Measuring and improving the quality of care from the healthcare user perspective: the Consumer Quality Index

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Measuring and improving the quality of care from the healthcare user perspective: the Consumer Quality Index

Het meten en verbeteren van de kwaliteit van zorg vanuit het zorggebruikers perspectief: de Consumer Quality Index

PROEFSCHRIFT

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‘Patients’ experiences should be the fundamental source of the definition of quality.’

‘Measurement is necessary but not sufficient for quality improvement.’

Donald M. Berwick

Contents

Part 1. Methodological aspects of the CQ-index

Part 2. The actual use of CQI information for quality improvement

1

General introduction

In recent years, the Dutch Ministry of Health, Welfare and Sport (VWS) has increasingly emphasized the position of healthcare users in relation to that of healthcare providers and health insurers (Delnoij et al., 2002). In so doing, the government stresses the measurement of quality of care and public disclosure of comparative quality information. The idea behind providing transparency is to eliminate the information asymmetry between the healthcare user and the healthcare provider. In addition, evaluating quality of care and the public disclosure of these outcomes are a potential mechanism to improve the quality of healthcare, another aim of the Dutch government. Generating comparative information is possible if all organisations in a sector use the same instrument(s), and measure, analyse and report the outcomes according to a similar format. An instrument that measures the quality of healthcare in such a standardized manner is the Consumer Quality Index (CQ-index or CQI). More specifically, CQI questionnaires assess what healthcare users regard as important and also allow to evaluate their actual experiences with healthcare.

The use of CQI methodology to provide quality information is new in the Dutch context, because the users themselves are considered as a source of information with respect to quality of care. Generally, information on quality (similar to data on adverse events and mortality) is drawn from clinical and administrative records. That healthcare users are increasingly involved in quality evaluations can be seen from the various Dutch research reports using CQI methodology to develop new CQI questionnaires (e.g. Damman et al., 2007; Wiegers et al., 2007; Zuidgeest et al., 2007; Claessen et al., 2009). However, until now, research on CQI methodology has focused on specific topics. A number of studies have explored the adjustment of CQI data (case mix) to provide comparative information between healthcare providers (Damman et al., 2009b; Damman et al., 2011), and others have investigated effective presentation approaches for healthcare users to select the ‘best’ healthcare provider (Damman et al., 2009b; Damman et al., 2010). Others examined the outcomes of CQI questionnaires, comparing healthcare experiences (over several years) or the importance that patients attach to different quality aspects (Hendriks et al., 2009; De Boer et al., 2010; Rademakers et al., 2011). However, studies on methodological aspects with respect to data collection are scarce, as are studies on the use of these data to improve quality (Winters et al., 2010).

The work in this thesis mainly addresses these two latter topics. First, the methodological aspects of the CQ-index are investigated. Second, the actual use of CQI information for quality improvement by healthcare organisations and client councils in the nursing and caring sector is addressed. The thesis ends with a discussion on the most important conclusions emerging from this work, and some recommendations are made.

In this introductory chapter, before outlining the aims and research questions, the Dutch healthcare sector is briefly described to provide an outline of the context in which the healthcare user's experiences are measured and published (**Section 1.1**). The main focus of **Section 1.2** is evaluation of the quality of healthcare from the user's perspective: here we address the background theory of CQI methodology, as well as the origin and current practice of CQI questionnaires. **Section 1.3** deals with the relation between transparency and quality of care. Finally, **Section 1.4** presents the aims, research questions and general outline of the thesis.

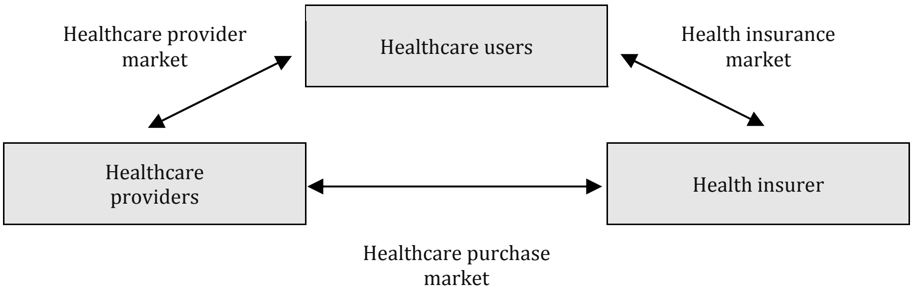
1.1 Dutch healthcare sector

As in most developed countries, Dutch policy aims at delivering care based on the needs of healthcare users. To put the healthcare user at the centre of care, the Dutch government introduced laws and regulations that contribute to the empowerment of healthcare users, as well as to the efficiency of care and the quality of care. One of the major changes in this respect was the reform of the Dutch healthcare system that was implemented in 2006.

1.1.1 Dutch healthcare reform and transparent quality information

With the introduction of the Health Insurance Act in 2006, the difference between the Sickness Funds and private health insurance disappeared, creating a universal healthcare insurance for all Dutch citizens (Van de Ven and Schut, 2008). Having passed this law, the government's role changed from regulating the healthcare system to controlling the quality, accessibility, and affordability of healthcare as a whole (Schaefer et al., 2010). Responsibilities were delegated to the actors in the three healthcare markets: the insurers, providers, and healthcare users (Commissie Structuur en Financiering Gezondheidszorg, 1987; Ministerie van VWS, 2001), thereby creating three regulated markets with freedom of choice: the healthcare provider market, the health insurance market, and the health purchase market (Figure 1.1).

Figure 1.1 The three types of healthcare markets in the Netherlands



On the health insurance market, this means that insured persons can switch insurer if they are dissatisfied with their premium or the quality of insured care. This provides incentives for insurers to offer good prices, packages, and purchase good quality of care for their insured. At the same time, insurers purchase care from different healthcare providers. These providers need to compete for contracts based on production, price, and quality (healthcare purchase market). On the healthcare provider market, healthcare users can choose providers based on the quality aspects they prefer (Culter, 2002; Schut and Van de Ven, 2005; Van de Ven and Schut, 2008).

For the function of the three healthcare markets, transparent information is a precondition. Transparent information should not only contain information on the price of services, but also on the quality of care (Delnoij, 2009a). This is captured in the Healthcare Market Regulation Act (WMG, 'Wet Marktordening Gezondheidszorg'), that was also implemented in 2006. According to this law, healthcare organisations are obliged to inform the public about price, quality, and other healthcare characteristics.

1.1.2 Quality information

What is quality of care and how can it be measured? Quality of care is defined by the Institute of Medicine (IOM) as: '*doing the right thing, at the right time, in the right way, for the right person, and having the best possible results*' (Institute of Medicine, 2001). This definition refers to a number of concepts which are considered as essential to quality: safety, effectiveness, patient-oriented, timeliness, efficiency, and equity. In the Dutch Care Institutions Quality Act three of these concepts *effectiveness* (neither underuse nor overuse of the best-available techniques), *efficiency* (constantly seeking to reduce the waste), and *patient orientation* (promoting an active role of patients in making decisions about their care) are addressed and summarized as an obligation to provide appropriate or responsible care (The Quality of Health Care Institutions Act, 1996; Institute of Medicine, 2001). Since the publication of the IOM report 'To err is human', there has been a substantial increase in the attention paid to patient safety research (Institute of Medicine, 2000). In the following years safety programs were introduced in Dutch hospitals: to evaluate the quality of care, various quality indicators are used to measure effectiveness and safety, as well as the patient's experiences.

Delivering appropriate care is, in the first place, the responsibility of the healthcare professionals. In the healthcare sector, the Dutch Health Care Inspectorate - which controls healthcare professionals/organisations based on legislation and regulation (Hout et al., 2010) - is the supervisor of the production of sets of quality indicators. The Health Care Inspectorate works jointly with healthcare providers, insurers, and representative groups of patients to produce appropriate indicator sets. To this end, in 2007 the Health Care Transparency Program ('Zichtbare Zorg') started to support sectors in making quality transparent, and to guarantee that published information is valid, reliable, and comparable. A website -www.zichtbarezorg.nl- was designed to provide an overview on the current state of affairs in different health sectors on different quality initiatives. The major focus of the Program is on effectiveness indicators (also called 'professional' or 'care content' indicators). The user perspective on quality aspects (such as access, timeliness, information and communication, and respectful treatment) is also a part of national quality frameworks. The same joint parties in the healthcare field are responsible for determining the effectiveness indicators, as well as the indicators from the user perspective. The development, implementation, and protection of the user perspective is supervised by the Dutch Centre for Consumer Experience in Health Care (see Section 1.2.2). Information gathered with the developed quality indicators of the quality framework are publicly disclosed on www.kiesBeter.nl, a special website of the Dutch government. Results of measurements are now available for the sectors hospitals, care for the disabled, homecare, residential care facilities, and nursing homes (www.kiesBeter.nl).

1.2 Evaluating quality of healthcare from the user perspective

1.2.1 The user perspective

Research on evaluating healthcare from the user perspective is often conceptualised as patient satisfaction, which has been extensively studied over the years. A definition of satisfaction is 'fulfilling expectations, needs or desires'

(Sitzia and Wood, 1997; Van Campen et al., 1995). Satisfaction suggests that healthcare users compare their expectations against the actual service and that this leads to either a positive or negative feeling. If expectations are exceeded, healthcare users are more satisfied (Harteloh et al., 1992). Because satisfaction is a result of both expectations and actual experience, variations in scores can be a result of differences in *expectations* or in *experiences* (Sixma et al., 1998). For example, when healthcare users have unrealistically high expectations their experiences will never meet these criteria thus resulting in low satisfaction. This is a serious problem when patients' perceptions are used as an outcome for identifying better performers, or to identify where improvements in quality are needed (Sofaer and Firminger, 2005).

To overcome this, considerable effort has been made to develop a method to 'report about events' (experiences). A definition of reporting on events is '*Reports on experiences illustrate if healthcare users did or did not experience an action in their interactions with healthcare providers and the healthcare system*' (Browne et al., 2010). Reporting on events tend to better reflect the quality of care. In addition, this type of reporting is more interpretable and actionable for quality improvement purposes (Cleary et al., 1991; Cleary et al., 1993; Sixma et al., 1998). For that reason, and for comparability of quality of care in the Netherlands, a new instrument has been developed to measure quality of care from the perspective of patients, clients, consumers or healthcare users: the Consumer Quality Index.

1.2.2 The Consumer Quality Index

The Consumer Quality Index (CQ-index or CQI) methodology is a standardised approach for:

1. Developing new CQI questionnaires.
2. Measuring, analysing, and reporting healthcare users' experiences in the Netherlands.

These experiences are collected by means of postal questionnaires, Internet questionnaires, or face-to-face interviews. If healthcare users are unable to express their experiences due to problems with thinking, understanding, and/or judgment, representatives (often family members) are asked about their experiences. The CQ-index is a registered trademark guarded by the Dutch Centre for Consumer Experience in Health Care (CKZ, 'Centrum Klantervaring Zorg'), which indicates that an approved contractor, according to CQI rules and instructions, collects information with an approved CQI questionnaire. Box 1.1 presents a brief overview of the CQ-index.

Box 1.1 Consumer Quality Index (Sixma et al., 2008a)

What is the Consumer Quality Index (CQ-index or CQI)?

- National standard to measure healthcare quality from the perspective of healthcare users.
- Based on American CAHPS and Dutch QUOTE instruments.
- Collection of instruments (surveys or interview protocols).
- Collection of protocols and guidelines for sampling, data collection, analysis, and reporting formats.
- Registered trademark owned by the Dutch Centre for Consumer Experience in Health Care.

What is measured by the CQ-index?

- What healthcare users find important in healthcare.
- What their actual experiences are.
- How they rate the overall quality of care.

What types of questions are included in the CQ-index?

- Frequency with which quality criteria are met: Never, sometimes, usually, and always.
- Importance of quality criteria: Not important, fairly important, important, and extremely important.
- Access to care and the degree to which lack of access is perceived as a problem: A big problem, a small problem, and not a problem.
- General rating of the quality of care: Scale from 0 (worst possible) to 10 (best possible).
- Effects of care and adherence to professional guidelines.
- Background characteristics: Age, gender, ethnicity, education, and general health status.

Origin

The CQ-index is based on the American CAHPS questionnaires (*Consumer Assessment of Healthcare Providers and Systems*) and QUOTE instruments (*QUality Of care Through the patient's Eyes*). The CQ-index was developed by NIVEL in cooperation with the department Social Medicine of the AMC (Academic Medical Center/University Hospital, Amsterdam) and health insurer Agis. From the CAHPS, frequency questions with answering categories on a four-point scale (never, sometimes, usually, and always) asking if the access to care was perceived as a problem (a big problem, a small problem, and not a problem), the layout and general ratings (ranging from 0 to 10, with a score of 10 indicating the best possible score) of the quality of care were adapted. CAHPS also refers to standardized protocols and manuals concerning sampling, data collection, data entry, data analyses, and data reporting. From QUOTE the importance of quality aspects (answering categories 'not important', 'fairly important', 'important', and 'extremely important') and the frequency of experienced events in a certain time period were adopted so that improvement scores could be calculated. The quality improvement score is a score that gives healthcare providers information about which quality aspects are particularly eligible for improvement; the higher the score, the more potential there is for improvement. This leads to two types of CQI surveys: one about *experiences* and one about the *importance* of quality aspects.

Developing new CQI questionnaires

The development of new CQI questionnaires can be divided into different phases (Rademakers et al., 2008). First, literature, existing surveys and guidelines are reviewed, with the aim to assemble a wide variety of quality of care aspects. In the second step, focus group discussions with patients are performed to incorporate the most important quality aspects from the patient's perspective into the pilot survey. After creating a draft pilot survey and incorporating stakeholders' input into this survey, the next step is to perform a pre-test among a small group of patients. The adapted pilot questionnaire is then tested in larger samples of 600 to 1,200 patients using quantitative methods; these tests examine the psychometric properties. Finally, the questionnaire is tested among a total of 2,000 to 4,000 patients of (minimum) 20 healthcare providers to assess differences between these providers. This is also called the test for discriminative power. This process of developing new questionnaires is guided by an expert group of different stakeholders (healthcare users, patient organisations, health insurers, healthcare providers, Health Care Inspectorate), which meet, debate and cooperate so that results are relevant for all parties (Delnoij et al., 2010).

CQI questionnaires and approved contractors

CQI questionnaires that are developed according to the guidelines and instructions are formally approved by the Dutch Centre for Consumer Experience in Health Care and are published on their website, www.centrumklantervaringzorg.nl. This Centre develops, implements, and protects the national standard -the CQ-index- for valid and reliable measurements and comparisons of consumer experiences in healthcare. Besides its task to approve new questionnaires, the Centre also evaluates whether approved contractors follow the CQI rules and guidelines, and give a CQI accreditation if they do so. Thus, a CQI accreditation is required to be allowed to conduct CQI research (from sampling to reporting) and is partly based on the ISO 20252 quality system developed for market, opinion, and social research. Organisations can also get an accreditation to do a part of the process of CQI research. For example, approved contractors may only perform interviews and/or send postal questionnaires and/or obtain responses through the Internet. The rules and instructions that need to be followed are written down in the Manual *measuring* and *reporting* about sampling and data collection (part 1), cleaning data and comparative analysis (part 2), and reporting (part 3) (Sixma et al., 2009; Sixma et al., 2008b; Sixma et al., 2008c). The Manual with rules and instructions is adapted when necessary and follow developments in the field of practice and research.

Users of CQI information

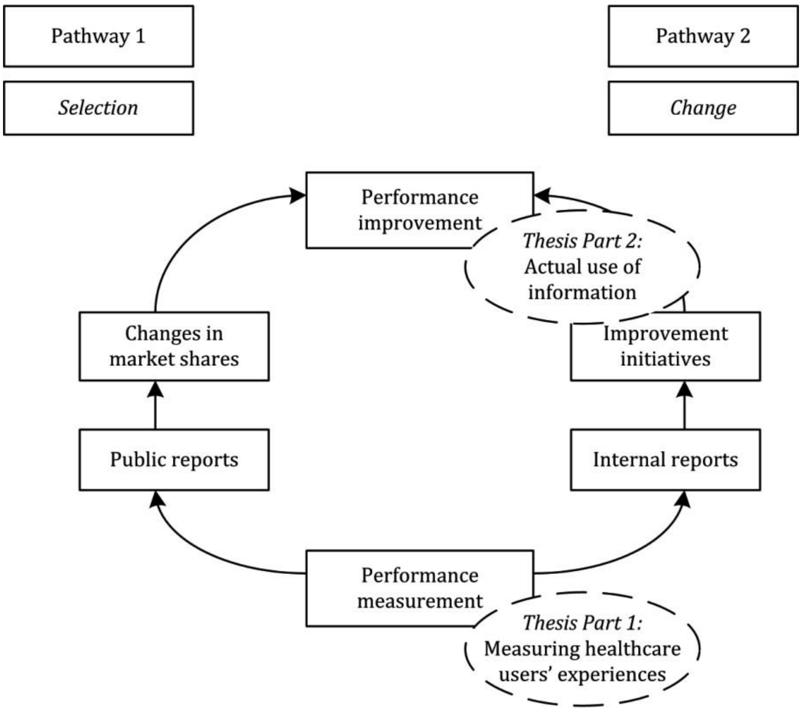
One of the goals of the CQ-index is to make the healthcare sector transparent about healthcare users' experiences for different stakeholders (Delnoij et al., 2010). Using standardized information is efficient; several parties (each with their own needs) are provided with performance information through one single measurement. Collected information should serve seven users:

1. Healthcare users on the healthcare market who are increasingly expected to act as informed decision makers.
2. Managers and professionals in healthcare to monitor their healthcare quality.
3. Health insurers on the health purchaser market.
4. Patient and client organisations that represent patients' interests and needs.
5. Health Care Inspectorate to supervise healthcare quality.
6. Government to monitor general healthcare quality performance over years and across healthcare sectors.
7. Researchers to address various scientific questions.

1.3 Healthcare organisations: measuring and improving quality of care

Among the seven stakeholders that should use CQI information are the managers and/or professionals of healthcare organisations. Based on CQI information, organisations can identify areas in which they can improve their quality of care. Berwick et al. (2003) describe a potential mechanism between measuring quality of care and improving care. Their theory includes two linked and synergistic pathways for the relationship between them: the selection pathway and the change pathway (Figure 1.2).

Figure 1.2 The selection and change pathways, based on the principles of quality measurement and improvement (Berwick et al., 2003)



The first pathway (namely: *selection*) implies that healthcare users first identify the outcomes of importance to them, then find information about the performance level of the healthcare professional and healthcare organisations, and then choose. Consequently, the selection pathway will not automatically improve the care provided by healthcare organisations, but market shares of healthcare organisations will shift: organisations with high scores will attract more healthcare users than organisations with lower scores (Berwick et al., 2003; Marshall et al., 2003). In theory this is a strong mechanism; however, research results show that publishing performance outcomes has limited influence on the active use of information by healthcare users (Fung et al., 2008; Faber et al., 2009). Some researchers argue that it is only a matter of time before healthcare users become active, because the right information will be available or because they are becoming more accustomed to the idea of selecting (Groenewoud, 2008). Others state that we cannot expect healthcare consumers to *select* the best provider, but that healthcare providers need to *change* and transform the care delivery to these users (Porter, 2008).

The second pathway (namely: *change*) presumes that healthcare organisations start initiatives to improve the quality of care after they are informed about their own performance generating knowledge about processes and results. This pathway requires that the healthcare organisations and care delivery staff take actions based on the results. To take action, the organisation needs reliable information, needs to educate and train employees in techniques for improvement, needs time and change management to alter core work processes, needs to align organisational incentives with care improvement objectives, and needs leadership to inspire (Berwick et al., 2003). For its effect the mechanism relies on the ability of healthcare organisations to undertake systematic change. Measurement alone will not suffice; it requires motivation to change (Berwick et al., 2003; Marshall et al., 2003; Fung et al., 2008). Intrinsic motivators like pride, love, the need for achievement or curiosity are very powerful for individuals, but if care is delivered in complex systems where many care providers are active, this is not sufficient. External motivation, like selection by healthcare users and health insurers, or regulation is also a powerful mechanism that interlinks the two pathways. These motivations can lead to actually using the performance scores to improve performance.

For example, in the USA, after receiving performance information, nursing homes have investigated the reasons for their scores, reorganized quality improvement programs, and started new quality-assurance programs (Castle, 2005; Mukamel et al., 2007; Werner et al., 2009). In hospitals the quality improvement activities were stimulated after publicly releasing performance data (Fung et al., 2008). Furthermore, nursing homes (Mukamel et al., 2007) and health insurers (Hendriks et al., 2009) with poor quality scores reported more improvement actions, or increased their quality scores, compared with homes and insurers with better scores.

1.4 Overview of the thesis

Following the rationale to measure the quality of healthcare organisations in order to improve healthcare quality, this thesis is divided into two parts. *Part 1* provides information on the methodological aspects regarding the measurement of healthcare user's experiences with quality of care, and *Part 2* provides information on the actual use of information by healthcare organisations and client councils in the sector nursing and caring to improve the quality of healthcare.

1.4.1 Research aim and research questions

The aim of this work is to gain insight into the methodological aspects of measuring the user perspective and the actual use of healthcare user's experience information. Therefore, this thesis addresses the following research questions:

1. *'How is quality of care from the user perspective measured in the CQ-index? More specifically: How is the reliability and validity of the CQ-index tested?' (Part 1)*

2. *'To what extent is CQI information used in nursing homes and homes for the elderly for quality improvement?' (Part 2)*

3. *'To what extent do CQI scores of nursing homes, homes for the elderly, and homecare organisations change over time?' (Part 2)*

1.4.2 Design, methods, and structure of thesis

Part 1. Methodological aspects of the CQ-index

The first research question is addressed by means of studies investigating different CQI surveys. These studies serve to illustrate the CQI methodology.

Firstly, developing the CQI 'Rheumatoid Arthritis' is an example on how quality of care through the perspective of healthcare users is assessed in the Netherlands, up to the phase of testing the psychometric properties of the questionnaire. Not only were the experiences of healthcare users measured, but also the importance they attached to different quality aspects is addressed. In addition, improvement scores were calculated (**Chapter 2**).

Secondly, to establish whether data collection methods other than standard paper questionnaires are an option for measuring healthcare users' experiences, two data collection methods were compared: a mixed-mode survey (i.e. Internet supplemented with a paper questionnaire for non-respondents) versus paper surveys only. Data were assessed during the last phase of developing a new CQI questionnaire, i.e. the test of determining discriminative power of the CQI 'Breast Care' (**Chapter 3**).

Thirdly, in **Chapter 4,** data of two previously conducted pre-tests (developing the CQI 'Rheumatoid Arthritis' and the CQI 'Breast Care') were compared with a new reporting framework for cognitive interviewing (CIRF) to investigate how a more systematic procedure for pretesting patient experience questionnaires could be accomplished, and how pretesting results could be reported.

Lastly, in the case that healthcare users are not able to express their experiences (e.g. people with dementia) regarding the quality of care, their representatives (e.g. family members) are asked to provide this information via paper questionnaires. On the other hand, nursing staff can also observe the behaviour of residents with dementia to obtain this information. Therefore, in **Chapter 5**, these two methods (paper questionnaires filled out by family members and observational assessment of nursing staff) were compared.

Part 2. The actual use of CQI information for quality improvement
To answer the second research question, **Chapter 6** presents a study on the factors that determine the actual use of information of the CQI 'Long-term Care'. Data collection for this study contained interviews with the staff (day-to-day worker, representatives of middle and senior management and quality manager) of twelve healthcare organisations.

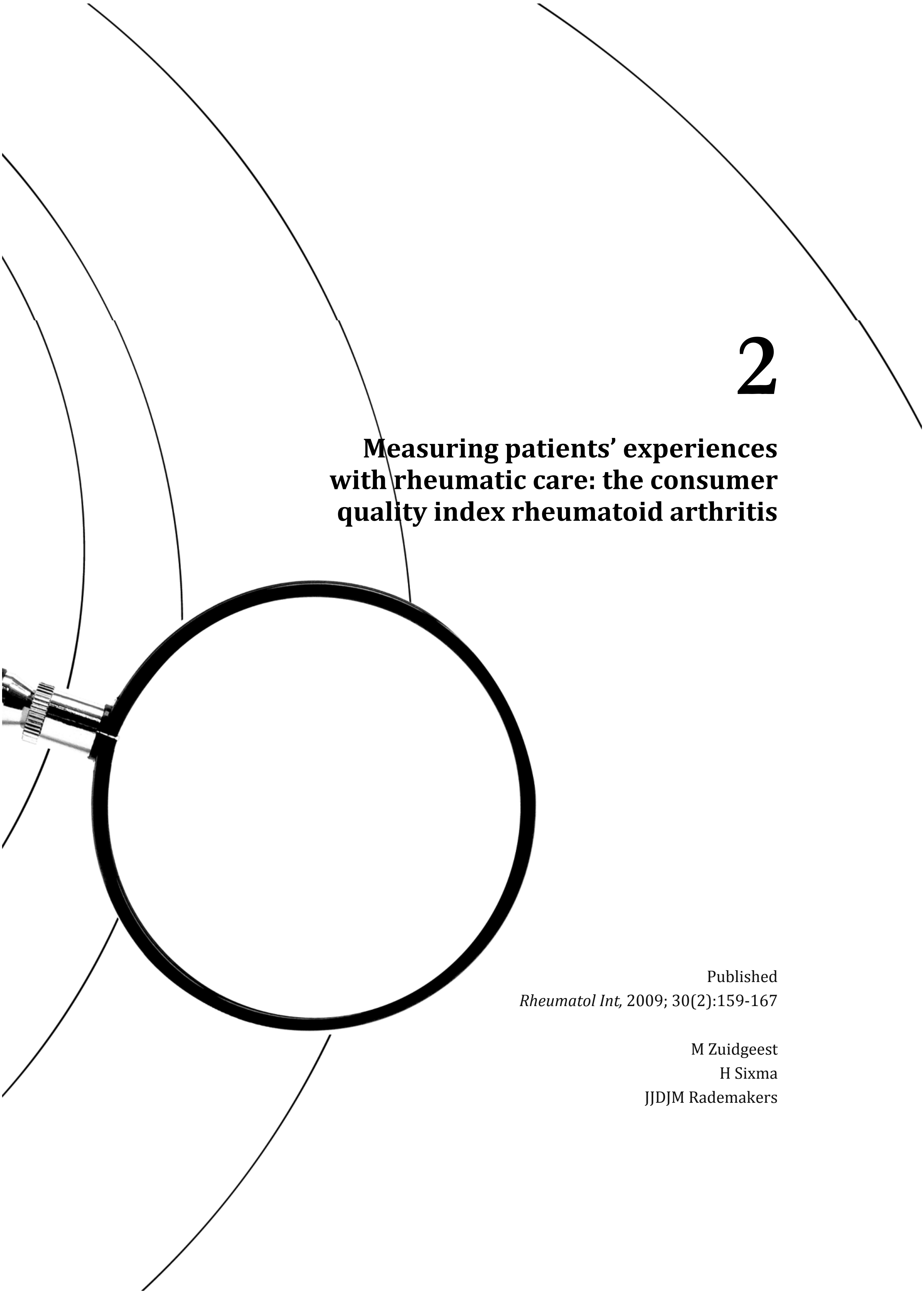
Chapter 7 deals with the involvement of client councils in the process of measuring healthcare users' experiences and their perception that they can exercise their right on (quality) issues in healthcare organisation. To investigate this, postal questionnaires were sent to 1,540 client councils of residential care facilities and nursing homes.

To answer the third research question, in **Chapter 8** we used CQI information that was collected to provide information for the national quality framework Responsible Care in the sector Nursing, Caring and Homecare. This information is publicly disclosed on the Internet. According to theory, public disclosure and information regarding organisations' own performance should stimulate quality improvement initiatives. Therefore, we investigated whether CQI scores of residential care facilities, nursing homes and homecare organisations show differences in performance scores over the years. Data were available for two measurement points.

Finally, **Chapter 9** presents a summary and discussion of the major findings of this thesis, and recommendations are made based on the work in the previous chapters.

Part 1.

Methodological aspects of the CQ-index



2

Measuring patients' experiences with rheumatic care: the consumer quality index rheumatoid arthritis

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2.1 Introduction

Quality of care has become increasingly important in the evaluation of healthcare and healthcare services (Avis et al., 1995; Richards, 1999; Groenewegen et al., 2005). Evaluating rheumatic healthcare quality is a major issue given the care need profile of patients with rheumatoid arthritis (RA) and their long-term dependency on healthcare (Jacobi et al., 2001). Evaluation of quality of care is often performed by healthcare professionals. However, patients' perspectives on healthcare quality differ from the views of healthcare professionals and policy makers (Potts et al., 1984; Batalden, 1987; Bensing, 1991). Also, patients' perspectives on the quality of care have become more prominent in research and policy since the introduction of the concept of patient-centred care in many countries (Gabel et al., 2002; Herzlinger and Parsa-Parsi, 2004). This concept aims to empower patients with respect to their healthcare decisions and to (re)structure the healthcare system according to their needs.

Patients' views on quality of care have often been conceptualised as patient satisfaction (Van Campen et al., 1995; Kirsner and Federman, 1997; Sitzia and Wood, 1997). A disadvantage of these surveys is that the scores influenced by personal preference and patient expectation (Yang and Thoms, 2000). Caregivers and healthcare services cannot influence patients' expectations, but can change the actual experiences. Therefore, a more refined instrument for evaluating healthcare quality from the patients' perspective seems necessary. The Consumer Quality index (CQ-index or CQI) provides such an instrument (Delnoij et al., 2006; Sixma et al., 2007).

The CQ-index is based on two families of surveys that measures patients' experiences. The first family of surveys that is used is the Consumer Assessment of Healthcare Providers and Systems (CAHPS®), which is well-established and widely used in the USA (www.cahps.ahrq.gov). This methodology comprises standardized protocols and manuals concerning sampling, data collection, data-entry, data-analysis and data reporting, which are also used as reference for CQI research. Furthermore, the lay out and answering categories on a four-point scale (never, sometimes, usually, always), three-point scale (not a problem, a small problem, a big problem), global ratings (ranging from 0 to 10, with a score of 10 indicating the best possible score) and referring to the frequency of experienced events in a certain time period ('In the last 12 months, how often…') were taken from the CAHPS. The second family of instruments that is used is QUOTE (QUality Of care Through the patient's Eyes), which has been developed in the Netherlands (Nijkamp et al., 2002; Sixma et al., 1998; Sixma et al., 2000; Van der Eijk et al., 2001; Van Campen, 1998a). From this methodology the questions about importance (answering categories 'not important', 'fairly important', 'important' and 'extremely important') were added into the CQI methodology. Also, the concept to include disease-specific items of healthcare services is derived from the QUOTE instruments. The combination of these survey features has as outcome that every CQ-index exists of two parts: one about patients' experiences and one about the important patients' award to quality aspects.

Within rapid development of CQI instruments (up to 25), priority has been given to the development of a new instrument for patients with RA (Rheumatoid Arthritis). The CQI 'RA' is a disease-specific survey, designed to assess patients' experiences and importance on quality aspects. Patients with RA are 'heavy healthcare users', most of them use two types of healthcare services besides the rheumatologist (Jacobi et al., 2001). For patients to decide which specific provider to choose, consumer information about the quality of care of these providers can be helpful. Measuring patient experiences enables us to provide such information. In addition, the CQ-index allows professionals to compare the quality of care they provide with colleagues in the same profession. This instrument may also be an important tool for healthcare providers to monitor their quality of care. Finally, the CQI information identifies elements of care that, according to patients, are particularly eligible for improvement.

The aim of this article is to provide an instrument to measure patients' experiences about the healthcare. For this purpose, information on the content and psychometric characteristics of the developed CQI 'RA', as well as on the importance patients assign to the different quality aspects are presented.

2.2 Patients and methods

2.2.1 The creation of the CQI 'Rheumatoid Arthritis' questionnaire

The survey was formed following the protocols of the CQI standard, which is based on the CAHPS and the QUOTE (Dillman, 2000; Sixma et al., 2007). A draft questionnaire was constructed using input from two focus group discussions with in total 22 patients with RA, existing questionnaires measuring patients' experiences with quality of rheumatic care (e.g. QUOTE-Rheumatic patients (Van Campen et al., 1998a) and professional guidelines for RA (developed by the Dutch Institute for Healthcare Improvement [CBO]). The draft questionnaire was presented to an expert panel (health insurers, a patient organisation, healthcare providers, patients with RA) to assemble comments and improve the instrument. Their comments were included in the second draft of the questionnaire, which was used, after cognitive testing, to test its psychometric properties.

CQI 'RA' Experience questionnaire

The pilot instrument consisted of two parts, the CQI 'RA' Experience and the CQI 'RA' Importance. The first part, the CQI 'RA' Experience questionnaire, contained 15 items on person characteristics (e.g. age, education, patient's self-reported physical and psychological health), 6 global ratings (of caregiver during control of care, professional who gives medication, specialized nurse, therapist, medical specialist who performs the surgical procedure, and rheumatic care in general), and 114 experience items regarding the actual experiences of patients with specific quality aspects of care. Other items were instruction items or items with answering categories other than the standard format. The items were divided in 16 themes (Table 2.1).

Table 2.1 Content CQI 'RA' Experience (number of questions)

1. Introduction (1)	9. Occupational physician (8)
2. Care by general practitioner (7)	10. Cooperation and adaptation (9)
3. First visit rheumatologist (9)	11. Operation (11)
4. Control of care (20)	12. Information and knowledge (11)
5. Prescribing medication (5)	13. Financial compensations (6)
6. Specialised nurse (13)	14. Global rating rheumatic care (1)
7. Therapist about RA (12)	15. General items (15)
8. Psychosocial care (12)	16. Improving questionnaire (2)

The answering formats of the experience items were:

1. Never, sometimes, usually, and always.
2. Not a problem, a small problem, and a big problem.
3. Yes and no.

The global ratings ranged from 0 to 10, with a score of 10 indicating the best possible score. If questions were not applicable an answering option was added. The grade of education was dived into 'no education and secondary education' and 'higher than secondary education'. The self-reported physical and psychological health was assessed using a five-point scale: 'excellent', 'very good', 'good', 'fair', and 'poor'. The instrument instructed respondents to reflect on their experiences in the last 12 months.

CQI 'RA' Importance questionnaire

In the second part, the CQI 'RA' Importance questionnaire, 69 importance items were included, which were designed to assess the importance that patients attribute to aspects of healthcare, using a four-point scale: 'not important', 'fairly important', 'important', and 'extremely important'. The importance survey contained fewer items because quality aspects such as 'to be taken seriously' applied to healthcare professionals in general rather than each healthcare professional of a particular discipline.

2.2.2 Subjects

A total of 590 patients with RA were selected from the files of four health insurers. Inclusion criteria were:

1. Being older than 18 years of age.
2. Having received rheumatic care in the last 12 months (based on declared costs).
3. Not being approached in the past for other CQI surveys.

Selecting patients from the files of health insurers provided us with a random selection of the RA population, which was heterogeneous in treatments they received.

2.2.3 Data collection

This study was conducted in the Netherlands in the summer of 2007. All selected patients received a mailing from their health insurers with the request to fill out the CQI 'RA' Experience and CQI 'RA' Importance questionnaires. A 'thank you' card was sent to all patients one week later. Non-respondents received a second survey and letter in the fifth week, and a reminder letter in the seventh week. The mailing packs with the questionnaires included a stamped addressed envelope (Dillman, 2000).

