

# **Continuity of care**

## **Perspective of the patient with a chronic illness**

**Annemarie A. Uijen**

## Colophon

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## **Perspective of the patient with a chronic illness**

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**Promotoren**

Dhr. prof. dr. W.J.H.M. van den Bosch  
Dhr. prof. dr. F.G. Schellevis (VUmc)

**Copromotor**

Dhr. dr. H.J. Schers

**Manuscriptcommissie**

Dhr. prof. dr. K.C.P. Vissers (voorzitter)  
Dhr. prof. dr. B.R. Bloem  
Mw. prof. dr. H. van der Horst (VUmc)

**Paranimfen**

Mw. dr. L.J.A. Hassink-Franke  
Mw. drs. F. Stevens-Kroeze

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# 1

## Introduction



‘Seeing a doctor who knows you’ is a core value of general practice.<sup>1-3</sup> In the 1950s already, the function of the general practitioner (GP) in the Netherlands was defined as ‘to assume the responsibility for continuous, integral and personal care for the health of the individuals and their families who entrust themselves to him’.<sup>4</sup> Recently, these core values were confirmed in a position paper of the Dutch College of GPs.<sup>5</sup> Seeing the same doctor (personal continuity) is related to better health outcomes<sup>6-9</sup>, more confidence in the care provider<sup>10;11</sup>, more satisfied patients<sup>11;12</sup>, and higher quality of patient’s life<sup>6;7</sup>. Both patients and GPs value personal continuity.<sup>13-17</sup> However, it is getting more difficult for patients to see their own doctor as much as they would like. An increasing number of care providers is nowadays involved in patient’s care, especially for patients with a chronic disease.<sup>18</sup> Most GPs in the Netherlands work part-time, which challenges the building and maintenance of the personal relationship. In addition, nurse physicians and practice nurses are getting involved in the care for chronically ill patients. Moreover, patients often see several medical specialists, even in the same hospital department. These developments may lead to discontinuity and fragmentation of care. Sharing of information and working according to an agreed plan are therefore increasingly important aspects of continuity of care.<sup>19;20</sup> This is illustrated by the history of Mrs K. in the case vignette.

### Definition of continuity of care

The concept of continuity of care is not well defined. Many definitions and terms have been used over time, none of which is universally accepted. However, from the 1990s on, there seems to be global consensus that continuity of care comprises at least<sup>19-22</sup>:

1. Personal continuity: Having a personal care provider in every separate care setting who knows and follows the patient;
2. Team continuity: Communication of relevant patient information and cooperation between care providers within one care setting to ensure that care is connected;

3. Cross-boundary continuity: Communication of relevant patient information and cooperation between care providers from different settings to ensure that care is connected.

In this thesis, the concept of continuity of care includes these three dimensions.

#### **Case vignette**

Mrs. K, 30 years old, suffers from type I diabetes since her early childhood. She is pregnant. Every 3 weeks she contacts her gynaecologist in the hospital outpatient department. She is pregnant for 25 weeks, so one should expect that her gynaecologist knows her by now. However, every 3 weeks she sees another gynaecologist and every 3 weeks she is asked questions like: 'what type of medication do you use?' and 'who is controlling your diabetes, the internist or the general practitioner?'. She feels none of the gynaecologists knows her. For her diabetes, she frequently contacts her internist and the diabetes nurse practitioner. She feels that they know about her and her concerns. In the last months, she also contacted her general practitioner twice, once for a urinary tract infection and once for pelvic pain. She is getting to know her general practitioner better now. She experiences low levels of communication and cooperation between most care providers. Her internist asks her questions about the care from her gynaecologist and vice versa. Her gynaecologist is not informed about her urinary tract infection and pelvic pain by her general practitioner. The only good communication and cooperation is between her internist and the diabetes nurse practitioner. She feels that they know from each other what they do and they never give contradictory advices.

#### **Aim of this thesis**

The aim of this thesis is to increase the knowledge of the different dimensions of continuity of care. The following research questions will be addressed:

*Which concepts are related to continuity of care and what are their main overlaps and differences?*

As previous research resulted in many definitions of continuity of care<sup>22</sup>, we needed to have a clear definition of continuity of care to avoid confusion. When reading the literature, we also found that many concepts, such as integration of care and coordination of care, seemed to be related to continuity of care. We wanted to

know more about their overlaps and differences in order to clarify the concept of continuity of care in relation to these other concepts.

*What levels of continuity of care do patients with different chronic diseases experience?*

After obtaining a clear definition, we were interested in the levels of continuity of care experienced by different patient groups, especially patients with a chronic disease, who value continuity of care far more than patients with minor problems.<sup>23-26</sup> As care should be patient centered, it is important to know how patients experience continuity in their care and to what extent improvements could be made. Patients' experiences with personal continuity are well researched in the literature<sup>12:27-29</sup>, but less is known about their experiences with communication and cooperation between care providers. Moreover, we were interested in the relation between the three dimensions of continuity of care and care outcomes.

*Which questionnaires measuring continuity of care exist and what is known about their measurement properties? Which instrument should preferably be used when measuring continuity of care?*

As many instruments measuring continuity of care exist, it is difficult to choose the appropriate instrument for a specific target population. We aimed to provide an overview of all these instruments, their target populations and the continuity dimensions that they measure. We systematically compared these instruments on the quality of their measurement properties in order to recommend one or more instruments for a comprehensive measurement of continuity of care.

*Is it possible to develop a well-validated questionnaire measuring patients' experienced personal, team and cross-boundary continuity in primary as well as in secondary care, regardless of patients' morbidity?*

While performing the systematic review, we found that no well validated questionnaire exists that measures continuity of care as a multidimensional concept regardless of patient's morbidity and across multiple care settings. Therefore we decided to develop and validate such a questionnaire. This questionnaire would allow us to identify problems and evaluate interventions aimed at improving

continuity of care and would enable us to compare continuity experiences of patients with different diseases and multimorbidity patterns.

### **Outline of this thesis**

*Chapter 2* provides a historical overview of the definitions of continuity of care and related concepts over time and identifies their main overlaps and differences. Subsequently, we were able to identify the core elements of care to patients.

*Chapter 3* explores the experiences of different patient groups with continuity of care. *Chapter 3.1* shows heart failure patients' experiences with continuity of care, and explores the relation between continuity and medication adherence.

*Chapter 3.2* explores COPD patients' experiences with continuity and analyses whether experienced continuity changes after the introduction of an integrated self-management intervention or regular monitoring by a practice nurse. Besides, it analyses the relation between continuity and quality of patients' life.

*Chapter 3.3* describes the levels of experienced continuity of care in patients at risk for depression, and compares these with those of patients having a somatic illness.

*Chapter 4* shows the results of a systematic review identifying which questionnaires measuring continuity of care exist, assessing the dimensions of continuity measured and evaluating the measurement properties of these questionnaires.

*Chapter 5* describes the development (*chapter 5.1*) and validation (*chapter 5.2*) of a generic questionnaire that measures personal, team and cross-boundary continuity of care. In addition we comment on an article measuring continuity from the electronic medical record (*chapter 5.3*) and on an article describing another questionnaire measuring patients' experienced continuity of care regardless of morbidity and across multiple care settings (*chapter 5.4*).

*Chapter 6* contains a general discussion about the results presented in this thesis. It provides recommendations for daily practice, future research and medical education.

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# 2

## **How unique is continuity of care? A review of continuity and related concepts**

Annemarie A. Uijen  
Henk J. Schers  
François G. Schellevis  
Wil J.H.M. van den Bosch

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## Abstract

**Background** The concept of ‘continuity of care’ has changed over time and seems to be entangled with other care concepts, for example coordination and integration of care. These concepts may overlap, and differences between them often remain unclear.

**Objective** In order to clarify the confusion of tongues and to identify core values of these patient-centred concepts, we provide a historical overview of continuity of care and four related concepts: coordination of care, integration of care, patient-centred care and case management.

**Methods** We identified and reviewed articles including a definition of one of these concepts by performing an extensive literature search in PubMed. In addition, we checked the definition of these concepts in the Oxford English Dictionary.

**Results** Definitions of continuity, coordination, integration, patient-centred care and case management vary over time. These concepts show both great entanglement and also demonstrate differences. Three major common themes could be identified within these concepts: personal relationship between patient and care provider, communication between providers and cooperation between providers. Most definitions of the concepts are formulated from the patient’s perspective.

**Conclusion** The identified themes appear to be core elements of care to patients. Thus, it may be valuable to develop an instrument to measure these three common themes universally. In the patient-centred medical home, such an instrument might turn out to be an important quality measure, which will enable researchers and policy makers to compare care settings and practices and to evaluate new care interventions from the patient perspective.

## Background

Continuity of care has been identified as an essential element of good primary care, along with other concepts such as coordination of care, patient-centred care and integration of care<sup>1,2</sup> There is evidence that a high performance on these concepts is associated with better quality of care, better health, greater equity and lower cost for people and populations.<sup>3</sup>

The definition of continuity of care has changed over time due to contextual factors such as the growing number of group practices and the rise of the consumer movement. Definitions of continuity of care have shown great overlap with relating concepts.<sup>4</sup> The overlaps and differences between these concepts are often unclear. This makes it difficult to analyse the value of the different concepts. Moreover, results of studies on different concepts are often not commensurable. The aim of this study is to provide a historical overview of the definitions of continuity of care and related concepts over time and to identify their main similarities and differences in order to identify the core values of these patient-centred concepts.

## Methods

We identified related concepts by reading all titles of the 9479 articles found by searching for ‘Continuity of Patient Care [MESH]’ in PubMed (1948 to January 2009). Box 1 summarizes the concepts that seemed to be related to continuity of care. We decided to focus our further exploration on continuity of care and on the four most frequently mentioned concepts, namely coordination of care, integration of care, patient-centred care and case management.

Subsequently, we performed a literature search in PubMed combining Search 1 AND Search 2 (1948 to February 2009) (Box 2). We searched for English or Dutch language articles. We made no restrictions regarding article type. We found that articles about e.g. integration dated back to the 1950s, while articles about e.g. continuity of care dated back to the 1970s. In order to find older articles about the five concepts, we exclusively used Search 1. We assessed the potential relevance of all titles and available abstracts from the electronic searches. We retrieved full-text

copies of all articles judged to be potentially relevant, of which we assessed inclusion. Articles were relevant when including a definition of one of the five concepts. We also screened the reference list of the included articles for relevant literature and analyzed known articles on these concepts not found in the literature search. Two reviewers (AAU and HJS) independently screened titles, abstracts and reference lists of the articles retrieved by the literature search. The full-text articles were reviewed by the same two independent reviewers (AAU and HJS) for relevance. Disagreements were resolved by consensus by a third reviewer (WJHMvdB).

As articles in PubMed date back only to 1948, we also checked the definition of these concepts in the Oxford English Dictionary (OED) ([www.oed.com](http://www.oed.com)), a historical dictionary describing the meaning and history of individual words. Thus providing a limited history of the concepts before 1948.

In the discussion section we discuss some contextual factors that may have influenced the changing of definitions.

<b>Box 1. Related concepts of continuity of care</b>	
Coordination (of care) / Co-ordination (of care) / Coordinated (care) / Co-ordinated (care) / Coordinating (care) / Co-ordinating (care)	Follow up (care) / Follow-up (care) Medical home Transfer (of care)
Integration (of care) / Integrated (care) / Integrating (care)	Team (care) Shared (care)
Patient centered (care) / Patient centred (care) / Patient-centered (care) / Patient-centred (care) / Patient focused (care) / Patient-focused (care)	Ongoing (care) Seamless (care) Consistent (care)
Case management	Connected (care)
Transition (of care) / Transitions (of care) / Transitional (care)	Collaborative (care) Cooperative (care)
Discharge planning	Transmural (care)
Continuum (of care)	Smooth (care)
Continuing (care)	Accessibility (to care) / Access (to care)
Continuous (care)	Multidisciplinary (care)
Continued (care)	Interdisciplinary (care)

## Results

With the combined search we found 653 articles, of which 58 met our inclusion criteria. Additionally, we included 18 older articles based on Search 1. Finally, we included 52 other articles/books extracted from the reference list of the included articles and 8 articles we already knew.

Overall, we included 34 discussion papers/opinion articles, 20 reviews, 20 original quantitative researches, 17 descriptive articles, 9 original qualitative researches, 8 reports, 6 editorials, 5 case studies, 5 articles describing the development and/or validation of a measurement instrument, 5 books, 4 historical articles, 1 comment, 1 lecture and 1 biography.

We did not refer to all included articles in this manuscript, as some articles did not add new information.

<b>Box 2. Search strategies</b>
<b>Search 1</b>
Continuity[ti] OR coordination[ti] OR co-ordination[ti] OR coordinated[ti] OR co-ordinated[ti] OR coordinating[ti] OR co-ordinating[ti] OR integration[ti] OR integrated[ti] OR integrating[ti] OR patient centered[ti] OR patient centred[ti] OR patient-centered[ti] OR patient-centred[ti] OR patient focused[ti] OR patient-focused[ti] OR case management[ti]
<b>Search 2</b>
Definition[ti] OR definitions[ti] OR define[ti] OR defined[ti] OR defining[ti] OR dimension[ti] OR dimensions[ti] OR component[ti] OR components[ti] OR concept [ti] OR concepts [ti] OR conceptualization[ti] OR conceptualizations[ti] OR conceptualisation[ti] OR conceptualisations[ti] OR meaning[ti]

### Continuity of care

The OED describes continuity as the state or quality of being uninterrupted in sequence or succession. Related terms are connectedness, coherence and unbrokenness. Quotations in which this term is used this way date back to 1603.

In the found literature, continuity of care first appeared in the 1950s. Initially, the concept focused on having a personal care provider.<sup>5,6</sup> In the 1970s, the focus

shifted to the relatedness between past and present care<sup>7</sup> and to a focus on care that was coordinated and uninterrupted.<sup>8</sup>

Later on, multidimensional models were introduced to define continuity of care.<sup>9;10</sup> One of these models describes continuity as ‘the care provider following his patient and taking into account changes over time (chronological continuity), providing care regardless of the site (geographical continuity), treating diverse illnesses in one patient (interdisciplinary continuity), earning ‘trust’ from patients, families and colleagues (interpersonal continuity) and having knowledge of his patients (informational continuity)’.

Another multidimensional model, introduced in the same period, describes continuity as ‘the planning of care according to patient’s needs (individual dimension), providing an ongoing relationship with a care provider (relationship), communicating with patients and other care providers (communication) and enabling patients to move orderly through services (longitudinal dimension), having a broad range of services available (cross-sectional continuity), being able to move between services flexible (flexibility) and having easy access to care services (accessibility)’.<sup>11</sup>

After the mid-1970s, the emphasis was placed on continuity as a measurable concept. Continuity increasingly became a synonym for seeing the same doctor, who knows the patient and has an ‘implicit contract’ with the patient.<sup>12;13</sup> Several measurement instruments were developed for this purpose, such as the continuity of care index (COC)<sup>14</sup>, the number of providers seen (NOP)<sup>15</sup>, the sequential continuity index (SCN)<sup>16</sup> and the usual provider index (UPC)<sup>17</sup>.

From the 1990s on, multidimensional models re-emerged. Continuity was defined from the patient’s point of view as ‘the patient’s experience of a coordinated and smooth progression of care’.<sup>18</sup> To achieve this, excellent information transfer, effective communication, flexibility, relational continuity and care from as few professionals as possible are needed.

A hierarchical model of continuity was also introduced at this time, in which informational continuity was positioned at the lowest level, longitudinal continuity at the middle level and interpersonal continuity at the highest level.<sup>19</sup> Longitudinal continuity involves, in addition to informational continuity, that every patient has a medical home where the patient receives most care. At the highest level, an ongoing relationship exists between the patient and a personal care provider.

Other multidimensional models distinguish between informational, relational and management/team/cross-boundary continuity. A care provider uses information on past events to deliver care that is appropriate to the patient's current circumstances, providers develop an ongoing personal relationship with patients and connect their care in a coherent way.<sup>20-22</sup>

## Coordination of care

The OED describes coordination as the action of placing or arranging (things) in proper position relatively to each other and to the system of which they form parts, to bring into proper combined order as parts of a whole. Quotations date back to 1837.

The concept 'coordination of care' has been used in the found literature since the end of the 1940s. Until the 1970s, coordination was used interchangeably with integration. It was described as the cooperation between care providers.<sup>23-25</sup> Coordination meant keeping each other up to date by effective communication and linking different programs and activities.<sup>26;27</sup>

In the 1970s and 1980s, a more narrow definition was introduced. Coordination was defined as the extent to which care providers recognize information on patients from one visit to the next and are aware of the involvement of other care providers.<sup>28-33</sup> This definition seems rather comparable with informational continuity.<sup>21;22</sup>

In the 1990s, the patient's perspective emerged. Coordination was defined as the patient's perception of their care provider's knowledge of other visits to them and visits to specialists as well as the follow-up of problems through subsequent visits or phone calls.<sup>34</sup> This approximates the patient-centred definition of continuity of care.<sup>18</sup>

After the mid-1990s, coordination and case management were often used interchangeably: care coordinators or case managers were supposed to have an overview of all patient's care needs and already available care, to make a care plan and to execute this plan. They link patients to services to provide them with optimal health care.<sup>4;35-38</sup>

In 2008, a new definition was introduced in which coordination was defined as 'the delivery of services by different care providers in a timely and complementary

manner in order to achieve connected and cohesive patient care'.<sup>39</sup> Thus, again resembling the patient-centred definition of continuity.<sup>18</sup>

### **Integration of care**

The OED describes integration as the making up or composition of a whole by adding together or combining the separate elements. It is the combination into an integral whole and is often opposed to differentiation. Quotations in which this term is used this way date back to 1620.

Integration of care has been used since the 1950s in the found literature, and was then considered the core of good care.<sup>40</sup> Later on, integration was described as the opposite of fragmentation, bringing care providers together instead of separating them.<sup>41-45</sup> This reflects team and management continuity.<sup>20-22</sup> The aim of integration was to provide unity by working together.<sup>46-48</sup> To ensure integration, care providers needed to establish common objectives, identify specific characteristics of the team members and it is necessary that the organization facilitates optimal cooperation, coordination and communication.<sup>43;45;48-50</sup>

In the past 10 years, integrated care is frequently used interchangeably with managed care in the USA, shared care in the UK and transmural care in the Netherlands. Other European countries mention seamless care, continuous care or multidisciplinary care.<sup>51-53</sup>

Integration is also seen as a continuum with three levels: linkage, coordination and full integration.<sup>54;55</sup> Linkage, the minimalist approach to integration, means that different care providers function within their own rules, responsibilities and funding constraints. At the level of coordination, care is organized in a way that promotes information sharing and prevents fragmentation. This compares to informational continuity.<sup>21;22</sup> In case of full integration, responsibilities, resources and financing from multiple systems are combined under one organization.

Later definitions bring together delivery, responsibility, management and organization of care to achieve coordinated and continuous care.<sup>53;56-63</sup> Case managers could enhance integration of care by serving as a communication link between care providers.<sup>64</sup>

## Patient-centred care

The OED describes centered as placing at the centre or in a central position. Quotations in which this term is used this way date back to 1590. Patient-centred care is not explicitly described in the OED.

Patient-centred care or patient-focused care has been increasingly mentioned in the literature since 1970, contrasting disease centred care, in which only the health care provider's agenda was addressed.<sup>65</sup>

Patient-centred care was defined as care in which the care provider tries to see the illness through the patient's eyes.<sup>66-68</sup> The care provider tries to understand the patient's complaints not only in terms of illnesses but also as expressions of the patient's unique individuality, his tensions, his conflicts, and problems.<sup>69-71</sup> This definition approaches that of the individual dimension of continuity.<sup>11</sup>

From the mid-1980s on, more practical definitions emerged. Patient-centred care was described as care in which the care provider is supportive and encourages the patient to express himself and the patient speaks openly about the reasons for consulting, asks questions and offers suggestions.<sup>66;72-75</sup>

In 1995, a patient-centred clinical model was developed,<sup>76</sup> which has been frequently used in later years.<sup>77-79</sup> This model consists of exploring both the disease and the illness experience, understanding the whole person (resembling the first descriptions of continuity of care<sup>5;6</sup>), shared decision-making, enhancing the patient-doctor relationship (comparable with relational continuity<sup>21;22</sup>), incorporating prevention and health promotion, and being realistic. In 2000, a comparable five-dimensional model was presented<sup>80</sup> which has since frequently used<sup>81;82</sup>. This model combines the prior model with the care provider's awareness of the influence of personal qualities and subjectivity on daily practice.

Other definitions came up from 2000 and onwards in which shared decision-making and patient involvement are the central elements.<sup>83-86</sup>

## Case management

The OED describes case management as the coordinated course of action determined for a particular person's medical care, social support, etc. It is the organized implementation of such a programme. Quotations in which this term is used date back to 1918. A case manager is a person such as a doctor, nurse or

social worker who is assigned to coordinate and monitor the care or support of a particular individual. This term dates back to 1969.

At the end of the 1970s, the central theme of case management was to provide patients with a case manager: an individual who is responsible for helping the patient to coordinate their care within a complex care system to ensure that patients receive the care they need in an efficient manner.<sup>87-91</sup> This is similar to the longitudinal, individual and relationship dimensions of continuity of care<sup>11</sup>. Case management was based on the assumption that patients with complex health problems need assistance in using the healthcare system effectively.<sup>90</sup> It reduces fragmentation and promotes continuity of care.<sup>92;93</sup>

Until the 1990s, case managers were responsible for identifying eligible patients, assessing patient's needs, planning to meet those needs, linking patient to care provider(s), linking care providers, monitoring patient's care participation, detecting changing needs and advocating for patient's rights.<sup>91;94;95</sup> The latter is almost identical with McWhinney's definition of continuity of care,<sup>12</sup> while the linking of care providers resembles management/team/cross-boundary continuity.<sup>20-22</sup>

Other definitions expand case management to the patients' physical and social environments, including e.g. housing, income, transportation, insurance and social networks.<sup>89;96</sup>

Since the 1990s, definitions of case management vary by the responsibility of case managers. Some describe case management as primarily a matter of coordinating and/or matching services, while others define case management as a broader concept, including case identification, assessment, planning, implementation, linking, facilitation, coordination, integration, providing a continuing relationship between patient and care provider, advocacy, referral, monitoring and evaluation.<sup>97-108</sup> The responsibility and discipline of the case manager (social worker, nurse or physician) varies, also depending on its responsibility for just one care setting or for patient's total care.<sup>105;108</sup>

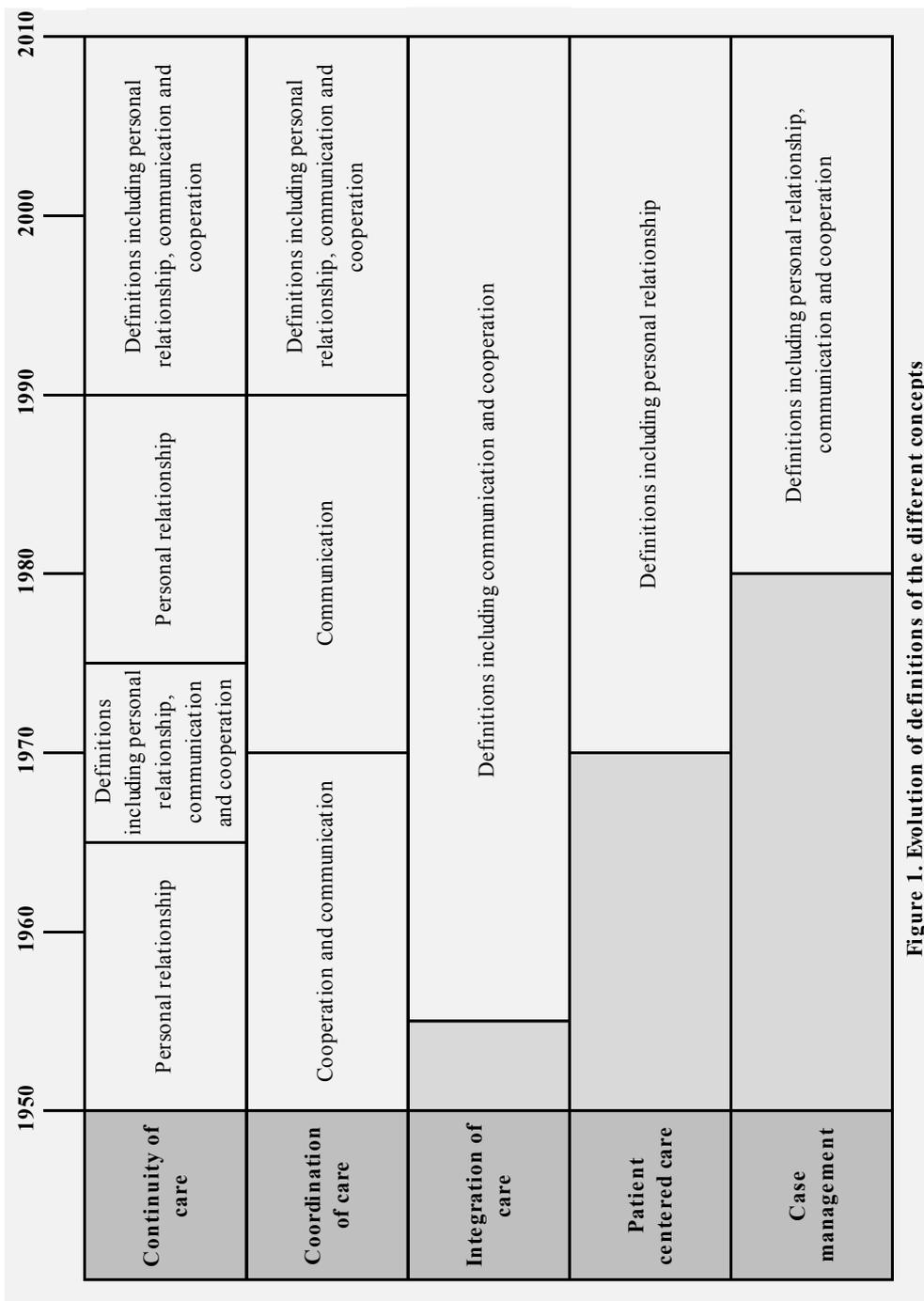


Figure 1. Evolution of definitions of the different concepts

## Discussion

Continuity of care, coordination of care, integration of care, patient-centred care and case management all are concepts describing core qualities of care. Surprisingly, most concepts have changed their meanings and definitions substantially throughout the years and are conceptually entangled (Figure 1). However, we found that researchers using one concept hardly ever refer to overlapping concepts. They seem to operate mainly within their own conceptual framework and literature.

### Overlaps and differences between concepts

We found that most definitions are formulated from the patient's perspective. In general, the definitions of continuity of care comprise of three major themes: (1) a personal care provider in every separate care setting who knows and follows the patient; (2) communication of relevant patient information between care providers; and (3) cooperation between care providers, both in a specific care setting and between care settings, to ensure that care is connected. These themes recur to a certain extent in the other described concepts. Coordination of care is about the teamwork between different care providers and thereby comprising the themes communication and cooperation. The definitions of integration of care over time also comprise the themes communication and cooperation but also include the sharing of responsibilities and care organization. Both definitions of coordination and integration of care do not include the importance of a personal care provider. Patient-centred care is all about involving the patients in their own care. A personal relationship between patient and care provider will facilitate patient-centred care but is not a necessary element. Communication and cooperation between care providers are not included in the definitions of patient-centred care. Lastly, case management describes all activities needed to guide a patient through health care, including the provision of a personal care provider and communication and cooperation between providers.

## Implications for practice and future research

We have shown a great entanglement between the different concepts and provide clarity by historically reviewing their definitions. We believe it is impossible to unravel the entanglement of these concepts. However, we could identify three major themes: (1) having a personal care provider who knows and follows the patient, (2) communication between care providers and (3) cooperation between care providers. Because the various descriptions of care processes often cover these three themes, these three themes are apparently core elements of care to patients. To our knowledge, no measurement instrument exists to measure these themes universally yet. We think it would be valuable to develop such an instrument. This will enable researchers and policy makers to focus on the core elements of patient care, while researchers can still add other themes depending on the concept they want to focus on. Such a measurement instrument will make it possible to compare studies and to evaluate new interventions or developments in care from the patient's perspective.

## Context of changing definitions

Developments in care contribute to the different priorities and definitions of the concepts over the years. The changing definitions of continuity of care, for example, are related to developments in general practice. In the 1950s, the first researchers in general practice were trying to explore and define their discipline. Single-handed practices prevailed in which a personal care provider guaranteed continuity of care. In the 1960s the number of partnership practices increased in the UK, while in the USA general practice became virtually extinct and had to be reborn as family practice. In the 1970s, concerns about the growing size and anonymity of group practices came up.<sup>109</sup> Nowadays, the number of group practices is still growing and multidimensional models of continuity are introduced including aspects such as team continuity. Other contextual factors explaining the changing definitions include the increasing specialization and subspecialization of hospital-based care, the rise of the consumer movement and the women's movement, the rise of the primary care team and the expansion of medical science and technology.

## **Limitations**

We searched for articles solely in PubMed and searched for terms solely in the title. As our aim was to describe the development of the different concepts over time and to show their entanglement, we do not think that potentially missing some minor articles has influenced the found result. Because we additionally analyzed already known articles, we do not think that we have missed important influential articles.

As we searched in PubMed from 1948 onwards, we can only provide a historical overview from this year on. Definitions before 1948 are missing.

## **Comparison with previous studies**

We found one article reviewing definitions and comparing care concepts. This study reviewed discharge planning, transitional care, coordination and continuity by using articles published between 2000 and 2006 with a hospital-focused perspective.<sup>4</sup> The authors do not describe common themes, but conclude that the concepts are interrelated. They propose a conceptual model in which these four concepts are included.

## **Conclusion**

Descriptions of care processes from the patient's perspective often cover the themes personal relationship, communication between providers and cooperation between providers. These themes are apparently core elements of care to patients, associated with better quality of care, better health, greater equity and lower cost for people and populations.<sup>3</sup> Developments in care should be aimed to improve the outcome of these themes. We think it would be valuable to develop an instrument to measure the three common themes universally. In the patient-centred medical home, such an instrument might turn out to be an important quality measure, which will enable researchers and policy makers to compare care settings and practices and to evaluate new care interventions from the patient perspective.

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# 3

## **Experiences of different patient groups with continuity of care**



# 3.1

## **Heart failure patients' experiences with continuity of care and its relation to medication adherence: a cross-sectional study**

Annemarie A. Uijen  
Marije Bosch  
Wil J.H.M. van den Bosch  
Hans Bor  
Michel Wensing  
Henk J. Schers

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## Abstract

**Introduction** A growing number of health care providers are nowadays involved in heart failure care. This could lead to discontinuity and fragmentation of care, thus reducing trust and hence poorer medication adherence. This study aims to explore heart failure patients' experiences with continuity of care, and its relation to medication adherence.

**Methods** We collected data from 327 primary care patients with chronic heart failure. Experienced continuity of care was measured using a patient questionnaire and by reviewing patients' medical records. Continuity of care was defined as a multidimensional concept including personal continuity (seeing the same doctor every time), team continuity (collaboration between care providers in general practice) and cross-boundary continuity (collaboration between general practice and hospital). Medication adherence was measured using a validated patient questionnaire. The relation between continuity of care and medication adherence was analysed by using chi-square tests.

**Results** In total, 53% of patients stated not seeing any care provider in general practice in the last year concerning their heart failure. Of the patients who did contact a care provider in general practice, 46% contacted two or more care providers. Respectively 38% and 51% of patients experienced the highest levels of team and cross-boundary continuity. In total, 14% experienced low levels of team continuity and 11% experienced low levels of cross-boundary continuity. Higher scores on personal continuity were significantly related to better medication adherence ( $p < 0.01$ ). No clear relation was found between team- or cross-boundary continuity and medication adherence.

**Conclusions** A small majority of patients that contacted a care provider in general practice for their heart failure, contacted only one care provider. Most heart failure patients experienced high levels of collaboration between care providers in general practice and between GP and cardiologist. However, in a considerable number of patients, continuity of care could still be improved. Efforts to improve personal continuity may lead to better medication adherence.

## Introduction

**H**eart failure is a chronic disease with a high prevalence, reaching 1-2% in western countries.<sup>1</sup> Its burden is expected to rise in the coming decades due to an ageing population and longer survival from cardiovascular disease.<sup>1;2</sup> Heart failure is associated with major morbidity and high health care costs, due to high hospital admission rates.<sup>3</sup>

Heart failure patients, among other patients with a chronic disease, are known to value continuity of care, in particular seeing the same doctor (personal continuity).<sup>4</sup> Having a personal care provider is related to more confidence in the care provider<sup>5;6</sup>, more patient satisfaction<sup>6;7</sup>, increased feelings of being helped forward<sup>6</sup> and higher quality of patient's life<sup>8;9</sup>.

However, for patients with a chronic disease, recent developments in care can result in lack of continuity. An increasing number of care providers is nowadays involved in their care. Many patients contact several general practitioners (GPs) in one practice and probably also contact several specialists in one department. In addition, nurse physicians and practice nurses are often involved in the care for chronically ill patients. This could lead to discontinuity and fragmentation of care, which in turn may reduce trust and result in poorer medication adherence.<sup>10;11</sup> Communication and cooperation between all providers involved becomes increasingly important to guarantee continuity.<sup>12-15</sup>

Patients experiences with personal continuity are well researched. However, little is known about patients experiences with communication and cooperation between care providers in general practice (team continuity) and between general practice and specialist care (cross-boundary continuity).

The aim of this article is therefore to analyse the degree to which heart failure patients contact their usual care provider (personal continuity) and the degree of communication and cooperation between several care providers involved in the care for these heart failure patients (team and cross-boundary continuity). We will also analyse the relation between continuity of care and patients' medication adherence, for which the evidence is still inconclusive.<sup>10;11</sup>

## Methods

### Participants

In the Netherlands, every patient is enlisted with a GP who functions as a gatekeeper for specialist care. Most heart failure patients in the Netherlands obtain the medical care for their heart failure by their GP on their own initiative. Nurse practitioners have more and more taken over the monitoring of blood pressure and other risk factors.

