

Experienced Continuity of Care When Patients See Multiple Clinicians: A Qualitative Metasummary

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ABSTRACT

PURPOSE Continuity of care among different clinicians refers to consistent and coherent care management and good measures are needed. We conducted a metasummary of qualitative studies of patients' experience with care to identify measurable elements that recur over a variety of contexts and health conditions as the basis for a generic measure of management continuity.

METHODS From an initial list of 514 potential studies (1997-2007), 33 met our criteria of using qualitative methods and exploring patients' experiences of health care from various clinicians over time. They were coded independently. Consensus meetings minimized conceptual overlap between codes.

RESULTS For patients, continuity of care is experienced as security and confidence rather than seamlessness. Coordination and information transfer between professionals are assumed until proven otherwise. Care plans help clinician coordination but are rarely discerned as such by patients. Knowing what to expect and having contingency plans provides security. Information transfer includes information given to the patient, especially to support an active role in giving and receiving information, monitoring, and self-management. Having a single trusted clinician who helps navigate the system and sees the patient as a partner undergirds the experience of continuity between clinicians.

CONCLUSION Some dimensions of continuity, such as coordination and communication among clinicians, are perceived and best assessed indirectly by patients through failures and gaps (discontinuity). Patients experience continuity directly through receiving information, having confidence and security on the care pathway, and having a relationship with a trusted clinician who anchors continuity.

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INTRODUCTION

Continuity of care is the extent to which a series of health care services is experienced as connected and coherent and is consistent with a patient's health needs and personal circumstances.¹ As patients increasingly receive care from multiple professionals and organizations, improving continuity of care has become a research priority. Although continuity of care is understood differently across health disciplines, an interdisciplinary review of concepts and measures of continuity of care found all disciplines would recognize 3 types of continuity.^{1,2}

Relational continuity is the therapeutic relationship between a patient and 1 or more clinicians that bridges episodes of care and provides coherence through clinicians' growing comprehensive knowledge of the patient. It is most valued in primary care and family medicine. Informational continuity ensures connectedness and coherence by the uptake of information on past events and is most emphasized in the nursing sciences.³⁻⁶ Management continuity refers to consistent and coherent management by different clinicians

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through coordinated and timely delivery of complementary services. It is most emphasized in disease management and is the type most invoked in policy documents.

There is a dearth of generic measures of management continuity, and our initial intent was to develop such a measure from the patient's perspective that can be applied to a variety of conditions and not be confounded by technical quality of care. Existing measures focus on a specific care transition, such as discharge from hospital,^{7,8} or a health condition, such as diabetes,^{9,10} mental illness,¹¹⁻¹⁴ heart disease,^{15,16} or cancer.¹⁷ Some measures include the content of care, confounding technical quality of care with continuity. Some primary care evaluation tools include generic measures of care coordination¹⁸⁻²² but focus only on the primary care clinician rather than on the patient's experience across the system.^{23,24}

Ideally, the design of such an instrument is informed by qualitative inquiry. Freeman and colleagues²⁵ noted that continuity was principally defined by professionals, and they called for qualitative studies to explore what continuity means to patients and how best to measure that experience. Rather than undertaking our own qualitative study, we decided to build on the wealth of information produced after Freeman et al's call for studies. Despite our intention to identify management continuity themes, we also found elements of informational and relational continuity. Consequently, this article presents recurrent continuity-related themes in qualitative studies of patients' experience with care received from various clinicians, in a variety of contexts, and for various conditions, with a view to measure development.

METHODS

We conducted a metasummary of reports of qualitative study to identify continuity-related themes. In a metasummary the unit of analysis is the study report rather than transcripts of interviews from different studies. As outlined by Sandelowski and Barroso,²⁶ it consists of systematic identification of relevant qualitative studies, critical appraisal of the studies' quality, and coding of report extracts to identify emerging themes. The metasummary is an analysis of the data-driven integrated judgments and/or pronouncements made by researchers. We considered this method most suitable for identifying continuity-related issues across a variety of conditions and care settings. The study was approved by the Charles-Lemoyne Hospital ethics review committee.