2.2.4 Analyses

Response

The response rate was calculated after excluding the patients who were not willing or able to participate, replied double, or responded negatively to the question whether they had received rheumatic care in the past 12 months. Furthermore, patients who stated that they did not answer the questions themselves and who filled out less than half of the core items (items that should be answered by all respondents) were also excluded (CAHPS Survey Users' Network, 2002; Sixma et al., 2007).

Subjects

To determine whether the respondents and non-respondents differ they were compared on age (*t* test) and sex (χ^2 test).

Dimension structure

Conducting one explorative factor analysis with a direct oblimin rotation was not possible, because not all items applied to all patients. Therefore, several explorative factor analyses (EFA) with a direct oblimin rotation were conducted on groups of different items (themes) of the experience survey to examine the structure of the questionnaire and the relationship between items with similar answering categories. The factor analyses were accurate if the Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) was higher than 0.60. The number of factors per factor analyse was determined by Kaiser's criterion (Eigenvalues >1.00). If the factor loading of an item exceeded the criterion of 0.40, the item was assigned to that particular factor. If an item loaded across multiple factors, it was assigned to the factor where it had the highest loading.

Reliability

The internal consistency reliability of the scales from the experience data was estimated using Cronbach's alpha, where an alpha value of 0.70 or more was considered satisfactory (Cronbach, 1951). Item-total correlations (ITC) were also calculated, to correct for item overlap and check for homogeneity of the simple-summated scales, which were created from items that loaded strongly on the factors (criterion >0.4 ITC) (Streiner and Norman, 2003). For one module (first visit rheumatologist), the reliability of a scale was calculated by the Kuder-Richardson Formula 20 (KR-20), which is the alternative method to assess the reliability for dichotome items (yes/no) (Ward, 1997).

Importance

The importance scores were calculated to determine the mean importance of each quality aspect (not important=1, important=2, fairly important=3, extremely important=4).

Quality improvement score

This score represents the proportion of respondents who had have a negative experience ('never/sometimes', 'no' or 'a big problem') on a quality aspect multiplied by the importance score of the same quality aspect (range 1 'not important' to 4 'extremely important'). The quality improvement score is a score that gives healthcare providers information about which quality aspects are particularly eligible for improvement; the higher the score, the more potential there is for improvement. Analyses were performed using SPSS 14.0®.

2.3 Results

2.3.1 Response

At the end of the data collection period, 472 patients returned the CQI 'RA' Experience questionnaire en 445 patients returned the CQI 'RA' Importance questionnaire. After exclusion, the experience data of 407 patients (69%) and the importance data of 385 patients (65%) were analysed.

2.3.2 Subjects

The majority of the respondents were female (73%), and had an education on a secondary or lower level (50%). The self-reported physical health was moderate (47%) or good (41%), and the self-reported psychological health was mostly good (61%) followed by very good (12%) and excellent (12%). Respondents and non-respondents differed from each other concerning age (mean age was 62.9 versus 59.7 years; t=2.86; p=.004), but not concerning gender (χ^2=1.76; p=.18).

2.3.3 Dimensional structure experience survey

Eight explorative factor analyses (EFA) were performed for different themes of the CQI 'RA' experience survey (themes 4-10, 13; see Table 2.1). For one explorative factor analysis (theme 13 'Financial compensation') the KMO value was not sufficient (KMO=0.50). The primary factor loadings based on the pattern matrix are presented in Table 2.2. In total, twelve factors were formed:

1. Conduct caregiver during control of care.
2. Competence caregiver during control of care.
3. Remaining items control of care.
4. Competence caregiver medication.
5. Conduct specialized nurse.
6. Competence specialised nurse.
7. Conduct therapist.
8. Remaining items therapist.
9. Conduct psychological care.
10. Conduct occupational physician.
11. Cooperation.
12. Remaining items cooperation.

With the exception of question 35 (Q35, factor 1, α=0.38), all items used in the scales exhibited factor loadings exceeding 0.40. Q35 was removed from factor 1. All items which did not fit in a scale were reported separately (not presented in this article).

Reliability

The fourth column (α1) of Table 2.2 shows the Cronbach's alpha coefficients for the 12 formed factors which ranged from 0.00 to 0.94. Three factors had poor reliability resulting in Cronbach's alpha coefficients of 0.00, 0.37, and 0.39. Removal of any of the items did not increase the alpha coefficient to the threshold of 0.70 (see column 5 of Table 2.2), and therefore, we were not able to create reliable scales with these items. One factor displayed a relatively low reliability (factor 6; α=0.67), after removing Q50 from this factor, Cronbach's alpha increased to 0.86. The internal consistency was tested for a thirteenth factor consisting of seven dichotomous items. In this factor Q17 had a low ITC, which showed that this question does not fit well in this factor. Excluding this item resulted in a KR-20 coefficient of 0.86, indicating a good reliability for factor 13 'conduct rheumatologist'. Regarding the other formed scales, (except for the scales with a poor reliability) the item-total correlation was adequate. In total, ten reliable scales ranging from 0.77 to 0.94 were constructed (factors 1-2, 4-7, 9-11, 13; see Table 2.2).

Table 2.2 Factor loadings of the items in the CQI 'RA' Experience questionnaire according to the eight explorative factor analysis with oblim rotation (EFA1-EFA8)

Nr	**Item description**	**Factor loading**	**α1**	**α2**	**ITC**
EFA 1	*Factor 1:* ***Conduct caregiver control of care*** *(rheumatologist or specialized nurse)*		0.86		
Q20.	Caregiver took me seriously	0.83		0.85	0.66
Q21.	Caregiver spent enough time	0.82		0.83	0.72
Q22.	Caregiver listened carefully	0.88		0.81	0.80
Q23.	Caregiver took interest in you as a person	0.88		0.80	0.77
Q24.	Caregiver took into account your personal situation	0.80		0.86	0.68
Q35.	Caregiver was always the same person	**0.38**[a]		-	-

- table 2.2 continues -

- table 2.2 continued -

Nr	Item description	Factor loading	α1	α2	ITC
EFA 1	*Factor 2:* ***Competence caregiver control of care***		0.85		
Q29	Caregiver explained research results clearly	0.42		0.82	0.63
Q30.	Discussed whether the current treatment was best for you	0.68		0.81	0.71
Q31.	Decisions about treatment were shared between you	0.73		0.81	0.71
	and caregiver	0.61		0.80	0.76
Q32.	Caregiver took into account your wishes about treatment	0.86		**0.86**^{b}	0.41
Q33.	Rapid access to rheumatologist if complaints got worse	0.74		0.83	0.60
Q34.	Opportunity to ask questions				
EFA 1	*Factor 3: Remaining items control of care*		0.00		
Q25.	Seen within 15 minutes of your appointment	-0.60		n.c.	**-0.00**^{c}
Q36.	Caregiver referred you to other caregivers if you wanted	0.69		n.c.	**-0.00**
EFA 2	*Factor 4:* ***Competence medication giver***		0.77		
Q39.	Caregiver was aware of your personal situation	0.81		0.72	0.57
Q40.	Caregiver considered other medication when prescribing drugs	0.86		0.64	0.65
Q41.	Receiving adequate assistance with administering drugs	0.82		0.70	0.59
EFA 3	*Factor 5:* ***Conduct specialized nurse***		0.89		
Q44.	Specialised nurse took you seriously	0.82		0.86	0.76
Q45.	Specialised nurse spent enough time	0.87		0.85	0.82
Q46.	Specialised nurse listened carefully	0.79		0.85	0.80
Q47.	Specialised nurse showed personal interest	0.86		0.89	0.64
Q48.	Specialised nurse explained information clearly	0.79		0.87	0.65
Q49.	Opportunity to ask questions	0.70		0.87	0.67
EFA 3	*Factor 6:* ***Competence specialized nurse***		0.77		
Q50.	Specialised nurse referred you to other caregivers if you wanted	0.70		0.86	0.30
Q51.	Specialised nurse gave advice, instructions and/or education about RA	0.78		0.41	0.66
Q52.	Specialised nurse advised you to function as normal as possible	0.76		0.45	0.58
EFA 4	*Factor 7:* ***Conduct therapist***		0.81		
Q60.	Therapist spent enough time	0.71		0.76	0.65
Q61.	Therapist listened carefully	0.80		0.74	0.74
Q62.	Therapist had personal attention for you	0.77		0.77	0.63
Q63.	Therapist clarified the importance of compliance to his	0.69		0.80	0.53
	treatment	0.64		0.80	0.51

- table 2.2 continues -

- table 2.2 continued -

Nr	Item description	Factor loading	α1	α2	ITC
Q66	Opportunity to ask questions	0.64		0.80	0.51
EFA 4	*Factor 8: Remaining items therapist*		0.37		
Q59.	Therapist took you seriously	-0.62		**0.53**	**0.01**
Q64.	Treatment improved daily activities	0.55		-0.03	**0.37**
Q65.	Therapist informed you about possible adjustments	0.50		0.07	**0.31**
EFA 5	*Factor 9: **Conduct psychosocial caregiver***		0.94		
Q72.	Psychosocial caregiver took you seriously	0.82		0.94	0.75
Q73.	Psychosocial caregiver spent enough time	0.96		0.93	0.93
Q74.	Psychosocial caregiver listened carefully	0.94		0.93	0.89
Q75.	Psychosocial caregiver showed personal attention	0.96		0.93	0.92
Q76.	Psychosocial caregiver enquired possible emotional problems	0.96		0.93	0.94
Q77.	Psychosocial caregiver enquired your partner or/and children	0.90		0.93	0.85
Q78.	Psychosocial caregiver advised you, despite the rheumatoid arthritis, to function as good as possible	0.56		**0.97**	0.50
Q79.	Opportunity to ask questions	0.91		0.93	0.88
EFA 6	*Factor 10: **Conduct occupational physician***		0.89		
Q82.	Occupational physician took you seriously	0.82		0.88	0.73
Q83.	Occupational physician spent enough time	0.90		0.87	0.81
Q84.	Occupational physician listened carefully	0.87		0.87	0.77
Q85.	Occupational physician had personal attention	0.93		0.85	0.88
Q86.	Occupational physician advised you to function as normal as possible	0.75		0.89	0.67
Q87.	Opportunity to ask questions	0.68		0.90	0.58
EFA 7	*Factor 11: **Cooperation***		0.89		
Q88.	Parallel treatments were adjusted to one another	0.85		0.86	0.77
Q89.	Various advises were integrated	0.89		0.85	0.81
Q90.	Caregivers kept their appointments	0.88		0.85	0.83
Q92	Caregivers were aware of other activities of caregivers	0.78		0.89	0.67
Q94.	After leaving a message, you were phoned within one workday	0.76		0.89	0.63
EFA 8	*Factor 12: Remaining items cooperation*		0.39		
Q91.	Caregivers gave conflicting information	0.77		-	**0.26**
Q93.	Telling the same story more than once to different caregivers	0.82		-	**0.26**

- table 2.2 continues -

- table 2.2 continued -

Nr	**Item description**	**Factor loading**	**α1**	**α2**	**ITC**
-	*Factor 13:* ***Conduct rheumatologist***		0.87[d]		
Q10.	Rheumatologist took you seriously	-		0.74	0.59
Q11.	Rheumatologist spent enough time	-		0.70	0.80
Q12.	Rheumatologist listened carefully	-		0.70	0.80
Q13.	Rheumatologist showed personal attention	-		0.72	0.58
Q15.	Rheumatologist explained things clearly	-		0.74	0.51
Q16.	Opportunity to ask questions	-		0.74	0.61
Q17.	Rheumatologist referred to a specialized nurse	-		0.86	**0.23**

Factor loading, Cronbach's alpha whole scale (α1), Cronbach's alpha of scale if item deleted (α2), and the item total correlation correcting for overlap (ITC) are displayed.
With two items in one scale, Cronbach's alpha of scale if item is deleted (α2) cannot be calculated
n.c. = not calculated

[a] Bold typeface factor loading: item does not meet factor loading criterion of 0.4
[b] Bold typeface α2: Cronbach's alpha improves when item is deleted
[c] Bold typeface ITC: item does not meet item total correlation criterion of 0.4
[d] KR-20 instead of α

Importance scores

Table 2.3 presents the ten most important quality aspects mentioned by the respondents.

Table 2.3 The ten highest importance scores

Question	***To what extent would you consider the following important:***	**Importance score**
Q40.	...caregivers consider your other medication when prescribing drugs	3.65
Q100.	...the specialist explains the risks of a surgical procedure	3.62
Q7.	... you have a rapid accessibility to a rheumatologist after referral	3.60
Q6.	...the general practitioner quickly provides referral to rheumatologist	3.59
Q102.	... you are being informed about long-term consequences of a surgical procedure	3.58
Q33.	...you are being rapidly sent to the rheumatologist if your complaints get worse	3.57
Q101.	...a specialist explains the surgical procedure.	3.56
Q3.	...caregivers take you seriously	3.51
Q103.	...the specialist provides rules for what (not) to do after a surgical procedure	3.50
Q96.	...discuss arrangements regarding what to do when RA deteriorates, like in an acute attack	3.49

Patients rate the item ‘caregivers consider other medication when prescribing drugs’ as the most important quality aspect (importance score=3.7). Information about the risks and the long-term consequences of a surgical procedure, the process of the surgical procedure, and the rules for what (not) to do after a surgical procedure are important (3.5-3.6). The rapid accessibility and availability of care (3.5-3.6) are also valued highly. Finally, caregivers have to take patients seriously (3.5) and patients need to discuss arrangements about what to do when RA deteriorates (3.5). Items that did not fit a scale were candidates to be removed from the questionnaire (reliability analysis). Other arguments for adjusting this instrument were based on the dimensional structure, importance scores, and comments of expert panel. For more details see report of Zuidgeest et al. (2007).

2.3.4 Quality improvement score

In Table 2.4, ten quality aspects with improvement scores are presented.

Table 2.4 Top ten quality improvement scores (Q) with corresponding importance scores (I) and experience score, as proportion negative experience (E) are displayed

No.	Quality aspect	I	E	Q
Q110.	Providing information of a special website of the hospital about RA	2.61	0.81	2.11
Q122.	Information about reimbursements and contribution about support and devices	3.31	0.51	1.69
Q5.	General practitioner asked about having rigid joints	2.98	0.54	1.61
Q119.	Information about reimbursements of different supplementary insurances of different insurance companies	3.32	0.48	1.60
Q116.	Reporting a mistakes	3.32	0.48	1.59
Q65.	Therapist informed you about getting home adjustments	3.14	0.48	1.51
Q96.	Discussed arrangements regarding what to so when RA deteriorates	3.49	0.43	1.50
Q123.	Domestic support	3.27	0.44	1.44
Q124.	Support for your personal care	3.30	0.41	1.35
Q117.	Caregivers discussed things that went wrong	3.34	0.40	1.34

A score of 2.11 is the highest quality improvement score for the quality aspect ‘information on a website of the hospital about RA’. ‘Information about reimbursements and contributions about support and devices’ (Q=1.69) and ‘general practitioner asked about having rigid joints’ (Q=1.61) were second and third in this overview. Other aspects concerned ‘reporting of a mistake’

(*Q*=1.59), 'more information about adjustments at home' (*Q*=1.51), 'support concerning domestic activities' (*Q*=1.44), 'personal care' (*Q*=1.35), and 'talking with caregivers if something went wrong' (*Q*=1.34).

2.4 Discussion

The aim of this study was to illustrate that patients' experiences can be reliably measured with the CQ-index and therefore data collected with this instrument can be an important source to evaluate quality of care. The content, the psychometric characteristics of the CQ-index instrument for patients with RA, and patients' views on the quality of rheumatic care were investigated. Our findings show that the multidisciplinary provides us information regarding experiences of patients with RA with several healthcare professionals (rheumatologist, specialized nurse, therapist, occupational physician, medical specialist, psychological caregiver). The final version of the questionnaire consists of ten scales with good reliability ranging from 0.77 to 0.94. Analysis revealed that the utmost important issue according to patients' was alertness when prescribing drugs. Providing information on a special website of the hospital about RA was the quality aspect that needs the most consideration, as appeared from the quality improvement score.

Measuring patients' experiences to evaluate quality of care is relatively new and goes beyond measuring patient satisfaction, which is a multidimensional concept, influenced by personal preferences and patient expectations. By separating the dimensions 'experience' and 'importance' individual providers and healthcare organisations get a clearer view on the quality aspects that are susceptible for improvement; where the actual care does not meet the needs and expectations of patients. Patients' experiences are useful as an extra source for quality assessment, next to clinical indicators and methods.

The fact that this new instrument represents a multidisciplinary survey is a rather unique feature, as most research predominantly focuses on a particular discipline, e.g. rheumatology (Ward, 1997). Jacobi et al. (2004) was the first who discussed research of multidisciplinary healthcare utilization among patients with RA with different caregivers (general practitioner, medical specialists, allied healthcare, and homecare). They reported inadequate quality in the field of rheumatic expertise, particularly for general practitioners, physiotherapists, home nurses and home help, and in the field of information on medication and treatment for rheumatologists and general practitioners

(Jacobi et al., 2004). We were able to partly replicate this finding in our study. We also found inadequate quality on the aspect 'giving information about home adjustments' and on aspects regarding information topics. In our study home nurses, and home help were not evaluated.

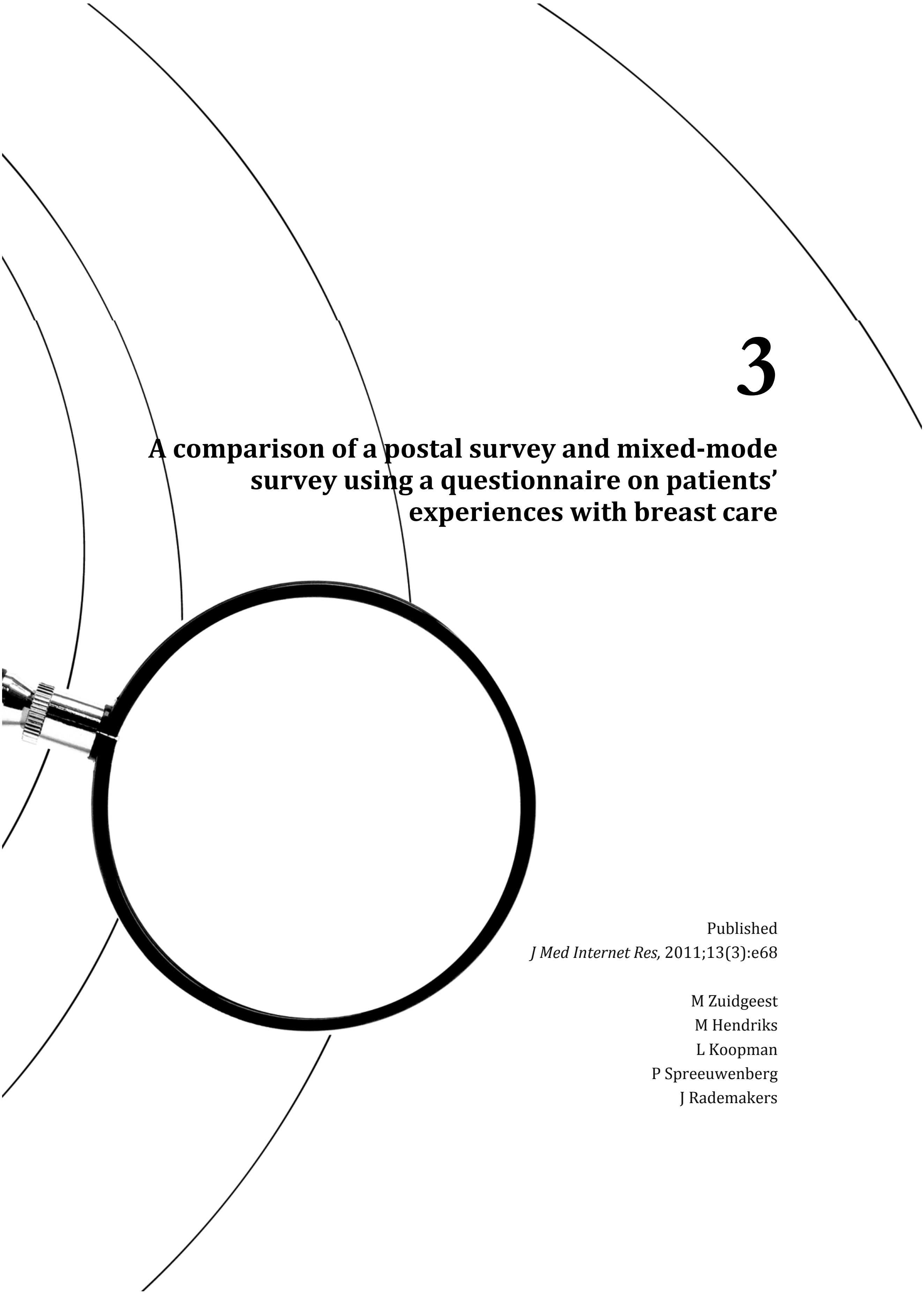
Our finding that alertness when prescribing drugs is the utmost important aspect according to patients is not very surprising, considering the average daily intake of two doses of drugs (Blomqvist et al., 2000). The ten displayed quality aspects differed little (importance score between 3.49 and 3.65), which showed that patients with RA regard these quality aspects in general as 'important' to 'extremely important'. The aspect with the highest possibility for improvement was providing information on a special website of the hospital. A study of Culver and Chadwick revealed that the Internet is a poor source of English information for patients with RA. Quality information was scarce and finding information was time-consuming (Culver and Chadwick, 2005). Hospitals may anticipate on this by providing their own information about RA as service to their patients.

Though the CQI 'RA' was a relatively long questionnaire, the response rate was 69%. This is consistent with other disease-specific surveys (Nijkamp et al., 2002). The fact that three reminders were sent may have contributed to the relatively high response (Dillman, 2000). It is known that elderly women are more likely to return the questionnaire than young men (Delnoij et al., 2006). In our study, we also found that older patients returned the questionnaire more often than younger patients, there was, however, no difference between male and female respondents. This could have had an effect on the results, because older people generally report more positive experiences than younger people (Zaslavsky et al., 2001; O'Malley et al., 2005). In other words, the experiences of patients could be biased in a positive direction.

CQI instruments are based on a multi-phase development process, starting with focus group discussions and ending with large quantitative testing. In this large quantitative testing relevant case-mix adjusters are selected and used in the instruments developed so far (Damman et al., 2009b). Also other CQI instruments have revealed good ability to measure differences between healthcare providers, so called discriminative power (Stubbe et al., 2007a; Stubbe et al., 2007b). Information derived from CQI instruments was successfully translated in public choice information on a special website (www.kiesBeter.nl).

Because the CQI method is standardized in measuring consumer experiences, a big advantage is that quality information can be compared between different settings and/or different healthcare sectors. This contributes to the increasing transparency and performance providing of different healthcare providers. Providers can look to each others performance and adopt, where necessary, initiatives that have been used successfully in the past.

In conclusion, it is possible to reliably measure patients' experiences with the quality of rheumatic care. The CQI 'RA' is able to identify those aspects of care that require extra consideration. In addition, the instrument can be used in further surveillance tools in evaluating performance of different healthcare providers. Therefore, in a next phase, the CQI 'RA' will be adjusted and tested on its ability to discriminate between healthcare providers on the constructed scales and quality aspects.



3

A comparison of a postal survey and mixed-mode survey using a questionnaire on patients' experiences with breast care

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3.1 Introduction

In the Netherlands, healthcare policy stresses regulated competition between healthcare providers (Schut and Van de Ven, 2005). Efforts are made to enhance transparency of healthcare quality, to stimulate informed decision-making among consumers, and to improve the performance of healthcare providers. Comparative information about the performance of healthcare providers is needed for consumers to make informed decisions. This comparative information can be gathered in different ways. One possibility is to ask a sample of patients about their actual experiences concerning quality of care provided by healthcare providers.

Measuring the quality of care from the patients' perspective has been standardized in the Netherlands since 2006, using a new instrument called the Consumer Quality Index (CQ-index or CQI) (Delnoij et al., 2006). CQI questionnaires are usually self-administered paper questionnaires (e.g. CQI 'Rheumatoid Arthritis' (Zuidgeest et al., 2009), CQI 'Breast Care' (Damman et al., 2009a). Individual structured interviews are conducted in cases where a self-administered paper questionnaire is not feasible because of respondents' visual, physical, or cognitive limitations (e.g. CQI 'Care for the Disabled' [Brandt et al., 2010] and CQI 'Long-term care' [Triemstra et al., 2010]). Postal surveys (with multiple reminders) and interviews are relatively expensive and time consuming. It would therefore be interesting to know whether other data collection methods can be applied in this field.

The Internet is increasingly considered to be an efficient medium for assessing quality of care from a patient's perspective. In populations that already use Internet, Internet surveys have been found to be a useful means of conducting research (Couper, 2001; Kaplowitz et al., 2004; Sills and Song, 2002). Efficiency gains are found in shorter response times and field costs reductions (50-80%) (Kiesler and Sproull, 1986; Kwak and Radler, 2000; Schaefer and Dillman, 1998). In contrast to paper questionnaires, Internet questionnaires can contain various interactive features that allow complex skip patterns that are invisible to respondents; the Internet allows validation of responses by utilizing an instant feedback function while respondents are still online (Schaefer and Dillman, 1998; Schmidt, 1997). Consequently, the quality of data collected with an Internet survey is higher. Some Internet surveys have shown promising response rates (up to 94% in web forums) (Kiesler and Sproull, 1986; Schaefer and Dillman, 1998; Tse, 1998). The extreme response in Web forums can be explained by the fact that probably a selection bias occurred in these studies.

Those who participate in web forums are most likely people who are familiar with the Internet and frequently use the Internet leading to a higher response rate to Internet questionnaires. This high response rate has not been realized in other studies; response rates ranged from 17% to 70% (Leece et al., 2004). In CQI research, the response rate to paper questionnaires varied from 20% to 79% with an average response rate of 55% (Zuidgeest et al., 2008b). One CQI study compared an Internet questionnaire with a paper questionnaire. The response rate to the Internet questionnaire (8%) was considerably lower than to the paper questionnaire (35%) (De Boer et al., 2007; Slijkhuis, 2008a). To increase the response rate one can send a prenotification or reminders, give an incentive, or use short questionnaires. A salient subject of a questionnaire also increases the response rate (Edwards et al., 2007).

The potential of Internet surveys should, however, be balanced against an equally large weakness. The Netherlands has the largest percentage of households with Internet access in the European Union, but there are still 1.2 million Dutch people (7.3% of the population) with no Internet access at home and 0.5 million Dutch people (3.1% of the population) who do not use the Internet (Hoksbergen, 2008). People who use the Internet are more affluent, better educated, more often male, and younger than people who do not use Internet. Only a part of the population can thus be reached through the Internet (Kiesler and Sproull, 1986; Kwak and Radler, 2000; Madden, 2009). To compensate for the selection of people in an Internet survey, a combination of data collection methods can be used such as combining an Internet questionnaire with a more traditional postal follow-up (Edwards et al., 2007.

It is known that the way questionnaires are administered has an effect on answers of respondents (so-called mode-effects). For example, telephone respondents were found to be more likely to rate healthcare positively and their own health status negatively than postal respondents (Van Campen et al., 1998b; De Vries et al., 2005). This finding is similar to a study where telephone respondents provide more positive ratings than Web respondents (Christian et al., 2007). Another example is students who completed a Web-based questionnaire responded more favourably on different scales (such as college challenge and learning, education, and personal and social gains) than students who filled out a paper questionnaire (Carini et al., 2010). It is suggested that computer anxiety affects participants' responses. Moreover, biases could occur in the way people perceive and process questions presented on screen versus on paper. A study that tested the difference in test-retest reliability and internal consistency between Internet and paper versions of the SF-36, however, found little or no evidence for mode effects (Basnov et al., 2009). Knowing that these mode effects exist, it is important to investigate whether the answers of respondents in a postal and mixed-mode survey differ.

To examine whether a mixed-mode survey can be an alternative to postal survey, our research question is: 'What are the differences between a mixed-mode survey (Internet with paper follow-up) and a more traditional postal survey in terms of respondent characteristics, response rates and time, quality of data, costs and mode effects?' The differences were examined within a sample of breast care patients who reported their experiences with healthcare using the CQ-index Breast Care questionnaire.

3.2 Methods

3.2.1 Sample

Data was collected within a larger study assessing the usability of the CQI 'Breast Care' (Koopman and Rademakers, 2010). For the mixed-mode survey, 200 patients with a benign abnormality and 200 patients with breast cancer were selected from the reimbursement files of seven Dutch health insurance companies. Inclusion criteria were:

1. Being older than 18 years.
2. Having received breast care in the last 24 months.

We used the same procedure to select 3,955 patients who received the questionnaire by mail only as part of another study. Of these 3,955 patients, we selected 400 patients (200 with breast cancer and 200 with benign abnormalities) for the comparison of the two surveys. These 400 patients were not randomly selected, but matched by age and gender to the respondents in the mixed-mode survey.

3.2.2 Data collection

Patients received a letter from their health insurer with the request to fill out a paper questionnaire (postal survey) or an Internet questionnaire with unique username and password (mixed-mode survey). A total of three reminders were sent and in both surveys non-respondents received a paper version of the questionnaire in the third mail-shot. This data protocol was based on Dillman et al. (2009) (See Figure 3.1 for detailed information on the mail-shots). The data were collected in the Netherlands in the spring of 2008.

Figure 3.1 Mail-shots sent to the patients

	Postal survey	Mixed-mode survey
Week 0	Letter and postal questionnaire (n=400)	Letter with request to fill out an Internet questionnaire (n=400)
Week 1	Thank you card as reminder	Thank you card as reminder
Week 4	Nonrespondents received another postal questionnaire	Nonrespondents received reminder for the Internet questionnaire and a paper version of the questionnaire
Week 6	Nonrespondents: reminder to fill out previously received postal questionnaire	Nonrespondents: reminder to fill out Internet questionnaire or previously received paper questionnaire

3.2.3 Questionnaire

The CQI ‘Breast Care’ contains items measuring the actual experiences of patients with breast examinations, surgery for breast cancer, other treatment, subsequent treatment, cooperation between healthcare providers, continuity of care, accessibility of care and expertise of healthcare providers (Damman et al., 2009a). There are two versions of the CQ-index; one for patients with breast cancer (151 items) and one for patients with a benign abnormality (60 items). The questionnaire for patients with a benign abnormality is the same as the questionnaire for breast cancer, except that it does not contain questions about surgery and treatments. Both questionnaires have three scales in common, and the questionnaire for patients with breast cancer consists of 11 extra scales. Cronbach’s alpha for these scales varied between 0.74 and 0.93. Example items are presented in Table 3.1. The questionnaires additionally contain items on respondent’s characteristics (e.g. age, education, ethnicity, patient’s self-assessed physical and psychological health) and global ratings of healthcare providers (general practitioner, hospital care in the diagnostic phase, surgeon, nurses, radiotherapy, chemotherapy, and hospital care in general). In the present study, we focused on the global ratings of the healthcare providers. These ratings ranged from 0 to 10, with a score of 0 indicating the worst possible healthcare or provider and a score of 10 indicating the best possible healthcare or provider. The respondents were asked to report their experiences in the last 24 months.

Table 3.1 Scales in the CQ 'Breast Care', their reliability (Cronbach's alpha for internal consistency) and example items

Scale	Number of items	α^1	α^2	*total*	Example of item
1. Conduct of professionals during breast examination	7	0.90	0.91	0.90	How often did caregivers listen to you carefully?
2. Conduct of general practitioner	4	0.91	0.88	0.90	How often did your general practitioner take you seriously?
3. Conduct of nurses	5	-	0.87	0.87	How often did nurses pay personal attention to you?
4. Conduct of surgeon	4	-	0.89	0.89	How often did the surgeon spend enough time with you?
5. Autonomy regarding treatment	4	-	0.82	0.82	How often did you get the chance to decide about your treatment?
6. Autonomy regarding follow-up treatment	2	-	0.93	0.93	How often were your specific wishes about follow-up treatment taken into account?
7. Conduct of professionals during radiotherapy	5	-	0.88	0.88	How often did you get the opportunity to ask questions about radiotherapy?
8. Information about radiotherapy	2	-	0.78	0.78	How often did you get enough information about radiotherapy?
9. Conduct of professionals during chemotherapy	4	-	0.92	0.92	How often did caregivers listen carefully to you?
10. Information about chemotherapy	4	-	0.80	0.80	How often did caregivers explain aspects of chemotherapy in a way that was easy to understand?
11. Cooperation	5	0.91	0.87	0.89	How often did caregivers make good arrangements with each other?
12. Continuity of psychosocial care	3	-	0.84	0.84	Were you informed about the options for psychosocial care?
13. Continuity of physiotherapy	3	-	0.74	0.74	Were you assisted with a referral to physiotherapy?
14. Continuity of rehabilitation	3	-	0.80	0.80	Did you have as rapid access to a rehabilitation program as you wanted?

^{1} = Questionnaire for patient with benign abnormality

^{2} = Questionnaire for patients with breast cancer

3.2.4 Statistical analyses

Respondent characteristics

In order to check whether our matching procedure was successful, we compared the selected patients within the two surveys on age and gender. Respondents were compared concerning age, level of education, self-reported physical and psychological health (Mann-Whitney test), and gender (χ^2-test).

Response rate and time

Response rates were calculated as the number of valid received questionnaires divided by the number of patients in the starting sample. The response time was calculated as the number of days between the first letter (January 31, 2008) and the return date of the valid questionnaire. For the mixed-mode survey, the number of days between sending the paper questionnaire (February 28, 2008) and receiving the valid paper questionnaire was also calculated. The closing date of the data collection was April 1, 2008. A chi-squared test was used to examine the differences in response rates between the two surveys because of the dichotomous variable (respondent/non-respondent). The differences in response time were determined using a Mann-Whitney test because the response time is a continuous variable.

Quality of data

The percentage of items that were skipped while they needed to be answered (missing items) and the percentage of the items that were answered while they needed to be skipped (invalid answers) were calculated. These percentages were compared between two surveys using a Man-Whitney test because these percentages are continuous variables.

Total costs

Expenses considered in cost calculations included setup costs (document layout, programming and testing of the questionnaire for each survey, and mailing supplies), field costs (postage, technical support, and project management staff), and scanning data costs (data-entry of paper questionnaires). The costs per valid questionnaire received were calculated by dividing the total costs by the number of valid questionnaires received.

Mode effects

We performed multi-level regression analyses to examine the mode effects. Multi-level regression analyses takes into account the hierarchic structure of our data: individual patients (level 1) are nested within hospitals (level 2). The analyses were conducted using MLwiN version 2.02 software package (Centre for Multilevel Modelling, University of Bristol, Bristol, UK). Mode effects were examined by comparing the estimated mean scores on seven global ratings of the general practitioner, hospital care in the diagnostic phase, surgeon, nurses, radiotherapy, chemotherapy, and hospital care in general using a chi-squared test ($p<.05$ if $\chi^2>3.84$ and $p<.001$ if $\chi^2>6.63$). The mean scores were adjusted for the influence of age, education level, and self-reported health status of respondents.

In addition, within the mixed-mode survey, we examined the differences in respondent characteristics, differences in response rates, and time and mode effects for respondents who filled out the Internet questionnaire and the paper questionnaire.

3.3 Results

3.3.1 Respondent characteristics

Characteristics of the sample are presented in Table 3.2. Our matching procedure was successful since age and gender of the selected patients did not differ between the postal and mixed-mode survey. Patients with benign abnormalities were younger then patients with breast cancer (*p*<.001).