In the period 2005–2006, we invited 415 general practices in 15 different hospital regions to participate in this study of which 72 GPs in 42 practices agreed to participate. These practices are representative for Dutch practices regarding urbanization rate and type of practice. All patients with a diagnosis of chronic heart failure, according to their GP, were eligible to be included. We excluded patients with a terminal disease, a mental impairment, Dutch language problems or when the GP decided that patients should not be included in the study for other reasons. The study is powered on the primary study outcome ‘health related quality of life’. This article focuses on continuity of care and medication adherence as outcome measures, for which we performed no power calculations. Ethical permission for the study was obtained from the ethics committee Arnhem-Nijmegen. More detailed information regarding this study has been previously published.<sup>16</sup>

### Measurements

#### *Continuity of care*

We measured the experienced continuity of care using a previously developed questionnaire (see Table 2 for specific items). This questionnaire is based on 30 patient interviews that were conducted as part of a study on continuity of care and consists of 11 items.<sup>17</sup> The questionnaire was tested among six GPs/senior researchers and eight patients (content validity) to make sure no significant items were missing and all items were understood correctly. After the test phase, minor changes to the questionnaire were made.

Three dimensions of continuity can be identified in the questionnaire, corresponding to the literature<sup>12;15;18</sup>:

1. Personal continuity (1 item): the number of care providers (GPs and/or nurses) that patients saw in general practice for their heart disease in the last year.

To further analyse this dimension of continuity of care, we also reviewed the patients' medical records for the total number of contacts with the general practice in the last year. Due to limited resources, the collection of medical record data was limited to a random sample of maximum 15 patients per practice.

2. Team continuity in general practice (6 items): the extent to which care providers (GPs and/or nurses) in general practice have knowledge of the patient and communicate and cooperate with each other.
3. Cross-boundary continuity (4 items): the extent to which GP and cardiologist communicate and cooperate with each other.

For the domains 2 and 3, responses were recorded on a five-point scale (1=never, 5=always). We tested the questionnaire in a sample of Dutch patients with COPD, heart failure or a mental illness and subsequently performed principal factor analysis on the 10 items of domain 2 and 3, which confirmed the two presumed factors (construct validity). The eigenvalues of both factors were 8.064 (team continuity) and 1.135 (cross-boundary continuity). The two factors together explained a total variance of 83.6% (respectively 42.7% and 40.9%).

### *Medication adherence*

We measured patients' medication adherence by using the validated measure of Morisky et al.<sup>19</sup> This scale measures self-reported intentional (two items) and unintentional (two items) non-adherence to medicines. The items can be answered on a 5-point Likert scale ranging from 1 (no adherence) to 5 (full adherence). Medication adherence was measured as the sum score of the four questions, varying from 4 to a maximum of 20.

Both (anonymous) questionnaires were sent simultaneously by mail. In case of non-response, a reminder was sent after three to four weeks.

## Analysis

First, we explored the results on the items measuring personal, team and cross-boundary continuity. We excluded cases in which half or more of the questions of a specific factor were missing, i.e. 3 or more questions on team continuity or 2 or more questions on cross-boundary continuity. All remaining missing values were imputed by patient's mean of the non-missing items on the specific factor. The answers on the negatively keyed questions were then recoded.

The total score of team continuity ranged from 6 to a maximum of 30 and the total score of cross-boundary continuity ranged from 4 to a maximum of 20. Due to the wide range in total scores, we sub-classified the total score of team and cross-boundary continuity into 5 subcategories. These categories consisted of the maximum score and subsequently 4 subcategories with an equal range. For team continuity: (1) 30 (max), (2) 24-29, (3) 18-23, (4) 12-17 and (5) 6-11. For cross-boundary continuity: (1) 20 (max), (2) 16-19, (3) 12-15, (4) 8-11 and (5) 4-7.

We sub-classified the total score of team and cross-boundary continuity into 5 subcategories: the maximum score and subsequently 4 equal subcategories.

All analyses were performed using SPSS 16. We analysed the relation between continuity of care and patients' medication adherence by using chi-square tests. A p-value  $<0.05$  was considered statistically significant.

Analyses were performed both including and excluding the patients that did not have contact with any care provider in general practice in the last year for their heart failure. As the results in both analyses did not differ, we present the analyses including these patients in this article.

## Results

We sent the questionnaire measuring continuity of care to 461 patients. In total, 370 patients (80%) responded. We excluded 43 patients due to missing values (3 or more questions on team continuity or 2 or more questions on cross-boundary continuity). Consequently, we analysed data from 327 patients. Most patients were Dutch (93%), above 70 years of age (73%) and could be classified as NYHA class I (49%). Patients' sex was equally distributed (Table 1).

**Table 1. Characteristics of the study population (N=327)**

<b>Characteristics</b>	<b>n (%)</b>
<b>Age, mean (SD)</b>	74.9 (10.1)
<65	54 (17%)
65-70	33 (10%)
71-75	59 (18%)
76-80	78 (24%)
81-85	62 (19%)
>85	41 (13%)
<b>Sex</b>	
Male	164 (50%)
Female	163 (50%)
<b>Nationality</b>	
Dutch	305 (93%)
Other	12 (4%)
Missing	10 (3%)
<b>NYHA class</b>	
Class I	159 (49%)
Class II	72 (22%)
Class III	87 (27%)
Class IV	7 (2%)
Missing	2 (1%)

*SD: standard deviation, NYHA: New York Heart Association*

### Levels of experienced continuity

Table 2 shows the results of the items measuring continuity of care. A total of 53% of patients stated not seeing any care provider (GP or nurse) in general practice in the last year for their heart failure. In total, 54% of these patients that did not contact their general practice, did contact a cardiologist in the last year. Based on the medical record review, we found that only 10 patients (4.1%) did not have any contact with a care provider in general practice at all in the last year.

In total, 25% saw one care provider in general practice for their heart failure, 14% saw two care providers and 8% of patients saw 3 or more care providers in general practice.

Table 2. Results of items measuring continuity of care

<b>Personal continuity in general practice</b>		<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4 or more</b>
1.	How many different care providers have you seen in general practice in the last year for your heart disease? ( <i>N</i> =303)	161 (53%)	76 (25%)	42 (14%)	19 (6%)	5 (2%)
2.	Total number of contacts with general practice in last year (according to medical record) ( <i>N</i> =245)	10 (4%)	9 (4%)	14 (6%)	16 (7%)	196 (80%)
<b>Team continuity in general practice</b>		<b>Never</b>	<b>Seldom</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
1.	The treatment of my heart disease in general practice goes smoothly ( <i>N</i> =249)	25 (10%)	9 (4%)	19 (8%)	43 (17%)	153 (61%)
2.	The care of the different care providers in general practice for my heart disease is connected ( <i>N</i> =255)	21 (8%)	11 (4%)	18 (7%)	63 (25%)	142 (56%)
3.	The care providers in general practice often give me contradictory advice about my heart disease ( <i>N</i> =259)	129 (50%)	79 (31%)	29 (11%)	8 (3%)	14 (5%)
4.	The care providers in general practice involved in the care for my heart disease communicate well with each other ( <i>N</i> =257)	21 (8%)	7 (3%)	24 (9%)	64 (25%)	141 (55%)
5.	The care providers in general practice involved in the care for my heart disease have knowledge of my medical record ( <i>N</i> =255)	12 (5%)	11 (4%)	31 (12%)	54 (21%)	147 (58%)
6.	The care providers in general practice involved in the care for my heart disease have knowledge of previous visits ( <i>N</i> =253)	20 (8%)	12 (5%)	27 (11%)	50 (20%)	144 (57%)
<b>Cross-boundary continuity</b>		<b>Never</b>	<b>Seldom</b>	<b>Sometimes</b>	<b>Often</b>	<b>Always</b>
1.	The care of the GP and the cardiologist is connected ( <i>N</i> =191)	9 (5%)	12 (6%)	11 (6%)	38 (20%)	121 (63%)
2.	The GP and the cardiologist often give me contradictory advice about my heart disease ( <i>N</i> =195)	110 (56%)	48 (25%)	22 (11%)	9 (5%)	6 (3%)
3.	The GP and the cardiologist transfer information about my heart disease well between each other ( <i>N</i> =195)	9 (5%)	11 (6%)	14 (7%)	37 (19%)	124 (64%)
4.	The GP and the cardiologist communicate well ( <i>N</i> =190)	12 (6%)	12 (6%)	17 (9%)	40 (21%)	109 (57%)

*GP: General practitioner; Items are measured using a patient questionnaire unless otherwise indicated*

The questions concerning team continuity and cross-boundary continuity mostly scored positive: each item scored maximum by at least half of the patients.

Table 3 shows the total score of team and cross-boundary continuity. Almost 38% of patients experienced maximum team continuity (score 30), while 51% of patients experienced maximum cross-boundary continuity (score 20). Respectively 14% and 11% of patients experienced very low levels of team and cross-boundary continuity (total score less than 18 or 12, respectively).

## 3.1

**Table 3. Total score of team and cross-boundary continuity**

Total score	n (%)
<b>Team continuity in the medical home (N=261)</b>	
30	99 (38%)
24-29	94 (36%)
18-23	32 (12%)
12-17	18 (7%)
6-11	18 (7%)
<b>Cross-boundary continuity (N=195)</b>	
20	99 (51%)
16-19	50 (26%)
12-15	24 (12%)
8-11	12 (6%)
4-7	10 (5%)

*The score of team continuity varied between 6 (minimum) and 30 (maximum).*

*The score of cross-boundary continuity varied between 4 (minimum) and 20 (maximum)*

### Continuity and medication adherence

In total, 74% of patients were fully adherent (score 20), 15% scored 19 points on the medication adherence measure, 7% scored 18 points and 5% scored 17 points or less.

Table 4 shows the relation between experienced continuity of care and patients' medication adherence. Patients who saw three or more care providers in general practice were less likely to be fully adherent than patients who saw less care providers ( $p < 0.01$ ). We found a non-linear relation between experienced team

continuity and medication adherence: both high and low levels of team continuity were associated with maximum medication adherence, while the mid-levels of team continuity were associated with the lowest medication adherence ( $p=0.04$ ). No relation was found between cross-boundary continuity and medication adherence.

**Table 4. Relation between continuity of care and medication adherence**

	Medication adherence			
	17 or less	18	19	20 (maximum)
<b>Personal continuity in general practice (<math>p&lt;0.01</math>)</b>				
0 care providers	4 (3%)	5 (3%)	28 (18%)	119 (76%)
1 care provider	9 (12%)	6 (8%)	5 (7%)	55 (73%)
2 care providers	1 (2%)	5 (12%)	4 (10%)	31 (76%)
3 or more care providers	0 (0%)	4 (17%)	4 (17%)	16 (67%)
<b>Team continuity (<math>p=0.04</math>)</b>				
30	3 (3%)	4 (4%)	11 (11%)	81 (82%)
24-29	5 (5%)	8 (9%)	15 (16%)	66 (70%)
18-23	3 (10%)	6 (19%)	6 (19%)	16 (52%)
12-17	3 (18%)	0 (0%)	1 (6%)	13 (77%)
6-11	0 (0%)	2 (12%)	3 (18%)	12 (71%)
<b>Cross-boundary continuity (<math>p=0.19</math>)</b>				
20	2 (2%)	3 (3%)	14 (15%)	77 (80%)
16-19	3 (6%)	4 (8%)	10 (20%)	32 (65%)
12-15	1 (4%)	3 (13%)	2 (9%)	17 (74%)
8-11	0 (0%)	3 (25%)	1 (8%)	8 (67%)
4-7	1 (11%)	0 (0%)	1 (11%)	7 (78%)

*Medication adherence varied between 4 (minimum) and 20 (maximum). Because of the small number of patients scoring 17 or less, we grouped these patients together*

## Discussion

Based on a self-report, we found that more than half of the patients did not contact any care provider in general practice for their heart failure in the last year, though half of them did have contact with a cardiologist. About half of the patients who did contact general practice, had contact with two or more care providers. Most patients experienced acceptable levels of communication and cooperation between care providers in general practice and between GP and cardiologist, while 10-15% experienced very low levels.

Medication adherence was significantly less in patients who saw three or more care providers. Patients who did not contact any care provider at all in the last year had high levels of medication adherence. Team continuity was related to medication adherence, but in a non-linear way. No relation was found between cross-boundary continuity and medication adherence ( $p=0.19$ ).

### Implications for practice and research

We found that better personal continuity is also related to better medication adherence. Better medication adherence may lead to lower hospitalization rates, lower morbidity and mortality and lower health care costs.<sup>20-23</sup> Most Dutch heart failure patients experience high levels of personal, team and cross-boundary continuity of care. However, in a considerable amount of patients, personal continuity can be improved in order to achieve more confidence in the care provider, more patient satisfaction and higher quality of patient's life.

A possible explanation for the relation between personal continuity and medication adherence could be that patients have less trust in care providers when contacting more care providers.<sup>24</sup> Nowadays, an increasing number of care providers work part-time, thus making it more likely for a patient to have contact with more than one care provider. Nevertheless, we think personal continuity can still be improved as most contacts are non-urgent, making it possible to make an appointment with their own care provider.

When more care providers are involved in the care of a patient, we found that team and cross-boundary continuity can be improved in at least 10-15% of patients.

Team and cross-boundary continuity can for example be improved by better communication between care providers (e.g. better registration in the electronic medical record and faster communication by mail between general practitioner and specialist).

The importance of the non-linear relationship between team continuity and medication adherence is unknown. It should be interpreted with caution. More research is needed before firm conclusions can be drawn about this relationship.

### **Comparison with previous studies**

Previous studies found comparable levels of experienced continuity of care.<sup>6;25-27</sup>

We found only two studies investigating the relation between personal continuity and medication adherence. One of them found a positive relation between seeing the care provider who prescribed the medication and medication adherence<sup>10</sup>, while the other study found no relation between the proportion of consultations with the usual physician and medication adherence<sup>11</sup>. We found no studies investigating the relation between team or cross-boundary continuity and medication adherence.

### **Limitations**

One of the limitations of this study is that 53% of patients answered that they did not see any care provider in general practice in the last year for their heart failure. However, most of these patients did fill in the other continuity questions, which can make the reliability of the answers doubtful. We made the assumption that most of the patients stating not have seen any care provider in general practice in the last year for their heart failure, saw their GP for other disorders in that year during which the GP also monitored their heart failure (e.g. blood pressure). This assumption is strengthened by the fact that, based on the medical record search, only 10 patients (4.1%) did not have any contact at all with a care provider in general practice in the last year. The results of the analyses of the data including and excluding these patients did not differ.

Another limitation is the cross-sectional design of this study. As a consequence, we can only hypothesize about the causality of the relation between continuity and medication adherence and our results should be interpreted with caution.

A last limitation is that the study is powered on the outcome measure 'health related quality of life'. Possibly, too few patients were included to find a relation between team- or cross-boundary continuity and medication adherence.

## **Conclusions**

A small majority of patients that contacted a care provider in general practice for their heart failure, contacted only one care provider (personal continuity). Most heart failure patients experienced high levels of collaboration between care providers in general practice (team continuity) and between GP and cardiologist (cross-boundary continuity). However, in a considerable amount of patients continuity can still be improved. Efforts to improve personal continuity may lead to better medication adherence.

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## **Continuity in different care modes and its relationship to quality of life: a randomised controlled trial in patients with COPD**

Annemarie A. Uijen  
Erik W.M.A. Bischoff  
François G. Schellevis  
Hans H.J. Bor  
Wil J.H.M. van den Bosch  
Henk J. Schers

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## Abstract

**Background** New care modes in primary care may affect patients' experienced continuity of care.

**Aim** To analyse whether experienced continuity for patients with chronic obstructive pulmonary disease (COPD) changes after different care modes are introduced, and to analyse the relationship between continuity of care and patients' quality of life.

**Design and setting** Randomised controlled trial with 2-year follow-up in general practice in the Netherlands.

**Method** A total of 180 patients with COPD were randomly assigned to three different care modes: self-management, regular monitoring by a practice nurse, and care provided by the GP at the patient's own initiative (usual care). Experienced continuity of care as personal continuity (proportion of visits with patient's own GP) and team continuity (continuity by the primary healthcare team) was measured using a self-administered patient questionnaire. Quality of life was measured using the Chronic Respiratory Questionnaire.

**Results** Of the final sample ( $n=148$ ), those patients receiving usual care experienced the highest personal continuity, although the chance of not contacting any care provider was also highest in this group (29% versus 2% receiving self-management, and 5% receiving regular monitoring). There were no differences in experienced team continuity in the three care modes. No relationship was found between continuity and changes in quality of life.

**Conclusion** Although personal continuity decreases when new care modes are introduced, no evidence that this affects patients' experienced team continuity or patients' quality of life was found. Patients still experienced smooth, ongoing care, and considered care to be connected. Overall, no evidence was found indicating that the introduction of new care modes in primary care for patients with COPD should be discouraged.

## Introduction

**C**hronic obstructive pulmonary disease (COPD) is highly prevalent and one of the leading causes of morbidity and mortality worldwide.<sup>1</sup> Its prevalence is predicted to rise in the coming decades, which will result in an increased burden on healthcare systems.<sup>1;2</sup>

In primary care, new care modes are being introduced to improve quality and to cope with the increased workload of COPD in primary care globally. Practice nurses take over elements of COPD care and self-management programmes are introduced to increase patients' self-care. There are concerns that the introduction of these new care modes may be a threat to patients' experienced continuity in primary care, both in terms of personal continuity (seeing the same care provider) and team continuity (continuity by the primary healthcare team). Other studies have shown that decreased personal continuity is related to less confidence in care providers<sup>3;4</sup> and less satisfaction with care<sup>4-6</sup>. Moreover, patients' adherence to treatment and prevention might decrease.<sup>7</sup> The evidence is still inconclusive as to whether decreased levels of continuity are also related to reduced quality of life.<sup>8-11</sup> In this study the experienced continuity of care of patients with COPD who were receiving different modes of care was compared. This was done to ascertain whether the level of experienced personal and team continuity of COPD patients changes after the introduction of a self-management intervention or regular monitoring by a practice nurse, compared with usual GP care at the patient's own initiative. It was hypothesised that experienced personal and team continuity would decrease when receiving self-management or regular monitoring, compared with usual care, because patients contact an additional care provider and more care providers have to communicate and collaborate. The relationship between experienced continuity of care and quality of life was also examined.

## Method

### Design

In the Netherlands, patients with COPD are primarily treated in primary care. GPs act as gatekeepers to secondary care. This study was embedded in a 24-month, multicentre, single-blinded, parallel-group, randomised controlled trial comparing three care modes for patients with COPD in primary care. The study is powered on the primary study outcome, which was quality of life. This article focuses on continuity of care as the outcome measure. The randomised controlled trial has been registered in the international clinical trial register, *ClinicalTrials.gov* (Identifier NCT00128765).

### Participants

Between June 2004 and November 2006 15 general practices from the Nijmegen region (10 general practices of the academic network of the Department of Primary and Community Care of the Radboud University Nijmegen Medical Centre and five additional general practices from the Nijmegen/Achterhoek region) selected patients aged  $\geq 35$  years, who were considered to have COPD, based on recorded International Classification of Primary Care codes R95/R91, diagnostic labels, and prescription records for respiratory medication (Anatomical Therapeutic Chemical code R03). GPs excluded patients who 1) had severe co-morbid conditions with a reduced life expectancy; 2) were unable to communicate in Dutch; 3) obtained care by a lung specialist at baseline; or 4) should, according to the GP, not be included in the study for other reasons. GPs invited selected patients to their general practice for an intake visit. During this visit pre- and post-bronchodilator lung function was measured. All patients who fulfilled the following inclusion criteria were asked to participate in the study: 1) post-bronchodilator forced expiratory volume in 1 second (FEV1)/forced vital capacity (FVC) $<0.7$ , according to the Global initiative for chronic Obstructive Lung Disease (GOLD) criteria - COPD is diagnosed below this threshold;<sup>12</sup> and 2) post-bronchodilator FEV1 $\geq 30\%$  predicted. Patients were excluded if they had objections to one of the disease management modes in the study.

Before the start of the study all patients received usual GP care. After signed, informed consent was given, patients were allocated to one of the three study arms using a computer-generated, two-block randomisation procedure with stratification on COPD severity according to GOLD classification (mild or moderate versus severe), smoking status (current versus former smoker), and exacerbation frequency in the previous 24 months ( $< 2$  versus  $\geq 2$  exacerbations). All investigators were blinded for individual treatment allocation.

## 3.2

### **Interventions**

#### *Usual care*

Patients received care at their own initiative, provided by their GP. Most patients visited their GP only when symptoms were aggravated.

#### *Self-management as an adjunct to usual care*

A Dutch translation of the Canadian COPD-specific self-management programme Living Well with COPD was provided to all patients in this group.<sup>13</sup> The programme consisted of the following topics: COPD disease knowledge; use of medication and breathing techniques; managing exacerbations; maintaining a healthy lifestyle; managing stress and anxiety; and home exercise. Using motivational interviewing techniques, the practice nurses of each practice gave the programme to patients in four individual sessions of 60 minutes each. During the 2-year follow-up, the practice nurses followed up with the patients with telephone calls to reinforce the intended behaviour changes. In case of an exacerbation, patients contacted their GP.

#### *Regular monitoring as an adjunct to usual care*

Patients were invited to participate in structured controls by the practice nurse and the GP. The frequency of these provider-initiated visits (minimum twice a year, maximum four times a year, of which one was a GP visit) depended on the severity of both airflow obstruction and dyspnoea. The content of the monitoring program was based on national and international COPD guidelines<sup>14;15</sup> and included spirometry, inhalation instructions, and assessment of dyspnoea and quality of life. In case of an exacerbation, patients contacted their GP.

## Outcome and measurements

All patients visited the lung-function department of the Radboud University Nijmegen Medical Centre at baseline, 1 year, and 2 years for spirometry and an assessment of demographic characteristics, smoking history, and continuity of care.

### *Continuity of care*

Continuity of care was defined as a three-dimensional concept including personal continuity from the same care provider, team continuity from the primary care team, and cross-boundary continuity across primary-secondary care settings.<sup>16;17</sup> Cross-boundary continuity was not measured as patients were excluded when treated by a lung specialist.

Personal continuity was measured using the Usual Provider of Continuity (UPC) index<sup>18</sup>, which measures the proportion of visits with the usual care provider, that is the GP. The UPC index was calculated for each patient as:

### Number of visits for lung disease with own GP during the study

Total number of visits for lung disease in general practice during the study

The score of the UPC index varies between 0 (low personal continuity) and 1 (high personal continuity). A patient questionnaire was used at 1 year and 2 years after baseline to obtain the number of visits during the last year that were used to calculate the UPC index.

Team continuity was then measured using a questionnaire including the following six items on team continuity:

- the treatment of my lung disease in primary care goes smoothly;
- the care of the different providers in primary care for my lung disease is connected;
- the care providers in primary care often give me contradictory advice about my lung disease;
- the care providers in primary care involved in the care for my lung disease communicate well with each other;
- the care providers in primary care involved in the care for my lung disease have knowledge of my medical record; and
- the care providers in primary care involved in the care for my lung disease have knowledge of previous visits.

This questionnaire, based on 30 patient interviews that were conducted as part of a study on continuity of care,<sup>19</sup> was tested among six GPs/senior researchers and eight patients (content validity) to make sure that no significant items were missing and that all items were understood correctly. After this testing was done, minor changes to the questionnaire were made. Responses were to be recorded on a five-point scale (1=never, 5=always). The questionnaire was tested on a sample of Dutch patients with COPD, heart failure, or a mental illness; principal factor analysis was subsequently performed, which confirmed this presumed factor (construct validity).

### *Quality of life*

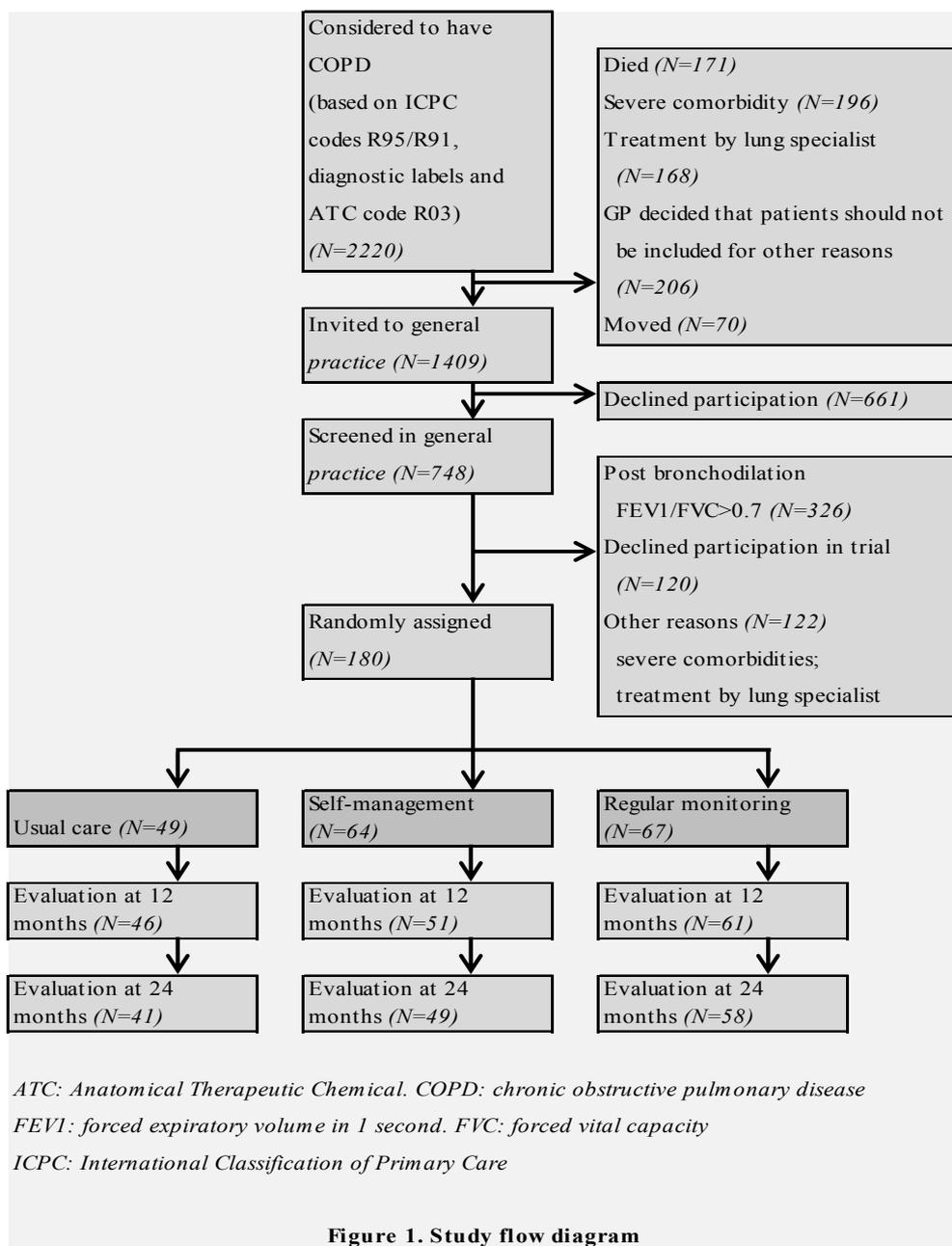
Disease-specific health-related quality of life was measured with the self-administered Chronic Respiratory Questionnaire (CRQ).<sup>20</sup> This instrument consists of 20 questions that are scored on a seven-point Likert-scale. The minimal clinically important difference of the CRQ has been established at 0.5 points.<sup>21</sup> The CRQ was assessed at baseline, 6 months, 12 months, 18 months, and 24 months.

### **Analysis**

Patient and disease characteristics were calculated and compared between the three groups using analysis of variance and  $\chi^2$  tests; a *P*-value of <0.05 determined statistical significance. The UPC index was calculated over the total 2 years of the study; however, if data on the second year were missing the UPC index over the first year was calculated.

The answers on the items measuring team continuity at baseline were described, then the total score of team continuity in the three care modes at baseline, after 1 year, and after 2 years calculated and compared. If  $\geq 3$  questions on team continuity were missing from a case, that case was excluded. All remaining missing values were imputed by patient's mean. The answers on the negatively keyed question were recoded.

A general linear model was used to compare the UPC index between the three care modes and to assess the difference in team continuity score between baseline and 1 year, and between baseline and 2 years between the three care modes. In this model, care mode was included and controlled for age, sex, GOLD-stage, and existence of comorbidity (cancer, heart failure, anxiety and/or depression).



The relationship between continuity of care and quality of life was analysed; the difference between CRQ score ( $\Delta$ CRQ) at baseline and in the second trial year (mean score measured at 18 and 24 months) was calculated. Differences in  $\Delta$ CRQ in different levels of personal and team continuity were examined, and the Pearson's correlation coefficient ( $r$ ) of  $\Delta$ CRQ and personal and team continuity were calculated.

Data including and excluding patients who reported that they did not see any care provider in primary care in the last year were analysed. As the results of these two analyses did not differ, this article presents the analyses including these patients' data.

SPSS (version 16.0) was used for all statistical analyses.

3.2

## Results

### Patient selection

A sample of 180 patients was randomly assigned to the three care modes (Figure 1). After 2 years, 148 patients had completed the study. The overall drop-out rate was 18%; reasons for drop-out were consent withdrawal, miscellaneous medical conditions, and loss to follow-up, and were comparable between the three study groups. Patients who dropped out did not statistically significantly differ in age ( $P=0.94$ ), sex ( $P=0.91$ ), post-bronchodilator FEV1 ( $P=0.295$ ), or CRQ score ( $P=0.06$ ) from patients who did not drop out.

### Patient characteristics

At baseline, patients' mean age was 64.5 years and 63% were male. In total, 18% of patients were classified as being in GOLD stage I, 64% in GOLD stage II, and 18% in GOLD stage III or IV. A breakdown of patient characteristics by care mode is given in Table 1.

**Table 1. Patient characteristics at baseline**

	Usual care (N=49)	Self- management (N=64)	Regular monitoring (N=67)	P-value
<b>Age in years, mean (SD)</b>	63.5 (± 10.3)	64.3 (± 11.2)	65.3 (± 9.3)	0.65
<b>Male sex, n (%)</b>	25 (51.0)	42 (65.6)	47 (70.1)	0.10
<b>GOLD-stage, n (%)</b>				0.32
GOLD I	11 (22.4)	13 (20.3)	8 (11.9)	
GOLD II	29 (59.2)	42 (65.6)	45 (67.2)	
GOLD III/IV	9 (18.4)	9 (14.1)	14 (20.9)	
<b>Lung function, mean (SD)*</b>				
FEV1 % predicted	67.0 (± 18.0)	65.8 (± 16.3)	62.6 (± 15.3)	0.32
FEV1 (L)	1.96 (± 0.68)	1.98 (± 0.61)	1.94 (± 0.62)	0.94
FEV1/FVC	0.57 (± 0.12)	0.58 (± 0.10)	0.56 (± 0.12)	0.74
<b>Smoking status, n (%)</b>				0.47
Smoker	14 (30.4) (N=46)	22 (37.3) (N=59)	19 (30.6) (N=62)	
Former smoker	26 (56.5) (N=46)	28 (47.5) (N=59)	37 (59.7) (N=62)	
<b>GP-diagnosed exacerbations in previous 24 months, mean (SD)</b>	0.8 (± 1.1)	1.5 (± 2.0)	1.0 (± 1.2)	0.08
<b>Pulmonary medication, n (%)</b>				
No medication	19 (38.8)	12 (18.8)	18 (26.9)	0.06
Long-acting bronchodilators	25 (51.0)	35 (54.7)	39 (58.2)	0.80
Inhaled corticosteroids	19 (38.8)	41 (64.1)	34 (50.7)	0.04

\* Post-bronchodilator measurement. FEV1: forced expiratory volume in 1 second;

FVC: forced vital capacity; GOLD: Global Initiative for Chronic Obstructive Lung Disease;

SD: standard deviation

Denominators vary owing to missing values

## Personal continuity

Of 24 (17%) patients, data on the second trial year were missing, so the UPC index of these patients was calculated over the first year. Data on both the first and second trial year were missing of 24 patients. Table 2 shows the estimated marginal means (controlled for age, sex, GOLD stage, and existence of comorbidity) of the

**Table 2. Mean score of personal continuity and difference in team continuity in the different study groups**

Intervention group	mean UPC index during trial* (95% CI)	Mean difference in team continuity between baseline and 1 year* (95% CI)	Mean difference in team continuity between baseline and 2 years* (95% CI)
Usual Care**	0.74 (0.61 to 0.86)	0.31 (-1.14 to 1.76)	-0.05 (-1.84 to 1.74)
Self-management	0.36 (0.25 to 0.47) ( $p=0.00$ )	0.92 (-0.37 to 2.20) ( $p=0.500$ )	-0.21 (-1.66 to 1.25) ( $p=0.883$ )
Regular monitoring	0.50 (0.39 to 0.61) ( $p=0.02$ )	0.87 (-0.45 to 2.19) ( $p=0.528$ )	0.12 (-1.43 to 1.68) ( $p=0.873$ )

\* Estimated marginal mean controlled for age, sex, GOLD-stage, and existence comorbidity; \*\* Reference group; GOLD: Global initiative for chronic Obstructive Lung Disease; UPC: Usual Provider of Continuity (range 0-1); team continuity range 6-30

**Table 3. Experienced team continuity in general practice at baseline (N=162)**

Questionnaire item	Never	Seldom	Sometimes	Often	Always
The treatment of my lung disease in general practice goes smoothly	2 (1.2%)	3 (1.9%)	7 (4.3%)	33 (20.4%)	117 (72.2%)
The care of the different care providers in general practice for my lung disease is connected	5 (3.1%)	1 (0.6%)	15 (9.3%)	44 (27.2%)	97 (59.9%)
The care providers in general practice often give me contradictory advice about my lung disease	132 (81.5%)	22 (13.6%)	3 (1.9%)	3 (1.9%)	2 (1.2%)
The care providers in general practice involved in the care for my lung disease communicate well with each other	4 (2.5%)	9 (5.6%)	7 (4.3%)	54 (33.3%)	88 (54.3%)
The care providers in general practice involved in the care for my lung disease have knowledge of my medical record	4 (2.5%)	5 (3.1%)	18 (11.1%)	46 (28.4%)	89 (54.9%)
The care providers in general practice involved in the care for my lung disease have knowledge of previous visits	5 (3.1%)	6 (3.7%)	10 (6.2%)	50 (30.9%)	91 (56.2%)

UPC score during the trial in the different study groups. Personal continuity was significantly higher for patients receiving usual care compared with patients in the other care modes: the mean UPC score was 0.74 for patients receiving usual care, compared with 0.50 for those receiving regular monitoring and 0.36 for patients who were self-managing. The UPC index was >0.80 in 44% of the patients in the usual care group, compared with 23% of those receiving regular monitoring, and 6% of those self-managing.

