Perspectives of Patients and other Stakeholders on Healthcare Quality in Ophthalmology

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Perspectives of Patients and other Stakeholders on Healthcare Quality in Ophthalmology

Het perspectief van patiënten en andere stakeholders op de kwaliteit van zorg binnen de oogheelkunde

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CHAPTER 1

General introduction

1.1 BACKGROUND

The use of rankings is common within healthcare. Newspapers, for example, publish rankings of hospitals, ranking them from best to worst. This may lead to indignation about why one hospital is ranked higher than another, as criteria for ranking are often unclear and subject to debate. Some have referred to `hospital rankings´ as *`oliebollen-lijstjes`*, rankings of '*deep-fried raisin buns*', a typical Dutch snack that is traditionally consumed in the Netherlands on the last day of the year. Over the past decennia, a ranking of the best *'oliebol'* was published by a daily Dutch newspaper in December. The ranking was more and more criticized over the years, despite continues efforts of the newspaper to improve on objectivity, validity and transparency. A few years ago, as a result of the continuous criticism, the newspaper finally gave up on the annual tradition and stopped publishing the ranking [1]. However despite being criticized as well, rankings continue in the healthcare domain. This suggests that we cannot give up on defining, comparing and improving quality of care, despite the complexity of the task and despite that the validity of such ranking is disputed. If indeed we want to proceed with rankings of health care facilities, we need to advance our understanding in the interest of patients and all other stakeholders involved. These thoughts and ambitions gave rise to this thesis, which identifies, analyses and integrates various perspectives on quality of care.

Many definitions exist for quality of care. Based on earlier definitions, the World Health Organisation (WHO) defines quality of care as the extent to which health care services provided to individuals and patient populations improve desired health outcomes. To achieve this, health care must be effective, efficient, accessible, acceptable, equitable and safe [2]. These six domains of quality are shown in Box 1. The Institute of Medicine (IOM) in the United States of America suggested – in line with the WHO definition - that improvement of quality of care should be focused on these six domains [3].

Measuring the ´quality of care´ is perhaps just as challenging as defining it, as the concept covers different domains and different stakeholders perceive different domains as most important [4]. For instance, when assessing the quality of general practitioners, one could evaluate guideline adherence, efficiency, and empathy. These aspects can be evaluated by various stakeholder groups, such as patients, clinicians, or health insurers. Each of these groups may put different importance to these aspects, which may result in different rankings of who is `the best general practitioner'. Moreover, differences in perspectives may not only exist among stakeholders, but also among cultures and countries. Quality of care may therefore be difficult to define, measure and compare across countries [4].

Box 1. WHO definition - 6 domains of quality of care

- Effective, delivering health care that is adherent to an evidence base and results in improved health outcomes for individuals and communities, based on need;
- Efficient, delivering health care in a manner which maximizes resource use and avoids waste;
- Accessible, delivering health care that is timely, geographically reasonable, and provided in a setting where skills and resources are appropriate to medical need;
- Acceptable/patient-centred, delivering health care which takes into account the preferences and aspirations of individual service users and the cultures of their communities;
- Equitable, delivering health care which does not vary in quality because of personal characteristics such as gender, race, ethnicity, geographical location, or socioeconomic status;
- Safe, delivering health care which minimizes risks and harm to service users.

Several types of data can be used to measure quality of care, such as medical record data, administrative data and disease-specific registers, and these data are mostly generated by healthcare providers. Such data can for instance be used to measure whether the treatment process has been in compliance with clinical guidelines, or to measure the clinical outcomes, i.e. the measurable medical changes in health that result from a given treatment.

As it is known that patients perceive quality of care in different way than physicians, the patient perspective on quality of care is justified, and the assessment of quality of care should additionally cover patient-reported data [5]. For example, one can argue that patients can best report themselves on how a given treatment contributes to their quality of life. Including quality of life in relation to or as part of quality of care is relatively new. Within this context, one speaks of `health-related quality of life' which refers to the perceived quality of an individual's well-being associated with their medical condition and its treatment [6]. Health-related quality of life is a multidimensional construct encompassing physical, social, and emotional well-being [6]. Measures of treatment outcomes from the patient's perspective are called patient-reported outcome measures (PROMs). PROMs can provide a patient-led assessment of health-related quality of life, but also of outcomes like functional status, symptoms and symptom burden. For example, the Catquest-9SF is an outcome measure designed to measure functional status in cataract patients [7]. Next to outcome measures patients may also report on process measures, such as timeliness, courtesy, and empathy. Measure to assess quality of care from a patient's perspective with a focus on process are called patient-reported experience measures (PREMs). PREMs provide a patient-led assessment of patient's experience with healthcare.

With such measures at hand, quality rankings are typically composed by adding up the (weighted) scores for a selection of clinical and /or patient-reported data. This way of reasoning however may oversimplify the relationship between scores on a set of measures and the overall quality as perceived by the various stakeholders. Why would the overall valuation of quality follow such an additive logic? Contemporary valuation modes on welfare and health suggest that other logics may be more accurate. Prospect Theory for instance takes into account that the value attached to measurement scores is not absolute but relative, that is, dependent on the stakeholder's reference point and that quality losses may weigh heavier than quality gains.

1.2 SETTING: QUALITY OF CARE IN OPHTHALMOLOGY

This thesis focuses on quality of care in ophthalmology; More specific, we focus on two eye diseases: cataract and chronic uveitis.

Cataract is a clouding of the normally clear eye lens and leads to a decrease in vision. According to estimates in 2010, cataract is responsible for 20 million blind people, 5% of blindness in developed countries and 50% of blindness in low- and middle-income countries [8]. Cataract treatment for patients with impaired vision consists of surgery. Cataract surgery is a generally safe and effective procedure and is one of the most frequently performed surgical procedure worldwide.

Chronic uveitis is an eye inflammation that affects the middle layer of tissue in the eye wall (uvea). Patients are burdened by the unpredictability of inflammations, transient visual acuity, and sometimes permanent vision loss also in patients in the working age group. Uveitis is rare, affecting 17 to 52 per 100,000 people worldwide each year [9]. Steroid medicine is the main treatment for uveitis. The sooner uveitis is diagnosed and treated, the more successful treatment is likely to be.

The motivation to include cataract is that this disease is associated with high volume care for which many quality indicators from several perspectives are available. This is in contrast with chronic uveitis, as this is a rare disease with a limited number of quality indicators from limited perspectives available. By including both ends of the continuum, we have the opportunity to study perspectives on quality of care in ophthalmology in the broadest sense.