Table 3.2 Sample characteristics

	Postal survey	**Mixed-mode survey**	**Mean difference**	**95% CI**	***p***
Overall (n)	**400**	**400**			
Mean age (SD) years	55.5 (14.5)	55.5 (14.8)	-0.1	-2.1-1.9	.93
% female	97.3	97.3	0.0	0.0	1.00
Breast cancer (n)	**200**	**200**			
Mean age (SD) years	61.3 (12.7)	61.8 (12.9)	-0.4	-2.9-2.1	.77
% female	99.0	99.0	0.0	0.0	1.00
Benign abnormalities (n)	**200**	**200**			
Mean age (SD) years	49.5 (13.7)	49.3 (14.0)	0.2	-2.5-2.9	.89
% female	95.5	95.5	0.0	0.0	1.00

Table 3.3 shows that also the characteristics of the respondents did not differ between the postal and mixed-mode survey.

Table 3.3 Respondents' age, gender, level of education, and self-reported physical and psychological health

	Postal survey	**Mixed-mode survey**	**Mean difference**	**95% CI**	***p***
Overall (n)	**256**	**242**			
Mean age (SD) years	55.8 (13.5)	57.0 (13.6)	-1.2	-3.6-1.2	.32
% female	97.6	97.5	0.1	-2.6-2.8	1.00
Breast cancer (n)	**134**	**132**			
Mean age (SD) years	60.2 (12.4)	62.1 (12.4)	-1.9	-5.0-1.0	.26
% female	98.5	99.2	0.7	-3.3-3.3	1.00
Benign abnormalities(n)	**122**	**110**			
Mean age (SD) years	50.8 (13.1)	50.8 (12.4)	0.1	-3.2-3.4	.29
% female	96.7	95.5	1.2	-3.7-6.2	.74
Education level (n)	**251**	**232**			
Mean (SD)	4.4 (1.9)	4.6 (1.8)	-0.2	-0.6-0.1	.09
Less than high school	41.1%	31.0%			
High school graduate	20.3%	25.0%			
Higher education	31.6%	39.3%			
College degree	4.8%	2.2%			
Other	2.4%	2.6%			
Self reported physical health (n)	**254**	**239**			
Mean (SD)	2.9 (0.8)	2.8 (0.9)	0.1	-0.04 -0.3	.29
Excellent	5.1%	11.2%			
Very good	20.1%	16.5%			
Good	55.5%	55.0%			
Fair	17.3%	13.2%			
Poor	2.0%	2.9%			
Self-reported psychological health (n)	**255**	**239**			
Mean (SD)	2.6 (1.0)	2.6 (1.0)	0.1	-0.1-0.2	.40
Excellent	16.9%	18.4%			
Very good	18.4%	23.0%			
Good	51.8%	44.4%			
Fair	11.4%	13.4%			
Poor	1.6%	0.8%			

Table 3.4 Respondents' characteristics within the mixed-mode survey: age, gender, level of education, and self-reported physical and psychological health

	Paper	**Internet**	**Mean difference**	**95% CI**	***P***
Overall (n)	**114**	**128**			
Mean age (SD) years	61.8 (14.0)	52.7 (11.6)	-9.1	-12.3– -5.8	<.001
% female	99.1	96.1	-3.0	-6.9 – 0.9	.22
Breast cancer (n)	**68**	**64**			
Mean age (SD) years	67.9 (11.2)	56.0 (10.5)	-12.0	-15.7 – 8.2	1.00
% female	98.5	100	1.5	-1.5 – 4.5	1.00
Benign abnormalities (n)	**46**	**64**			
Mean age (SD) years	52.7 (12.9)	49.5 (11.9)	-3.2	-7.9 – 1.5	.18
% female	100	92.2	-7.8	-15.7 – 1.0	.07
Education level (n)	**105**	**127**			
Mean (SD)	4.2 (1.8)	4.9 (1.8)	0.7	0.3-1.2	.002
Less than high school	38.1%	25.2%			
High school graduate	41.0%	38.6%			
Higher education	18.1%	29.9%			
University degree	0.0%	3.9%			
Other	2.9%	2.4%			
Self-reported physical health (n)	**112**	**127**			
Mean (SD)	2.9 (0.9)	2.7 (0.9)	-0.1	-0.4 – 0.1	.14
Excellent	12.5%	10.2%			
Very good	11.6%	21.3%			
Good	55.4%	55.9%			
Fair	17.9%	9.4%			
Poor	2.7%	3.1%			
Self-reported psychological health (n)	**112**	**127**			
Mean (SD)	2.7 (1.0)	2.4 (0.9)	-0.3	-0.5 – -0.03	.02
Excellent	17.0%	19.7%			
Very good	17.0%	28.3%			
Good	46.4%	42.5%			
Fair	18.8%	8.7%			
Poor	0.9%	0.8%			

Within the mixed-mode survey, differences were found between those who filled out the Internet questionnaire and those who filled out the paper questionnaire. Internet respondents were younger, were more often highly educated and reported better psychological health compared with respondents who filled out the paper questionnaire (Table 3.4). Also, both paper and Internet respondents with benign abnormalities were younger than their counterparts with breast cancer (*ps*<.001; not in table).

3.3.2 Response rates and times

The response rate did not differ between the two surveys and was 64.0% (256/400 patients) for the postal survey and 60.5% (242/400 patients) for the mixed-mode survey (*p*=.31; Table 3.5). While the response rates of patients with breast cancer and of patients with benign abnormalities did not differ in the postal survey (67.0% versus 61.0%, respectively; *p*=.21), the response rate was significantly higher for patients with breast cancer than for patients with benign abnormalities in the mixed-mode survey (66.0% versus 55.0%, respectively; *p*=.02).

In the mixed-mode survey, 52.9% (128 patients of 242) of the respondents filled out the questionnaire online. The percentage of patients with benign abnormalities who filled out the questionnaire online was higher (64/110, 58.2%) than the percentage of patients with breast cancer (64/134, 48.5%;). However, this difference was not significant (*p*=.13).

Table 3.5 Response rates for each survey and for patients with breast cancer or benign abnormalities

	Postal survey		**Mixed-mode survey**		**Mean difference**	**95% CI**	***p***
Overall response	64.0%	256/400	60.5%	242/400	3.4%	-3.2 – 10.2%	.32
- breast cancer	67.0%	134/200	66.0%	132/200	1.0%	-8.3 - 10.3%	.83
- benign abnormality	61.0%	122/200	55.0%	110/200	6.0%	-3.7 - 15.7%	.23

Figures 3.2 and 3.3 show the cumulative percentage of questionnaires received by days after the first mail-shot. The vertical lines in the graphs represent the reminders that were sent. In the postal mode survey, questionnaires were returned 20 days earlier than in the mixed-mode survey (z=-3.59, *p*<.001). The median number of days expired before the questionnaire was returned was 12 days (range 4 to 60 days) in the postal survey and 32 days (range 2 to 61 days) in the mixed-mode survey.

In the mixed-mode survey, the paper questionnaires were sent in week four (second reminder). The median number of days expired before these paper questionnaires were returned was seven days (range 4 to 33 days). The median number of days expired before online questionnaires were filled out was nine days (range 2 to 59 days). In other words, the larger response time in the mixed-mode survey was mainly caused by the group who did not respond using the Internet.

Figure 3.2 Percentage of received questionnaires by days after first mail-shot for the Postal and Mixed-mode surveys

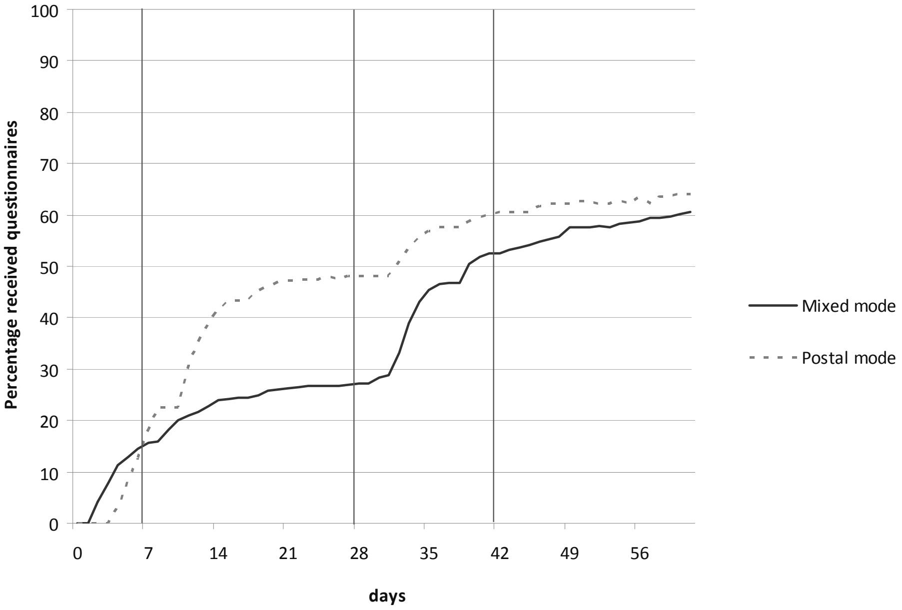
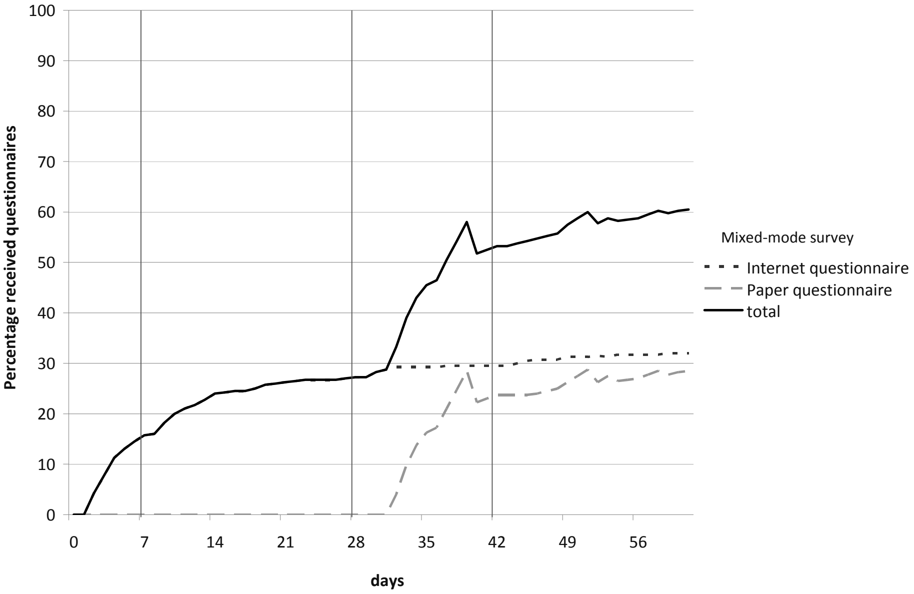


Figure 3.3 Percentage of received questionnaires by days after first mail-shot for the Internet and paper questionnaire within the mixed-mode survey



3.3.3 Quality of data

The mean percentage of missing items per question differed significantly between the two surveys (z= -3.08; *p*=.002); the mean percentage of missing items was lower in the mixed-mode survey than in the postal survey (3.4% versus 4.4%, respectively). In addition, the mean percentage of invalid answers was twice as high in the postal survey as in the mixed-mode survey (6.2% versus 3.2%, respectively; z= -3.68, *p*<.001).

3.3.4 Costs

The costs per valid questionnaire returned were higher in the postal survey than in the mixed-mode survey (25.8 Euros versus 23.9 Euros per valid questionnaire returned, respectively). Compared to the postal survey, the variable costs were reduced by 17% of the total costs in the mixed-mode survey, but the fixed costs were raised by 17% (Table 3.6).

Table 3.6 Fixed and variable costs per valid questionnaire returned

Costs	**Postal survey**		**Mixed-mode survey**	
	%	**Costs**	**%**	**Costs**
Fixed costs	**41.5**	**10.7**	**58.4**	**14.0**
General	3.6	0.9	2.1	0.5
Information technology (programming software, scanning, designing Internet questionnaire)	35.0	9.0	53.8	12.9
Process results and make a data file	2.9	0.8	2.5	0.6
Variable costs	**58.5**	**15.1**	**41.6**	**9.9**
Material (paper, envelopes)	1.4	0.4	0.9	0.2
Printing (letters, survey, reminders)	26.3	6.8	21.6	5.2
Preparing tasks (folding forms/questionnaires, thank you cards, filling envelopes)	4.2	1.1	4.6	1.1
Response processing (open envelope, checking, data scanning)	8.6	2.2	4.6	1.1
Postal cost	17.9	4.6	9.9	2.4
Total	**100.0**	**25.8**	**100.0**	**23.9**

3.3.5 Mode effects

In Table 3.7, the mean scores on seven global ratings of different healthcare providers are presented. These mean scores have been corrected for hospital, age, level of education, and self-reported health status. The global rating scores are relatively high, ranging from 8.3 to 9.0. Respondents in the postal survey gave the radiotherapist a score of 9.0 and the total care in the hospital a score of 8.3. The respondents in the mixed-mode survey rated the general practitioner and chemotherapy care the highest (score= 8.8) and gave care at the hospital in the diagnosis phase and hospital care a score of 8.4. We found no significant differences in global ratings between the two surveys.

Table 3.8 shows the differences in global ratings given by respondents to the paper and Internet questionnaires within the mixed-mode survey. The global ratings of nurses differed significantly between these two groups; respondents filling out the paper questionnaire rated the nurses significantly more positively than respondents filling out the questionnaire online (score 9.2 versus score 8.4, respectively; $\chi2>3.84$).

Table 3.7 Mean scores on global ratings of different healthcare providers (corrected for hospital, age, education, and self-reported health status) for respondents to the postal survey and mixed-mode survey

Ratings of healthcare providers	Postal survey			Mixed-mode survey			χ^2
	n	Mean#	SE	n	Mean#	SE	
1. General practitioner	105	8.5	0.21	114	8.8	0.22	2.1
2. Hospital care in diagnostic phase	240	8.4	0.11	220	8.4	0.11	0.0
3. Surgeon*	85	8.9	0.19	102	8.5	0.20	2.6
4. Nurses*	75	8.7	0.19	77	8.7	0.20	0.1
5. Radiotherapy*	68	9.0	0.19	80	8.7	0.22	2.1
6. Chemotherapy*	41	8.9	0.24	50	8.8	0.23	0.2
7. Hospital care in general	239	8.3	0.11	222	8.4	0.14	0.5

* Only in breast cancer questionnaire, # measured on an 11-point scale from 0 (worst possible) to 10 (best possible)

Table 3.8 Mean scores on global ratings of different healthcare providers (corrected for hospital, age, education, and self-reported health status) for respondents to the paper or Internet questionnaire within the mixed-mode survey

Ratings of healthcare providers	Paper questionnaire			Internet questionnaire			χ^2
	n	Mean#	SE	n	Mean#	SE	
1. General practitioner	48	8.7	0.25	66	8.7	0.23	0.0
2. Hospital care during diagnosis phase	96	8.4	0.16	124	8.3	0.16	0.3
3. Surgeon*	49	8.7	0.26	56	8.2	0.25	3.0
4. Nurses*	35	9.2	0.33	42	8.4	0.28	5.6
5. Radiotherapy*	38	8.7	0.28	43	8.5	0.26	0.3
6. Chemotherapy*	21	9.0	0.34	30	8.7	0.28	1.4
7. Care at hospital	98	8.4	0.16	124	8.3	0.16	0.3

* Only in breast cancer questionnaire, # measured on an 11-point scale from 0 (worst possible) to 10 (best possible)

3.4 Discussion

This study examined whether a mixed-mode survey (Internet questionnaire with paper follow-up) is an alternative to the more traditional postal survey. The results showed that combining an Internet questionnaire with a paper follow-up improved the quality of data and was less expensive than a postal survey. However, the time before questionnaires were received was longer in the mixed-mode survey. No differences between the mixed-mode survey and postal survey were found concerning respondent characteristics, response rates, and global ratings of different healthcare providers.

The findings showed that the characteristics of the respondents were the same for the two surveys. This means that mixed-mode surveys attracts the same population as postal surveys. In total, 53 percent of respondents in the mixed-mode survey filled out the questionnaire online. It appeared that in the mixed-mode survey Internet respondents were younger and more often highly educated and that they reported a better psychological health than paper respondents. The younger people probably were more familiar with the Internet and were more likely to have access to the Internet than older people (Kwak and Radler, 2000; Madden, 2009). To overcome the problem of possible exclusion of the elderly and less highly educated, a mixed-mode survey should be chosen rather than an Internet survey (Kwak and Radler, 2000; Dickerson and Gentry, 1983).

The response rate was relatively high for both surveys (over 60%). In other CQ-index surveys, the response rates varied between 20% and 79% (Zuidgeest et al., 2008a). Perhaps the relatively high response rate is due to the subject under study, namely abnormality of the breast. The response rate among women referred for mammography in another study was comparably high, both for the Internet (64%) and paper questionnaire (77%) (Basnov et al., 2009). Breast abnormality has a huge impact on the emotional and physical quality of life of patients. A review showed that saliency regarding the subject of questionnaires yields higher response rates (Edwards et al., 2007). Our results confirm those review results. In the mixed-mode survey, the response rate for patients with breast cancer was higher than the response rate for patients with benign abnormalities, even though the questionnaire for breast cancer was longer.

The response time for the return for the questionnaires was longer in the mixed-mode survey than in the postal survey. This effect was unexpected because the Internet can reduce the time taken to return a questionnaire

(Kiesler and Sproull, 1986; Kwak and Radler, 2000; Schaefer and Dillman, 1998). Both groups in the mixed-mode survey (paper and Internet respondents) responded relatively quickly (median number of days 7 and 9 days respectively), but respondents with no access to or interest in the Internet questionnaire only responded when the paper questionnaire was sent four weeks after the original contact. The relatively quick response by paper respondents in the mixed-mode survey could be explained by the fact that respondents had already been informed about the study. Use of pre-notification has been shown to shorten response times (Edwards et al., 2007; Ritter et al., 2004). Another method to reduce the return time is sending the paper questionnaire out earlier.

Research has shown that an Internet surveys results in more complete data compared with a postal survey (Larsson et al., 2010). This conclusion is confirmed in our study; the quality of data was higher in the mixed-mode survey than in the postal survey. One of the advantages of using the Internet for survey research is that questionnaires can be designed so that complex skip patterns are invisible to respondents. As a consequence, the online questionnaire resulted in zero missing items and zero invalid answers (e.g. answers to questions that had to be skipped). However, given the fact that some groups of people are under-represented on the Internet (for instance, the elderly), considering surveys through Internet alone is not (yet) possible (Kwak and Radler, 2000; Madden, 2006).

One of the key potential advantages of using the Internet over paper questionnaires is reducing costs. This study showed that the cost per returned questionnaire is two Euros lower in the mixed-mode survey than in the postal survey. In the present study, the information technology costs were, however, relatively high for the mixed-mode survey. This was due to the need to program two applications, one for scanning the paper questionnaires and one for the Internet questionnaires. In the future, more costs can possibly be saved by using the same program for the different data collection methods within a mixed-mode survey. In addition, the variable costs per questionnaire were lower and the fixed costs per questionnaire were higher in the mixed-method survey than in the postal survey. Fixed costs per questionnaire can be reduced if a larger sample is taken, because the fixed activities are divided over the number of returned questionnaires. In other words, the larger the sample, the more money can be saved by using a mixed-mode survey.

Our study was the first to examine so-called mode effects between a mixed-method survey (Internet with paper follow-up) and postal survey. We found no differences between the two surveys concerning global ratings respondents gave to different healthcare providers. This is beneficial, because it implies that there is no bias in the scores that is a function of the manner of data collection. Other studies did find mode effects between the answers of telephone respondents and postal respondents (De Vries et al., 2005), Internet respondents and telephone respondents (Christian et al., 2007), and Internet respondents and postal respondents (Carini et al., 2010; Dillman et al., 2009; Kongsved, 2007). One study investigated the differences between a postal and an Internet questionnaire, where a subset of the participants filled out also the alternative version (Internet and paper questionnaire, respectively). They found little or no evidence for a difference in test-retest reliability and internal consistency when they compared the Internet and paper versions of the questionnaire (Basnov et al., 2009).

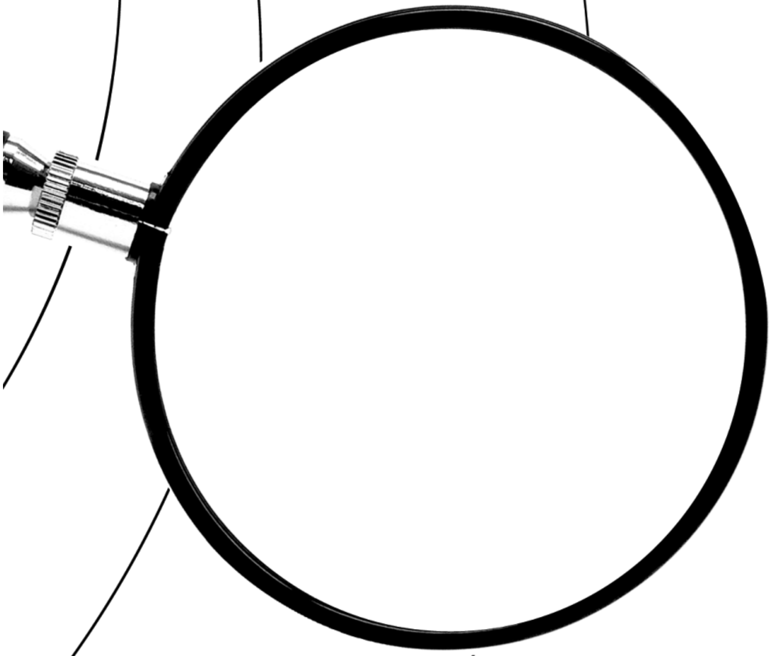
We did not ask why respondents in the mixed-mode survey did not fill out the questionnaire online. In one study among non-respondents of an Internet questionnaire, the non-respondents indicated that they did not have a computer or access to the Internet. Other reasons were having no experience with Internet or not trusting the Internet (Ritter et al., 2004). This corresponds with findings by other researchers, who showed that factors influencing response times are privacy concerns and computer anxiety (Edwards et al., 2007; Dillman et al., 2009). These findings demonstrate that solely providing an Internet questionnaire is only feasible for specific populations, such as younger and more highly educated people.

Our findings are subject to some limitations. We compared a mixed-mode survey with a postal survey in a group of patients having received breast care. As a consequence, the main part of our target group was female. Additional studies should examine whether our findings hold for other populations such as males and the elderly. Furthermore, we decided to compare a mixed-mode survey with a postal survey to determine whether combining an Internet questionnaire with a paper follow-up is an alternative to the more traditional paper questionnaire. Further research should investigate whether differences exist between a mixed-mode and Internet survey and should compare the three modes of surveys directly (postal, Internet, Internet with paper follow-up). Another limitation is that the participants of the study were not randomly assigned to either the postal survey or mixed-mode survey.

In conclusion, compared to a more traditional postal survey, the mixed-mode survey resulted in a comparable response rate and the respondents did not differ in terms of age, gender, level of education, and self-reported health. In addition, no differences in respondents' evaluations of quality of healthcare were found. These are important findings, as mixed-mode survey offers researchers many advantages such as lower costs and data of higher quality. Both these advantages were confirmed in the present study. The findings suggest that researchers should consider the use of a mixed-mode survey instead of a postal survey, especially when investigating a younger or more highly educated population.

4

Pretesting patient experience questionnaires: a case report of the Dutch Consumer Quality Index



Submitted

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DMJ Delnoij

4.1 Introduction

In many Western countries, comparative information about healthcare quality from the perspective of patients has become increasingly available. Systematic evaluation of patients' experiences has been performed in several European countries (Denmark, Norway, England, and The Netherlands), in Canada, and in the USA (Delnoij, 2009b). The USA and England have the longest tradition through, respectively, the CAHPS (Consumer Assessment of Healthcare Providers and Systems) surveys (CAHPS, 2010) and the surveys of the Picker Institute Europe for the English National Health Service (NHS, 2010). In the Netherlands, measuring patients' experiences has been standardized since 2007, using an instrument called the Consumer Quality index (CQ-index or CQI) (e.g. Damman et al., 2009a; Zuidgeest et al., 2007; Stubbe et al., 2007a; Stubbe et al., 2007b). The process of developing a new CQI instrument is described in detail in the CQI manual of the Dutch Centre for Consumer Experience in Health Care (Sixma et al., 2008a). This Centre coordinates the development of CQI questionnaires and owns the CQ-index registered trademark (CKZ, 2010). Box 4.1 presents the characteristics of the CQ-index.

Box 4.1 Characteristics of the Consumer Quality Index

What is the Consumer Quality Index?

- National standard to measure healthcare quality from the patients' perspective.
- Based on American CAHPS (Consumer Assessment of Healthcare Providers and Systems) and Dutch QUOTE (QUality Of care Through the patient's Eyes) instruments.
- Collection of instruments (surveys or interview protocols).
- Collection of protocols and guidelines for sampling, data collection, analysis, and reporting.
- Registered trademark owned by the Dutch Centre for Consumer Experience in Health Care.

What is measured by the Consumer Quality Index?

- What patients find important in healthcare.
- What their actual experiences are.
- How they rate the overall quality of care.

What types of questions are included in the Consumer Quality Index?

- Frequency with which quality criteria are met: never, sometimes, usually, always.
- Importance of quality criteria: not important - extremely important.
- Access to care and the degree to which lack of access is perceived as a problem: a big problem, a small problem, not a problem.
- General rating of the quality of care: scale from 0 (worst possible) to 10 (best possible).
- Effects of care and adherence to professional guidelines.
- Background characteristics: age gender, ethnicity, education, general health status, co morbidity.

Most of the procedures regarding the development of a CQI questionnaire have been highly refined and standardized during the past few years. For example, the methods for focus group discussions, discussing of draft surveys with stakeholders, and the quantitative tests are now carefully prescribed in the CQI manual (Sixma et al., 2008a). However one specific procedure - the pre-test - has received comparatively little attention. Pretesting a survey is relevant because the routing, language used, and the number of items included are aspects that can only be evaluated by patients for whom the questionnaire is intended. Pretesting a questionnaire can be done by testing the questionnaire among 10 to 15 patients using qualitative or semi-quantitative methods. This method is also prescribed in the CQI manual. There is, however, no standard format for describing the pre-test results in the CQI research reports, and results are currently described only briefly.

Further, as a departure from regular CQI testing methods, using cognitive interviewing methods as part of pre-testing may provide more insight into defects of questionnaires. Two main cognitive interviewing techniques of question-and-answer processes are *think aloud interviewing* and *probing.* With the first technique, respondents are asked to think out loud as they complete the questionnaire. In the second technique, interviewers asked specific questions or *probes* which are designed to obtain information about how the respondent answered the question (Collins, 2003). A study about the Hospital CAHPS survey - which combined both techniques - resulted in the revision and/or deletion of 70% of the survey questions (Levine et al., 2005). In this study, there were five broad categories of problems:

1. Respondents did not have the information or knowledge to answer the questions.
2. Items were not clear or ambiguous, which caused them to be inconsistently understood.
3. Items failed to measure the intended construct.
4. Items were not applicable for a large group of respondents.
5. Items designed to measure different constructs were basically measuring the same thing in the eyes of the respondents, because the distinctions were too fine for respondents to differentiate them in their answers.

Despite these kinds of problems demonstrated in the US, the Dutch CQI procedure still lacks a systematic methodology for pretesting patient experience questionnaires.

In our opinion, the current lack of systematic pretesting methods is problematic since a good pre-test contributes to the validity and applicability of items of patient experience questionnaires. In this article, we will use the Cognitive Interviewing Reporting Framework (CIRF) described by Boeije and Willes (submitted) to illustrate how pretesting patient experience questionnaires could benefit from more systematic quality criteria derived from qualitative research and how pre-test results should be reported. We will answer the following research question: *'How can the pre-test procedures of CQI questionnaires be improved and reported using the criteria of the Cognitive Interviewing Reporting Framework?'*

4.2 Methods

4.2.1 Procedure and analysis

To answer our research question, we used a case report approach consisting of two different phases. First, we assessed the results of two CQI pre-tests - the CQI 'Rheumatoid Arthritis' ('RA') (Zuidgeest et al., 2009) and the CQI 'Breast Care' (breast cancer and benign breast abnormality) (Damman et al., 2009a) to illustrate the current way of working and the kind of problems encountered in the surveys. General information about the development of these surveys is displayed in Table 4.1.

Table 4.1 General information of the development of the CQI surveys

CQI survey	Questionnaire development	Working group with key stakeholders	Topics in draft version
Rheumatoid Arthritis	2 focus group discussions (n=8, n=14)	Patient organisation, one individual patient, health insurers, healthcare professionals (rheumatologist and specialized nurse), researchers	88 items: Introduction, General practice care, First visit rheumatologist, Control of care, Medication, Specialized nurse, Therapist, Psychological care, Occupational physician, Cooperation, Information about operations, Information and knowledge, Reimbursements, Global ratings
Breast care (breast cancer and benign breast abnormality)	3 focus group discussions (n=11, n=9, n=7)	Patient organisation, health insurers, healthcare professionals (surgeon, radiologist, radiotherapist, nurse practitioner, oncological psychologist), researchers	166 items: Introduction, Diagnostic examinations, Breast abnormality, Surgical treatment breast cancer, Nurse practitioner, Chemotherapy, Other treatments, After treatment, Cooperation and alignment, Accessibility, Professionals' expertise, Global ratings

In brief, pretesting of these questionnaires consisted of sending them to a small number of patients, who were mailed the CQI questionnaires asked to review them and indicate where they had difficulty in understanding the questions, or where the items did not adequately capture their experiences. Hence, rather than a cognitive interview, participants were asked to conduct a type of 'expert review.' Two researchers (MZ and OD) scored the original pre-test results on the problems reported by respondents (Zuidgeest et al., 2009; Damman et al., 2007). Problems were listed on general and item level. MZ and OD discussed the results and made a list of most important themes together.

Second, to judge the different qualitative aspects of the applied procedures, we used the cognitive interviewing reporting framework (CIRF) developed by Boeije and Willes (submitted). MZ and OD together assessed to what extent the quality criteria were met concerning the two CQI questionnaires. The recently developed CIRF is based on different checklists and cross-validated by consulting other literature on quality of reported qualitative research. The CIRF describes how cognitive interviews should be reported based on different quality criteria, namely:
1a. Research objectives.
1b. Review of relevant background literature.
2. Research design.
3. Ethics.
4. Participation selection.
5a. Data collection.
5b. Data structure and data management procedure.
6a. Data analysis.
6b. Quantitative evidence.
7. Findings.
8. Conclusion, implications and discussion.
9. Strengths and limitations.
10. Report format.

4.3 Results

4.3.1 Findings from the pre-tests

Problems encountered by respondents in the two pre-tests are displayed in Tables 4.2 and 4.3. As can be seen in Table 4.2, the most frequently mentioned problem for respondents of the CQI 'RA' was that different items measured the same construct. For example, respondents found it difficult to distinguish healthcare professionals who ‘listen carefully’ from professionals who ‘show personal attention’. As a result, respondents experienced that the questionnaire was made up of ‘similar questions’. Furthermore, two other problems concerning the interpretation of the content appeared. First, the DAS score (which is a score frequently measured among RA patients to assess the activity of the disease) was not comprehended by several respondents. Second, certain types of medication for RA patients (such as biologicals) were labelled in the questionnaire by using the name of ground materials. One respondent suggested that it would be better to use the brand name that is publicly known (like ‘Humira’). Other problems mentioned by respondents were related to the ease of using the questionnaire. For example, according to several respondents, explanatory texts and particular answering categories were missing. Finally, respondents of the CQI ‘RA’ mentioned five topics that were missing in the questionnaire. These topics mainly concerned psychosocial aspects of care and practical help, such as Internet facilities for young patients with RA.

Table 4.2 Pre-test results of the CQI ‘RA’

Findings CQI ‘RA’ (n=25)	
General	
Two or more items measuring the same construct	7
Specific unclear items	
DAS-score (activity score of RA) was not comprehended	3
Certain medications were labelled by their ground materials	1
Go through was not specified (question number was omitted)	4
Absent aspects (but important according to patients)	
Missing question:	5
- Information item on satisfaction about illness, medication, Internet	
- Procedures of health insurance company/health plan	
- Personal attention in the form of psychosocial care	
- Specific aspects relevant for young people e.g. student counsellor	
- Social aspects, e.g. relations, partners, family and friends	
Missing answering categories (e.g. not applicable)	4
Space for general comments	1

The most frequently mentioned problem for respondents of the CQI ‘Breast Care’ (Table 4.3) was that explanatory text was missing at certain items in the questionnaires. For example, it was unclear for one respondent what was meant by the word ‘treatment’. Breast cancer patients usually undergo different treatments (e.g. surgical treatment, chemotherapy, radiotherapy). Using the term ‘treatment’ might be a general term capturing all these different types of treatments, but the risk is that the term is too vague or that different respondents interpret it differently. Furthermore, respondents mentioned seven aspects that were missing in the questionnaire. Just like RA patients, breast cancer patients missed items concerning psychosocial care and items about care for younger patients. Other problems encountered related to the ease of using the questionnaire, especially the order of the questions. This was a problem for two patients who had had the diverse types of treatments in a different chronological order than the order displayed in the questionnaire.

Table 4.3 Pre-test results of the CQI ‘Breast Care’

Findings CQI ‘Breast Care’ (n=20)	
General	
Explanatory text was missed (e.g. what is meant by ‘treatment’?)	4
Order of questions	2
Specific unclear items	
Difference between mamma care nurse and nurse practitioner	1
Irrelevant questions	1
Social aspects about relations, partner, family and friends	1
Absent aspects (but important according to patients)	
Missing question:	7
- Amputation	
- Items for men	
- Lymphedema therapist	
- Multi disciplinary reflection	
- Emotional aspects	
- Patient organisation	
- Young women and items about child wish, breast feeding	
Missing answering category (PET-scan)	2

4.3.2 Applying the CIRF to the CQI pre-test results

In the following section, we address each of the major CIRF categories, and consider the extent to which our CQI pre-test addressed each of these.

(CIRF category 1a.) Clear research objective: The definition of a clear research objective in the CIRF is ‘not only the argument of pretesting new questions, but also the justification for the need of the study, direct motivation and the context (which parties are involved, how much modification is allowed)’. When comparing the reported research objectives in the two CQI questionnaires with

this definition, we see that CQI research only refers to the argument of testing new questions for the specific patient groups (e.g. rheumatoid arthritis patients, patients with breast cancer or a benign abnormality). Importantly, the justification of the need to do this (namely to add to the validity and applicability of the questionnaire in large groups of patients) is not explained in the reports.

However, there is more information about the research objective that is not reported. For example, the aim of assessing whether the questionnaire makes sense as a whole is not described, although this was in fact an implicit aim and we did ask participants to judge the questionnaire in general. In addition, the typical procedure involving multiple stakeholders could have been reported. That is, it could be explained what the purpose of stakeholders' involvement was in the specific stage of pretesting that was conducted. Specifically, the CQI procedure typically involves multiple stakeholders represented in a working group that interact with the researchers (see Table 4.1). In the construction phase of the questionnaire they help researchers with the exact formulation of questions and the translation of complex medical terms into lay language (Delnoij et al., 2010).

