

How is continuity of care experienced by people living with chronic kidney disease?

Sarah Brand RN, MSc, BA, Senior Research Nurse¹  | Kristian Pollock PhD, MA, PGCHE, Principle Research Fellow²

¹Renal and Transplant Unit, Nottingham University Hospitals Trust, Nottingham, UK

²School of Health Sciences, University of Nottingham, Nottingham, UK

Correspondence

Sarah Brand, Renal and Transplant Unit, Nottingham University Hospitals Trust, Nottingham, UK.

Email: sarah.brand@nuh.nhs.uk

Aims and objectives: To explore patients' perceptions of continuity of care within a hospital-based specialist service.

Background: Patient journeys through health care are becoming increasingly complex. For patients with chronic conditions, the longevity of their illness and common multiple co-morbidities make this complexity more pronounced. Continuity of care is most challenging to provide for these patients. A multifaceted model of continuity is widely accepted, but despite this, much literature focuses exclusively on relational aspects. In addition, the majority of the literature has focused on primary and family care settings whilst continuity within specialist and hospital care has not been widely researched.

Design: A qualitative descriptive design was used.

Methods: Thirteen semi-structured interviews with patients accessing services as at a Renal and Transplant Unit at a UK hospital were conducted in 2014. Data were analysed thematically to identify commonality as well as diversity amongst participants.

Results: Five themes of time, being known, knowledge, knowing the system and responsibility were identified within patient experiences of continuity. The multidisciplinary team was more important in relational continuity than literature has previously suggested. Patients' expectations in relation to continuity were notably different in their interactions with hospital-based services in comparison with community and family-based care.

Conclusions: Patients accessing specialist care services may perceive continuity differently to those receiving care in the community. Generic guidance concerned with patient experience outcomes may be difficult to implement in practice.

Relevance to clinical practice: Nurses and the wider healthcare team play a fundamental role within the provision of continuity, even in predominantly medically led specialist services. The differences between primary and secondary care in terms of patient expectation and experience should be recognised to ensure effective models of care are implemented which both meet patient expectations and improve their experience of care.

KEYWORDS

chronic, health care, health policy/policy analysis, illness and disease, interviews, nephrology, patient-provider, professional, qualitative, relationships, research, semistructured, users experience

1 | BACKGROUND

The way that health care is delivered is changing globally. Advances in treatments increasingly require patients to attend specialist centres where expertise is concentrated. In contrast, routine care is being relocated from institutional to community or home settings in an attempt to provide care nearer to the patient's place of residence. Patient care journeys are becoming increasingly complex. A chronic, or long-term, condition is one which cannot, at present, be cured but can be controlled by medication or other therapies (Department of Health 2013). The extended duration of conditions such as renal failure or diabetes and the common occurrence of multiple co-morbidities often result in requirements for care from a number of healthcare providers to meet complex needs with greater potential for discontinuity in services (Aspinal, Gridley, Bernard, & Parker, 2012; Williams, Dunning, & Manias, 2007). Within the UK, it has been suggested that "the current fragmented services fail to meet the needs of the population" (Ham & Walsh, 2013, p.1). The increase in prevalence of long-term conditions and their associated co-morbidities in many developed countries amplify these difficulties in maintaining continuity (AIHW, 2008, House of Commons Select Committee 2014; Jackson, Orr Walker, Smith, Papa, & Field, 2009).

Continuity of care describes the effective coordination and smooth progression of care over time as viewed from the perspective of the patient (Freeman, Shepperd, Robinson, Ehrich, & Richards, 2001). Providing continuity both within services for the extended duration of a long-term condition and across organisational boundaries is challenging, particularly considering the financial, organisational and legislative constraints which are in place. Internationally, the World Health Organization has called for sustained efforts to maintain and enhance continuity whenever possible (WHO, 2001). There have also been a number of national programmes looking at how continuity is defined, measured and delivered (Freeman et al., 2001, 2007; Parker, Corden, & Heaton, 2011; Reid, Haggerty, & McKendry, 2002). UK NICE clinical guidance recommends that continuity of care is experienced by all patients within UK NHS services (NICE, 2012a). Continuity is a concern which affects key aspects of healthcare delivery, including patient experience, safety, quality and effectiveness of care.

Enhanced continuity has been associated with improved communication and increased levels of patient trust in medical staff (Parchman & Burge, 2004) as well as with early diagnosis of chronic diseases and decreased hospitalisation (van Servellen, Fongwa, & Mockus D'Errico, 2006). Continuity of care is allied to the work on integration and coordination of care, but continuity specifically emphasises the patient, rather than a systems, perspective (Freeman et al., 2001). Strauss, Fagerhaugh, Suczek, and Wiener (1985) identified some elements of continuity in their recognition of articulation work: the arrangement of discrete pieces of work into a coherent whole with the aim of contributing to identified goals of care. More recently, a multifaceted model of continuity of care has been developed and refined by Freeman et al. (2001) Freeman et al. (2007) and Haggerty et al. (2003) (Table 1.)