1.3 PROBLEM DEFINITION AND RESEARCH AIM

As mentioned above, the problems associated with using rankings in healthcare give rise to this thesis. Each stakeholder, or stakeholder group has his/her own perspective on what constitutes quality. This means that dependent on which stakeholder you follow, the ranking will be different. Because each stakeholder group has their own perspective, a plethora of indicators exist that gave rise to different rankings. This problem holds true for many areas in healthcare, including ophthalmic care. There seems to be a lack of consensus among stakeholders on what constitutes 'quality'. This lack of consensus makes it difficult to compare the quality of care provided by hospitals. What should be taken into account? The risk of arbitrariness is particularly undesirable for patients, but certainly also for other stakeholders such as physicians and health insurers. Therefore, the aim of this thesis is to *identify various perspectives on quality of care in ophthalmology by systematically addressing commonalities and differences among the perspectives of patients and other stakeholders*. The first part of this thesis focuses on the patient perspective. In the second part of this thesis, multi-stakeholder perspectives are addressed.

1.4 RESEARCH QUESTIONS

This thesis has two objectives, each with three research questions. These objectives and their corresponding research questions are described below.

Objective I: Understanding patient perspectives on the quality of ophthalmic care

1.1 Which factors are considered important by adult patients with chronic uveitis when evaluating treatment?
1.2 Is a digital patient-led checklist for cataract surgery feasible according to experiences of patients and nurses?
1.3 Is the Catquest-9SF of added value to clinical parameters for the measurement of the quality of cataract care?

Objective II: Understanding commonalities and differences about perspectives on quality of cataract care between various stakeholders

2.1 What are commonalities and differences among the perspectives on quality of cataract care between various stakeholders?
2.2 What are commonalities and differences among the perspectives on quality of cataract care between The Netherlands and Singapore?
2.3 What are commonalities and differences in the valuation of quality indicator scores between various stakeholders?

1.5 OUTLINE OF THIS THESIS

Following the above presented logic and partition of research questions, this thesis consists of two parts. The focus of Part I is explicit on the patient perspective within cataract care and chronic uveitis. Part I covers chapter 2 till chapter 4.

First, we explored the domains that patients noticed to be important in quality of care for chronic uveitis. This qualitative study based on *focus group interviews* is conducted to determine which factors chronic uveitis patients consider important when evaluating the impact of their disease and treatment, outlined in **Chapter 2**. We developed a conceptual model that can contribute to the development of an uveitis specific set of indicators to measure quality of uveitis care in adult patients. This study is previously published in *BMC Ophthalmology*.

Second, we studied the experience of patients and nurses with a digital application for information provision to increase patient engagement during their treatment. A qualitative study based on *semi-structured interviews* with patients and *focus group discussion* with nurses is conducted to explore the feasibility of a digital patient-led checklist for cataract surgery, outlined in **Chapter 3**. This study described a simple application using a digital checklist called EYEpad to engage cataract patients in their care pathway. Where Chapter 2 and Chapter 4 focus on the outcome of treatment, this study rather focus on the treatment process. This study is previously published in *JMIR Perioperative Medicine*.

Third, **Chapter 4** considers the patient perspective in relation to the clinical perspective of ophthalmologists. it compares health-related quality of life data reported by patients using Catquest-9SF with clinical data retrieved from patients' medical files. The patient-reported outcomes were collected before and after cataract surgery in five Dutch hospitals for *clinical validation* of the Catquest-9SF. Catquest-9SF is a validated and short patient-reported outcome measure for cataract care. This study is previously published in *Acta Ophthalmologica*.

Part II focuses on multi-stakeholder perspectives within cataract care and covers chapter 5 till chapter 7.

Fourth, Part II starts with the development of an inclusive and consensus-based definition of quality of cataract care by multiple stakeholders, among whom are patients and ophthalmologists. We conducted a *concept mapping* study to define a multi-stakeholder perspective on quality that enabled the expression of differences between stakeholders, as outlined in **Chapter 5.** We first identified and classified stakeholders of cataract care

in The Netherlands using Stakeholder Theory [10]. With the input from the thus included stakeholders, we established a multi-stakeholder perspective on quality of cataract care using concept mapping. The consensus-based quality dimensions were subsequently defined in a plenary session with participants resulting in a shared definition bases on indicators, while allowing different stakeholders to attach different importance to the indicators. This study is previously published in *International Journal of Quality in Health Care*.

Fifth, we elaborated further on the commonalities and differences in stakeholder perspectives and considered them in different two cultures and countries. A *concept mapping* study was conducted to advance understanding of globally validity versus country-specificity of (the importance of) quality dimensions and indicators, as perceived by relevant stakeholders. This study is presented in **Chapter 6**. Following the approach of Chapter 5, stakeholder representatives of cataract care in Singapore established a multi-stakeholder perspective on quality of cataract care using a concept mapping approach. Thereafter, Singaporean dimensions were matched with dimensions obtained in The Netherlands to identify internationally commonalities and differences. This study is previously published in *BMJ Open*.

Sixth, we explored the valuation of quality indicator scores by different stakeholders. To this purpose, a *bisection procedure* was conducted to elicit and compare stakeholders' preferences and trade-offs when evaluating quality indicator scores for cataract care. The study is presented in **Chapter 7**. This study elaborates the valuations of three different stakeholders, patients, ophthalmologists and health insurers using Prospect Theory [11]. It provides insight in the validity of the additive logic so commonly applied in rankings and to advance (shared) decision making. This study is submitted for publication.

As noted, where ranking of the best '*oliebol*' is given up, rankings continue in healthcare domain. The studies described in Chapter 2 to Chapter 7 advanced our understanding in the interest of patients and all other stakeholders involved in defining and comparing quality of care. A discussion of the findings and the interpretation and reflection of the results of this thesis from the perspective of the patient, clinician, the hospital manager and the health insurer are presented in **Chapter 8**.

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PART I

Patient perspectives

CHAPTER 2

Outcomes in patients with chronic uveitis: which factors matter to patients?

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ABSTRACT

Purpose

Outcome measurements currently used in chronic uveitis care fail to cover the full patient perspective. The aim of this study is to develop a conceptual model of the factors that adult patients with chronic uveitis consider to be important when evaluating the impact of their disease and treatment.

Methods

A qualitative study design was used. Twenty chronic uveitis patients were recruited to participate in two focus groups. Data were transcribed verbatim and analysed using thematic analysis in ATLAS.ti.

Results

Coding of the transcripts resulted in a total of 19 codes divided over five themes: 1) disease symptoms and treatment; 2) diagnosis and treatment process; 3) impact on daily functioning; 4) emotional impact; and 5) treatment success factors.

Conclusion

The conceptual model resulting from this study can contribute to the development of future uveitis specific measures in adults.

