
Qualitative Research

'Falling through gaps': primary care patients' accounts of breakdowns in experienced continuity of care

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Abstract

Background. Experienced continuity is important for good quality primary care but may be challenging to achieve. Little is known about how discontinuities or gaps in care may arise, how they impact on patients' experiences and how best to understand them so that they can be avoided or managed.

Objectives. Using the theoretical framework of candidacy, we aim to explore patients' experiences of discontinuities in care and to gain insight into how gaps come to be bridged and why they might remain unresolved.

Methods. A secondary analysis was undertaken of interview data from a large study into continuity in primary care, involving a diverse sample of 50 patients, recruited from 15 general practices, one walk-in centre and community settings in Leicestershire, UK. Analysis was conducted using a constant comparative approach.

Results. Experiences of gaps in care were common, arising from failures in communication and coordination of care. Although some gaps were easily bridged, many patients described 'falling through gaps' because of difficulties establishing their candidacy for ongoing care when gaps occurred. These patients commonly had complex, chronic conditions and multi-morbidity. Bridging gaps required resources; relationship continuity was a valuable resource for preventing and repairing gaps in care. When gaps were not bridged, distress and dysfunctional use of health services followed.

Conclusion. This study demonstrates that some patients with complex chronic conditions and multi-morbidity may be unable to get the continuity they need and highlights the potential for relationship continuity to help prevent vulnerable patients falling through gaps in care.

Key words: Chronic illness; comorbidity; continuity of patient care; primary health care; qualitative research; quality of care.

Introduction

The provision of primary care is increasingly complex, given the growing number of patients with chronic diseases and multi-morbidity whose care is commonly shared and transferred between different health professionals and across boundaries between primary care

and other services (1). This context presents challenges to patients' experiences of continuity over time. Experienced continuity, defined as 'the experience of a coordinated and smooth progression of care from the patients' point of view' (2), is an important element of good quality care and encompasses continuity of interpersonal

relationships and consistent and coordinated management of patient care and patient information throughout the patient journey (3).

A variety of procedures and mechanisms have been developed to help promote continuity and coordination, including discharge planning to improve linkage to community services following discharge from hospital (4), 'medical home' models of primary care (5) and the use of care plans for patients with long-term conditions (6). Despite efforts to improve continuity and focus it where it is most needed, there remains considerable potential for discontinuities to occur. Discontinuities and 'gaps' in care can pose significant risks to patient safety, such as medication error and inconsistencies in treatment, and compromise quality of care (7–10). While there has been extensive research into the meaning of continuity of care, and into aspects of patients' experiences of continuity (11,12), there has been relatively little work focusing specifically on patients' experiences of discontinuities or gaps in care. Our aim in this article is to explore patients' accounts of discontinuities or gaps in care within primary care and across the boundaries between primary care and other care providers, and to gain insight into how gaps come to be bridged and why they might remain unresolved. Understanding how and under what conditions discontinuities emerge and persist has important implications both for the way health care is organized for patients most at risk from breakdowns in their care, and to inform further research into continuity.

In examining patients' accounts, our analysis has been informed by the theoretical framework of 'candidacy'. The concept of candidacy emerged as a unifying theme from an interpretive synthesis of literature on access to health care in vulnerable populations. Candidacy is the outcome of the ways in which 'people's eligibility for medical attention and intervention is jointly negotiated between individuals and health services' (13). Access to care is a product of the way people present and negotiate their claim for care, the adjudication of health care providers on their eligibility and the permeability, or ease of use, of the available services. Drawing on this theoretical framework, experienced continuity can be seen as dependent on the highly dynamic and contingent negotiation between patients and service providers around the eligibility of individuals for access to health care over time and, particularly, at transition points in their care.