(CIRF category 1b.) Review of relevant background literature: The CIRF states that previous research on the use of the current items should be described, as well as whether any other pretesting sessions had been done. For developing a new CQI questionnaire, (inter)national literature, existing questionnaires concerning developing a questionnaire, disease specific guidelines and questionnaires are usually reviewed to find out if the topics to be measured were the ones used previously in already developed patient experience questionnaires. When we look at the CQI 'RA', we see that it was based on the disease specific questionnaire and guideline: QUOTE-RA (Van Campen et al., 1998a) and on the national professional guideline for RA (NVR, 2009). The CQI 'Breast Care' was based on that CAHPS hospital questionnaire (Crofton et al., 2005; O'Malley et al., 2005) and on the QUOTE-Breast Care (Kok et al., 2007). So existing questionnaires are used as an important source for collecting quality of care aspects, and focus group discussions provide more input for the items in the questionnaires. The sources of the items in the questionnaires were documented in the CQI research reports. However, we did not have access to the results of other pretesting sessions of the selected items, because no detailed information about pre-testing the items was available.

(CIRF category 2.) Research design: Describing the features of the overall research design, which gives legitimacy to the conducting of cognitive interviews, is an important criterion of the CIRF. Key questions are whether to use paper-and-pencil or web-based questionnaires and whether to make comparisons between subgroups of patients. The research design of pretesting the CQI 'RA' and 'Breast Care' were comprehensively explained by the researchers. Both researchers sent mailings to participants asking whether the items of the questionnaire were clear and whether they missed particular aspects of care in the questionnaire.

(CIRF category 3.) Ethics: In the CIRF reporting framework the criterion 'ethics' encloses approval of ethical committee or institutional review board, information about the settings, how people were motivated to participate, confidentiality and anonymity of participants and data management. For the CQI 'RA', CQI 'Breast Care' and most of the other developed CQI questionnaires, no ethical approval was needed, as research surveys that are not sensitive and/or hazardous for patients (i.e. the once-only completion of a questionnaire containing questions that do not constitute a serious encroachment on the person completing it) is not subject to the Dutch Medical Research Involving Human Subjects Act (WMO, 'Wet Medisch-wetenschappelijk Onderzoek met mensen'). Participants were free to respond to the questionnaire and they were informed about the aim of the pretesting of the survey.

(CIRF category 4.) Participant selection: This criterion of the reporting framework describes the participant selection methods used (such as demographics), if the selection of participants satisfies the study objective and what degree of saturation was achieved. Participants who were involved in pre-tests of the CQI questionnaire were recruited from a previously conducted phase, namely from focus group discussions. RA patients were recruited through the patient organisation and a health insurer involved in the working group. Breast cancer patients were invited through website announcements and the health insurer involved in the working group. Characteristics of all the participants of the focus group discussions were recorded and described in the reports, but the characteristics of the subgroup of participants who were involved in pre-tests were not recorded. There was only one test round and the researchers did not aim for saturation.

(CIRF category 5a.) Data collection: Providing information about the data collection includes basic information like who conducted the interviews, who trained the interviewers, if sessions were recorded (audio or video), if notes

were taken, what type of verbal reporting method was used, information about the interview protocol (items and instructions) and if the protocol was adjusted after experiences during the research process. The method used for data collection of pre-testing the two CQI questionnaires described was a mailing to participants asking whether the items of the questionnaire were clear and whether they missed aspects of care. No qualitative methods like cognitive interviews were conducted to collect data. Therefore, many of the above described criteria were not applicable. In total, 25 rheumatoid arthritis patients and 20 breast cancer patients participated in the pre-tests.

(CIRF category 5b.) Data structure and data management procedures: This quality criterion asks information about the storage of data, the recording of quotes, the transcription of interviews, and the collection of answers to the evaluated survey questions. The researchers provided no information about the data structure and management procedure in their reports. The results of the pre-tests were stored according to the rules of the research organisation that has an accreditation for ISO 9001 (the internationally recognized standard for the quality management of businesses) (Edelstein, 2001).

(CIRF category 6a.) Data analysis: All the items in the CIRF reporting framework about data analysis (like matrices, summaries, coding schemes, training interviewers, taking notes) are inapplicable to the two CQI questionnaires because no cognitive interviews were conducted. The analyses conducted consisted of assembling and interpreting the written comments on the pilot questionnaire. These comments were counted per item and adjusted if this was achievable. This was an activity performed by the researchers involved in the project, without systematic evaluation.

(CIRF category 6b.) Quantitative evidence: Not *during* the phase of pretesting, but in the next phase of psychometric testing, analyses were conducted to assess the appropriateness and validity of items and the dimensional structure of the questionnaire. These analyses included item analyses, explorative factor analyses, and reliability analyses.

(CIRF category 7.) Findings: This CIRF criterion describes that the findings need to be reported in a systematic and clear way (per item or for the entire questionnaire). It is preferred to give descriptions of problem areas, the causes of problem areas and possible solutions. For the studied CQI questionnaires in this article we summarized pre-test data into themes like ‘general’, ‘unclear items’ or ‘absent items’. See Table 4.2 and 4.3 for an example of the findings.

(CIRF category 8.) Conclusion, implications and discussion: This quality criterion implies that a copy of modified questions needs to be available and the findings and solutions must be discussed in the light of previous evidence. However, in our pre-test, there was no systematic presentation of the conclusions of the two CQI pre-tests.

(CIRF category 9.) Strengths and limitations: This CIRF quality criterion prescribes:

1. Reporting previous experiences of similar questionnaires, projects that could have biased the research, and how researchers dealt with possible influences.
2. Discussing the generalization of the results to a wider population.
3. Contribution to methodological development and future practice.

For our two pretested CQI questionnaires, there was no information available about the issues of relevant expectations, or previous experiences with similar questionnaires or projects. The generalization to a wider population and contribution to methodological development of pretesting was also left unreported.

(CIRF category 10.) Report format: The reporting format aspects described in the CIRF (summary, introduction, methods, participants information, findings, conclusions and implications) correspond to the research report format of developing a new CQI questionnaire (from pre-test till quantitative tests). Within the overall report concerned with developing a new questionnaire, the findings of the pre-test are only briefly mentioned. As such, this report again does not meet the CIRF criterion.

4.4 Reflection on the use of CIRF criteria

This article describes a case report of two previously conducted pre-tests of Dutch patient experience questionnaires (CQI 'RA' and CQI 'Breast Care'). The current CQI practice was compared with a new reporting framework for cognitive interviewing (CIRF).

When comparing the pre-tests of two CQI questionnaires with the CIRF we viewed that CQI questionnaires have not been pretested using cognitive interviewing methods. The objective of current CQI pre-tests is to find out which questions are incomprehensible and which aspects are missing. A main finding of the pre-tests was that some items failed to measure the intended construct (e.g. items about 'listening carefully' and 'showing personal attention') and that particular terms were badly comprehended by patients. Researchers and key stakeholders thought that these constructs and terms were clear to respondents. To get insight into this kind of difficulties or misinterpretations, we propose that systematic cognitive interviews should be used in the pre-test. As explained by Boeije and Willes (submitted), cognitive interviewing is a method consisting of think out loud and verbal probing protocols. Cognitive interviews pay explicit attention to mental processes respondents use to answer survey questions and to identify problems (Collins, 2003). When people are explicitly asked to think out loud and/or to explain concepts and terms in their own words, misinterpretations will be more easily discovered.

If cognitive interviewing is not used as a pretesting method information about the categories of the CIRF should be reported when describing the results of the pretesting procedure. However, we also believe that not all CIRF criteria need to be fully incorporated in the Dutch CQI procedures. CIRF is specially designed for cognitive interviewing, were modification for CQI research is desirable because of a more focused research aim and an already existing CQI manual that describes many of the CIRF criteria for developing new CQI questionnaires in general.

Another important finding from our pre-tests is that several respondents could not get on with certain medical terms referring to diseases and drugs. This is likely to be a problem among respondents with low health literacy. In our opinion, people with low health literacy are an important groups of respondents of patient experience questionnaires, since they may experience other types of problems in healthcare than people with higher levels of literacy. A finding in support of group comparison is that we found younger patients to miss certain aspects in the questionnaires. If we want patient experience questionnaires to be useful for such different groups of people, pretesting methods should consist of group comparisons that focus on differences in comprehension of items. By performing cognitive interviews with different groups one is more able to generalize the findings and know whether the items in the questionnaire are usable for subgroups of respondents.

The following recommendations for researchers who develop patient experience questionnaires can be given:

1. Conduct a literature search about the possible difficulties for respondents or misinterpretations made by respondents. Use existing manuals and

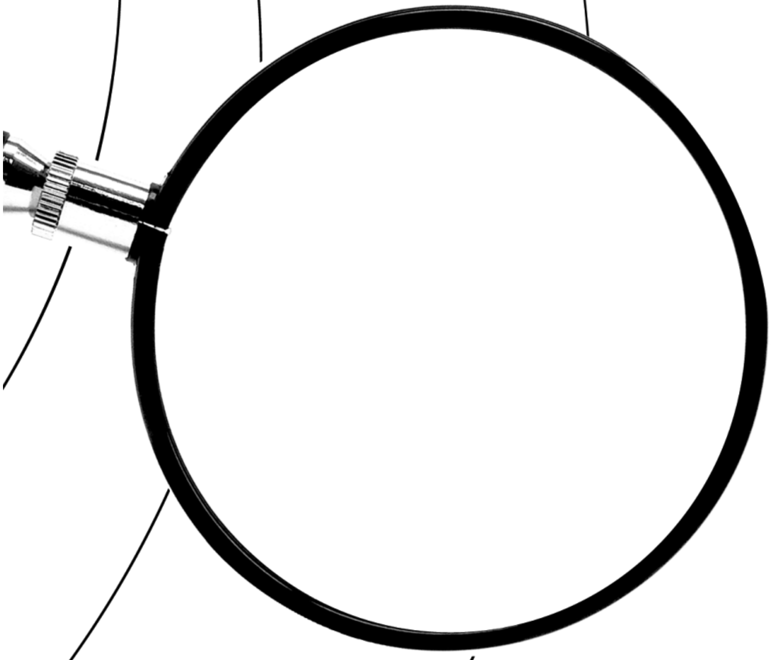
databases that are developed for national measurement of patient experiences (e.g. the CQI database and previously developed CQI questionnaires in the Netherlands).

2. Focus on the purposes of the pre-test and design your test accordingly. In most cases, the aim of pretesting patient experience questionnaires is to identify problems and misinterpretations with regard to the different items in (different groups of) respondents.
3. Considering the purpose of pretesting patient experience questionnaires, cognitive interviewing using think out loud and verbal probing protocols should be the standard.
4. Consider the benefits and costs for participants and organize the pre-test in such a way that costs for participants are minimized. Ethics may be especially relevant for certain patient groups like patients who receive palliative care.
5. Data collection should focus on different groups of patents, importantly people with a lower education and/or lower health literacy. Researchers have to make an effort to include these groups.
6. Analyse the findings systematically by identifying five broad problem categories developed by Levine et al. (2005) (respondents do not have information to answer the questions, no clear questions, failure to measure the intended construct, items were not applicable for a large group of respondents and items measure similar constructs).
7. Report the findings in a systematic way. The topics that should minimally be described are the pre-test's objectives, the reviewed literature, the research design, participant selection, the findings, and the conclusion and implications.

The two studied CQI 'RA' and 'Breast Care' questionnaires were developed before the publication of the CQI manual (Sixma et al., 2008a; Sixma et al., 2008b; Sixma et al., 2008c; Sixma et al., 2009) with guidelines and instructions of the Dutch Centre for Consumer Experience in Health Care. Now there are standard CQI items and there is a public CQI database (CKZ, 2009) where researchers can search for items that were used in previously designed CQI questionnaires. Encountered problems with these items are not systematically reported yet. However, the Manual and database are tools that help researchers in their formulation of adequate questions. By combining these tools with a systematic pre-test, patient experience questionnaires will be more applicable to a wider population of patients.

5

Comparing proxy-reports: do family members and nursing staff assess the quality of dementia care similarly with different instruments?



M Zuidgeest
APA van Beek
PP Groenewegen
DMJ Delnoij

5.1 Background

Performance indicators provide nursing homes and homes for the elderly with valuable insights into their healthcare provision and into areas in which improvements can be made. These indicators can be distinguished into measurements of quality of care and quality of life (Rijckmans et al., 2005) alongside measurements of effectiveness and safety (Institute of Medicine, 2001; Ministerie van VWS, 2001; Fleming et al., 2006). Information on indicators is often collected from the residents in long-term care themselves. However, this is often impossible for residents with dementia because of their cognitive impairments. Therefore, information on performance indicators for these residents is often gathered through proxy-reports, such as questionnaires mailed to family members of residents with dementia or observational assessments by the nursing staff. This article sheds light on the relation between these types of proxy-reports regarding the same residents.

The underlying assumption in collecting information on residents through proxies, is that proxies have knowledge of the residents' health and use of services. In the Netherlands, representatives (often family members) of residents with dementia are asked to provide information on the quality of care for long-term care facilities through a mail questionnaire. This questionnaire is part of the CQI 'Long-term care', which also includes an interview protocol for residents without dementia and a mail questionnaire for clients receiving homecare in order to assess the quality of the long-term care (Triemstra et al., 2010). These questionnaires belong to an approach that is a national standard in the Netherlands for measuring healthcare quality from the perspective of healthcare users (Box 5.1). This approach was introduced to create comparative quality information and to make the healthcare sector transparent with respect to healthcare users' experiences. The CQI 'Long-term care' reports on what residents, family members, or homecare clients experienced during a particular period in their interactions with healthcare providers and the healthcare system (Cleary and Edgemen-Levitan, 1997; Browne et al., 2010) because this tends to better reflect interpretable and actionable quality improvement purposes than patient satisfaction questionnaires (Cleary et al., 1991; Cleary et al., 1993; Sixma et al., 1998).

Box 5.1 Consumer Quality Index (Sixma et al., 2008a)

What is the Consumer Quality Index (CQ-index or CQI)?

- National standard to measure healthcare quality from the perspective of healthcare users.
- Based on American CAHPS and Dutch QUOTE instruments.
- Collection of instruments (surveys or interview protocols).
- Collection of protocols and guidelines for sampling, data collection, analysis, and reporting formats.

What is measured by the CQ-index?

- What healthcare users find important in healthcare.
- What their actual experiences are.
- How they rate the overall quality of care.

Every two years, facilities are obligated to measure their quality of care from the family members' perspective with the CQI 'Long-term Care' by an approved contractor. This is a relatively expensive and time-consuming procedure (Zuidgeest et al., 2008b). The approved contractor sends mail questionnaires and two reminders, and the follow-up period takes weeks. In order to provide more frequent and shorter period quality information, observing the behaviour of residents can be conducted by the nursing staff. Because both types of measurements are applied in long-term care facilities to obtain information of residents, it is relevant to investigate if both types of reports are interchangeable, so that the evaluations could be alternated in order to provide insight into the healthcare provision of long-term care facilities. An additional argument for looking at the similarities between different sources is that there is no 'golden standard' for measuring quality of life for residents with dementia. Lawton argues that understanding quality of life will be enhanced by looking for congruence and incongruence between sources, and by attempting to explain the observed differences in quality of life scores (Lawton, 1997).

Assessments that observe the behaviour of residents in long-term care include the Social Well-being of Nursing home residents (SWON) instrument and the Revised Index for Social Engagement (RISE) (Gerritsen et al., 2010; Gerritsen et al., 2007; Gerritsen et al., 2008). Social well-being and social engagement are important contributors to quality of life for residents living in long-term care facilities (Gerritsen et al., 2004; Mor et al., 1995; Smit et al., 2005). More specifically, it has been found that a high level of social engagement has a protective effect on mortality in long-stay nursing home populations (Kiely and Flacker, 2003) and social disengagement has been associated with cognitive impairments in older adults (Bassuk et al., 1999).

In the current study, it is hypothesised that scales of the CQ-index for family members of residents with dementia are related to nursing staff' perceptions of residents' social well-being and social engagement as measured with the SWON and RISE. In addition, we look at residents' cognitive and physical functioning as these aspects influence the scores on the RISE and SWON (Gerritsen et al., 2008, Bassuk et al., 1999). The relationship with the cognitive and physical functioning of residents has not been investigated for any CQI questionnaire. Because we hypothesised that outcomes on the CQI questionnaire for family members are related to residents' social well-being and social engagement, we also hypothesize that outcomes of the CQI indicators of family members are influenced by cognitive and physical functioning of the residents for whom the questionnaire is completed.

Consequently, our research questions are *'Are outcomes of CQI questionnaire for family members related to residents' social well-being and social engagement?'* and *'Do scores of CQI questionnaires for family members need to be corrected for cognitive and psychological functioning of residents?'*.

5.2 Methods

The data for this analysis were collected in an evaluation of small innovative projects in fifteen long-term care organisations that provide care for residents with dementia (Van Beek et al., 2009). According to Dutch law, submission to a research ethics committee was not required: results were not obtained by the residents report, but rather by the observations of the nursing staff and by mail questionnaires to family members. Family members were asked to give informed consent for the observations by the nursing staff and to link these observations to their answers on the CQI outcomes. Between January and April 2009, data was collected and the paired data of a total of 107 residents was available for the analysis. Anonymity and confidentiality for the family members and nursing staff were guaranteed.

5.2.1 Questionnaire to family members

The mail questionnaires to family members of residents with dementia contained questions from the CQI 'Long-term Care' for representatives' questionnaire that, among others, contains the scales Atmosphere and Daily activities (Triemstra et al., 2010) (Table 5.1). Response categories on the items of these scales are: 1. Never; 2. Sometimes; 3. Usually; and 4. Always.

The mean scale scores were calculated, where a higher score represents a more positive opinion of the representative. The background information of family members and residents was also collected: family members' age and gender, relationship to the resident, frequency of visits, residents' age and gender, and length of stay in the nursing home.

Table 5.1 Items in the CQI scales

Scale	Items
Atmosphere	1. Are the public rooms, such as the living room and passage, pleasant places to stay (comfortable, clean, a pleasant smell)? 2. Do residents interact with each other pleasantly/sociably? 3. Does the home offer enough companionableness and opportunities for residents to have contact with others?
Daily activities	1. Does the resident have enough opportunities to participate in (daily) activities? 2. Does the home organise enough activities? 3. Do the organised activities match what the resident considers pleasant? 4. Is there any support provided for going outside or on trips?

5.2.2 Social Well-being of Nursing home residents-scale (SWON)

SWON (Gerritsen et al., 2010) uses 9 items to measure three basic human social desires: need for affection, need for behavioural confirmation, and need for status (Table 5.2). These subscales theoretically range from 0-6. Answering categories for items 1 to 3 are '0' once a month or less, '1' once a week, '2' several times a week, '3' once a day, and '4' several times a day or the entire day. Questions 4 to 7 have the answering categories '1' yes and '0' no. The last two items, belonging to the sub-scale status, have the answering categories '1' yes with most, '0.5' yes with some, and '0' no. The overall social well-being scale ranges from 0-18 where higher values represent greater social well-being.

The SWON theoretically matches with the CQI indicator Atmosphere: both scales contain questions regarding the possibilities of (social) contact with others, although from a different perspective. Namely, the SWON observes how residents interact with nursing staff, family members, and other residents; the Atmosphere scale contains questions regarding the possibilities offered by the facility to make contact with others.

Table 5.2 Items of the Social Well-being of Nursing home residents-scale (SWON) and Revised Index of Social Engagement (RISE)

Items
SWON - Affection
1. How often does this resident show appreciation or affection towards the nursing staff?
2. How often does this resident get a hug (or an embrace, etc.) from the nursing staff or others?
3. How often is there humour in the contact with this resident (nursing staff or others)?
SWON-Behavioural confirmation
4. Does this resident usually try to take others into consideration?
5. Is this resident sympathetic towards others?
6. Does this resident usually try to keep to the agreements made?
SWON-Status
7. Does this resident have a positive presence on the ward (e.g. humour, always happy, a special talent)?
8. Is this resident popular with the other residents?
9. Is this resident popular with the nursing staff?
Composite score on the scores of the three SWON sub-scales
RISE
1. At ease interacting with others.
2. At ease doing planned or structured activities.
3. Pursues involvement in the life of the facility.
4. Accepts invitations to most group activities.
5. Initiates interaction(s) with others.
6. Reacts positively to interactions initiated by others.
Composite score on the RISE scores

5.2.3 Revised Index of Social Engagement (RISE)

The RISE (Gerritsen et al., 2008) measures the positive features of long-term care residents' social behaviour through 6 dichotomous items with the answering categories '1' yes applicable and '0' not applicable. For the specific questions, see Table 5.2. Scores range from 0 to 6: higher values represent greater social engagement.

The RISE theoretically relates to the CQI indicator Daily activities because both reflect residents' social behaviour. More specifically, the RISE observes residents' behaviour concerning activities, and the Daily activities scale measures the opportunities offered by the facility to participate in (sufficient and joyful) activities.

5.2.4 Care need of residents

Care need (cognitive and psychical functioning) was determined by observing the residents' cognitive and physical functioning by the nursing staff.

Cognitive functioning was measured with the Cognitive Performance Scale (CPS) (Morris et al., 1994) of the Minimal Data Set (MDS) of the Resident Assessment Instrument (RAI) (Morris et al., 1990). The CPS comprises four items that combines information on decision-making, memory, making oneself understood, and eating into a scale that ranges from 0 (intact cognition) to 6 (very severe impairment).

Physical functioning in daily living was measured using an MDS Activities Daily Living-Hierarchy scale (ADL-H) (Morris et al., 1999). This scale is based on four ADL items: indoor locomotion, eating, usage of toilets, and personal hygiene. Scores range from 0 (total independence or no or little help with an activity) to 6 (totally dependent) (Morris et al., 1999).

5.2.5 Data analyses

Firstly, the characteristics of residents, family members, and nursing staff are described. Secondly, a description of the data of the used instruments is given: the scale Atmosphere was compared with the SWON and the scale Daily activities was compared with the RISE using Spearman's rank correlation coefficients to assess whether these variables correlated. Non-parametric correlation tests were used instead of Pearson's correlation because the tests of normality of the used variables were significant. Thirdly, the descriptive data of care need is presented and the Spearman's rank correlation between the CQI scales and care need was calculated. A level of significance of $p<.05$ was used. Analyses were performed using SPSS ® version 17.0.

5.3 Results

5.3.1 Description

Table 5.3 shows the characteristics of nursing home residents and family members. The average age of nursing home residents was 83 years, where the youngest resident was 59 years and the oldest 98 years. Three-quarters of the residents were female and more than half of the residents (57%) had been staying two years or longer in the homes.

Table 5.3 Characteristics of residents with dementia and their family members (n=107)

Nursing home residents		Family members	
Age, mean (SD)	82.90(8.3)	**Age, mean (SD)**	60.99(11.7)
≤74 years, %	11.2	35-49 years, %	15.2
75-84 years, %	43.9	50-69 years, %	61.9
85-94 years, %	39.3	70-79 years, %	17.1
≥95 years, %	5.6	≥80 years, %	5.7
Gender, %		**Gender, %**	
Female	75.5	Female	69.2
Length of stay, %		**Relationship to resident, %**	
6–12 months	12.1	Spouse	15.0
1-2 months	29.9	Son or daughter	60.7
>2 years	41.1	Family but not son/daughter	15.0
>5 years	16.8	Other, no family	9.3
Care need		**Frequency of visit, %**	
CPS, mean (SD)	3.97(1.75)	daily	12.1
ADL, mean (SD)	3.75(1.55)	3-6 times per week	25.2
		1-2 times per week	48.6
		1-2 times per month	12.1
		1-2 times per 3 months	0.9
		less than once per 3 months	0.9

The average age of the family members was 61 years (SD=11.7), and most of them were female (69%). In 61% of the cases, the family members were the residents' children. Half of the spouses visited the residents daily. Sons, daughters, and other family members visited the residents 1 to 2 times per week. The nursing staff was on average 42 years old (SD=10.9), mostly female (92%), and they worked on average 27 hours a week (SD=7.5) (not shown in Table).

5.3.2 Description of measurements and the correlation between the CQI scores and nursing staff' perception

The CQI scales Atmosphere and Daily activities had mean scores of 3.06 (SD=0.61) and 2.90 (SD=0.61), respectively, indicating that their experiences were met ‘often’. The mean score of the SWON was 10.95 (SD=4.50) and the mean scores for the subscales need for affection, behavioural confirmation, and status were 4.14 (SD=1.68), 3.07 (SD=2.59), and 3.72 (SD=1.50), respectively. The mean overall score of the RISE was 2.90 (SD=2.07).

The results showed that there was no significant correlation between the scale Atmosphere and SWON (r=0.193; *p*=.068). However, between the scale Daily activities and the RISE there was a small but positive and significant correlation (r=0.221; *p*<.05).

5.3.3 CQI scales and care need

Overall, the residents were moderately to severely cognitively impaired (mean CPS=3.97 [SD=1.75]). A total of 17.8% of the residents had mild cognitive impairment (CPS ≤2), 30.9% had moderately severe cognitive impairments (CPS=3 and 4), 29.9% was severely impaired (CPS=5), and 21.5% had very severe impairments (CPS=6).

Generally, residents were also impaired in their psychical functioning (ADL-H= 3.73 [1.54]). Thirty percent of the residents needed full assistance with eating, locomotion (ADL-H= 6 or 5, respectively), 53% needed extensive assistance in personal hygiene, toileting, or eating (ADL-H= 3 or 4), and 16% of the residents needed no or only limited assistance with activities (ADL-H ≤2).

There were no relationships between the scale Atmosphere and cognitive (r=-0.106; *p*=.284) and psychical functioning (r=-0.055; *p*=.583). However, the scale Daily Activities did correlate with cognitive (r=-0.245, *p*<.05) and physical functioning (r=-0.311, *p*<.05).

5.4 Discussion

The focus of this study was on the relationship between two types of proxy-reports for measuring the quality of life indicators of residents with dementia: mail questionnaires that were filled out by family-members of residents with dementia and nursing staff’ perception of resident’s social well-being and social engagement. For this, two scales of the CQI ‘Long-term Care’ for representatives - Atmosphere and Daily activities - were compared with the observational assessments Social Well-being of Nursing home residents (SWON) and Revised Index for Social Engagement (RISE). In addition, the influence of cognitive and psychological functioning of residents with dementia on the outcomes of the

CQI questionnaire for family members was analysed. The quality of life indicators -social-well-being and social engagement- were chosen because they are important contributors to the quality of life for the residents living in long-term care facilities (Gerritsen et al., 2004; Mor et al., 1995; Smit et al., 2005).

Our hypothesis was that family members of residents with dementia as measured with CQI scales (Atmosphere and Daily Activities) relates to nursing staff' perception of residents social well-being (SWON) and social engagement (RISE), because more opportunities offered by long-term care facilities to be active and to engage in social contacts should result in doing more activities. This hypothesis was partly confirmed. Social well-being measurements (CQI scale Atmosphere and SWON) did not correlate. Concerning the social engagement of residents with dementia (CQI scale Daily activities and RISE), there was a small, but statistically significant correlation.

The second hypothesis was that cognitive and physical functioning would affect the scores on the CQI scales. For the scale Atmosphere, the results did not confirm our hypothesis. However, there was a correlation for the scale Daily activities: more cognitive impairment or problems with physical functioning coincides with fewer opportunities for social interaction. This result is confirmed in studies where being more physical activity was associated with lower risks of cognitive impairment (Laurin et al., 2001; Li et al., 1989; Bro et al., 1990). So results are inconclusive regarding the correction of the outcomes of CQI questionnaire of representatives for cognitive and psychological functioning of residents of whom the questionnaire is completed. Therefore, future research should focus on CQI scores and the relationship with care need of residents to provide more insight into this finding and thereby answering the question if CQI scores need to be corrected.

Even though the measurements corresponded little, the findings provide valuable insight into two types of proxy's that are often used in Dutch long-term care facilities to evaluate dementia care. As Lawton argued, understanding quality of life will be enhanced by looking for congruence and incongruence between sources, and by attempting to explain observed differences in quality of life scores because there is no golden standard for measuring quality of life for residents with dementia (Lawton, 1997).

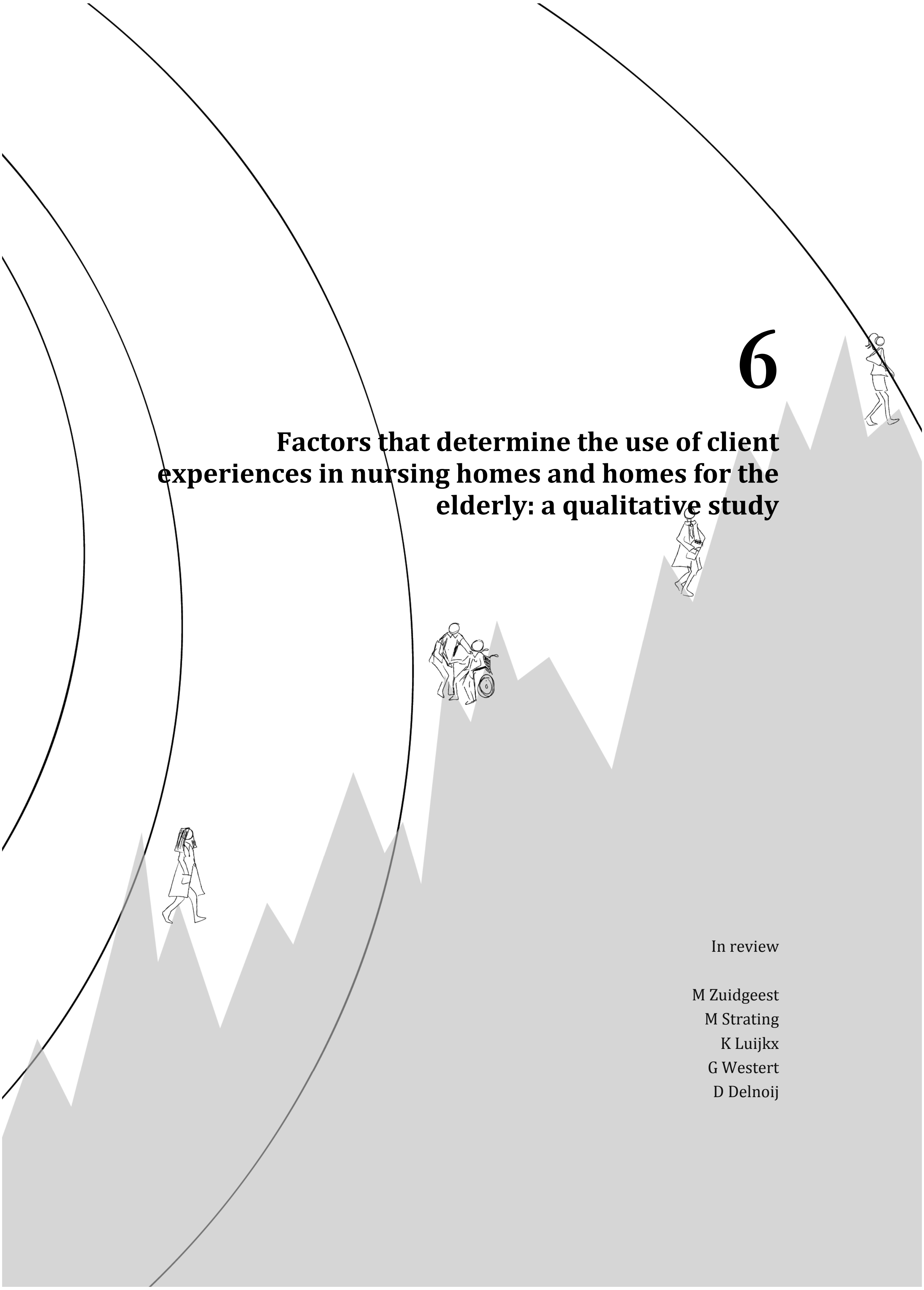
The congruence between the two types of proxy-reports is their intention to evaluate dementia care for residents in Dutch long-term care facilities. The incongruence between the two proxy-reports is the manner of data collection:

observational assessments measure the behaviour of residents, whereas the questions in the mail questionnaires filled out by family members are more about general organisational characteristics. The CQI scales differ in the types of items measuring the concepts social well-being and social engagements: the Atmosphere scale contains questions about the ambiance and residents' pleasant interactions, whereas the Daily activities scale questions concern the opportunities to participate in activities. These last questions may better reflect the behaviour of residents, which could explain the little correspondence with the observational scale RISE. On the other hand, the limited correspondence could probably be explained by the little variance of the CQI scores: the used CQI scales were mostly positive.

Our findings imply that proxy-reports assess different aspects on the quality of dementia care. This means that reports are not interchangeable and evaluations cannot be altered to provide insight into the healthcare provision of long-term care facilities: their views on dementia care are unique. This finding is consistent with other literature where people with dementia, the staff, and family members were interviewed. The three groups had different views regarding activities that were meaningful for people with dementia (Harmer and Orrel, 2008). A study exploring the answers of residents self-report to staff and family proxies' reports on selected quality of life domains (measured with the same instrument) showed that we cannot simply substitute the different perspectives (Kane et al., 2005). This indicates that the perspective of clients and their family members are important sources of quality information, which differs from the perspective of professionals and differs from each other. By combining different perspectives, supplementary quality information is gathered for nursing homes and homes for the elderly.

Part 2.

The actual use of CQI information for quality improvement



6

Factors that determine the use of client experiences in nursing homes and homes for the elderly: a qualitative study

In review

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6.1 Introduction

Every year, Dutch nursing homes and homes for the elderly account for the quality of their care in an accountability report (www.jaarverslagenzorg.nl). This quality information relates to effectiveness, safety, and patient experiences (Delnoij et al., 2002). This latter is done using a standardized methodology called the Consumer Quality Index (CQ-index or CQI). In addition to guidelines for measuring the client experiences (Sixma et al., 2009), this methodology also contains guidelines for analysing and reporting (Sixma et al., 2008b; Sixma et al., 2008c). The use of this single approach makes it possible to obtain and compare results in a similar way.

In the nursing and caring sector, the CQ-index approached consists of three questionnaires:

1. An interview questionnaire for residents of nursing homes and homes for the elderly.
2. A mail questionnaire for the representatives of psycho-geriatric residents.
3. A mail questionnaire for clients receiving care at home (Wiegers et al., 2007; Triemstra et al., 2010).

Every two years, an approved contractor that is allowed to conduct CQI research administers these questionnaires. They also provide a report for the organisational unit, location, or concern, containing the data collected. The collected results are also included in a national database, where they are corrected for relevant case-mix variables such as age, health-status, and level of care required. Additional, the data is converted into relative performance scores in the form of stars (* for much below average to ***** for much above average), -that after approval by the organisation- will be published on a website for choice information (e.g. www.kiesBeter.nl). The intention behind the CQ-index approach is that the results should be applicable for multiple purposes (Delnoij and Hendriks, 2008). For example, a CQI measurement serves to provide information for care organisations for making improvements, as well as information for care purchasers, supervisory agencies, and consumers. It is still an open question whether CQI data is actually used within care organisations to improve the quality of care. No study of this has yet been performed in the Netherlands. However, this question is relevant because quality improvement is an important objective of these measurements.

According to Berwick et al. (2003) there are two mechanisms whereby the measurement of quality can lead to improvement. Firstly, this can occur via the *selection mechanism.* This means that - on the basis of the published results of the quality measurements - (future) healthcare users choose, and health insurers contract, care organisations that perform better. This causes shifts in market shares, so that organisations that perform well grow and those that perform poorly shrink or even collapse (Berwick et al., 2003). However, research has shown that transparent quality information has little effect on the consumption behaviour of healthcare users (Fung et al., 2008; Faber et al., 2009).

