Continuity of care in type 2 diabetes: patients', professionals' and carers' experiences and health outcomes

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prepared by

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Executive summary

Background and objectives

This project investigated the experience of health care of patients with type 2 diabetes mellitus. We asked 'What is continuity of care?', 'How can it be measured?' and 'Is continuity of care associated with better health outcomes for patients?'

We adapted the conceptual framework developed by Freeman and colleagues, identifying two ideals: continuity of care as a 'continuous caring relationship' between patient and professional, and continuity of care as the delivery of a 'seamless service'.

Aims and objectives

Mixed methods were used to evaluate and measure patients', carers' and providers' experiences of continuity of care in type 2 diabetes and to determine whether continuity of care was associated with clinical and patient outcomes. The study was set in two inner-London primary care trusts with young, mobile and ethnically diverse populations, high levels of deprivation and a number of existing models of diabetes care provision.

The specific objectives of the project were to:

1 hold in-depth interviews with diabetic patients in order to understand their values and experiences with respect to continuity in diabetes care;

2 develop an experience-based measure of continuity of care in type 2 diabetes and test the reliability and validity of the measure in quantitative data;

3 evaluate changes in clinical and patient outcomes over time and to evaluate whether these are associated with continuity in the experience or delivery of care;

4 conduct further qualitative work including the evaluation of the views and experiences of carers and South Asian patients;

5 evaluate health professionals' experiences and values with respect to continuity of care and develop a questionnaire measure of continuity in the delivery of care.

Experienced continuity of care: patients' values and experiences

What we did: we held in-depth semi-structured interviews with 25 type 2 diabetic patients from 14 general practices. Interviews were transcribed and analysed thematically using a framework approach.

What we found: patients valued receiving regular reviews with clinical testing and provision of advice longitudinally over time. They valued a relationship with a named 'usual' professional who knew and understood them, was concerned and interested, and took time to listen and explain. Patients were more likely to trust and confide in a usual professional. Continuity was facilitated if patients could make and change appointments flexibly in response to changing needs or unexpected situations, or speak to their usual professional when they needed advice. Patients discussed questions of consistency and coordination between different members of staff, and between hospital and general practice or community settings. Patients who only received hospital-based care for their diabetes described less favourable experiences of seeing usual providers and less flexibility in adapting to changing needs.

What we conclude: these empirical data from patients are consistent with four dimensions of experienced continuity of care: longitudinal, relational, flexible and team and cross-boundary continuity.

Experienced continuity of care: development and evaluation of a new measure

What we did: we used the qualitative data to develop a 19-item measure of experienced continuity of care in type 2 diabetes mellitus (ECC-DM). The measure includes four sub-domains: longitudinal continuity (four items), flexible continuity (four items), relational continuity (six items) and team and cross-boundary continuity (five items). Scores ranged from 0 to 100. The measure was administered by interview in a survey of 209 type 2 diabetic subjects registered with 19 general practices.

What we found: the mean score was 62.1 (SD ±16.0). The average inter-item correlation was 0.343 and Cronbach's alpha was 0.908. Factor analysis revealed four factors which were generally consistent with the four sub-domains of continuity of care. The questionnaire was additionally tested in self-completion and telephone interview formats with satisfactory results. Test-retest reliability was good. Mean scores varied significantly (P=0.001) from 46 to 78 among patients registered with different general practices. Experienced continuity of care was lower for subjects who only received diabetes care from hospital-based clinics than for subjects who received diabetes care from their general practice (difference 13.7, 95% confidence interval 8.2 to 19.2, P<0.001). Patients gave higher continuity-of-care scores at general practices with a named lead doctor for diabetes (difference 8.2, 2.7 to 13.6, P=0.003).

What we conclude: the experienced continuity-of-care measure gives reliable, valid results and is easily applied. Patients' experiences of continuity depend on the organisation of care: if general practices have a named lead professional for diabetes then their patients generally experience better continuity of care; patients attending

hospital diabetes clinics for most of their diabetes care tend to experience lower continuity of care.

Continuity of care and clinical and patient outcomes

What we did: we conducted a cohort study of type 2 diabetic patients attending 19 general practices in two inner-London boroughs. Subjects were interviewed at home; the study questionnaire included the experienced continuity-of-care measure, the short-form 12 (SF-12) questionnaire, a measure of global satisfaction with care and confounding variables. Measurements were made of height, weight, blood pressure and glycated haemoglobin (HbA1c). Patients were followed-up with repeat interviews and measurements after 10 months. Analyses were adjusted for baseline values, age, sex, ethnicity, duration of diabetes, diabetes treatment, education, housing tenure and living alone.