Methods

In this article, we report findings from a secondary analysis (14) of qualitative data from a large study of patients' experience of continuity in primary care, collected in 2002 and 2003 (15). Data comprised semi-structured patient interviews about continuity in primary care. Patients were recruited from 15 general practices and one walk-in centre in Leicestershire (UK). Each practice selected patients from their list at random to fill a purposive sampling frame in terms of age, gender and health status, generating a list of 10 patients per practice. Patients were sent an invitation to be interviewed; interested patients returned a reply slip to the researchers. Recruitment was monitored against a maximum variation sampling frame to ensure that a wide range of interviewees were represented in terms of gender, age, ethnicity, health status, caring status, living arrangements, social class and employment. Under-represented groups were identified and recruited via community groups and snowball sampling. Face-to-face interviews were conducted by CT or KW in participants' own homes or the general practice premises, and participants were offered the option of having a friend or relative present with them at interview. Interviews followed a narrative structure,

informed by a topic guide (summarized in Table 1). Written consent was obtained prior to interview, and interviews were audio-taped and transcribed verbatim.

Analysis drew on the constant comparative method (16). A sample of transcripts was open coded, then codes were grouped to produce an initial coding frame. The coding frame was iteratively tested and amended by applying it systematically to subsequent transcripts and through discussion within the research team. The final coding frame was applied to the whole data set, using QSR N6 software. Participants' accounts of gaps or discontinuities in care were identified by KW and CT independently and compared for consistency. These accounts were summarized into charts for analysis. During the process of reviewing themes and interpreting coded data, we identified the theoretical framework of candidacy as having value in making sense of our findings (13).

Results

Participants

Fifty interviews were conducted, six of which also included a member of the patients' family. Patient characteristics are described in Table 2. Seventy per cent of participants had at least one chronic health problem. Around a third suffered from multi-morbidity. Fourteen participants described themselves as carers of people with conditions including dementia, multiple sclerosis, learning disability and head injury.

Experiences of gaps in care

In more than half of the interviews, 29 (58%) participants reported one or more recent discontinuities or gaps in care. In 18 of these 29 cases, lack of coordination of services at a transition between different services contributed to the gap in care (e.g. services following discharge not being arranged); in 11/29 cases, problems with information transfer were implicated (e.g. GP not receiving letters from outpatient clinics) and in 13/29 cases, issues arose due to problems in the coordination of management, treatment or responsibility for care between multiple different health professionals concurrently involved in the patient's care.

Of the 35 participants who reported a chronic condition, 26 (74%) reported experiencing gaps, compared with only 3 (21%) of the 14 who reported not having a chronic condition. In around half (13) of the cases where gaps were reported, patients or their carer described the gaps or discontinuities they had experienced as being relatively minor and as having been resolved with little impact on their care. However, in 16/50 interviews, participants described significant, longer term gaps in care, which were not easily resolved. These participants reported experiences of falling through gaps in the health system. Nearly, all of these people (14/16, 88%) had, and/

Table 1. Topic guide for interviews with patients

The positive and negative aspects of their GP practice and other recently used primary care services
Their experiences of accessing primary care over the past year (what were their priorities, where and whom did they consult and what happened?)
Their views, experiences and choices in relation to continuity of carer (e.g. seeing the same GP)
Their views, experiences and choices in relation to continuity of care (e.g. how well information is shared between different health professionals involved in their care)

Table 2. Summary of the characteristics of patients who took part in interviews ($n = 50$)

	Number (%) ^a
Sex	
Male	19 (38)
Female	31 (62)
Age	
13–17	4 (8)
18–29	7 (14)
30–59	20 (40)
60–79	15 (30)
80+	3 (6)
Ethnicity	
White British	42 (84)
Other ethnic group	7 (14)
Health status	
One chronic condition	17 (34)
Multiple chronic conditions	18 (36)
No chronic condition	14 (28)
Employment	
Full-time employment	8 (16)
Part-time employment	11 (22)
Retired/not in paid employment	24 (48)
Student	6 (12)

^aPercentages may not add to 100 due to missing data.

or were caring for someone with, multiple long-term, complex and life-disrupting conditions.