The second mechanism possibly works through *change*. This presumes that, if there is dissatisfaction about the results, care providers will themselves initiate changes because of their intrinsic motivation to provide good quality care (Berwick et al., 2003; Marshall et al., 2003). Making the data public provides an extra stimulus (Berwick et al., 2003; Hibbard et al., 2005). This is apparent, for example, from research in the United States, where homes for the elderly reorganise their quality programmes and start up new programmes as a reaction to comparative quality information (Castle, 2005; Mukamel et al., 2007; Werner, 2008). This effect was stronger among homes performing less well than among homes that scored better (Mukamel et al., 2007), and was also observed by Dutch health insurers (Hendriks et al., 2009).

The internal use of information from CQI measurements to improve quality may depends on many factors. The framework of Davies and Cleary consists of three categories of factors that affect the use of information from feedback measurements (Davies and Cleary, 2005):

1. *Data-related factors* such as the credibility, reliability, validity, and user-orientation of data. With relevant, understandable, verifiable, timely, and realistic data, an organisation is willing to take responsibility for the data (Cummings and Worley, 2005). The level of detail of data, reporting at the right level, and structured feedback, increase the chance of results being used (Davies and Cleary, 2005).
2. *Staff-related factors* such as being open to feedback and no resistance to change. Focused training, selection, and support of staff also promote the use of information (Davies and Cleary, 2005). Furthermore, repeating a measurement creates a more positive attitude among staff to the use of results. Lack of time and resources - such as knowledge of statistics - are barriers to the use of results (Reeves and Seccombe, 2008).

3. *Organisation-related aspects* such as capacity, skills, and an infrastructure for quality improvement. A barrier to quality improvement is lack of consideration for the needs of the patient when decisions are taken (Davies and Cleary, 2005). There is a greater chance of success in initiating and maintaining quality improvements when senior management is involved (Strating et al., 2008) and when the management demonstrates leadership (Davies and Cleary, 2005).

Based on this framework, we formulate the following main research question: '*According to the staff of nursing homes and homes for the elderly, what data-related, staff-related, and organisation-related factors influence the use of CQI information for improving quality?'*

6.2 Method

6.2.1 Selection of long-term care organisations

The aim was to interview staff of 15 nursing homes or homes for the elderly. For this purpose, 60 organisational units (OEs) were approached, that were selected from among 998 nursing home and care home OEs that had published their data via the annual document Accountability Report ('Maatschappelijke Verantwoording'). Because there were performance differences between OEs (De Boer et al., 2008), the results for two indicators were considered when selecting the nursing homes and homes for the elderly. These were the indicators 'Perceived autonomy' and 'Perceived involvement and consultation' with star ratings '(much) below average (1 or 2 stars)', 'average (3 stars)' and '(much) above average (4 or 5 stars)' (Zuidgeest et al., 2010). Changes in these outcomes can, in principle, be achieved quickly.

6.2.2 Recruitment of long-term care organisations

The Boards of Management of the selected long-term care organisations received a letter inviting them to participate in this study. After two weeks, the quality manager or the secretariat was contacted by telephone to ask whether the letter had been received and whether the organisation wished to take part in this study.

6.2.3 Interviews

In 2010, semi-structured interviews were held with various members of staff within each of a number of organisations. One interviewer (MZ) interviewed an employee responsible for day-to-day care, a representative of middle management (manager, team leader, or coordinator), a quality manager, and/or a representative of senior management (director, location or regional director) to get a complete picture of how CQI results are put into effect within the organisation. Subjects that were discussed in the interview were: the organisation, quality policy, and CQI results. With permission, interviews were recorded digitally. Those interviewed received a summary of the interview for confirmation. The interviews were at the locations of the participating organisations.

The interviews were transcribed and analysed using Atlas.ti version 6 with open coding (Boeije, 2005). This means that the text determines which codes arise. The themes to which the codes belonged were then determined. The texts were coded and analysed by the researcher (MZ). Selected interviews (1 or 2 interviews per employee type) were also coded by a second researcher (KL).

6.3 Results

6.3.1 Participating organisations and staff interviewed

Twelve long-term care organisations distributed throughout the Netherlands took part in this study. Table 6.1 shows how they performed on the two indicators ‘Perceived autonomy’ and ‘Perceived involvement and consultation’.

Reasons given by long-term care organisations for not taking part in this study were either that they were occupied with a merger/integration process or that they were engaged in certification or other (obligatory) investigations. However, the majority of the organisations approached decided - with or without consultation with the Board or location manager - not to take part in this study without giving a reason.

In total, 47 employees were interviewed. Table 6.1 also shows the number of people interviewed per organisation and per employee type.

Table 6.1 The number of stars per indicator and the number of interviewees per group for each participating organisation

Organisation	Number of stars per indicator*		Interviewees				Total
	Autonomy	Involvement and consultation	Care worker	Middle management	Quality manager	Senior management	
1	1	1	-	2	1	1	4
2	4	1	1	1	1	1	5
3	4	4	1	2	-	1	4
4	1	2	-	2	1	1	4
5	3	4	1	1	1	2	5
6	3	3	-	2	1	-	3
7	1	2	-	1	2	2	5
8	2	4	-	1	1	2	4
9	2	4	1	1	1	1	4
10	2	2	1	1	1	1	4
11	2	4	-	2	2	-	4
12	4	3	-	-	-	1	1
Total			5	16	12	14	47

* 1 or 2 stars=below average, 3 stars=average, and 4 or 5 stars=above average

6.3.2 Factors that affect the use of CQI data

The following sections show the results from the interviews for each of the categories of factors that affect the use of information:

1. Data-related factors.
2. Staff-related factors.
3. Organisation-related factors.

Ad. 1. Data-related factors

In the past, it was only through the complaints of patients that care organisations learned about improvements that could be made in the care provided. With the standardised measuring of the experiences of a random selection of clients by an independent approved contractor, the care organisation obtains a more comprehensive picture of how of a group of typical clients perceives the care. Some remarks about the CQI results by those interviewed were: *'The results keep the organisation alert'* (home 2, senior management) and *'The results are an incentive to keep us on our toes'* (home 8, senior management). These are reasons for the measurement of client experiences to be seen as very important and valuable by those interviewed. Organisations also use the CQ-index in measuring client experiences because it is a national instrument that enables comparison of their own scores with the scores of other organisations, and comparative data provides a frame of reference. For some organisations, this was a reason for not using their own instrument for measuring the quality of care.

However, some organisations decided not to include any comparative analyses in their CQI reports. If no frame of reference is provided, there is room for individual interpretation of what are acceptable norms. By way of illustration, a quote in which an own interpretation of the results is sought:

> '*The score on the question about loneliness was around 65-68%. In an investigation [not a CQI report] among people living in their own homes in [...], the loneliness for 65 years and older was 63%. Here in this home, the residents are somewhat more lonely, but not much more than the normal 65 years and older.*' (home 1, senior management)

In general, those interviewed found the results to be reliable, recognisable, and relevant to the way their organisation works. If the data had not been recognisable, interviewees would have had doubts about the instrument. This was the case with one organisation. The interviewee found it difficult to place the relatively poor scores. The conclusion of the approved contractor was that this could have been due to the particular interviewer who conducted the interviews (interviewer effect).

Because the CQI methodology employs questionnaires with predefined categories of answers, some quality managers and senior management representatives thought that the extra information received from clients during the interview was lost. They would like to put follow-up questions, and record the extra information. It was their opinion that this would provide information on the needed improvement actions shown up by the results. On the other hand, interviewees from other care organisations indicated that, as follow-up to the CQI results, the management itself must determine which aspects they want to focus on, and this is different for every organisation.

Ad. 2. Staff-related factors

The theory of Berwick et al. presumes that intrinsic motivation is a possible mechanism through which the measuring of quality can lead to improvement. The following quotes show that, for some staff, intrinsic motivation and being open to feedback were a stimulus to provide good care and to take action as follow-up to the results:

> *'I find it satisfying to score well when the aim is to do our best for the clients.'* (home 1, care worker)
>
> *'The research results must always be taken seriously, and they should be acted upon. These are things that the clients have experienced in the home, things that the home must deal with, since the home wants to provide good care.'* (home 6; middle management)

After permission from the organisation, the CQI results are published on www.kiesBeter.nl. The theory of Berwick et al. presumes that the publication of the data also provides an extra stimulus to improve quality. Those interviewed were divided in their opinions on this:

> *'I think that making data public is an extra stimulus [to provide good care].'* (home 1, care worker)
>
> *'Publishing the results on Internet in the form of stars is an extra stimulus for the organisation to get a better score.'* (home 6, care worker)
>
> *'Openness about performance can be a reason to perform better.'* (home 3, senior management)
>
> *'It shouldn't be the case, of course [that the publication of data stimulates the provision of better care], and I don't think it is.'* (home 11, middle management)

Organisations deal differently with CQI data. This is partly determined by the mission and structure of the organisation. Some quality managers are simply there to support quality changes, because senior management thinks that quality must be fundamental to the daily work. This means that changes must be handled at the workplace since that is where the quality is delivered. Should the support of a quality manager be needed, then he/she supports the staff on the work floor. The following quote illustrates this.

> *'Quality must be a fundamental part of the day-to-day work. Quality cannot be dependent on just a few people, but must be ingrained in the way everyone carries out the day-to-day work together. 'Together' means 'including the Management and the staff of the support services'. This makes for a qualitatively good organisation.'* (home 4, quality manager)

In other organisations it was precisely the quality manager who pointed out, on the basis of the CQI report, which aspects of care required attention. However, how these aspects were to be improved was left to the middle management. These two examples show that quality managers support others in the preparation of changes, but that the care workers are critical in the actual implementation.

A manager with authority can also decide, based on a CQI measurement, to change the care and services provided. Two examples illustrate this. The first example that came out of the CQI measurement as a point for improvement concerned hot meals. Previously, clients filled in a menu list two weeks in advance. The Director felt that clients should have a greater choice, so the preparation process was changed: now the hot meal is served in dishes on the table at midday, and there is a choice of vegetables, a variety of potatoes, meat, and a dessert. This initiative met resistance from the client council. The argument against this change was that the clients would be given reheated food in the evening. This point was put before the national arbitration panel. The Director won the argument, and the change was put into effect. The second example concerns a low score on the 'autonomy' indicator. The Director attributed this to residents who wanted to have their own keys to the home, as follows.

> *'Of the 90 residents, four wanted their own keys. These residents are still quite independent, and found it irritating to have to ring the bell of the home where they live. This resulted in a discussion of safety if a key should be lost. The conclusion was that I should make a wise decision, and so I did: I gave the residents their own keys. The report helped in this because it stated that autonomy could be improved.'* (home 1, senior management)

Changes in the care and service provided can also be introduced because staff on the work floor come up with improvement initiatives. The following example relates to a poor score on the indicator 'respectful approach'. Staff explained this score as resulting from their being too busy. At a location meeting, the CQI results were put to the care workers, and they were asked 'How can staff appear calm even when they are busy?'. A care worker thought up 'Thea's count to 5' for this, whereby staff enter a resident's room in less of a rush:

> *' 'Thea's count to 5' means that carers stop and count to five before they ring at a client's room. They go in and sit down for a moment with the client. In this way, the client has the feeling: 'She is sitting down, so she can't be so rushed'.'* (home 8, care worker)

Ad. 3. Organisation-related factors

Organisation-related factors that influence the use of information from feedback measurements are the existence of an infrastructure for quality improvement and consideration for the client. The possession of a certificate such as *Harmonisation of quality assessment in the care sector* (HKZ, 'Harmonisatie Kwaliteitsbeoordeling in de Zorgsector') or *Performance in care* (PREZO, 'PREstaties in de ZOrg') for the provision of sound care is evidence of an infrastructure for quality improvement. Consideration for the client is shown by the CQI measurement of the quality of care from the perspective of the client. Senior management representatives indicated that both aspects count in the negotiations with care purchasers. Specific demands relating to the CQ-index concerned:

1. The frequency of a measurement of client experiences (biennially).
2. The publication of the data on www.kiesBeter.nl.

CQI data is published on the Internet only after approval by the Board and senior management. There was hardly any resistance to such publication because, for many organisations, the CQ-index was being carried out for the second time. Publication was also supported by the policy and attitude of the organisation towards transparency, as expressed in the following quote: 'The organisation wants to be transparent about the care that it provides, and publishing on www.kiesBeter.nl is part of that' (home 3, middle management). Some health insurers set more-specific requirements such as an evaluation score of at least 7 for the care by the home, or at least 3 stars on a set of questions from the CQI questionnaire. In some care purchase discussions, improvement plans based on the results were also central. These plans had to be approved by the client council in order to guarantee the client perspective. Failure to meet the demands of the health insurer resulted in a lower budget:

> *'The health insurer sets pre-conditions that the organisation must satisfy. The experiences of the clients must be at least x, and so much this and so much that. This determines the amount that we as an organisation receive for the care. If the organisation does not score well enough on certain aspects, a deduction of a certain percentage from our tariff is imposed.'* (home 6, senior management)

Staff at various levels of organisations that have been certified for some length of time spoke more often about coming up with ideas for improvement actions, and implementing, monitoring, and evaluating them, while with recently certified organisations this was to be seen mainly among the quality managers. Most of the quality managers work for the concern (the overall organisation), and locations within the concern hire in the services of the quality manager. Because of this, in some organisations, quality managers were assigned only for obtaining or extending a certificate, and not for actions in response to a CQI measurement, because the costs come from the budget of the location. Analysing the CQI information, and coming up with and initiating improvement actions, therefore fell to the middle management and the care workers of the locations.

Through mergers and cost containment in several organisations, the middle management was replaced by a single regional manager who had overall responsibility for several locations. These structural changes meant that care workers got (even) more tasks, leading to increased workload for them. This resulted in the postponement or cancellation of (improvement) actions stemming from the CQI measurement.

6.4 Discussion

The Berwick model (2003) relating to transparency and improvement of quality assumes that organisations will initiate quality improvements following dissatisfaction with the results. In this study we interviewed staff in 12 nursing homes and homes for the elderly to investigate the factors influencing the use of CQI information for quality improvement.

6.4.1 Factors that influence the use of CQI data

1. Data-related factors

From the literature it is to be seen that reliable and recognisable information are aspects that support care organisations in the continual improvement of their performance. The CQ-index fulfils this role. Those interviewed think that the measurement of client experiences by an independent approved contractor makes a positive contribution to valid and reliable data. Recognisable results concerned the food, the autonomy of clients, and respectful treatment of clients. This picture of the CQ-index confirms the findings of a study commissioned by ActiZ and carried out by the University of Maastricht. Of the appropriate care coordinators, 65 percent think that CQI results give a representative picture (Haastregt et al., 2008). A threat to the credibility of CQI data is the role of the interviewer, as was pointed out by one of the interviewees. The research report of the development of the CQI 'Long-term care' questionnaires (Wiegers et al., 2007), the Accountability Report on the evaluation of Nursing, Caring, and Home Care ('Verantwoording evaluatie VV&T') (CKZ, 2010), and an English publication (Winters et al., 2010) confirmed these interviewer effects. Such effects apply to one of the three CQI 'Long-term care' questionnaires. This questionnaire was used to interview clients of long-term care facilities about their experiences of the care. Possible explanations for the perceived interviewer effects are:

1. Interviewers work per corridor or department, so that real differences between corridors/departments seem to be interviewer effects.
2. Interviewers work in a particular region, so that regional differences distort the results.
3. Interviewers must sometimes interpret ambiguous answers from clients (CKZ, 2010).

In the meantime, the Dutch Centre for Consumer Experience in Health Care (CKZ, 'Centrum Klantervaring Zorg') has tightened up the guidelines for interviews. Interviewer effects can be avoided by performing the interviews with a minimum of 3 interviewers at any location, by dividing clients randomly over the interviewers, and by allowing the interviewer to accept only answers within the answer categories (CKZ, 2010).

A minority of those interviewed thought that the picture given by the CQ-index was too general. In their investigation, Davies and Cleary (2005) demonstrated that detailed information at the right level encourages the use of information. This argues for the collecting of as much detailed information as possible. However, it is always possible to add detail to the findings by supplementing them through a qualitative approach such as talking afterwards about what works well and what does not, and getting concrete and significant examples (Alhaus, 2008). This could be done by the approved contractor that carries out a CQI measurement, or by the organisation itself.

2. Staff-related factors

The use of information and the start of the change process were initiated by a quality manager, a manager, or a care worker. This choice was affected by the mission and structure of the organisation. The literature shows that knowledge of change management among the staff facilitates the use of information for achieving change (Davies and Cleary, 2005). This would mean that several levels of the organisation must have this knowledge if changes are to be realised. Furthermore, every care organisation initiates its own activities to stimulate quality improvement. This is extremely ad hoc, and it is questionable whether this actually leads to the improvement of care. There is (as yet) no standard training or support for (quality) staff to facilitate the use of the results of CQI measurements. The organisation can decide to take part in programmes to promote the quality of care. For example, for care-related indicators, consideration could be given to *'How to provide better care'* ('Zorg voor Beter [Plus]') that is aimed explicitly at staff in the primary process (care-related indicators give a picture of subjects such as skin problems, ability to do things independently, and eating and drinking.) *Zorg voor Beter* provides methods, good examples, and advice from experts for providing good care now and in the future. Learning from each other is fundamental. The method developed by the LOC National Organisation of Client Councils ('LOC-Zeggenschap'), *'From measurement to improvement'* ('Van meten naar verbeteren'), can also be considered. This method includes a step-by-step procedure for setting up an improvement plan in a short time (LOC, 2007).

The literature showed that leadership is a necessary condition for initiating change (Davies and Cleary, 2005). The Results section reported that two managers had initiated changes (relating to hot meals and autonomy). These managers demonstrated decisiveness. There is still doubt as to whether they also kept the client perspective in mind. The changes relating to the meals were not supported by the client council in this specific case. And whether giving four clients their own keys also contributes to a higher autonomy score, remains to be seen.

3. Organisation-related factors

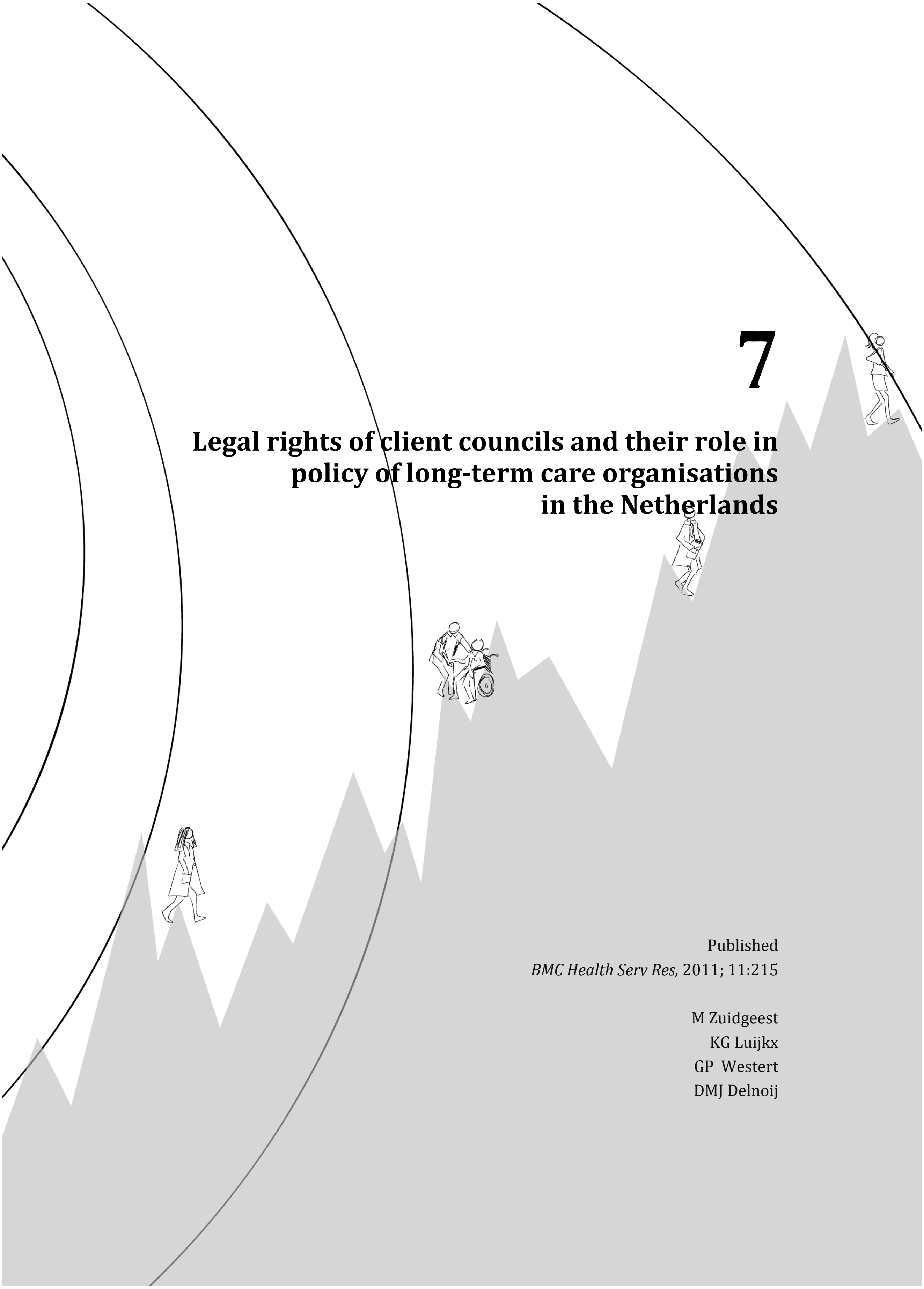
The client perspective was expressed by the health insurer as measuring and publishing client experience data. The results from this measurement, as well as the points for improvement, were also taken into account in purchasing contracts with the organisations. In this way, the use of CQI results was stimulated by an external party. The infrastructure for quality improvement differed from organisation to organisation. In the case of recently certified organisations, the improvement cycle was familiar to the quality managers and not to other staff. This can probably be explained by the fact that the quality managers were hired in by the middle management in order to gain specific (HKZ or PREZO) certificates. With organisations that had been certified for any length of time, this cycle was also familiar to the management. If quality managers were not hired in to undertake actions, this meant that improvement actions had to be carried out by the middle management and care workers. These people can probably relate the results to the working processes better than the quality manager. These tasks are still not part of the normal activities, so there is insufficient time for achieving change. This is a barrier to the use of CQI results.

6.4.2 Limitations of the study

This article gives an initial description of the factors that affect the use of CQI information. The long-term care organisations that have taken part probably represent a positive selection. They had their own questions about the CQ-index, or recognised the importance of the study. The Health Care Inspectorate (IGZ, 'Inspectie van de Gezondheidszorg') was not discussed with those interviewed. *IGZ* states that, besides care-related indicators, CQI data is used in the recognition of risk in the nursing, caring and homecare sector (Van Dijk, 2010), and is a determining factor in setting visiting priorities (IGZ, 2008). One consequence of insufficiently safe, effective, or client-oriented care is intensified supervision. The organisation then has to prepare an action plan within a month, and the care must be improved significantly within three months. However, this situation has not arisen for any of the interviewed organisations. One limitation of the investigation is that statements by interviewees on the use of information were not verified by the checking of documents (data triangulation).

6.4.3 In conclusion

The present study has shown that, when the results of CQI measurements give rise to dissatisfaction, improvement actions are initiated by various levels of the organisation so as to improve the quality of care. Who it was that carried out the action - from quality manager to staff involved in the day-to-day care - depended on the policy of the organisation. Some quality managers remained relatively aloof from the improvement actions and the fact that the middle management or the care workers themselves set up improvement actions. The effects of a different balance between the contribution of the quality manager and the implementation by other staff needs to be investigated further, as does the effectiveness of the actions taken (do they lead to measurably better client experiences?). The factors that seem to affect the use of client experiences are primarily related to the characteristics of the data collected; and an external party promoted the use of information. Organisation-related factors such as mergers and cost containment impeded the use of information for initiating improvement actions.



7

Legal rights of client councils and their role in policy of long-term care organisations in the Netherlands

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7.1 Background

In the Dutch healthcare system, the emphasis is shifting from provider domination to client orientation (Westert et al., 2009; Mead and Bower, 2000), where the role and position of clients have been strengthened in recent decades in a number of ways including legislation (Baur et al., 2010). For example, the Dutch 'Participation by clients of Care Institutions Act (WMCZ, 'Wet Medezeggenschap Cliënten Zorginstellingen') mandates *every* healthcare organisation to have a functioning client advisory council; a board whose members are recruited from the users of the organisation and who will represent them (WMCZ, 1996). In practice, most councils have between five and ten members, depending on the size of the organisation. In nursing homes and residential care facilities, spouses (of deceased clients) and volunteers are members of these councils along with clients themselves. Healthcare organisations facilitate these councils by providing resources such as office space and equipment, meeting rooms, budget, et cetera (Savornin Lohman, 2000). The *WMCZ* gives client councils the right to advise the management of the organisation about quality of care, and the law prescribes that the healthcare organisation asks for this advice.

More specifically, according to this law councils have been granted the following rights: to have meetings with management about organisation policy, to receive information, to request an investigation into mismanagement, to be consulted, and the right to consent (WMCZ, 1996). *The right to be consulted* allows councils to give their advice regarding issues on changing the aim and policy of the organisation, merger with another organisation, and financial matters, but the management can ignore this advice. *The right to consent* implies that councils need to formally approve plans concerning issues that affect the daily living of clients (food and drink, safety, recreation, and leisure), hygiene, the quality of healthcare for residents, changes to the complaints procedure, and Consumer Quality Index (CQ-index or CQI) research. The management cannot carry out changes regarding these issues without approval of the client council (WMCZ, 1996; LOC, 2007). CQ-index is a standard methodology used in the Netherlands to measure, analyse, and report experiences of clients regarding the quality of healthcare. Besides this, the methodology includes also protocols for developing new CQI questionnaires. Questionnaires can be developed to assess the quality of care of a sector, professionals or treatment of a disease (Delnoij and Hendriks, 2008; Delnoij et al., 2010).

The CQ-index for the nursing and caring sector - the CQI 'Long-term Care' - (Triemstra et al.; 2010) consist of several questionnaires targeting various client populations and domestic settings with tailored data collection:

1. A face-to-face interview protocol for residents.
2. A mail questionnaire for representatives of psycho geriatric clients.
3. A mail questionnaire for homecare clients.

Outcomes of these questionnaires (also called client-related indicators) together with clinical indicators (e.g. incidence of skin ulcers, falls, malnutrition, and medication errors) form the national Quality Framework of Responsible Care (Steering Committee Responsible Care, 2007). This information is also disclosed on the Internet, which creates transparent information about providers' performance (Delnoij, 2009a). The framework consists of 19 indicators on four domains:

a. Quality of life.
b. Quality of caregivers.
c. Quality of care organisation.
d. Technical aspects.

The CQ-index relates to indicators in the first three domains. Biennially, CQI data are collected, analysed, and reported by approved contractors. These contractors meet certain minimum performance standards based on ISO 20252, which is an international standard for market, opinion and social research. Healthcare organisations can choose any approved contractor. These contractors differ in price and the type of information products they provide. Some offer feedback reports that only report on the findings for one's own organisations, others offer benchmark reports in which one's own performance is compared to that of other organisations. Some contractors offer the opportunity to have an additional presentation of the findings, for instance, for the client council and/or for staff members. Because CQI research provides quality information regarding residents' daily living, councils have the right to consent to choose an approved contractor, but they have also a voice in pointing out improvement activities based on CQI results.

In 2004, an evaluation of the effect of client councils on decision-making of the organisation showed that councils influence on issues covered by the right to consent was small. According to a representative group of client councils in nursing homes, only half of these councils were given notice of decisions on which they had right to consent (Hoogerwerf et al.; 2004).

Research about the role of client councils in the Netherlands is scarce and we do not know whether and to what extent client councils use their rights. Therefore, our first research question is: '*Do client councils exercise their rights 'to be consulted' and 'to give their consent'?'* Because the CQ-index is relatively new, we were particularly interested in the role of client councils in the process of measuring client experiences and their opinion about the CQ-index. Therefore, our second research question is '*What is the role of client councils in the process of measuring clients' experiences with the CQ-index and what is their opinion about the CQ-index?'.*

7.2 Methods

In 2010, we mailed 1,540 questionnaires to contact persons of client councils in nursing homes and residential care facilities about the use and usability of CQI information. Addresses were obtained via the Nationwide organisation for client councils (LOC Zeggenschap in Zorg). All client councils in nursing homes and homes for the elderly are members of this organisation. However, only members who had given *LOC* permission to sent questionnaires were contacted. One reminder was sent as a 'thank you' card ten weeks after the initial postal questionnaire. The contact persons were informed about the aim of the questionnaire and were free to respond or not. According to the Dutch Medical Research Involving Human Subjects Act (WMO, 'Wet Medisch-wetenschappelijk Onderzoek onder mensen'), ethical approval of the survey research was not necessary.

The questionnaires contained:

1. Background questions.
2. Questions about councils' influence on organisational policy with 5 response categories 'totally not involved', 'only informative (client council receives only information which informs them, no action of council is required)', 'right to be consulted (client council has the right to give their advice, but the management can ignore this)', 'right to consent (client council needs to formally approve changes ; this approval is mandatory and cannot be ignored by the management)', and 'Don't know'.
3. Statements about the CQ-index with response categories on a 5-point Likert scale (ranging from 'totally disagree' to 'totally agree').

Descriptive analyses were performed using SPSS version 17.0 ®.

7.3 Results

7.3.1 Background information of client councils

The response rate to the postal questionnaire was 34% (n=524). No information was available of contact persons who did not respond. Most responding councils consisted of seven members, with a minimum of five and maximum of twelve members. One out of four members participating in the client councils were residents themselves. Volunteers (25%), Family of residents (22%), family members of deceased residents (15%), and assisted living clients (13%) also participated in the councils.

Client council meetings occurred once in four to twelve weeks and meetings with the management were held less often (Table 7.1). In the meetings, they discussed topics regarding organisational issues -financial matters (82% of the councils), vision of the health organisation (71%), annual report (77%), new employees (51%), accommodation (81%), and laundry costs (82%) - and topics regarding client care - organisation of care (52%), food and drinks (89%), handling complaints (83%), respectful treatment and privacy of residents (76%), choice for improvement projects (75%), variety of activities (69%), and CQI research (74%)-.

The councils' role varied with respect to the frequency of giving written advice to the management of organisations: 0 advices per year (28% of the councils), 1 to 5 advices per year (58%), 6-10 advices (11%), and more than 10 advices per year (3%). Quality improvement priorities were formulated by the client council alone (16%), by the management alone (21%), and by the management and client councils together (51%).

Table 7.1 Meetings of client councils with members only and of members with the management

Once per:	**N**	**4 weeks**	**6 weeks**	**8 weeks**	**12 weeks**	**Different frequency**
Client council members only	515	51%	30%	14%	2%	4%
With management	513	36%	25%	27%	5%	7%

7.3.2 Client councils and their involvement in decision-making

Table 7.2 provides information regarding the degree of involvement of councils in decision-making on organisational issues. With respect to these issues, client councils have the *right to be consulted.* This means that the management has to ask for the advice of the client council, but the management is free to ignore this advice. As can be seen in the Table, 31% to 46% of the councils exercised this right with respect to issues from finance to accommodation. However, almost the same percentage of respondents believes that their involvement in these issues is of an ‘only informative’ nature (23% to 46%). So, they believe that the management shares information about these with them, but they are not aware of the fact that the management should ask for their advice. On the other hand, 12 to 27% of the client councils report that they have the right to consent on these issues. When the percentages of the ‘rights to be consulted’ and ‘right of consent’ are summated, for almost every organisational issue more than 50% councils exercise their legal right or are even more involved than would be necessary from a legal point of view.

Table 7.2 The degree of involvement of client councils in decision-making on various topics for which they have the right to be consulted

Issues	**N**	**Not involved** **%**	**Only infor-mative** **%**	**Right to be consulted** **%**	**Right to consent** **%**	**Don’t know** **%**
Financial matters (e.g. budget)	505	10	45	31	12	2
Vision of the organisation	497	5	37	36	19	2
Annual report	500	6	46	34	12	2
New employee	499	25	23	33	18	2
Accommodation	498	5	30	46	17	3
Laundry costs	497	6	27	38	27	2

Table 7.3 displays issues concerning the councils’ *right to consent* in decision-making of the healthcare organisation on client care (e.g. food and drink, complaints registration, respectful treatment and activities). With respect to these issues, the client council has to formally approve any plans or change of policy that the management proposes. Only 18% to 36% of the client councils experienced that they actually had this right. More client councils reported that with respect to these issues they had the ‘right to be consulted’ (31% to 50%). Some of the client councils (16% to 35%) even perceived their involvement with these issues as ‘only informative’.

For the CQI survey and for choosing improvement projects, only 18% and 22% of the councils perceived that they had the right to consent, respectively. These results indicate that councils’ degree of involvement in decision-making in healthcare organisation is less than expected based on their legal rights.

Table 7.3 The degree of involvement of client councils in decision-making on various topics for which they have the right to consent

Issues		**Not involved**	**Only infor-mative**	**Right to be consulted**	**Right to consent**	**Don't know**
	N	%	%	%	%	%
Organisation of care	498	21	26	31	19	3
Food and drink	510	7	16	42	36	1
Complaints procedure	497	5	27	37	27	3
Respectful treatment and privacy	501	5	24	41	27	3
Choice of improvement projects	505	4	21	50	22	3
Variety of activities	508	8	32	36	21	2
CQ-index research	466	5	35	37	18	3

7.3.3 Role of client councils in the process of measuring clients' experiences

If client councils are involved in CQI research they need information from the management about when a next measurement is to take place. Most of the councils were given timely notice when a new CQI survey was to start (87%): the preferred notice period was two months and three-quarters of the client councils were adequately informed about the CQI survey.

To ensure that measurements of client experiences are embedded in the decision-making process of the organisation, client councils have the right to consent regarding the selection of an approved contractor to perform the CQI survey. This enables client councils, for example, to choose a contractor who offers information products, such as reports and presentations that are tailored to client councils' needs. Twenty-nine percent of the respondents replied that they were involved in this selection; implicating 71% of the councils had no role in choosing a contractor. Among those client councils that found it important to be involved in this process (69%), 41% were involved.

Statements about measuring clients' experiences with the CQI method showed that respondents were positive about the CQ-index. Two-thirds of the client councils agreed that the CQI questionnaire was a good questionnaire to measure clients' experiences with care and almost the same percentage agreed that CQ-index provided clear questions. Although the CQ-index provided recognizable results, the councils disagreed about the extent to which results were representative. Seventy-six percent of the respondents think that results point out improvement potential (Table 7.4).

Table 7.4 Statements measuring respondents' experiences with the CQ-index method

		(totally) Disagree	**Disagree**	**Neutral**	**Agree**	**(totally) Agree**
	N	**%**	**%**	**%**	**%**	**%**
Results show improvement potential	453	2	4	9	67	18
There are recognizable results	443	2	7	23	59	9
CQ-index is a good questionnaire for measuring clients' experiences of care	448	3	6	25	55	11
Questions in the survey are clear	445	2	11	20	58	9
Results show a representative image of the experiences of clients	438	4	21	28	40	7

7.4 Discussion

The aim of this article was two-fold. First, we assessed whether client councils exercise their legal rights in decision-making of nursing and residential facilities. More specifically, we looked at their rights 'to be consulted' and 'to give their consent' on several issues. Second, we examined what the role of client councils is in the process of measuring clients' experiences with the Consumer Quality index (CQ-index or CQI) 'Long-term Care' and what their opinion about this CQ-index is.