In the usual care group, 13/45 (29%) patients did not contact any care provider at all for their COPD during the study (UPC index was missing), compared with one (2%) patient who was self-managing, and 3/60 (5%) patients who received regular monitoring.

**Table 4. Total score of experienced team continuity in general practice in the three care modes at baseline, after 1 year, and after 2 years**

<b>Score of team continuity by care mode*</b>	<b>Baseline, %</b>	<b>After one year, %</b>	<b>After two years, %</b>
<b>Usual Care</b>	<b>N=40</b>	<b>N=30</b>	<b>N=27</b>
30	30	30	30
24-29	53	57	48
18-23	10	10	15
12-17	5	0	4
6-11	3	3	4
<b>Self-management</b>	<b>N=59</b>	<b>N=45</b>	<b>N=43</b>
30	31	38	33
24-29	58	49	54
18-23	9	13	9
12-17	3	0	5
6-11	0	0	0
<b>Regular monitoring</b>	<b>N=63</b>	<b>N=52</b>	<b>N=41</b>
30	35	35	29
24-29	44	56	46
18-23	16	8	24
12-17	2	2	0
6-11	3	0	0

\* Total score of team continuity range: 6-30

## Team continuity

At baseline, most patients scored high on the items measuring team continuity (Table 3). No great differences were seen in the team continuity scores at baseline among the three care modes ( $P=0.693$ ) and, after 1 and 2 years, no clear differences in the score of team continuity were seen at group level (Table 4). Most patients showed no or only small differences (0-2 points) in experienced team continuity after 1 year; these differences seemed to become even smaller after 2 years. Patients in the usual care group show the smallest difference in team continuity (data not shown).

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**Table 5. Changes in CRQ score between baseline and the second trial year in different continuity classes**

<b>Personal continuity: UPC index</b>	<b><math>\Delta</math>CRQ*</b>	<b>SD</b>	<b><i>n</i></b>
0.00 - 0.20	0.06	± 0.51	31
0.21 - 0.40	0.01	± 0.51	27
0.41 - 0.60	0.04	± 0.61	27
0.61 - 0.80	0.28	± 0.48	23
0.81 - 1.00	0.16	± 0.59	28
No care provider at all during trial	-0.01	± 0.59	16
<b>Team continuity: difference between baseline and 2 years</b>			
≤-2	-0.01	± 0.52	20
-1.99 to 1.99	0.09	± 0.43	53
≥2	0.19	± 0.59	29

\*Difference in CRQ score between baseline and the second trial year; CRQ: Chronic Respiratory Questionnaire; SD: standard deviation; UPC: Usual Provider of Continuity

## Continuity and quality of life

Table 5 shows the relationship between continuity of care and changes in quality of life. No clinically relevant difference in CRQ score ( $>0.50$ ) was seen for different UPC scores. Pearson's correlation coefficient of  $\Delta$ CRQ and personal continuity was 0.117. A slightly higher quality of life was found after 2 years when the UPC score exceeded 0.60, however this difference was not clinically relevant. The

experienced quality of life did not change for patients who saw no care provider at all during the trial; in addition no clinically relevant difference was found between different levels of team continuity and quality of life. Pearson's correlation coefficient of  $\Delta$ CRQ and team continuity was -0.041.

## **Discussion**

### **Summary**

Although personal continuity – that is, the proportion of visits with patient's own GP – was found to be highest when receiving usual care and lowest when self-managing (which would be expected from the organisation of the care modes), in contrast to this study's hypothesis, no differences in experienced team continuity in primary care among the three care modes were found. Patients in all three care modes, independent of the number of care providers seen, felt that their care went smoothly, was connected, and that care providers communicated well and knew them.

Although the proportion of visits with the patient's own GP was highest when receiving usual care, it was found that the chance of not contacting any care provider at all was also highest in this care mode (almost 30%). There was no evidence that a decreasing (personal) continuity affects patients' quality of life.

### **Strengths and limitations**

One limitation to be aware of is that the study is powered on the quality-of-life outcome measure and not on continuity of care. It could be that too few patients were included to find differences in experienced team continuity.

Another limitation is the high level of experienced team continuity at baseline, which makes it difficult to show an increase in team continuity during the study. However, as it was hypothesised that the experienced continuity would decrease when patients were self-managing or receiving regular monitoring because they need to contact an additional care provider in these care modes, it is not thought that this limitation negatively influenced these results.

A considerable number of patients saw no care provider at all for their COPD during the trial, especially in the group of patients receiving usual care. Some of these, however, did answer the questions about team continuity, which can make the reliability of the answers doubtful. Data including and excluding patients who reported that they did not see any care provider for their COPD were analysed; the results of these two analyses did not differ.

Many patients thought to have COPD finally did not participate in the trial, which could lower the generalisability of the results. However, the age, sex, and severity of COPD (according to the GOLD stage) of those patients who were included are comparable with the same characteristics of primary care patients with COPD who have participated in other studies.<sup>22;23</sup>

To the authors' knowledge, this is the first study analysing changes in experienced personal and team continuity after the introduction of new care modes.

## 3.2

### **Comparison with existing literature**

The relationship between continuity of care and quality of life has been investigated in previous studies. Chien et al<sup>9</sup> also found no relationship between the UPC index and quality of life, but Hanninen et al<sup>10</sup> found a positive correlation between seeing the same GP for at least 2 years and quality of life in patients with diabetes. Adair et al<sup>8</sup> and King et al<sup>11</sup> investigated the relationship between a multidimensional definition of continuity of care and quality of life. King et al performed a cross-sectional study in patients with cancer and found no relationship. Adair et al performed a prospective study in patients with severe mental illness and found a positive relationship between continuity and quality of life.

### **Implications for practice**

Regular monitoring by a practice nurse and self-management are increasingly introduced in primary care to anticipate the growing load of this chronic disease in primary care. As patients contact an additional care provider (practice nurse) in these new care modes, they experience less personal continuity. However, as guidelines advise the review of patients with COPD regularly to provide high levels of quality of care<sup>14;15</sup>, these new care modes reduce the chance of not being

reviewed at all. Although patients contact an additional care provider, they still experience that their care goes smoothly, is connected, and that care providers communicate well and know their patients. Overall, no evidence was found that the newly introduced care modes have a negative impact on patients with COPD.

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## **Experienced continuity of care in patients at risk for depression in primary care**

Annemarie A. Uijen  
Henk J. Schers  
Aart Schene  
François G. Schellevis  
P. Lucassen  
Wil J.H.M. van den Bosch

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## Abstract

**Background** Existing studies about continuity of care have focused on patients with a severe mental illness.

**Objective** To explore the levels of experienced continuity of care of patients at risk for depression in primary care, and to compare these to those of patients with a chronic somatic illness.

**Methods** Cross-sectional study comparing patients at risk for depression (patients with medically unexplained symptoms, frequent attenders and patients with mental health problems) with chronic heart failure patients. Continuity of care was measured using a patient questionnaire and defined as (1) number of care providers contacted (personal continuity), (2) collaboration between care providers in general practice (team continuity) and (3) collaboration between general practice and care providers outside general practice (cross-boundary continuity).

**Results** Most patients at risk for depression contacted several care providers throughout the care spectrum in the past year. They experienced high levels of team continuity and low levels of cross-boundary continuity. Compared to heart failure patients, they contacted significantly more different care providers in general practice for their illness ( $p < 0.01$ ). Patients at risk for depression, however, experienced better collaboration between these care providers: 2 points on a 24-point scale ( $p = 0.03$ ), but lower levels of collaboration between care providers of different care settings: 2 points on a 16-point scale ( $p = 0.01$ ).

**Conclusion** Care providers should make efforts to increase the levels of personal continuity for patients at risk for depression. Interventions to increase the collaboration between care providers from different settings are also needed, especially for patients at risk for depression.

## Introduction

**M**ental disorders, defined by the criteria listed in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV)<sup>1</sup> are highly prevalent<sup>2:3</sup> and are associated with a decreased quality of life<sup>4:5</sup> and high health care costs<sup>6</sup>.

Patients with a mental illness, equally to patients with a somatic illness, are known to value continuity of care.<sup>7:8</sup> As far as we know, existing studies about continuity of care in patients with a mental illness have focused on patients with a severe mental illness (e.g. schizophrenia or bipolar disorder) recruited in secondary care. Seeing the same doctor (personal continuity) facilitates recovery from a chronic severe mental illness and is related to better quality of life.<sup>9</sup> Continuity of care - not only contacting the same care provider whenever possible but also good communication and cooperation between care providers - is significantly associated with better quality of life, better community functioning, lower severity of symptoms, greater service satisfaction and lower health care costs in patients with a severe chronic mental illness.<sup>10:11</sup>

In primary care, most patients suffer from minor mental health problems or have an undiagnosed mental disorder, e.g. depression. These patients may benefit even more from high levels of continuity of care than primary care patients with a somatic illness, because the bond between therapist and patient (therapeutic alliance) is an essential element of the therapeutic process in these patients.<sup>12:13</sup> However, patients with a mental illness seem to experience lower levels of personal continuity and communication/cooperation between care providers<sup>10:14</sup> than patients with a somatic illness<sup>15:16</sup>, although comparison is difficult because different measurement instruments were used and patients were recruited in different care settings.

The aim of this study is therefore to explore the levels of experienced continuity of care in patients at risk for depression recruited in primary care. We not only explore the levels of personal continuity but also of communication and cooperation between care providers within one care setting (team continuity) and between different care settings (cross-boundary continuity). Moreover, we compare the levels of experienced continuity of care of patients at risk for depression with those of patients with a chronic somatic illness recruited in primary care, in this

case chronic heart failure patients. We test the hypothesis that patients at risk for depression experience at least the same level of continuity of care as patients with a chronic somatic illness.

## Methods

### Setting and participants

#### *Patients at risk for depression*

In the Netherlands, every patient is enlisted with a GP who is the first health care professional to be consulted in case of medical (somatic and psychological) needs. The GP functions as a gatekeeper for specialist care. Our cross-sectional study was part of a project that was designed to screen for depression in a primary care population.<sup>17;18</sup> We included patients between 18 and 70 years of age from 30 general practices in two regions in the Netherlands who were at high-risk for depression<sup>19-21</sup>: patients with medically unexplained symptoms for at least 3 months, frequent attenders (10% most frequently consulting men and women in two age groups (18-44 and 45-70 years)) and patients with a newly presented mental health problem up to 3 months prior to the selection date. These high-risk groups were selected on the basis of their electronic medical records. After applying exclusion criteria (patients suffering from schizophrenia, psychosis, bipolar disorder, major depressive disorder, serious somatic disease, mental retardation, or having difficulties with Dutch or English language) all remaining patients were invited to fill out a questionnaire on how they experienced continuity of care (see below). More information regarding the screening study has been previously published.<sup>18</sup>

#### *Patients with a chronic somatic illness*

We measured experienced continuity of care of chronic heart failure patients by using baseline data from another cross-sectional study.<sup>15</sup> These patients were recruited in 42 Dutch primary care practices (72 GPs). All patients with a diagnosis of chronic heart failure according to their GP were eligible to be included. Patients were excluded if they had a terminal illness, a cognitive impairment, Dutch

language problems or when the GP decided that patients should not be involved in the study for other reasons. All remaining patients were invited to fill out the same questionnaire on how they experienced continuity of care (see below). More information regarding this study has been previously detailed.<sup>15</sup>

## Measurement instrument

### *Continuity of care*

We measured patients' experienced continuity of care using a questionnaire including 11 items. This questionnaire was based on 30 patient interviews that we conducted as part of a study on continuity of care.<sup>22</sup> Principal component analysis in a population of chronically ill patients from general practice (both patients with a mental and somatic illness) revealed three dimensions of continuity in the questionnaire, corresponding to the dimensions captured in the literature<sup>23;24</sup>:

1. Personal continuity (1 item): number of care providers that patients contacted in general practice for their illness in the past year;
2. Team continuity in general practice (6 items): the extent to which care providers in general practice have knowledge of the patient and communicate and cooperate with each other;
3. Cross-boundary continuity (4 items): the extent to which GPs and care providers outside general practice communicate and cooperate with each other.

The patients at risk for depression completed one extra question on personal continuity about the number of care providers they contacted overall (both inside and outside general practice) for their illness in the past year.

For the domains 2 and 3, items were scored on a five-point scale (1=never, 5=always). The questionnaire was sent by mail. In case of non-response, we sent a reminder after two weeks.

## Analysis

We explored the results on the items measuring personal, team and cross-boundary continuity and calculated the total scores of team continuity (ranging from 6 to a maximum of 30) and cross-boundary continuity (ranging from 4 to a maximum of

20) for both groups. We excluded cases when half or more of the items of one of the continuity dimensions were missing, i.e. 3 or more questions on team continuity or 2 or more questions on cross-boundary continuity. All remaining missing values were imputed by the patient's mean of the non-missing items. The answers on the negatively keyed question were recoded.

We used chi-square testing to compare the personal continuity score between the two patient groups. We considered a  $p$ -value  $< 0.05$  as statistically significant.

We conducted a multivariate analysis using a general linear model to compare the total scores of team and cross-boundary continuity between the two patient groups. In this model we included team and cross-boundary continuity as outcomes and controlled for age and sex. As no dependency of the outcomes within practices existed when controlling for the two patient groups, a multilevel analysis was not deemed necessary.

## Results

We sent the continuity questionnaire to 366 patients at risk for depression. In total, 264 patients (72%) returned the questionnaire. We also sent the questionnaire to 461 heart failure patients, of whom we finally analysed 327 (71%). Table 1 shows characteristics of both patient groups.

### **Experienced continuity in patients at risk for depression**

Most patients at risk for depression (45%) answered to have contacted one care provider in general practice in the past year for their illness, 34% contacted two or more care providers in general practice. Throughout all care settings, more than half of the patients (54%) contacted two or more care providers, while 13% did not contact any care provider at all in the past year for their illness.

Most patients experienced high levels of communication and cooperation between care providers in general practice: e.g. 72% of the patients experienced that the care providers in general practice communicated well with each other. Most patients experienced low levels of communication and cooperation between

general practice and care providers outside general practice: e.g. 38% of patients at risk for depression experienced that the care between GP and the care provider outside general practice was well connected.

In total, 15% of patients experienced maximum team continuity in general practice (score 30), while 9% of patients experienced very low levels of team continuity (total score less than 18). In comparison, 5% of patients experienced maximum cross-boundary continuity (score 20), and 40% of patients experienced very low levels of cross-boundary continuity (total score less than 12).

**Table 1. Characteristics of the study populations**

	<b>Patients at risk for depression (N=264)</b>	<b>Heart failure patients (N=327)</b>
<b>Age, mean (SD)</b>	46.1 (11.9)	74.0 (10.1)
≤30	31 (11.7%)	0 (0.0%)
31-40	56 (21.2%)	2 (0.6%)
41-50	75 (28.4%)	6 (1.8%)
51-60	71 (26.9%)	25 (7.6%)
61-70	30 (11.4%)	63 (19.3%)
71-80	1 (<0.1%)	139 (42.5%)
>80	0 (0.0%)	92 (28.1%)
<b>Sex</b>		
Male	59 (22.3%)	164 (50.2%)
Female	205 (77.7%)	163 (49.8%)

*SD: standard deviation*

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### Comparison with heart failure patients

Heart failure patients contacted significantly less care providers in general practice in the past year for their illness ( $p<0.01$ ) (Table 2).

Table 3 shows the estimated marginal means (controlled for age and sex) of the team and cross-boundary continuity scores in both patient groups. Patients at risk for depression experienced significantly better collaboration between care providers in general practice than heart failure patients: the mean score of team continuity was respectively 25.7 and 23.7 ( $p=0.03$ ). Patients at risk for depression

**Table 2. Results of items measuring personal, team and cross-boundary continuity of care**

	Patients at risk for depression				Heart failure patients			
	<i>N</i>	0	1	2 or more	<i>N</i>	0	1	2 or more
<b>Personal continuity</b>								
1. Total number of care providers in general practice contacted in past year for illness	262	21%	45%	34%	303	53%	25%	22%
2. Total number of care providers contacted in past year for illness (in- and outside general practice)	262	13%	33%	54%	-	-	-	-
<b>Team continuity in general practice</b>								
	<i>N</i>	Never/ Seldom	Some- times	Often/ Always	<i>N</i>	Never/ Seldom	Some- times	Often/ Always
1. The treatment of my illness in general practice goes smoothly	183	8%	19%	74%	249	14%	8%	79%
2. The care of the different care providers in general practice for my illness is connected	168	6%	23%	71%	255	13%	7%	80%
3. The care providers in general practice often give me contradictory advice about my illness	177	85%	11%	4%	259	80%	11%	9%
4. The care providers in general practice involved in the care for my illness communicate well with each other	165	7%	21%	72%	257	11%	9%	80%
5. The care providers in general practice involved in the care for my illness have knowledge of my medical record	173	10%	17%	73%	264	9%	12%	79%
6. The care providers in general practice involved in the care for my illness have knowledge of previous visits	169	10%	18%	72%	253	13%	11%	77%

Table 2. Continued

Cross-boundary continuity	Patients at risk for depression				Heart failure patients			
	N	Seldom	Some-times	Often/Always	N	Seldom	Some-times	Often/Always
1. The care of the GP and the care provider outside general practice is connected	111	39%	23%	38%	191	11%	6%	83%
2. The GP and the care provider outside general practice often give me contradictory advice about my illness	114	85%	13%	2%	195	81%	11%	8%
3. The GP and the care provider outside general practice transfer information about my illness well between each other	111	37%	23%	41%	195	10%	7%	83%
4. The GP and the care provider outside general practice communicate well	112	46%	19%	35%	190	13%	9%	78%

GP: General practitioner

Table 3. Mean score of team and cross-boundary continuity

	Patients at risk for depression	Heart failure patients	Difference
Mean score of team continuity* (95% CI)	25.7 (24.5 to 27.0)	23.7 (22.8 to 24.7)	2.0 (0.2 to 3.9) ( $p=0.03$ )
Mean score of cross-boundary continuity* (95% CI)	14.0 (13.0 to 15.2)	16.1 (15.4 to 16.9)	-2.1 (-3.6 to -0.5) ( $p=0.01$ )

\* Estimated marginal mean controlled for age and sex; CI: Confidence interval; The score of team continuity varied between 6 (minimum) and 30 (maximum); The score of cross-boundary continuity varied between 4 (minimum) and 20 (maximum)

experienced significantly lower levels of collaboration between GP and care providers outside general practice than heart failure patients: the mean score of cross-boundary continuity was respectively 14.0 and 16.1 ( $p=0.01$ ).

## Discussion

To our knowledge, this is the first study exploring the levels of experienced continuity of care in primary care patients at risk for depression. We found that most patients at risk for depression contacted one care provider in general practice and two or more care providers throughout all care settings. Most patients experienced high levels of collaboration between care providers in general practice, but low levels of collaboration between care settings. In comparison to heart failure patients, patients at risk for depression contacted significantly more care providers in general practice (lower personal continuity). They, however, experienced better collaboration between these care providers (higher team continuity): 2 points on a 24-point scale. Patients at risk for depression experienced lower collaboration between GP and care providers outside general practice (lower cross-boundary continuity): 2 points on a 16-point scale. This means that patients at risk for depression score on average 0.5 points lower on every item about the collaboration between GP and care providers outside general practice.

The differences in personal continuity might be explained by the fact that patients at risk for depression often feel they are not listened to, and therefore probably contact more care providers.<sup>25</sup>

The differences in the collaboration between care providers might be explained by the fact that other types of care providers have to collaborate for patients at risk for depression (e.g. GP and psychologist/social worker) than for patients with a somatic illness (e.g. GP and medical specialist). Possibly, collaboration between physicians is easier because they speak the same language, whereas collaboration between a physician and a psychologist or social worker can be harder because of their different professional backgrounds.

The differences might also be explained by the fact that patients at risk for depression perceive lower levels of life satisfaction and quality of life, which might negatively influence the answers on the continuity of care questionnaire.<sup>26</sup>

## Limitations

One of the limitations of the study is the possible recall bias. In total, 20% of patients at risk for depression answered to have contacted no care provider in general practice in the past year. However, according to the inclusion criteria, all patients should have contacted general practice at least once in the past year. Depending on the symptoms of the patient consulting the GP, we asked patients about the continuity of care for their ‘depressive symptoms’, ‘panic or anxiety symptoms’, ‘medically unexplained symptoms,’ or ‘symptoms’. When patients do not recognize their symptoms in these definitions, they probably answer to have contacted less care providers than they actually have. Therefore, patients at risk for a depression might have contacted even more care providers than they reported.

The comparison between patients at risk for depression and patients with a somatic illness has some limitations. The recruitment of the different patient groups differed: patients at risk for depression were identified from the consultation lists of the previous months, while heart failure patients were identified on the basis of a diagnosis in the medical record. This makes it harder to compare scores of personal continuity. We compared patients at risk for depression with only one group of patients having a somatic illness. It is possible that patients with other chronic somatic illnesses experience lower levels of continuity of care than heart failure patients. However, personal and team continuity of COPD patients (measured with the same instrument) show comparable levels of experienced continuity of care between patients with heart failure and COPD.<sup>16</sup>

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## Comparison with existing literature

Existing studies about continuity of care in patients with a mental illness focus on patients with a severe mental illness recruited in secondary care.<sup>10;14</sup> Chien et al. studied the levels of personal continuity in schizophrenia patients and found, similar to our results, that most patients contacted several care providers in the past year: almost 20% saw their usual provider less than half the times and about one quarter of schizophrenia patients saw their usual provider 90% or more of the times.<sup>14</sup> Adair et al. studied the experienced continuity in patients with a severe mental illness using a multidimensional measure of continuity of care, including continuity across services and a consistent relationship with the primary caregiver

and treatment team. These patients reported a mean continuity score of 131 out of a possible 185 ( $131/185=0.71$ ).<sup>10</sup> The scores of the different dimensions were not published. In comparison, we found a slightly higher score (0.75) for mean team continuity, and lower score (0.54) for mean cross-boundary continuity.

In previous research we showed that COPD patients experience comparable levels of continuity of care as heart failure patients.<sup>16</sup> Comparison of patients having a mental illness with patients having a somatic illness from different previous studies is difficult because different measurement instruments were used and patients were recruited in different care settings.

### **Implications for practice and research**

Most patients at risk for depression contact several care providers throughout the care spectrum. They experience low levels of collaboration between care providers of different care settings. They seem to experience lower levels of both personal and cross-boundary continuity of care compared to patients with a somatic illness, while continuity of care is probably even more important in patients with a mental illness because it is an essential element of the therapeutic process in these patients.<sup>12;13</sup> Further research is needed to find out more about the origin of these differences.

Care providers involved in the care for patients at risk for depression should make efforts to increase the levels of continuity of care as there is evidence that high levels of both personal continuity and communication/cooperation between care providers are related to better quality of life, better community functioning, lower severity of symptoms, greater service satisfaction and lower health care costs.<sup>10;11</sup>

This means that involved care providers should attempt patients not to contact more care providers than needed, e.g. by taking their time and listening to the patient. Moreover, providers in different care settings should, regardless of their background, communicate better about the patient and make sure that their care is connected.

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# 4

## **Measurement properties of questionnaires measuring continuity of care: a systematic review**

Annemarie A. Uijen  
Claire W. Heinst  
François G. Schellevis  
Wil J.H.M. van den Bosch  
F.A. van de Laar  
Caroline B. Terwee  
Henk J. Schers

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## Abstract

**Background** Continuity of care is widely acknowledged as a core value in family medicine. In this systematic review, we aimed to identify the instruments measuring continuity of care and to assess the quality of their measurement properties.

**Methods** We did a systematic review using the PubMed, Embase and PsycINFO databases, with an extensive search strategy including ‘continuity of care’, ‘coordination of care’, ‘integration of care’, ‘patient centered care’, ‘case management’ and its linguistic variations. We searched from 1995 to October 2011 and included articles describing the development and/or evaluation of the measurement properties of instruments measuring one or more dimensions of continuity of care: (1) care from the same provider who knows and follows the patient (personal continuity), (2) communication and cooperation between care providers in one care setting (team continuity), and (3) communication and cooperation between care providers in different care settings (cross-boundary continuity). We assessed the methodological quality of the measurement properties of each instrument using the COSMIN checklist.

**Results** We included 24 articles describing the development and/or evaluation of 21 instruments. Ten instruments measured all three dimensions of continuity of care. Instruments were developed for different groups of patients or providers. For most instruments, three or four of the six measurement properties were assessed (mostly internal consistency, content validity, structural validity and construct validity). Six instruments scored positive on the quality of at least three of six measurement properties.

**Conclusions** Most included instruments have problems with either the number or quality of its assessed measurement properties or the ability to measure all three dimensions of continuity of care. Based on the results of this review, we recommend the use one of the four most promising instruments, depending on the target population: Diabetes Continuity of Care Questionnaire, Alberta Continuity of Services Scale-Mental Health, Heart Continuity of Care Questionnaire, and Nijmegen Continuity Questionnaire.

## Introduction

**C**ontinuity of care is an important characteristic of good health care.<sup>1-4</sup> In the literature, continuity often refers to the extent by which care is provided by the same person (personal continuity). Personal continuity is relatively easy to measure as it can be expressed as an index, based on duration of provider relationship, density of visits, dispersion of providers or sequence of providers.<sup>5</sup> From the 1990's on, however, continuity of care is increasingly seen as a multidimensional concept.<sup>6</sup> Besides personal continuity, it also includes the seamless provision of care by a group of professionals in the medical home (team continuity), and continuity between different care settings, e.g. general practice and specialist care (cross-boundary continuity).<sup>6-8</sup> As more and more care providers are involved in individual patient care, the communication and cooperation aspects of care become increasingly important.

Measuring continuity of care in its multidimensional meaning requires a robust and solid measurement instrument. Reviews have shown that many instruments have been developed over time.<sup>9-13</sup> These reviews, however, did not include recent publications and have focused solely on one concept. As we found that other concepts like coordination and integration of care show great overlap with continuity of care<sup>6</sup>, the limited continuity scope seems too narrow for a complete overview of instruments. Moreover, existing reviews have not systematically appraised the measurement properties of the instruments found. Therefore, we performed a systematic review to identify the instruments measuring continuity of care, to assess the dimensions of continuity in those instruments, and to evaluate their measurement properties.

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## Methods

### Search strategy

We searched the computerized bibliographic databases of PubMed, Embase and PsycINFO from 1995 to October 2011. We chose to start searching in 1995, as the multidimensional concept only emerged from then on.<sup>6</sup> It would therefore be very

unlikely that relevant instruments developed before 1995 would use multidimensional definitions of continuity of care. We used the keywords ‘continuity of care’, ‘coordination of care’, ‘integration of care’, ‘patient centered care’, ‘case management’ and its linguistic variations in combination with a search filter developed for finding studies on measurement properties of measurement instruments (see appendix A).<sup>14</sup> We restricted our search to English or Dutch language articles. Reference lists were screened to identify additional relevant studies.

### **Selection criteria**

We included all articles describing the development and/or evaluation of the measurement properties of an instrument measuring - what we will define in this review as - continuity of care<sup>6-8</sup>: (1) care from the same provider who knows and follows the patient (personal continuity), (2) communication and cooperation between care providers in one care setting (team continuity), and (3) communication and cooperation between care providers in different care settings (cross-boundary continuity). Instruments measuring only one or two of these dimensions were also included. Instruments based on a single item or index or instruments also measuring other concepts besides these three dimensions of continuity of care were excluded.

Two reviewers (AU and CH) independently screened titles, abstracts and reference lists of the studies retrieved by the literature search. If there was any doubt as to whether the article met the inclusion criteria, consensus was reached between the reviewers. The full-text articles were reviewed by two independent reviewers (AU and CH) for in- and exclusion criteria. If necessary a third independent reviewer (HS) was consulted.

### **Data extraction**

Data extraction and assessment of measurement properties and methodological quality were performed by two reviewers (AU and CH) independently. In case of disagreement, a third reviewer (CT) made the decision. One of the found measurement instruments was developed and validated by AU<sup>15;16</sup>, so CH and CT

scored this instrument. All instruments were questionnaires with pre-defined answering categories. The following data were extracted:

#### *Dimensions of continuity of care*

For each questionnaire we identified which dimensions of continuity of care (personal, team and/or cross-boundary continuity) are measured.

#### *Measurement properties*

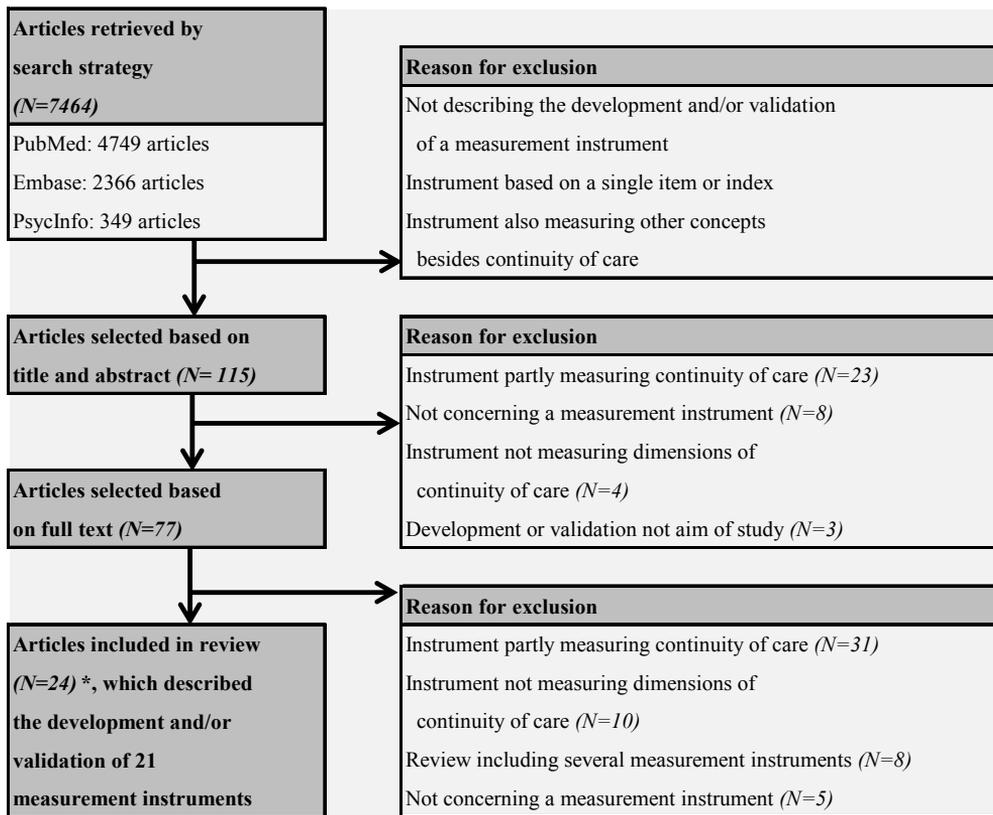
We describe the measurement properties of each questionnaire divided over three domains, according to the COSMIN taxonomy<sup>17</sup>: (1) reliability (including internal consistency, reliability, measurement error), (2) validity (including content validity, structural validity and hypothesis testing (construct validity)), and (3) responsiveness. These measurement properties are defined in Table 1. In addition, interpretability is also described. Interpretability is the degree to which one can assign qualitative meaning to quantitative scores.<sup>17</sup> This means that investigators should provide information about clinically meaningful differences in scores between subgroups, floor and ceiling effects, and the minimal important change (MIC).<sup>18</sup> Interpretability is not a measurement property, but an important characteristic of a measurement instrument.<sup>17</sup>

#### *Quality assessment*

Assessment of the methodological quality of the included studies was carried out using the COSMIN checklist.<sup>19</sup> This checklist consists of nine boxes with methodological standards for how each measurement property should be assessed.<sup>20</sup> Each item was rated on a 4-point scale (poor, fair, good or excellent). An overall score for the methodological quality of a study was determined by taking the lowest rating of any of the items in the nine boxes.

### **Best evidence synthesis – levels of evidence**

Some studies evaluated the same measurement properties for a specific questionnaire. To determine the overall quality of each measurement property established in different studies we combined the results of the different studies for each questionnaire, taking into account the number of studies, the methodological



\* We included one extra article about the validation of one of the measurement instruments which was not yet published.

Figure 1. Flowchart search and selection

quality of the studies and the direction (positive or negative) and consistency of their results.

The possible overall rating for a measurement property could reach 8 different categories (+++, ++, +, +/-, ?, -, -- or ---)<sup>21;22</sup> (Table 2). For example, when two studies of the same questionnaire show good methodological quality on evaluating ‘reliability’, then the overall rating would be either ‘+++’ or ‘---’ (Table 2), depending on the result (positive or negative) of the measurement property for

which we used criteria based on Terwee et al.<sup>23</sup> (Table 1). These criteria were derived from existing guidelines and consensus within the research group of Terwee et al.

In this case, when both studies showed intraclass correlation coefficient (ICC) <0.70, the overall rating would be ‘---’. This means that there is strong evidence (multiple studies of good methodological quality) for low levels of reliability. However, when there is only one study of fair methodological quality showing ICC>0.70, the overall rating would be ‘+’. When one study shows ICC>0.70, while another study shows ICC<0.70, the overall rating would be ‘+/-’. When there are only studies of poor methodological quality, the overall rating would be ‘?’, independent of the result of the measurement property.