INTRODUCTION

Chronic uveitis, a disease characterized by intraocular inflammations, is a complex and variable eye condition potentially leading to blindness and affecting adults in the working age group [1]. It is often treated systemically. Patients diagnosed with chronic uveitis not only have problems with the chronicity of the disease and side effects of the medication, but also with the unpredictability of inflammations, transient visual acuity, inflammatory activity changes, and sometimes unexpected complications of the disease and the medication used [2–4].

A previous review found high heterogeneity of outcome measures that are currently used for the evaluation of uveitis treatment. Common outcome measures were classified in several domains: 1) disease activities, 2) visual function, and 3) tissue damage or other disease complications. However, those clinical outcomes are limited in the extent to which they inform us on how patients experience the impact of their disease. For example, patients' evaluation of their ability to conduct daily activities, such as reading and driving, are not included [5, 6]. As chronic uveitis can have a huge impact on health-related quality of life [2–4], currently used primary outcome measures may therefore fall short of appropriately addressing what patients consider as most important [7].

Commonly used instruments for patients with chronic uveitis are the SF-36 Health Survey [8] to measure health-related quality of life in a generic way and the 25-item National Eye Institute Visual Function Questionnaire (NEI-VFQ-25) [6] to measure quality of life in a domain specific way, i.e. vision-related quality of life. However, as these instruments are not specifically developed for the complex and variable condition chronic uveitis [9, 10], the resulting assessment may be incomplete. There is a disease specific instrument developed for uveitis, EYE-Q [11], but this instrument is meant for a paediatric population, while chronic uveitis is most prevalent in adults.

The development of an instrument for the adult population firstly requires understanding which factors chronic uveitis patients consider relevant. So far, there has been published no substantial qualitative in-depth research effort that focused on the patient perspectives on disease and treatment [7]. The aim of the current study is to develop a conceptual model of the factors that adult patients with chronic uveitis consider to be important when evaluating the impact of their disease and treatment. This conceptual model can contribute to the development of future uveitis specific measures in adults.

METHODS

Study design

To determine the factors that patients with chronic uveitis consider important when evaluating the impact of their disease and treatment, we used a qualitative study design based on focus group discussion [12]. Such a focus group approach is recommended in several relevant guidelines like those of ISPOR [13] and the FDA [14], in order to assure that all factors of disease and treatment that patients consider important are determined.

This study is part of TopZorg, a project subsidized by the Dutch Organisation for Health Research and Development (ZonMw). TopZorg aims to stimulate scientific research on highly specialized care in non-academic hospitals. This study has been approved by the medical ethics committee METC of Erasmus Medical Center (MEC-2017-557).

Study sample

We invited chronic uveitis patients of The Rotterdam Eye Hospital to participate in this study. To include a representative cross section of all chronic uveitis patients, patients were selected from the registries by means of stratified random sampling. Strata used were type of chronic uveitis, time since diagnose, gender and age. The inclusion criteria were 1) diagnosed with chronic uveitis [15] for more than 3 months; 2) having anterior segment uveitis, posterior segment uveitis, or panuveitis. We used the Dutch reimbursement codes 502 and 503, respectively referring to anterior segment uveitis and to posterior segment uveitis (intermediate and posterior) and panuveitis. These codes match with ICD-10 codes H20.x, H30.x and H44.1; 3) 18 years or older. We excluded patients who did not have a good command of the Dutch language. Two focus groups, one with 9 and one with 11 participants, were conducted to draw out different perspectives and generate discussion, thereby allowing each person to talk in detail about their perspective [16]. Selected patients received a letter with study information signed by their treating ophthalmologist. They were subsequently contacted by phone and invited to participate in the focus groups. Besides the selected patients, we invited the chairman of the uveitis patient association from the Dutch Eye Patient Association. The chairman met the inclusion criteria. All participants signed informed consent.

Data collection

Focus group data were collected between February 2018 and March 2018. The focus groups took place at The Rotterdam Eye Hospital and were chaired by a moderator (HK). This moderator facilitated open exchange among participants. The moderator made use of a predefined semi-structured topic list with open-ended questions (Appendix 1) to structure the discussion and to prevent missing relevant topics. The topic list was based

on a literature review and on input from representatives of the Dutch uveitis patient association. An observer (LK) was present to observe non-verbal communication and support the moderator if necessary. At the start of discussion, participants were asked to be respectful to each other, and the moderator emphasized the importance of hearing from every participant. The focus groups had a duration of 2 h, including a 15 min break. Focus groups were audio and video recorded and transcribed verbatim.

Data analysis

Thematic analysis was conducted applying a deductive approach to theme generation. Themes were selected based on the questions in the topic list (Appendix 1). Two researchers (LK and AS) carefully read the transcripts. Each of the two independently developed a structured analysis framework consisting of preliminary themes and codes. They compared their frameworks to reach consensus. Thereafter, two researchers (HK and AS) independently indexed the transcripts line by line according to this framework using ATLAS.ti [17]. Coders used memos for comments during coding. When coding was finished and the code 'other' was used, this code was renamed into a new or existing codename best reflecting the contents of the otherwise uncategorized transcripts. Coders compared their coding and discussed until consensus was achieved [18–20]. Subsequently, the framework was refined by removing, adding or combining codes in order to maximise internal homogeneity and external heterogeneity [21]. The final framework is added in Appendix 2. After coding was finished, the cohesion and inter-relations between codes were analysed and visually depicted in a map.

Additional external validation

After conducting two focus groups we concluded that data saturation was achieved, i.e. no new information emerged in the second group. As there was discussion within the research group whether two focus groups might look insufficient to achieve data saturation, we decided to conduct an additional external validity check by asking chronic uveitis patients to reflex on the results, and test whether they consider the results to be complete. Such a validity check is a recommended method by Green & Thorogood [22]. More specifically, we presented the findings to six members of the uveitis patient division of the Dutch Eye Patient Association, asking them whether they concurred with the topics in the structured analysis matrix (Appendix 2), which of these topics they considered to be important, and to note missing topics.

RESULTS

Participants

There were two focus group sessions involving 20 participants in total. The characteristics of the participants are described in Table 1.

Table 1. Patients' characteristics participants' focus group

	Focus group 1	Focus group 2	Total
N	11	9	20
Women, n (%)	7 (64)	5 (56)	12 (60)
Age in years, mean (range)	56 (32 – 74)	53 (38 - 65)	55 (32 - 74)
Diagnose code, n (%)			
- ICD-10 H20.x Anterior segment	5 (45)	5 (56)	10 (50)
- ICD-10 H30.x Posterior segment	4 (36)	2 (22)	6 (30)
- ICD-10 H44.1 Panuveitis	2 (18)	2 (22)	4 (20)
Years since diagnosis, median (range)	10 (3 - 13)	7 (1 - 14)	9 (1 -14)

Structure

Thematic analysis of the focus groups yielded five central themes characterising factors that patients with chronic uveitis consider to be important when evaluating the impact of their disease: 1) disease symptoms and characteristics; 2) diagnosis and treatment process; 3) impact on daily functioning; 4) emotional impact; and 5) treatment success factors. Table 2 lists those themes and underlying codes including a summary of the content.