The respondents from client councils of nursing homes and residential care facilities were drawn from available addresses of the Nationwide organisation for client councils. These councils agreed to receive incidental questionnaires. In 2009, there were 2,082 nursing homes and residential facilities in the Netherlands (Deuning, 2009). With our sample we reached 73% of the homes. No information was available of the councils that were not reached or did not respond to the questionnaire. The low response rate of the questionnaire (34%) may have biased the results. It is likely that the responses are too positive because a subgroup did not respond. For the non-respondents, CQI research is probably less well known and more complex than for the respondents. Continuing this line of argument, councils may use their legal voice less often than was presented in the results.

The composition of the councils in this study was the same as in the evaluation report of the Participation by clients of Care Institutions Act in 2004 (Savornin Lohman, 2000). Nevertheless, this composition - only one in four members is a client - needs attention (Zuidgeest et al., 2010). When entering a home, clients are elderly and have physical complaints that limit them in joining the client council. This is a concern for the next decades, because client councils have a legal voice on policy regarding healthcare facilities. If clients are not able to use this voice individually or through a client council others must do so for them.

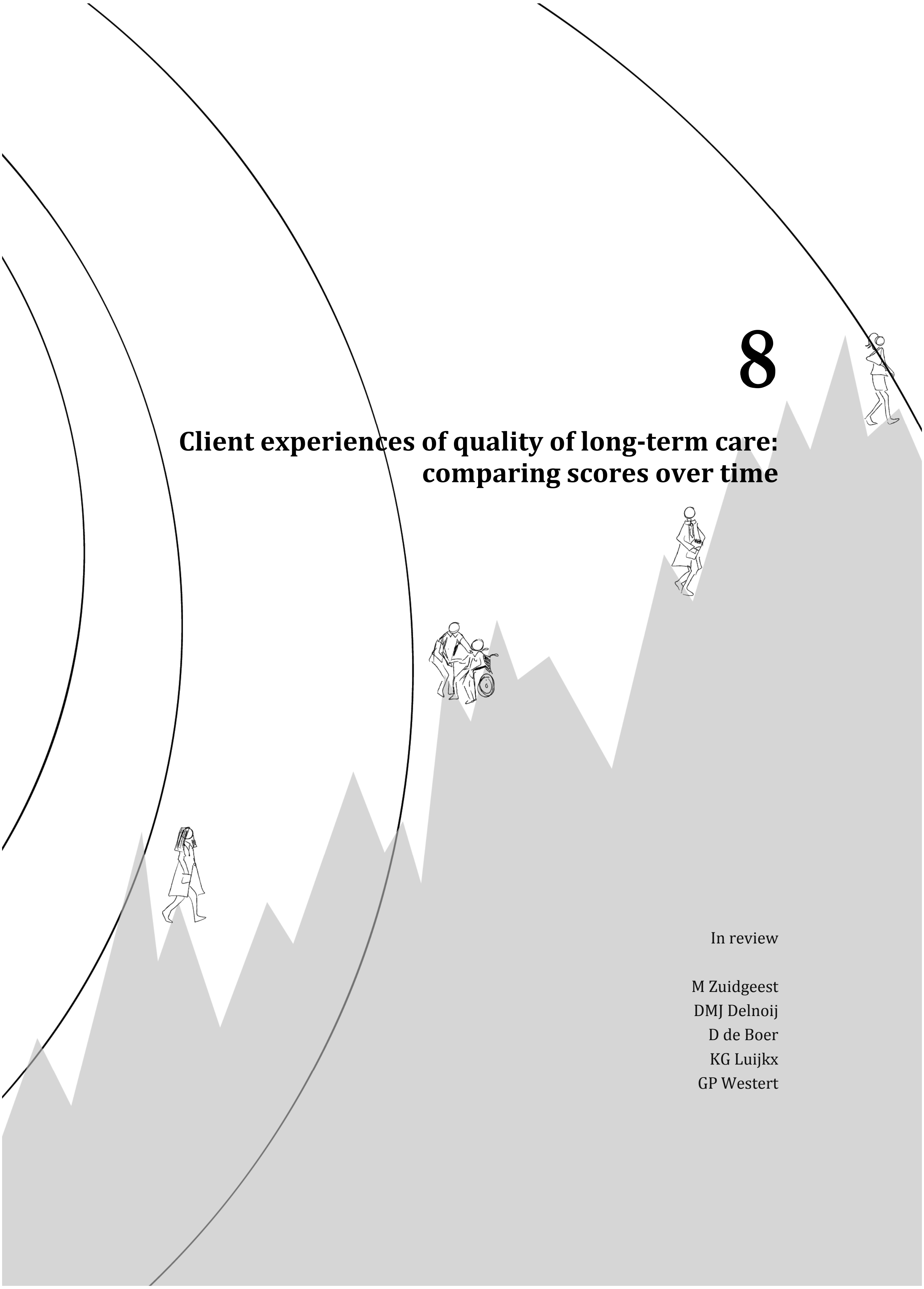
The involvement of client councils in decision-making of healthcare organisations is embedded in legislation. However, less than half (31%-46%) of the client councils perceived that they could exercise their *right to be consulted* on organisational issues like finance, vision, annual report and accommodation. Even fewer councils (18%-36%) perceived that they could exercise their *right to consent* about issues concerning client care (e.g. food and drink, complaints registration, respectful treatment and activities). The fact that not many councils are involved in decision-making and policy of healthcare organisations is in contrast with a national agreement between stakeholders about client council rights (LOC, 2007).

Concerning CQI research, client councils have the *right to consent* regarding the selection of an approved contractor to perform the CQI survey. However, our results showed that client councils did mostly not choose approved contractors. Client councils have hardly any role in the process of measuring clients' experiences with CQI surveys: only one fifth of the client councils perceived that they could exercise their right to consent regarding CQI research.

The literature shows that recognizable results promote the use of client feedback (Cummings and Worley, 2005). Despite the fact that the CQI results were recognizable, some client councils were not involved in formulating priorities for quality improvement. Management needs to notify councils when a CQI survey is to take place and should encourage councils to be more actively involved in pointing out own improvement priorities. Actively involving client councils in the identification of priorities and quality activities reduces the amount of undesirable outcomes (e.g. the prevalence of pressure ulcers, restricted mobility and behavioural problems) (Wagner et al., 2006).

7.5 Conclusion

In conclusion, measuring clients' experiences should constitute a mean to strengthen the position and role of clients in nursing homes and residential care facilities. Nevertheless, councils hardly use their legal voice and they tend to have a passive role. Measuring clients' experiences is part of client-oriented policy, aimed at improving quality of care, but the current practice shows that the management of healthcare organisations dominates the process involved. This is a top-down approach and conflicts with the national policy aimed at client empowerment.



8

Client experiences of quality of long-term care: comparing scores over time

In review

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8.1 Background

Various countries publish quality information about nursing homes and residential care facilities on the Internet in the form of report cards which serve multiple purposes (Van Nie et al., 2010; Du Moulin et al., 2010; Grabowski, 2010). Firstly, information is available for choices by (future) clients or for families of these clients. Secondly, it can be used by nursing homes to account for their performance to healthcare regulators and government. Thirdly, information informs health insurers on performance differences across nursing homes, which can be incorporated into their purchasing decisions. Lastly, it can be used by nursing homes themselves to monitor their quality of care, to improve transparency about the quality, and to promote quality improvement initiatives (ActiZ, 2007). In this article, the focus will be on the monitor function of available information.

Countries differ in the quality information they provide on the report cards. Quality information can include *structure indicators* which refers to the conditions under which care is provided, *process indicators* which relates to the professional activities associated with providing care, and *outcome indicators* which denotes the effects of care (Donabedian, 1980). Most countries provide the first two types of indicators and only some countries (Austria, Germany, the Netherlands, Sweden, USA) present the outcome measurements such as care-related safety, satisfaction, and experiences of residents or representatives (Du Moulin et al., 2010).

In the Netherlands, the national indicator set for long-term care for the elderly is called the ‘Quality Framework Responsible Care’ (ActiZ, 2007). It includes patient experience indicators which are measured with three separate questionnaires: an interview protocol for residents, a mail questionnaire for representatives of psycho geriatric patients, and a mail questionnaire for homecare clients. These questionnaires belong to the so-called Consumer Quality Index (CQ-index or CQI) which is the Dutch standard for measuring patient and client experiences in healthcare (Delnoij, 2009a). The national indicator set also includes clinical indicators like skin problems, depression, fall incidents, physical restraints, malnutrition, and medication errors. The present paper is focused on patient experiences indicators.

Every organisational unit in the long-term care (mostly a location of a nursing home, residential care facility or homecare organisation) is obliged to measure their performance on the experience and clinical indicators. This obligation is defined by a national steering committee in which client organisations, providers in long-term care for the elderly, healthcare regulator, Ministry of Health, Welfare and Sport, and health insurers are represented (Delnoij et al., 2010). This national agreement is reinforced by the umbrella organisation of nursing homes, homes for the elderly, and homecare organisations (ActiZ). Membership of ActiZ is terminated if members do not comply with the obligation to measure and publish results of measuring client experiences. In addition, health insurers will cut budgets of healthcare providers who do not measure these indicators. These incentives spur homes to measure and publish these scores. In 2007, at start of publishing the results, 62% of the organisational units published their outcomes (www.zorgvoorbeter.nl, 2008) which increased to nearly all homes in 2010.

Providers can choose the exact timing of measuring experiences of clients, family members, and homecare clients as long as they conduct CQI surveys with an interval of approximately two years. Since 2007, several providers measured and published their CQI survey results twice. In this article, we analyse CQI survey results of those providers in order to describe changes in their performance over time. Analyses of performance over time will be done while taking into account all three CQI instruments for long-term care for the elderly. The results of those surveys are published on the level of indicators. Indicators correspond to items and scales that have been established during the development of the questionnaires (Triemstra et al., 2010).

We hypothesize that the publication of the CQI survey results on the first measurement will trigger quality improvement activities which lead to an improved performance on the second measurement. Studies in the USA have shown that homes reorganized quality improvement programs and started new quality-assurance programs (Mukamel et al., 2007; Werner et al., 2009; Castle, 2005). In addition, homes with poor quality scores were more likely to act on these performance scores compared with homes with better scores (Mukamel et al., 2007), a phenomenon that has also been observed for hospitals (Fung et al., 2008) and health insures (Hendriks et al., 2009). Accordingly, we hypothesize that homes with substandard performance on the first measurement will show more improvement than homes whose performance was already relatively good.

Our first research question is '*Have scores with respect to client experiences of nursing homes, residential care facilities, and homecare providers improved between the first (t_o) and the second (t_1) measurement?*'.

Furthermore, investigation of scores will take place with respect to homes, residential care facilities, and homecare organisations that performed '(much) below average' on the first measurement compared with organisations that performed on 'average' and '(much) above average'. The second research question is therefore: *'Have nursing homes, residential care facilities, and homecare providers that performed '(much) below average' improved more between t_0 and t_1 than those that performed 'average' and '(much) above average'?*

8.2 Methods

8.2.1 Sample

Homes, residential care facilities and homecare providers publish their CQI indicator scores in their annual documents (www.jaarverslagenzorg.nl). Between 2007 and 2009 a total of 499 organisational units (mostly a location of a nursing home, residential care facility or homecare organisation) had performed CQI surveys twice. Of these organisational units, 370 published CQI findings on t_0 and t_1 of the face-to-face interviews with residents; 190 published findings of the questionnaire for representatives of psycho geriatric patients, and 122 published findings of the homecare clients' questionnaires. One organisational unit can perform multiple questionnaires.

8.2.2 Quality Framework Responsible Care

Client and clinical indicators belong to the Quality Framework 'Responsible Care' which encompasses seven quality domains. Four domains relate to quality of life: physical well-being and health, domestic and living conditions, participation and social handiness, mental well-being. Other domains are quality of caregivers, quality of care organisation and indicators with respect to more technical aspects of care (see Table 8.1) (Zichtbare Zorg VV&T, 2010).

8.2.3 CQI questionnaires and client indicators

Biennially, the actual experiences of residents are measured in a face-to-face interview, whereas experiences of family members and homecare clients are measured with mail questionnaires. Typically, response categories in the interview protocol and mail questionnaires refer to the frequency with which quality criteria were met: '1' never, '2' sometimes, '3' usually, and '4' always. The questionnaires belong to the CQI 'Long-term care' (Triemstra et al., 2010). Collecting CQI data (e.g. conducting interviews, sending postal questionnaires and sending reminders), analysing and reporting the results is not done by the organisational units themselves, but can only be performed by approved contractors with a CQI accreditation. Since this process takes a lot of time and effort, data collection is possible during a two year period. Data of all homes are stored in a national databank.

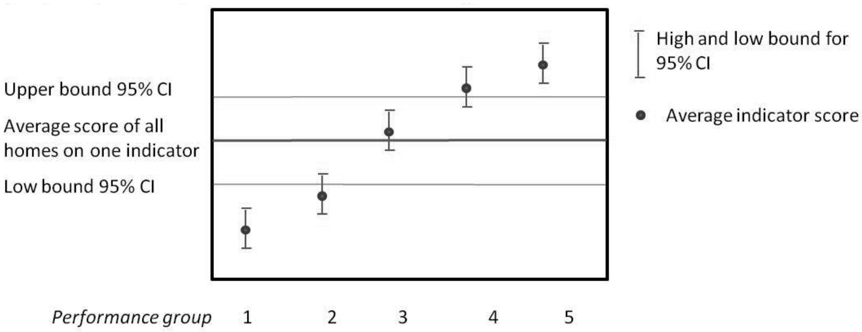
8.2.4 CQI indicators

The development of CQI surveys and indicators are described in various publications (Zuidgeest et al., 2007; Damman et al., 2007; De Boer et al., 2010) including a paper specifically focused on the CQI 'Long-term care' (Triemstra et al. 2010). In brief, CQI indicators have been determined by factor and reliability analysis (Triemstra et al., 2010; Wiegers et al., 2007). The scores of the indicators were calculated for each respondent provided that half or more of the items were available. All indicator scores ranged from 1 to 4. In total, 19 indicators (items and scales) were distinguished with the three questionnaires (Table 8.1). The analytical strategy used to compare CQI scores between healthcare providers has been described in a number of publications (Stubbe et al., 2007a; Stubbe et al., 2007b; Damman et al., 2009b). In brief, multi-level linear regression analyses (respondents were nested within homes) were performed to yield an empirical Bayes (EB) estimate per indicator and per organisational unit. A comparison interval was calculated for each EB estimate (+/- 1.39 * SE) which ensures that non-overlapping intervals represent a significant difference (p<.05) (Goldstein and Healy, 1995. Indicator scores were corrected for case-mix because client populations may differ on characteristics beyond the control of care providers (Damman et al., 2009b; De Boer et al., 2008). For the interview protocol, the case-mix variables were age, education, perceived health, and length of stay. The indicator scores of the postal questionnaire to representatives were corrected for the kind of representative (e.g. spouse, son or daughter), residents' age and education, and length of stay. For the homecare clients questionnaire indicator scores were corrected for age, education, length of care, help filling out questionnaire, and kind of care (cleaning house, personal care or assistant) (De Boer et al., 2008). The corrected indicator scores were divided into five performance groups using:

1. The average score of all homes on one indicator.
2. The average score of the higher bound of the comparison intervals.
3. The average score of the lower bound of the comparison intervals.

Figure 8.1 illustrates the classification of the performance groups representing '1' performance much below average to '5'representing performance much above average. We performed secondary analyses based on the corrected scores on two measurement points.

Figure 8.1 Determining, based on indicator score and the 95% confidence interval, the performance group: 1st ‘worst’ to 5th best’



8.2.5 Analysis

Per questionnaire, descriptive analyses on indicators scores (mean scores and the observed 5th and 95th percentile) were performed on the data of the first measurement (t_0). The 90% range scores of organisational units is a proxy of potential for improvement because it gives insight into the achievable scores of other organisational units. A change score per indicator was calculated by subtracting the indicator scores between those two measurement points (t_0 - t_1). Per CQI questionnaire and per indicator we analysed these change scores. In addition, we examined the overall change scores per questionnaire for different so-called performance groups. Performance groups refer to the performance at t_0 and varied from 1 (much below average) to 5 (much above average, see Figure 8.1). Differences in change scores across performance groups were tested using an ANOVA test. If the assumption of equal variances was violated, the Welch test of robust test of equality of means was used. Tukey post-hoc tests were used to compare the mean difference score of every performance group to the means of every other performance group and identifies where the differences between two means is greater than the standard error would be expected. Effect sizes were measured with omega squared (ω^2). A small, medium and large effect respectively are ω^2=0.01, 0.06 and 0.14 respectively (Kirk, 1996). A level of significance of $p<.05$ was used. Analyses were performed using SPSS ® version 17.0.

8.3 Results

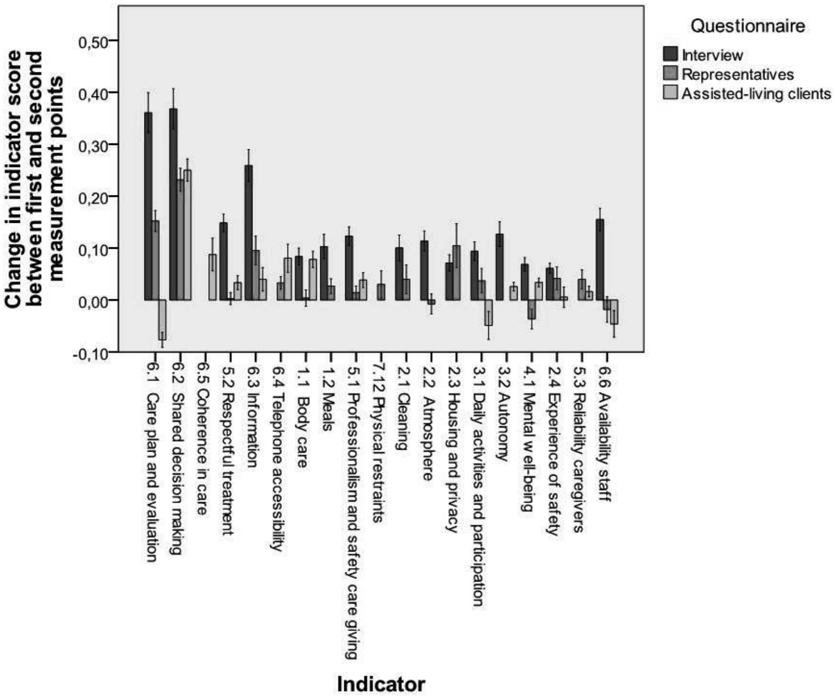
Table 8.1 presents per indicator and per questionnaire the mean scores and the 5th and 95th percentile of the organisational unit means. Experiences of respondents on all indicators on t_0 were positive for the interview questionnaire and the mail questionnaire for representatives and homecare clients: 3.24 (2.82-3.55), 3.20 (2.90-3.41), and 3.33 (3.16-3.46), respectively. Of the interview questionnaire the observed 90% range was 0.73 and for the mail questionnaires for representatives and homecare clients this was 0.51 and 0.31, respectively. The biggest difference between the 5th and 95th percentile of the interview questionnaire were observed for indicators 3.2 'Autonomy' (1.08), 6.1 'Care plan and evaluation' (1.06), and 6.2 'Shared decision making' (1.05). Housing and privacy (indicator 2.3) is an indicator of the representatives' questionnaire that shows a lot of variation between organisational units (1.25). No indicators of the third questionnaire diverged as much as the other questionnaires. Indicator 6.5 'Coherence in care' showed the most variation (0.54).

In Figure 8.2 the change scores per indicator are displayed for all three questionnaires. We expected change scores to be limited by 90% observed range on the first measurement and this range varied between indicators and questionnaires (see Table 8.1). Theoretically, an indicator score can change 3 points (from 1 to 4 and reverse). The change scores for the interview questionnaires were all positive (0.06-0.37). For the interviews with residents and the mail questionnaire for representatives the top three indicators improving the most were indicators 6.2 'Shared decision making' (0.37; 0.23), 6.1 'Care plan and evaluation'(0.36; 0.15), and 6.3 'Information'(0.26;0.10). Indicator 2.3 'Housing and privacy' also changed with 0.10 for the representatives questionnaire. Scores of the questionnaire for homecare clients improved the most with respect to indicators 6.2 'Shared decision making'(0.25), 6.5 'Coherence in care'(0.09), and 6.4 'Telephone accessibility'(0.08). The surveys of representatives showed a decline of indicator scores 4.1 'Mental well-being' (-0.04), 6.6 'Availability staff' (-0.02), and 2.2 'Atmosphere' (-0.01). Three indicators (6.1 'Care plan and evaluation' [-0.08], 3.1 'Daily activities' [-0.05], and 6.6 'Availability staff' [0.05]) of the homecare clients questionnaire showed a decline. The change score of the homecare clients did not diverge as much as the other change scores of the other questionnaires (change score from -0.08 to 0.25).

Table 8.1 Seven themes and patient experience indicators scores (mean, 5th and 95th percentile) within the Quality Framework Responsible care

	Questionnaire								
	Interview			Representatives			Homecare clients		
Indicator	**Mean**	**P05**	**P95**	**Mean**	**P05**	**P95**	**Mean**	**P05**	**P95**
1 Physical well-being and health									
1.1 Body care	3.38	3.08	3.60	3.15	2.93	3.31	3.46	3.31	3.59
1.2 Meals	2.94	2.44	3.36	3.45	3.26	3.59	-	-	-
2 Domestic and living conditions									
2.1 Cleaning	3.28	2.75	3.63	3.14	2.70	3.49	-	-	-
2.2 Atmosphere	3.36	3.00	3.61	3.07	2.77	3.27	-	-	-
2.3 Housing and privacy	3.69	3.10	3.94	3.47	2.67	3.92	-	-	-
2.4 Experience of safety	3.72	3.55	3.83	2.80	2.50	3.05	3.43	3.26	3.55
3 Participation and social handiness									
3.1 Daily activities and participation	3.41	3.11	3.64	2.92	2.59	3.16	2.84	2.62	3.00
3.2 Autonomy	3.34	2.64	3.72	-	-	-	3.42	3.35	3.48
4 Mental well-being									
4.1 Mental well-being	3.18	2.96	3.37	3.22	3.01	3.39	3.37	3.30	3.45
5 Quality of caregivers									
5.1 Professionalism + safety care giving	3.43	3.14	3.67	3.28	3.09	3.40	3.51	3.35	3.63
5.2 Respectful treatment	3.37	3.06	3.62	3.46	3.29	3.58	3.58	3.42	3.67
5.3 Reliability caregivers	-	-	-	3.15	2.88	3.40	3.67	3.56	3.74
6 Quality of care organisation									
6.1 Care plan and evaluation	3.16	2.60	3.66	3.41	3.19	3.63	3.65	3.56	3.71
6.2 Shared decision making	2.61	2.09	3.14	2.81	2.59	3.00	2.94	2.76	3.13
6.3 Information	2.74	2.23	3.17	3.25	2.88	3.56	3.16	2.99	3.32
6.4 Telephone accessibility	-	-	-	3.35	3.16	3.48	3.23	2.94	3.46
6.5 Coherence in care	-	-	-	-	-	-	3.08	2.80	3.34
6.6 Availability staff	2.92	2.51	3.26	2.97	2.66	3.17	3.25	2.97	3.41
7 Technical aspects									
7.12 Physical restraints	-	-	-	3.48	3.16	3.65	-	-	-
Average score per questionnaire	3.24	2.82	3.55	3.20	2.90	3.41	3.33	3.16	3.46

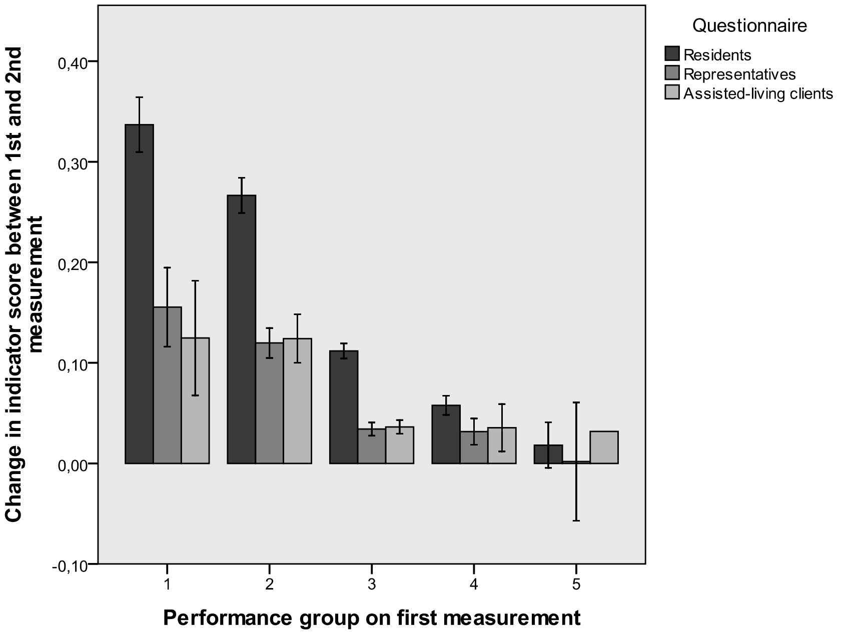
Figure 8.2 Change scores on all indicators between two measurement points and 95% confidence interval



To illustrate the differences in scores between questionnaires, Figure 8.3 shows the mean change scores over all indicators between two measurement points (t_0 and t_1). As expected, there appeared to be a negative relationship between prior performance and change (see Figure 8.3). The organisational units of performance group 1, 2 and 3 on t_0 showed an average improvements of 0.34 (SD=0.29), 0.27 (0.23), and 0.11 (0.20), respectively. Organisational units of performance group 4 and 5 on t_0 improved on average 0.06 (0.12) and 0.02(0.12), respectively.

Change scores of the indicators based on the interview questionnaire changed more profoundly than the scores of the other two questionnaires: all scores between the performance groups differed significantly (*p*<.000) and the effect was large (ω^2=.16). For the questionnaire for representatives significant difference was visible between the performance groups (*p*<.000), the effect was medium (ω^2=.05). Performance groups 1 and 2 differed from all the other performance groups. Performance groups 3, 4 and 5 did not differ from each other (*p*>.05). Regarding the questionnaire for homecare clients we observed a significant difference between the first four performance groups (*p*<.000) which was a large effect (ω^2=.15). Performance group 5 was excluded from the analysis, since there was only one indicator in group 5 on t_0.

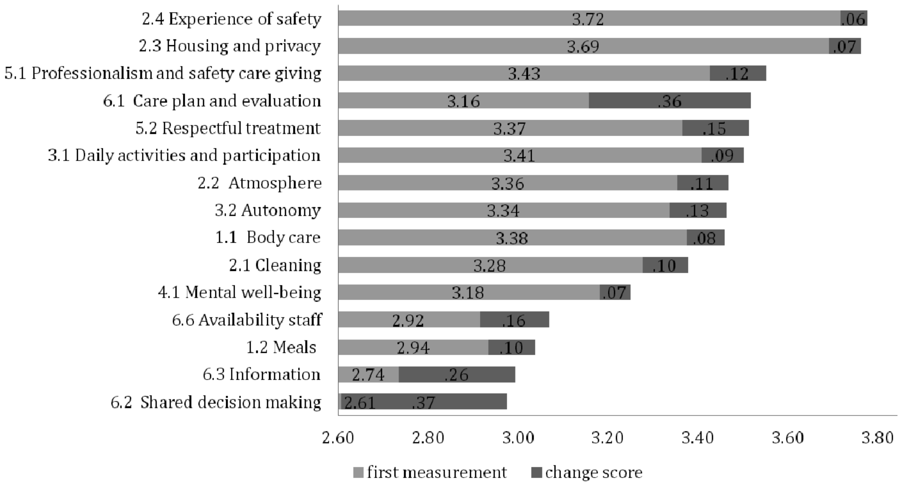
Figure 8.3 Mean difference in average score on all indicators and 95% confidence interval



By combining change scores with the scores of the first measurement, it is possible to give insight into the improvement potential per indicator. To illustrate this, Figure 8.4 shows the scores on t_0 together with the change scores (t_1-t_0) for the indicators based on the interview questionnaire. The same information for the indicators can be constructed for the other two questionnaires and is presented in the Appendix Figure A8.1 and A8.2, but main findings of both figures are described. The top 3 highest indicator scores of the second measurement were indicators 2.4 'Experience of safety' (3.78), 2.3 'Housing and privacy' (3.76) and 5.1 'Professionalism and safety care giving' (3.55). Top three highest indicator scores of the questionnaire for representatives were 2.3 'Housing and privacy' (3.58), 6.1 'Care plan and evaluating' (3.56), and 7.12 'Physical restrains' (3.51). Top three scores for the assisted living clients were 5.3 ‘Reliability caregivers’ (3.69), 5.2 ‘Respectful treatment’ (3.61) and 6.1 ‘Care plan and evaluation’ (3.57).

Although indicator 6.2 ‘Shared decision making’ changed the most between the t_0 and t_1, the score on t_1 remained the lowest (2.98) of the interview questionnaire. Indicators 6.3 Information’, 1.2 ‘Meals’, and 6.6 ‘Availability staff’ are also indicators which can improve most in a future measurement (2.99, 3.04, 3.07, respectively), also because their 5th and 95th range shows differences between homes (>0.75 range score).

Figure 8.4 Per indicator the score of the first measurement (t_0) and the change score ($t_1 - t_0$) for the interview questionnaire



Indicator 2.4 based on questionnaires for representatives/family members (‘Experience of safety’) barely changed between t_0 and t_1. The score on indicator 6.2 ‘Shared decision’ increased a lot, but is still one of the lowest indicator scores. Indicators that scored high on the t_0 and remain high on t_1 were indicators 2.3 ‘Housing and privacy’, 6.1 ‘Care plan and evaluation’, 7.11 ‘Physical restrains’, and 1.2 ‘Meals’.

Overall, the indicator scores of the questionnaire to homecare clients showed minor changes (0.01 to 0.09). One indicator stands out. Indicator 6.2 ‘Shared decision making’ changed the most (0.25), but still was one of the lowest scores (2.94). Indicators which scored low on t_0 and remained low were indicators 3.1 ‘Daily activities and participation’ (2.84) and 6.5 ‘Coherence in care’ (3.08).

8.4 Discussion

This study aimed to investigate client experiences of quality of long-term care for the elderly. More specifically, we looked at scores over time to judge if indicator scores of nursing homes, residential care facilities, and homecare providers had improved and if healthcare organisations that performed (much) below average improved more than healthcare organisations that performed on average and (much) above average.

Our first hypothesis was that publishing CQI survey results of the first measurement (t_0) triggered quality improvement activities which have lead to an improved performance on the second measurement (t_1). Our results confirm that most indicator scores improved on t_1. Performance improved the most with respect to topics regarding the quality domain 'Quality of care organisation'. Indicators belonging to this quality domain are *care plan, shared decision making,* and *coherence in care*. None of the indicator scores based on interviews with residents decreased. The indicators based on mail questionnaires for representatives and homecare clients showed a decline of the scores for three indicators. Additionally, the results showed that indicators that showed a larger 90% observed range at the first measurement also showed more improvement at the second measurement. This suggests that scores with a great range can improve more easily and even need to prove when the scores on t_0 are very low.

A preliminary Dutch report (Winters and Deen, 2009) failed to show the phenomenon of improvement in scores. Possible because a much smaller sample of organisational units were included in the analyses and they used data on client level whereas our study was based on overall average scores per indicator per organisational unit. Moreover, our data misses variance per indicator scores. However, while the scores missed the variance to compare over time, the calculated scores of both measurement points are based on the original corrected scores with the confidence intervals. Nevertheless, our findings are both consistent with the international literature as well as with theories on quality management and quality improvement (Mukamel et al., 2007; Fung et al., 2008; Hendriks et al., 2009). Studies in the USA have shown that homes reorganized quality improvement programs and started new quality-assurance programs in response to public performance scores (Mukamel et al., 2007; Castle, 2005; Mukamel et al., 2008). In the Netherlands, we do not have any study referring to specific actions nursing homes, residential care facilities or homecare organisations under-took to improve their scores. However, a qualitative study has indicated that organisations start various quality improvement activities in reaction to the CQI results (Zuidgeest et al., 2010).

When looking at specific changes in indicator scores, we see that the indicator '*Care plan and evaluation*' improved. One explanation is the modification in the method of data collection of the interview protocol. Explaining the term '*care plan'* was not allowed on t_0 but on t_1 interviewers explained that '*care plan*' could be the '*green folder*', '*red folder*', or '*care-living plan*' or whatever the care plan was called in that specific organisational unit. Health insurers also have their own teams to perform administrative controls and trigger improvement in this area. Another explanation for improvement of indicator scores is involvement of the health insurer. If insurers point out a certain quality aspect as important and reward higher scores, organisations will probably improve more on these quality aspects (Zuidgeest et al., 2010).

The second hypothesis stated that nursing homes, residential care facilities, and homecare providers with substandard performance on t_0 will show more improvement than nursing homes, residential care facilities, and homecare providers whose performance was already relatively good. The overall change scores for the five performance groups showed that healthcare organisations in group 1 improved more than organisations in group 5. This relationship was stronger for the indicators based on the interview questionnaire with residents than for the indicators based on the mail questionnaires. For the mail questionnaire for representatives, performance groups 3, 4 and 5 did not differ significantly from each other regarding changes over time. Our results are comparable with the results of Mukabel et al. who also found that homes with poor quality scores were more likely to act on performance scores compared with homes with better scores (Mukamel et al., 2007). This may have something to do with the sense of urgency that managers and professionals in poor performing organisations experience. For instance, Baier et al. found that homes with ambitious targets improve more than homes with less-ambitious targets (Baier et al., 2009). More research is needed to analyse in depth the responses of nursing homes' staff and board members on the CQI results in terms of strategic orientation (Zinn et al., 2008).

8.4.1 Limitations

There are several limitations of the current study. Firstly, the response categories in the interview protocol and questionnaires refer to '1' never' to '4' always. This means that there is a ceiling effect when the frequency of the quality criteria is always good. Some indicators reached this ceiling already on t_0, meaning that there was not much opportunity for improvement. For example, indicator 'Experience of safety' of the interview questionnaire attained a score of 3.78 on t_1 and indicator 'Housing and privacy' attained a score of 3.76 indicating experiences of clients were very positive and relatively poor performing organisational units had more room for improvement.

Secondly and lastly, the indicator score represent a case-mix corrected score per healthcare organisation based on data on the level of individual clients. For our study, we only had access to the average indicator scores per organisational unit. We could analyse improvement over time on the level of organisational units, looking at different groups of organisations and aggregated indicator scores. However, client level data were not provided by the national databank, meaning that it was not possible to look at the variance of the indicator scores on client level.

Future studies should preferably look at changes over time using data on the level of clients nested in organisational units. To analyse over time changes per organisational unit, multilevel analysis with three levels is necessary:

1. Patient.
2. Are nested in organisations.
3. Are available per year.

By using this data processing method, it is possible to determine whether single organisational units have significantly improved over time.

