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DOI: https://doi.org/10.3399/BJGP.2023.0208

To access the most recent version of this article, please click the DOI URL in the line above.

Received 27 April 2023
Revised 07 September 2023
Accepted 19 September 2023

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When citing this article please include the DOI provided above.
An observational study of how clinicians, patients and the health care system create the experience of joined up, continuous primary care in the absence of relational continuity

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Abstract

Background

There is an international trend towards the at-scale provision of primary care services, with such services often provided in different settings by a clinician unfamiliar to the patient. It is often assumed that, in the absence of relational continuity, any competent clinician can deliver joined up, continuous care if they have access to clinical notes.

Aim

We use case study data of care delivered away from a patient’s regular practice, by a different organisation and set of staff. We studied this “extreme” example of a system where joined up, continuous care will be more difficult, to better understand the factors which affect the potential for providing such care.

Design and Setting

Case studies of two initiatives to improve access to primary care. Data collected included observations, interviews, and documentation.

Method

Case studies used an inductive approach. Cross-case comparison took place using a constant-comparison approach. Data were coded. A model of factors affecting continuity was constructed.

Results

The potential for joined up, continuous care appears dependent upon patient, staff and system factors. This includes diverse elements such as the attitude of clinicians to care coordination to the ability of an organisation to retain to staff.
Discussion

Healthcare systems increasingly rely on the assumption that any competent clinician can deliver joined up, continuous care if they have access to clinical notes. This appears not to be the case. We present a model of factors affecting the patient experience of continuity. The model needs validating in in-hours general practice and other settings.
How this fits in

The way that many modern healthcare systems are designed increasingly relies on the assumption that, in the absence of relational continuity, any competent clinician can deliver joined up, continuous care if they have access to clinical notes. This study of a primary care environment, where patients are usually seen by a clinician they have not seen before, demonstrates multiple connected patient, clinician, and system factors that appear important for a patient to experience joined up, continuous care. Considering these factors in the design of primary care systems may have the potential to improve experience for patients.
Introduction

Continuity of care has long been considered a key element in the delivery of good quality primary care.[1] Its precise definition and place in healthcare and research has been debated, and subsequently evolved, over the last 40 years.[2,3] It can refer simply to a continuous relationship between a patient and a healthcare professional (relational continuity). However, it can also encompass a range of concepts and paradigms including biomedical, sociotechnical or health systems factors.[4] Continuity can be viewed from several perspectives – the patient, the clinician and the health system. This paper considers continuity from the perspective of the patient.

There are several conceptual models of patient experienced continuity.[5–7] The commonly cited Haggerty model defines continuity as

“the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s medical needs and personal context”[6]

It then breaks down continuity into three principal components.

- Relational continuity – An ongoing relationship between the patient and one (or more than one) provider of healthcare
- Informational continuity – Clinicians and patients having appropriate access to information to enable healthcare
- Management continuity – the extent to which the approach to healthcare over time, and potentially between different providers, is responsive, joined up and coherent.

It can be claimed that Haggerty’s concept of management continuity is the same as care co-ordination [7] and some have argued that it could be simplified into just two elements: relational continuity and the seamless delivery of care.[8] However, the model recognises that there is interplay between the different elements of continuity and that elements of continuity cannot always be neatly categorised. Due to its relative simplicity, flexibility and widespread use, we use it as our conceptual lens. To clarify the perceived overlap between “co-ordination” and “management continuity”, we use the term “co-ordination” to refer to
the tasks/organisation of patient care.[9] We use “management continuity” to refer to how joined up and coherent that process may appear to the patient.

The patient experience of continuity is, to a degree, subjective. Tools, such as questionnaires, that attempt to provide quantitative measures of patient experienced continuity use questions that different patients, experiencing the same episode of care, could legitimately answer in different ways.[10,11] For that reason in this study we refer to the potential for patients to experience joined up and continuous care.