Systematic Identification of Studies

We identified published qualitative studies from a search of electronic databases (MEDLINE, Embase,

CINAHL, PsycINFO) between 1997 and May 2007, containing the MeSH term "qualitative research" and related text phrases for "assessment of healthcare processes or outcomes" or "continuity of care" or "coordination of care," and consumer/spatient/client perceptions/understanding. We did not limit the search to "continuity of patient care" because we wanted to expand beyond an intended focus on continuity. We reviewed all research reports within the "continuity of care" priority areas funded by the Canadian Health Services Research Foundation and the National Institute for Health Research in England.

The abstracts and/or full text were scanned to ensure studies met all of 4 inclusion criteria: (1) used qualitative methods, (2) examined perception and experience of patients or an informal caregiver (not health professionals), (3) referred to care over time, and (4) referred to care received from more than 1 clinician. We excluded articles specifically focusing on the experience of a disease or treatment rather than on health care received. We wrote to the principal investigators of all eligible studies requesting a more detailed report. The unit of analysis remained the study, not the articles or reports.

Critical Appraisal of the Studies

All studies were appraised critically using the Walter et al (2004)²⁷ scoring grid for qualitative articles. We found that the scoring grid scored the quality of reporting rather than the methods, however, so we did not formally integrate the quality score into our analysis; instead, we prioritized findings that were well supported by citations and where we judged saturation was achieved.

Coding

Three of the authors (J.L.H., G.K.F., D.R.) independently coded the extracts to identify themes. Codes were defined clearly to ensure consistency between analysts and studies, then were collapsed or split and redefined through consensus meetings until there was minimal conceptual overlap. Codes were entered in NVivo (QSR International)²⁸ and grouped by continuity of care dimension. Only codes seen in more than 1 care context or condition were identified as generic.

RESULTS

We identified 514 potentially eligible studies; 34 met our inclusion criteria. We obtained additional reports for 8 studies. As shown in Table 1, studies addressed a wide variety of health conditions and care contexts. Below we describe the findings from this metasummary and show how the importance of connectedness

Table 1. Studies Included in the Metasummary, in Chronological Order, Showing Author, Year, Country, Qualitative Design, and Patient Population