What does this paper contribute to the wider global clinical community?

- The current models of continuity of care do not adequately account for patients' experiences of continuity within specialist hospital-based services.
- Nurses and the wider healthcare team have a fundamental role to play in provision of continuity of care, even in predominantly medically led specialist hospital-based services.
- Guidance and policy concerned with patient experience should be more aware of context and the differences in patient expectations of care in a variety of settings. It must also be well defined to be practically useful.

Despite widespread recognition of Haggerty's model incorporating different facets of continuity—relational, management and informational continuity (Alazri, Neal, Heywood, & Leese, 2006; Cowie, Morgan, White, & Gulliford, 2009; Nair, Dolovich, Ciliska, & Lee, 2005), much emphasis has been placed on the relational aspect of care and in particular the relationship between a patient and their medical practitioner, both in policy (NICE, 2012b) and research (Boulton, Tarrant, Windridge, Baker, & Freeman, 2006; Gjevjon, Eika, Romøren, & Landmark, 2014; Guthrie & Wyke, 2006; Saultz, 2003; Saultz & Albedaiwi, 2004). Evidence within the literature is conflicting, particularly in the case of patients with chronic conditions. There are suggestions that relational continuity is important for patients with chronic conditions (Pandhi & Saultz, 2006). Others propose that this element of continuity is not of prime importance to this group of patients (Waibel, Henao, Aller, Vargas, & Vázquez, 2012) as they feel that a number of healthcare professionals know them equally well. In the case of chronic illness particularly, it could be argued that the emphasis on the doctor–patient relationship is unhelpful when multidisciplinary working is common and many care needs are met by nonmedical members of the healthcare team. Few conclusions about the importance of informational or management continuity have been drawn for this group of patients, and even less in the specialist care setting.

TABLE 1 Elements of continuity of care (adapted from Haggerty et al., 2003)

Element of continuity of care	Meaning
Informational	Use of information on past events and personal circumstances to make current care appropriate for each individual
Management	Consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs
Relational	An ongoing therapeutic relationship between a patient and one or more providers

Continuity has been acknowledged as an important part of the care provided by primary or family care services for some time. This may stem from the fact that a coordination role is an accepted part of the primary or family care service remit. Continuity features in most definitions of primary care within the UK as the general practitioner (GP) is seen as the care coordinator of services in both the community and acute sectors (Freeman & Hughes, 2010). In contrast, continuity of care within acute care services has not been widely explored within the literature. There is evidence that continuity is poorer in secondary care and that hospital staff appear to value continuity less highly than primary care health professionals (Gulliford, Naithani, & Morgan, 2006).

Chronic illnesses, such as renal or liver disease, which often require management by specialist hospital-based services, provide a rich context in which to study continuity of care as patients must navigate their way through a complex network of community generalist services as well as specialist hospital services during the course of their healthcare management. Locational, organisational (Santos & Eisenhardt, 2005) and knowledge (Brown & Duguid, 2001) boundaries must be negotiated through patient contact with a number of different service providers and individual healthcare professionals. This constitutes a context in which the effects of continuity, or lack of it, may be most stark, and the ability to provide continuity most challenging in practice. Diabetes is the only chronic disease which has been studied widely in the literature (Alazri et al., 2006; Gulliford et al., 2006; Nair et al., 2005; Naithani, Gulliford, & Morgan, 2006) and commonly in the community setting only.

Despite continuity of care being a concept focused on the perspective of the patient and therefore having an affinity with qualitative methods, there has been limited work done using qualitative methods to explore this issue. A number of systematic reviews have appraised the literature on continuity of care (Saultz, 2003; van Servellen et al., 2006; van Walraven, Oake, Jennings, & Forster, 2010), but only a very small number have contained any studies using qualitative methods (Pandhi & Saultz, 2006; Waibel et al., 2012). Of those that have used qualitative methods, there is an overwhelming focus on primary or family care (Boulton et al., 2006; von Bültzingslöwen, Eliasson, Sarvimäki, Mattsson, & Hjortdahl, 2006; Gallagher et al., 2013; Guthrie & Wyke, 2006). This is significant given that there have been questions raised within the literature as to whether continuity of care is valued equally by patients across settings (Naithani et al., 2006).

Qualitative studies have identified the individuality of the experience of continuity. It has been found that patients can have similar consulting patterns in primary care, but experience them differently (Boulton et al., 2006). This difference of experience depended on the importance that was attached to the different elements of continuity by individual patients. Patients could see the same healthcare professional at every consultation, but if this was not their priority, they did not experience or report it as continuity. This is an important insight as it suggests that patient reports of the experience of continuity are particularly significant and may lead to different conclusions than “objective” measures of continuity. It raises the

possibility that services may be delivering continuity in line with conceptual models or policy guidance, but patients will not necessarily experience this as continuity of care if it is not congruent with their priorities at the current time. These priorities may be different for patients accessing secondary care to those accessing primary or family care.