Theme 1 disease symptoms and treatment

The symptoms experienced and various treatment options were discussed at length. Patients reported symptoms related to vision and symptoms related to pain and discomfort. The extent to which they experienced symptoms depended on their personal condition and differed strongly between patients, e.g. from no vision to very good vision and from no pain at all to unbearable pain. Further, patients experienced difficulties attributing symptoms to chronic uveitis, since most patients suffered from comorbid conditions (comorbidity). As symptoms and comorbidity were different among patients, medication use and side effects of that medication use also differed between patients. Treatments given to patients included steroids, immunotherapy and biologicals. Medication use received much attention in the discussions. Patients were especially interested in each other's experiences with various types of medication, ways of taking medication – infuse, tablet, injection, drops – and dosage. Besides medication use, patients

also mentioned surgeries and hospitalizations, however they did so only in relation to comorbidity and not to uveitis.

Theme 2 diagnosis and treatment process

Most patients commented that it took long until they were correctly diagnosed with uveitis. This diagnostic process was characterized by slow referrals from the general practitioner to specialist care, many examinations - of which many were unnecessary -, and even misdiagnosis. For instance, a patient said: "Actually, my optician discovered it by chance. He said: there is an inflammation in your eye. Then it took me a long time to finally get my primary care doctor's permission. And, indeed, examination has shown that it was sarcoidosis". Even when patients were diagnosed with uveitis, they experienced a poor recognition of uveitis by the general practitioner, emergency care physicians, and ophthalmology residents in cases where their own specialist was not available. This poor recognition resulted in inadequate examinations and medication prescriptions or in long time to treatment, as is illustrated by the following quote: "And then you get there at the emergency department. And then you get all kinds of examinations with which you are even worse off. Sometimes also with medication that are of no use. When I get to my own ophthalmologist, I have the correct diagnosis and the right medication within five minutes, and I am done within five minutes". Further, patients reported that they experienced difficulties in reaching their own uveitis specialist. They experienced the limited accessibility as an unnecessary disease burden. "That you are in direct contact with him [own uveitis specialist], [...] you just want to be able to act quickly and now you are actually stopped by how it is organized.".

Theme 3 impact on daily functioning

Patients varied strongly in the impact chronic uveitis had on their daily function, including activities such as employment, sports, mobility, and watching TV or reading. For example, one patient reported to have lost her job because of chronic uveitis, by contrast, another patient reported to do fine with her fulltime job. Further, patients discussed different patterns of dependency including dependency on other people, lifelong dependency on medication, and dependency on devices. To illustrate, one patient said: "Yes, even if you just arrived in southern France and you have to say [to your spouse] the next morning: [we have to] go back again, because I have to go to Rotterdam. That has happened to me often". Further, the impact on daily functioning depends on support patients experience within relationships. Some patients experienced much understanding from their social environment, while others felt that their environment downplayed the severity of their disease which enlarged the impact of disease burden.

Table 2 Summary of themes and codes, including examples

Theme 1. Disease symptoms and treatment	
Code 1.01 Symptoms: vision	Difference between patients: range from no vision to very good vision; fluctuating vision; diminishing vision; vision in darkness; floaters; colour perception; contrast; blurred vision; field of vision; one or two eyes affected; vision influenced by medication
Code 1.02 Symptoms: pain and discomfort	Differences between patients: range from no pain at all to unbearable pain; numb / mushy feeling / burning feeling; contraction of muscles; red eyes; light sensitivity; fatigue; tearing eye; dry eyes; distinction between long or short time since diagnose; not visible for social environment
Code 1.03 Comorbidity	Differences between patients; cause of symptoms unclear due to comorbidity; influence of comorbidity on stability of uveitis; differences in diagnostic trajectory due to comorbidity
Code 1.04 Medication use and side effects	Diversity in kind of medicines, types and dosages; self-initiated start of medication; wrong medication; lifelong use of medication; medication in consultation with doctor; knowledge about side effects results in calmness; side effects; long term effects of medicines; individual differences in medication preferences; (no) medication use as treatment outcome
Theme 2. Diagnosis and treatment process	
Code 2.01 Recognition / diagnostic process	Diagnosis after a lot of examination; start with wrong diagnosis; diagnosis by coincidence; diagnosis by other specialist; slow referrals from general practitioner to specialist; fast referrals from general practitioner to eye hospital; general practitioner / hospital / acute care unit / doctor in training is unknown with uveitis; wrong diagnosis and wrong medication; adopt uveitis in protocols
Code 2.02 Easy access to treating specialist	Time consuming to get to see own doctor; short consultation – face-to-face or by phone – saves a daypart in the hospital; unnecessary disease burden through bad accessibility of doctor (time, examinations, daily function); knowledge about uveitis is limited at acute care unit and by doctors in training; patient records are badly read at acute care unit; lack of central point of contact or coordinator; gives peace of mind if you know you can reach someone in case of emergency; self-initiated start with medication because doctor is not available
Theme 3: Impact on daily functioning	
Code 3.01 Employment	Differences between patients; ranging from lost their job to being fine with fulltime job; work adjusted; no responsive work environment

Table 2 Continued.

Code 3.02 Sports	No influence on sport; see ball too late; sports glasses; pain during exercising
Code 3.03 Mobility	Limited mobility; complaints dependent on weather conditions; can bike / cannot bike; cannot drive a car
Code 3.04 Watching TV / reading	Difficulties with reading; difficulties' with watching TV
Code 3.05 Dependency	Need others to help travelling, small jobs in the house.; lifelong dependency of medication; dependency of glasses
Code 3.06 Relationships	Much understanding and social support; disorder is trivialized; difficulty in explaining the disease; not visible
Theme 4: Emotional impact	
Code 4.01 Uncertainty: inflammation or not?	Some patients clearly recognized an inflammation, others absolutely not; getting experienced in symptom recognition through the years; barrier to contact doctor because of doubts about having an inflammation; panic
Code 4.02 Uncertainty: future	Long term effects of medication; development of uveitis in future; fear of becoming blind; inheritability; fear that both eyes get affected; not getting better, only worse; or no worries about future
Code 4.03 Uncertainty: cause complaints	Cause is unknown, treatment cannot be focused on cause; differences between patients with or without underlying cause or comorbidity; more research into the cause of uveitis; different opinions about association food and symptoms; stress increase as a cause of symptoms
Code 4.04 Stress	Not being taken seriously by healthcare providers; accessibility of own doctor; barriers in daily functioning; uncertainty
Theme 5: Treatment success factors	
Code 5.02 Outcome improvement	Vision; quality of life
Code 5.01 Stability	Variety in the degree of stability; gladness when uveitis is stable; stability influenced by medication; stability is cycloid
Code 5.03 Shared decision making	Type of medication and side effects are important topics; doctor takes time and has knowledge; patient prepared for consultation; not always room for discussion; not own doctor following protocol no room for initiatives of patient; an intermediary such as rheumatism practitioner would be nice