There is considerable evidence showing an association between relational continuity of care and positive health outcomes.[12–14] There is also some evidence that improving non-relational elements of continuity can contribute to improved health outcomes.[15,16] However, as there is no agreed definition on what the important non-relational elements of continuity are, or how to measure them, this evidence comes from work in related areas such as care co-ordination or integrated health systems. It seems self-evident that non-relational factors may contribute to the extent to which care is experienced by patients as joined up and continuous.[17] Thus, for example, the failure of a clinician to be aware of information received from another provider may generate in a patient a feeling of lack of continuity, even in the context of a long-term therapeutic relationship. It is, therefore, important that we understand the factors that come together to create the potential for patients to experience care which feels joined up and continuous, beyond simply seeing the same clinician.

This paper uses qualitative data collected as part of two case studies to understand the mechanisms and factors which may influence patient experienced continuity. Studies using similar methods (interviews and observations) have been used previously to understand complex phenomenon such as continuity.[18,19] The case studies examine a primary care system where access is prioritised over continuity. Extended access is an England-wide scheme that enables patients to access routine care in the evenings and weekends.[20,21] Care through extended access is often delivered away from a patient’s regular practice, by a different organisation, and set of staff. Studying this “extreme” example of a system where continuity will likely be more difficult to achieve enables us to understand the factors which affect the potential for continuity. We use the data from the case studies to create a model of how different elements may interact to affect the potential for patients to experience
joined up and continuous care. The factors that make up this model are then discussed in detail.

**Method**

The study consists of a two-site comparative case study of extended access providers in the north of England (Table 1) between September 2021 and January 2022. Patients using the services were booked appointments by their registered general practice and were usually seeing a clinician they had not met before. Appointments were a mixture of face-to-face and telephone and for a mixture of routine and urgent issues. The study was based on the case study methodology described by Stake.\[22\] Data collection included: observation of 30 hours of patient-health care professional interactions with 11 different clinicians in 7 different extended access hubs, interviews with staff and patients (Table 2) and organisational documents and protocols. Data was gathered by Patrick Burch (PBu), a practicing GP and academic. Data analysis and coding was performed by PBu and Kath Checkland. All the authors contributed to the development of the final conceptual model.

Analysis ran concurrently with data gathering. The use of two different sites with contrasting organisational features allowed assumptions and theories generated at one site be tested on the other. The theory of continuity, as described by Haggerty was used as a sensitising concept and in the development of initial codes.\[6\] A priori codes were then supplemented with additional codes arising from the data. Analytical memos were written to facilitate the development of themes, and higher-level analysis. Emerging findings were discussed regularly at team meetings. Abductive, inductive and deductive reasoning were used to create a model of factors affecting continuity (Figure 1). These factors were coded and their relationship to one another were examined in existing data. The relationships that emerged from the data guided further data collection and hypothesis testing at both case study sites.

**Results**

Aspects of care which seemed to be related to generating the potential for an experience of continuity of care were drawn out and charted. These were combined to generate a model
of how aspects may interact to generate a patient experience of joined up, continuous care (Figure 1). Subsequent sections draw out, evidence, and explain the model in detail.
Clinician and staff factors