## Results

The search strategy resulted in 4749 articles from PubMed, 2366 articles from Embase and 349 articles from PsycInfo (Figure 1). From these searches, we included 23 articles in this review. We included one extra article that was not yet published which describes the validation of an included measurement instrument.<sup>16</sup> Reference tracking did not result in additional articles. Finally, we included 24 articles describing the development and/or evaluation of 21 questionnaires measuring continuity of care.<sup>15;16;24-45</sup>

Table 3 presents an overview of the identified questionnaires. Seventeen questionnaires measured continuity of care from the perspective of the patient<sup>15;16;24-27;29-35;37-41;43-45</sup>, four from the perspective of the care provider/program director<sup>28;36;42</sup>. From the instruments measuring continuity from the perspective of the patient, three were developed for diabetic patients<sup>29;33;44</sup>, three for patients with a mental illness<sup>24;30;37;41;43</sup>, two for patients with cancer<sup>38;45</sup>, two for previously hospitalised patients<sup>26;35</sup>, two for patients with complex and chronic care needs<sup>32;40</sup>, one for patients with heart failure or atrial fibrillation<sup>34;39</sup>, one for users of welfare services<sup>25</sup>, one for patients visiting their family practice physician<sup>31</sup>, one for patients living at home<sup>27</sup> and one for patients in general regardless of morbidity or care setting<sup>15;16</sup>.

Table 1. Quality criteria for measurement properties<sup>2,3</sup>

Property	Definition	Rating	Rating and quality criteria
<p>The degree to which scores for patients who have not changed are the same for repeated measurement under several conditions</p>			
<b>Reliability</b>			
Internal consistency	The degree to which items in a (sub)scale are intercorrelated, thus measuring the same construct	+ ?	+ (Sub)scale unidimensional AND Cronbach's alpha(s) $\geq 0.70$ ? Dimensionality not known OR Cronbach's alpha not determined
Reliability	The proportion of the total variance in the measurements which is because of "true" <sup>a</sup> differences among patients	- + ?	- (Sub)scale not unidimensional OR Cronbach's alpha(s) $< 0.70$ + ICC / weighted Kappa $\geq 0.70$ OR Pearson's $r \geq 0.80$ ? Neither ICC / weighted Kappa, nor Pearson's $r$ determined
Measurement error	The systematic and random error of a patient's score that is not attributed to true changes in the construct to be measured	- + ?	- ICC / weighted Kappa $< 0.70$ OR Pearson's $r < 0.80$ + MIC $>$ SDC OR MIC outside the LOA ? MIC not defined
		-	- MIC $\leq$ SDC OR MIC equals or inside LOA
<p>The degree to which the instrument measures the construct(s) it purports to measure</p>			
<b>Validity</b>			
Content validity	The degree to which the content of an instrument is an adequate reflection of the construct to be measured	+ ? -	+ The target population considers all items in the questionnaire to be relevant AND considers the questionnaire to be complete ? No target population involvement - The target population considers items in the questionnaire to be irrelevant OR considers the questionnaire to be incomplete
Structural validity	The degree to which the scores of an instrument are an adequate reflection of the dimensionality of the construct to be measured	+ ? -	+ Factors should explain at least 50% of the variance ? Explained variance not mentioned - Factors explain $<$ 50% of the variance

Table 1. Continued

Property	Definition	Rating	Rating and quality criteria
<b>Validity</b>			
Hypothesis testing (construct validity)	The degree to which the scores of an instrument are consistent with hypotheses (e.g. with regard to internal relationships, relationships to scores of other instruments, or differences between relevant groups) based on the assumption that the other instrument validly measures the construct to be measured.	+	+ Correlation with an instrument measuring the same construct $\geq 0.50$ OR at least 75% of the results are in accordance with the hypotheses AND correlation with related constructs is higher than with unrelated constructs ? Solely correlations determined with unrelated constructs - Correlation with an instrument measuring the same construct $< 0.50$ OR $< 75\%$ of the results are in accordance with the hypotheses OR correlation with related constructs is lower than with unrelated constructs
<b>Responsiveness</b>			
Responsiveness	The ability of an instrument to detect change over time in the construct to be measured	+	+ (Correlation with an instrument measuring the same construct $\geq 0.50$ OR at least 75% of the results are in accordance with the hypotheses OR $AUC \geq 0.70$ ) AND correlation with related constructs is higher than with unrelated constructs ? Solely correlations determined with unrelated constructs - Correlation with an instrument measuring the same construct $< 0.50$ OR $< 75\%$ of the results are in accordance with the hypotheses OR $AUC < 0.70$ OR correlation with related constructs is lower than with unrelated constructs
<p><sup>a</sup> The word 'true' must be seen in the context of the classical test theory, which states that any observation is composed of two components - a true score and error associated with the observation. 'True' is the average score that would be obtained if the scale were given an infinite number of t</p> <p>It refers only to the consistency of the score and not to its accuracy.</p> <p>MIC = minimal important change, SDC = smallest detectable change, LOA = limits of agreement, ICC = intraclass correlation coefficient, AUC = area under the curve</p> <p>+ = positive rating, ? = indeterminate rating, - = negative rating</p>			

Ten instruments measured aspects of personal, team and cross-boundary continuity<sup>15;16;24;26;30-35;37;39;41;44</sup>, while eleven instruments measured only one or two of these dimensions<sup>25;27-29;36;38;40;42;43;45</sup>.

Most questionnaires were originally developed in English, except for the Dutch questionnaires of Casparie et al.<sup>27</sup> and Uijen et al.<sup>15;16</sup>, the Chinese questionnaire of Wei et al.<sup>44</sup>, and the Swedish questionnaire of Ahgren et al.<sup>25</sup>

**Table 2. Levels of evidence for the overall quality of the measurement property<sup>22</sup>**

Rating	Criteria
+++ or ---	Consistent findings in multiple studies of good methodological quality OR in one study of excellent methodological quality
++ or --	Consistent findings in multiple studies of fair methodological quality OR in one study of good methodological quality
+ or -	One study of fair methodological quality
+/-	Conflicting findings
?	Only studies of poor methodological quality

*+ = positive rating, ? = indeterminate rating, - = negative rating*

Table 4 presents a description of the study populations. Eight of the instruments were solely developed and/or evaluated in primary care populations<sup>27;31-33;40;41;43;44</sup>, eight solely in secondary care populations<sup>26;34-36;38;39;42;45</sup> and five were developed and/or evaluated in both primary and secondary care populations<sup>15;16;24;25;28-30;37</sup>.

The methodological quality of the studies is presented in Table 5 for each questionnaire and measurement property. Most studies assessed the internal consistency, content validity, structural validity and construct validity of the instruments, although frequently the methodological quality of the studies regarding these measurement properties was fair or poor. The reliability and measurement error were only assessed in a minority of the studies and the methodological quality regarding these measurement properties was often fair or poor. Cross-cultural validity, criterion validity and responsiveness were not assessed in any of the studies.

Table 3. Description of identified instruments

Instrument	Reference number	Year of publication	Measurement aim	Target population	Language	Number of items and subdomains	Response options	Domains of continuity of care
CPCI ( <i>Components of Primary Care Index</i> )	31	1997	To measure several components of the delivery of primary care from the perspective of the patient	Patients visiting family practice physicians	English	19 items in 4 subdomains	5-point scale (range 1-5, mean factor scale score 1-5)	Personal continuity Team continuity Cross-boundary continuity
VCC ( <i>Continuity of Care from client perspective</i> )	27	1998	To measure continuity of care from the patient perspective	Patients living at home	Dutch	126 items in 4 subdomains	5-point scale (range 1-5, total range 1-5)	Team continuity Cross-boundary continuity
CCI ( <i>Care Continuity Instrument</i> )	26	2000	To measure continuity of care from the perspective of elders hospitalised for a chronic illness	Elders hospitalised for a chronic illness	English	12 items in 4 subdomains	7-point scale (range 1-7, total range 12-84)	Personal continuity Team continuity Cross-boundary continuity
CONNECT	43	2003	To measure continuity of care for mental health services	Patients who have serious mental illness	English	59 items in 14 subdomains	5-point scale (range 1-5). Each sub-domain was scored by summing the items and then rescaling to give a score out of 100	Team continuity Cross-boundary continuity

Table 3. Continued

Instrument	Reference number	Year of publication	Measurement aim	Target population	Language	Number of items and subdomains		Response options	Domains of continuity of care
						Language	subdomains		
CPCQ ( <i>Client Perceptions of Coordination Questionnaire</i> )	40	2003	To measure coordination of health care	Predominantly elderly patients with complex and chronic care needs	English	31 items in 7 subdomains	Most items were rated on a 5-point scale (range 1-5), 4 items were rated on a 3-point scale (range 1-3)	Team continuity Cross-boundary continuity	
ACSS-MH ( <i>Alberta Continuity of Services Scale – Mental Health</i> )	24; 30; 37	2004	To measure continuity of care for mental health services from the patient/client perspective	Patients using mental health services	English	32 items in 3 subdomains	5-point scale (range 1-5, mean factor scale score 1-5)	Personal continuity Team continuity Cross-boundary continuity	
CCPS-I ( <i>Continuity of Care Practices Survey – Individual level</i> )	42	2004	To measure the extent of continuity of care that staff (primary counselors/case managers) of substance use disorder programs provide to individual patients	Substance use disorder program staff (primary counselors/case managers)	English	23 items in 4 subdomains	Three subscales were scored on a 4-point scale, one subscale is scored as the mean of two percentages	Personal continuity Cross-boundary continuity	

Table 3. Continued

Instrument	Reference number	Year of publication	Measurement aim	Target population	Language	Number of items and subdomains	Response options	Domains of continuity of care
CCPS-P (Continuity of Care Practices Survey – Program level)	42	2004	To measure continuity of care from the perspective of substance use disorder program directors	Substance use disorder program directors	English	23 items in 4 subdomains	Three subscales were scored on a 4-point scale, one subscale is scored as the mean of two percentages	Personal continuity Cross-boundary continuity
DCCS (Diabetes Continuity of Care Scale)	29	2004	To measure continuity of care from the perspective of patients with diabetes	Diabetic patients	English	47 items in 5 subdomains	5-point scale (range 1-5, total score range 47-235)	Team continuity Cross-boundary continuity
HCCQ (Heart Continuity of Care Questionnaire)	34, 39	2004	To assess continuity of care from the perspective of patients with congestive heart failure and atrial fibrillation	Patients hospitalised for either congestive heart failure or atrial fibrillation	English	33 items in 3 subdomains	5-point scale (range 1-5, total range 1-5)	Personal continuity Team continuity Cross-boundary continuity
ECC-DM (Experienced continuity of care for diabetes mellitus)	33	2006	To measure continuity of care in type 2 diabetes mellitus	Type 2 diabetic patients	English	19 items in 4 subdomains	6-point scale. Each sub-domain was scored by summing the items and then rescaling to give a score out of 25 (total score range 0-100).	Personal continuity Team continuity Cross-boundary continuity

Table 3. Continued

<b>Instrument</b>	<b>Reference number</b>	<b>Year of publication</b>	<b>Measurement aim</b>	<b>Target population</b>	<b>Language</b>	<b>Number of items and subdomains</b>	<b>Response options</b>	<b>Domains of continuity of care</b>
King et al. (nameless instrument)	38	2008	To measure continuity of care in patients with cancer	Patients with cancer	English	18 items in 1 subdomain	5-point scale (range 0-4, total range 0-72)	Team continuity
CONTINU-UM (Continuity of Care – User Measure)	41	2008	To measure continuity of care in patients with severe mental illness	Patients who have severe mental illness	English	32 items in 16 subdomains	5-point scale (range unclear)	Personal continuity Team continuity Cross-boundary continuity
DCCQ (Diabetes Continuity of Care Questionnaire)	44	2008	To measure continuity of care in type 2 diabetes mellitus	Type 2 diabetic patients	Chinese	46 items in 8 subdomains	6-point scale, except for one subdomain (5-point scale). Each subdomain was scored by summing the items and then rescaling to give a score out of 100.	Personal continuity Team continuity Cross-boundary continuity
PCCQ (Patient Continuity of Care Questionnaire)	35	2008	To measure patient perceptions of factors impacting continuity of care following discharge from hospital	Patients previously hospitalised	English	27 items in 6 subdomains	5-point scale (range 1-5)	Personal continuity Team continuity Cross-boundary continuity

Table 3. Continued

Instrument	Reference number	Year of publication	Measurement aim	Target population	Language	Number of items and subdomains	Response options	Domains of continuity of care
Ahgren et al. (nameless instrument)	25	2009	To assess the integration of welfare services from the perspective of the service users	Users of welfare services	Swedish	22 structured and open questions in 3 subdomains	The structured questions were rated on different ordinal scales (total range unclear)	Team continuity Cross-boundary continuity
CRP-PIM ( <i>Communication with Referring Physicians Practice Improvement Module</i> )	36	2009	To assess the communication among physician consultants and referring physicians	Referring physicians	English	13 items in 2 subdomains	6-point scale (range 1-6)	Team continuity Cross-boundary continuity
CSI Survey ( <i>Cancer Services Integration Survey</i> )	28	2009	To measure integration of cancer services	Healthcare providers and administrators that had regular opportunities to interact with the cancer system	English	54 items in 4 subdomains	5-point scale (range unclear)	Team continuity Cross-boundary continuity
Gulliford et al. (nameless instrument)	32	2011	To measure continuity of care from the perspective of patients with a long-term illness	Patients with a long-term illness	English	16 items in 2 subdomains	4-point scale. In order to simplify further analysis, the authors used dichotomized item responses (0 or 1)	Personal continuity Team continuity Cross-boundary continuity

Table 3. Continued

Instrument	Reference number	Year of publication	Measurement aim	Target population	Language	Number of		Domains of continuity of care
						subdomains	items and subdomains	
CCCQ (Cancer Care Coordination Questionnaire)	45	2011	To measure patients' experience of cancer care coordination	Cancer patients in the treatment phase of the cancer journey	English	20	20 items in 2 subdomains	Team continuity Cross-boundary continuity
NCQ (Nijmegen Continuity Questionnaire)	15; 16	2011	To measure continuity of care from the patients' perspective across primary and secondary care settings	All types of patients, regardless of care setting and morbidity	Dutch	28	28 items in 3 subdomains	Personal continuity Team continuity Cross-boundary continuity

Table 4. Description of identified study populations

Article	Reference number	Instrument	Study population	Setting	N	Mean age (SD)	Male (%)	Country
Flooke	31	CPCI	Patients visiting family physicians	138 family practices	2899	42 (23)	38	USA
Casparie et al.	27	VCC	Patients living at home suffering from multiple sclerosis, rheumatoid arthritis, asthma, COPD, dementia or a mental impairment	Primary care	± 1000		?	The Netherlands
Bull et al. (Phase I+II)	26	CCI	Elders (> 55 years) admitted to a community hospital for a chronic illness	Hospital	32	69.3 (8.9)	?	USA
Bull et al. (Phase III)	26	CCI	Elders (> 55 years) recently hospitalized for an acute episode of congestive heart failure, chronic obstructive lung disease, or diabetes mellitus	Hospital	121	Range: 55-89 years	?	USA
Bull et al. (Phase IV)	26	CCI	Elders (> 55 years) hospitalized with heart failure for at least two days	Hospital	135	74.1 (9.0)	?	USA
Ware et al.	43	CONNECT	Patients diagnosed with serious mental illness	Public mental health services	400	Range: 18-71 years	63	USA
McGuinness et al.	40	CPCQ	1. Patients with chronic complex health problems who could benefit from improved coordination of their health and social care 2. Patients with chronic pain	1. General practice 2. General practice and a community-based chronic pain management course	1380	59.1	39	Australia

Table 4. Continued

Article	Reference number	Instrument	Study population	Setting	N	Mean age (SD)	Male (%)	Country
Adair et al.	24	ACSS-MH	Patients in mental health services	Mental health services	317			Canada
Durbin et al.	30	ACSS-MH	Users of community and outpatient mental health programs	Mental health programs	215	25 years and younger: 6.6% 65+: 4.2%	37.9	Canada
Joyce et al.	37	ACSS-MH	Patients with a severe mental illness (psychotic disorder, bipolar disorder, or unipolar depressive disorder of at least 24 months duration)	Mental health services	441	42.5 (10.3)	41.0	Canada
Schaefer et al.	42	CCPS-I	Staff (primary counselors/case managers) of substance use disorder programs	Specialized mental health care	?	?	?	USA
Schaefer et al.	42	CCPS-P	Directors of different substance use disorder treatment programs	Specialized mental health care	117	?	?	USA
Dolovich et al.	29	DCCS	Patients with diabetes	A group health centre consisting of 33 family physicians and 31 specialists	60	60.8 (11.4)	56.7	Canada
Kowalyk et al.	39	HCCQ	Patients who had been hospitalized approximately six months earlier for either congestive heart failure or atrial fibrillation	Hospitals	83	74 (12)	56.6	Canada

Table 4. Continued

Article	Reference number	Instrument	Study population	Setting	N	Mean age (SD)	Male (%)	Country
Hadjistravropoulos et al.	34	HCCQ	Patients who had been hospitalized at least six months earlier for either congestive heart failure or atrial fibrillation	Hospitals	350	73.9 (range: 40-99 years)	54.0	Canada
Gulliford, Nait hani et al.	33	ECC-DM	Patients with type 2 diabetes	19 family practices	193	65 (range: 32-90 years)	49.7	UK
King et al.	38	Nameless	Patients with breast, lung or colorectal cancer	National Cancer Networks	199	61.2 (11.8)	31.7	UK
Rose et al.	41	CONTINU-UM	Patients who had a diagnosis of psychosis and had been in touch with services for at least 2 years	Community mental health teams	167	43	56	UK
Wei et al.	44	DCCQ	Patients with type 2 diabetes	Community health centre	338	68.7 (9.7)	32.2	China
Hadjistravropoulos et al.	35	PCCQ	Patients discharged from either an orthopaedics unit or a family medicine unit	Hospitals	204	64.9 (17.4)	40.2	Canada
Ahgren et al.	25	Nameless	Users of different institutions in the rehabilitation field that provide services to people who have been ill or unemployed for a long time	Institutions in the rehabilitation field	454	40	40	Sweden
Hess et al.	36	CRP-PIM	Physicians referring to consultants (internists and subspecialists)	Hospital	12212	47 (3.9)	76	USA
Dobrow et al.	28	CSI	Healthcare providers and administrators that had regular opportunities to interact with the cancer system	Hospitals and community care access centres	1769	Between 40-60: 71%	31.0	Canada
Gulliford, Cowie et al.	32	Nameless	Patients aged 60 years or older	General practice	1125	?	45.5	UK

Table 4. *Continued*

Article	Reference number	Instrument	Study population	Setting	N	Mean age (SD)	Male (%)	Country
Young et al.	45	CCCQ	1. Patients in follow-up for any cancer that had been treated 3-12 months previously 2. Patients with a newly diagnosed colorectal cancer	Hospital	686	66.1 (13.3)	53.2	Australia
Uijen, Schellevis et al.	15	NCQ	Patients with one or more chronic diseases	General practice	288	64.6	46.2	The Netherlands
Uijen, Schers et al.	16	NCQ	Patients with one or more chronic diseases	General practice and hospital /outpatient department	268	62.2	48.5	The Netherlands

Table 5. Methodological quality of each article per measurement property and instrument (COSMIN Checklist)

Article	Reference number	Internal Consistency		Reliability	Measurement Error	Content Validity		Structural Validity	Hypotheses Testing	
		Internal Consistency	Reliability			Content Validity	Structural Validity		Testing	
CPCI										
Flocke	31	Good	-	-	-	Excellent	Good	Good	Fair	Fair
VCC										
Casparie et al.	27	Good	-	-	-	Excellent	Good	Good	-	-
CCI										
Bull et al. (Phase I+II)	26	Poor	-	-	-	Fair	-	-	Fair	Fair
Bull et al. (Phase III)	26	Excellent	-	-	-	-	Excellent	Excellent	Good	Good
Bull et al. (Phase IV)	26	Excellent	Excellent	-	-	-	Excellent	Excellent	Fair	Fair
CONNECT										
Ware et al.	43	Poor	Good	-	-	Good	-	-	Poor	Poor
CPCQ										
McGuinness et al.	40	Excellent	-	-	-	Fair	Fair	Fair	Fair	Fair
ACSS-MH										
Adair et al.	24	Fair	Fair	-	-	Excellent	Fair	Fair	-	-
Durbin et al.	30	Excellent	-	-	-	-	Excellent	Excellent	Fair	Fair
Joyce et al.	37	Good	-	-	-	-	Good	Good	Fair	Fair
CCPS-I										
Schaefer et al.	42	Poor	-	-	-	Poor	-	-	-	-
CCPS-P										
Schaefer et al.	42	Poor	-	-	-	Fair	-	-	Poor	Poor
DCCS										
Dolovich et al.	29	Poor	Fair	-	-	Fair	Poor	Poor	Fair	Fair
HCCQ										
Kowalyk et al.	39	Poor	-	-	-	Fair	-	-	Good	Good
Hadjistavropoulos et al.	34	Excellent	-	-	-	-	Good	Good	Good	Good
ECC-DM										
Gulliford, Naithani et al.	33	Excellent	-	-	Poor	-	Good	Good	Poor	Poor

Table 5. Continued

Article	Reference number	Internal Consistency	Reliability	Measurement Error	Content Validity	Structural Validity	Hypotheses Testing
King et al. (Nameless)							
King et al.	38	Poor	Fair	-	Excellent	-	-
CONTINU-UM							
Rose et al.	41	-	Fair	Fair	Poor	-	-
DCCQ							
Wei et al.	44	Fair	-	-	Fair	Poor	Fair
PCCQ							
Hadjistravopoulos et al.	35	Poor	-	-	Poor	Poor	Good
Ahgren et al. (Nameless)							
Ahgren et al.	25	Poor	-	-	Fair	-	-
CRP-PIM							
Hess et al.	36	-	Poor	-	-	Fair	-
CSI							
Dobrow	28	Poor	-	-	Excellent	Poor	-
Gulliford et al. (nameless)							
Gulliford, Cowie et al.	32	Fair	-	-	Poor	Fair	-
CCCC							
Young et al.	45	Excellent	Excellent	-	Excellent	Excellent	Poor
NCQ							
Uijen, Schellevis et al.	15	Excellent	-	-	Fair	Poor	-
Uijen, Schers et al.	16	Excellent	Excellent	Excellent	-	Poor	Excellent

*Cross-cultural validity, criterion validity and responsiveness were not evaluated*

- : no information available

Table 6. Quality of measurement properties and the interpretability per instrument

Instrument	Measurement properties						Interpretability		
	Internal consistency	Reliability	Measurement Error	Content Validity	Structural Validity	Hypotheses Testing	Differences in scores between subgroups	Floor/ceiling effects of subdomain(s)	Minimal important change (MIC)
CPCI	--	na	na	+++	++	+	Not reported	Unknown	Unknown
VCC	--	na	na	+++	++	na	Not reported	Unknown	Unknown
CCI	+++	---	na	+	+++	+/-	Not reported	Floor and ceiling effect	Unknown
CONNECT	?	--	na	++	na	?	Not reported	Floor effect	Unknown
CPCQ	---	na	na	+	+	+	Not reported	Unknown	Unknown
ACSS-MH	+/-	-	na	+++	---	+	Reported	Unknown	Unknown
CCPS-I	?	na	na	?	na	na	Not reported	Unknown	Unknown
CCPS-P	?	na	na	+	na	?	Not reported	Unknown	Unknown
DCCS	?	+	na	+	?	-	Reported	Ceiling effect	Unknown
HCCQ	+++	na	na	+	--	+++	Not reported	Unknown	Unknown
ECC-DM	---	na	?	na	++	?	Reported	Unknown	Unknown
King et al. (nameless)	?	+	na	+++	na	na	Not reported	Unknown	Unknown
CONTINU-UM	na	+	?	?	na	na	Not reported	Unknown	Unknown
DCCQ	+	na	na	+	?	-	Not reported	No floor/ceiling effect	Unknown
PCCQ	?	na	na	?	?	++	Reported	Unknown	Unknown
Ahgren et al. (nameless)	?	na	na	+	na	na	Not reported	Unknown	Unknown
CRP-PIM	na	?	na	na	-	na	Not reported	Ceiling effect	Unknown
CSI	?	na	na	+++	?	na	Not reported	No floor/ceiling effect	Unknown

Table 6. Continued

Instrument	Measurement properties					Interpretability			
	Internal Consistency	Reliability	Measurement Error	Content Validity	Structural Validity	Hypotheses Testing	Differences in scores between subgroups	Floor/ceiling effects of subdomain(s)	Minimal important change (MIC)
Gailliford et al. (nameless)	+	na	na	?	+	na	Reported	Unknown	Unknown
CCCQ	+++	---	na	+++	+++	?	Not reported	Ceiling effect	Unknown
NCQ	+++	+++	?	+	?	+++	Reported	No floor/ceiling effect	Unknown

+++ or --- = strong evidence positive/negative result, ++ or -- = moderate evidence positive/negative result, + or - = limited evidence positive/negative result, +/- = conflicting evidence, ? = unknown, due to poor methodological quality. na = no information available  
 Cross-cultural validity, criterion validity and responsiveness were not evaluated

The synthesis of results per questionnaire and their accompanying level of evidence are presented in Table 6. Six instruments (CPCI<sup>31</sup>, CCI<sup>26</sup>, CPCQ<sup>40</sup>, HCCQ<sup>34;39</sup>, CCCQ<sup>45</sup> and NCQ<sup>15;16</sup>) scored positive on the quality of at least three measurement properties. Information regarding the interpretability of the instruments was missing in most studies.

## Discussion

In this systematic review we found 21 instruments measuring - what we define as - continuity of care. We found six instruments that we would probably not have found when we would have focussed our review solely on continuity of care, instead of taking into account related concepts as coordination and integration.<sup>25;28;31;36;40;45</sup> CPCQ and CCCQ aim to measure ‘coordination of care’<sup>40;45</sup>, CSI and the instrument of Ahgren et al. measure ‘integration of care’<sup>25;28</sup>, CRP-PIM measures ‘communication among care providers’<sup>36</sup> and CPCI measures ‘attributes of primary care’<sup>31</sup>.

Most included instruments have problems with either the ability to measure all three dimensions of continuity of care or the number or quality of its assessed measurement properties.

Only about half of the questionnaires measured all three dimensions of continuity of care (personal, team and cross-boundary continuity). Of most instruments three or four measurement properties were assessed (mostly internal consistency, content validity, structural validity and construct validity). Only six instruments (CPCI<sup>31</sup>, CCI<sup>26</sup>, CPCQ<sup>40</sup>, HCCQ<sup>34;39</sup>, CCCQ<sup>45</sup> and NCQ<sup>15;16</sup>) scored positive on the quality of at least three measurement properties. These findings do not mean that the other questionnaires are of poor quality, but imply that studies of high methodological quality are needed to properly assess their measurement properties.

### Strengths and limitations

One of the strengths of this review is that our search not only focused on the concept of ‘continuity of care’, but also took into account the relating concepts

‘coordination of care’, ‘integration of care’, ‘case management’ and ‘patient centred care’. This resulted in the inclusion of instruments which measure the same aspects of care but are defined in different ways.

To our knowledge, this is the first review on measurement instruments for continuity of care that systematically appraised the measurement properties of the instruments found. This allows us to compare the instruments on the quality of their measurement properties.

We used a robust and standardized method to assess the quality of the measurement properties, which attributes considerably to the continuity knowledge base.

A limitation of this study is that we searched from 1995 onwards. Measurement instruments developed before this time were not included in our review. However, because of the changing definitions of continuity over time, we consider it very unlikely that we missed relevant instruments.<sup>6</sup>

Another limitation is that the raters had to make a large number of judgements on each study and each measurement instrument. Although the COSMIN checklist<sup>19</sup> and the quality criteria for the measurement properties<sup>23</sup> are defined as objective as possible, different raters could come to a different judgement. That is why two reviewers assessed the measurement properties and methodological quality of the studies, and in case of disagreement a third reviewer was consulted.

## **Comparison with existing literature**

Previous reviews have identified many instruments measuring continuity of care or one of its related concepts, such as patient centred care or integrated care.<sup>9-13</sup> Most reviews have limited their search to only one concept. We found only one review, identifying measures of integrated care, that broadened its search to concepts as continuity of care, care coordination and seamless care, but this review did not systematically appraise quality measures of the instruments.<sup>13</sup> Most instruments included in previous reviews have not been included in our review due to several reasons. Some studies did not describe the development or evaluation of the measurement properties at all, some did not measure - what we define in this review as - continuity of care, and some measured a much broader concept than

continuity of care (e.g. all key areas of primary care including accessibility and thoroughness of physical examination).

We found no review assessing the quality of the measurement properties of the included instruments. Hudon et al. systematically assessed the quality of the included articles, i.e. whether all relevant information such as characteristics of the study population was described.<sup>10</sup> However, the quality of the measurement properties was not assessed.

### Implications for practice and research

The decision which instrument to use will depend on the characteristics of the study population, the ability and desire to measure all three dimensions of continuity, the population in which the instrument was developed and/or validated, the quality of the measurement properties and the interpretability of the instrument.

For a comprehensive measurement of continuity of care, we recommend to use the the DCCQ<sup>44</sup> for diabetic patients, as both other questionnaires for diabetic patients (DCCS<sup>29</sup> and ECC-DM<sup>33</sup>) either do not measure all three dimensions of continuity of care or show lower quality of their measurement properties and interpretability.

For patients with a mental illness, we recommend to use the the ACSS-MH<sup>24;30;37</sup>. Both other questionnaires available for patients with a mental illness (CONNECT<sup>43</sup> and CONTINU-UM<sup>41</sup>) are only validated in primary care, do not measure all three dimensions of continuity of care or show lower quality of their measurement properties and interpretability.

For patients with heart failure or atrial fibrillation, we only found the HCCQ<sup>34;39</sup>. As this instrument measures relational, team and cross-boundary continuity and shows good quality of the measurement properties, this seems to be a proper questionnaire for this patient group.

For patients with a (chronic) illness (irrespective of the type of (chronic) illness), we found the CPCI<sup>31</sup>, VCC<sup>27</sup>, CPCQ<sup>40</sup>, the instrument of Gulliford et al.<sup>32</sup> and the NCQ<sup>15;16</sup>. For a comprehensive measurement of continuity of care, the NCQ is the only questionnaire that has been validated in primary and secondary care and shows the highest quality of its measurement properties and interpretability.

The instruments developed to measure continuity for patients with cancer (CCCQ<sup>45</sup> and the instrument of King et al.<sup>38</sup>), patients previously hospitalized (CCI<sup>26</sup> and

PCCQ<sup>35</sup>), and users of welfare services (instrument of Ahgren et al.<sup>25</sup>) all have problems regarding the limited number of dimensions of continuity measured, the limited quality of the measurement properties or the low interpretability of the instrument. The instruments developed to measure continuity of care from the perspective of the provider (CCPS-I<sup>42</sup>, CCPS-P<sup>42</sup>, CRP-PIM<sup>36</sup> and CSI<sup>28</sup>) need to be used with caution because of the limited quality of the measurement properties and interpretability.

For future research, we believe it is especially important to further evaluate the measurement properties and interpretability of the promising DCCQ, ACSS-MH, HCCQ and NCQ. For none of these instruments, responsiveness is evaluated, although this is an important characteristic of a questionnaire, especially when used to measure change in continuity of care. As the DCCQ and NCQ are originally developed in respectively Chinese and Dutch, cross-cultural validation needs to be evaluated.

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# 5

## **Development and validation of the Nijmegen Continuity Questionnaire (NCQ)**

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# 5.1

## **Nijmegen Continuity Questionnaire: Development and testing of a questionnaire that measures continuity of care**

Annemarie A. Uijen  
François G. Schellevis  
Wil J.H.M. van den Bosch  
Henk G.A. Mokkink  
Chris van Weel  
Henk J. Schers

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## Abstract

**Objective** To develop and pilot test a generic questionnaire to measure continuity of care from the patient's perspective across primary and secondary care settings.

**Methods** We developed the Nijmegen Continuity Questionnaire (NCQ) based on a systematic literature review and analysis of 30 patient interviews. The questionnaire consisted of 16 items about the patient-provider relationship to be answered for five different care providers and 14 items each on the collaboration between four groups of care providers. The questionnaire was distributed among patients with a chronic disease recruited from general practice. We used principal component analysis (PCA) to identify subscales. We refined the factors by excluding several items, for example, items with a high missing rate.

**Results** In total, 288 patients filled out the questionnaire (response rate, 72%). PCA yielded three subscales: 'personal continuity: care provider knows me', 'personal continuity: care provider shows commitment' and 'team/cross-boundary continuity'. Internal consistency of the subscales ranged from 0.82 to 0.89. Interscale correlations varied between 0.42 and 0.61.

**Conclusion** The NCQ shows to be a comprehensive, reliable and valid instrument. Further testing of reliability, construct validity, and responsiveness is needed before the NCQ can be more widely implemented.

## Introduction

Continuity of care is an important aspect of patient care. Having a personal care provider (personal continuity) is related to better health<sup>1</sup>, more confidence in the care provider<sup>2;3</sup>, more patient satisfaction<sup>3-5</sup>, higher quality of patients' life<sup>6;7</sup>, and less health care costs<sup>8;9</sup>. Over time, many instruments have been developed to measure personal continuity.<sup>10</sup>

However, because of recent developments in health care, the concept of continuity of care has changed.<sup>11-13</sup> With more subspecialization, fragmentation of health care, part-time practice, and an increase in the number of patients with multiple chronic diseases, an increasing number of care providers are involved in the care of patients. Continuity of care is nowadays considered a multidimensional concept, including not only personal or relational continuity but also informational continuity and team/cross-boundary continuity requiring communication and collaboration between care providers.<sup>11-13</sup> Some instruments have been developed to measure continuity of care as a multidimensional concept, but they all focus solely on a single disease.<sup>14-16</sup> Such measurement instruments do not take into account that continuity is particularly important in situations where multimorbidity exists.<sup>17</sup>

Moreover, most existing instruments are developed to measure continuity of care in one care setting, for example, in primary care, whereas a substantial number of chronic patients also contact medical specialists in the hospital or in an outpatient department.