Author Year, Country	Qualitative Design	Patient Population and Setting
American Hospital Association and The Picker Institute ²⁹ 1997, USA	Focus groups (n = 31) and Picker Institute patient surveys	Adult patients (public perceptions of health care and hospitals in 12 different states in the United States)
Burkey et al ³⁰ 1997, UK	In-depth semistructured interviews (n = 43); follow-up with 37 at 6 months	Patients followed at 5 general medical outpatient clinics (3 or more attendances) and discharged in April-May 1995
Adeyemi-Dalton et al ³¹ 1998, UK	Semistructured interviews about routine hospital follow-up (n = 113)	Women with breast cancer in remission discharged to usual care
Armitage et al ³² 1998, Australia	Telephone semistructured interviews (n = 29) at home (5 to 36 days after discharge) about discharge planning	Patients (inpatient >2 days) discharged from 3 medical wards of a large tertiary referral teaching hospital
Gallagher et al ³³ 1999, Canada	10 Individual semistructured interviews	Seniors from across Canada who use 2 or more health services, recruited in their community by Advisory Council members, themselves seniors
Wallace et al ³⁴ 1999, UK	Focus groups (n = 3)	Women with epilepsy recruited from tertiary hospital's Epilepsy Clinic and through the epilepsy support group
Wallace et al ³⁵ 1999, Canada	Focus groups (n = 9) with patients and family members separately (n = 41)	Psychiatry patients discharged from inpatient unit and still being treated in the outpatient department, and family members
McCourt et al ³⁶ 2000, UK	Semistructured narrative individual interviews (n = 20)	Visible minority women, one-half receiving caseload midwifery care and one-half conventional maternity care (ethnic categories: black Caribbean and African, South and East Asian, and Mediterranean or Middle Eastern)
Radwin et al ³⁷ 2000, USA	Interviews about quality nursing care with a semistructured schedule (n = 22)	Oncology patients in outpatient treatment at an urban medical center (19 hospitalized for cancer treatment at least once)
Bakker et al ³⁸ 2001, Canada	Interviews relatively unstructured in patient's home (n = 28)	Patients receiving chemotherapy at 1 of the 13 community chemotherapy clinics after medical oncology consultation at regional cancer center
Kai et al ⁵ 2001, UK	Individual in-depth interviews (n = 34)	Patients with enduring mental ill health registered with 4 general practices referred to 2 consultant psychiatrist-led community mental health teams at a local hospital inpatient unit
Bain et al ³⁹ 2002, Scotland	Focus groups (n = 4), 22 patients with colorectal cancer (and 10 of their relatives) and in-depth interviews conducted in the participants homes (n = 39 patients and 24 relatives)	Oncology and surgical outpatient clinics for colorectal cancer and from chemotherapy outpatients and in-patients. North and Northeast of Scotland
Harrison et al ⁴⁰ 2002, Canada	In-depth personal interviews and short telephone interviews to understand coordination of care	Patients (n = 26) discharged from an acute care hospital into the community with home care support, (n = 5 urban and 1 rural)
McKinney et al ⁴¹ 2002, UK	Phenomenological approach (interpretative Heideggerian approach, n = 6)	Patients (n = 6) who have been transferred from intensive care to general ward; before and after transfer from intensive care unit
Murray et al ⁴² 2002, UK	In-depth interviews every 3 months for 1 year with patients and their main caregiver plus professional identified as key by patients. Two multidisciplinary focus groups. Postbereavement interviews with caregivers and key professionals	Patients with inoperable lung cancer (n = 20) and patients with advanced cardiac failure (n = 20) receiving community terminal care, with caregivers and key professional carers
Osse et al ⁴³ 2002, The Netherlands	In-depth interviews with patients (n = 9) and relatives (n = 7) followed by interviews using a checklist (n = 31 and 15)	Adults cancer patients with metastatic disease in a palliative phase of cancer. Patients were selected through randomly chosen general practitioners and through patient organizations
Kroll et al ⁴⁴ 2003, USA	Semistructured telephone interviews (n = 30)	People with cerebral palsy, multiple sclerosis, or spinal cord injury, with reported problems of health insurance coverage and accessibility; across all services
O'Connell et al ⁴⁵ 2003, Australia	Focus groups (n = 12), mixed groups about transition from pediatric to adult care	Young adults (aged 16-25 years) with a disability, their caregivers, and health care service clinicians
Tarrant et al ⁴⁶ 2003, UK	Narrative-based individual interviews, "framework" approach. Followed by focus groups with patients (n = 4) and with health professionals (n = 4)	Adult patients (n = 40), practitioners (n = 13), practice and community nurses (n = 10), and practice administrative staff (n = 6) in 6 general practices in Leicestershire
Ware et al ¹⁴ 2003, USA	Ethnographic study using data collected through observation and open-ended interviewing	Severely mentally ill persons (n = 9) and their health professional, in public mental health services, Boston, Massachusetts
Arthur et al ⁴⁷ 2004, UK	Semistructured interviews (n = 10)	Rheumatology outpatients using antirheumatic drugs

Continued

Table 1. Studies Included in the Metasummary, in Chronological Order, Showing Author, Year, Country, Qualitative Design, and Patient Population (continued)