Staff that are involved in a patient’s care play a major role in shaping whether a patient experiences joined up, seamless and continuous care. In a patient-clinician encounter, the attitudes, knowledge, and experience of the clinician can shape how the care the patient receives links with past and future episodes of care (i.e., management continuity). Clinical knowledge is important as they must know how to treat, or facilitate the treatment of, a patient’s condition. However, without knowledge and experience of local health systems, even a medically knowledgeable clinician can fail to provide patients with seamless care. Attitudinal factors also play a role. The clinician’s approach to clinical practice and risk matters: do they take the entire history again despite it being written down; are they willing to take ownership of the patient’s issues; do they admit the borderline case to hospital or monitor at home? The clinician also has a degree of discretion in how “seamless” they can make a patient’s experience of care, both in perception and in fact. In terms of patient perceptions, the idea that people (including clinicians) behave in different ways depending on who is present and how they perceive their role is referred to as “role performance” in the sociological literature.[23] The variety of responses from clinicians in situations where a patient could have had more clinician help in co-ordinating their care shows that the degree to which different clinicians “perform continuity” varies. For example, some clinicians use cues from medical notes to demonstrate to the patient that they know about their previous care, asking questions or making comments designed to indicate knowledge of what has happened before, even if it is not strictly relevant to the current presentation. This has the potential to engender a feeling of continuity for the patient. In terms of actual delivery of co-ordinated care, clinicians may choose to co-ordinate an aspect of care themselves or, they may give this task to the patient. Furthermore, non-clinical staff also play a role in patient care. Whilst clinical knowledge/experience is less important for them, other factors (system knowledge/experience, attitude to practice/risk, willingness to take ownership of a problem and the option of “performing continuity” either via creating a perception or via their actions) are still likely to affect how staff-patient interactions play out. Finally, the length of time that any given clinician spends working in a particular place will affect many of these things. Staying in one clinical setting will allow the clinician to gain a good
knowledge of other local services, as well as making it possible to build personal
relationships with patients and with clinicians elsewhere.

“The patient was a lady in her 30s that came from the Advanced Nurse Practitioner (ANP)’s
practice. She had irregular vaginal bleeding on the contraceptive implant for several months.
The ANP looked through the clinical notes and took a history. She offered her several
management options including an injection of Depo-Provera. This is an unlicensed use of the
medication. The patient chose to go with this option. The ANP then logged off the hub IT
system and, on the same computer, logged onto her practice IT system. Whilst logging on
she told the patient roughly how long she would have to wait before being able to have the
injection in the surgery. The ANP loaded up the appointment calendar at her practice and
discovered she had no appointments free. She created an additional appointment and
booked the patient in. She told the patient she would come in at 0820 in 3 day’s time, before
the start of her booked surgery, to do the injection. She told me that, had the patient been
from a different practice, she would have simply asked the patient to contact her own
practice to arrange the injection.” Notes from clinical observation of ANP 12 – Site A - Case 1

The ANP in Case 1 had advanced knowledge of gynaecology and was, therefore, able to
offer several treatments including an off-licence treatment that not all primary care
clinicians are aware of. She took ownership of the patient’s problem. She had knowledge
and experience of local health systems. She went beyond what was required in her role in
providing a seamless service for the patient by booking the patient in with herself, a
“performance of continuity”. Furthermore, as an established staff member present in the
local area for a while she knew that she would be able to follow up the outcome of the
chosen treatment, providing an opportunity for a longer-term relationship to develop.

Clinicians had different views as to their role in providing seamless care for patients in the
extended access setting but many felt that the degree of responsibility taken on by the
clinician for co-ordinating care should reflect the ability or vulnerabilities of the patient
“[discussing who should take responsibility for co-ordinating care between extended access
hubs and general practice]

I think I would do it on an individual basis because I do think that patients have to take onus
of their own health and I do want to promote that they’ve got to be proactive and... sort
things out for themselves because sometimes patients will...they’ll let you do everything for them. So, I think it's got to be an individual basis.” ANP 11 – Site A

Patient factors

As the experience of patient continuity is individual to each patient, patient expectations play a key role in shaping the experience. The patient responses in Figure 2 show how the same experience can elicit different responses from different patients. Different patients have different expectations as to whether certain tasks of co-ordination should be undertaken by themselves or by healthcare staff. Physical, mental, social or psychological factors can also affect the degree to which patients are able or willing to co-ordinate their own care. In situations where informational continuity of the healthcare record is limited (e.g., where clinical staff cannot see the entire record), patient knowledge of their own medical information can help improve their experience of continuity. We observed several consultations where neither the patient nor the clinician knew why an appointment had been booked. In other consultations, in-depth patient knowledge of medical issues enabled the co-construction of an understanding of the problem and the development of an appropriate management plan, potentially avoiding unnecessary medication and/or repeat investigations. On the other hand, the complexity of a patient’s problems can negatively impact their experience of continuity, and patients who move around frequently are unlikely to experience joined up care, as records and information must be passed to new care providers.