Finally, we analysed the differences in performance between t_0 and t_1. We assume that organisational units have engaged in quality improvement strategies between those measurements. However, we did not have systematic information about those quality improvement activities. This is a relevant topic for future research, because it will help us to understand which initiatives lead to significant quality improvement in terms of client experiences.

8.5 Conclusions

By comparing long-term care indicator scores over time, it was observed that indicator scores improved. Nursing homes, residential care facilities, and homecare providers with substandard performance on the first measurement showed more improvement than homes, residential care facilities, and homecare providers whose performance was already relatively good.

Appendix Figures of two mail questionnaires including indicator score of the first measurement and the change score

Figure A8.1 Per indicator the score of the first measurement (t_0) and the change score (t_1 - t_0) for the CQI questionnaire for representatives

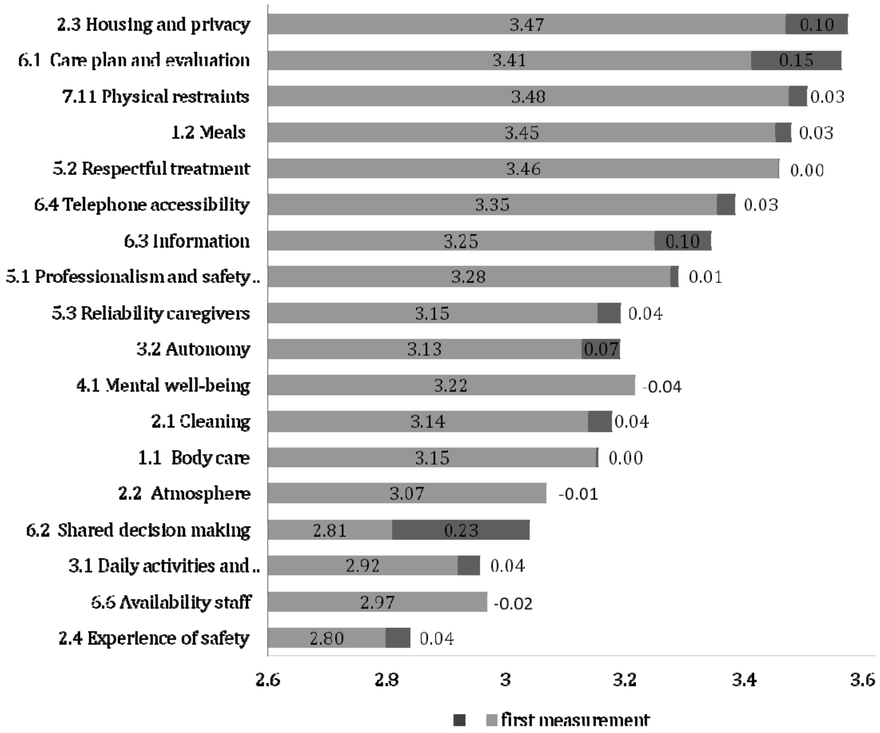
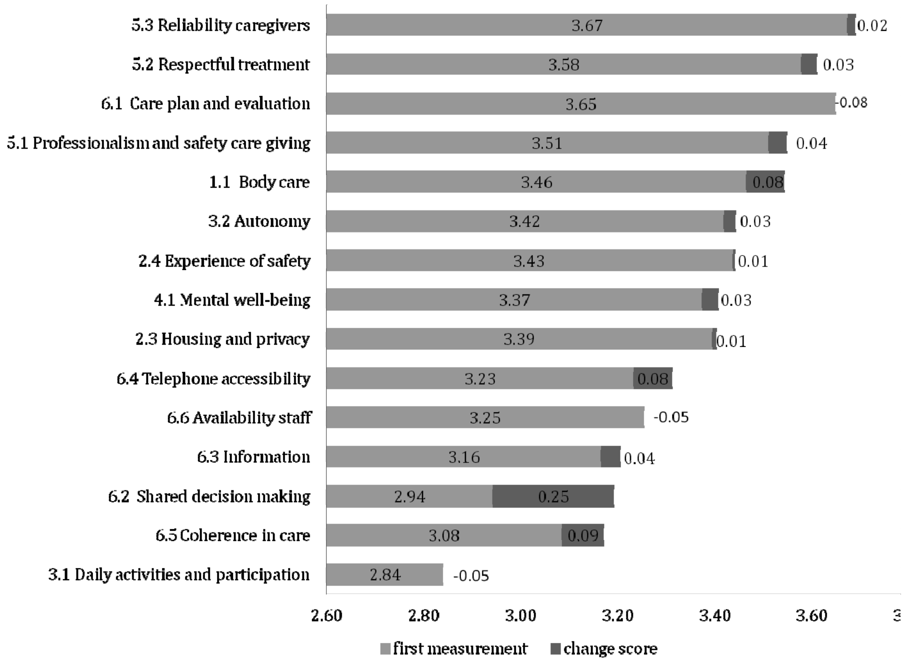


Figure A8.2 Per indicator the score of the first measurement (t_0) and the change score (t_1 - t_0) for the CQI questionnaire to homecare clients



9

Discussion and conclusions

Since the reform of the Dutch healthcare system in 2006, measuring and monitoring the quality of care, and transparency about the outcomes, have received increasing attention. Quality is operationalised in terms of effectiveness, safety, and patient experiences (www.zichtbarezorg.nl). In the Netherlands, healthcare users' experiences are measured with a standardized methodology called the Consumer Quality Index (CQ-index or CQI), which was embraced and stimulated by the Dutch Ministry of Health, Welfare and Sport (VWS). In addition to dealing with instruments to measure healthcare users' experiences, this approach also includes rules and instructions for data collection, analysing, and reporting (Sixma et al., 2008a; Sixma et al., 2008b; Sixma et al., 2008c; Sixma et al., 2009).

Some of the quality information collected with the CQI questionnaires has been used as public comparative information on the Internet (e.g. on www.kiesbeter.nl). Comparative information serves multiple purposes, such as choice by users, selective purchasing by health insurers, and as a source for managers and professionals of healthcare organisations to improve the quality of their care (Delnoij and Hendriks, 2008). Some research on the publication of comparative information for user choice has taken place; for example, a study on case-mix adjustment and effective presentation of CQI information (Damman, 2010). For all CQI questionnaires, research reports and scientific articles provide information regarding the construction of these questionnaires (e.g. Damman et al., 2007; Stubbe et al., 2007a; Stubbe et al., 2007b; Wiegers et al., 2007; Zuidgeest et al., 2007; Berendsen et al., 2009; Claessen et al., 2009; Damman et al., 2009a; Wiegers, 2009; Triemstra et al., 2010). However, studies about improving quality of care based on CQI information are scarce (Winters et al., 2010).

Berwick et al. (2003) provide a potential mechanism for measuring performance and improving quality of care. This mechanism includes two pathways which require action either from the healthcare users (namely: *selection*) or from the organisation whose performance was measured (namely: *change*). Porter states that we cannot expect healthcare consumers to *select* the best provider, but that healthcare providers need to *change* and transform the care delivery to these users (Porter, 2008). The latter pathway presumes that healthcare organisations start initiatives to improve the quality of care after they have been informed about their own performance (Berwick et al., 2003; Fung et al., 2008). To take appropriate action, the organisation needs reliable and valid information. If data are not reliable and valid, the discussions will tend to focus on the quality of the data (or on the instrument used) instead of on the quality of care. Therefore, it is highly relevant to evaluate whether the CQI methodology provides reliable and valid data that are useful for quality improvement.

The work in this thesis addresses two main topics. First, the methodological aspects of measuring quality from the user perspective are investigated (*Part 1*). Second, the actual use of information for quality improvement by healthcare organisations and client councils in the nursing and caring sector are addressed (*Part 2*).

Research questions related to these main topics are:

1. *'How is quality of care from the user perspective measured in the CQ-index? More specifically: How is the reliability and validity of the CQ-index tested?' (Part 1)*

2. *'To what extent is CQI information used in nursing homes and homes for the elderly for quality improvement?' (Part 2)*

3. *'To what extent do CQI scores of nursing homes, homes for the elderly, and homecare organisations change over time?' (Part 2)*

In this chapter, **Section 9.1** starts by describing the main findings of our work in relation to the individual research questions. Next, in **Sections 9.2** and **9.3**, these findings are discussed and appropriate recommendations are made. The chapter ends with some concluding remarks emerging from the work presented in this thesis (**Section 9.4**).

9.1 Main findings

Part 1: Methodological aspects of the CQ-index

When developing a new CQI questionnaire, the main question is whether it measures quality of care from the patients' perspective in a reliable and valid way. The reliability and validity of CQI questionnaires is tested, following the guidelines described in the so-called CQI Manual (Sixma et al., 2008a). To answer the first research question, in Chapters 2 to 5 a selection of methodological aspects related to measuring quality of care from the user perspective with the CQ-index is addressed. These Chapters demonstrate how the reliability and the validity of the CQI questionnaires are tested.

The CQI methodology measures quality of care from the user's perspective. From this perspective, quality not only takes into account the healthcare users' experiences but also covers user expectations by asking users how much importance they attach to various quality aspects (Sixma et al., 1998). These quality aspects are generated by following several phases that are written down in the CQI Manual. This process ensures that all new questionnaires are developed according to these guidelines (Figure 9.1).

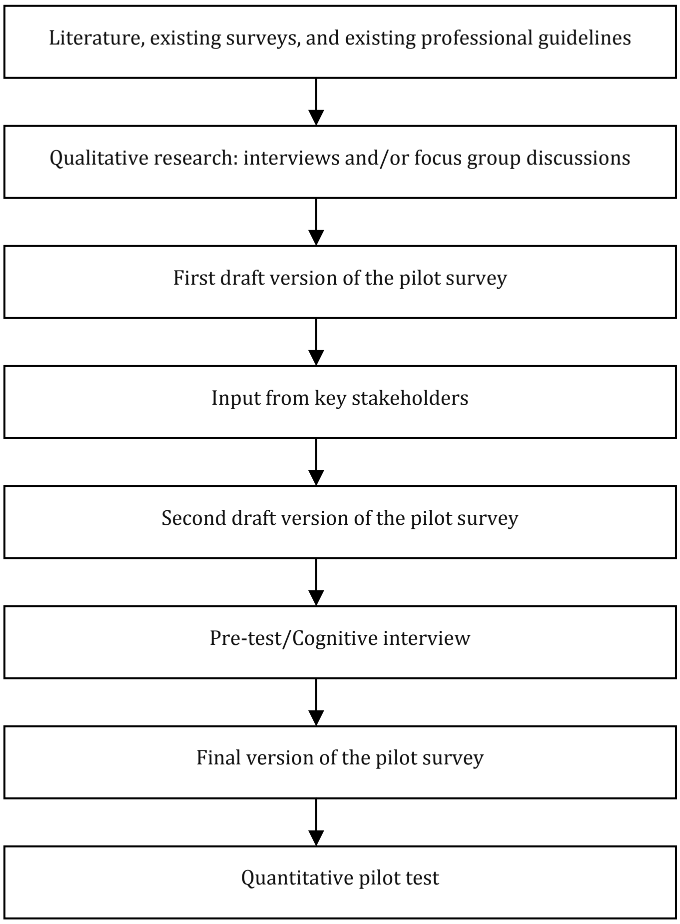
The guidelines prescribe that instruments should be developed using literature reviews and existing surveys and guidelines, with the aim to assemble a wide variety of quality of care aspects. In the second step, qualitative research is performed; in particular, focus group discussions are held with patients to incorporate the most important quality aspects from the patient's perspective into the pilot survey. This process is described with respect to the CQI 'Rheumatoid Arthritis' (RA) in Chapter 2.

After creating a draft pilot survey and incorporating the input of various users into this survey, the next step is to perform a pre-test among a small group of patients. This qualitative phase provides valuable information on question routing, the language used, and the number of questions. The results of Chapter 4 show that the current pre-test procedure of constructing new questionnaires is somewhat basic and rather limited in scope. To gain insight into difficulties or misinterpretations of a questionnaire, more qualitative cognitive interviews should be systematically included in the pre-test procedure. Additionally, the findings of pre-tests should be reported more extensively in the CQI development research reports.

In the next phase of the development of a certain CQI questionnaire, postal questionnaires are sent to 600 to 1,200 patients, together with three reminders to enhance the response rate. Important parameters regarding the reliability of the collected data are:

1. A high response rate.
2. A representative response group.

Figure 9.1 Construction phase of developing a new CQ-index survey



In the development phase of a CQ-index, paper surveys are used because they generate high response rates (over 60%; Chapters 2 and 3). However, paper surveys are relatively expensive compared to online methods of data collection (Zuidgeest et al., 2008b). Therefore, tests were conducted regarding the quality of a mixed-mode data collection, i.e. a combination of an online (Internet) survey with paper questionnaires for non-respondents. This test took place with respect to the CQI 'Breast Care' (Chapter 3). The CQI 'Breast Care' consists of two versions: one for patients with breast cancer and one for patients with benign abnormalities. Although the questionnaire for breast cancer was longer, the response rate in the mixed-mode was higher than the response rate of the version including patients with benign abnormalities. The speed of response for the postal survey was shorter than that for the mixed-mode survey. However, when non-respondents of the mixed-mode survey received the paper version, they returned the questionnaire faster than respondents of the initial paper questionnaire in the postal survey mode. Our results show that mixed-mode surveys are a valid alternative for the standard postal surveys used in the CQI methodology, because patients reported similar experiences. The costs of the mixed-mode questionnaires were lower and this mode yields better quality of data compared to the postal mode (Chapter 3).

In CQI reports, the characteristics of the response group are compared with patients who did not respond. For the postal questionnaire CQI 'Rheumatoid Arthritis' (RA), the results show that (on average) respondents were older than non-respondents (Chapter 2). Within the mixed-mode data collection we also compared the characteristics of Internet respondents with respondents of the paper questionnaire: respondents who filled out the questionnaire online were significantly younger, were more often highly educated and reported better psychological health than respondents who filled out the paper questionnaire (Chapter 3).

After collecting data, the next step in the construction phase is psychometric testing of the dimension, structure and reliability through factor analysis and reliability analysis. In the example of the CQI 'RA' (Chapter 2) this resulted in the construction of 10 reliable one-dimensional scales. In the CQI 'RA' Importance Questionnaire, quality aspects were mentioned that were highly valued by patients. For RA patients these aspects include 'considering medication when prescribing drugs', 'getting information' (about e.g. risks, long-term consequences after surgical procedure), 'rapid accessibility' and 'availability of care'. Combining the data of the experience and importance questionnaires generates a measure of potential for quality improvement. This provides management information that goes beyond priorities or experiences alone. It provides a topic list of improvement priorities (Chapter 2).

In CQI research, patients or clients are asked what they experienced during a particular period in their interaction with healthcare providers and the healthcare system. If they are unable to express their experiences due e.g. to problems with cognitive functioning, their representatives (often family members) are asked to evaluate the quality of care. Chapter 5 examines two proxy-reports methods for measuring the quality of care of nursing homes and homes for the elderly. Results show that representatives' experiences regarding the quality of care do not correspond well with the observational assessments made by the nursing staff; this indicates that both perspectives measure different aspects of quality of care and that they are not interchangeable (Chapter 5).

This first part of the thesis focuses on methodological aspects of measuring the user perspective with the CQ-index. Key messages on reliability and validity are:

1. CQI methodology provides rules and guidelines that lead to reliable and valid questionnaires. This has been demonstrated with respect to the CQI Rheumatoid Arthritis (Chapter 2).
2. A potential tool for quality improvement can be generated by combining the experience and importance scores related to the same quality aspects (Chapter 2).
3. The validity of a CQI questionnaire is enhanced by performing pre-tests. However, pre-testing is not yet extensively performed, and is only briefly described in the CQI development research reports. Therefore, this remains a limitation regarding the validity of the CQI methodology (Chapter 4).
4. Questionnaires distributed by two different modes (postal mode versus Internet supplemented by paper questionnaire mode) yield comparable findings with respect to response rates and respondents. Both modes reported similar ratings of quality of care. This indicates that different methods can be used to yield the same results that are comparable regarding their reliability (Chapter 3).
5. Using Internet questionnaires as data collection mode, a different respondent group was reached compared with paper questionnaires (Chapter 3).
6. Experiences of representatives and observational assessment of nursing staff showed few similarities concerning assessment of the quality of care, indicating that the two perspectives are unique (Chapter 5).

Part 2: Actual use of CQI information for quality improvement

The central topic in Chapters 6 and 7 concerns the actual use of CQI information with the intention to improve the quality of care by several actors in nursing homes and homes for the elderly, including client councils.

Data-related factors, factors related to staff, and organisational factors influencing the use of CQI information for quality improvement were investigated. For this, employees responsible for day-to-day care, quality staff members, as well as representatives of middle and senior management were interviewed. The findings show that data-related factors enabling the use of information were: reliable results, and the recognition and validity of the data. When CQI data met these factors, staff of the healthcare organisations could relate the outcomes to processes in the organisation. One organisation did not recognise themselves in the results and questioned the methodology of collecting the data. Some interviewees perceived the fixed response categories of the CQ-index as a disadvantage, because the extra information possibly given by residents in interviews is then not taken into account. This information is seen as essential to improve the quality of care by these interviewees. Others state that extra information is redundant, because the CQ-index is meant to provide a global picture. Additionally, the use of CQI information also depends on the approach of organisations towards quality improvement activities: in some organisations quality managers or quality of care staff are the leaders; in other organisations, operational staff are the leaders and quality managers merely support them. Leadership was seen as an enabling factor influencing the change of several quality aspects. Because measuring healthcare users' experiences now occurs every two years, publishing the results on the Internet is seen as the final part of the process of measuring healthcare users' experiences. The strategic management and their policy on transparency reinforced the publishing of results on the Internet. An organisational factor enabling the use of information was having an infrastructure for quality improvement. More specifically, the longer the organisations held a certificate for their quality management system, the more these organisations embraced a policy concerning continued quality improvement. Mergers and cost containment were organisational factors preventing professionals from implementing improvement actions, because employees had priorities other than improving the quality of care. In addition, in some organisations an external party (i.e. the health insurer) promoted change by requiring an approved action plan based on CQI results, supported by a client council to ensure the client perspective of the plan (Chapter 6).

Client councils (collectives of patients/clients) can also be a motivator for healthcare organisations to improve the quality of care. However, our results show that, although client councils of nursing homes and homes for the elderly have a right to be involved in decision-making on various organisational issues and on issues regarding the daily living of clients, in practice councils are hardly involved. The management of care organisations are dominant when it comes to strategic issues. Regarding CQI research, the majority of councils were not involved in choosing the approved contractor that performs CQI research, and only a small percentage pointed out quality improvement priorities. Consequently, improvement of quality is currently the sole domain of managers and professionals instead of a co-production between managers, professionals, and client councils (Chapter 7).

In Chapter 8, an analysis was made of the performance scores of somatic nursing homes, residential care facilities, and homecare providers who had measured the experiences of clients twice over a period of three years. These scores are published on www.kiesbeter.nl for comparative information and for accountability. Our first hypothesis was that publication of CQI results of the first measurement would trigger quality improvement activities leading to an improved performance on the second measurement. This hypothesis was confirmed: the change in scores between the two measurement points showed that most indicators improved, whereas only three indicators showed a minor decline. The change in scores was more profound for somatic nursing homes than for psycho geriatric care and homecare, because in somatic care there was more variation in change scores between providers at the first measurement, and thus more potential for improvement. The second hypothesis was that organisations with substandard performance on the first measurement would improve more than organisations whose performance was relatively good. This hypothesis was also confirmed. Again, this improvement was more profound for somatic nursing homes care than for psycho geriatric care and homecare (Chapter 8).

The second part of this thesis examined how CQI information is actually used with the intention to improve the quality of care in the sector nursing and caring, and to what extent CQI scores of healthcare organisations changed over time.

Key messages of this part are:

1. Factors influencing the use of CQI information for quality improvement are divers and complex: enabling factors were mainly related to the reliability, the recognition, and the validity of the data. Decisive leadership, an infrastructure for quality improvement, and repetition of a CQI measurement were also enabling factors. Unrecognizable results, cost containments, and mergers prevented employees from taking actions (Chapter 6).
2. Management dominates the decision-making process regarding the quality policy of healthcare organisations (including CQI research), whereas client councils are reactive (Chapter 7).
3. CQI scores improved between the two measurement points indicating that patients were more positively about the care.

4. Organisations with substandard performance on the first measurement improved more than organisations whose performance was relatively good.

9.2 Discussion of findings

9.2.1 Methodological aspects of the CQ-index

Qualitative research in developing new CQI questionnaires is important

In the phase of developing new CQI questionnaires, the perspective of healthcare users is guaranteed by doing qualitative research, such as focus group discussions and pre-testing (Chapter 2), which contribute to the reliability and validity of questionnaires. Performing focus group discussions allows important quality aspects from the patient's perspective to be taken into account. Regarding the methodology of pre-testing questionnaires, our results indicate that improvements are needed when *performing* and *reporting* them (Chapter 4). In this way, specific attention is paid to mental processes the respondents use to answer survey questions and to identify problems (Collins, 2003). This finding is confirmed by other studies which showed that by using more qualitative pre-testing techniques, such as respondent observations, respondent debriefing (Hak et al., 2004), think-aloud interviewing and probing (Levine et al., 2005), more value can be added in the validation of self-completion instruments.

Indicators for reliable data: response rate and respondents' characteristics

In research, both the respondents' characteristics and the response rate are important parameters for reliable data. More observations and a representative response group can be seen as indications for reliable results with a minimal risk of bias.

In this thesis, the response rates of CQI surveys were relatively high, over 60% (Chapters 2 and 3), which is consistent with other disease-specific surveys (Nijkamp et al., 2002) and other CQI surveys (Zuidgeest et al., 2008a). A main finding was that a salient topic (e.g. CQI 'Breast Care' version for breast cancer) yields a high response rate. This is also consistent with other studies (Edwards et al., 2007). The length of a CQI questionnaire (e.g. more than 100 questions) is often criticised by different key stakeholders in the developmental process of new CQI questionnaires (Hopman et al., 2011). A long questionnaire tends to yield a low response rate, which lowers the reliability of the collected data (Edwards et al., 2007). However, our study indicates that the length of the CQI questionnaire does not influence the response rate (Chapter 3). This finding is corroborated by an overview of the response rates of different CQI questionnaires (Zuidgeest et al., 2008a).

It has been shown that specific target groups respond to different types of data collection methods. In our studies, respondents of mail CQI questionnaires were on average older than non-respondents (Chapter 2) and Internet respondents were younger than postal respondents (Chapter 3). Compared to the traditional postal survey, the mixed-mode survey (Internet questionnaire supplemented with a postal follow-up) yields a similar group of respondents (Chapter 3). An assumption made regarding mail and Internet questionnaires is that the respondents have the ability to read and write, i.e. they are sufficiently literate in Dutch. Studies among ethnic minorities (often with less education and lower Dutch language reading proficiency) show that the data quality is lower for these groups (Roset et al., 2008). For some CQI questionnaires (CQI ‘Long-term care’, CQI ‘Care for the disabled’, CQI ‘Palliative care’), interviews are used to enhance the response rate (up to 100%) and to collect reliable data. If an interview with the clients themselves is not possible, their representatives are asked about their experiences with the quality of care (CQI ‘Long-term care’ and CQI ‘Care for the disabled’). Thus, it is important to realise that different CQI questionnaires need appropriate data collection methods in order to collect valid and reliable data from the specific target groups.

Healthcare users’ view is unique

Quality of care can be measured by different sources and is operationalised in the Netherlands in terms of effectiveness, safety, and patient experiences. According to Berwick, patients’ experiences should be the fundamental source of the definition of quality (Berwick, 2002). In quality measurement with the CQI methodology the patient’s perspective or the perspectives of representatives is assured. This is essential because patient experiences cannot be measured through the professionals (Chapter 5). A study comparing the perceptions of professionals with their patients’ experiences on fertility care, confirmed that professionals cannot adequately evaluate their performance with respect to patient-centeredness (Aarts et al., 2011). This was also concluded from a study in which people with dementia, as well as their staff and family members, were interviewed. All had different views regarding activities that were meaningful for people with dementia (Harmer and Orrell, 2008). A study among clients with cognitive impairment and their representatives showed that clients are more critical than representatives (Speet et al., 2004). Therefore, the perspective of the clients and their family members are unique and an important source of quality information, which differs from the perspective of professionals and which, in turn, can differ from each other. As these perspectives are unique and an important source of information on quality of care, future research on (parts of) CQI questionnaires should focus on the relation between healthcare users' experiences and other indicators of performance or quality of life, to provide even more comprehensive information on the validity of CQI questionnaires. For some CQI questionnaires Patient-Reported Outcome Measures (PROMS) can be included in surveys to assess the impact of services on health outcomes. In this way, parallel to the patients' experience of care, healthcare professionals can also assess the impact of interventions on healthcare users' health status.

9.2.2 Actual use of CQI information for quality improvement

Combining Experience and Importance scores: a missed tool for quality improvement?

Combining the data of the experience and importance questionnaires generates a measure of potential for quality improvement. For the presented studies (with the exception of Chapter 2), only data of experience questionnaires were used. In the sector 'nursing and caring', which is a forerunner in measuring client experiences and presenting data on the Internet (Hopman et al., 2011), the importance dimension is not yet used. Only (aggregated) data of the CQI 'Long-term Care' experience questionnaires are currently used as (comparative) information (www.kiesBeter.nl). These data are transformed to relative 'star' ratings: (much) above average (4 or 5 stars), average (3 stars), or (much) below average (1 or 2 stars). Star ratings are often misinterpreted: some persons associate them with the stars designated to hotels or restaurants (Hopman et al., 2011). These stars represent absolute differences in quality whereas CQI stars represent relative differences. These star ratings can be used to identify quality aspects because these scores are based on the mean score over all organisations.

However, the CQI methodology allows to separate the dimensions 'experience' and 'importance'. Based on this separation, healthcare organisations are provided with valuable management information on the quality aspects that are susceptible for improvement, i.e. in those cases where the actual care does not meet the needs and expectations of patients. For example, in long-term care the well-being of clients is important, and related priorities include accommodation, cleanliness, tasty meals, sufficient staff, and respectful treatment. Some of these experiences received a negative score (e.g. sufficient staff, cleanliness, tasty meals) and some scores were extremely positive (e.g.

respectful treatment). The main aspects that could be improved were 'communication and information on their rights and policy of the organisation' and 'sufficient staff' (Hopman et al., 2011). This example also shows that experience, importance and topics needing improvements do vary. To what extent the improvement scores really do support the identification of quality gaps that matter most to healthcare users, has not yet been investigated.

Quality improvement lacks the influence of client councils

Our findings on the use of information and improving the quality of care showed that, in the sector nursing and caring, measuring healthcare users' experiences and publishing the results on the Internet are no longer controversial. The entire cycle of measuring and publishing results had already taken place for the second time during our period of data collection, and interviewees saw publication as an integral part of the process of measuring quality from the user perspective (Chapter 6). In this process, the influence of client councils in decision-making and the policy of healthcare organisations was minimal. In the light of the Dutch government's agenda on client empowerment, this is undesirable. The nationwide organisation for client councils (*LOC Zeggenschap in Zorg*) state that the councils' minimal influence is caused by the organisation, as well as by the councils who rely on the management of the organisation to make the right decisions (Hopman et al., 2011). Councils can become more proactive if the management of healthcare organisations systematically involves them in decision-making. This then becomes a win-win situation, because councils which are actively involved in the identification of priorities and quality activities reduce the amount of undesirable outcomes (e.g. prevalence of bladder incontinence, pressure ulcers, urethral catheterisation, restricted mobility and behavioural problems) (Wagner et al., 2006). In addition, their involvement also guarantees that improvement aspects are supported by the client's perspective. On the other hand, councils do their best to participate in the policy of healthcare organisations; however, due to the age and physical complaints of some of the council members, the council cannot do more than they are currently doing. In order to support the councils, *LOC Zeggenschap in Zorg* provides volunteers that encourage client councils to be involved in the process of identifying improvement priorities; however, few councils take advantage of these services.

Research on behavioural change indicates that people first need knowledge (e.g. become familiar with CQ-index and be aware of their rights on decision-making in healthcare policy), then one needs to create a positive attitude (what can councils expect from their involvement and what can motivate them to be involved), and then one can expect people to display the desired behaviour (at least, if they have enough time and resources) (Cabana et al., 1999; Grol and Wensing, 2004). Therefore, it is important to first establish the state of knowledge of client councils regarding their rights in strategic decision-making within healthcare organisations, and to assess which problems the client councils encounter in this process.

Professionals, managers and leaders are important in organisational change

The use of results in healthcare organisations partly depends on the attitude and competence of the staff. ActiZ (Organisation of Care entrepreneurs) explored whether their staff is able and willing to start improvements. It was shown that managers were more able and willing to change than nursing staff. However, in Chapter 6 we found that the professionals related to direct care are made responsible for the actual changes. These professionals experience the greatest difficulties in their capability to change. This indicates that an inappropriate level of the organisation may have been made responsible for quality improvement, or that the staff is not involved in the right way. Reasons why the staff are often reluctant towards change are: past experiences were negative, changes were not implemented successfully, changes were implemented too rapidly, and there was no communication when the change had become part of the routine (ActiZ, 2010). This indicates that the implementation phase is a slow process which takes much time, and that leadership and management are important aspects when an organisation needs to change (Davies and Cleary, 2005; Strating et al., 2008; ActiZ, 2010). Leaders can be inspiring and motivating for the staff, but can also be decisive when quality needs to be improved (ActiZ, 2010).

Process and mechanisms leading to improvement is largely a 'black box'

Although quality improvement is one of the Government's aim, stakeholders believe that 5 years of the CQ-index is too soon to see real improvement in the quality of care (Hopman et al., 2011). However, the study in the sector nursing, caring, and homecare showed that in the period 2007-2009 the performance of these organisations (measured with CQI questionnaires) did improve (Chapter 8). We do not know which specific actions were undertaken that might explain the change in the scores. In other words, the processes and mechanisms that led to this improvement are largely a 'black box'. However, these findings are consistent with the international literature, as well as with theories on quality management and quality improvement (Mukamel et al., 2007; Fung et al., 2008; Hendriks et al., 2009). Studies in the USA have shown that care homes reorganized quality improvement programs and started new quality-assurance programs in response to public performance scores (Castle, 2005; Mukamel et al., 2007; Mukamel et al., 2008).

With respect to the Netherlands, no studies have investigated the specific actions that nursing homes, residential care facilities or homecare organisations took to improve their scores. We need to study this topic, in order to elucidate which initiatives lead to significant and measurable quality improvement in terms of client experiences. There have been national initiatives focusing on the procedural issues of *how* to change (e.g. who to consult, how to determine priorities, etc), such as 'Through Patients Eyes' (*Door Cliënten Bekeken*, NPCF), 'Measuring and Improving' (*Meten en Verbeteren*, LOC), and international initiatives like the CAHPS and Picker Institute Improvement guides. These methods focus on stimulating a dialogue between organisations and clients (collectives), and on finding starting points for identifying and prioritizing opportunities for improvement and enhancement. One study indicates that process aspects (e.g. doctor-patient communication and information) and structure aspects (e.g. waiting times, continuity of care) contribute the most to patients' overall evaluation of the quality of care as expressed in a global rating. Thus, improving these aspects have more priority than improving outcome aspects (Hopman et al., 2011; Rademakers et al., 2011). However, research on *which actions* need to be undertaken to improve client experiences is still lacking.

CQ-index does not stand alone

Although measuring quality from the healthcare users' perspective is relatively new in the Netherlands, many initiatives have been taken with respect to the measurement and improvement of care. For example, the hospital and long-term care programs (e.g. 'Better Faster' and 'Care for Better') stimulate quality improvement by implementing best practices via breakthrough collaboratives (www.zorgvoorbeter.nl; www.snellerbeter.nl). The aim of these programs is a qualitative, efficient and sustainable care with satisfied clients. In the long-term care, improvement projects focus on the topics of preventing sexual abuse, medication safety, fall prevention, as well as on own control of the patient, and food and drinks (Stoopendaal et al., 2008). The latter two are CQI topics which may change due to this program. One could explore whether a quality improvement collaborative program like 'Care for Better' influences healthcare users' experiences as measured with the CQ-index.

9.3 Recommendations

The main findings of this thesis provide more insight into methodological aspects and the actual use of CQI information for quality improvement. These two aspects are linked because reliable and valid data are a precondition for the actual use of CQI data for quality improvement. Based on the findings and discussion, several recommendations can be made to enhance the reliability and validity of the CQI methodology, and to improve the knowledge on using CQI information for quality improvement.

9.3.1 Methodological aspects

1. Pre-testing is crucial

Future research should focus on the quality of pre-testing when developing new CQI questionnaire, because a good pre-test enhances both validity and applicability. Apart from performing effective pre-testing, systematic analysis and reporting of these tests is also necessary. Problems encountered with CQI items in different questionnaires can be collected and integrated in the database of all items mentioned in CQI questionnaires; this database is available on the website of the Dutch Centre for Consumer Experience in Health Care (www.centrumklantervaringzorg.nl). This will enable new questionnaires to be developed based on the experiences of other researchers. Clustering the knowledge on this phase allows the CQI methodology to become more accessible to everyone concerned.

2. Data collection method and selective respondent bias

When selecting a data collection method for a CQI questionnaire, one needs to consider the characteristics of the target group in order to prevent selection bias. For example, working with postal surveys leads to overrepresentation of the elderly who are often more positive about healthcare, whereas working with online surveys leads to overrepresentation of young and higher educated respondents, who are often more critical. Organisations which rely on Internet surveys should be aware that these may reflect the experiences of only a specific subgroup of their clients. However, this may not be a problem when the aim is to compare the performance organisations and all these organisations used the same method.

9.3.2 Actual use of CQI information for quality improvement

3. Research on CQI information to improve quality of care

Our research shows that data-related, staff-related, and organisational factors both enable and inhibit quality improvement initiatives. These factors can be explored more systematically through quantitative research to provide more information on the context of care, the care facilities, and on structural changes and the processes involved. The actions taken by staff and healthcare organisations to improve their quality of care should be taken into account, because actions that lead to significantly improved outcomes are examples for others who want to improve quality aspects.

Additionally, the CQI methodology provides a tool for identifying quality aspects that need attention (combining *experience* and *importance* scores give *improvement* scores per item). However, for the sector nursing, caring and homecare, ratings for groups of items (scales) are calculated which are used for yearly accountability to the Government and health insurers. Both information types (improvement scores and star ratings) can be used to identify quality improvement aspects/projects; however, studies on both types are still lacking.

4. Co-production of client council and management

The CQ-index is relatively new for client councils and for staff in the healthcare organisation. Therefore, councils and professionals need to become familiar with the CQ-index and need advice on what they can do. On the one hand, councils can be the stimulating party by attracting the right people in their council who are active and willing to participate in this decision-making process of healthcare organisations. On the other hand, management needs to inform client councils about what is expected of the councils' role in CQI research in order to create a stimulating environment in which councils participate in decision-making policy.

5. Research program to contribute to knowledge on quality improvement

Research on using CQI information for quality improvement could be part of an attention shift from *developing* the CQI methodology to *using* CQI information. Measuring and improving healthcare users' experiences contributes to a quality-centred culture, which is a strong predictor of high-performance practices and also decreases staff turnover (Aligning forces, 2010). Until now, quality improvement of healthcare organisations is optional and this phase is relatively new and unknown. Organisations need knowledge and a quality infrastructure to continually enhance their quality. A research program to facilitate knowledge development has now been implemented. The 'National Program Quality of Care' (ZonMw, 2010) consists of four perspectives, in which the patient perspective is one. This Program aims at creating knowledge on appropriate care and how it can be delivered in an appropriate way. This can serve as best practice for healthcare organisations.