There remains a lack of evidence, particularly using qualitative methods, about patient perceptions of continuity of care within the secondary or acute healthcare sector. This is in addition to the debate already identified regarding the value patients with chronic illnesses attach to continuity of care. There is therefore an identifiable gap in the literature which this study aims to begin to address; specifically that concerned with the perceptions of patients with chronic illnesses accessing specialist care in the hospital-based secondary care setting.

In this study, we describe patients' experiences of continuity of care within an acute specialist hospital setting. We were concerned with exploring both how patients describe their experience of continuity of care and also how they understand the concept of continuity itself. Informed by the multifaceted model of continuity already developed (Haggerty et al., 2003), we sought to explore whether these various elements of continuity could be identified in discussion with chronically ill patients using a specialist secondary care provider and whether this model captured the entirety of their experiences.

2 | METHODS

2.1 | Methodological approach

As has been highlighted, continuity of care is contingent on the perspective of the patient. To explore the experiences of patients and how they understand and experience continuity of care within their healthcare interactions, a qualitative approach was deemed most appropriate. This study also aimed to inductively evaluate the relevance of current conceptual models of continuity, and therefore, a grounded theory approach was used as it advocates a close focus on data whilst simultaneously allowing consideration of conceptualisations of continuity (Strauss & Corbin, 1998). This approach allowed theory, either supportive of existing conceptualisations or otherwise, to develop from the data collected.

2.2 | Recruitment

The research context was a Renal and Transplant Unit operating within a large teaching hospital in the UK. The study was conducted January–May 2014. A convenience sampling approach was taken at a single site. The patients of a single consultant nephrologist were recruited to participate in the study. The cohort of patients selected were patients with stage 4–5 chronic kidney disease (CKD) (Renal Association 2014) who had not yet reached end stage renal failure. This group was recruited as they were attending the Renal and Transplant Unit regularly, for the majority at three monthly intervals, so it was anticipated they would have a view on continuity of care

provided by the unit. A list of all patients with CKD stage 4–5 being cared for by the specified consultant was compiled by the usual care team. The patient list was screened initially by the consultant, and a small number of patients were excluded for clinical reasons due to acute illness or lack of cognitive capacity for informed consent. All remaining 60 patients were sent an invitation letter from their consultant nephrologist. Patients responded by post or telephone directly to the researchers to express an interest in participating.

In total, 13 patients participated. One patient initially responded positively, but later declined to participate due to an emergency hospital admission. Nine participants were male, four were female, and the age range was 48–85 years.

2.3 | Ethical considerations

As the study was approved by the hospital Research and Innovation department as a service evaluation, permission was obtained on this basis. Formal ethical approval was not required. All participants were given study information on the first contact by their usual care team and required to give written informed consent prior to participating in the study.

2.4 | Data collection

All participants took part in a semi-structured interview with the researcher between March–May 2014 at the location of the patient's choice. Two interviews took place at the hospital and 11 at the patient's home. In eight interviews, a spouse or partner was present at the request of the patient and was encouraged to participate if they wished. The interviews were informed by an interview guide, but were largely patient led. The guide served as an "aide memoir" for the researcher conducting the interviews rather than a prescriptive interview schedule. All interviews were recorded on an audio recorder and transcribed verbatim by the researcher. The average duration of the interviews was 51 min (range 37–125).

2.5 | Data analysis

Thematic analysis was carried out. All transcripts were read closely and initially line by line coding was undertaken (Charmaz, 2006). Following identification of initial themes, focused coding was carried out and some of the initial codes were amalgamated to form broader codes which synthesised and explained larger amounts of data (Charmaz, 2006). At this point, active comparison between data from different interviews took place in order to explore the relevance of these broader codes to data from a number of interviews. Throughout this process, exemplars of the emergent themes as well as examples of data which did not fit within the themes were noted.

The literature was re-reviewed in the light of the themes identified, and the relationship between the literature and themes was considered. It was at this point that the relationship between the themes found in the data and the three elements of continuity

within the conceptual model was reflected upon. This ensured that themes emerged from the data initially, and their relationship to the model considered as a secondary stage of data analysis. This reduced the risk of "looking" for themes which supported the conceptual model, rather than those which arose naturally from the data itself. Discussion between the researchers of the emergent themes took place throughout the data analysis process to challenge and confirm the developing themes.