The interview with Patient 28 shows how medical complexity interacts with the design of health systems (and potentially clinician/staff factors) in creating inconvenience and poorly joined up care. At the opposite end of the spectrum, we observed and interviewed many patients who had less complex, more straightforward health problems who felt they received appropriate seamless care.

“I have to have a diabetic foot check, and because I’ve got [other] problems with my feet, I see a podiatrist occasionally, and I say, oh, while I’m here, can you do the diabetic foot check, no. Well, why not, I have to have it done every year, so why can’t you do it? Well, it doesn’t say that’s what you’ve come for. I mean, it takes about a minute, and if it’s not on the computer that that’s what I’ve gone for, they don’t do it, so then I’ve got to try and make
an appointment somewhere else and get it done. And it just doesn’t make sense, it’s just a complete waste of money and everybody’s time.” Patient 28 – Interview – Site A

Different patients took different levels of ownership over their health problems and coordinating between services. Some went to considerable lengths to co-ordinate their care between services whilst others assumed that co-ordination would occur automatically until they experienced otherwise.

System factors

The design of healthcare systems can play a large role in affecting the potential for a patient to experience continuity. The number of staff members and organisations involved in a patient’s care can impact on patient continuity and ability of staff members to try and provide a seamless service to patients. Moreover, staff turnover is a major factor impacting upon the extent to which patient experience of continuous, joined up care can be delivered.

We observed and interviewed staff who had regularly worked in the same extended access hub since the inception of the service and others who moved between hubs or had only recently started working in the service. New staff do not know systems, and continual turnover can be disruptive. System factors are therefore important in the extent to which they improve staff satisfaction and thereby reduce turnover.

Case 2 illustrates how limited capacity within services limits patient choice and can negatively affect the experience of continuity.

“Patient 2 was a lady in her 70s with a rash. She had seen a pharmacist yesterday who advised her that she needed to see a doctor. She had rung her doctors who she said told her there were no appointments and advised her to ring 111. 111 had passed her notes back to the GP saying that she needed to be seen by them within 24 hours. The GP surgery had then made an appointment for her at the extended access hub. The GP examined the rash, diagnosed shingles and gave her a prescription. She would then need to return to a pharmacist to pick up this medication.” Notes from clinical observation of GP 9 – Site B Case 2

The physical location, timing and modality of appointments can also be important. Aside from patients having to travel further or attend at an inconvenient time, these factors can
affect the treatment a patient receives. Some patients using extended access hubs co-located in their registered GP practice did not realise that they had been booked in with a different service. Other patients told us of difficulties they faced attending an extended access hub due to the location and/or timing of appointments when they would rather have been seen in their registered practice. Some clinicians reported that they were more likely to admit some patients to hospital when they were seen at particular times because of increased clinical risk or lack of available advice from other clinicians.

The flow of clinical information (informational continuity) is a well-recognised factor which contributes to the potential for patients to experience continuity. We found that clinicians with access to clinical notes were able to recommend treatment that linked in well with previous treatment a patient had received.

Rules and procedures, although usually well intentioned, can have the effect of impeding the patient experience of continuity. Rules and procedures around data protection, for example, can stop clinicians from effectively following up patients or make for some awkward patient encounters, such as that in the Case 3.

"The ANP called patient 2 – listed in the booking as a man in his 20s. The ANP had not accessed the patient record. He explained to me, he was not allowed to access it until the patient had given explicit consent. The person answering the phone said he was the patient’s father. He explained that his son had autism and couldn’t communicate well himself. It was evident that he expected to have a conversation about his son with the ANP and sounded surprised and put out when the ANP was insistent that the son/patient gave consent for him to speak to the father. After a prolonged wait the patient came to the phone and consented. The ANP then asked for additional consent to gain access to the son’s clinical record.” ANP 101 – Site A – Case 3

The booking systems at both sites were not designed to provide relational continuity. However, clinicians at site A were able to book patients follow up appointments, and often used this to create short term relational continuity. Clinicians at site B were unable to do this are rarely saw the same patient more than once.