What we found: interviews were obtained at baseline with 209/553 (38%) eligible subjects. Experienced continuity scores were obtained for 193 (85%) participants at baseline and 156 (75%) at follow-up. There were no differences in continuity scores or health measures between those followed-up and those lost to follow-up. Higher experienced continuity of care was associated with higher global satisfaction ratings. Experienced continuity of care was positively associated with number of consultations in the last 12 months, but negatively associated with the number of different individual professionals seen. Experienced continuity of care was not associated with HbA1c (coefficient for 10-unit increase in experienced continuity-of-care (ECC) score, −0.09%, −0.29 to 0.12, P=0.402). ECC scores were not associated with systolic or diastolic blood pressure, body weight, body mass index or physical or mental functioning.

What we conclude: experienced continuity of care encompasses patients' perceptions of the interpersonal aspects of their care and the degree of coordination of care. Dimensions of experienced continuity are therefore conceptually related to more traditional assessments of 'patient satisfaction'. Measurements of experienced continuity of care are associated with patients' global ratings of their overall satisfaction with care received.

In this health-care setting, experienced continuity of care is not associated with changes in glycated haemoglobin (HbA1c), blood pressure or body weight during approximately 10 months of follow-up; nor is experienced continuity of care associated with physical and mental functioning scores from the SF-12 questionnaire. Whereas a naïve model might suggest that experienced continuity should be associated with better health outcomes, experienced continuity may also be associated with disease progression and worse health. Discontinuities in care may be associated, at different times, with either improvement or deterioration in health measures.

Later qualitative work: carers and South Asian patients

What we did: in-depth interviews were held with seven carers of diabetic patients and 12 South Asian patients in order to understand their experiences with respect to continuity of care.

What we found: carers generally commented negatively on the quality of their relationships with health professionals. Carers perceived that professionals' reluctance to involve carers could result in a failure to fully appreciate patients' and carers' needs. This could be a particular problem with respect to mental health needs. South Asian patients generally expressed similar experiences and values with respect to continuity as other patients. Differences in language contributed to less favourable experiences of continuity of care, whereas services were sometimes not sufficiently flexible with respect to cultural differences, as for example in the provision of appropriate dietary advice.

What we conclude: differences in language, culture, disability or mental illness may contribute to difficulties in establishing and maintaining continuity of care.

Continuity in the delivery of care

What we did: we held interviews with 25 health professionals recruited from primary care and hospital-based diabetes services in order to understand their perceptions of continuity in the delivery of care. The data were used to develop a 28-item measure of continuity in the delivery of care. This was tested in a postal survey of staff in two primary care trusts and three hospitals.

What we found: professionals, like patients, endorsed the importance of regular reviews and checks with the development of systems to avoid loss to follow-up. Staff generally preferred to see the same patients at successive visits in order to develop a better understanding with the patient and deliver personally tailored care. Coordination between staff in the same setting and between different organisational settings were viewed as difficult issues. Flexibility in the delivery of services according to individual needs was considered to be an attribute of the system rather than a distinct dimension of continuity. The 28-item measure included the dimensions of longitudinal, relational, team, cross-boundary and informational continuity. The measure had good psychometric properties including excellent test-retest reliability. Continuity in the delivery of care was rated lower by hospital-based staff than by primary care professionals.

What we conclude: professionals' perceptions and values of continuity in the delivery of care generally endorse those described by patients. However, professionals generally showed greater awareness of organisational questions and the difficulties of delivering a 'seamless service'. These issues have been addressed in the development of

models of 'integrated care' and 'chronic disease management'. A questionnaire was developed to measure professionals' perceptions of continuity in the delivery of care. This has excellent psychometric properties.

Recommendations

1 Aspects of the patient experience that were identified by this research are important to consider in designing services for patients with diabetes and in assessing the quality of care.

2 Patients are vulnerable to experiences of loss of continuity when their health changes or when they move between health care organisations. It may be more difficult for some groups to establish and maintain continuity of care. Further research is required to develop and test interventions to enhance experiences of continuity through transitions in health and health care for different groups of patients.

3 Patients' experiences of continuity of care in diabetes should be monitored using the self-administered ECC-DM measure developed for this project. The instrument may also be used to evaluate the effectiveness of interventions to enhance continuity of care.

4 Further research is required to adapt the ECC-DM instrument into a form suitable for monitoring the experiences of patients with a range of chronic illnesses.

5 Organising care through an identified lead professional may enhance patients' experience of continuity of care.

6 Enhancing the patient experience of continuity of care is especially important for hospital-based services. Further research is required to develop and test interventions to enhance experiences of continuity of care in hospital-based clinics.

7 Assessment of professionals' views of continuity of care may be used to monitor service delivery and inform improvements in services.

8 Continuity of care is justified in terms of enhanced patient-centredness and acceptability of care rather than increased effectiveness. Experienced continuity of care should be valued because it represents, in the view of patients and professionals, the experience of more patient-centred care.

9 Additional research should investigate whether provider continuity is associated with patient safety or the frequency of serious adverse events.

Disclaimer

This report presents independent research commissioned by the National Institute for Health Research (NIHR). The views and opinions expressed therein are those of the authors and do not necessarily reflect those of the NHS, the NIHR, the SDO programme or the Department of Health

Addendum

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