3 | FINDINGS

Five key themes were identified from the data collected from the interviews. These were time, being known, knowledge, responsibility and understanding the system. These ideas recurred throughout the interviews, alongside a diversity of views on specific issues. Different, and sometimes conflicting, positions could be adopted by individual participants within the same interview.

3.1 | Time

Participants discussed the importance of time in their dealings with the department. They wanted to feel that they spent a minimum time within the department so that their visits impinged on their lives as little as possible. A number of participants highlighted that they were happy to see whichever individual healthcare professional led to their visit to the department being the shortest—registrar, nurse or consultant:

I want to be in and out. I want it to be... I want to be in and out and I want to be... I want them to say, yes, you're alright. I think the longer I'm in, the more ill I might become! P3

I don't mind [who I see]. The quickest one in and out. P9

When all was going well, the healthcare professional whom they saw was not important, and the participants were unconcerned whether they had ever seen this person before. However, in times of change or crisis with their disease, participants highlighted the desire to see the consultant as they felt that they needed the benefit of his expertise and decision-making capability:

It don't matter to us who we see 'cause they're all good. P8

But I think if I, if it had been at a point where things had gone wrong or I was called in I'd want to see him [the consultant] if you know what I mean. P4

Relational continuity, particularly in terms of that associated with seeing a familiar doctor, appears to be most important in times of change or crisis. In periods of stability, patients appeared to be willing to trade relational continuity for being seen more quickly.

3.2 | Being known

Despite patients often not being concerned which individual healthcare practitioner they saw within specific interactions, participants talked about being known by staff, including doctors, and how this improved their experience of care. This can be seen to be an intrinsic element of relational continuity. However, this sense of being known was relatively superficial—merely that healthcare professionals appeared to remember them and called them by name:

You're not a number, you're a name when they come to see you. This is the thing I always find important. P1

He knows when he comes out to shout my name. He knows where, you know, he knows the faces... 'Cause he doesn't, he's not hunting round like some of them, you know, hunting round or just stand there and shout the name. He'll come out and look at me and say 'ah'.
P10

But for some participants, the definition of being known was difficult to articulate:

You feel as though he [the consultant] knows you as a patient rather than you being just a name or a number on a piece of paper... I get on well with [the consultant] and the nurses really, everyone really. Not that I feel that they know me. P3

Indeed, there was not always an expectation that healthcare professionals should know the patient as an individual other than in terms of the details of their illness:

They've got the information about me; about the problems and that's all they really need to know. They don't need to know what I had for breakfast! P2

Well how can he know us very well 'cause he's got that many patients really haven't they? P10

Participants did not expect that staff would have detailed knowledge of them as a person. Rather, importance was attached to whether individuals demonstrated good communication skills and appeared to have time for the participant. A number of participants experienced relational continuity from their GP and did not appear to expect the same kind of relationship from a specialist within the hospital setting. For some participants, a desire for interpersonal relationships was fulfilled by their interactions with the broader healthcare staff team rather than medical staff:

They all seem to know us. 'Even the receptionists.' 'Within three visits in the clinic... every person knew my first name... It tells me that they're just a caring... They've got a caring attitude'. Wife of P8

The assumption of some participants was that the consultant was too busy to foster a personal relationship, and therefore, it was not to be expected. The need for this element of continuity could be met by other members of the healthcare team. It was also important to participants that the personnel in the wider healthcare team were consistent:

Close knit staff. They're all the same staff. You haven't got, you know, change of staff every time you go. P2

Whilst the consultant appeared to be the most important member of the healthcare team based on which healthcare professional patients talked about most during their interviews, it is clear that the wider healthcare team played an important role for some participants in the provision of relational continuity of care.

3.3 | Knowledge

For many participants, an important role of doctors rather than any other health professional was as a source of knowledge, the authority for which was legitimated by the professional credentials. Much emphasis was placed on the depth and specialist nature of the unit doctors' knowledge, and this was sometimes compared to the more general knowledge, and consequent perceived lower status, of their family doctor. In addition, patients relied on the knowledge of the unit doctors to tell them how their condition was progressing and whether a management plan was successful. This reliance was largely due to the patients being unable to assess for themselves, from physical signs and symptoms, whether their condition was improving or deteriorating. They therefore depended on visits to the specialist clinic to give them information on the progress of their condition:

I tend to work on the theory he's the one that went to 15 years of training. He can tell me what it is... Well, providing that they've got the right qualifications, I'm not bothered. P2

I end up having to check everything they're [the GP] going to give me... If they want to stick me on antibiotics and things like this, I'm going to have to tell them that I've got a renal problem and... because otherwise they'll give me the wrong ones. I've got to watch everything they're doing. P1

When I get to [the hospital]... they can tell me what's up, what's down... They tell you what, you know, your readings are and all that and you know, what your kidney function is. P12

There was not always an expectation that it was necessary to see the same doctor in order to receive informational continuity. Patients considered that informational continuity was achieved largely by objects such as medical notes and technology such as the hospital computer system:

Normally [the doctor] goes through erm, with his computer and tells me all the different details about what's happening to me... because it's all computerised. P11

This was also the case in managing the boundary between specialist and community care. The specialist hospital department copied letters documenting the outcome of consultations to both patients and the family doctor. Patients placed a great emphasis on these letters as a mechanism of facilitating informational continuity:

The hospital can write to my GP and tell them something and they... send me a copy so I know, I know they've wrote to my GP. P13

It is interesting to compare the theme of being known to that of knowledge. Being known was related more to relational continuity—in being recognised and remembered, in a personal but not necessarily clinical sense—in contrast to knowledge which related more to informational continuity in terms of specialised clinical knowledge.

3.4 | Responsibility

Regardless of whether, and how often, they met in consultations, participants voiced a sense of 'belonging' to their allocated consultant and a feeling that he felt a personal responsibility towards them and ownership of their care which they did not sense with any other healthcare professional. When a participant was asked why he preferred to see the consultant, he replied:

Well, well, I just wanted err, you know, he's the guy that I'm seeing; who's got my notes. I'm supposed to be under him. P6

Maybe I feel, well, he's my doctor, so to speak, and he would help me. P4

Despite articulating a preference to see the consultant, this was at times off set by the desire to spend as little time as possible within the hospital environment, as demonstrated in the theme of time, and so there was some conflict within patients' narratives. This conflict appeared to be managed by patients by this feeling of responsibility which the consultant had for their care, independent of face to face interactions. Even in nonacute phases, patients felt that the ultimate decision-making powers lay with the consultant and understood that more junior staff and nurses discussed their case with the consultant to ensure that any plan of care was appropriate. This may be why in these nonacute phases, time became more important than which healthcare professional was seen:

I think they [the decisions] get made by [the consultant] don't they, when they... they'll all say 'We'll see [the consultant] about it'. P10

When they've done, they still speak to [the consultant] anyway. P7

Patients felt that the consultant retained the ultimate responsibility for their care and for a number of participants this was sufficient. Seeing the consultant face to face was not necessary as they felt confident that he was still in charge of, and actively directing, their care. Management continuity could therefore be maintained without relational continuity so that it was not essential that the patient always saw the same doctor face to face.

Responsibility also applied to the patient, however, to comply with medical advice, to work with the system and also to make the system work for the benefit of both healthcare staff and patients:

And I think a lot depends on the patient as well. P5

Well, you do what you're told don't you? P11

It's silly. I go there and they do a blood test when I go and they get the results after I've been. And we suggested having the blood tests done before. Two or three days before so that he's got the results when I go. P8

In this sense, continuity was not merely provided for the patient by healthcare staff and the system within which they operated, but was something which the patients themselves could influence and facilitate.

3.5 | Knowing the system

In their experiences of continuity, patients valued familiarity with the system of the department which they visited, the routine and the expectations of them as patients. This relates to the previous theme in the sense that patients' familiarity with and understanding of the system allowed them to feel and potentially take some responsibility for the process of health care. On the one hand, a familiar routine and obvious efficiency inspired confidence, but conversely, patients also appreciated flexibility in the system and the ability to adapt it to meet their specific needs:

It works the same way every time we goes in... Well, it's continuity. Everybody knows what everybody's doing. So nothing gets missed. You know somebody knows it's their job. It's, it's, it's just organized. P2

It's my choice to [have blood samples done before clinic] because I feel as though I'm doing my bit to help them to help me. P1

The importance of knowing the system is difficult to map onto relational, management or informational continuity, but was a very important element for a number of participants.

3.6 | Participants' understanding of continuity of care

Whilst not a theme per se, it is interesting to review what understanding participants had of continuity of care as a concept. Participants were asked directly during the interview what continuity of care meant to them. It was clear that it was not a concept which many participants had considered previously. Whilst continuity was articulated during the narratives of the interview, participants found it difficult to express directly how they would define continuity. When questioned, however, all participants felt that they received continuity of care in their dealings with the Renal Unit.

A number of participants identified continuity in its relational sense—seeing the same people—but none identified this being important only for the medical staff which they saw. Relational continuity was also facilitated by seeing the same reception and nursing staff during their visits to the healthcare setting, independent of whether they saw the same medical staff within the consultation itself:

Well basically I've always seen the same people which is good. I think that is the main thing. If you're seeing all and sundry, there's no continuity... you've got no link between them. P12

All saw this in relation to the wider healthcare team, and some recognised it in the broadest sense of keeping their care within the same location without actually identifying the importance of any individuals within that location:

As far as I'm concerned, I would like to carry on going [to the same hospital] and not go anywhere else. P8

Some participants identified management continuity in their understanding of continuity of care—being looked after over time and having someone to solve any problems or issues which may develop in the future:

Keep being checked over. Keep their eye on us... they're looking after us all the time and we feel confident enough that if anything is wrong, they'd... let us know. P3

This included having a treatment plan and knowing what that plan was.