Continuity can be improved by having co-ordination mechanisms in place. However, it is important that these mechanisms are known to staff, easy to use and effective. Otherwise,
staff will circumvent them or ask patients to co-ordinate their own care. In both our case study sites there were several procedures for co-ordination in place that staff generally did not follow. They told us that this was because they did not believe that tasks would be acted on, were not aware of the procedure or thought that another method of co-ordination was more effective. At its worst, such complex and user-unfriendly processes might contribute to increased staff turnover or difficulties in recruiting, as staff may be reluctant to work in a setting in which complex workarounds are required.

Synthesis: a model of factors impacting patient experience of continuity

We found that the extent to which it is possible for patients to experience continuity of care is complex and mediated by multiple factors. Relational continuity was limited by design of the booking and appointment system. Despite this, some staff managed to provide it in the short term. Informational continuity, in terms of clinicians having access to clinical notes, was generally present. However, the ability for patients to experience continuity was sometimes hampered by a lack of effective co-ordination between extended access and in-hours general practice. Whether patients experienced management continuity (joined up, coherent care) was influenced heavily by the complexity of the patient’s conditions, clinician behaviour and what the patient perceived as joined up and coherent care. To what degree continuity is something that “just happens” when the appropriate elements are in place and to what degree individuals need to take responsibility for informational continuity, decision making and co-ordination to ensure the delivery of continuity, appears to vary between cases, often depending on the complexity of the patient’s health needs.

Whilst longer term clinician-patient relationships might seem to axiomatically represent ‘continuity’, our study suggests that the complexity of modern medicine means even patients who know the clinician that they are seeing might not experience seamless and continuous care, as many other factors are also important. Moreover, our study suggests that even in the absence of those longer-term relationships, an experience of continuity can be delivered by optimising systems and modifying individual behaviours to prioritise this aspect of the patient experience.
Discussion

Summary

When patients are seen outside of their usual primary care setting, there are multiple patient, staff and system factors that interact to create the potential for a patient to experience continuity (or discontinuity). Although the experience of continuity is unique to an individual patient, consideration of these factors, when planning healthcare systems could lead to improvements in experienced continuity for patients. Moreover, whilst longer term clinician-patient relationships provide an important route to support the delivery of experienced continuity, surrounding system factors are also important.

Strengths and limitations

To our knowledge, this is the first study that has used qualitative data to generate a model of how and why patients may experience continuity of care. By examining what happened when patients were seen outside of their normal practice systems, we were able to identify factors effecting continuity that may not have been evident in routine general practice. This, along with the large amount of observational and interview data collected, allowed a model to be generated, tested and refined. However, the theory has not been tested outside of the two case study sites. It has not been tested in the context of routine general practice, and this will be important if it is to be useful. Relational continuity plays a major role in the patient experience of continuity, but this was rare in our case study sites because of their nature as extended access hubs. However, we observed individual clinicians striving to develop those longer-term relationships, and the model highlights some elements which may enable or inhibit the development of those such relationships. Whilst the study authors were reflexive in their data collection and analysis, the role of PBu as a practicing clinician, may have influenced the practice of some observed clinicians and of interview data that was collected.[24]
Comparison with existing literature

Relationship-based care, a method of practice promoted by some primary care professional bodies, incorporates the concept that the patient-clinician dynamic is important, even if just for a one-off encounter.[25] Our findings feed into this way of thinking, and provides evidence for factors that have the potential to influence this relationship. The degree of responsibility that clinicians feel towards patients and the extent to which they take ownership of their patients’ health problems has previously been shown to be related to the length of time they have known the patient.[26] However, our study suggests that some clinicians also feel a sense of ownership even when they see patients for the first time or in a short term setting. This may be seen as usefully ‘performing’ continuity in our terms, or alternatively it may be seen as disempowering patients. Whether this impacts on outcomes requires further research.