6. Patient perspective on the agenda

The Ministry of Health, Welfare and Sports aims to create a national Quality Institute for Healthcare (‘*Kwaliteitsinstituut Gezondheidszorg’*) to enhance the quality of care and reduce unnecessary costs. Therefore, the aim of this Institute will be to bundle the strengths in the healthcare sector to deliver safe and efficient care (http://www.rijksoverheid.nl/nieuws/2010/05/28/kwaliteitsinstituut-voor-de-zorg-opgericht.html). This Institute will have the power to enforce a quality framework if this is missing, or if it is not provided in time in a certain sector. Quality frameworks consist of professional or care content indicators (e.g. prevalence of skin problems, restrictions, medication errors) and indicators from the healthcare users’ perspective. It is important that both the professional perspective and the patient perspective is on the agenda of this new Institute, because both measure different aspects with respect to the quality of care.

9.3 Concluding remarks

In recent years, much effort and energy has been directed at measuring the quality of care from the user’s perspective in a standardized manner. This is reflected in this thesis. Part 1, which addresses methodological issues, includes five studies. Part 2, which deals with the actual use of CQI for quality improvement, includes three studies. This thesis shows that the user’s perspective is foremost in the development of CQI questionnaires, and that the data collection methods used ensure that the user’s experiences are measured in a valid and reliable way. However, as soon as users’ experiences have been measured and reported, the providers ‘take over’. That is, managers and professionals in nursing homes, homes for the elderly and homecare, determine which performance areas are prioritized and which actions are to be taken. The legally embedded rights of client councils to be involved in CQI research in nursing homes and homes for the elderly and subsequent improvement activities are largely a ‘paper tiger’. This raises the question whether the observed improvement in performance might have been better if clients had also been involved in the improvement strategies.

This thesis illustrates that although healthcare users’ experiences are the fundamental source of measuring quality of care with the CQ-index, it is not solely sufficient for quality improvement.

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Summary

Measuring and publishing data on the quality of healthcare in a reliable and accessible way is one of the cornerstones of the policy of the Dutch government. This policy aims to make the care system more patient-oriented, whereby the questions and needs of patient/clients are central. To accomplish this, it is necessary to measure various experiences with the delivered care, using a consistent and systematic approach, i.e., the Consumer Quality Index (CQ index, or CQI). By means of questionnaires or interviews, answers are collected regarding what patients find important and about their actual experiences with healthcare. The CQI approach includes rules and instructions for measuring, analysing, and reporting patients' (also called 'healthcare users') experiences, as well as a manual for developing new CQI questionnaires. The Dutch Centre of Consumer Experience in Health Care tests whether the development of new questionnaires meets the required rules and instructions, and whether approved contractors are indeed allowed to collect CQI data.

Some of the CQI information has been used as comparative information for the public and is available on the Internet (e.g. on www.kiesbeter.nl). However, it has been reported that just measuring care is not sufficient to actually improve care - another aim of the Dutch government. A potential mechanism between the measurement of quality of care and improving such care takes place though *selection*. Selection for the best possible healthcare organisations occurs if healthcare users choose to avoid organisations that under-perform, if health insurers refuse to contract these organisations, and if regulators control and supervise these organisations more intensively. A second mechanism, namely *change*, between measuring quality of care and improving care involves healthcare providers changing and transforming the delivery of care to healthcare users their needs and preferences. Comparative information can provide a motivation for this change and can stimulate action towards improvement, but only if the data are collected in a reliable and valid way. Therefore, it is highly relevant to evaluate whether the CQI methodology does indeed provide reliable and valid data (*Part 1* of this work), and whether the CQI information is in fact applied for quality improvement (*Part 2* of this work).

Main findings

Part 1: Methodological aspects of the CQ-index

The first part of this thesis deals with the methodological aspects that need to be considered when testing the reliability and validity of CQI questionnaires. Therefore, in Chapters 2 to 5 an evaluation is made of a random selection of methodological aspects related to measuring quality of care from the user's perspective. The main findings follow the phases that are required in order to develop a new questionnaire. First, results are presented on the construction phase (including CQI improvement scores). This is followed by findings related to pre-testing the new CQI questionnaires, to collecting data using two different methods, and results that emerge after comparing the view of two different groups on delivered care.

Construction phase

Chapter 2 illustrates how the Consumer Quality Index 'Rheumatoid Arthritis' (CQI 'RA') was created. Constructing a questionnaire in a patient-oriented way involves incorporating findings from focus-group discussions and patients taking part in an expert panel that guides development of the questionnaire. After the phase of formulating the quality aspects needed for a new questionnaire, the questionnaire is evaluated among a small number of patients (pre-testing) to enhance its validity. For this, not only the current practice with the CQI 'RA' but also the CQI 'Breast Care' was evaluated, by referring to the Cognitive Interviewing Reporting Framework (CIRF) (**Chapter 4**). Results show that CQI questionnaires have not been pre-tested using the cognitive interviewing methods of the type described in the CIRF (e.g. think-aloud and verbal probing protocols). Reporting of the findings should be done more extensively in CQI research reports and should, at least, include: the objectives of the pre-test, details of the reviewed literature, research design and participant selection, the actual findings, and the conclusions and implications emerging from the pre-tests.

CQI improvement scores

After creating a CQI 'Experience' questionnaire, all quality aspects are transformed to a CQI 'Importance' questionnaire. By combining the data of both questionnaires a measure of potential for improving care is generated. This provides professionals and management with additional information about patients' experience, because the most valued items, as well as items with the highest negative rating, differ from the quality aspects that are generated as improvement scores. This is illustrated with the CQI 'RA' in **Chapter 2**.

Key messages emerging from the construction phase and the improvement scores:

- CQI methodology provides rules and guidelines that result in reliable and valid questionnaires, and create a potential tool for quality improvement.

- Pre-testing of CQI questionnaires is not yet performed extensively enough, is only briefly described in the CQI development research reports, and is a limitation to the validity of the CQI methodology.

Collection of data

CQI questionnaires are generally sent by regular post to healthcare users, followed by up to three reminders to enhance the response rate. The response rates of two specific CQI questionnaires ('RA' and 'Breast Care') were relatively high, i.e. over 60% (**Chapters 2 and 3**). A study in the field of breast care showed that a meaningful topic raises the response rate despite a relatively long questionnaire (**Chapter 3**), and that elderly persons showed a higher response to paper questionnaires than their younger counterparts (**Chapter 2**).

To establish whether the data collection method 'Internet supplemented by a paper questionnaire for non-respondents' (mixed-mode survey) can be used instead of the standard approach of paper questionnaires (postal survey), data from these two data collection methods were compared. For this study, the questionnaire for breast care patients (CQI 'Breast Care', **Chapter 3**) was used. Results showed that these two data collection methods yield a similar group of respondents. However, only *within* the mixed-mode survey, the Internet respondents tended to be younger, higher educated, and reported better psychological health compared with respondents who filled out a paper questionnaire.

Respondents in the postal survey returned their questionnaires quicker than respondents of the mixed-mode survey. Also, for respondents of the mixed-mode survey the quality of data was more complete and accurate, and the costs of sending a mixed-mode survey was less than the costs of a postal survey. No differences were found regarding the global rating of different healthcare providers (**Chapter 3**).

Key message related to data collection:

- Different methods (postal mode versus Internet supplemented by paper questionnaire mode) can be used to yield the similar results with respect to response rates, respondents and ratings of quality of care.

Comparing opinions of family members of residents with dementia with those of nursing staff

Generally, CQI information is collected from the patients themselves. However, this is not always possible, e.g. for residents with dementia or other cognitive impairments. In these cases information on quality of care is often gathered via proxy reports, such as questionnaires sent to family members of residents with dementia, or observational assessments acquired from the nursing staff. In **Chapter 5** we firstly examine the relationship between these two types of proxy reports. Secondly, we explore whether the opinions of the family members need to be corrected based on the specific care need (cognitive and physical functioning) of residents with dementia. Results showed that the view of the family members and of the nursing staff regarding the social well-being/social engagement of residents with dementia (measured with the SWON and RISE, respectively) was different. Correcting the family members' perspective on the cognitive and physical functioning of residents with dementia with respect to the measured concepts was inconclusive. This implies that different perspectives provide different quality information with regard to dementia care.

Key message after comparing family and staff viewpoints:

- Views of family members of residents with dementia and their nursing staff showed few similarities regarding assessment of the quality of care, indicating that the two perspectives are unique.

Part 2: Actual use of CQI information for quality improvement

The second part of this thesis concerns the actual use of CQI information by several actors in nursing homes and homes for the elderly for improving care. Specific attention is paid to the factors influencing this use, and the position of client councils (functioning as a Board, whose members are drawn from the users [or relatives] of the homes and who will represent them) in those homes. This section ends with a study that compares performance scores of healthcare organisations over time. The aim was to establish whether it is possible to improve CQI scores which, in turn, is an indication for the improvement of care.

In order to collect information, we performed 47 face-to-face interviews with staff involved in the daily work of 12 residential homes, i.e. the quality manager, and representatives from middle and senior management. Actual improvement actions were driven mainly by data-related factors from the CQ-index, namely the reliability, recognisability, and validity of the data. Decisive leadership, a framework for quality improvement, and the repetition of a CQI measurement were also enabling factors. In addition, in some organisations, an external party (the health insurer) promoted change by requiring an approved action plan based on the CQI results. Factors inhibiting improvement of the quality of care were mainly organisation-related aspects (mergers and cost containments) that prevented employees from implementing improvement actions (**Chapter 6**).

Key message of factors involved in improvement actions:
- Enabling factors for quality improvement were mainly related to the data, whereas organisational factors prevented employees from taking actions.

Chapter 7 provides more detail on the role and position of client councils in nursing homes and residential care facilities. Although councils have a legal right to be consulted for organisational issues such as finance, vision, annual report and accommodation, less than half of the councils (31-46%) reported that they exercised this right. The legal right to consent was perceived by 18-36% of the councils regarding client care issues like food and drink, complaints registration, respectful treatment, and activities. For CQI research, only 18% of the client councils perceived a right to consent. Their rights to choose an approved contractor - who performs CQI research - and to indicate improvement priorities, were hardly used. In conclusion, client councils play a relatively passive role in determining the policy on quality of long-term care.

Key message on the position and role of client councils:
- Management dominates the decision-making process regarding the quality policy of healthcare organisations (including CQI research), whereas client councils are mainly reactive.

In **Chapter 8**, we analysed the performance scores of nursing homes, residential care facilities, and homecare providers who measured the experiences of their clients at two different time points between 2007 and 2009. Change in CQI scores between the two measurements showed that most indicators had improved. This change in scores was more pronounced in nursing homes facilities than in residential care facilities or homecare providers. Organisations with substandard performance on the first measurement improved their scores to a greater extent on the second measurement compared with organisations whose performance was relatively good. Again, this improvement was more pronounced in nursing homes than in residential care facilities or homecare providers.

Key message on the performance scores of care organisations:

- Patients experienced the care more positively on the second measurement, and organisations with substandard performance on the first measurement showed a greater improvement than organisations whose performance was already relatively good.

Discussion of findings

Chapter 9 begins by discussing the importance of qualitative research in developing new CQI questionnaires. It is essential that not only the performance of a pre-test is optimal, but also the way that it is reported. Hereby, more value is added during the validation of self-completed instruments. The response rate and characteristics are also discussed, because these parameters give valuable insight into the reliability of the collected data. Further, it is emphasised that the view of healthcare users is unique. Therefore, CQI methodology should be considered as an important source of quality information. Not only the 'Experience' questionnaire of this methodology but also the 'Importance' questionnaire and the measure for quality improvement should be used more often in practice. The fact that the process of improving care currently lacks the influence of client councils is undesirable. Steps should be taken to make the councils more familiar with what they can do with CQI information, before the desired behaviour, i.e. their participation in decision-making, can be expected. Implementing the necessary changes is often left to everyday staff, who may not be willing or may lack the time to do so. Implementing changes is a slow process that takes time and effort through leadership and the commitment of management. Therefore, the involvement of professionals, managers and other leaders are important when changes need to be implemented. Although the measurement of healthcare user's experiences has been ongoing for five years, most stakeholders consider it too early to observe real improvement. The work presented here shows that experiences in the long-term care were more positive with a second measurement. This is an indication that the care improved. The processes and mechanisms that have led to improvement are, until now, a black box. There are methods to promote change, but the specific actions that need to be undertaken to actually improve healthcare users' experiences are still lacking. Finally, the CQI approach does not stand alone; many other initiatives are taking place with the aim to measure quality and to improve healthcare in the Netherlands.

Recommendations

Based on the findings from these studies, some recommendations can be made. First, pre-testing of the CQI questionnaires is essential because insight into possible difficulties faced by respondents helps researchers to create effective and comprehensible questionnaires which enhance the validity of the questionnaire. Additional systematic analysis and reporting of these tests is also necessary. Second, when evaluating care, it should be kept in mind that the selected data collection method may attract different subgroups of respondents. For example, elderly persons tend to respond to paper questionnaires, whereas younger and higher educated persons tend to prefer online questionnaires. Third, research on (the actual use of) CQI information to improve care is scarce. More studies are needed to provide insight into the context of care, care facilities, structural changes and the various processes involved. Fourth, management of care facilities can create a stimulating environment in which client councils are encouraged to participate in the decision-making policy. In doing so, client councils have the ability to stimulate the organisation (co-production) to apply and improve the CQI results. Fifth, the previous focus was on developing CQI methodology, but now information is needed on how CQI information can be used to improve care. A research program can facilitate the development of such knowledge. Finally, to enhance the quality of care, the Dutch Ministry of Health, Welfare and Sports plans to create a National Quality Institute for Healthcare. Although this Institute will be able to enforce quality frameworks it should be noted that, within this framework, the professional's and the healthcare user's perspective may be very different and both are very important.

Concluding remarks

There has been increasing interest in the measurement of quality of care from the user's perspective using the Consumer Quality Index (CQ index, or CQI), resulting in considerable methodological studies on the CQI approach. Further investigation is needed with respect to the use of CQI information to improve care. The work presented here shows that long-term care organizations indeed improve and it has raised the question whether the observed improvement in performance might have been better if clients had also been involved in the improvement strategies.

Samenvatting

Het betrouwbaar en eenduidig meten en publiceren van kwaliteitsgegevens over de gezondheidszorg is een van de kernpunten van het Nederlandse overheidsbeleid. Dit beleid is erop gericht het zorgstelsel meer vraaggericht te maken waarbij de vragen en behoeften van patiënten/cliënten centraal staan. Om dit te bereiken is het nodig om de ervaringen met de geleverde zorg te meten door middel van een consistente en systematische methode, namelijk de Consumer Quality Index (CQ-index of CQI). Via vragenlijsten of interviews worden antwoorden verkregen over wat patiënten belangrijk vinden én wat hun ervaringen zijn met de zorg. De CQI methodiek bevat regels en instructies om ervaringen van patiënten (ook wel zorggebruikers genoemd) te meten, te analyseren en te rapporteren, maar bevat ook een handleiding voor de ontwikkeling van nieuwe CQI vragenlijsten. Het Centrum Klantervaring Zorg toetst of de ontwikkeling van nieuwe vragenlijsten aan de CQI regels voldoen en of meetbureaus CQI gegevens mogen verzamelen.

Een deel van de verzamelde CQI informatie wordt als vergelijkende informatie gepresenteerd voor het publiek en is beschikbaar op het Internet (o.a. op www.kiesbeter.nl). Het is echter bekend dat alleen het meten van zorg niet voldoende is om de zorg daadwerkelijk te verbeteren, wat een ander doel is van de Nederlandse Overheid. Een mogelijk mechanisme tussen het meten van de kwaliteit van zorg en het verbeteren van de zorg vindt plaats door selectie. Selectie voor de best mogelijke zorgorganisatie gebeurt bijvoorbeeld als zorggebruikers bepaalde organisaties die benedengemiddeld presteren vermijden, als zorgverzekeraars weigeren contracten te sluiten met deze organisaties, en/of als deze organisaties intensievere supervisie krijgen. Een tweede mechanisme - verandering - veronderstelt dat zorginstellingen veranderen en hun zorg transformeren naar de wensen en behoeften van de zorggebruikers. Vergelijkende informatie kan een motivatie zijn om te veranderen en kan ook verbeteracties stimuleren als de gegevens op een betrouwbare en valide manier gemeten zijn. Daarom is het relevant om te evalueren of de CQI methodiek inderdaad betrouwbare en valide gegevens geeft (*Deel 1* van dit proefschrift) en of CQI gegevens daadwerkelijk gebruikt worden om de kwaliteit van zorg te verbeteren (*Deel 2* van dit proefschrift).

Bevindingen

Deel 1: Methodologische aspecten van de CQ-index

Het eerste deel van dit proefschrift kijkt naar de methodologische aspecten die een rol spelen bij de betrouwbaarheid en validiteit van CQI vragenlijsten. Daarom behandelen **Hoofdstukken 2** tot en met **5** een willekeurige selectie van methodologische aspecten die gerelateerd zijn aan het meten van de kwaliteit van zorg vanuit het gebruikers perspectief. De bevindingen volgen de fases die noodzakelijk zijn voor het ontwikkelen van nieuwe vragenlijsten. Eerst worden de resultaten met betrekking tot de constructiefase inclusief het construeren van verbeterscores gepresenteerd. Daarna volgen de bevindingen die gaan over het pretesten van nieuwe CQI vragenlijsten, het verzamelen van gegevens door twee methoden en bevindingen rondom het vergelijken van het perspectief van twee actoren.

Constructie fase

Hoofdstuk 2 illustreert hoe de Consumer Quality Index ‘Reumatoïde Artritis’ (CQI ‘RA’) is ontworpen. Een vragenlijst op een patiëntgerichte manier creëren gebeurt enerzijds door het betrekken van de uitkomsten van focusgroep discussies bij het opstellen van kwaliteitsaspecten en anderzijds door patiënten deel laten nemen in de commissie die de ontwikkeling van nieuwe vragenlijsten begeleidt. Na de fase van het formuleren van kwaliteitsaspecten voor de nieuwe vragenlijst wordt door een klein aantal patiënten de nieuwe vragenlijst geëvalueerd (pretest) om de validiteit te vergroten. Hiervoor is niet alleen de huidige praktijk van de CQI ‘RA’ bekeken, maar is ook de CQI ‘Borstzorg’ geëvalueerd door gebruik te maken van het Cognitive Interviewing Reporting Framework (CIRF) (**Hoofdstuk 4**). De resultaten laten zien dat de pretests van de CQI vragenlijsten niet hebben plaatsgevonden volgens de cognitieve interview methoden die beschreven worden in het CIRF (hardop denken en probing protocollen). Het rapporteren van de pretest bevindingen kan uitgebreider beschreven worden in CQI onderzoeksrapporten en zou minimaal het volgende moeten omvatten: doel van de pretests, geraadpleegde literatuur, het onderzoeksdesign, selectie van de participanten, bevindingen en conclusie en implicaties van de prestest.

CQI verbeterscores

Na het opstellen van een CQI Ervaringen-vragenlijst worden alle kwaliteitsaspecten omgezet naar de CQI Belangen-vragenlijst. Door het combineren van de gegevens van beide vragenlijsten wordt een potentieel van verbetering gegenereerd. Dit geeft professionals en het management in de zorg extra informatie, omdat de scores die gegenereerd worden meer vertellen dan alleen wat de belangrijkste kwaliteitsaspecten zijn volgens patiënten of waar patiënten de meeste negatieve ervaringen mee hebben. Dit is geïllustreerd met de CQI 'RA' in **Hoofdstuk 2**.

Kernboodschappen die naar voren zijn komen uit de constructie fase en de CQI verbeterscores zijn als volgt:

- De CQI methodologie geeft regels en richtlijnen die leiden tot betrouwbare en valide vragenlijsten en die een mogelijk instrument voor kwaliteitsverbetering creëert.
- Het pretesten van CQI vragenlijsten vindt niet uitvoerig plaats en wordt slechts kort in CQI onderzoeksrapporten beschreven. Dit is een beperking voor de validiteit van de CQI methodologie.

Verzamelen van gegevens

CQI vragenlijsten worden over het algemeen per post verstuurd aan zorggebruikers, inclusief drie herinneringen om het respons percentage te vergroten. Het responspercentage van twee specifieke CQI vragenlijsten ('RA' and ' Borstzorg') waren relatief hoog, namelijk meer dan 60%. (**Hoofdstuk 2** and **3**). De studie over borstzorg liet zien dat het responspercentage hoger kan liggen als het een belangrijk onderwerp betreft vanuit het perspectief van patiënten, ondanks het feit dat het een lange vragenlijst betrof (**Hoofdstuk 3**). Ook werd aangetoond dat ouderen meer reageerden via een schriftelijke vragenlijst dan jongeren (**Hoofdstuk 2**).

Om te bepalen of de methode van gegevensverzameling via 'Internet aangevuld met een schriftelijke vragenlijst voor non-respondenten (gecombineerde methode) gebruikt kan worden in plaats van een standaard methode van alleen papieren vragenlijsten (schriftelijke methode), werden de gegevens van deze twee verzamelingmethoden vergeleken. Voor deze studie werd de CQ-index voor borstzorg patiënten gebruikt (CQI 'Borstzorg', **Hoofdstuk 3**). Resultaten lieten zien dat de twee methoden een vergelijkbare groep respondenten opleverden. Alleen *binnen* de gecombineerde methode waren de Internet respondenten jonger en hoger opgeleid, en rapporteerden ze een betere psychologische gezondheid vergeleken met respondenten die een schriftelijke vragenlijst invulden. Respondenten stuurden de vragenlijst in de schriftelijke methode sneller terug dan respondenten van de gecombineerde methode. Bovendien was de kwaliteit van de gegevens meer compleet en correct bij de gecombineerde methode, terwijl de verzendkosten lager waren in vergelijking met de schriftelijke methode. Geen verschillen werden er gevonden wat betreft de waarderingscijfers van verschillende zorgverleners (**Hoofdstuk 3**).

De kernboodschap over de methoden van gegevens verzamelen is:
- Verschillende verzamelingmethoden (schriftelijk versus internet aangevuld met een schriftelijke vragenlijst) kunnen gebruikt worden om dezelfde resultaten te verkrijgen met betrekking tot het response percentage, de respondenten en de waarderingscijfers over de kwaliteit van zorg.

Vergelijken van meningen van familieleden van bewoners met dementie met die van verzorgenden
Normaal gesproken wordt CQI informatie verzameld bij de patiënten zelf. Dit is echter niet altijd mogelijk, bijvoorbeeld bij bewoners met dementie vanwege hun cognitieve beperkingen. In deze gevallen wordt informatie over de kwaliteit van zorg daarom vaak verzameld via naasten. Vragenlijsten worden dan per post verstuurd aan familieleden van bewoners met dementie. Een andere manier om informatie te verkrijgen is bewoners te laten observeren door verzorgenden. In **Hoofdstuk 5** onderzochten we eerst de relatie tussen deze twee perspectieven. Ten tweede onderzochten we of de meningen van familieleden gecorrigeerd diende te worden voor de speciale zorgbehoefte die bewoners met dementie nodig hebben. Resultaten laten zien dat het perspectief van verzorgenden en familieleden met betrekking tot het sociaal welbevinden en sociale betrokkenheid van bewoners met dementie (gemeten met de SWON en RISE, respectievelijk) verschillend was. Het corrigeren van het perspectief van familieleden voor cognitief en fysiek functioneren van bewoners in relatie tot de gemeten concepten leverde geen eenduidige resultaten op. Dit impliceert dat verschillende perspectieven leiden tot verschillende kwaliteitsinformatie over dementiezorg.

De kernboodschap na het vergelijken van de meningen van familieleden en verzorgenden is als volgt:
- De perspectieven van familieleden van bewoners met dementie en hun verzorgenden tonen weinig overeenkomsten met betrekking tot het beoordelen van de kwaliteit van zorg. Dit geeft aan dat hun perspectieven uniek zijn.

Deel 2: Feitelijke gebruik van CQI informatie voor kwaliteitsverbetering

Het tweede gedeelte van dit proefschrift omvat het feitelijke gebruik van CQI informatie door verschillende actoren binnen verpleging en verzorgingshuizen bij het verbeteren van de zorg. Specifieke aandacht is er voor factoren die dit gebruik beïnvloeden en de positie van cliëntenraden (die functioneren als een raad die zijn leden haalt uit de gebruikers [of familieleden] van de huizen die ze vertegenwoordigen). Dit deel eindigt met een studie die de prestaties van zorginstellingen vergelijkt door de tijd. Het doel was om vast te stellen of het mogelijk is CQI scores te verbeteren, wat een aanwijzing zou zijn dat de zorg verbetert.

Om informatie te verzamelen zijn 47 face-to-face interviews gehouden met het dagelijks personeel in 12 verpleeghuizen, zoals verzorgenden, kwaliteitsmedewerkers en vertegenwoordigers van het midden en hoger management. Het bleek dat daadwerkelijke verbeteracties vooral gebaseerd waren op gegevens gerelateerde factoren van de CQ-index, namelijk de betrouwbaarheid, de herkenbaarheid en de validiteit van de gegevens. Leiderschap, een infrastructuur voor kwaliteitsverbetering en de herhaling van CQI metingen waren bevorderende factoren. In sommige organisaties was een externe partij (zoals de zorgverzekeraar) een stimulans om te veranderen omdat deze partij een verbeterplan eiste op basis van de CQI gegevens. Factoren die verbetering belemmerden waren voornamelijk gerelateerd aan organisatieaspecten (fusies en kostenbesparingen) die de implementatie van verbeteracties afremden (**Hoofdstuk 6**).

De kernboodschap met betrekking tot verbeteracties is:
- Bevorderende factoren voor kwaliteitsverbetering waren hoofdzakelijk gerelateerd aan de gegevensgerelateerde factoren. Organisatiefactoren hadden een belemmerende invloed op het ondernemen van acties door medewerkers.

Hoofdstuk 7 geeft meer gedetailleerde informatie over de rol en positie van cliëntenraden in verpleeg- en verzorgingshuizen. Hoewel cliëntenraden wettelijke rechten hebben om advies te geven over organisatieonderwerpen zoals financiën, visie, jaarrekening, en accommodatie, rapporteerde minder dan de helft van de raden (31-46%) dat ze dit recht ook ervoeren Het verzwaard adviesrecht met betrekking tot eten en drinken, klachtenregistratie, respectvolle behandeling en activiteiten werd door 18 tot 36% van de cliëntenraden ervaren. Voor CQI onderzoek rapporteerde slechts 18% van de raden dat ze het recht tot verzwaard advies hadden. Hun rechten om een geaccrediteerd meetbureau te kiezen die CQI onderzoek uitvoert en om verbeterprioriteiten te identificeren werden nauwelijks gebruikt. Om het kort samen te vatten: cliëntenraden zijn relatief passief bij het bepalen van het kwaliteitsbeleid in de langdurige zorg.

De kernboodschap met betrekking tot de positie en rol van cliëntenraden is:

- Het management is de dominerende partij tijdens het beslissingsproces over het kwaliteitsbeleid van zorgorganisaties (inclusief CQI onderzoek), terwijl cliëntenraden hoofdzakelijk reactief zijn.

In **Hoofdstuk 8** analyseerden we de prestatiescores van verpleeghuizen, verzorgingshuizen en thuiszorgorganisaties die de ervaringen van hun cliënten tussen 2007 en 2009 tweemaal gemeten hadden. Veranderingen in CQI scores tussen deze twee metingen toonden aan dat de meeste indicatoren verbeterden. Deze verandering van scores was meer aanwezig bij verpleeghuizen dan bij verzorgingshuizen of thuiszorginstellingen. Organisaties die benedengemiddeld presteerden bij het eerste meetmoment verbeterden meer bij het tweede meetmoment vergeleken met organisaties die al redelijk goed presteerden. Dit was wederom sterker bij verpleeghuizen dan bij verzorgingshuizen en thuiszorginstellingen.

De kernboodschap met betrekking tot de prestatiescores van zorgorganisaties is:

- Patiënten ervaren de zorg positiever tijdens de tweede meting en organisaties die benedengemiddeld presteerden bij de eerste meting verbeteren meer dan organisaties waar de prestaties al relatief goed waren.

Discussie van de bevindingen

Hoofdstuk 9 begint met het discussiëren van het belang van kwalitatief onderzoek bij het ontwikkelen van nieuwe CQI vragenlijsten. Het is essentieel dat niet alleen de uitvoering van een pretest optimaal is, maar ook dat er goed over gerapporteerd wordt. Op deze manier wordt extra waarde toegevoegd aan de validatie van instrumenten die zelfstandig worden ingevuld. Het respons percentage en de kenmerken van respondenten werden ook bediscussieerd omdat deze parameters waardevolle inzichten geven in de betrouwbaarheid van de verzamelde gegevens. Verder werd benadrukt dat het perspectief van zorggebruikers uniek is. Daarom moet de CQI methodiek beschouwd worden als een belangrijke kwaliteitsbron. Naast de ervaringenvragenlijst die op dit moment vaak centraal staat, zouden ook de belangenvragenlijst en de verbeterscores meer gebruikt moeten worden in de praktijk. Een ander belangrijk discussiepunt was de rol van cliëntenraden bij kwaliteitsverbeteringen; het is onwenselijk dat bij het verbeteren van de zorg de invloed van cliëntenraden gemist wordt. Om cliëntenraden meer te betrekken bij de participatie in kwaliteitsbeleid dienen er stappen ondernomen te worden; vooral om cliëntenraden meer bekend te laten raken met wat zij kunnen doen met CQI informatie. Het implementeren van de noodzakelijke veranderingen naar aanleiding van een CQI meting wordt op dit moment overgelaten aan medewerkers op de werkvloer die wellicht niet bereid zijn om te veranderen of er de tijd niet voor hebben. Het implementeren van veranderingen is een langzaam proces dat tijd en moeite vergt waarbij leiderschap en verbintenis van het management essentieel zijn. Daarom is de betrokkenheid van professionals, managers en andere leiders belangrijk wanneer er veranderingen geïmplementeerd dienen te worden. Hoewel het meten van de ervaringen van zorggebruikers inmiddels al vijf jaar gebeurt, denken belanghebbenden dat het nog te vroeg is om daadwerkelijk veranderingen te zien. Dit proefschrift laat zien dat ervaringen in de langdurige zorg positiever zijn bij een tweede meting, wat een aanwijzing is dat de zorg verbetert. De exacte mechanismen die leiden tot verbetering zijn -tot nu toe- onbekend. Er zijn bestaande methoden om verandering te promoten, maar de specifieke acties die ondernomen moeten worden om daadwerkelijk de ervaringen van zorggebruikers te verbeteren zijn nog onbekend. Ten slotte staat de CQI methodiek niet op zichzelf. Er zijn heel veel initiatieven in Nederland met als doel de kwaliteit van zorg te meten en de zorg te verbeteren.

Aanbevelingen

Op basis van de bevindingen van de studies, worden de volgende aanbevelingen gedaan. Ten eerste is pretesten van CQI questionnaires essentieel omdat dit inzicht geeft in de eventuele problemen die respondenten ervaren. Dit helpt onderzoekers effectieve en begrijpelijke vragenlijsten te maken, wat de validiteit vergroot. Daarnaast is het systematisch analyseren en rapporteren van deze tests noodzakelijk. Ten tweede moet -wanneer de zorg wordt geëvalueerd- goed in gedachten worden gehouden dat de gekozen methode om gegevens te verzamelen een bepaalde doelgroep aantrekt. Zo neigen ouderen meer te reageren op papieren vragenlijsten en jongeren en hoger opgeleiden op Internet vragenlijsten. Ten derde is meer onderzoek nodig naar (het feitelijke gebruik van) CQI informatie voor het verbeteren van de kwaliteit. Dit is nodig om inzicht te verkrijgen in de context van zorg, de zorg faciliteiten, structurele veranderingen en de hierbij belangrijke processen. Ten vierde kan het management van zorginstellingen een meer stimulerende omgeving creëren waarin cliëntenraden worden aangemoedigd te participeren bij het maken van beslissingen met betrekking tot het kwaliteitsbeleid. Om dit te doen krijgen cliëntenraden de mogelijkheid om organisaties te stimuleren (samen te werken) bij het gebruik en verbetering van CQI resultaten. Ten vijfde is er informatie nodig over hoe CQI informatie gebruikt kan worden bij het verbeteren van zorg. Tot nu toe is de focus gericht geweest op het ontwikkelen van de CQI methodiek. Een onderzoeksprogramma kan de kennisontwikkeling faciliteren. Tenslotte is het belangrijk om te noemen dat de oprichting van een Kwaliteitsinsituut voor de zorg op het progamma van het Ministerie van Volksgezondheid, Welzijn en Sport staat om de kwaliteit van zorg te verbeteren. Dit instituut kan het maken van kwaliteitsraamwerken afdwingen maar dient te realiseren dat binnen deze raamwerken de medewerkers en het gebruikersperspectief verschillend zijn, hoewel beide zeer belangrijk.

Concluderende opmerkingen

Er is meer interesse gekomen in het meten van de kwaliteit van zorg vanuit zorggebruikersperspectief met de Consumer Quality Index (CQ-index or CQI) wat resulteert in veel methodologische studies met betrekking tot de CQI methodiek. De focus van toekomstig onderzoek zou zich echter moeten richten op het gebruik van CQI informatie om de zorg te verbeteren. Dit proefschrift heeft laten zien dat organisaties in de langdurige zorg daadwerkelijk verbeteren. Deze verbetering wordt nu vooral door zorgorganisaties gedaan. Dit proefschrift stelt de vraag of de geobserveerde verbetering in prestaties nog beter had gekund als cliënten betrokken waren geweest bij verbeter-strategieën.

Dankwoord

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About the Author

Marloes Zuidgeest was born on December 24th 1981 in Rotterdam, the Netherlands. After graduation from pre-university education (Sint Laurens College, Rotterdam), she studied Human Movement Science at the Free University of Amsterdam, with a specialisation in Healthcare. She graduated in 2005 and started work as a researcher on the CHECK project of the Department of Orthopaedics at the Erasmus Medical Centre, Rotterdam.

From April 2006 until July 2010, she was involved in several projects that focused on measuring healthcare users' experiences with the Consumer Quality Index (CQI) approach at NIVEL (Netherlands Institute for Health Services Research). In addition, she participated in the workgroup Quality at NIVEL and was a member of staff of the Dutch Centre for Consumer Experience in Health Care ('*Centrum Klantervaring Zorg*', CKZ), which aimed to evaluate whether survey vendors were entitled to receive CQI accreditation.

In 2010, Marloes obtained a Master's in Care Management from the Institute of Health Policy and Management (iBMG) of Erasmus University Rotterdam.

From June 2009 to December 2011, she worked as researcher at the Tranzo department of Tilburg University. Here she continued and expanded her study of CQI methodology with a project in which she observed the actual use of CQI information to improve care in nursing home and residential care facilities, client councils and health purchasers.

This thesis is the culmination of her work at NIVEL and Tranzo.

In addition to her professional activities, Marloes does volunteer work for the LVVP (National Association for Vitiligo Patients) and for her local speed skating society (*Schaatsvereniging Lansingerland*).

She is married to Bartjan Kerstens and they have one son, Tobias, born in 2011.

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