Author Year, Country	Qualitative Design	Patient Population and Setting
Dolovich et al ⁹ 2004, Canada	Focus groups with patients (n = 7) and health care clinicians (n = 2), approximately one-half being physicians	Patients with a diabetes diagnosis registered in a multidisciplinary health service organization in Ontario
Infante et al ⁴ 2004, Australia	Focus groups (n = 12)	Health consumers with chronic illnesses, followed in general practice
Miles et al ⁴⁸ 2004, UK	Single semistructured interviews (n = 7) about transition	Adolescent patients human immunodeficiency virus (HIV) infection transferred from hospital pediatric unit to the adult HIV outpatient center
Williams et al ⁴⁹ 2004, Australia	Colaizzi's phenomenological method using single semistructured interviews (n = 12)	Patients with multiple chronic illnesses for approximately 5 years, admitted to acute care hospital from home, during hospital care of at least 4 days' duration
Woodward et al ⁵⁰ 2004, Canada	Interviews home care case managers (n = 13), home service clinicians (n = 19), clients (n = 25), and their caregivers (n = 5) and 3 physicians	Home care cases with different entry mechanisms to home care (from hospital or from the community) and different availability of family caregivers
Pâquet et al ⁵¹ 2005, Canada	Focus groups (n = 3) from rural, semirural and urban milieu, about cardiac rehabilitation programs	Adults hospitalized for a cardiovascular event: myocardial infarction, angina, or percutaneous angioplasty
Alazri et al ⁶ 2006, UK	Focus groups (n = 12) about primary diabetes care	Patients with type 2 diabetes from 2 rural and 5 urban practices in Leeds of different sizes
Fraenkel et al ⁵² 2006, UK and USA	Focus groups (n = 8, 4 per setting)	Patients with hepatitis C attending the outpatient liver clinics in 2 different settings
McCurdy et al ⁵³ 2006, Canada	Qualitative case study approach, 4 focus groups with young adults about pediatric to adult care transition	Patients aged 19-24 years, after transfer at 18 years from pediatric to adult center after kidney, liver, or heart transplant
Naithani et al ⁵⁴ 2006, UK	In-depth semistructured interviews in patient's home	Type 2 diabetic patients from general practices in 2 inner London boroughs with young, mobile, and ethnically diverse populations and high level of deprivation
Hildingsson et al ³ 2007, Sweden	Written response to 1 open-ended question about maternity services	Women seen in a Swedish prenatal clinic
Lester et al ⁵⁵ 2007, UK	Focus groups (n = 18) (separate with patients, physicians, practice nurses)	Patients with broadly defined serious mental illness in 6 primary care trusts, West Midlands
Burns et al ¹³ 2007, UK	In-depth interviews with 20 psychotic patients and 11 nonpsychotic patients	Patients with mental illness (and their caregivers) in 2 London mental health National Health Service accessing a variety of health and social services

and patients as active participants were important to patients' perception of continuity. A summary of the identified themes are displayed in Table 2.

Connectedness as Security and Confidence, Not Seamlessness

Terms such as "seamlessness," "smoothness," and "uninterrupted care" were used by researchers to describe the degree of connectedness between health care encounters,^{14,57-60} but patients seem to experience continuity as feelings, either positively as security,^{3,31,37,38,61} confidence,^{33,36,38,40,46,54} safety,^{61,62} or support⁴⁰; or they experience them negatively as uncertainty,^{32,41} insecurity,^{33,34} lostness,^{52,55} vulnerability,^{37,56} or mistrust.^{34,49} They may respond by seeking alternate care (including self-care), mistrusting their clinician, becoming noncompliant, or withdrawing from the formal care system.⁵⁴

...trust was linked to care coordination. In particular, patients felt more confident that mistakes were less likely to happen and that clinicians would be "on top of things" because they were connected to a "responsible party."³⁷

Connectedness Beyond Health Care Encounters

Perhaps not surprisingly, patients' experience of continuity transcends health care encounters to include connectedness between their personal lives and the health system.

They regarded visits to their doctor as part of their lives, in which their diseases were integrated. The patients felt it was important for their health care that the doctor be informed of their life situation, to create a sense of coherence.⁶⁰

Predictability and stability are hallmarks of well-organized health care and successful transitions, providing a sense of security, coping, and confidence about future care.^{14,29,40,42} Even so, predictability needs to be balanced with flexibility and adaptation to changing needs, knowing that appointments can be more frequent or that a contingency plan is in place if the patient needs it.^{14,29,54}

Patients as Active Agents

The patient's role emerged in management, informational, and relational continuity. Many patients want

and expect to be involved in their care, specifically in communicating, monitoring, and self-management.^{3,40} They want their role and ideas to be acknowledged, however, especially from their most trusted clinician.

A very dramatic finding...was the importance of consumers in coordinating their own care.... This...involvement may include a variety of actions that have been classified as consumer roles: communicate, monitor, prepare, and manage.⁴⁰

Additionally, patients emphasized how patient self-care and self-responsibility are integral parts of continuity of care... given that patients with a chronic condition make many healthcare decisions external to the healthcare system, and are required to continually and consistently adhere to their decisions to maintain their health....⁹

But not all patients are willing or able to take such a role,⁴ notably those who are not familiar with the health system, have low health literacy, or are simply not able to advocate for themselves.⁴⁶ This group can include otherwise-proactive patients whose illnesses worsen. These patients' sense of security and connectedness depends on coordinating actions taken on their behalf.