At last, some instruments measure continuity of care from the provider's perspective or using medical records, whereas we believe that continuity of care should be measured from the patient's perspective.<sup>18</sup>

To our knowledge, there is no instrument available yet that measures patients' experienced continuity of care as a multidimensional concept regardless of morbidity and across multiple care settings. Such a measurement instrument would allow us to identify problems and evaluate interventions aimed at improving continuity of care. Moreover, it would enable us to compare continuity experiences for different diseases and multimorbidity patterns.

The aim of this study is, therefore, to develop and pilot test a generic questionnaire to measure continuity of care from the patient's perspective as a multidimensional concept and across multiple care settings.

<b>Box 1. Key domains of interest</b>
<b>Personal care provider</b>
The patient has a personal care provider in every care setting with whom he/she can develop an ongoing relationship (personal/relational continuity)
<b>Communication and cooperation between care providers</b>
Care providers in the same care setting and between different care settings communicate and cooperate to connect their care in a coherent way. Care providers use information on past events to deliver care that is appropriate to the patient's current circumstances (informational/cross-boundary/management continuity)

## Methods

### Development: item generation

We performed a systematic literature review of articles describing measurement instruments for continuity of care. We searched PubMed for articles focusing on continuity of care or related concepts, such as coordination or integration of care published from January 1997 to January 2007. We also searched in the reference list of all included articles and screened articles about continuity of care from our own database on continuity. We included all articles describing or using measurement instruments that included items about having a personal care provider and/or communication or cooperation between care providers (see Box 1). We screened 3,152 articles and finally included and analyzed 83 articles in which 82 different measurement instruments are described (search strategy and list of articles and instruments available on request). None of these 82 instruments measured patients' experienced continuity of care as a multidimensional concept regardless of morbidity and across multiple care settings.

We generated items for our questionnaire by including all items measuring aspects of the key domains of interest (Box 1) from the 82 identified instruments. We merged items with exactly the same content by using formulations that we think are easiest to understand and fit the Dutch situation.

In addition, we analyzed 30 patient interviews that were conducted as part of a study on continuity of care for additional items.<sup>19</sup>

This resulted in a draft questionnaire (Nijmegen Continuity Questionnaire (NCQ)) including 20 general items (about types of care providers seen, age, sex, ethnicity etc.) and 136 items about continuity (16 items about the patient-provider relationship to be answered for five different care providers (80 items): most important care provider in general practice, other care provider in general practice, most important care provider in hospital/outpatient department, other care provider in hospital/outpatient department, and care provider outside general practice and hospital/outpatient department, and 14 items on the collaboration between four groups of care providers (56 items): between care providers within general practice, between care providers within the hospital/outpatient department, between general practice and hospital/outpatient department, and between general practice and care providers outside general practice and hospital/outpatient department). The items on continuity were rated according to a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with an additional option to choose '?' ('I do not know'). Some items were negatively worded to reduce bias.

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### **Validity: face validity and reading level**

Subsequently, we tested face validity by interviewing 15 patients with chronic diseases (varying in age, number of chronic diseases, number of care providers seen, and type of general practice in which they were listed) according to the 'thinking aloud technique'.<sup>20</sup> Patients were asked to think aloud when they answered each question. Interviews were audiotaped, and the interviewer wrote down verbal and non-verbal reactions indicating difficulties in instruction and item wording. Difficulties were corrected and tested in subsequent interviews. After 13 patients no new difficulties in the questionnaire were identified; therefore, we assumed that data saturation was achieved after 15 interviews, which corresponds to the description of Streiner and Norman.<sup>20</sup> Finally, the questionnaire included 136

items on continuity and 21 general items. The reading level of the NCQ was then assessed according to the Flesch-Kincaid Grade Level.<sup>21</sup>

### **Pilot testing: participants**

In January 2009, 31 general practitioner (GP) trainees working in practices in the eastern part of the Netherlands were asked to distribute 25 questionnaires each to patients with one or more chronic diseases. For these patients, continuity is particularly important, and most of them would have contacted a medical specialist in the hospital/outpatient department in the previous year. We excluded patients under the age of 18 years or who were unable to speak or read Dutch. Patients filled out the NCQ at home and could send it back directly to the researchers. The GP trainees registered age, sex, and type of chronic disease(s) of all participating patients and filled out some questions about the type of practice they worked in. In the Netherlands, every patient is enlisted with one GP. The GP functions as a gatekeeper for specialist care.

### **Analysis**

We used SPSS version 16.0 (SPSS Inc., Chicago, IL, USA) to analyze the data. We assessed item completion rates, means, standard deviation (SD), and percentage respondents with the highest and lowest score per item (ceiling and floor effect). We treated the items as continuous variables. Principal component analysis (PCA) was used to identify subscales. We performed PCA on 16 items about the patient-provider relationship across multiple care settings and per care setting separately. In the first analysis, several observations from one patient are included (e.g., observations from the care provider in general practice and hospital/outpatient department), whereas in the second analysis, the observations are all independent. We also performed PCA on 14 items about the collaboration and information exchange between the groups of care providers across multiple care settings and per care setting separately. We compared varimax rotation with direct oblimin rotation and finally chose the rotation that resulted in factors with the highest interpretability. We retained the factors with eigenvalues greater than 1. We refined the factors by excluding items for several reasons: we excluded items that

decreased the interpretability of the factor, had a relatively high rate of missing values, were relatively highly correlated to other items, had a relatively low SD, had a relatively high floor or ceiling effect, loaded high on two factors or loaded low on all factors. Reliability of the subscales was assessed using Cronbach  $\alpha$ . We excluded items until Cronbach  $\alpha$  was  $<0.90$ , to avoid item redundancy. For preliminary validation of the subscales, we assessed the mean, SD and mean interitem correlations of the subscales and calculated Pearson correlations between the subscales.

## Results

### Reading level

The estimated reading level was seven, indicating that respondents would need a seventh-grade education to understand the questionnaire.<sup>21</sup> The seventh grade is the seventh school year after kindergarten. Seventh graders are usually 12-13 years old.

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### Questionnaire response

In total, 24 GP trainees participated, and they asked 398 patients to fill out the questionnaire, of which 288 (72%) were returned.

### Patient characteristics

Table 1 shows patients' characteristics and their medical care. Responders and nonresponders did not differ in age ( $p=0.77$ ), number of chronic diseases ( $p=0.19$ ) and type of general practice they were listed in ( $p=0.30$ ). Responders were more likely to be males ( $p=0.03$ ).

Most patients perceived general practice or hospital/outpatient department as their most important site of care (74% and 21%, respectively) and their GP and medical specialist as their most important care provider at these sites (264 of 288 patients (91.6%) and 177 of 179 patients (98.9%), respectively).

**Table 1. Characteristics and medical care of responders and nonresponders**

<b>Patient characteristics</b>	<b>Responders (N = 288), n (%)</b>	<b>Nonresponders (N = 110), n (%)</b>
Age (mean)	64.6	64.9
<50	35 (12.2)	14 (12.7)
50-59	61 (21.2)	17 (15.5)
60-69	77 (26.7)	25 (22.7)
70-79	86 (29.9)	35 (31.8)
≥80	29 (10.1)	11 (10.0)
Missing	0 (0)	8 (7.3)
Male sex	133 (46.2)	39 (35.5)
<b>Ethnicity</b>		
Dutch	259 (89.9)	
Other	29 (10.1)	
<b>Medical care</b>		
Number of chronic diseases according to care provider (mean)	1.91	1.72
<b>Type of chronic diseases</b>		
Diabetes Mellitus	106 (36.8)	46 (41.8)
Asthma / chronic obstructive pulmonary disease	58 (20.1)	23 (20.9)
Myocardial infarction	17 (5.9)	5 (4.5)
Cerebrovascular accident / transient ischemic attack	0 (0)	1 (0.9)
Hypertension	123 (42.7)	33 (30.0)
Mental disorder	9 (3.1)	2 (1.8)
Malignancy	13 (4.5)	1 (0.9)
Disorder of muscles, bones, or joints	33 (11.5)	16 (14.5)
Other	83 (28.8)	27 (24.5)
Listed in single-handed general practice	45 (15.6)	35 (31.8)
<b>Total number of care providers in last year (mean)</b>	3.97	
In general practice (mean)	2.02	
In hospital (mean)	1.30	
<b>Total number of contacts in the last year in general practice</b>		
0 times	0 (0.0)	
1-2 times	40 (13.9)	
3-5 times	128 (44.4)	
> 5 times	116 (40.3)	
Missing	4 (1.4)	
<b>Total number of contacts in the last year in hospital/outpatient department</b>		
0 times	88 (30.6)	
1-2 times	86 (29.9)	
3-5 times	58 (20.1)	
> 5 times	54 (18.8)	
Missing	2 (0.7)	

*Values are in numbers (percentages) unless otherwise indicated*

Therefore, in this article, we will focus on the patient-provider relationship of the most important care provider in general practice and in hospital/outpatient department and on the collaboration and information exchange between care providers within general practice, between care providers within the hospital/outpatient department, and between general practice and hospital/outpatient department.

### **Item analysis**

Table 2 shows item means, SDs, missing rates, and percentage of respondents with the lowest and highest scores (floor and ceiling effect). Most items were weakly to moderately negatively skewed. The items about the collaboration between care providers within the hospital/outpatient department and the collaboration between general practice and hospital/outpatient department showed highest missing rates (mean of 26.1% and 24.9%, respectively).

### **Subscales**

Before we performed PCA, we excluded items 3 and 9 (about trust and relationship), because these items were not distinctive for measuring continuity of care. For example, we found that patients could be negative about the continuity of their specialist (according to the other items) but still reported to experience a lot of trust in this care provider. Item 3 also showed poor variability.

PCA showed that the negatively worded items (item 6, 13, 20 and 25) loaded on a separate factor, which we could not interpret well. We found that patients answered these items more frequently with extreme values (higher ceiling effect). Patients answered inconsistently when comparing the negatively with the positively worded items, which was also shown in other research.<sup>22</sup> Therefore, we decided to exclude the negatively worded items.

We performed PCA on the remaining items 1-16 about the most important care provider across multiple care settings and per care setting separately. Table 3 shows the varimax-rotated factor loadings of this first analysis. It resulted in the same factors as the last analysis. We compared varimax rotation with direct oblimin rotation and found no difference in final results. Two factors were

generated, both with an eigenvalue above 1: ‘personal continuity: care provider knows me’ and ‘personal continuity: care provider shows commitment’, explaining a total variance of 70.3%.

We also performed PCA on the remaining items 17-30 about the collaboration between the groups of care providers across multiple care settings and per care setting separately, which resulted in the same single factor (‘team/cross-boundary continuity’). Table 3 shows the factor loadings of this first analysis. This factor explained 73.7% of total variance.

### **Item reduction**

We refined the factors by excluding some items. Table 3 shows the items that we excluded with their reasons for exclusion. From the first factor, we successively excluded items 2, 10 and 4. After excluding these items Cronbach  $\alpha$  was still high (0.90) and, therefore, we excluded item 8 as well. Factor 1 finally consisted of items 1, 5, 7, 11, and 12. We did not exclude items from the second factor, because it included only three items (items 14, 15 and 16).

From the third factor, we successively excluded items 17, 19, 24, 30, 26, 21, and 29. After excluding these items Cronbach  $\alpha$  was still high (0.92) and, therefore, we excluded item 22 as well. Factor 3 finally consisted of items 18, 23, 27, and 28.

The final version of the NCQ can be found in Appendix B (English version) and Appendix C (Dutch version).

### **Reliability**

Table 4 shows the mean interitem correlations and Cronbach  $\alpha$  for the subscales after item reduction, as well as their means and SDs. Mean interitem correlation of the subscales varied between  $r = 0.58$  and  $r = 0.71$ . Internal consistency (Cronbach  $\alpha$ ) ranged from 0.82 to 0.89.

To assess the cohesiveness of the scale, correlations between the subscales were examined. The mean correlation between subscales ‘personal continuity: care provider knows me’ and ‘personal continuity: care provider shows commitment’ was  $r = 0.61$ . The mean correlation between subscales ‘personal continuity: care provider knows me’ and ‘team/cross-boundary continuity’ was  $r = 0.42$ . The mean

correlation between subscales ‘personal continuity: care provider shows commitment’ and ‘team/cross-boundary continuity’ was  $r = 0.49$ .

Because of the relatively high correlation between ‘personal continuity: care provider knows me’ and ‘personal continuity: care provider shows commitment’ we hypothesized that showing commitment is a cumulative quality of personal continuity. When care providers know their patients very well, they can either show or not show the cumulative quality commitment. However, care providers who do not know their patients very well, will probably not show commitment. In other words ‘knowing the patient well’ is a prerequisite for ‘showing commitment’. We found support for this hypothesis in our data. Of all patients who answered that their care provider knew them very well (mean score  $<4$ ), 59% answered that their care provider showed the cumulative quality commitment (mean score  $\geq 4$ ), whereas 41% of patients answered that their care provider did not show this cumulative quality well. Of the patients that answered that their care provider did not know them very well, 82% also answered that this care provider did not show the cumulative quality commitment well.

### **Construct validity**

The construct validity of the NCQ was partly supported by the results of the PCA. In accordance with the definition of continuity in the literature, both personal continuity and team/cross-boundary continuity were identified in our questionnaire. We did not find a differentiation between informational continuity and team/cross-boundary continuity. We found that personal continuity might be subclassified in ‘care provider knows me’ and ‘care provider shows commitment’.

Construct validity was further supported by the high internal consistency of the subscales. The moderate correlations between ‘personal continuity’ and ‘team/cross-boundary continuity’ provide evidence of good discriminant validity. The high correlation (0.61) between ‘personal continuity: care provider knows me’ and ‘personal continuity: care provider shows commitment’ was expected because they both measure aspects of personal continuity.

**Table 2. Item means, SDs, missing rates, floor effect and ceiling effect**

	Most important care provider ...									
	... In general practice (N=269)					... In hospital/ outpatient department (N=166)				
	Mean	SD	Mis- sing/? n (%)	Floor effect n (%)	Ceiling effect n (%)	Mean	SD	Mis- sing/? n (%)	Floor effect n (%)	Ceiling effect n (%)
1. I know this care provider very well	3.89	0.815	3 (1.1)	2 (1.2)	61 (22.7)	3.21	0.996	5 (3.0)	10 (6.0)	11 (6.6)
2. This care provider knows me very well	3.92	0.786	5 (1.9)	2 (1.2)	60 (22.3)	3.24	1.025	6 (3.6)	11 (6.6)	12 (7.2)
3. I have a lot of trust in this care provider	4.13	0.702	5 (1.9)	0 (0.0)	79 (29.4)	4.02	0.635	4 (2.4)	0 (0.0)	32 (19.3)
4. This care provider knows very well which care I receive more	3.97	0.823	19 (7.1)	2 (1.2)	63 (23.4)	3.38	0.960	16 (9.6)	5 (3.0)	14 (8.4)
5. This care provider knows my medical history very well	3.59	0.965	18 (6.7)	3 (1.8)	44 (16.4)	3.02	1.066	18 (10.8)	12 (7.2)	11 (6.6)
6. I always have to repeat my story when I see this care provider again	2.19	0.873	15 (5.6)	2 (1.2)	49 (18.2)	2.38	0.829	14 (8.4)	0 (0.0)	19 (11.4)
7. This care provider always knows very well what he/she did previously	3.51	0.917	17 (6.3)	3 (1.8)	32 (11.9)	3.26	0.937	19 (11.4)	5 (3.0)	8 (4.8)
8. This care provider remembers me very well when he/she sees me	4.10	0.790	17 (6.3)	3 (1.8)	75 (27.9)	3.41	1.032	14 (8.4)	9 (5.4)	14 (8.4)
9. I have a very good relationship with this care provider	3.80	0.861	13 (4.8)	1 (0.6)	59 (21.9)	3.26	0.963	7 (4.2)	9 (5.4)	12 (7.2)
10. This care provider knows my relevant medical data very well	3.56	0.919	23 (8.6)	3 (1.8)	37 (13.8)	3.15	0.975	19 (11.4)	8 (4.8)	9 (5.4)
11. This care provider knows my familial circumstances very well	3.32	1.057	19 (7.1)	10 (5.9)	34 (12.6)	2.48	0.929	21 (12.7)	18 (10.8)	2 (1.2)
12. This care provider knows my daily activities very well	3.12	1.001	27 (10.0)	10 (5.9)	20 (7.4)	2.46	0.941	17 (10.2)	20 (12.0)	3 (1.8)
13. This care provider has always forgotten what I told before	1.97	0.789	21 (7.8)	4 (2.4)	65 (24.2)	2.42	0.819	19 (11.4)	0 (0.0)	18 (10.8)

**Table 2. Continued**

	Most important care provider ...																	
	... In general practice (N=269)			... In hospital/ outpatient department (N=166)														
	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)						
14. This care provider contacts me if it is needed, I do not have to ask	3.16	1.109	31 (11.5)	18 (10.7)	26 (9.7)	3.04	1.133	25 (15.1)	7 (4.2)	15 (9.0)								
15. This care provider knows very well what I believe is important in my care	3.53	0.873	2.6 (9.7)	7 (4.1)	22 (8.2)	3.21	0.975	17 (10.2)	6 (3.6)	9 (5.4)								
16. This care provider keeps in contact sufficiently when I see other care providers	3.26	0.971	3.9 (14.5)	10 (5.9)	20 (7.4)	2.98	0.929	33 (19.9)	6 (3.6)	5 (3.0)								
Collaboration between care providers ...																		
	... Within general practice (N=154)						... Within hospital/ outpatient department (N=77)						... In general practice and hospital/ outpatient department (N=152)					
	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)	Mean	SD	Mis- sing/? n (%)	Floor- effect n (%)		
	17. These care providers communicate very well with each other	3.83	0.733	2.2 (14.3)	3 (1.9)	15 (9.7)	3.34	0.965	19 (24.7)	2 (2.6)	5 (6.5)	3.48	0.887	39 (25.7)	3 (2.0)	9 (5.9)		
18. These care providers transfer information very well to each other	3.83	0.763	2.2 (14.3)	2 (1.3)	21 (13.6)	3.37	0.927	18 (23.4)	1 (1.3)	4 (5.2)	3.63	0.805	30 (19.7)	1 (0.7)	10 (6.6)			
19. The care of these care providers is very well adapted to each other	3.80	0.751	2.4 (15.6)	3 (1.9)	15 (9.7)	3.28	0.978	20 (26.0)	1 (1.3)	5 (6.5)	3.50	0.821	37 (24.3)	1 (0.7)	9 (5.9)			
20. I often get contradictory information from these care providers	1.99	0.722	9 (5.8)	2 (1.3)	28 (18.2)	2.42	0.824	11 (14.3)	1 (1.3)	6 (7.8)	2.19	0.765	16 (10.5)	1 (0.7)	19 (12.5)			
21. The care between these care providers goes very smoothly	3.82	0.626	2.1 (13.6)	1 (0.6)	13 (8.4)	3.44	0.834	22 (28.6)	1 (1.3)	4 (5.2)	3.46	0.723	41 (27.0)	1 (0.7)	4 (2.6)			

**Table 2. Continued**

		Collaboration between care providers ...														
		... Within general practice (N=154)				... Within hospital/ outpatient department (N=77)				... In general practice and hospital/ outpatient department (N=152)						
		Mis-	Floor	Ceiling	Mis-	Floor	Ceiling	Mis-	Floor	Ceiling	Mis-	Floor	Ceiling			
		sing/?	effect	effect	sing/?	effect	effect	sing/?	effect	effect	sing/?	effect	effect			
		n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)			
		Mean	SD		Mean	SD		Mean	SD		Mean	SD				
22.	These care providers are very well informed of each other	3.78	0.719	31 (20.1)	2 (1.3)	14 (9.1)	3.28	0.878	23 (29.9)	0 (0.0)	3 (3.9)	3.39	0.893	43 (28.3)	2 (1.3)	6 (3.9)
23.	These care providers work together very well	3.80	0.668	21 (13.6)	1 (0.6)	15 (9.7)	3.47	0.823	24 (31.2)	0 (0.0)	4 (5.2)	3.39	0.835	37 (24.3)	2 (1.3)	5 (3.3)
24.	These care providers always agree about the care I receive	3.60	0.724	33 (21.4)	1 (0.6)	8 (5.2)	3.36	0.851	27 (35.1)	1 (1.3)	3 (3.9)	3.44	0.737	49 (32.2)	1 (0.7)	4 (2.6)
25.	I always have to tell my story again when I see the other care provider	2.64	0.988	13 (8.4)	2 (1.3)	16 (10.4)	2.77	0.941	11 (14.3)	2 (2.6)	4 (5.2)	2.70	0.971	20 (13.2)	4 (2.6)	9 (5.9)
26.	These care providers are very involved in each other's care	3.64	0.725	30 (19.5)	2 (1.3)	11 (7.1)	3.25	0.918	24 (31.2)	1 (1.3)	4 (5.2)	3.35	0.810	48 (31.6)	2 (1.3)	4 (2.6)
27.	The care of these care providers is very well connected	3.74	0.619	17 (11.0)	1 (0.6)	8 (5.2)	3.29	1.014	15 (19.5)	3 (3.9)	6 (7.8)	3.50	0.784	35 (23.0)	2 (1.3)	6 (3.9)
28.	These care providers always know very well from each other what they do	3.63	0.669	31 (20.1)	1 (0.6)	8 (5.2)	3.11	1.021	21 (27.3)	4 (5.2)	3 (3.9)	3.25	0.841	47 (30.9)	2 (1.3)	4 (2.6)
29.	These care providers know the results of each other's medical examination very well	3.67	0.653	26 (16.9)	1 (0.6)	8 (5.2)	3.20	1.122	23 (29.9)	4 (5.2)	5 (6.5)	3.45	0.808	42 (27.6)	2 (1.3)	5 (3.3)
30.	These care providers know very well who else is concerned in my care	3.55	0.764	33 (21.4)	1 (0.6)	10 (6.5)	3.04	1.098	23 (29.9)	6 (7.8)	3 (3.9)	3.22	0.872	45 (29.6)	3 (2.0)	4 (2.6)

Mean score (1 = strongly agree, 2 = agree, 3 = neutral, 4 = disagree, 5 = strongly disagree)  
 Floor effect: number (percentage) of respondents with the lowest score. Ceiling effect: number (percentage) of respondents with the highest score.  
 SD: standard deviation

Table 3. Factor loadings and excluded items with their reasons for exclusion

Type of continuity	Factor loadings			Excluded items	Reasons for exclusion
	Factor 1 Eigenvalue: 7.304	Factor 2 Eigenvalue: 1.130	Factor 3 Eigenvalue: 8.617		
<b>PCA on items 1, 2, 4, 5, 7, 8, 10, 11, 12, 14, 15, 16</b>					
<b>Personal continuity: care provider knows me</b>					
2. This care provider knows me very well ( <i>N</i> =424)	0.880			x	Highly correlated to item 1 (0.924) but more difficult to answer
1. I know this care provider very well ( <i>N</i> =427)	0.870				
5. This care provider knows my medical history very well ( <i>N</i> =399)	0.806				
11. This care provider knows my familial circumstances very well ( <i>N</i> =395)	0.746				
8. This care provider remembers me very well when he/she sees me ( <i>N</i> =404)	0.743			x	Relatively high ceiling effect and relatively low SD
4. This care provider knows very well which care I receive more ( <i>N</i> =400)	0.739			x	Relatively high ceiling effect and relatively low SD
10. This care provider knows my relevant medical data very well ( <i>N</i> =393)	0.726	0.427		x	High loading on two factors and relatively high missing rate
12. This care provider knows my daily activities very well ( <i>N</i> =391)	0.702				
7. This care provider always knows very well what he/she did previously ( <i>N</i> =399)	0.629				
<b>Personal continuity: care provider shows commitment</b>					
14. This care provider contacts me if it is needed, I do not have to ask ( <i>N</i> =379)			0.887		
16. This care provider keeps in contact sufficiently when I see other care providers ( <i>N</i> =363)			0.791		
15. This care provider knows very well what I believe is important in my care ( <i>N</i> =392)	0.495		0.705		
<b>PCA on items 17, 18, 19, 21, 22, 23, 24, 26, 27, 28, 29, 30</b>					
<b>Team and cross-boundary continuity</b>					
23. These care providers work together very well ( <i>N</i> =301)					0.901

Table 3. Continued

Type of continuity	Factor loadings			Excluded items	Reasons for exclusion
	Factor 1 Eigenvalue: 7.304	Factor 2 Eigenvalue: 1.130	Factor 3 Eigenvalue: 8.617		
22. These care providers are very well informed of each other ( $N=286$ )			0.884	x	Relatively high missing rate
19. The care of these care providers is very well adapted to each other ( $N=302$ )			0.880	x	Highly correlated to item 18 (0.808) but more difficult to answer
26. These care providers are very involved in each other's care ( $N=281$ )			0.876	x	Relatively high missing rate
17. These care providers communicate very well with each other ( $N=303$ )			0.867	x	Highly correlated to item 18 (0.860) but more difficult to answer
18. These care providers transfer information very well to each other ( $N=313$ )			0.850		
27. The care of these care providers is very well connected ( $N=316$ )			0.849		
29. These care providers know the results of each other's medical examination very well ( $N=292$ )			0.849	x	Content is comparable to item 19, but with higher missing rate and lower SD
28. These care providers always know very well from each other what they do ( $N=284$ )			0.848		
24. These care providers always agree about the care I receive ( $N=274$ )			0.819	x	Relatively low loading on factor, relatively low SD, relatively high missing rate
30. These care providers know very well who else is concerned in my care ( $N=282$ )			0.796	x	Decreases the interpretability of the factor, relatively high missing rate, relatively low loading on factor
21. The care between these care providers goes very smoothly ( $N=299$ )			0.739	x	Relatively low SD, relatively high missing rate, relatively low loading on factor

Values <0.40 are suppressed. Missing values were excluded pairwise.  
PCA: principal component analysis; SD: standard deviation

Table 4. Summary statistics of the subscales of the NCQ

	Personal continuity: Personal continuity: Team and			
	care provider knows me	care provider shows commitment	cross-boundary continuity	
Number of items	5	3	4	
<b>Mean interitem correlation (range)</b>				
Most important care provider in general practice	0.58 (0.17) (N = 233)	0.61 (0.16) (N = 219)	-	-
Most important care provider in hospital/outpatient department	0.58 (0.26) (N = 133)	0.66 (0.14) (N = 124)	-	-
Collaboration between care providers within general practice	-	-	0.67 (0.16) (N = 117)	-
Collaboration between care providers within hospital/outpatient department	-	-	0.71 (0.25) (N = 52)	-
Collaboration between general practice and hospital/outpatient department	-	-	0.67 (0.15) (N = 98)	-
<b>Cronbach <math>\alpha</math></b>				
Most important care provider in general practice	0.87	0.82	-	-
Most important care provider in hospital/outpatient department	0.87	0.85	-	-
Collaboration between care providers within general practice	-	-	0.89	-
Collaboration between care providers within hospital/outpatient department	-	-	0.89	-
Collaboration between general practice and hospital/outpatient department	-	-	0.89	-
<b>Potential range of scores</b>				
	1-5	1-5	1-5	1-5
<b>Mean of patient scores (SD)</b>				
Most important care provider in general practice	3.48 (0.77)	3.32 (0.82)	-	-
Most important care provider in hospital/outpatient department	2.90 (0.78)	3.12 (0.89)	-	-
Collaboration between care providers within general practice	-	-	3.76 (0.59)	-
Collaboration between care providers within hospital/outpatient department	-	-	3.37 (0.81)	-
Collaboration between general practice and hospital/outpatient department	-	-	3.47 (0.71)	-

Missing values were excluded listwise; NCQ: Nijmegen Continuity Questionnaire; SD: standard deviation

## Discussion

Initial testing of the NCQ shows that it is a comprehensive, reliable, and valid generic instrument to measure patients' experiences of continuity of care as a multidimensional concept across multiple care settings. To our knowledge, this is the first generic questionnaire that measures continuity of care as a multidimensional concept from the patient's perspective regardless of care setting and morbidity. The NCQ allows us to identify problems and evaluate interventions aimed at improving continuity of care. Moreover, it will enable us to compare continuity experiences for different diseases and multimorbidity patterns.

The NCQ subscales reflect recent definitions of continuity of care.<sup>11-13</sup> However, contrary to conceptual literature, patients did not differentiate between informational continuity and team/cross-boundary continuity. Haggerty et al. also found that these two dimensions are hard to differentiate for patients.<sup>23</sup> Face and content validity of the NCQ are supported by the involvement of patients and published literature in the development of the questionnaire. Readability, which was tested by interviewing patients and calculating the Flesch-Kincaid grade level, was good. The internal consistencies of the subscales and the interscale correlations provide evidence of a reliable and valid questionnaire with good discriminant abilities. The correlation between the subscales 'personal continuity: care provider knows me' and 'personal continuity: care provider shows commitment' was highest (0.61). We found support for the hypothesis that 'knowing the patient well' is a prerequisite for 'showing commitment'. Although this hypothesis is tested on the same data as it is based upon, we think that patients are able to differentiate between 'care provider knows me' and 'care provider shows commitment'. Maintaining both these subscales will enrich the questionnaire and enable us to better differentiate personal continuity.

Further testing of reliability (test-retest), responsiveness, and construct validity against external criteria, such as satisfaction and confidence in care provider, is needed before the NCQ can be more widely implemented.

The sample size and response rate of participants in this study were high, which strengthens our results and conclusions.

It is important to realize that this questionnaire measures continuity of care from the patient's perspective, which we believe it should be measured from.<sup>18</sup>

Information from health records is not used in this measure. This makes it even more important to further test the reliability (test-retest).

### **Item reduction**

Most patients perceived general practice or hospital/outpatient department as their most important site of care and their GP and specialist as their most important care provider at these sites. For future research, we decided, therefore, to reduce the items of the NCQ by focusing solely on the personal continuity provided by these care providers and on the team/cross-boundary continuity between these care providers (see Appendix B and C). This shortens the questionnaire without losing important data, which will improve patients' motivation to fill out the questionnaire.

### **Generalizability to other countries**

Our questionnaire is developed and tested in the Netherlands, a country where the GP has a gatekeeping role. This questionnaire is, therefore, easily applicable in other countries with the same care system, such as the United Kingdom. We think that our questionnaire is also useful in countries with a different care system. Possibly, the GP can be replaced by another care provider, which makes the questionnaire applicable to other care systems.

**5.1**

### **Limitations**

One of the limitations of this study is that we solely recruited patients from general practice. Because most patients also contacted the hospital/outpatient department in the last year, we assume that our results are also applicable to patients recruited via the hospital/outpatient department. Further study is however needed to confirm this. Another limitation is that we solely included patients with a chronic disease, which lowers generalizability. However, continuity of care seems to be most important for patients with a chronic disease, and we do not think that our main results will differ substantially for patients without a chronic disease.

A last limitation is that most GP trainees approached less than 25 patients each. We do not have data of patients who met the inclusion criteria but who were not approached by the GP trainees. This may have resulted in a slight bias in the recruitment of participants. However, it is unlikely that this has influenced the factors identified in the PCA nor would it result in main differences in initial testing of reliability and construct validity. It may yield differences in individual experiences of continuity of care, but we did not aim to describe this.

## **Conclusion**

This study provides initial evidence for the comprehensiveness, reliability, and validity of the NCQ as a generic questionnaire that measures continuity of care as a multidimensional concept from the patient's perspective across multiple care settings. Further testing of reliability (test-retest), construct validity, and responsiveness is needed before the NCQ can be more widely implemented.

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# 5.2

## **Measuring continuity of care: psychometric properties of the Nijmegen Continuity Questionnaire**

Annemarie A. Uijen  
Henk J. Schers  
François G. Schellevis  
Henk G.A. Mokkink  
Chris van Weel  
Wil J.H.M. van den Bosch

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## Abstract

**Background** Recently, the Nijmegen Continuity Questionnaire (NCQ) was developed. It aims to measure continuity of care from the patient perspective across primary and secondary care settings. Initial pilot testing proved promising. Aim: To further examine the validity, discriminative ability and reliability of the NCQ.

**Design** A prospective psychometric instrument validation study in primary and secondary care in the Netherlands.

**Method** The NCQ was administered to patients with a chronic disease recruited from general practice (n=145) and hospital outpatient departments (n=123) (response rate 76%). A principal component analysis was performed to confirm three subscales that had been found previously. Construct validity was tested by correlating the NCQ score to scores of other scales measuring quality of care, continuity, trust, and satisfaction. Discriminative ability was tested by investigating differences in continuity subscores of different subgroups. Test-retest reliability was analysed in 172 patients.

**Results** Principal factor analysis confirmed the previously found three continuity subscales - personal continuity: care provider knows me, personal continuity: care provider shows commitment, and team/cross-boundary continuity. Construct validity was demonstrated through expected correlations with other variables and discriminative ability through expected differences in continuity subscores of different subgroups. Test-retest reliability was high (the intraclass correlation coefficient varied between 0.71 and 0.82).

**Conclusion** This study provides evidence for the validity, discriminative ability, and reliability of the NCQ. The NCQ can be of value to identify problems in continuity of care.

## Introduction

**C**ontinuity of care is an important characteristic of good health care. It has a positive impact on the health of people and populations and reduces medical errors.<sup>1-4</sup> Continuity of care is, nowadays, considered a multidimensional concept.<sup>5-8</sup> It comprises providers' knowledge of the patient as a person, the development of an ongoing relationship (personal continuity), and communication and collaboration between care providers to connect care. For this last dimension, slightly different concepts of informational continuity, management continuity, or team/cross-boundary continuity are used in the literature, although they have proven difficult to differentiate for patients.<sup>9</sup>

Measuring continuity allows for the identification of problems and evaluation of interventions or changes in healthcare systems aimed at improving continuity of care. To explore and improve health care, it is especially important to measure continuity of care from the patients' perspective, particularly patients with multimorbidity.<sup>10</sup> Disease-specific instruments cannot be used for this purpose.