Falling through gaps and candidacy

While gaps in care opened up due to failures in communication and coordination, the 16 patients who experienced falling through gaps all described how they had had difficulties in establishing their eligibility for care and accessing appropriate services going forward. As such, the experience of falling through gaps was closely linked with an inability to establish (or re-establish) candidacy. Failures to establish candidacy did not seem to arise from patients' lack of awareness of services or lack of recognition of themselves as candidates for care (13). Rather, problems arose from service providers' adjudications about their legitimacy as recipients of care, as described by this patient with a long standing chronic problem, coupled with depression:

I was at home on my own and I just, couldn't cope with it. I was iller [...] than I had been before and they'd said, "There's nothing wrong, we can't do anything" (Interview 50)

Judgements about their legitimacy to use a particular service could change as the patients' health status changed, or care was transferred from one provider to another. Candidacy established within one service did not automatically carry across to other services. A lack of support to gain entry to new services could result in patients being unable to access longer term care, particularly if they were unable to muster the resources themselves to assert and establish their candidacy. One participant described a lack of support in ensuring ongoing care for her mother-in-law with newly diagnosed dementia:

Social services, [... I thought] they'd come along and assess your situation and kick start things but they didn't, you know, and the doctor hasn't taken it on board. She's not booked in anywhere. She's not under anybody's system. (Interview 48)

Particular problems also arose when care was shared between multiple providers, but none was willing to accept the patient's attempts

to assert their candidacy or take on the responsibility of providing care, as described by this patient with advanced cancer.

My hospital consultant says, "Certain conditions are GP orientated and this should have been resolved by your doctor" and obviously they don't understand, I was seen by a locum [GP] and this locum was saying, "Oh, when you're seeing the consultant you report this to them." (Interview 40)

Bridging gaps in care

Where patients had experienced a gap in care, special efforts were needed to bridge the gap and re-establish ongoing care. Bridging the gap could require participants taking the initiative themselves. Some described engaging in forms of 'character work' (17): presenting themselves (or those they cared for) as worthy and legitimate candidates for care. For example, participant 22 presents herself as a measured and responsible user of health care services and so as deserving of care when she asks for it:

To be quite honest I don't ring them up very often. In fact I bet we see a doctor fewer times in a year than the majority of the rest of the people we know. (Interview 22)

Participants also described drawing on their own time, money, knowledge of alternative services and the support of relatives, and taking actions such as getting a private appointment, or making threats and demands, in order to gain access to care.

I got to the pitch where I could hardly walk and I thought, "This is just not on." And I said to (GP), "Oh look, I just want to go to see a specialist, I don't care how much it costs, I'll go." [...] I rang up and I went, and I went privately (Interview 31)

Well [dad] had a urinary infection in the nursing home [following surgery...] and he was going downhill very fast over a period of five or six days. [...] I went in [to the nursing home] next morning and I said to [staff member...] "I want a doctor here straight away." So she says, "I don't think they'll come." I said, "Now let's get this straight," I said, "If he was in his own home he would be entitled to a home visit. Now," I says, "This is home now". (Interview 17)

For many participants, a known and trusted health professional (often a GP) was a valuable resource in helping to bridge gaps. This was particularly the case for those who had few resources to draw upon—patients who were particularly sick, isolated, vulnerable or who had multiple complex needs. These patients wanted to be able to rely on the health professionals involved in their care to repair discontinuities and rescue them from falling through gaps. What was critical was that patients were able to establish their legitimacy with a particular health professional and could rely on the actions of this professional to protect them from the need to repeatedly negotiate and re-establish their candidacy. One participant described how her GP had stepped in when a lack of communication between hospital departments about diagnosis had led to delayed treatment leaving her in pain and distressed:

[GP]'s been so brilliant with us as a family with all the problems that we've had. [...] He's come out twice and sorted out, you know, given me the Valium and all the other sort of things that I need to try and get myself better. (Interview 09)

It was notable that of the nine patients who reported chronic health problems, but had not experienced gaps in their care, seven explicitly described having their 'own' GP with whom they had a good relationship.

