complex studies – critical interpretive synthesis, stemming from meta-ethnography (Dixon-Woods *et al*, 2006) – examined how continuity of care was defined by the research studies. Narrative synthesis brought together findings on what influenced continuity of care and what outcomes it led to, while descriptive synthesis outlined and compared the continuity of care measures and their psychometric properties. The final stage of analysis triangulated and compared findings in our study with those in the initial scoping review (Freeman *et al*, 2001), a Canadian review of continuity of care (Reid *et al*, 2002), and Freeman's interim review (Freeman *et al*, 2007). Our conclusions included implications for policy, practice and further research.

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The full report: Parker, G., Corden, A. and Heaton, J. (2010) *Synthesis and Conceptual Analysis of the SDO's Programme's Research on Continuity of Care*, National Institute for Health Research Evaluations, Trials and Studies Coordinating Centre, Southampton, is available from: php.york.ac.uk/inst/spru/pubs/1241/

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