Well I would say you... [know what] the plan was yeah. You've always got somebody to ask. You know what's going on. P1

No patients identified informational continuity within their understanding of continuity of care as a concept, although, as indicated above, the significance of this throughout the contact with the unit was apparent during the interview narratives.

Undoubtedly, the relational aspect of continuity featured most heavily in participants understanding of continuity of care, but it was clear that most were unsure of how they would define the concept. Indeed, one participant stated that continuity of care “had never cropped up” [P8], so it was clearly not part of her current understanding of her healthcare experiences. All elements of continuity were articulated within the interviews, but not in the terms used in the conceptual model.

4 | DISCUSSION

The three facets of continuity (Haggerty et al., 2003) were identified in the data, but an additional element of continuity associated with familiarity with the system of care was found which is not accounted for in the currently available models. These findings support other suggestions in the literature that familiarity with the system and routine of care are important to patients' experiences of continuity (Cowie et al., 2009; McCormack, Mitchel, Cook, Reed, & Childs, 2008). The model may need to be revised to represent the importance of familiarity with the organisation of care which spans elements of management and relational continuity but is not adequately explained in the current model.

Relational continuity was undoubtedly the most prominent element of participants' perceptions of continuity of care. However, in this study, participants routinely valued speed of access to care over relational continuity in relation to routine care, issues and appointments. However, in times of uncertainty or crisis, participants were prepared to wait for care in order to see the consultant. This is contrary to what has been reported in the existing literature based on primary care services where routinely patients would wait longer for care in order to see their usual healthcare provider. However, in times of acute illness, general practice patients were prepared to trade relational continuity for faster access to care and then settle for seeing an unfamiliar healthcare professional (Boulton et al., 2006).

A further difference between community and specialist care which has been suggested in the literature is that patient expectations of continuity of care are different for the two contexts (Cowie et al., 2009). The findings of the study support this in the element of relational continuity as a number of participants appeared to expect a closer personal relationship with their family doctor than with their specialist care provider. In specialist care, a desire for interpersonal relationships was fulfilled by interactions with the broader healthcare staff team rather than being contingent on contact with specific senior medical staff. This may be due to patients perceiving that specialist care within the hospital context was part of a much more complex system of care and that this precluded personal relationships with doctors in particular. The perceived difference in professional status and expertise between specialist hospital staff and staff in general practice and community services may also influence these differences in expectations between the two care settings. Much previous research has focused on the relationship

between the patient and medical staff as the key healthcare relationship, rather than relationships built up with other members of the healthcare team such as nurses or receptionists. In this study, the importance of the wider healthcare team appears to be much more prominent. The evidence presented here would indicate that patients' experience of continuity in this secondary care setting derives from contact with the healthcare team in its broadest sense.

In the UK, policy in the form of NICE guidance has focused exclusively on relational aspects of continuity. The NICE guidance quality standard (NICE, 2012b) has no clear practical definition however. The term "single episode of care" used in the quality standard is not clearly defined, and therefore, it is impossible to evaluate whether the data collected would indicate that the standard was being met. All patients reported seeing several healthcare professionals during the course of their care within the Renal and Transplant Unit, and some reported never having seen their allocated doctor, but this did not deter them from testifying that they had received continuity of care. This corroborates Boulton et al.'s (2006) findings within primary care that patient expectations and priorities influence their reported experience of continuity of care and that this may not align with professional constructions and measured indices of continuity. There are then difficulties for healthcare providers in demonstrating compliance, or otherwise, with some policy edicts. This study has indicated that some measurable indices do not accurately represent reported patient experience. This may be common to other guidance associated with patients' experiences of care using measurable indices which are particularly difficult to measure objectively.

There are indications in this study that patients accessing specialist care services may experience continuity differently to those receiving care in the community. This may be partly based on differing expectations of care in the varying contexts borne out of patient concerns about the severity and significance of the conditions being treated in each context. This has implications for the delivery of care as understandings of the importance of continuity based on evidence in primary care may not prove applicable to hospital-based specialist care settings. The literature has focused firmly on relationships between patients and medical staff, but this study indicates that continuity is founded on a wide range of health-related relationships. Nurses' influence on patients' experiences of continuity have been largely confined to investigation of nurse-led services (Pontin & Lewis, 2009). It may be unnecessary for care providers to strive for relational continuity in terms of seeing the same doctor, if this need can be met by the wider healthcare team. Nurses, and other healthcare staff, are fundamental to patient experience of continuity of care, even within services which are essentially medically led. Equally, changes to service organisation may influence patients' experiences of continuity of care much more fundamentally than might be anticipated and therefore need to be managed more carefully than initially expected. Further work is needed to explore these issues due to the scarcity of literature, particularly that using qualitative methods, focusing on the specialist care setting rather than community care environments.