Unresolved gaps in care

Within these accounts, we identified six participants for whom gaps in their care had opened up and remained unresolved: these

participants described being unable to access the care or support they felt they needed or to make progress in their care. These patients saw themselves as vulnerable and as struggling to gather the resources to actively assert their candidacy; they expressed a feeling that health services should have been proactive in supporting them and offering care in their time of need. None of these patients had a particular health professional whom they could rely upon to take primary responsibility for their care.

Common to all these accounts was a feeling of being unwanted or rejected by health care providers and shut out by the health system. One participant who had chronic conditions herself and was a carer for her husband and elderly mother, both of whom had severe chronic health problems, described her distress as a result of feeling abandoned by the health service.

The biggest problem that I feel that we've had is a lack of continuity of help [becomes tearful]. We just felt as if we'd been put through the door and the door had been closed. (Interview 22)

Unresolved breakdowns in care had significant negative consequences, resulting in anguish and distress. Some patients described a loss of trust in and disengagement from the health service, and their accounts were suggestive of despair and helplessness. Other participants described a pattern of high levels of relatively chaotic use of health services that ultimately failed to resolve their problems. This was the case for the following couple, of whom one had a brain injury and the other a chronic condition:

Well they keep deterring us not to go [to the GP surgery] and sometimes it's so bad we have to go, but because we haven't made an appointment, if we do get seen we get seen last and there's many hours of waiting [...] and when all else fails we just have to go to emergency doctor [...] or just go to A&E [accident and emergency]. But they can't offer us any help, so you know, it's like we don't have many choices. (Interview 03)

Discussion

Our study found that experiences of gaps in care were common and arose from failures in communication and coordination of care. Although some gaps were minor or easily bridged, many patients described falling through gaps because of difficulties establishing (or re-establishing) their candidacy for ongoing care when gaps opened up.

Bridging gaps in care can require patients or their informal caregivers to act on their own behalf to assert their candidacy, which requires significant personal resources and commitment (18–20). A known and trusted health professional, who accepts the patient's needs as legitimate and is willing and able to act on their behalf, is, if obtainable, a valuable additional resource. Patients with complex conditions, who lack personal resources (whether capacity, money or social support) and who do not have an ongoing relationship with a trusted health professional, are likely to be particularly vulnerable to unresolved breakdowns in care. For some patients, the resultant despair and helplessness may mean that they give up trying actively to get help, whereas others may resort to high levels of chaotic service use that fails to meet their needs.

One key implication of our study is the finding that patients who are most vulnerable to falling through gaps are those with complex problems and with the fewest resources. This echoes findings from research focusing specifically on patient subgroups such as those in the last year of life (21). It is not surprising that the experience of continuity and progress in care is more fragile when care is complex and is being shared or transferred between providers. Research involving patients with multiple long-term conditions found that 'As

patients move between sites, experiences of informational discontinuity and lack of effective communication, or feeling in limbo are common' (22). Our findings suggest that these patients with complex multi-morbidities may face particular difficulties in establishing candidacy, being less likely to match the stereotype of the good patient that services such as primary care are set up to manage, and having problems that cannot easily be resolved or referred on (23). The gatekeeping role of health professionals, particularly GPs, means that they may have valid reasons for denying access to services in certain circumstances, and it is easy to see how some of the patients in this study could come to be seen as excessively demanding or problem 'heartsink' patients; nonetheless, these patients expressed significant unmet need and distress. High demand may not always be unreasonable but may result from perceptions of unmet need, and there would be value in further research exploring the negotiation of candidacy with patients who have a history of high demand.