Theme 4 emotional impact

Patients highlight several emotional consequences of chronic uveitis. A main topic is the uncertainty patients experienced because of the unpredictability of the disease. We distinguished three different kinds of uncertainty. The first is uncertainty about the inflammation. Some patients could clearly recognize an inflammation, while others were unable to do so. Patients who experience difficulties in recognition made remarks like: "But in this case: do I have it or not? And then you cross that threshold to go to a doctor. That for me is the uncertainty." Secondly, there is uncertainty about the future: the long-term effects of medication, the development of chronic uveitis, the fear of becoming blind and questions regarding inheritability. For instance, a patient said: "That is really the rottenest thing I have, I think. Most frightening […] and uh, yes, I am afraid that my other eye, my good eye, will be like that too." Lastly, patients perceive uncertainty about causes of complaints. It involves doubt about whether it is the uveitis that causes certain complaints or whether those results from a comorbid disorder. In addition, patients often named stress as an important factor. The emotional stress may be caused by the feeling of not being taken seriously by health professionals, by lack of timely access to their own ophthalmologist, by experienced barriers in daily functioning, or by the dependency caused by the chronic uveitis.

Theme 5 treatment success factors

Treatment success factors emerged as a fifth theme. Patients perceived three main treatment success factors: 1) outcome – in terms of improvement in vision and/or quality of life; 2) stability – in terms of happiness when the uveitis is under control; and 3) the degree of shared decision making between patient and ophthalmologist - in terms of having enough time for consultation, sharing knowledge and experiences, and being able to exert influence on decision making on medication use. To illustrate stability, one patient mentioned: "eh I also see my treatment as very successful. It has taken eight nine years, continuous bleeding, flares and inflammations in my eye. Nerves and it all. That has now completely calmed down. No bleeding, no inflammation. So, I am a happy person." Medication use and side effects were important topics in shared decision making. Patients noticed that shared decision making was not always there, whereas they would have liked otherwise to experience their treatment as successful. Cohesion between themes and codes The cohesion and inter-relations between themes and codes is depicted in Fig. 1. Medication and side effects is placed in the middle indicating its central role. It is closely related to accessibility and shared decision making. This is because (questions about) medication use are an important reason for the desire for easily accessible care and an important topic during consultations according to patients. Further, it is notable that codes belonging to one and the same theme are clustered close together, which indicates the uniformity of defined themes (see Fig. 1).

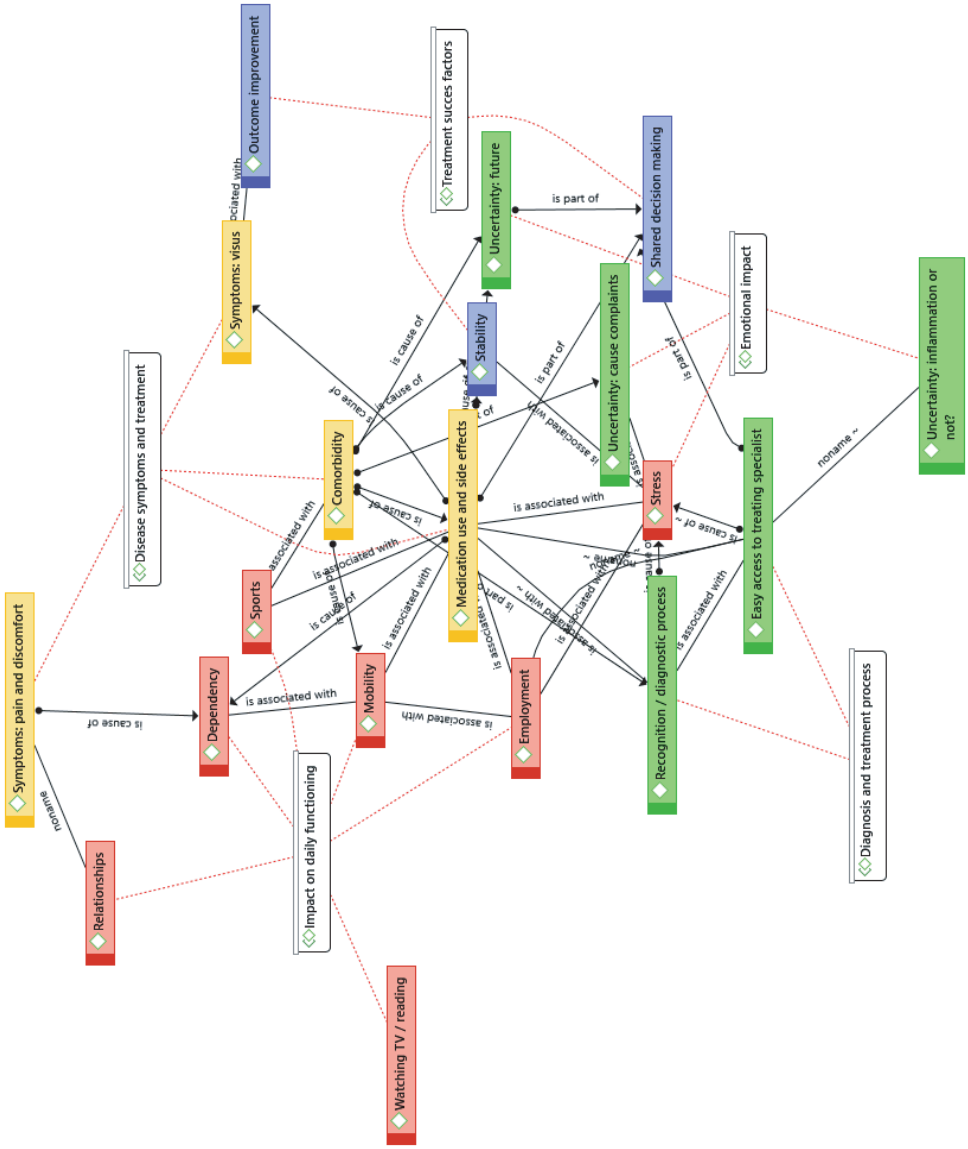

Figure 1. A summary model depicting the relationships between themes and codes

Lastly, we noticed that the code stress came up in between codes across various themes underwriting the importance of stress due to chronic uveitis in patients' daily life.