5 | CONCLUSIONS

Policy and guidance concerned with continuity of care, and potentially other aspects of patients' experience, should take greater account of the potential differences between community and specialised hospital-based care, as well as other possible contextual differences. Whilst the aim of such documents is to distil current understandings into concise statements, this process risks misrepresenting the multifaceted concept of continuity of care. This has implications for the relevance and application of generic guidance to varying contexts and the ability of providers to demonstrate compliance. This raises wider questions about the role of policy documents and guidelines in improving the patient experience of care.

6 | RELEVANCE TO CLINICAL PRACTICE

An appreciation within clinical practice that continuity of care is a multifaceted concept is essential when designing and improving services. Continuity is not merely associated with patients seeing the same member of the medical staff, but is influenced by the wider healthcare team, organisational factors and service system designs. The role of nurses and other healthcare professionals within the provision of continuity in predominantly medically led services has received little recognition. Further work is required to explore how the multidisciplinary team can be used to enhance patients' experience of continuity of care. In addition, the differences between primary and secondary care in terms of patient expectation and experience should be recognised to ensure effective models of care are implemented which both meet patient expectations and improve their experience of specialist secondary care.

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CONTRIBUTIONS

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REFERENCES

- Alazri, M. H., Neal, R. D., Heywood, P., & Leese, B. (2006). Patients' experiences of continuity in the care of type 2 diabetes: A focus group study in primary care. *British Journal of General Practice*, *56*, 488–495.
- Aspinal, F., Gridley, K., Bernard, S., & Parker, G. (2012). Promoting continuity of care for people with long-term neurological conditions: The role of the neurology nurse specialist. *Journal of Advanced Nursing*, *68*, 2309–2319.
- Australian Institute of Health and Welfare (2008) *Australia's health 2008*. Canberra, ACT: AIHW.