Patients talk about how assertive they must be to get answers, and the frustrations of trying to coordinate care among many different specialists. Many of these patients worry about what will happen if and when they are too sick to manage such things on their own behalf.³⁹

Management Continuity or Experienced Coordination

Coordination Assumed, Not Observed

Studies consistently specified that coordination is fundamental to care being connected and coherent, but coordination, by definition, refers to collabora-

tive actions among clinicians, and little evidence was provided in the studies about patient awareness of such actions.⁵⁴ An ethnographic study of continuity of care for patients with severe mental health problems observed a variety of coordination mechanisms to create connectedness and smoothness,¹⁴ but it was clinicians who were conscious of these behaviors, not patients. Patients presume communication between clinicians, consistent retrieval of available information, and the existence of an agreed-upon care pathway. Coordination is inferred when no problems have occurred:

When care was coordinated, patients felt that clinicians had communicated with one another.³⁷

Clients are least likely to talk about care management as important to continuity; only clients who had experienced care management problems that resulted in discontinuities commented on it.²⁹

Likewise, patients seldom observe the negotiation of roles and complementary actions among different professionals, although role clarity emerged as a recurrent finding. Again, role clarity is assumed until proven otherwise and enters patients' awareness as discontinuity when different clinicians work at cross-purposes or when care is compromised because of lack of coordination or communication.^{49,51,52}

Physicians' confusion regarding perceived roles and responsibilities for the care of patients with HCV [hepatitis C virus] resulted in frustration on the part of patients and physicians, and poor treatment of patients' symptoms.⁵²

An indicator of confused or unclear roles is when patients receive conflicting advice or information.^{50,51,54} Inconsistent messages or lack of role clarity shakes patients' faith in their clinicians' overall competence and expertise.^{5,51}

Patients considered that consulting more than 1 doctor could disorganize the treatment plan initiated by their named GP [general practitioner], as they might receive different opinions from the various doctors, confusing them about whose advice to follow.⁶

Clinicians' Care Plans Are Not Patients' Care Plans

The care plan used by clinicians outlines the content and timing of services on the clinical pathway, and study reports consistently emphasize its importance. Again, patients presume their different clinicians share such a plan.^{6,14,54} Simply receiving written information about treatment does not constitute a functional care plan

Table 2. Summary of Identified Themes Related to Experienced Continuity of Care When Seeing Multiple Clinicians

Dimension	Emerging Finding
Overarching themes	Connectedness experienced as security and confidence, not seamlessness Connectedness beyond health care encounters: between personal lives and health care Patients as active agents: for most but not all patients
Management continuity or experienced coordination	Coordination assumed, not observed Clinician care plans are not patient care plans; patients want to know what to expect, what to do Every transition benefits from discharge planning
Informational continuity	Information among clinicians experienced through gaps Information from clinicians enables patient agency and empowerment
Relational continuity	One, most trusted clinician among many Beyond empathy to partnership
Care coordinator	An identified and proactive connector and advocate who knows the patient

for patients, especially when the treatment plan fails to account for comorbidities⁴⁹ or presupposes resources or capacity that is unrealistic for the patient.^{33,50-52} For patients, a functional care plan provides a sense of their future care or health trajectory and can be integrated into their lives. Patients want to know how their health condition will likely change over time and what they can do, and they want to have predictable scheduling and content of care, a specific plan for when things go wrong, and confidence their care will change in a timely way when and if their health condition changes.^{6,39,46,50,54}

Every Transition Benefits From Discharge Planning

The literature consistently indicated the transition across organizational boundaries as the breaking point for continuity of care, and our analysis underlines this problem. Most of the focus is on discharge from a hospital, but whenever a patient crosses an organizational boundary, care is vulnerable to discontinuity.