Additional external validation

Six members of the uveitis patient division of the Dutch Eye Patient Association took part in the additional external validity check to maximize validity (Table 3). Results were in line with our findings and no new topics came up.

Table 3. Patients' characteristics of members from uveitis patient association involved in validity check

	Total
N	6
Women, n (%)	4 (67)
Age in years, mean (range)	55 (43 - 67)
Years since diagnosis, median (range)	12 (2 - 30)

DISCUSSION

This study shows a conceptual model with five themes that patients with chronic uveitis consider to be of importance when evaluating the impact of their disease and treatment: disease symptoms and treatment, diagnosis and treatment process, impact on daily functioning, emotional impact, and treatment success factors. Therefore, we recommend these five themes to be included in the development of future uveitis specific measures in adults.

Considering how these themes relate to the most frequently used instruments, SF-36 and VFQ-25, we notice that they only partly cover the patient perspective. The generic SF-36 may measure the theme 'impact on daily function' accurate yet fails to cover uveitis-specific outcomes in the themes 'disease symptoms and treatment', 'diagnosis and treatment process', specific 'emotional impact', and 'treatment success factors'. Next, even though the VFQ-25 distinguishes 11 vision-related subscales, this instrument also fails to address the themes 'diagnosis and treatment process', 'emotional consequences' and some of the 'treatment success factors' found to be of significance for chronic uveitis by adult patients. Our findings therefore reveal that - in addition to clinical and quality of life outcomes - process factors are also relevant when measuring the impact of this complex and variable condition from a patient perspective.

Next to our main results, there are several findings worth further consideration. First, we note that access to an uveitis specialist familiar with the patient appears highly valued

by patients. A trained coordinator may be beneficial to this purpose. Such a person may have added value in improving accessibility, the interdisciplinary monitoring of disease-activities, ensuring timely and accurate referral and the management of in-between visits questions that do not require a visit to the clinic. A second finding worth highlighting is the uncertainty patients experience about short- and long-term disease outcomes. Providing information and clear communication on these matters may help patients to better prepare for the sometimes capricious disease course of chronic uveitis. A third finding for further consideration relates to the difficulties patients experience in coping with prolonged medication. Our findings suggest that better alignment with patients about risks and benefits of specific types and dosages of medication may provide patients with more control and understanding of their treatment. That may have a positive effect on how patients evaluate the outcome of their treatment, as shared decision making about medication can increase patients' satisfaction [23]. This being said, we note that shared decision making in case of chronic uveitis can be complicated by the limited number of prospective randomized controlled trials studying the various systemic medication treatments and the complexity of the disease.

A major strength of this study was the diversity of patients who were selected by stratified sampling from patients' records. The methods used ensured that a wide variety of chronic uveitis patients were included in the focus groups. However, we also note that by deliberately making heterogeneous groups, comparing results between subgroups becomes complex. A limitation of this study is therefore that we can only report about the heterogeneous group of chronic uveitis patients as a whole and not about subgroups e.g., patients diagnosed with ocular sarcoidosis or Birdshot retinochoroidopathy.

In conclusion, we have proposed a conceptual model containing five themes that are important when evaluating the impact of chronic uveitis in adult patients. These themes with their underlying codes can be used to develop a disease specific measurement instrument for adult chronic uveitis patients. With such an instrument patients' disease experiences can be monitored and used to further improve the care provided and their quality of life.

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APPENDIX 1. TOPIC LIST FOCUS GROUP

1. Welcome and introduction
2. Discussion
   - Which complaints of uveitis do you experience or have you experienced? And which complaints do you experience as most stressful?
   - What impact do these complaints have on your daily life and functioning?
3. Break
4. Continue discussion
   - What do you think are success factors in the treatment?
   - What do you hope to achieve with the treatment you are undergoing or has undergone?
   - When are you satisfied with the care provided? When do you consider your treatment as successful as possible?
5. Closing

APPENDIX 2. FINAL STRUCTURED ANALYSIS MATRIX

Themes	Codes
Disease symptoms and treatment	Symptoms: vision
	Symptoms: pain and discomfort
	Comorbidity
	Medication and side effects
Diagnosis and treatment process	Recognition / diagnostic process
	Easy access to treating specialist
Impact on daily function	Employment
	Sports
	Mobility
	Watching TV / reading
	Dependency
	Relationships
Emotional impact	Uncertainty: inflammation or not?
	Uncertainty: future
	Uncertainty: cause complaints
	Stress
Treatment success factors	Stability
	Outcome improvement
	Shared decision making

CHAPTER 3

A digital patient-led hospital checklist for enhancing safety in cataract surgery: qualitative study

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ABSTRACT

Background

Surgery holds high risk for iatrogenic patient harm. Correct and sufficient communication and information during the surgical process is a root solution for preventing patient harm. Information technology may substantially contribute to engaging patients in this process.

Objective

To explore the feasibility of a digital patient-led checklist for cataract surgery, we evaluated the experiences of patients and nurses who have used this novel tool with a focus on use, appreciation, and impact.

Methods

A multidisciplinary team, including cataract surgeons, nurses, pharmacists and administrative representatives developed a 19-item digital patient-led checklist for cataract patients who underwent surgery in an ambulatory setting. This "EYEpad" checklist was distributed to patients and their companions during their hospital visit via an application on a tablet. It contained necessary information the patient should have received before or during the surgical preparation (8 items), before anesthesia (2 items), and before discharge (9 items). Patients and their companions were invited to actively indicate the information they received, or information discussed with them, by ticking on the EYEpad. Our qualitative research design included semi-structured individual interviews with 17 patients and a focus group involving 6 nurses. The transcripts were analyzed by 2 independent coders using both deductive and inductive coding.

Results

All but one of the 17 patients used the EYEpad, occasionally assisted by his or her companion (usually the partner). In several cases, the checklist was completed by the companion. Most patients felt positively about the usability of the EYEpad. Yet, for most of the patients, it was not clear why they received the checklist. Only 4 of them indicated that they understood that the EYEpad was used to determine if there were sufficient and correct information discussed or checked by the nurses. Although most nurses agreed the EYEpad was easy to use and could be a useful tool for improving patient engagement for improving safety, they felt that not all elderly patients were willing or capable of using it and it interfered with the existing surgical process. They also anticipated the need to spend more time explaining the purpose and use of the EYEpad.