- Boulton, M., Tarrant, C., Windridge, K., Baker, R., & Freeman, G. (2006). How are different types of continuity achieved? A mixed methods longitudinal study. *British Journal of General Practice*, *56*, 749–755.
- Brown, J. S., & Duguid, P. (2001). Knowledge and organization: A social-practice perspective. *Organization Science*, *12*, 198–213.
- von Bültzingslöwen, I., Eliasson, G., Sarvimäki, A., Mattsson, B., & Hjortdahl, P. (2006). Patients' views on interpersonal continuity in primary care: A sense of security based on four core foundations. *Family Practice*, *23*, 210–219.
- Charmaz, K. (2006). *Constructing grounded theory*. London: SAGE.
- Cowie, L., Morgan, M., White, P., & Gulliford, M. (2009). Experience of continuity of care of patients with multiple long-term conditions in England. *Journal of Health Services Research and Policy*, *14*, 82–87.
- Department of Health (2013) *Improving quality of life for people with long term conditions*. Retrieved from <http://www.gov.uk/government/policies/improving-quality-of-life-for-people-with-long-term-conditions> (Accessed 31 August 2014).
- Freeman, G., & Hughes, J. (2010). *Continuity of care and the patient experience*. London: The Kings Fund.
- Freeman, G., Shepperd, S., Robinson, I., Ehrich, K., & Richards, S. (2001). *Report of a scoping exercise for the National Co-ordinating Centre for NHS Service Delivery and Organisation R & D (NCCSDO)*. London: NCCSDO.
- Freeman, G., Woloshynowyc, M., Baker, R., Boulton, M., Guthrie, B., Car, J., ... Tarrant, C. (2007). *Continuity of care 2006: What have we learned since 2006 and what are the policy imperatives now?*. London: NCCSDO.
- Gallagher, N., MacFarlane, A., Murphy, A. W., Freeman, G. K., Glynn, L. G., & Bradley, C. P. (2013). Service users' and caregivers' perspectives on continuity of care in out-of-hour primary care. *Qualitative Health Research*, *23*, 407–421.
- Gjevjon, E. R., Eika, K. H., Romøren, T. I., & Landmark, B. F. (2014). Measuring interpersonal continuity in high frequency home healthcare services. *Journal of Advanced Nursing*, *70*, 553–563.
- Gulliford, M., Naithani, S., & Morgan, M. (2006). *Continuity of care in type 2 diabetes: Patients', professionals' and carers' experiences and health outcomes*. London: NCCSDO.
- Guthrie, B., & Wyke, S. (2006). Personal continuity and access in UK general practice: A qualitative study of general practitioners' and patients' perceptions of when and how they matter. *BMC Family Practice*, *7*, 11–19.
- Haggerty, C., Reid, R., Freeman, G., Starfield, B., Adair, C., & McKendry, R. (2003). Continuity of care: A multi-disciplinary review. *BMJ*, *327*, 1219–1221.
- Ham, C., & Walsh, N. (2013). *Making integrated care happened at scale and pace*. London: The Kings Fund.
- House of Commons Select Committee (2014). *Managing the care of people with long-term conditions*. London: The Stationary Office Limited.
- Jackson, G., Orr Walker, B., Smith, J., Papa, D., & Field, A. (2009). Hospital admissions for people with diagnosed diabetes: Challenges for diabetes prevention and management programmes. *New Zealand Medical Journal*, *122*, 13–21.
- McCormack, B., Mitchel, E. A., Cook, G., Reed, J. A. N., & Childs, S. (2008). Older persons' experiences of whole systems: The impact of health and social care organizational structures. *Journal of Nursing Management*, *16*, 105–114.
- Nair, K. M., Dolovich, L. R., Ciliska, D. K., & Lee, H. N. (2005). The perception of continuity of care from the perspective of patients with diabetes. *Family Medicine*, *37*, 118–124.
- Naithani, S., Gulliford, M., & Morgan, M. (2006). Patients' perceptions and experiences of 'continuity of care' in diabetes. *Health Expectations*, *9*, 118–129.
- National Institute for Health & Clinical Excellence (2012a). *Patient experience in adult NHS services. Improving the experience of care for people using adult NHS services. Patient experience in generic terms. Clinic Guidance. Methods, evidence and recommendations*. London: NICE.
- National Institute for Health & Clinical Excellence (2012b) *Quality standard for patient experience in adult NHS services. NICE quality standard 15*. London: NICE.
- Pandhi, N., & Saultz, J. W. (2006). Patients' perceptions of continuity interpersonal continuity of care. *Journal of the American Board of Family Medicine*, *19*, 390–397.
- Parchman, M. C., & Burge, S. K. (2004). The patient-physician relationship, primary care attributes, and preventative services. *Family Medicine*, *36*, 22–27.
- Parker, G., Corden, A., & Heaton, J. (2011). Experiences of and influences on continuity of care for service users and carers: Synthesis of evidence from a research programme. *Health and Social Care in the Community*, *19*, 576–601.
- Pontin, D., & Lewis, M. (2009). Maintaining the continuity of care in community children's nursing caseloads in a service for children with life-limiting, life-threatening or chronic health conditions: A qualitative analysis. *Journal of Clinical Nursing*, *18*, 1199–1206.
- Reid, R., Haggerty, J., & McKendry, R. (2002). *Defusing the confusion: Concepts and measures of continuity of healthcare*. Ottawa, Ontario: Canadian Health Services Research Foundation.
- Renal Association (2014). The UK eCKD Guide. Retrieved from www.renal.org/information-resources/the-uk-eckd-guide/ckd-stages#sthash.6uKQXl87.dpbs (Accessed 31 August 2014).
- Santos, F. M., & Eisenhardt, K. M. (2005). Organizational boundaries and theories of organization. *Organization Science*, *16*, 491–508.
- Saultz, J. W. (2003). Defining and measuring continuity of care. *Annals of Family Medicine*, *1*, 134–143.
- Saultz, J. W., & Albedaiwi, W. (2004). Interpersonal continuity of care and patient satisfaction: A critical review. *Annals of Family Medicine*, *2*, 445–451.
- van Servellen, G., Fongwa, M., & Mockus D'Errico, E. (2006). Continuity of care and quality outcomes for people experiencing chronic conditions: A literature review. *Nursing and Health Sciences*, *8*, 185–195.
- Strauss, A., & Corbin, J. (1998). Grounded theory methodology: An overview. In N. K. Denzin & N. K. Lincoln (Eds.), *Strategies of qualitative inquiry* (pp. 158–183). London: SAGE.
- Strauss, A., Fagerhaugh, S., Suczek, B., & Wiener, C. (1985). *Social organisation of medical work*. Chicago, IL: University of Chicago Press.
- Waibel, S., Henao, D., Aller, M. B., Vargas, I., & Vázquez, M.-L. (2012). What do we know about patients' perceptions of continuity of care? A meta-synthesis of qualitative studies. *International Journal for Quality in Health Care*, *24*, 39–48.
- van Walraven, C., Oake, N., Jennings, A., & Forster, A. J. (2010). The association between continuity of care and outcomes: A systematic and critical review. *Journal of Evaluation in Clinical Practice*, *16*, 947–956.
- Williams, A., Dunning, T., & Manias, E. (2007). Continuity of care and general wellbeing of patients with comorbidities requiring joint replacement. *Journal of Advanced Nursing*, *57*, 244–256.
- World Health Organisation (2001). *The Lubljana charter on reforming health care*. Geneva: WHO.

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