Recently, the Nijmegen Continuity Questionnaire (NCQ), a generic questionnaire that aims to measure patients' perceptions of personal, team and cross-boundary continuity, regardless of morbidity and care setting, was developed.<sup>11</sup> In a preliminary study, the NCQ proved to be promising for use with patients in primary care; however, further testing of reliability and validity is needed before it can be more widely implemented. The aim of this study, therefore, was to assess the psychometric properties (validity and reliability) of the NCQ.

5.2

## Method

### Participants and design

In the Netherlands, every patient is registered with a GP. The GP functions as a gatekeeper for secondary care, which is provided in a hospital/outpatient department.

In a previous pilot study, the NCQ was distributed among patients with a chronic disease recruited from general practice.<sup>11</sup> As the NCQ had been changed during the

pilot testing, and it was wanted to test it in both primary and secondary care, another sample of participants was used.

In January 2010, 19 GP trainees working in practices in the eastern part of the Netherlands were asked to distribute 20 NCQs each to patients with  $\geq 1$  chronic diseases. For these patients, continuity is particularly important. At the same time, six medical specialists (oncologist, internist, cardiologist, lung specialist, psychiatrist, and rheumatologist) working in an academic hospital in Nijmegen were asked to distribute 30 questionnaires each to patients in the polyclinic outpatients department.

Patients aged  $< 18$  years or those who were unable to speak or read Dutch were excluded. Patients filled in the NCQ at home and could send it back to the researchers. The GP trainees and specialists registered age, sex, and type of chronic disease(s) of participating patients; GP trainees completed some questions on the type of practice in which they worked.

Ethical approval for the study was granted by the ethics committee Arnhem-Nijmegen.

### **Measurement instruments**

The NCQ (Appendix B (English version) and Appendix C (Dutch version)) consists of 28 items within the following three subscales:

- personal continuity: care provider knows me (five items each for two different providers);
- personal continuity: care provider shows commitment (three items each for two different providers); and
- team/cross-boundary continuity (four items each for three different groups of providers).

Items were scored on a five-point Likert scale ranging from 1 (strongly disagree) to 5 (strongly agree), with an additional option to choose “?” (“I do not know”). Patients recruited by the specialist also filled in questions about their GP and vice versa.

As well as the NCQ, all patients were asked to complete the following:

- The ‘care suits patient’ subscale of the Consumer Quality Index General Practice Care questionnaire<sup>12</sup>: The questionnaire measures patients’ experiences with general practice care and the subscale measures whether that care suits the patient, corresponding to their experiences with continuity. The subscale consists of nine items, which are scored on a four-point scale ranging from ‘never’ to ‘always’ (Appendix D). The option ‘not applicable’ was available for some items. The Consumer Quality Index has shown to be a valid and reliable instrument for measuring the quality of general practice; the higher the score, the better the primary care experience.
- The Continuity of Care from the Client Perspective (VCC) questionnaire<sup>13</sup>: This Dutch questionnaire was developed in 1998 to measure continuity of care from the perspective of patients with a chronic disease living at home. The questionnaire comprises items concerning patients’ experiences with their GP, medical specialist, physiotherapist, occupational therapist, dietitian, speech therapist, podiatrist, and home care. Patients were asked to answer only the questions concerning their GP (13 items) and their medical specialist (14 items) (Appendix E). Items are scored on a five-point scale, with an additional option of ‘not applicable’. Initial testing has shown that this questionnaire is a valid instrument with medium reliability.
- Two questions on satisfaction (‘I am satisfied with the care I receive from my GP/specialist’).
- Two questions about trust (‘I have trust in my GP/specialist’).

## Validity

The following hypotheses were generated to assess construct validity:

1. Principal component analysis would confirm the previously found three continuity subscales<sup>11</sup> - personal continuity: care provider knows me, personal continuity: care provider shows commitment, and team/cross-boundary continuity.
2. Higher scores on the three subscales about general practice (personal continuity: GP knows me, personal continuity: GP shows commitment,

team/cross-boundary continuity between care providers within general practice) would be highly positively associated with scores on the Consumer Quality Index subscale ‘care suits patient’, the VCC subscale general practice, and GP trust and satisfaction scores.

3. Scores on the three subscales about hospital/outpatient department care (personal continuity: specialist knows me, personal continuity: specialist shows commitment, team/cross-boundary continuity between care providers within hospital/outpatient department) would be highly positively associated with scores on the VCC subscale specialist care and specialist trust and satisfaction scores.
4. Scores on the team/cross-boundary continuity between GP and specialist subscale would be at least moderately positively associated with scores on the Consumer Quality Index care suits patient subscale, the VCC subscales, and GP and specialist trust and satisfaction scores.

### **Discriminative ability**

The discriminative ability was tested by examining differences in the NCQ subscores for different subgroups. The following hypotheses were generated:

1. Patients recruited from general practice would experience greater continuity in general practice than in hospital/outpatient departments, whereas patients recruited from hospital/outpatient departments would experience greater continuity in hospital/outpatient department. It was expected that, in general, patients recruited from general practice would contact the hospital/outpatient department less frequently than patients recruited from hospital/outpatient department and vice versa. Contacting a department infrequently was likely to diminish the levels of continuity experienced by the patient.
2. Patients who were psychiatrically ill would experience less continuity than those who were somatically ill, for example, those with diabetes mellitus. This hypothesis is powered from the literature.<sup>1;14;15</sup>
3. Patients registered in a general practice in a small town ( $\leq 40,000$  inhabitants) would experience more continuity in general practice than patients registered in a general practice in a large town. Patients from a

small town are often found to be healthier than their counterparts in larger towns<sup>16</sup>, thereby probably seeing fewer care providers, and tending to move less often to another general practice<sup>17</sup>, which increases experienced continuity of care.

4. Patients who contacted one provider in the previous year would experience more personal continuity - be that in general practice or in hospital/outpatient departments - than patients who contacted >1 provider.

## Reliability

Test-retest reliability was assessed by having participants complete the NCQ a second time, two weeks after their initial completion. No intervention took place in these two weeks. In the first questionnaire, participants were asked whether they were willing to fill in one more questionnaire after two weeks; if so, they had to write down their address so the retest could be sent by mail. No reminder was sent when participants did not respond.

## Analyses

SPSS (version 16.0) was used to analyse the data. Item means, total subscale scores, and the percentage responders with the highest and lowest subscale scores (ceiling and floor effect) were assessed. The subscale scores were calculated as the mean of the items in each subscale. To calculate this score, cases that were missing more than one question within a subscale were excluded.

Confirmatory principal component analysis with varimax rotation was used to verify the three continuity subscales that had been found previously.<sup>11</sup> Principal component analysis was performed on the eight items about the patient-provider relationship across the multiple care settings and per care setting separately. In the first analysis, several observations from one patient are included (observations from the provider in general practice and in hospital/outpatient departments); in the second analysis, the observations are all independent. Principal component analysis was also performed on the four items regarding the collaboration and information exchange between the groups of providers across the multiple care settings and per care setting separately.

Validity was determined by examining the correlations between the total scores for all scales using Pearson's product moment correlations. A moderate correlation was considered to be 0.3 to <0.5 and a high correlation was defined as  $\geq 0.5$ .<sup>18;19</sup> To calculate the total score for each scale, cases were excluded if more than one question within each scale was missing.

Independent student t-tests were conducted to determine the discriminative ability. To determine test-retest reliability, the intraclass correlation coefficient (ICC, two-way random effects model, absolute agreement) for the subscale scores was calculated. Reliability was assessed as good with an ICC of  $\geq 0.70$ .<sup>20</sup> Furthermore, the consistency of measurements was verified using the method described by Bland and Altman.<sup>21</sup> The mean difference between the two measurements and the 95% limits of agreement (mean  $\pm 1.96$  standard deviation of difference) were calculated for each subscale score. The consistency of measurement according to a Bland-Altman plot for one subscale was visualised.

## Results

In total, 14 GP trainees and six specialists participated; respectively they asked 192 and 162 patients to fill in the questionnaires, of which 145 (76%) and 123 (76%) respectively were returned. In total, 268 patients participated.

### Patient characteristics

Table 1 shows patients' characteristics and their medical care. Responders and non-responders did not differ in age ( $p=0.34$ ). Responders were more likely than non-responders to be male ( $p=0.006$ ).

### Item and subscale analyses

Table 2 shows item means, total subscale scores, the percentage of patients with the highest and lowest subscale scores, and Cronbach's alpha for the subscales. The

**Table 1. Characteristics and medical care of responders and non-responders**

<b>Patient characteristics</b>	<b>Recruited by GP (N=145), n (%)</b>	<b>Recruited by specialist (N=123), n (%)</b>	<b>Non-responders (N=86), n (%)</b>
<b>Age (mean)</b>	66.0	57.7	56.4
<50	13 (9)	31 (25)	25 (29)
50-59	21 (15)	32 (26)	18 (21)
60-69	54 (37)	36 (29)	16 (19)
70-79	40 (28)	20 (16)	17 (20)
≥80	17 (12)	4 (3)	2 (2)
missing	0 (0)	0 (0)	8 (9)
<b>Male sex</b>	67 (46)	63 (51)	25 (32)
<b>Ethnicity</b>			
Dutch	137 (95)	114 (93)	
Other	8 (6)	9 (7)	
<b>Assessment of patients' own health status (5-point scale)</b>			
(Very) good	80 (55)	31 (25)	
Neutral	52 (36)	59 (48)	
(Very) bad	12 (8)	30 (24)	
missing	1 (1)	3 (2)	
<b>Medical care</b>			
<b>Number of chronic diseases according to patient (mean ± SD)</b>			
	1.87 ± 1.03	2.13 ± 1.20	
<b>Type of chronic diseases</b>			
Diabetes Mellitus	52 (36)	25 (20)	
Asthma / chronic obstructive pulmonary disease	28 (19)	20 (16)	
Myocardial infarction	15 (10)	24 (20)	
Cerebrovascular accident / transient ischemic attack	7 (5)	6 (5)	
Hypertension	91 (63)	38 (31)	
Mental disorder	5 (3)	21 (17)	
Malignancy	11 (8)	26 (21)	
Disorder of muscles, bones or joints	31 (21)	40 (33)	
Other	23 (16)	44 (36)	
<b>Number of care providers in last year (mean)</b>			
GPs	1.2	1.1	
Medical specialists	1.1	2.1	
Other*	1.3	1.5	
Total	3.6	4.7	

**Table 1. Continued**

<b>Medical care</b>	<b>Recruited by GP (N=145), n (%)</b>	<b>Recruited by specialist (N=123), n (%)</b>	<b>Non- responders (N=86), n (%)</b>
<b>Total number of contacts in the last year in general practice</b>			
0 times	0 (0)	14 (11)	
1 time	7 (5)	18 (15)	
2 times	12 (8)	23 (19)	
3-5 times	67 (46)	30 (24)	
>5 times	53 (37)	34 (28)	
Missing	6 (4)	4 (3)	
<b>Total number of contacts in the last year in hospital/outpatient department</b>			
0 times	51 (35)	0 (0)	
1 time	21 (15)	4 (3)	
2 times	20 (14)	14 (11)	
3-5 times	25 (17)	42 (34)	
>5 times	24 (17)	61 (50)	
Missing	4 (3)	2 (2)	

*Values are in n (%) unless otherwise indicated*

*\* Mainly nurse practitioners, physician assistants, physiotherapist, occupational therapist, psychologists, social worker, home care, and alternative healer*

percentage of patients with the highest or lowest subscale score was low (<7.5%), so the NCQ does not show a ceiling or floor effect.

Internal consistency (Cronbach's alpha) ranged from 0.86 to 0.96.

Principal component analysis confirmed the three factors that were found in a previous study (hypothesis one, construct validity);<sup>11</sup> it was performed on the eight items about the GP and most important medical specialist together and for each care setting separately. Table 3 shows the factor loadings of this first analysis. It resulted in the same two factors as the last analysis - personal continuity: care provider knows me; personal continuity: care provider shows commitment - explaining 73.8% of the overall variance. A principal component analysis was also performed on the four items about collaboration between the groups of providers across the multiple care settings and per care setting separately. This resulted in the same single factor (team/cross-boundary continuity), explaining 88.8% of total variance.

Table 2. Item means and total subscale score

	GP		Most important medical specialist	
	Mean		Mean	
<b>Subscale 1. Personal continuity: Care provider knows me</b>				
1. I know this care provider very well	3.85 (N=249)		3.80 (N=202)	
2. This care provider knows my medical history very well	4.00 (N=247)		3.97 (N=198)	
3. This care provider always remembers what he/she did during my last visit(s)	3.90 (N=240)		4.02 (N=200)	
4. This care provider knows my family circumstances very well	3.69 (N=246)		3.12 (N=195)	
5. This care provider knows very well what I do in my day-to-day life	3.28 (N=246)		3.22 (N=196)	
T total subscale score	3.74 (N=245)		3.63 (N=198)	
Patients with highest subscale score (ceiling effect), <i>n</i> (%)	19 (7.1)		11 (4.1)	
Patients with lowest subscale score (floor effect), <i>n</i> (%)	0 (0)		2 (0.7)	
Internal consistency (Cronbach alpha)	0.89		0.89	
T test-retest: Intraclass correlation coefficient (95% CI)	0.82 (0.76 to 0.87)		0.81 (0.75 to 0.87)	
	(N=150)		(N=123)	
T test-retest: Mean difference between measurements (95% limits of agreement)	0.07 (-0.82 to 0.97)		-0.02 (-0.90 to 0.86)	
	(N=150)		(N=123)	
<b>Subscale 2. Personal continuity: Care provider shows commitment</b>				
1. This care provider contacts me when necessary without me having to ask him/her to do so	3.08 (N=236)		3.27 (N=184)	
2. This care provider knows very well what I think is important when it comes to my care	3.50 (N=236)		3.60 (N=192)	
3. This care provider maintains enough contact with me when I am seen by other care providers	3.14 (N=228)		3.38 (N=178)	
T total subscale score	3.23 (N=238)		3.41 (N=188)	
Patients with highest subscale score (ceiling effect), <i>n</i> (%)	18 (6.7)		18 (6.7)	
Patients with lowest subscale score (floor effect), <i>n</i> (%)	11 (4.1)		7 (2.6)	
Internal consistency (Cronbach alpha)	0.86		0.90	
T test-retest: Intraclass correlation coefficient (95% CI)	0.79 (0.72 to 0.85)		0.80 (0.72 to 0.86)	
	(N=145)		(N=117)	

Table 2. Continued

	GP Mean	Most important medical specialist Mean
<b>Subscale 2. Personal continuity: Care provider shows commitment</b>		
Test-retest: Mean difference between measurements (95% limits of agreement)	(-1.31 to 1.23) (N=145)	-0.10 (-1.27 to 1.06) (N=117)
<b>Collaboration between care providers ...</b>		
	... within general practice Mean	... within hospital/ outpatient department Mean
		... in general practice and hospital/outpatient department Mean
<b>Subscale 3. Team/cross-boundary continuity</b>		
1. These care providers pass on information to each other very well	3.83 (N=154)	3.71 (N=142)
2. These care providers work together very well	3.87 (N=152)	3.68 (N=141)
3. The care given by these care providers is well-connected	3.83 (N=151)	3.68 (N=140)
4. These care providers always know very well what the other care providers have done	3.67 (N=144)	3.50 (N=139)
Total subscale score	3.80 (N=148)	3.65 (N=141)
Patients with highest subscale score (ceiling effect), n (%)	19 (7.1)	17 (6.3)
Patients with lowest subscale score (floor effect), n (%)	0 (0)	5 (1.9)
Internal consistency (Cronbach alpha)	0.96	0.96
Test-retest: Intraclass correlation coefficient (95% CI)	0.71 (0.58 to 0.81) (N=77)	0.71 (0.58 to 0.80) (N=81)
Test-retest: Mean difference between measurements (95% limits of agreement)	0.11 (-1.02 to 1.24) (N=77)	0.09 (-1.30 to 1.48) (N=81)

Mean score (1=strongly disagree, 2=disagree, 3=neutral, 4=agree, 5=strongly agree)

Table 3. Results of confirmatory principal component analysis

	Factor loadings		
	Factor 1 Eigenvalue: 5.207	Factor 2 Eigenvalue: 0.695	Factor 3 Eigenvalue: 3.552
<b>Type of continuity</b>			
<b>Principal component analysis on items about patient-provider relationship</b>			
<b>Personal continuity: care provider knows me</b>			
1. I know this care provider very well (N=443)	0.808		
2. This care provider knows my medical history very well (N=437)	0.799		
4. This care provider knows my family circumstances very well (N=432)	0.799		
3. This care provider always remembers what he/she did during my last visit(s) (N=432)	0.638	0.441	
5. This care provider knows very well what I do in my day-to-day life (N=433)	0.629	0.533	
<b>Personal continuity: care provider shows commitment</b>			
1. This care provider contacts me when necessary without me having to ask him/her to do so (N=411)			0.857
3. This care provider maintains enough contact with me when I am seen by other care providers (N=397)			0.840
2. This care provider knows very well what I think is important when it comes to my care (N=419)	0.488		0.723
<b>Principal component analysis on items about the collaboration and information exchange between care providers</b>			
<b>Team and cross-boundary continuity</b>			
2. These care providers work together very well (N=361)			0.959
3. The care given by these care providers is well-connected (N=360)			0.947
1. These care providers pass on information to each other very well (N=373)			0.933
4. These care providers always know very well what the other care providers have done (N=353)			0.930
<i>Values &lt;0.40 are suppressed. Missing values were excluded pairwise</i>			

Table 4. Correlations among factors and patient variables

	Personal continuity			Team/cross-boundary continuity		
	GP knows me	GP shows commitment	Specialist shows commitment	Between care providers within general practice	Between care providers within hospital	Between GP and specialist
<b>Personal continuity</b>						
GP shows commitment	0.76** (N=234)	-	-	-	-	-
Specialist knows me	0.28** (N=185)	0.26** (N=183)	-	-	-	-
Specialist shows commitment	0.24** (N=175)	0.29** (N=177)	0.80** (N=185)	-	-	-
<b>Team/cross-boundary continuity</b>						
Between care providers within general practice	0.55** (N=141)	0.63** (N=136)	-0.03 (N=106)	-0.05 (N=104)	-	-
Between care providers within hospital / outpatient department	0.18* (N=131)	0.12 (N=131)	0.46** (N=134)	0.46** (N=131)	0.19 (N=79)	-
Between GP and specialist	0.39** (N=145)	0.48** (N=142)	0.39** (N=140)	0.39** (N=133)	0.54** (N=91)	0.51** (N=115)
Care suits patient subscale of the Consumer Quality index General Practice Care questionnaire	0.57** (N=147)	0.75** (N=146)	0.06 (N=124)	0.07 (N=119)	<b>0.68**</b> (N=94)	0.06 (N=94)
VCC GP	0.61** (N=49)	0.61** (N=48)	0.06 (N=45)	0.11 (N=45)	<b>0.58**</b> (N=37)	0.39* (N=38)
VCC Specialist	0.35* (N=40)	0.14 (N=41)	<b>0.56**</b> (N=40)	<b>0.63**</b> (N=40)	0.17 (N=25)	<b>0.73**</b> (N=36)
						0.47** (N=103)
						0.56** (N=43)
						0.65** (N=34)

Table 4. Continued

	Personal continuity			Team/cross-boundary continuity		
	GP knows me	GP shows commitment	Specialist shows commitment	Between care providers within general practice	Between care providers within hospital	Between GP and specialist
Trust in GP	<b>0.63**</b> (N=242)	<b>0.64**</b> (N=235)	0.05 (N=192)	<b>0.59**</b> (N=146)	0.02 (N=137)	<b>0.30**</b> (N=147)
Trust in specialist	0.18** (N=197)	0.16** (N=195)	<b>0.56**</b> (N=187)	0.09 (N=110)	<b>0.46**</b> (N=140)	0.27** (N=145)
Satisfaction from care of GP	<b>0.63**</b> (N=242)	<b>0.67**</b> (N=235)	0.04 (N=192)	<b>0.63**</b> (N=146)	0.03 (N=137)	0.38** (N=147)
Satisfaction from care of specialist	0.17* (N=195)	0.14 (N=193)	<b>0.54**</b> (N=185)	0.10 (N=108)	<b>0.48**</b> (N=139)	<b>0.33**</b> (N=144)

\*  $p < 0.05$ ; \*\*  $p < 0.01$ ; GP: General practitioner; VCC: Continuity of care from the Client Perspective questionnaire

High correlation ( $\geq 0.5$ ) expected

At least moderate correlation ( $> 0.3$ ) expected

Table 5. Continuity subscores of different subgroups

	Personal continuity			Team/cross-boundary continuity		
	GP knows me	GP shows commitment	Specialist knows me	Specialist shows commitment	Between care providers within general practice	Between care providers within hospital and specialist
Patients recruited from general practice	3.86 (0.70) (N=135)	3.45 (0.87) (N=128)	3.31 (0.82) (N=75)	2.96 (1.04) (N=92)	4.03 (0.64) (N=81)	3.61 (0.98) (N=46)
Patients recruited from hospital / outpatient department	3.59** (0.78) (N=110)	2.97** (1.07) (N=110)	3.85** (0.64) (N=117)	3.71** (0.84) (N=113)	3.44** (0.82) (N=56)	3.20 (0.92) (N=90)
Patients with a psychiatric disease	3.41 (0.78) (N=26)	2.72 (1.03) (N=26)	3.63 (0.81) (N=23)	3.29 (1.04) (N=21)	3.60 (0.73) (N=12)	3.40 (1.12) (N=17)
Patients with diabetes mellitus	3.77* (0.74) (N=214)	3.29** (0.97) (N=208)	3.62 (0.76) (N=171)	3.43 (0.99) (N=163)	3.83 (0.78) (N=133)	3.29 (0.91) (N=129)
Patients registered in a general practice in a town ≤ 40.000 inhabitants	3.81 (0.72) (N=183)	3.31 (1.00) (N=175)	3.54 (0.79) (N=143)	3.33 (1.02) (N=132)	3.89 (0.74) (N=115)	3.61 (0.98) (N=99)
Patients registered in a general practice in a town > 40.000 inhabitants	3.54* (0.79) (N=61)	2.97* (0.93) (N=62)	3.86** (0.64) (N=54)	3.58 (0.90) (N=55)	3.53* (0.80) (N=32)	3.78 (0.93) (N=41)
Patients who saw 1 care provider in the last year	4.18 (0.76) (N=12)	3.85 (0.66) (N=10)	3.55 (0.07) (N=2)	3.33 (0.00) (N=2)	-	-
Patients who saw >1 care provider in the last year	3.72* (0.74) (N=230)	3.20* (1.00) (N=225)	3.64 (0.77) (N=192)	3.42 (1.00) (N=182)	3.74 (0.76) (N=134)	3.66 (0.99) (N=136)

Data are shown as mean (SD); \* $p < 0.05$ ; \*\* $p < 0.01$ ; SD: standard deviation

### Construct validity

Table 4 shows the correlations between the NCQ and patient variables. As in hypothesis two, high correlations were found between the three subscales on general practice and the care suits patient subscale of the Consumer Quality Index ( $r=0.57-0.75$ ,  $p<0.01$ ), the general practice subscale of the VCC questionnaire ( $r=0.58-0.61$ ,  $p<0.01$ ) and GP trust ( $r=0.59-0.64$ ,  $p<0.01$ ) and satisfaction ( $r=0.63-0.67$ ,  $p<0.01$ ) scores.

High correlations were also found between the three subscales on hospital/outpatient department care and the specialist care subscale of the VCC questionnaire ( $r=0.56-0.73$ ,  $p<0.01$ , hypothesis three). Two subscales (personal continuity: specialist knows me; personal continuity: specialist shows commitment) were highly correlated to specialist trust ( $r=0.56-0.59$ ,  $p<0.01$ ) and satisfaction ( $r=0.54-0.59$ ,  $p<0.01$ ) scores, whereas one subscale (team/cross-boundary continuity between care providers within hospital/outpatient departments) was moderately correlated to specialist trust ( $r=0.46$ ,  $p<0.01$ ) and satisfaction ( $r=0.48$ ,  $p<0.01$ ) scores (hypothesis three).

The team/cross-boundary continuity between GP and specialist subscale was at least moderately associated with the care suits patient subscale of the Consumer Quality Index ( $r=0.47$ ,  $p<0.01$ ), VCC subscales ( $r=0.56-0.65$ ,  $p<0.01$ ), GP trust ( $r=0.30$ ,  $p<0.01$ ), GP satisfaction ( $r=0.38$ ,  $p<0.01$ ), and specialist satisfaction ( $r=0.33$ ,  $p<0.01$ ) scores. It was weakly correlated with specialist trust scores ( $r=0.27$ ,  $p<0.01$ ) (hypothesis four).

### Discriminative ability

Table 5 shows the continuity subscores of different subgroups. As outlined in hypothesis one, patients recruited from general practice experienced significantly more personal and team continuity in general practice, whereas patients recruited from hospital/outpatient departments experienced more personal continuity in hospital/outpatient departments. The score of team continuity in hospital/outpatient departments did not differ between these subgroups.

In agreement with the second hypothesis, patients who were psychiatrically ill experienced significantly less personal continuity from their GP than those with diabetes. No difference was found in other continuity subscores.

As suggested in hypothesis three, patients registered in a general practice in a small town experienced more personal and team continuity in general practice than patients registered in a general practice in a larger town.

Patients who saw one provider in the previous year experienced more personal continuity in general practice than patients who saw more providers (hypothesis four). No differences in personal continuity in hospital/outpatient departments were found (hypothesis four).

### **Reliability**

In total, 184 patients (69%) agreed to fill in a repeat questionnaire, of whom 172 (93%) returned the retest. Patients who agreed to participate did not differ from those who did not agree in terms of age ( $p=0.87$ ), sex ( $p=0.47$ ), number of chronic diseases ( $p=0.76$ ), and NCQ subscale scores (0.18 to 0.96).

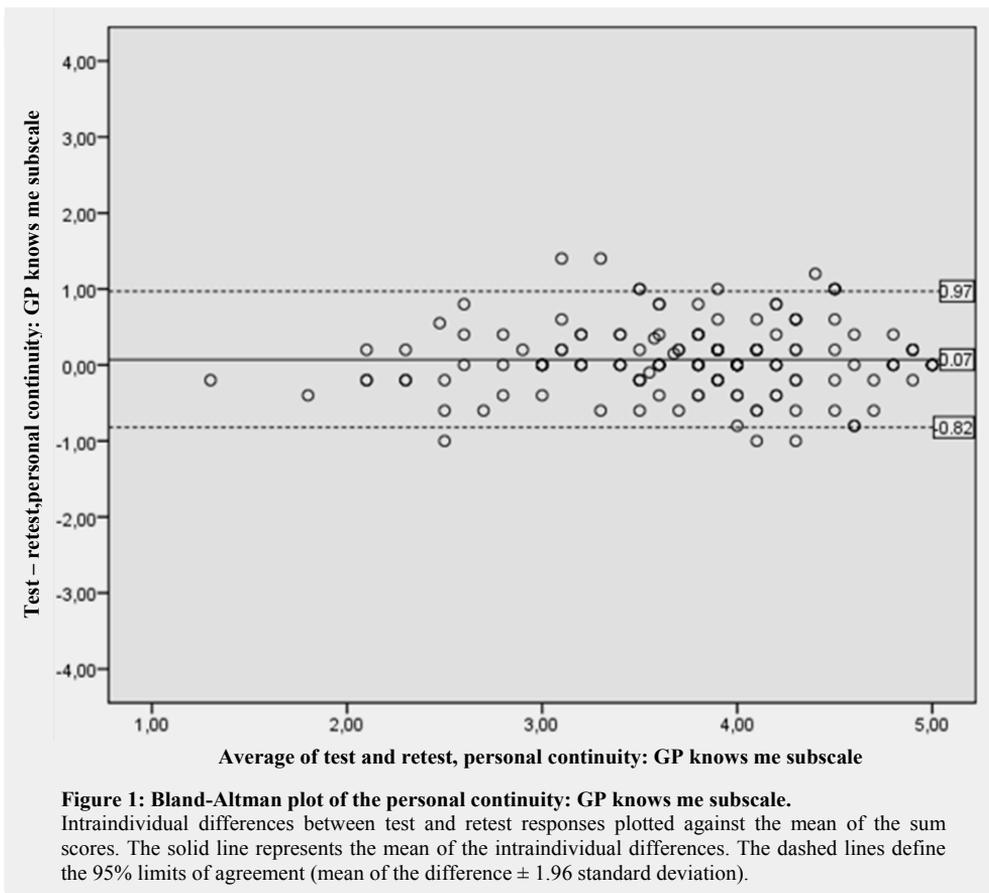
Table 2 shows the ICC per subscale for each provider or group of providers; ICCs varied between 0.71 and 0.82. Table 2 also shows the mean difference between the two measurements and the limits of agreement for each subscale. The mean difference between the two measurements varied between -0.10 and 0.11. The limits of agreement are smallest for the personal continuity: care provider knows me subscale. Figure 1 shows the Bland-Altman plot of the personal continuity: GP knows me subscale. It visually shows the mean difference between test and retest (0.07) with its 95% limits of agreement (-0.82 to 0.97) plotted against the mean of the sum scores.

## **Discussion**

### **Summary**

This study provides evidence for the validity, discriminative ability, and reliability of the NCQ as a generic questionnaire that measures patients' experiences of continuity of care as a multidimensional concept, regardless of care setting and morbidity.

Building on previous research<sup>11</sup>, this study provides further evidence of its construct validity through the results of the confirmatory principal component analysis and the hypothesised correlations found between the NCQ and other scales measuring quality of care, continuity of care, trust, and satisfaction. Evidence for the discriminative ability of the NCQ is provided by (hypothesised) differences in continuity subscores of different subgroups. The reliability is further supported with the results of the test-retest and the internal consistencies of the subscales.



### **Strengths and limitations**

One limitation is that only patients with a chronic disease were included, which reduces generalisability of the tool. However, patients with  $\geq 1$  chronic disease were purposively selected as, for these patients, continuity is particularly important.<sup>22-24</sup>

Another limitation is the possible recruitment bias. Providers could decide for themselves which patients to ask to participate. GP trainees, more than medical specialists, approached fewer patients than requested. Data of patients that met the inclusion criteria, but were not approached by their provider, were not available.

A last limitation is the finding that, as hypothesised, patients experienced more continuity over the place of recruitment. This may also reflect the likeliness to express satisfaction with the care organisation in which participants are given the questionnaire. The study tried to reduce this potential bias by asking patients to fill in the NCQ at home and send it back to the researchers.

A Cronbach's alpha of  $>0.90$  was found on the team/cross-boundary subscale, which can imply item redundancy. However, this subscale includes only four items, so was not necessary to shorten the questionnaire.

The NCQ does not show a floor or ceiling effect, so it could perhaps be capable of showing changes in continuity scores over time (responsiveness). This will need further testing.

A strength of this study is that patients from both primary and secondary care were included. The sample size and response rate of participants were high, which strengthens the results and conclusion of this study.

### **Comparison with existing literature**

In a previous study, the NCQ proved to be promising for use with patients in primary care.<sup>11</sup> In this preliminary study, the internal consistencies of the subscales and the interscale correlations also provided evidence of a reliable and valid questionnaire with good discriminant abilities.

### **Implications for practice**

Nowadays, an increasing number of providers are involved in the care of patients, especially patients with a chronic disease; this can threaten the continuity of patients' care. The NCQ is able to identify problems and could evaluate interventions or changes in healthcare systems aimed at improving continuity of care. This will be an important area for further research, given that poor continuity is suspected to have a negative impact on the health of people and populations and also increases medical errors.<sup>1-4</sup> Moreover, the NCQ can be used to compare continuity experiences for different diseases and multimorbidity patterns.

### **Generalisability to other countries**

The questionnaire was developed and tested in the Netherlands, a country where the GP is a gatekeeper. It is likely that it is easily applicable in other countries that have the same care system, such as the UK. In countries with a different care system, the GP could perhaps be replaced by another provider, which could make the questionnaire applicable to other care systems. More research is needed regarding the generalisability of the tool to other countries.

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# 5.3

## **Continuity of care preferably measured from the patients' perspective**

Annemarie A. Uijen  
Henk J. Schers  
Chris van Weel

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Continuity of care is an important characteristic of good health care. There is evidence that continuity has a positive impact on the health of people and populations and reduces medical errors.<sup>1-4</sup> However, there are grave concerns of fading continuity. Continuity is particularly at risk when multimorbidity exists which prevalence is still rising<sup>5;6</sup>, or when patients are referred from one healthcare setting to another. The study by van Walraven et al.<sup>7</sup> published in this issue of the *Journal of Clinical Epidemiology* shows in detail what happens to the continuity of care over time in patients discharged from hospital. It is an interesting study because it simultaneously measures provider and information continuity during this transition. A large group of patients were followed over time, and for each physician visit after discharge, both provider and information continuity were measured. Their approach is very useful to gain insight in the movements of patients through the health care system. Simultaneously, it is important to realize that their approach to continuity is only one part of the story. Continuity of care is a complicated concept, and besides relational and information continuity, management continuity is an important aspect (Box 1).<sup>8</sup> Continuity of care acquires its meaning within the context of different providers caring for one patient and within the framework of patients' expectations and priorities. Measuring provider continuity with the Usual Provider of Continuity (UPC) Index, as the authors did, has many restrictions.<sup>9</sup> It only measures the proportion of visits that patients see the same care provider. However, discharged patients will often contact more than one care provider, and the involvement of different care providers will often be in the interest of patients with complex health problems. High provider continuity measures might therefore sometimes reflect low quality of care. Moreover, nowadays many patients have more than one preferred care provider.<sup>10</sup> When transitions in care occur, communication and collaboration between care providers (management and information continuity) are more important than provider continuity. An interesting aspect of the study of van Walraven et al. was that they measured the level of information transfer between the different care providers – in their method as the proportion of visits having the hospital discharge summary or information from previous physician visits. This is at the core of continuity of care, as different interventions, directed at different health problems, at different moments in time, by different providers, should integrate to serve patients' lasting health status. It is a worrying, although not

<b>Box 1. Dimensions of continuity of care</b>
<b>Relational continuity</b>
Providers develop an ongoing relationship with patients. The provider has knowledge of the patient as a person
<b>Information continuity</b>
Care provider uses information on past events to deliver care that is appropriate to the patient's current circumstance
<b>Management continuity</b>
Care providers connect their care in a coherent way

unexpected finding of the study that only in a minority of visits, the information of interest was available.