Conclusions

Our results showed that a digital patient-led checklist is a potentially valid way to increase patient participation in safety improvement efforts, even among elderly patients. It also illustrates the crucial role nurses play in the implementation and diffusion of technological innovations. Increased patient participation will only improve safety when both healthcare workers and patients feel empowered to share responsibility and balance their power.

INTRODUCTION

Health care delivery is too often not "free from accidental injuries," according to the Institute of Medicine definition of patient safety [1]. In Dutch hospitals, about 2.6% patients die and 1.6% are harmed annually due to preventable, unnecessary actions [2]. The associated costs are estimated at 0.5% of the national hospital care budget and, since only direct costs were considered, this calculation is likely an underestimation of the real costs [2].

Surgery is a high-risk area for iatrogenic patient harm [3,4]. Iatrogenic harm is the unintended or unnecessary harm or suffering arising from any aspect of the health care delivery besides the patient's condition [3]. Errors that cause iatrogenic harm to patients should be mitigated before they can cause harm [3].

The last decade has seen increasing awareness and focus on patient safety [5-9]. Traditionally, patient safety has been viewed as the sole responsibility of health professionals with patients as passive recipients. Nowadays, patient participation is increasingly being recognized as a key component in the improvement of health care since, in contrast to health care staff, patients are around during all steps of the care pathway [10-13]. However, few studies show patients as active participants in safety efforts, and these studies mostly focus on listening well and speaking up when concerned [14-17].

Communication between patients and professionals is a major issue in safety [18]. The handover of information from professional to patient is critical for successful recovery after surgery and compliance with postsurgical instructions [19]. Studies have shown that a lack of communication between patients and professionals in surgical care resulted in less optimal outcomes [18,20]. Insufficient and contradictory postsurgical information on health status and patient behavior requests are major safety issues.

Although it is known that communication of the "right things" at the "right moment" is important for preventing iatrogenic patient harm, it is difficult to optimize this process because patients are concerned with many things during their care pathways. Information technology may substantially contribute to engaging patients in activities to improve patient safety [21,22].

To increase patient participation in enhancing safe care, we developed an online checklist called the EYEpad for cataract patients to be used during their admission. Cataract surgery involves removal of opaque lens and replacement with an implanted artificial intraocular lens (IOL) is the most frequently performed surgery in the world [23]. The

feasibility of this checklist—in terms of utilization, appreciation, and impact—according to patients and nurses has not yet been determined. To explore the feasibility of the digital checklist for cataract surgery, we evaluated the experiences of patients and nurses who have used the checklist at the Rotterdam Eye Hospital in the Netherlands.

METHODS

Design

We used a qualitative approach to explore patients' and nurses' experiences with the digital EYEpad checklist. The definition of semistructured interviews by Green and Thorogood is "In a semistructured interview, the researcher sets the agenda in terms of the topics covered but the interviewee's responses determine the kinds of information produced about those topics, and the relative importance of them" [24]. At appointments, we conducted semistructured interviews with patients and their companions, and a focus group with nurses.

Setting

Participants were recruited at the Rotterdam Eye Hospital, the only eye hospital in the Netherlands providing secondary and tertiary eye care. The hospital has a specialized ambulatory cataract pathway where about 6500 cataract surgeries are performed annually.

Intervention: the EYEpad

Patients often had questions about how to care for their treated eyes after discharge from the hospital. To prevent this, initially a paper card was designed to relay information to patients before their discharges. The card served as a memory aid for nurses to inform patients about these points, but was rarely used. Subsequently, a checklist for patients was designed. A multidisciplinary team, including cataract surgeons, nurses, pharmacists, and administrative representatives developed a 19-item patient-led checklist for cataract patients who underwent surgery in an ambulatory setting. The items were based on a review of nurses' current, often inconsistent, and not formally acknowledged, check moments. An initial gross-list of more than 30 items was reduced to 19, all of which were agreed upon by the multidisciplinary team. The checklist was first tested on paper by patients and later modernized into an application for the tablet called EYEpad. This checklist was distributed to patients and their companions via the application EYEpad, on a tablet, during their hospital visits. It contained 3 lists with necessary information the patient should have received during three contact moments with medical professionals on the day of their surgery: before or during surgical preparation (8 items), before

anesthesia (2 items), and before discharge (9 items; see Figure 1 for the screenshot of the subchecklist and Textbox 1 for all 19 items).

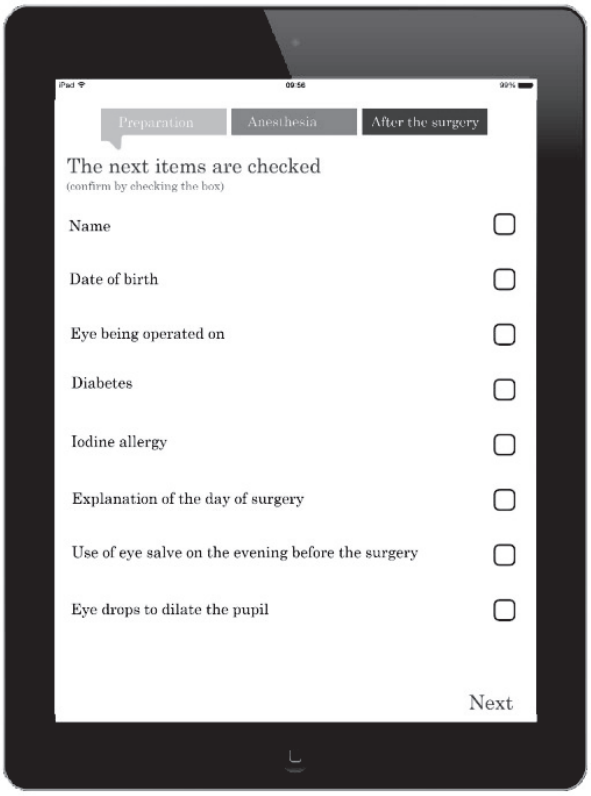

Figure 1. Overview of the first subchecklist (preparation), containing information on specific events in the care pathway.

The EYEpad is handed to the patient on the day of the surgery. The patient is supposed to indicate whether the predefined information on the checklist was discussed with the nurse. Based on this checklist, the patient is expected to address the nurse regarding the missing items. The checklist is also used by the nurse, to confirm whether all information has been addressed in a consistent manner. While the nurse checks the list, he or she can provide missing information for the patient and perform a formal acknowledgment ("check"). Finally, the patient can add his or her own questions to ensure that these questions are addressed during the dismissal conversation. Patients could also use the tablet for other general, educational, or entertainment functions, such as news services and games.

Box 1. Overview of the 19-item checklist.