There has been research that has attempted to quantify the patient experience of continuity when patients are seen by multiple clinicians, but it has not closely examined the underlying factors that may contribute to the patient experience.[10,11,27] The factors that combine to create the patient experience of continuity echo findings from research into multi-morbidity and treatment burden.[28,29]

Implications for research and practice

Healthcare systems are increasingly complex and fragmented. The growing importance of primary care networks (PCNs) in the UK mean that increasing amounts of primary care are being delivered away from a patient’s registered practice, often by a clinician that a patient has not met before. There are multiple initiatives in place to try and improve the patient experience of continuity. These include clinicians having access to patient notes, and electronic messaging systems between practices. However, as this study shows, an isolated intervention, however well-meaning, is often not enough to enable a patient to experience joined up, seamless care. Within extended access services, triaging patients so that more complex patients are dealt with in their registered practice, recruiting staff who work in local daytime practices or simplifying co-ordination mechanisms and rules around data sharing could all potentially improve the patient experience of continuity.
Further sociological studies in in-hours general practice, and other settings, utilising observation and interviews could help validate our model. Collection of quantitative data about the patient experience of continuity and examining their association with patient, clinician and healthcare system characteristics would be valuable. The model potentially provides a framework within which to think about these issues and could, with validation, be used to support quality improvement and work around system design and operation.
Funding

This research was part of a PhD Fellowship funded by THIS Institute.

Ethical approval

Ethical approval for the study was given by Greater Manchester East Research Ethics Committee (Approval number:21/NW/0217)

Competing interests

None declared

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Table 1 – Details of extended access providers

<table>
<thead>
<tr>
<th>Service</th>
<th>A</th>
<th>B</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients covered</td>
<td>600,000</td>
<td>1.2 million</td>
</tr>
<tr>
<td>Number of sites</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>IT integration</td>
<td>Variable</td>
<td>Good</td>
</tr>
<tr>
<td>Predominant clinical staff</td>
<td>GPs</td>
<td>Advanced nurse practitioners (ANPs)</td>
</tr>
<tr>
<td>Default appointment type</td>
<td>Face-to-face</td>
<td>Telephone</td>
</tr>
<tr>
<td>Patients clinically triaged before appointment?</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Staff able to follow up within the hub?</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>
Table 2 – Details of formal interviews

<table>
<thead>
<tr>
<th>Extended access provider</th>
<th>A</th>
<th>B</th>
</tr>
</thead>
<tbody>
<tr>
<td>GPs/Advanced Nurse Practitioners (ANPs)</td>
<td>8</td>
<td>4</td>
</tr>
<tr>
<td>Administration staff, managerial staff, clinical</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>leads and commissioners</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Local practice GPs/ANPs</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Patients</td>
<td>10</td>
<td>10</td>
</tr>
</tbody>
</table>

Staff have only been included in one category. However, some staff could be included in more than one category e.g., several hub GPs, ANPs and receptionists worked in practices that were local to the service, hub clinical leads were also involved in the managerial and clinical aspects of the service.
Figure 1 – Model of factors influencing patient experienced continuity

“I have to repeat everything. I have to ask them to look at my notes and it’s just a nightmare.” Patient 29 – Site A

“A little bit, yeah. You would think, if they could have the information in front of them, they could read up on it. I don’t know if it’s like a standard practice thing, so they know whether you’re lying or not, or putting stuff on, ‘cause you’re having to repeat yourself, I don’t know.” Patient 36 – Site B

“I don’t mind that, because even though they’ve got the shared information, they should really be checking things, and things might have changed anyway,” Patient 40 – site B

Figure 2 – Responses from 3 separate patient interviews when discussing how it feels when a clinician repeats questions that have already been asked by a different staff member/clinician