For several reasons, we believe that research on continuity of care would benefit from a much stronger focus on the patients' perspective. First, measuring continuity from the patients' perspective will allow us to take into account patients' perceived needs. In a recent study, we found that patients' need for contact with their family physician (FP) when in hospital depended highly on their reason for admission.<sup>11</sup> Only a minority of patients who were admitted for minor health problems did express a need to stay in contact with their FP, whereas most patients admitted for a serious condition, such as a malignancy, wanted such contact. Many patients, moreover, preferred only follow-up by telephone. Second, knowing the care provider well is more important than seeing the same care provider. Higher levels of such relational continuity are related to more trust in care providers<sup>12;13</sup>, which in turn is related to higher quality of care.<sup>14</sup> Nowadays, where care providers in many countries work increasingly part time, many patients will perceive to have more than one trusted care provider. Relational continuity from the patients' perspective, therefore, is a more suitable indicator for continuity than mathematical indices, such as the UPC. Third, patients' experienced continuity of care will largely depend on their notice of communication and collaboration between care providers (e.g., how well is the care connected?).

Studies on continuity of care will be strengthened when measuring patients' experienced continuity of care as a multidimensional concept (Box 1). However, at this moment research is hampered by the fact that existing measurement instruments either only measure the personal aspect of continuity of care<sup>9</sup>, not

taking into account the importance of communication and collaboration between care providers, or focus on only one disease<sup>15-18</sup>, not taking into account the fact that continuity is particularly important in situations where multimorbidity exists. Patients consult their care provider(s), particularly their FP(s), for more than one disease. The development of a generic measurement instrument that brings together the various dimensions of continuity (Box 1) is a priority for research to explore and improve health care. The bottom line should be that continuity is not an aim in itself but one of the critical determinants of health care that matters to people.

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# 5.4

## **Which questionnaire to use when measuring continuity of care**

Annemarie A. Uijen  
Henk J. Schers

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The Nijmegen Continuity Questionnaire (NCQ) measures patients' experienced personal, team and cross-boundary continuity of care regardless of morbidity and across multiple care settings.<sup>1</sup> We agree with Aller et al<sup>2</sup> that existing measurement instruments should be taken into account when developing a new instrument. That is why we performed a systematic literature review to assess all existing instruments measuring continuity of care or related concepts, such as coordination or integration of care. This resulted in 82 identified instruments measuring items about continuity of care. We used these items to develop the NCQ.<sup>1</sup>

We regret that we did not identify the Continuity of Care Across Care Levels Questionnaire (CCAENA).<sup>3</sup> This questionnaire was published after we performed our literature review, and we probably did not notice this questionnaire afterward because it is published in Spanish.

The CCAENA, similar to the NCQ, also measures patients' experienced continuity of care as a multidimensional concept, regardless of morbidity and across multiple care settings. The CCAENA seems to be a useful instrument. As Aller et al<sup>2</sup> also describe, there are several differences between the two instruments, of which we would like to add the following comments:

- The CCAENA also include items about the accessibility (e.g., whether patients had to wait a long time for an appointment with a care provider), the extent to which care providers provide enough information to the patient, and whether the patient should recommend the care provider to others. We believe these items do not measure continuity of care but measure the quality of care of which continuity of care is one dimension.
- Because far more items are included in the CCAENA, it takes almost 34 minutes to finish the instrument, whereas the NCQ takes only 5-10 minutes to complete.
- Patients often contact several care providers in one care setting, e.g., several general practitioners and/or a nurse practitioner in general practice. That is why we believe that measuring continuity of care not only between care settings but also within a specific care setting is one of the strengths of the NCQ.

- After the initial testing of the NCQ, we now more extensively tested the psychometric properties of the NCQ including a test-retest, a second principal component analysis to confirm the first analysis, a correlation of the NCQ score to scores of other scales measuring quality of care, continuity, trust, and satisfaction and an assessment of the discriminative ability by showing differences in continuity subscores of different subgroups. This provides more extensive evidence for the validity, discriminative ability, and reliability of the NCQ.<sup>4</sup>
- As Aller et al<sup>2</sup> describe, the CCAENA can measure continuity of care for a given episode taking place in the last three months. The NCQ is developed to measure the experienced continuity of care in the last 12 months. However, we have no reason to believe that the items of the NCQ cannot measure continuity for another period of time.

The CCAENA and NCQ are both useful instruments allowing us to identify problems and possibly evaluate interventions or changes in health care systems aimed at improving continuity of care. They both enable us to compare continuity experiences for different diseases and multimorbidity patterns. We believe that the final NCQ would not have changed substantially when we did identify the CCAENA earlier. A lot of items in the CCAENA are comparable to the items in the NCQ. However, there are some main differences. When choosing which instrument to use for measuring continuity of care, researchers have to decide what they exactly want to measure (e.g., do they also want information about accessibility or information about the experienced continuity within a specific care setting?), what the acceptable length of the questionnaire is for the patients being researched, and how extensively they want the questionnaire to be tested on its psychometric properties.

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# 6

## Discussion



The aim of this thesis was to increase the knowledge of the three dimensions of continuity of care: (1) having a personal care provider (personal continuity), (2) communication and cooperation between care providers within one setting (team continuity) and (3) communication and cooperation between care providers from different care settings (cross-boundary continuity).

In this final chapter, our research questions will be answered based on the results of the previous chapters. We discuss the strengths and limitations of this thesis. Finally, we discuss the implications of the results of this thesis for clinical practice, research and medical education.

### Summary of main findings

We will use our research questions as a guide to summarize our main findings.

*Which concepts are related to continuity of care and what are their main overlaps and differences?*

Coordination of care, integration of care, patient-centered care and case management are the most frequently mentioned concepts in the literature that are conceptually entangled with continuity of care. All these concepts describe core qualities of care. Most concepts have changed their meanings and definitions substantially throughout the years. Three major themes could be identified in the definitions of continuity of care: (1) a personal care provider in every separate care setting who knows and follows the patient; (2) communication of relevant patient information between care providers; and (3) cooperation between care providers, both within a specific care setting and between care settings, to ensure that care is connected. These themes recur to a certain extent in the conceptually entangled concepts, and therefore they might be considered as core elements of care to patients.

*What levels of continuity of care do patients with different chronic diseases experience?*

We found that many patients (about 30-50%) with a chronic somatic illness who received usual care by their GP, did not contact general practice at all for that illness in the time frame of a year. If patients did contact general practice in the

past year, they most likely contacted several care providers. Patients at risk for depression contacted even more care providers in general practice than patients with a chronic somatic illness.

Most patients with a chronic somatic illness and patients at risk for depression perceived high levels of communication and cooperation between care providers in general practice (team continuity), although about 10-15% of both patient groups experienced very low levels of team continuity.

Most patients with a chronic somatic illness also perceived high levels of communication and cooperation between care providers from different care settings (cross-boundary continuity). In total, 11% experienced very low levels of cross-boundary continuity. However, most patients at risk for depression experienced low levels of cross-boundary continuity, 40% experienced very low levels.

The introduction of practice nurses in general practice resulted, by definition, in lower levels of personal continuity. However, patients receiving care by practice nurses did not differ in their perceived team continuity from patients receiving usual care. Moreover, the chance of not contacting any care provider at all was lower after the introduction of practice nurses.

Higher scores on personal continuity were significantly related to better medication adherence. We found no clear relationship between perceived team or cross-boundary continuity and medication adherence. We also found no relationship between the continuity dimensions and the quality of patients' life.

*Which questionnaires measuring continuity of care exist and what is known about their measurement properties? Which instrument should preferably be used when measuring continuity of care?*

We included 21 questionnaires, developed for different groups of patients or providers. Most instruments had problems with either the number or quality of its assessed measurement properties or the ability to measure all three dimensions of continuity of care. We recommend the use of one of the four most promising questionnaires, depending on the target population: Diabetes Continuity of Care Questionnaire (DCCQ), Alberta Continuity of Services Scale-Mental Health (ACSS-MH), Heart Continuity of Care Questionnaire (HCCQ), and Nijmegen Continuity Questionnaire (NCQ).

*Is it possible to develop a well-validated questionnaire measuring patients' experienced personal, team and cross-boundary continuity in primary as well as in secondary care, regardless of morbidity?*

As we did not identify a well-validated questionnaire that measures continuity of care in its three dimensions and is suitable for different patient groups, we developed and validated the Nijmegen Continuity Questionnaire (NCQ). The NCQ proved to be a comprehensive, reliable and valid instrument to measure patients' experiences of continuity of care, regardless of morbidity and across multiple care settings. This questionnaire allows us to identify problems in continuity of care and to compare continuity experiences of patients with different diseases and multimorbidity patterns.

In conclusion, patients with a chronic somatic illness experience high levels of continuity of care, even patients that do not contact their GP every time but are regularly controlled by a practice nurse. Improvements are desirable in the continuity of care for patients at risk for depression, mainly in personal continuity and continuity between care providers from different care settings. To better comprehend and equalize future research in the field of continuity of care or any of its related concepts, it is necessary that the concept being researched is always clearly explained and that researchers use the same questionnaires as much as possible. In this thesis we recommend some promising questionnaires and developed and validated a questionnaire that can be used regardless of morbidity and care setting.

### **Strengths and limitations**

A strength of this thesis is that it not only focused on the concept of 'continuity of care', but also took into account relating concepts such as 'coordination of care' and 'integration of care'. This has resulted in a much broader scope of aspects of care that are defined in different ways. For example, in the development phase of the NCQ we also included items aimed to measure 'coordination of care' or 'case management'. In the systematic review, we found six instruments that we would probably not have found when we would have focussed our review solely on continuity of care, instead of taking into account relating concepts.

One of the limitations when asking patients on their experiences with continuity of care is the possible recall bias. To reduce this type of bias, we asked patients on their experiences for no longer than the previous year. As patient centered care gains importance, patients' experiences are increasingly important for the evaluation and improvement of care. That is why we chose to ask patients despite the possible recall bias.

Another limitation is that we initially used a self-developed questionnaire that was only partly validated to measure patients' experiences with continuity of care. At that time, no better validated questionnaire was available to measure the three dimensions of continuity of care in different patient groups.

The cross-sectional design of studying the relation between continuity of care and medication adherence (*chapter 3.1*) and quality of patients' life (*chapter 3.2*) has its weaknesses. Although it shows relationships, it cannot prove causality. Moreover, we recognise that these studies were not powered to establish differences between subgroups regarding continuity of care. Therefore, the question whether more continuity of care leads to higher levels of medication adherence and patient's quality of life could not be answered.

In this thesis, we purposefully selected patients with one or more chronic diseases. These patients value continuity of care far more than patients with minor problems.<sup>1-3</sup> This however means, that our results can only be generalised to this population.

## **Recommendations for clinical practice**

### *Case management team*

We found that many patients with a chronic somatic illness receiving usual care did not contact any care provider at all in general practice in the past year. However, in several guidelines concerning chronic illnesses<sup>4,6</sup>, GPs are advised to monitor chronically ill patients every three months to a year in order to provide high levels of quality of care and to be able to act proactively. As we found that care from a practice nurse reduces the chance of not contacting any care provider at all in a year for that specific disease, this supports the development in which practice nurses take over more elements of care, especially for elderly patients or patients with a chronic illness. GPs and practice nurses working in close collaboration

could act as a ‘case management team’ for these patients<sup>7</sup>, being aware of all other providers involved in patient’s care and, because of the regular control rate, being able to act proactively in order to identify and resolve or treat problems in an early stage. This will probably increase quality of care without having a negative impact on patients’ perceived team continuity and quality of life (*chapter 3.2*).

### *Electronic medical record accessible to all care providers*

In this thesis, we found that the levels of communication and cooperation between care providers, especially care providers from different care settings, can be improved. But how can this be achieved, especially in a time when most care providers work part-time and time to communicate with other care providers is scarce? Although we did not study new interventions to improve communication and cooperation between care providers in this thesis, we do have some suggestions. Continuity of care might be improved when there is only one electronic medical record for each patient, that is accessible to all involved care providers, regardless of care setting or professional background. As all care providers already have to report their findings in a medical record, it does not take extra time. With a shared electronic medical record, all care providers will have up-to-date information of the care of others, without spending much time on communication. Such an electronic medical record should promote easy access to relevant patient information, such as medication use, allergies, contra-indications and medical history. The privacy of the patient can be assured if only the patient is able to allow new care providers to access his/her medical record.

This intervention might improve team- as well as cross-boundary continuity. We suggested in *chapter 3.3* that the communication and cooperation between physicians is possibly easier because they speak the same language, whereas it can be harder for a physician and a psychologist or social worker to communicate and cooperate because of their different professional backgrounds. Sharing the same patient record might improve the continuity between care providers with a different professional background as well, without spending much time on structured consultations or reports to inform each other.

In the Netherlands, MijnZorgNet (MyCareNet) provides a digital community in which patients and care providers can communicate with other patients and care providers regardless of care setting or professional background. Care is centered

around the patient, and patients become a collaborative partner in their own care. This initiative provides opportunities to improve continuity of care, especially when patients with multimorbidity do not have to participate in different (disease-centered) communities and care providers do not have to spend much extra time.

### *Smaller GP teams*

Although communication and cooperation between care providers become increasingly important as more care providers are involved in patient's care<sup>7</sup>, we have reasons to believe that it cannot be a substitute for the value of having a personal care provider (*chapter 3.1*): we found that higher scores on personal continuity are significantly related to better medication adherence, while we found no relation between team or cross-boundary continuity and medication adherence.

Personal continuity in general practice can be improved. Many patients with a chronic somatic illness contact several care providers in general practice in the time frame of a year.

Patients at risk for a depression contacted even more care providers in general practice. GPs working in large practices could organize in smaller units in order to increase personal continuity and to provide closer team communication. Probably, it is preferable to form the smallest possible team, i.e. two GPs, that is responsible for the care of a patient group. This was recently also recommended in a position paper of the Dutch College of GPs.<sup>8</sup>

## **Recommendations for future research**

### *The value of team and cross-boundary continuity*

From previous research we already know a lot about the value of personal continuity. Having a personal care provider is related to more confidence in the care provider<sup>9;10</sup>, more patient satisfaction<sup>10;11</sup>, increased feelings of being helped forward<sup>10</sup>, higher quality of patient's life<sup>12;13</sup>, better health outcomes<sup>12-15</sup>, less health care costs<sup>16-18</sup> and less hospitalizations and emergency department use<sup>19-23</sup>. In this thesis, we found evidence that higher scores on personal continuity are also related to better medication adherence (*chapter 3.1*). Less is known about the value of team and cross-boundary continuity, although these dimensions are becoming increasingly important since more care providers are involved in patient's care.<sup>7</sup>

We found no relation between team or cross-boundary continuity and medication adherence or quality of patient's life (*chapter 3.1 and 3.2*). We suggest to further investigate the value of team and cross-boundary continuity. Are they related to, for example, better health outcomes or less health care costs?

#### *Comparison of continuity of care experiences between different patient groups*

This thesis shows differences in experienced continuity of care between different patient groups. Patients at risk for a depression seem to contact more care providers throughout the care continuum and seem to experience less communication and cooperation between care providers of different care settings than patients with a chronic somatic illness. We suggest to further research the experienced continuity of care of patients with different (multi)morbidity patterns and to compare these patient groups. This provides us greater understanding of which patient groups benefit most of interventions aimed at improving continuity of care. How do, for example, patients at the end of their lives or parents of a chronically ill child experience continuity of care? The NCQ can be used to measure continuity of care in these different patient groups.

#### *Analysis of patients and/or practices*

In order to gain more insight into the care experiences that underlie the continuity of care scores, we suggest to analyse patients and/or practices scoring very high or very low, preferably by using a qualitative research design. Why do these patients and/or practices score such high or low levels of continuity of care? This will provide us greater insight in how to increase the levels of continuity of care.

#### *Evaluation of interventions aimed to improve continuity of care*

Interventions aimed to improve continuity of care should be evaluated. Most existing studies of interventions aiming to improve continuity of care surprisingly did not measure continuity of care as one of their outcomes.<sup>24</sup> This can be due to the lack of well validated instruments to measure continuity of care. We describe in this thesis the four most promising questionnaires measuring continuity of care that can possibly be used for evaluating new interventions. The responsiveness of these questionnaires needs to be tested before interventions can be evaluated.

*Concept should be explained*

Finally, we recommend researchers to always clearly explain the concept being researched. What one research group defines as e.g. ‘integration of care’, is defined as ‘continuity of care’ by another research group. This thesis shows that researchers always have to take into account related concepts when researching continuity of care or any of its related concepts, because of their great entanglement.

**Recommendations for medical education**

More attention should be paid to competences regarding collaboration and to the concept of ‘continuity of care’ in medical education, to increase the emphasis on the value of continuity of care for future care providers.

*Combine education for different specialisms*

At the start of medical education, all future doctors follow the same education for several years, irrespective of the specialism they will choose in the future. After graduating MD, the education splits into all different types of specialisms. In these years, different types of doctors rarely follow collaborative educational programs. This may be one of the reasons that both GP and medical specialist perceive low levels of mutual communication.<sup>25;26</sup> We believe that combining education for different doctors will probably result in more awareness of each other and greater mutual understanding, which will probably increase communication and cooperation in the future.

*Internships with other health care disciplines*

This thesis shows that patients at risk for depression seem to experience lower levels of continuity of care between care providers from different care settings than patients with a chronic somatic illness (*chapter 3.3*). We discuss that these differences might be explained by the fact that other care providers have to collaborate for patients at risk for depression (e.g. GP and psychologist or social worker) than for somatically ill patients (e.g. GP and specialist). Continuity of care between different types of health care providers (e.g. doctor and psychologist or doctor and social worker) can probably be improved by paying attention in

medical education as well. During medical education, future health care providers do short internships with other health care disciplines. During these internships, attention should be paid to the information that care providers do or do not know from other involved providers and its consequences for patient's care.

*Measure continuity of care in GP training practices*

To increase the awareness of continuity of care among GP trainees, we recommend to use instruments measuring continuity of care in medical education. In the Netherlands, the first and third year of GP training take place in a general practice. We suggest that GP trainees distribute about 30 NCQs each to patients they contact in general practice. As GP trainees have one day a week training at the university, the results of these questionnaires could be discussed in their training group. It will show to what extent continuity of care can be improved, comparisons between different general practices can be made, and it allows GP trainees to think about interventions to improve continuity of care in their general practice which makes the concept 'continuity of care' less abstract.

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# **Appendix A**

## **Search Strategy Systematic Review**



## Search strategy Pubmed

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## **AND**

(instrumentation[sh] OR methods[sh] OR Validation Studies[pt] OR Comparative Study[pt] OR “psychometrics”[MeSH] OR psychometr\*[tiab] OR clinimetr\*[tw] OR clinometr\*[tw] OR “outcome assessment (health care)”[MeSH] OR outcome assessment[tiab] OR outcome measure\*[tw] OR “observer variation”[MeSH] OR observer variation[tiab] OR “Health Status Indicators”[Mesh] OR “reproducibility of results”[MeSH] OR reproducib\*[tiab] OR “discriminant analysis”[MeSH] OR reliab\*[tiab] OR unreliab\*[tiab] OR valid\*[tiab] OR coefficient[tiab] OR homogeneity[tiab] OR homogeneous[tiab] OR “internal consistency”[tiab] OR (cronbach\*[tiab] AND (alpha[tiab] OR alphas[tiab])) OR (item[tiab] AND (correlation\*[tiab] OR selection\*[tiab] OR reduction\*[tiab])) OR agreement[tiab] OR precision[tiab] OR imprecision[tiab] OR “precise values”[tiab] OR test–retest[tiab] OR (test[tiab] AND retest[tiab]) OR (reliab\*[tiab] AND (test[tiab] OR retest[tiab])) OR stability[tiab] OR interrater[tiab] OR inter-rater[tiab] OR intrarater[tiab] OR intra-rater[tiab] OR intertester[tiab] OR inter-tester[tiab] OR intratester[tiab] OR intra-tester[tiab] OR interobserver[tiab] OR inter-observer[tiab] OR intraobserver[tiab] OR intra-observer[tiab] OR intertechnician[tiab] OR inter-technician[tiab] OR intratechnician[tiab] OR intra-technician[tiab] OR interexaminer[tiab] OR inter-examiner[tiab] OR intraexaminer[tiab] OR intra-examiner[tiab] OR interassay[tiab] OR inter-assay[tiab] OR intraassay[tiab] OR intra-assay[tiab] OR interindividual[tiab] OR inter-individual[tiab] OR intraindividual[tiab] OR intra-individual[tiab] OR interparticipant[tiab] OR inter-participant[tiab] OR intraparticipant[tiab] OR intra-

participant[tiab] OR kappa[tiab] OR kappa's[tiab] OR kappas[tiab] OR repeatab[tiab] OR ((replicab\*[tiab] OR repeated[tiab]) AND (measure[tiab] OR measures[tiab] OR findings[tiab] OR result[tiab] OR results[tiab] OR test[tiab] OR tests[tiab])) OR generaliza\*[tiab] OR generalisa\*[tiab] OR concordance[tiab] OR (intraclass[tiab] AND correlation\*[tiab]) OR discriminative[tiab] OR “known group”[tiab] OR factor analysis[tiab] OR factor analyses[tiab] OR dimension\*[tiab] OR subscale\*[tiab] OR (multitrait[tiab] AND scaling[tiab] AND (analysis[tiab] OR analyses[tiab])) OR item discriminant[tiab] OR interscale correlation\*[tiab] OR error[tiab] OR errors[tiab] OR “individual variability”[tiab] OR (variability[tiab] AND (analysis[tiab] OR values[tiab])) OR (uncertainty[tiab] AND (measurement[tiab] OR measuring[tiab])) OR “standard error of measurement”[tiab] OR sensitiv\*[tiab] OR responsive\*[tiab] OR ((minimal[tiab] OR minimally[tiab] OR clinical[tiab] OR clinically[tiab]) AND (important[tiab] OR significant[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR (small\*[tiab] AND (real[tiab] OR detectable[tiab]) AND (change[tiab] OR difference[tiab])) OR meaningful change[tiab] OR “ceiling effect”[tiab] OR “floor effect”[tiab] OR “Item response model”[tiab] OR IRT[tiab] OR Rasch[tiab] OR “Differential item functioning”[tiab] OR DIF[tiab] OR “computer adaptive testing”[tiab] OR “item bank”[tiab] OR “cross-cultural equivalence”[tiab])

## NOT

(“addresses”[Publication Type] OR “biography”[Publication Type] OR “case reports”[Publication Type] OR “comment”[Publication Type] OR “directory”[Publication Type] OR “editorial”[Publication Type] OR “festschrift”[Publication Type] OR “interview”[Publication Type] OR “lectures”[Publication Type] OR “legal cases”[Publication Type] OR “legislation”[Publication Type] OR “letter”[Publication Type] OR “news”[Publication Type] OR “newspaper article”[Publication Type] OR “patient education handout”[Publication Type] OR “popular works”[Publication Type] OR “congresses”[Publication Type] OR “consensus development conference”[Publication Type] OR “consensus development conference, nih”[Publication Type] OR “practice guideline”[Publication Type]) NOT (“animals”[MeSH Terms] NOT “humans”[MeSH Terms])

## Search strategy Embase

(Continuity of care or Continuity of health care or Continuity of healthcare or Continuity of patient care or Continuity of service or Continuity of services or Care continuity or Healthcare continuity or Service continuity or Services continuity or Coordination of care or Coordination of health care or Coordination of healthcare or Coordination of patient care or Coordination of service or Coordination of services or Care coordination or Healthcare coordination or Service coordination or Services coordination or Co-ordination of care or Co-ordination of health care or Co-ordination of healthcare or Co-ordination of patient care or Co-ordination of service or Co-ordination of services or Care co-ordination or Healthcare co-ordination or Service co-ordination or Services co-ordination or Coordinated care or Coordinated health care or Coordinated healthcare or Coordinated patient care or Coordinated service or Coordinated services or Co-ordinated care or Co-ordinated health care or Co-ordinated healthcare or Co-ordinated patient care or Co-ordinated service or Co-ordinated services or Coordinating care or Coordinating health care or Coordinating healthcare or Coordinating patient care or Coordinating service or Coordinating services or Co-ordinating care or Co-ordinating health care or Co-ordinating healthcare or Co-ordinating patient care or Co-ordinating service or Co-ordinating services or Integration of care or Integration of health care or Integration of healthcare or Integration of patient care or Integration of service or Integration of services or Care integration or Healthcare integration or Service integration or Services integration or Integrated care or Integrated health care or Integrated healthcare or Integrated patient care or Integrated service or Integrated services or Integrating care or Integrating health care or Integrating healthcare or Integrating patient care or Integrating service or Integrating services or Patient centered care or Patient centered health care or Patient centered healthcare or Patient centered service or Patient centered services or Patient centred care or Patient centred health care or Patient centred healthcare or Patient centred service or Patient centred services or Patient focused care or Patient focused health care or Patient focused healthcare or Patient focused service or Patient focused services or Case management).ti,ab.

**AND**

exp questionnaire/ OR exp "named inventories, questionnaires and rating scales"/ OR exp psychometry/ OR exp outcome assessment/ OR exp validity/ OR exp reliability/ OR ((questionnaire or named inventory or reliability or rating scale or psychometry or outcome assessment or validity).tw.)

**Search strategy PsycInfo**

(Continuity of care or Continuity of health care or Continuity of healthcare or Continuity of patient care or Continuity of service or Continuity of services or Care continuity or Healthcare continuity or Service continuity or Services continuity or Coordination of care or Coordination of health care or Coordination of healthcare or Coordination of patient care or Coordination of service or Coordination of services or Care coordination or Healthcare coordination or Service coordination or Services coordination or Co-ordination of care or Co-ordination of health care or Co-ordination of healthcare or Co-ordination of patient care or Co-ordination of service or Co-ordination of services or Care co-ordination or Healthcare co-ordination or Service co-ordination or Services co-ordination or Coordinated care or Coordinated health care or Coordinated healthcare or Coordinated patient care or Coordinated service or Coordinated services or Co-ordinated care or Co-ordinated health care or Co-ordinated healthcare or Co-ordinated patient care or Co-ordinated service or Co-ordinated services or Coordinating care or Coordinating health care or Coordinating healthcare or Coordinating patient care or Coordinating service or Coordinating services or Co-ordinating care or Co-ordinating health care or Co-ordinating healthcare or Co-ordinating patient care or Co-ordinating service or Co-ordinating services or Integration of care or Integration of health care or Integration of healthcare or Integration of patient care or Integration of service or Integration of services or Care integration or Healthcare integration or Service integration or Services integration or Integrated care or Integrated health care or Integrated healthcare or Integrated patient care or Integrated service or Integrated services or Integrating care or Integrating health

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**AND**

exp measurement/ OR exp test construction/ OR exp interrater reliability/ OR exp statistical analysis/



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# Appendix B

## Nijmegen Continuity Questionnaire (NCQ)

English version



# Continuity Questionnaire

We are interested in hearing about your experiences with the care providers that you have come in contact with over the past 12 months.

This questionnaire includes 28 statements and will take about 5 - 10 minutes to complete.

There are no right or wrong answers.

Your honest opinion is what counts.

For each statement, choose the answer that best describes your opinion.

All the information you provide will be kept completely confidential. Your answers will not be passed on to your care providers or others.

This questionnaire, Nijmegen Continuity Questionnaire (NCQ), is developed by the Department of Primary and Community Care, Radboud University Nijmegen Medical Centre, Nijmegen.

Date of completion (day-month-year)

-   -

**1. The following statements are about your (own) general practitioner**

*If you have not seen your general practitioner these past 12 months, please skip to the next section.*

- a** I know my general practitioner very well
- b** My general practitioner knows my medical history very well
- c** My general practitioner always remembers what he/she did during my last visit(s)
- d** My general practitioner knows my family circumstances very well
- e** My general practitioner knows what I do in my day-to-day life very well
- f** My general practitioner contacts me when necessary without me having to ask him/her to do so
- g** My general practitioner knows very well what I think is important when it comes to my care
- h** My general practitioner maintains enough contact with me when I am seen by other care providers

Strongly agree    Agree    Neutral    Disagree    Strongly disagree    ?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	?
a	<input type="checkbox"/>					
b	<input type="checkbox"/>					
c	<input type="checkbox"/>					
d	<input type="checkbox"/>					
e	<input type="checkbox"/>					
f	<input type="checkbox"/>					
g	<input type="checkbox"/>					
h	<input type="checkbox"/>					

Strongly agree    Agree    Neutral    Disagree    Strongly disagree    ?

**2. The following statements are about how care providers in general practice work together (e.g. your general practitioner and the nurse practitioner or between general practitioners).**

*If this section does not apply to you, please skip to the next section.*

- a** These care providers pass on information to each other very well
- b** These care providers work together very well
- c** The care given by these care providers is well-connected
- d** These care providers always know very well what the other care providers have done

<input type="checkbox"/>					
<input type="checkbox"/>					
<input type="checkbox"/>					
<input type="checkbox"/>					

**3. The following statements are about your (most important) specialist**

*If you have not seen a specialist these past 12 months, please skip to the next section.*

- a** I know this care provider very well
- b** This care provider knows my medical history very well
- c** This care provider always remembers what he/she did during my last visit(s)
- d** This care provider knows my family circumstances very well
- e** This care provider knows what I do in my day-to-day life very well
- f** This care provider contacts me when necessary without me having to ask him/her to do so
- g** This care provider knows very well what I think is important when it comes to my care
- h** This care provider maintains enough contact with me when I am seen by other care providers

Strongly agree    Agree    Neutral    Disagree    Strongly disagree    ?

	Strongly agree	Agree	Neutral	Disagree	Strongly disagree	?
a	<input type="checkbox"/>					
b	<input type="checkbox"/>					
c	<input type="checkbox"/>					
d	<input type="checkbox"/>					
e	<input type="checkbox"/>					
f	<input type="checkbox"/>					
g	<input type="checkbox"/>					
h	<input type="checkbox"/>					

Strongly agree    Agree    Neutral    Disagree    Strongly disagree    ?

**4. The following statements are about how care providers in hospital work together (e.g. your specialist and a nurse or between specialists)**

*If this section does not apply to you, please skip to the next section.*

**a** These care providers pass on information to each other very well

**b** These care providers work together very well

**c** The care given by these care providers is well-connected

**d** These care providers always know very well what the other care providers have done

**5. The following statements are about how your general practitioner and your specialist work together.**

*If this section does not apply to you, you're finished the questionnaire.*

**a** These care providers pass on information to each other very well

**b** These care providers work together very well

**c** The care given by these care providers is well-connected

**d** These care providers always know very well what the other care providers have done





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# Appendix C

## Nijmegen Continuity Questionnaire (NCQ)

Dutch version



## Vragenlijst Continuïteit

Deze vragenlijst gaat over uw ervaringen met de hulpverleners met wie u in de afgelopen 12 maanden contact heeft gehad.

De antwoorden op de vragen zullen anoniem worden verwerkt.

Uw antwoorden worden niet doorgegeven aan uw hulpverleners of anderen.

De vragenlijst zal ongeveer 5-10 minuten van uw tijd in beslag nemen.

Deze vragenlijst, Nijmegen Continuity Questionnaire (NCQ), is ontwikkeld door de afdeling Eerstelijngeneeskunde van het UMC St Radboud te Nijmegen.

Datum van invullen (dag-maand-jaar)

-   -

**1. De volgende vragen gaan over uw (eigen) huisarts**

*Heeft u in het afgelopen jaar geen contact gehad met uw huisarts, ga dan naar vraag 2.*

	<i>Zeereens</i>	<i>Eens</i>	<i>Neutraal</i>	<i>Oneens</i>	<i>Zeeroneens</i>	<i>?</i>
<b>a</b> Ik ken mijn huisarts heel goed	<input type="checkbox"/>					
<b>b</b> Mijn huisarts kent mijn medische voorgeschiedenis heel goed	<input type="checkbox"/>					
<b>c</b> Mijn huisarts weet altijd wat hij/zij in eerdere contacten heeft gedaan	<input type="checkbox"/>					
<b>d</b> Mijn huisarts kent mijn familie-omstandigheden heel goed	<input type="checkbox"/>					
<b>e</b> Mijn huisarts kent mijn dagelijkse bezigheden heel goed	<input type="checkbox"/>					
<b>f</b> Mijn huisarts neemt zelf contact met mij op als dat nodig is, zonder dat ik er om vraag	<input type="checkbox"/>					
<b>g</b> Mijn huisarts weet heel goed wat ik belangrijk vind in mijn zorg	<input type="checkbox"/>					
<b>h</b> Mijn huisarts houdt voldoende contact met mij als ik gezien wordt door andere hulpverleners	<input type="checkbox"/>					

**2. De volgende vragen gaan over de samenwerking in de huisartsenpraktijk (bijvoorbeeld huisarts-praktijkondersteuner of eigen huisarts-andere huisarts)**

*Is deze vraag niet op u van toepassing, ga dan naar vraag 3.*

**a** Deze hulpverleners dragen informatie heel goed aan elkaar over

**b** Deze hulpverleners werken heel goed samen

**c** De zorg van deze hulpverleners sluit heel goed op elkaar aan

**d** Deze hulpverleners weten van elkaar altijd wat ze doen

Zeereens   Eens   Neutraal   Oneens   Zeeroneens   ?