Other literature has emphasized the role of patient involvement and responsibility in enhancing continuity (24,25). Although some patients in our sample were able to assert their candidacy and attain progress when gaps occurred, not all patients had the resources to take on this role and were severely disadvantaged in obtaining care. Our study demonstrates the importance of a known and trusted health professional in helping bridge gaps in care for vulnerable patients. This is in line with studies indicating the important role of relationship continuity in ensuring that there is a 'care coordinator' when patients see multiple clinicians (26). Drawing on the framework of candidacy, it is likely to be most effective when the key coordinating role and long-term relationship is with a health professional in a highly 'permeable' service such as primary care, which functions as first-contact points of entry to the health system, and enables patients to assert their own candidacy. Access to ongoing care for patients who are less able to advocate for themselves requires a long-term therapeutic relationship with someone who is able to take on navigational roles and who adds their voice to the assertions or adjudications of candidacy to other providers. Patients who are most likely to fall through the gaps are those whose primary care provider has not assumed this role.

Relationship continuity (an ongoing therapeutic relationship with one or more care providers) (27) has been argued to be 'the antidote to an increasingly fragmented and depersonalized health care system' (28). In many countries, levels of relationship continuity are argued to be suboptimal (29), and in the UK, relationship continuity has been in decline (30). Our research adds weight to the growing body of evidence of the value of relationship continuity (12,31), particularly for patients with multi-morbidity and complex needs (1), and adds emphasis to efforts to promote and revive relationship continuity for these patients (28). Although policy changes in England, including the introduction into the GP contract of a requirement for a named GP for patients over the age of 75, may help reverse this trend (32), relationship continuity has not been prominent in the policy agenda for health system reform. Relationship continuity has been taken for granted but will erode unless reinforced by professional, financial and system policies. Ensuring that vulnerable patients have access to a primary care provider who can act to navigate their access through their care may need to be addressed through wider changes to policies and systems for working with vulnerable patients in primary care (33). Alongside this, GPs need support and training in managing and supporting patients who may be difficult to work with (34,35). This will help ensure that vulnerable patients do not become detached from health care, and help reduce the overuse of emergency services such as GP out-of-hours services and A&E (accident and emergency) that can happen when patients do not know where else to turn.

Our findings also have implications for the way experienced continuity is conceptualized. Our use of candidacy as a unifying concept helps build theoretical links between the concepts of access and continuity in that types of continuity, and issues to do with access, are all manifestations of candidacy negotiations in action; our findings provide evidence of the extent to which these concepts are closely interwoven (12). Our findings position experienced continuity of care as an issue of ongoing access and highlight how gaps in care can open up when ongoing access is thwarted by contested candidacy. In addition, current conceptualizations of experienced continuity see both management continuity (consistent and coherent management of patient care) and relationship continuity as contributing to patients' experience of how care is connected over time (12). Our findings shed light on how these two types of continuity interact, suggesting that while breakdowns in management continuity can lead to gaps in care, relationship continuity can provide a bridge to repair or overcome these gaps.

A key strength of our study is that our sample was relatively large for a qualitative study and included a diverse range of patients, providing reassurance that our characterization of falling through gaps is robust. Our focus on discontinuity, as opposed to continuity, is relatively novel. A potential weakness is the length of time since the interviews were conducted, as aspects of the organization and delivery of care in the UK have changed since then. We did not interview clinicians involved in the care of the patients, nor did we examine patient records. We make no judgements about the legitimacy of patients' claims in their accounts of their experiences; these may be seen in a different light by clinicians. Further research into clinician and manager perspectives on discontinuities in care would be of value.

Conclusions

Drawing on the theoretical framework of candidacy, we have described how gaps open up in care and identified that whether these gaps are bridged or remain unresolved is a result of negotiation between both patients and service providers around the eligibility of individuals—their candidacy—for health care. Relationship continuity, when it is possible, can help bridge gaps that open up in care and is a particularly important resource for vulnerable patients who lack the resources to assert their candidacy. But some vulnerable patients are unable to get the continuity they need, contributing both to their distress and to dysfunctional and potentially costly use of health services.

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