Patients often experience a discontinuity of care as they move back and forth between inpatient, outpatient, and home care settings. They do not understand the institutional and functional boundaries and find it difficult to negotiate the system actively.³⁹

Professionals often forget that every transition is a new experience for patients, who need transition support. Learning from hospital discharge planning, transition care provides information to help patients anticipate and understand the new environment and know where to get help, and it outlines a contingency plan for returning to a safe care environment in the case of unmanageable distress.^{35,40,41,43,51}

Informational Continuity

Information Among Clinicians Experienced Through Gaps

Patients assume clinicians are communicating until proven otherwise. Communication failures defined patients' experience of discontinuity in almost two-thirds of the studies. Evidence of failure to transfer or use appropriate information occurs when important patient comorbidities or life circumstances are ignored,^{29,49} when clinicians are unaware of other professionals' treatment decisions,⁶ and when patients get conflicting messages.^{5,50} Patients find repeating information for every clinician particularly disturbing and burdensome,^{37,51,60} especially when it is sensitive or embarrassing and is probably in the medical record.^{5,14}

Information From Clinicians Enables Patient Agency

Information transfer between patients and clinicians was included by one author as part of management continuity⁵⁴ and by another as an element of relational

continuity and self-management.⁹ We include it as a dimension of informational continuity given how often it was raised in this context. This dimension overlaps and interacts with the functional care plan, above.

Many participants described the importance of communication links. These links referred to communication between the patients and their specific health care clinicians as well as to the communication between health care professionals.³⁸

Patients, especially those who see themselves as agents of their own care, want to be part of the information loop around their care, both giving and receiving information.⁴⁸ Information needs most commonly identified were about the health condition and effects of treatment,^{30,31,42,52,62} prognosis,^{32,47} what to expect in a new environment or on discharge,^{41,49,53} self-management and treatment,⁴⁰ and contingency plans for complications or unexpected events.⁵³ Information empowers patients, giving them a sense of partnership and control,^{3,37,43} particularly for informal caregivers.^{44,60} Just as most information transfer between clinicians depends upon documentation, written information for patients is important for achieving continuity and a sense of security. Several studies suggest that enabling patients with information is more problematic in primary than in secondary care.^{44,53,57}

Relational Continuity

One Most Trusted Clinician Among Many

Two-thirds of the studies referred to the importance of a therapeutic relationship, especially with an individual clinician who has developed a comprehensive knowledge of the patient as a whole person and uses that in managing a health condition.^{4,46,60} This relationship was characterized by "trust" in 16 studies. When patients see various clinicians, having a single trusted clinician is particularly important for sensitive or embarrassing aspects of care and for managing comorbidity.^{5,6,49}

Responders consistently highlighted the importance of building a continuing relationship with one individual over time. This allowed responders to feel that the professional had developed an understanding of their problems and of possible solutions achievable within the particular context of their own social and medical histories.⁵

The relationship is so important that some patients trade off the clinical expertise of specialists for the security of being looked after by a known and trusted family physician.^{38,45,55,60} Patients are often proactive in maintaining a continuing relationship, typically by making appointments when not necessarily ill. This activity is legitimized through wellness care in general practice,^{4,46,60} but it also occurs in such other contexts as mental health.⁵

Beyond Empathy to Partnership

Partnership seems especially important for patients seeing multiple clinicians, especially if they assume an active role in care. Partnership involves sharing power in the therapeutic relationship.^{4,9,51,60} Patients want to be taken seriously, be empowered to share in decision making, and have their contribution to care enabled and recognized.^{5,37,51,54,60}

Health professionals were often key people with whom responders could discuss their problems and mental distress, given these contexts. Some felt that this had formed one important source of support over time, which had helped them overcome barriers. They felt more empowered to identify solutions and establish control over their lives and illness experience.⁵

Care Coordinator

Typically, the clinician with comprehensive knowledge is also the care coordinator, reinforcing ongoing trust and relationship,* but this relationship can change when care is intensified in a specific context, such as in a hospital, with home care, or with active cancer treatment.^{31,36,37} Likewise, some patients trade off comprehensive knowledge for care coordination by a specialist who can assure the highest quality of care.^{44,47,52}

The notion of care coordinator was expressed succinctly as "the one in charge of your health care in the system."⁶ Although not always aware of specific actions, patients know the care coordinator organizes the care journey, is their advocate, and generally is "on top of things" for them.^{29,37}

They felt their clinician should not only be knowledgeable about their health care needs, but also provide assistance with navigating the complexity of...care delivery systems.⁴⁴

Patients emphasize that security comes from knowing that a personal GP assumes responsibility, keeps care coordinated, and refers to other professionals when needed.⁶⁰