<input type="checkbox"/>					
<input type="checkbox"/>					
<input type="checkbox"/>					
<input type="checkbox"/>					

**3. De volgende vragen gaan over uw (belangrijkste) specialist**

*Heeft u in het afgelopen jaar geen contact gehad met een specialist, ga dan naar vraag 4.*

- a** Ik ken deze specialist heel goed
- b** Deze specialist kent mijn medische voorgeschiedenis heel goed
- c** Deze specialist weet altijd wat hij/zij in eerdere contacten heeft gedaan
- d** Deze specialist kent mijn familie-omstandigheden heel goed
- e** Deze specialist kent mijn dagelijkse bezigheden heel goed
- f** Deze specialist neemt zelf contact met mij op als dat nodig is, zonder dat ik er om vraag
- g** Deze specialist weet heel goed wat ik belangrijk vind in mijn zorg
- h** Deze specialist houdt voldoende contact met mij als ik gezien wordt door andere hulpverleners

Zeereens   Eens   Neutraal   Oneens   Zeeroneens   ?

	Zeereens	Eens	Neutraal	Oneens	Zeeroneens	?
a	<input type="checkbox"/>					
b	<input type="checkbox"/>					
c	<input type="checkbox"/>					
d	<input type="checkbox"/>					
e	<input type="checkbox"/>					
f	<input type="checkbox"/>					
g	<input type="checkbox"/>					
h	<input type="checkbox"/>					

**4. De volgende vragen gaan over de samenwerking in het ziekenhuis (bijvoorbeeld specialist-andere specialist of specialist-verpleegkundige)**

*Is deze vraag niet op u van toepassing, ga dan naar vraag 5.*

- a Deze hulpverleners dragen informatie heel goed aan elkaar over
- b Deze hulpverleners werken heel goed samen
- c De zorg van deze hulpverleners sluit heel goed op elkaar aan
- d Deze hulpverleners weten van elkaar altijd wat ze doen

**5. De volgende vragen gaan over de samenwerking tussen uw huisarts en uw specialist.**

*Is deze vraag niet op u van toepassing, dan bent u klaar met het invullen van deze vragenlijst.*

- a Deze hulpverleners dragen informatie heel goed aan elkaar over
- b Deze hulpverleners werken heel goed samen
- c De zorg van deze hulpverleners sluit heel goed op elkaar aan
- d Deze hulpverleners weten van elkaar altijd wat ze doen

Zeereens   Eens   Neutraal   Oneens   Zeeroneens   ?

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**Eventuele opmerkingen kunt u hieronder vermelden:**

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**Hartelijk dank voor uw medewerking!**



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# **Appendix D**

**Consumer Quality (CQ) Index  
‘General Practice Care’, subscale  
‘Care suits patient’**



**The following questions are about the contacts with your GP in the last 12 months**

1. Did the GP inform you well about the treatment options for your health problems?
  - never
  - sometimes
  - often
  - always
2. How often did your GP gave you the possibility to participate in decisions about het treatment you received?
  - never
  - sometimes
  - often
  - always
3. Did your GP inform you about possible side effects of prescribed drugs?
  - never
  - sometimes
  - often
  - always
  - not applicable (no drugs prescribed)
4. Did your GP explain why it was important to follow his/her advice?
  - never
  - sometimes
  - often
  - always
5. Did you get enough help in 'finding the way' in health care (such as information on providers, hospitals, waiting lists, making an appointment etc.)?
  - never
  - sometimes
  - often
  - always
  - not applicable (never needed)
6. How often did your GP worked together well with other care providers (such as nurse practitioner, physiotherapist, home care, medical specialist etc.)?
  - never
  - sometimes
  - often
  - always
  - not applicable (I did not contact another care provider)
7. Did your doctor pay attention to possible emotional problems related to your health?
  - never
  - sometimes
  - often
  - always
8. How often did your doctor offered you help in the prevention of diseases or in improving your health (e.g. weight or blood pressure controls, giving advice on weight or lifestyle)?
  - never
  - sometimes
  - often
  - always
9. How often did treatment by your GP caused a reduction in your health problems?
  - never
  - sometimes
  - often
  - always

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# **Appendix E**

**Questionnaire ‘Continuity of care  
from the client perspective’ (VCC)**



**GP**

*The following questions are about the care of the **GP** in the last 12 months.*

*If you did not contact a **GP** in the last 12 months, please go on to the next section.*

The GP gave me the medical care I needed	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
When my situation changed, the GP adjusted the care, if necessary	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
In urgent cases I could very quickly get care from my GP	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP stuck to the agreed time	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP was accessible by telephone	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The care of the GP was well connected to the care of the medical specialist	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP worked together well with other care providers	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
In the absence of the GP, a substitute was present	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP gave his/her substitute enough information about my situation	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The advices of the GP were contrary to the advices of other care provider(s)	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP referred me to another care provider, if necessary	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP provided enough information about my situation to the care provider referring to	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					
The GP visited me at home, if necessary	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>					

**Medical specialist**

*The following questions are about the care of the **medical specialist** in the last 12 months. If you did not contact a **medical specialist** in the last 12 months, than you finished the questionnaire. If you contacted more than one medical specialist, please complete the following questions for the specialist from whom you received the most care.*

The specialist gave me the medical care I needed	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
When my situation changed, the specialist adjusted the care, if necessary	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
In urgent cases I could very quickly get care from the specialist	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The specialist stuck to the agreed time	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The specialist was accessible by telephone	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The care of the specialist was well connected to the care of the GP	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The specialist worked together well with other care providers	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
In the absence of the specialist, a substitute was present	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The specialist gave his/her substitute enough information about my situation	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The advices of the specialist were contrary to the advices of other care provider(s)	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
When I wanted to change an appointment with the specialist, I could quickly get a new appointment	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The specialist referred me to another care provider, if necessary	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
The specialist provided enough information about my situation to the care provider referring to	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				
I quickly got help from the specialist in the last 6 months (not on a waiting list)	no	<input type="checkbox"/>	yes	n.a.	<input type="checkbox"/>				

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# **English summary**



**C**ontinuity of care is an important aspect of patient care, especially for chronically ill patients.

The objectives of this thesis were to (1) describe the overlaps and differences between concepts related to continuity of care; (2) investigate how patients with different chronic diseases experience continuity of care; (3) review the literature on existing instruments measuring continuity of care in order to assess the quality and utility of these instruments for a comprehensive measurement of continuity of care, and (4) develop and validate a generic questionnaire measuring patients' experienced continuity of care regardless of care setting and morbidity, as such an instrument was still lacking.

## Chapter 1 Introduction

In this chapter, the rationale, aim and outline of this thesis are described.

Previous research on continuity of care has focused mainly on personal continuity (seeing the same care provider). However, an increasing number of care providers are nowadays involved in patient's care. Communication and cooperation between all involved providers become increasingly important to guarantee continuity of care. Less is known about these latter dimensions of continuity of care.

This thesis aims to increase the knowledge of the different dimensions of continuity of care:

1. Personal continuity: Having a personal care provider in every separate care setting who knows and follows the patient;
2. Team continuity: Communication of relevant patient information and cooperation between care providers within one care setting to ensure that care is connected;
3. Cross-boundary continuity: Communication of relevant patient information and cooperation between care settings to ensure that care is connected.

## **Chapter 2 How unique is continuity of care? A review of continuity and related concepts**

This chapter provides a historical overview of the definitions of continuity of care and related concepts. We identified all concepts that might be related to continuity of care. We decided to focus our further exploration on continuity of care and the four most frequently mentioned related concepts, namely coordination of care, integration of care, patient-centred care and case-management. It appeared that most concepts changed their meanings and definitions substantially throughout the years, and all were conceptually entangled. However, researchers using one concept hardly ever referred to overlapping concepts. They seem to operate mainly within their own conceptual framework and literature. Three major themes could be identified in the definitions of continuity of care: (1) a personal care provider in every separate care setting who knows and follows the patient; (2) communication of relevant patient information between care providers and (3) cooperation between care providers, both within a specific care setting and between care settings, to ensure that care is connected. As these themes recur to a certain extent in all related concepts, they are apparently core elements of care to patients. We conclude that it may be valuable to develop an instrument to measure these three common themes universally.

## **Chapter 3 Patients' experiences with continuity of care**

*Chapter 3* describes the levels of experienced continuity of care of different patient groups.

### **Chapter 3.1 Heart failure patients' experiences with continuity of care and its relation to medication adherence: a cross-sectional study**

In *chapter 3.1* we explored heart failure patients' experiences with continuity of care and analysed its relation to medication adherence. We found that more than half of the patients did not contact any care provider in general practice for their heart failure in the past year, though half of them did contact a cardiologist. Of the patients who did contact general practice, about half of them contacted two or more

care providers. Most patients experienced acceptable levels of communication and cooperation between care providers in general practice (38% experienced maximum team continuity) and between GP and cardiologist (51% experienced maximum cross-boundary continuity), while 10-15% experienced very low levels of team or cross-boundary continuity. Medication adherence was significantly worse in patients who contacted three or more care providers. We found no clear relation between medication adherence and team or cross-boundary continuity.

### **Chapter 3.2 Continuity in different care modes and its relationship to quality of life: a randomised controlled trial in patients with COPD**

In this chapter, we analysed whether the levels of experienced continuity for patients with COPD changes after the introduction of a self-management intervention or regular monitoring by a practice nurse, compared to usual GP care at the patient's own initiative. We also examined the relationship between experienced continuity of care and patients' quality of life. We found that patients receiving usual care experienced the highest personal continuity, although the chance of not contacting any care provider was also highest in this group (29% versus 2% receiving self-management, and 5% receiving regular monitoring). There were no differences in experienced team continuity in the three care modes. No relationship was found between continuity and changes in quality of life. We conclude that although personal continuity decreases when new care modes are introduced, we found no evidence that this affects patients' experienced team continuity or patients' quality of life. Patients still experienced smooth, ongoing and connected care. Overall, no evidence was found indicating that the introduction of new care modes in primary care for patients with COPD should be discouraged.

### **Chapter 3.3 Experienced continuity of care in patients at risk for depression in primary care**

In this chapter we explored the levels of experienced continuity of care of patients at risk for depression in primary care, and compared these to those of patients with a chronic somatic illness. We found that most patients at risk for depression contacted several care providers throughout the care spectrum in the past year.

They experienced high levels of team continuity and low levels of cross-boundary continuity. Compared to heart failure patients, they contacted significantly more different care providers in general practice for their illness. Patients at risk for depression, however, experienced better collaboration between these care providers, but lower levels of collaboration between care providers of different care settings. We conclude that care providers should make efforts to increase the levels of personal continuity for primary care patients at risk for depression, as personal continuity is an essential element of the therapeutic process in these patients. Moreover, interventions to increase the collaboration between care providers from different settings are needed, especially for patients at risk for depression.

#### **Chapter 4 Evaluation of the measurement properties of questionnaires measuring continuity of care: a systematic review**

This chapter shows the results of a systematic review identifying questionnaires measuring continuity of care. It assesses the dimensions of continuity measured and evaluates the measurement properties of these questionnaires. We included 21 instruments. Ten instruments measured all three dimensions of continuity of care. It appeared that most instruments were developed for different groups of patients or providers. For most instruments, three or four of the six measurement properties were assessed (mostly internal consistency, content validity, structural validity and construct validity). Six instruments scored positive on the quality of at least three of the six measurement properties. We conclude that most included instruments have problems with either the number or quality of its assessed measurement properties or the ability to measure all three dimensions of continuity of care. Based on the results of this review, we recommend the use of one of the four most promising instruments, depending on the target population: Diabetes Continuity of Care Questionnaire, Alberta Continuity of Services Scale-Mental Health, Heart Continuity of Care Questionnaire, and Nijmegen Continuity Questionnaire.

#### **Chapter 5 Nijmegen Continuity Questionnaire**

We found that the literature lacked a well-validated questionnaire measuring patients' experienced continuity of care as a multidimensional concept, regardless

of patient's morbidity and across multiple care settings. This chapter describes the development and validation of such a questionnaire: the Nijmegen Continuity Questionnaire (NCQ).

### **Chapter 5.1 Nijmegen Continuity Questionnaire: Development and testing of a questionnaire that measures continuity of care**

Chapter 5.1 describes the development and pilot testing of the NCQ. Items were based on a systematic literature review and analysis of 30 patient interviews. We tested face validity by interviewing 15 patients with a chronic illness and adjusted the questionnaire accordingly. Next, pilot testing was carried out on patients with a chronic disease recruited from general practice. Principal component analysis was used to identify the three subscales. We refined the factors by excluding items for several reasons, e.g. items with a high missing rate. Internal consistency of the subscales ranged from 0.82 to 0.89. Mean interitem correlations ranged from 0.58 to 0.71 and interscale correlations varied between 0.42 and 0.61. We conclude that the NCQ shows to be a comprehensive, reliable and valid instrument. However, further testing of reliability, construct validity and responsiveness was needed before the NCQ could be more widely implemented.

### **Chapter 5.2 Measuring continuity of care: psychometric properties of the Nijmegen Continuity Questionnaire**

*Chapter 5.2* describes the further assessment of validity and reliability of the NCQ. We administered the NCQ to 268 patients with a chronic disease recruited from general practice and hospital outpatient departments. Principal component analysis confirmed the three previously found continuity subscales: 'personal continuity: care provider knows me', 'personal continuity: care provider shows commitment' and 'team/cross-boundary continuity'. Construct validity was demonstrated through expected correlations between the NCQ score and scores of scales measuring quality of care, continuity, trust and satisfaction. Discriminative ability was demonstrated through expected differences in continuity subscores of different subgroups. Test-retest reliability was high (the intraclass correlation coefficient varied between 0.71 and 0.82). We conclude that evidence exists for the validity,

discriminative ability and reliability of the NCQ. The NCQ can be of value to identify problems and evaluate interventions aimed at improving continuity of care. Moreover, the NCQ enables the comparison between continuity experiences for different diseases and multimorbidity patterns.

### **Chapter 5.3 Continuity of care preferably measured from the patients' perspective**

In this chapter we comment on an article measuring continuity of care from the electronic medical record. We describe several reasons why we believe it is important to measure continuity of care from the patients' perspective.

### **Chapter 5.4 Which questionnaire to use when measuring continuity of care**

In *chapter 5.4* we comment on an article describing a Spanish questionnaire measuring patients' experienced continuity of care regardless of morbidity and across multiple care settings: the Continuity of Care Across Care Levels Questionnaire (CCAENA). We describe several differences between the CCAENA and the NCQ. We conclude that, when choosing the most appropriate instrument for measuring continuity of care, researchers have to decide what they exactly want to measure, what an acceptable length of the questionnaire is, and how extensively they want the questionnaire to be tested on its psychometric properties.

### **Chapter 6 Discussion**

This final chapter considers the results described in this thesis together with some methodological issues, and ends with implications and recommendations for clinical practice, future research and medical education.

We conclude that patients with a chronic somatic illness experience high levels of continuity of care, even patients that do not see their GP every time but are regularly controlled by a practice nurse. Improvements can be made in the continuity of care for patients at risk for depression, mainly in personal continuity

and continuity between care providers from different care settings. To better comprehend and equalize future research in the field of continuity of care or any of its related concepts, it is necessary that the concept being researched is always clearly explained and that researchers use the same questionnaires as much as possible. In this thesis we recommend some promising questionnaires and we developed and validated a questionnaire that could be used regardless of morbidity and care setting.

The most important recommendations for clinical practice are (1) practice nurses can take over more elements of care to patients and work in close collaboration with the GP as a case management team; (2) it would be desirable to provide access to the electronic medical record to all involved care providers, and (3) GPs could organize in smaller units.

The most important recommendations for future research are (1) further investigation of the value of team and cross-boundary continuity; (2) comparison of continuity of care experiences between different patient groups, and (3) evaluation of interventions aimed to improve continuity of care.

The most important recommendations for medical education are (1) to combine education for different medical specialisms, and (2) to use instruments measuring continuity of care in medical education.

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# **Dutch summary**



**C**ontinuiteit van zorg is een belangrijk aspect van de zorg voor patiënten, met name chronisch zieke patiënten. Het doel van dit proefschrift was om (1) de overeenkomsten en verschillen te beschrijven tussen concepten die gerelateerd zijn aan continuïteit van zorg; (2) te onderzoeken in welke mate patiënten met verschillende chronische aandoeningen continuïteit van zorg ervaren; (3) een overzicht te geven van de in de literatuur bestaande meetinstrumenten voor continuïteit van zorg en de kwaliteit en bruikbaarheid van deze meetinstrumenten te bepalen om zodoende continuïteit van zorg eenduidig te meten, en (4) een generieke vragenlijst te ontwikkelen en valideren die continuïteit van zorg meet vanuit het perspectief van de patiënt, onafhankelijk van de zorgsetting en morbiditeit, omdat een dergelijk instrument nog niet voorhanden is.

## Hoofdstuk 1 Introductie

In dit hoofdstuk beschrijven we de achtergronden, doelen en opbouw van dit proefschrift.

Eerder onderzoek naar continuïteit van zorg heeft zich vooral gericht op persoonlijke continuïteit (het zien van dezelfde hulpverlener). Tegenwoordig zijn echter een toenemend aantal hulpverleners betrokken in de zorg voor de individuele patiënt. Communicatie en samenwerking tussen alle betrokken hulpverleners worden steeds belangrijker om continuïteit van zorg te waarborgen. Er is weinig bekend over deze laatstgenoemde dimensies van continuïteit van zorg. Dit proefschrift heeft als doel om de kennis over de verschillende dimensies van continuïteit van zorg te vergroten:

1. Persoonlijke continuïteit: Een vaste hulpverlener in iedere afzonderlijke zorgsetting die de patiënt kent en volgt;
2. Team continuïteit: Communicatie van relevante patiënteninformatie en samenwerking tussen hulpverleners binnen één zorgsetting om zodoende de zorg op elkaar te laten aansluiten;
3. Cross-boundary continuïteit: Communicatie van relevante patiënteninformatie en samenwerking tussen hulpverleners uit verschillende zorgsettings om zodoende de zorg op elkaar te laten aansluiten.

## **Hoofdstuk 2 Hoe uniek is continuïteit van zorg? Een review naar continuïteit en gerelateerde concepten**

Dit hoofdstuk geeft een historisch overzicht over de definities van continuïteit van zorg en gerelateerde concepten. We identificeerden alle concepten die gerelateerd konden zijn aan continuïteit van zorg. Vervolgens besloten we onze verdere exploratie te richten op continuïteit van zorg en de vier meest frequent genoemde gerelateerde concepten, namelijk coördinatie van zorg, integratie van zorg, patiënt gecentreerde zorg en case-management. De betekenissen en definities van de meeste concepten bleken substantieel veranderd te zijn gedurende de afgelopen decennia, en alle concepten waren conceptueel met elkaar verstrikt. Onderzoekers die echter één concept onderzochten, refereerden vrijwel nooit naar overlappende concepten. Zij leken voornamelijk binnen hun eigen conceptuele kader en literatuur te werken.

We identificeerden drie belangrijke thema's in de definities van continuïteit van zorg: (1) een vaste hulpverlener in iedere afzonderlijke zorgsetting die de patiënt kent en volgt; (2) communicatie van relevante patiënteninformatie tussen hulpverleners, en (3) samenwerking tussen hulpverleners, zowel binnen één specifieke zorgsetting als tussen verschillende zorgsettings, om zodoende de zorg op elkaar te laten aansluiten. Deze thema's komen ook in zekere mate terug in de gerelateerde concepten. Blijkbaar zijn dit dus kernthema's in de patiëntenzorg. We concluderen dat het waardevol kan zijn om een instrument te ontwikkelen waarmee we deze drie kernthema's universeel kunnen meten.

## **Hoofdstuk 3 Patiënten ervaringen met continuïteit van zorg**

Hoofdstuk 3 beschrijft de mate waarin verschillende patiëntengroepen continuïteit van zorg ervaren.

### **Hoofdstuk 3.1 Continuïteit van zorg ervaren door patiënten met hartfalen en de relatie met therapietrouw: een cross-sectioneel onderzoek**

In hoofdstuk 3.1 onderzochten we de ervaringen met continuïteit van zorg bij patiënten met hartfalen en analyseerden de relatie met therapietrouw. We zagen dat meer dan de helft van de patiënten geen enkele hulpverlener in de huisartsenpraktijk had gecontacteerd in het afgelopen jaar, hoewel de helft van hen contact had gehad met een cardioloog. Van de patiënten die het afgelopen jaar de huisartsenpraktijk wel hadden gecontacteerd, had ongeveer de helft contact met twee of meer hulpverleners gehad. De meeste patiënten ervoeren een goede mate van communicatie en samenwerking tussen hulpverleners in de huisartsenpraktijk (38% ervoer maximale team continuïteit) en tussen huisarts en cardioloog (51% ervoer maximale cross-boundary continuïteit). Echter 10-15% van de patiënten ervoer een zeer slechte mate van team en cross-boundary continuïteit. De therapietrouw was significant slechter bij patiënten die contact hadden met drie of meer hulpverleners. We vonden geen duidelijke relatie tussen therapietrouw en team of cross-boundary continuïteit.

### **Hoofdstuk 3.2 Continuïteit in verschillende zorgvormen en de relatie met kwaliteit van leven: een gerandomiseerd, gecontroleerde trial bij COPD patiënten**

In dit hoofdstuk onderzochten we in hoeverre de mate van ervaren continuïteit van zorg verandert na invoering van een zelf-management interventie of regelmatige controle door een praktijkondersteuner, ten opzichte van gebruikelijke zorg van de huisarts op initiatief van de patiënt. We onderzochten ook de relatie tussen ervaren continuïteit van zorg en kwaliteit van leven.

Patiënten die de gebruikelijke zorg van de huisarts ontvingen, ervoeren de hoogste mate van persoonlijke continuïteit, alhoewel de kans dat de patiënt geen enkele hulpverlener zag ook het grootst was in deze groep (29% vergeleken met 2% in de zelf-management groep en 5% in de groep die gecontroleerd werd door de praktijkondersteuner). We vonden geen verschillen in ervaren team continuïteit tussen de drie zorgvormen. Bovendien vonden we geen relatie tussen continuïteit

en veranderingen in kwaliteit van leven. We concluderen dat alhoewel persoonlijke continuïteit daalt na invoering van nieuwe zorgvormen, er geen bewijs is dat dit van invloed is op ervaren team continuïteit of kwaliteit van leven van COPD patiënten. Patiënten ervaren nog steeds dat de zorg soepel en samenhangend verloopt. Al met al vonden we geen bewijs dat de invoering van nieuwe zorgvormen voor COPD patiënten in de huisartsenpraktijk ontmoedigd moet worden.

### **Hoofdstuk 3.3 Continuïteit van zorg ervaren door patiënten met een risico op depressie in de eerste lijn**

In dit hoofdstuk onderzochten we de mate van ervaren continuïteit van zorg bij patiënten met een risico op depressie in de eerste lijn, en vergeleken deze met die van patiënten met een chronische somatische aandoening. De meeste patiënten met een risico op depressie hadden in het afgelopen jaar contact met verschillende hulpverleners in de gehele zorgketen. Ze ervoeren een hoge mate van team continuïteit, maar een lage mate van cross-boundary continuïteit. Vergeleken met patiënten met hartfalen contacteerden ze significant meer verschillende hulpverleners in de huisartsenpraktijk voor hun aandoening ( $p < 0.01$ ). Echter, patiënten met een risico op depressie ervoeren meer samenwerking tussen de hulpverleners in de huisartsenpraktijk: 2 punten op een 24-punts schaal ( $p = 0.03$ ). Daarentegen ervoeren ze minder samenwerking tussen hulpverleners uit verschillende zorgsettings: 2 punten op een 16-punts schaal ( $p = 0.01$ ). We concluderen dat hulpverleners zich moeten inspannen om de mate van persoonlijke continuïteit bij eerstelijns patiënten met een risico op depressie te verbeteren, omdat persoonlijke continuïteit een essentieel onderdeel is van het therapeutische proces bij deze patiënten. Bovendien zijn er interventies nodig om de samenwerking tussen hulpverleners uit verschillende zorgsettings te verbeteren, voornamelijk voor patiënten met een risico op depressie.

## **Hoofdstuk 4 Evaluatie van de meeteigenschappen van vragenlijsten die continuïteit van zorg meten: een systematische review**

Dit hoofdstuk beschrijft de resultaten van een systematische review naar vragenlijsten die continuïteit van zorg meten. De review beschrijft welke dimensies van continuïteit van zorg iedere vragenlijst meet en evalueert de meeteigenschappen van deze vragenlijsten. We includeerden 21 instrumenten. Tien instrumenten maten alle drie dimensies van continuïteit van zorg. De instrumenten waren ontwikkeld voor verschillende groepen patiënten of hulpverleners. Van de meeste instrumenten waren drie of vier van de zes meeteigenschappen onderzocht (voornamelijk interne consistentie, inhoudsvaliditeit, structurele validiteit en construct validiteit). Zes instrumenten scoorden positief op de kwaliteit van tenminste drie van de zes meeteigenschappen. We concluderen dat de meeste instrumenten problemen hebben met óf het aantal óf de kwaliteit van de onderzochte meeteigenschappen óf de mogelijkheid om alle drie dimensies van continuïteit van zorg te meten. Gebaseerd op de resultaten van deze review, adviseren wij om één van de vier meest veelbelovende instrumenten te gebruiken, afhankelijk van de te onderzoeken populatie: Diabetes Continuity of Care Questionnaire, Alberta Continuity of Services Scale-Mental Health, Heart Continuity of Care Questionnaire en Nijmegen Continuity Questionnaire.

## **Hoofdstuk 5 Nijmegen Continuity Questionnaire**

In de literatuur ontbrak het aan een goed gevalideerde vragenlijst die continuïteit van zorg meet als een multidimensioneel concept vanuit het perspectief van de patiënt, ongeacht de morbiditeit van de patiënt en de zorgsetting(s) waaruit de zorg geleverd wordt. Dit hoofdstuk beschrijft de ontwikkeling en validatie van deze vragenlijst: de Nijmegen Continuity Questionnaire (NCQ).

### **Hoofdstuk 5.1 Nijmegen Continuity Questionnaire: ontwikkeling en toetsing van een vragenlijst voor continuïteit van zorg**

In hoofdstuk 5.1 beschrijven we de ontwikkeling en initiële toetsing van de NCQ. De vragen in deze vragenlijst zijn gebaseerd op een systematische literatuur review

en analyse van 30 interviews met patiënten. We onderzochten de gezichtsvaliditeit door 15 patiënten met een chronische aandoening te interviewen terwijl zij de vragenlijst invulden en pasten de vragenlijst hierop aan. Vervolgens toetsten we de vragenlijst ('pilot testing') bij patiënten met een chronische aandoening in de huisartsenpraktijk. Met behulp van principale componenten analyse identificeerden we drie subschalen. We hebben de subschalen verfijnd door enkele items te excluseren vanwege verschillende redenen, bijvoorbeeld items die door veel mensen niet ingevuld waren. De interne consistentie van de subschalen varieerde van 0.82 tot 0.89. De gemiddelde interitem correlatie varieerde van 0.58 tot 0.71 en de correlatie tussen de subschalen varieerde van 0.42 tot 0.61. We concluderen dat de NCQ een begrijpelijke, betrouwbare en valide vragenlijst is. Er is echter meer uitgebreide toetsing van betrouwbaarheid, construct validiteit en responsiviteit nodig voordat de NCQ op grotere schaal kan worden gebruikt.

## **Hoofdstuk 5.2 Het meten van continuïteit van zorg: psychometrische eigenschappen van de Nijmegen Continuity Questionnaire**

Hoofdstuk 5.2 beschrijft de uitgebreidere toetsing van validiteit en betrouwbaarheid van de NCQ. We lieten de NCQ invullen door 268 patiënten met een chronische aandoening uit zowel de huisartsenpraktijk als de polikliniek van het ziekenhuis. Principale componenten analyse bevestigde de drie eerder gevonden subschalen: 'persoonlijke continuïteit: hulpverlener kent me' , 'persoonlijke continuïteit: hulpverlener is betrokken' en 'team/cross-boundary continuïteit'. De verwachte correlaties tussen de NCQ score en scores op instrumenten die kwaliteit van zorg, continuïteit, vertrouwen en tevredenheid meten, toonden een goede construct validiteit. De verwachte verschillen in NCQ subscores tussen verschillende subgroepen toonden onderscheidend vermogen ('discriminative ability') aan. De test-hertest betrouwbaarheid was hoog (de intraclass correlatie coëfficiënt varieerde tussen 0.71 en 0.82). Concluderend blijkt de NCQ valide, betrouwbaar en een goed onderscheidend vermogen te bezitten. De NCQ kan waardevol zijn om problemen in continuïteit van zorg te identificeren en interventies gericht op het verbeteren van continuïteit te evalueren. Bovendien kunnen we met de NCQ ervaringen van patiënten met verschillende aandoeningen en multimorbiditeit met elkaar vergelijken.

### **Hoofdstuk 5.3 Continuïteit van zorg bij voorkeur gemeten vanuit het perspectief van de patiënt**

In dit hoofdstuk reageren we op een artikel waarin continuïteit wordt gemeten vanuit het elektronisch medisch dossier. We lichtten verschillende redenen toe waarom wij denken dat continuïteit van zorg gemeten zou moeten worden vanuit het perspectief van de patiënt.

### **Hoofdstuk 5.4 Welke vragenlijst moet gebruikt worden voor het meten van continuïteit van zorg**

In hoofdstuk 5.4 reageren we op een artikel waarin een Spaanstalige vragenlijst wordt ontwikkeld die continuïteit van zorg meet vanuit het perspectief van de patiënt, onafhankelijk van morbiditeit en tussen verschillende zorgsettings: de Continuity of Care Across Care Levels Questionnaire (CCAENA). We beschrijven enkele verschillen tussen de CCAENA en de NCQ. We concluderen dat onderzoekers, die het meest geschikte instrument moeten kiezen voor het meten van continuïteit van zorg, eerst moeten beslissen wat zij precies willen meten, wat een acceptabele lengte van de vragenlijst is en hoe uitgebreid zij de vragenlijst getest willen hebben op de psychometrische eigenschappen.

### **Hoofdstuk 6 Discussie**

Dit laatste hoofdstuk plaatst de resultaten van dit proefschrift in perspectief, bespreekt enkele methodologische kwesties en geeft enkele implicaties en aanbevelingen voor de dagelijkse praktijk, toekomstig onderzoek en medisch onderwijs.

We concluderen dat patiënten met een chronische somatische aandoening een hoge mate van continuïteit van zorg ervaren, zelfs de patiënten die niet iedere keer hun huisarts zien maar regelmatig gecontroleerd worden door een praktijkondersteuner. Continuïteit van zorg voor patiënten met een risico op depressie kan verbeterd worden, met name de persoonlijke continuïteit en de continuïteit tussen verschillende zorgsettings. Om toekomstig onderzoek naar continuïteit van zorg of een van de gerelateerde concepten begrijpelijk en eenduidig te maken, is het

belangrijk dat het concept dat onderzocht wordt altijd duidelijk gedefinieerd wordt en dat onderzoekers zoveel mogelijk dezelfde vragenlijsten gebruiken. In dit proefschrift raadden we enkele veelbelovende vragenlijsten aan en ontwikkelden en valideerden we een vragenlijst die gebruikt kan worden onafhankelijk van de morbiditeit en de zorgsetting van de patiënt.

De belangrijkste aanbevelingen voor de dagelijkse praktijk zijn: (1) praktijkondersteuners zouden meer taken in de zorg kunnen overnemen waarbij ze nauw samenwerken met de huisarts en zo acteren als case management team; (2) het zou wenselijk zijn als het elektronisch medisch dossier beschikbaar is voor alle betrokken hulpverleners; en (3) huisartsen zouden zich in kleinere teams kunnen organiseren.

De belangrijkste aanbevelingen voor toekomstig onderzoek zijn: (1) het verder onderzoeken van de waarde van team en cross-boundary continuïteit; (2) de mate van ervaren continuïteit vergelijken tussen verschillende patiëntengroepen, en (3) het evalueren van interventies die gericht zijn op het verbeteren van continuïteit van zorg.

De belangrijkste aanbevelingen voor medisch onderwijs zijn: (1) het combineren van onderwijs voor verschillende medische specialismen, en (2) het gebruik van meetinstrumenten voor continuïteit van zorg in het medisch onderwijs.



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# **List of publications**



## List of publications

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# **Curriculum Vitae**



## Curriculum Vitae

**A**nnemarie Alberta Uijen was born on October 5<sup>th</sup> 1979 in Nijmegen (The Netherlands). She is the daughter of Theo Uijen and Bep Uijen - van Nistelrooij. She grew up with her two older brothers, Willem and Joost in Wijchen. She completed high school (VWO) in 1997 at the Maaswaal College in Wijchen. The following year she obtained her propedeuse in biomedical health sciences at the Radboud University Nijmegen Medical Centre. In 1998, she was allowed to enter medical school at the Radboud University Nijmegen Medical Centre. In 2001, she did an 1-month internship in a hospital in Zimbabwe. In 2003, she conducted a research elective at the department of general practice of the Radboud University Nijmegen Medical Centre, supervised by Dr. Carel Bakx en Dr. Henk Mokkink. During this period, her enthusiasm for scientific research and general practice increased. She graduated as a medical doctor in 2003 and started to work at the department for youth health care of Public Health Service (GGD) Stedendriehoek in Apeldoorn. In 2004, she started with the 3-year general practice (GP) residency training at the Radboud University Nijmegen Medical Centre. After 1.5 years (2006), she started to combine the GP residency training with her PhD project on continuity of care at the department of primary and community care of the Radboud University Nijmegen Medical Centre (the combined residency and research training programme, 'AIOTHO-programme'). The results of this PhD project are described in this thesis. In 2008, she finished GP training and started to work as a GP in the general practice of Peter van der Burgt in Heesch. In 2010, she settled down in Oosterhout (Nijmegen), joining Tim olde Hartman in a shared private practice. In this academic health care centre, they work together with four other practicing GPs (Charles Verhoeff, Erna van Ewijk-van der Wielen, Han Beekwilder and Inge Nobacht-Wagenvoort).

Recently, she became coordinator of the Continue Morbiditeits Registratie (CMR), an academic practice-based research network recording all health problems presented by their patients.

Annemarie lives together with Bram Loeffen, who works at Sprinckler Management and Consultancy. They are the proud parents of Mathijs (2010).