The studies provide evidence of patients knowing when comprehensive knowledge about them is brought to bear on the care plan,^{5,38,46} when transfers are arranged,^{53,62} when information or the care plan is passed on to other clinicians,^{29,37} when monitoring and follow-up is proactive,^{40,55} and when the coordinator has good working relationships with other clinicians involved in their care.^{29,52}

DISCUSSION

This review of qualitative studies of the patient experience of seeking care from multiple clinicians was undertaken to gain insights initially as a basis for a

generic measure of management continuity from the patient perspective. Perhaps the most striking insight is that the desire for connectedness extends beyond health care encounters to include connectedness between health care and the rest of the patient's life, which translates to a sense of security and confidence more than of seamlessness. We could not extricate relational or informational continuity from management continuity, but new nuances emerge in the context of multiple clinicians. Patients often want to play an active role in connecting their health care, especially in ambulatory care for chronic conditions, which adds a partnership dimension to relational continuity with the most trusted clinician. Provision of information to patients enables and empowers them in their own care and emerges as a dimension of informational continuity and partnership. Care plans not only help different clinicians coordinate their complementary services but also outline an expected trajectory for patients, providing a sense of security and a basis for shared decision making. Not all patients are able to assume an active role, however, making the accumulated knowledge from relational continuity critical to adapting care.

Our investigation has strengths and limitations. The metasummary includes various study designs and addresses a broad range of contexts from different disciplinary perspectives. This approach is a strength for developing a generic measure based on recurring themes recurring across studies. The metasummary, however, limits us to findings considered important or significant by the researcher and may miss those considered minor in the original study that would have emerged as important across several studies. Another limitation is that the patient's voice is captured only in the citations in the report; limited exposure to the patient's voice poses a challenge for finding appropriate language for a patient questionnaire. There were additional issues or emphases pertinent to specific types of care or patient groups, and we purposely selected those generic for ambulatory care. Despite these limitations, we believe the metasummary provided information that was vastly richer than would have been obtained from doing another single qualitative study.

A final limitation is that our review ended with studies published in mid-2007, and several more recent studies would meet eligibility for inclusion. Although not submitted to the same level of analysis, the recent studies did not contradict or substantially change our conclusions.^{17,63-70} Our findings are highly coherent with a recent metasynthesis of 25 qualitative studies of patients' perceptions of continuity of care by Waibel and colleagues.⁷¹ Their synthesis aimed to contribute new knowledge to the conceptualization of continuity of care, whereas we were looking for measurable dimen-

* References: 4-6, 33, 44, 46, 50, 53, 55, 60.

sions in the multiple clinician context. We both identify patient involvement in care as a key element; Waibel et al classify patient involvement as a facilitator of continuity; however, and we believe that informing and educating patients are integral to informational continuity, and that supporting and recognizing the patient's role in care are dimensions of relational continuity that are particularly important when a patient's care spans multiple clinicians. We emphasize that confidence—a state of trust, reliance, and a feeling of hope—applies not only to relational continuity but is how patients experience management continuity as a proxy for seamlessness.

From a measurement perspective, this analysis shows that many aspects contributing to care continuity are assumed by patients. Eliciting their evaluations of communication between clinicians or of care planning will reflect their assumptions rather than their lived experience; however, they can accurately report on failures and gaps. Consequently, when we developed the measure of continuity of care,^{7,23} for some dimensions of management and information continuity, we elicited experience of discontinuity, such as observed lack of coordination and information gaps. Because patients can accurately evaluate whether they have received information giving them a care plan, whether their clinicians use comprehensive knowledge about them in care coordination, and whether they have a sense of partnership, we measured these attributes as positive expressions of continuity. Finally, we elicited experiences of abandonment or lostness, suffering, and recourse to nonplanned care as lack of seamlessness or fragmented care.

From the health service delivery perspective, clinicians need to recognize the stress for patients of crossing any care boundary. There is an implicit pledge that clinicians will communicate and coordinate across boundaries, and experienced failures shake patients' confidence and trust, often with negative health or health care consequences. Most patients are willing and able to assume some agency in management, however, and clinicians need to build this capacity through information sharing and partnership. Though most continuity-related reforms emphasize information and service integration, the patient's perspective underlines the need to support and protect relational continuity with trusted and trustworthy clinicians.

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Key words: continuity of patient care; primary health care; patient-centered care; quality of health care; patient satisfaction; process assessment (health care); qualitative research

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