I Preparation phase (8 items):
- Patient name
- Patient date of birth
- Eye to be operated on
- Diabetes status
- Iodine allergy status
- Explanation on day of surgery proceedings
- Explanation on eye balm application on eve of surgery
- Explanation of dilatation drops

II Anesthesia phase (2 items):
- Time-out
- Anesthetic eye drops

III Postsurgical phase (9 items):
- Review of surgical proceedings
- Pain assessment
- Postsurgical patient flyer
- Availability and application of eye drops at home
- Postsurgical telephone review (date and time)
- Removal of eye bandage
- Checking of pupil size and form
- Photo surgical team
- Eye drop application information and training

Participants

Patients During a period of two weeks, patients who were scheduled first and last in the morning and in the afternoon were approached to participate in the study. A registered nurse recruited participants according to the following inclusion criteria: (1) age older than 18 years, (2) first cataract surgery, (3) ability to understand Dutch, (4) absence of severe comorbidities, and (5) absence of mental or cognitive disorders.

The selected patients were approached by phone one day before their hospital visit. Patients were given information about the study and asked whether they wished to participate. It was emphasized that participation was voluntary and their decision about participating in the study would have no effect on their treatment. When patients agreed to participate, the researcher fixed a time for a short interview at the hospital immediately after the patient's discharge.

Nurses The ambulatory surgical center (ASC) manager invited all nurses to a regular department meeting and allowed the researcher to use a part of the meeting for a focus group.

Measurements

Participant Interviews Prior to the interview, the participants provided informed consent for participation and for tape recording of the interview. All interviews were conducted by a trained psychologist (JVDS). Interviews took an average of 10 minutes and took place in a separate room, behind closed doors, to preserve the patient's privacy.

During the interviews, an interview guide with 24 open-ended questions, derived from published literature and in consultation with staff members of the hospital and the University of Twente, was used. The interview questions focused on (1) EYEpad utilization: "Did you use the EYEpad?"; (2) appreciation of the EYEpad: "What did you like/dislike in the EYEpad?"; and (3) impact of the EYEpad: "What does feeling safe in a hospital mean to you?" Patients were asked explicitly to motivate and support their answers. All interviews were audiotaped. Ethical approval was obtained from the ethics committee of the University of Twente (#13196).

Focus Group with Nurses Prior to the focus group session, the nurses were asked to complete a 10-item questionnaire. This questionnaire was intended to stimulate the participants to think about the topics discussed during the focus group. We chose this approach to prevent group thinking by the participants.

All nurses were asked to provide consent for participation and tape recording of the focus group. The focus group lasted 60 minutes. During the focus group session, a script with open-ended questions, derived from published literature and in consultation with staff members of the hospital and the University of Twente, was used. The questions focused, as they did during the patient interviews, on (1) EYEpad utilization: "What instructions did you give to patients during handover of the EYEpad?"; (2) appreciation of the EYEpad: "What do you consider to be positive and negative aspects of the EYEpad?"; and (3) impact of the EYEpad: "What do you consider as benefits of the EYEpad?". Finally, the focus group addressed (4) the future of the EYEpad: "What needs to be changed for sustainable use of the EYEpad?" The minutes of the meeting were included in the analysis.

Data analysis

The audiotaped data from the interviews was transcribed verbatim. Transcripts were deductively coded into one of the three main categories: utilization, appreciation, and perceived impact. Next, the fragments in each category were further divided into

subcategories, using inductive analysis, meaning the categories were inferred from the data, rather than from the existing literature. Coding was conducted by 2 coders (JVDS, AS). Differences were discussed until a consensus was achieved [24].

RESULTS

Description of participants

From the 32 selected patients, 19 patients met the inclusion criteria. Seventeen patients accepted the invitation to participate in the study. Two patients refused to participate because they did not feel well enough to be interviewed after their surgeries. Eleven out of 17 (65%) patients were female. The average age was 69 years, ranging from 58 to 88. Almost all patients were accompanied by their partner (n=12) and others by their daughter (n=2), son (n=1), or another relative (n=1). One patient was not accompanied by a companion.

Six of the 18 registered nurses participated in the focus group. All nurses were female (n=6). The average age of the nurses was 46 years, ranging from 20 to 57. Most nurses (n=4) worked at the ASC for at least 5 years.

Description of themes

Three themes emerged from the data analysis: utilization, appreciation and impact. The subthemes that belong to these themes can be found in Appendix 1.

Utilization of the EYEpad

Patients All but one patient used the EYEpad. In several cases (n=9), the EYEpad checklist was completed by the companion as the patients could not clearly see because their eyes were dilated or their reading glasses were stored in a locker. The companions only entered the patients' answers.

I have completed it, but yes, actually I have only pressed the buttons. You have completed the answers.

Companion 3

Three patients completed the EYEpad on their own because they were more familiar with a tablet than their companion was. One patient and his companion did not use the EYEpad because they were not familiar with the use of a tablet device.

Most did not completely understand why they received the EYEpad. They took the EYEpad without further enquiries and assumed it was part of the hospital administration

or it was for quality improvement. In only four cases, respondents indicated that the EYEpad was meant to validate if all necessary information was given to the patients and if nurses checked important information for patients' safety.

[Silence] No, I assume things automatically; they need to know who you are, and they repeat that often. [Silence] I think that's part of the administration.

Patient 1

Besides using the EYEpad application, patients and their companions could use other functionalities on the tablet, like the web browser, playing a game, or watching movies. One patient read the news on the internet, to relax, before her surgery.

Yes, I have checked the news that was available, so I had something to read...That killed the waiting time, so I enjoyed it.

Patient 17

The others did not use the other functionalities on the tablet because they were unfamiliar with tablet functions or did not feel a need for it.

…And I was afraid that there was just one application [the EYEpad app], so I thought, yes [laughs], keep it like this, it is functioning well now, and I should not peddle someone else's tablet.

Patient 2

During the surgery, I have watched the [intraocular live viewing] monitor, so you don't need the iPad [tablet] at that time.

Companion 3

Fourteen participants, who already knew how to use a tablet, reported that the EYEpad was easy to use. However, some difficulties were experienced. First, some respondents reported that it was hard to fill in their birth date because the scroll menu moved fast. Second, some respondents did not understand the jargon used in the EYEpad, for example, "*time-out*." Further, it was not clear to all respondents when to use specific checklist tabs, considering there were 3 different tabs. Lastly, one respondent reported there was little time between the nurses' explanation and the use of the EYEpad; this patient did not have sufficient time to open the EYEpad and get used to it before he had to use it.

Yes, especially for that age, it was taking an aim.

Companion 2

Yes, that's right [laughing], a kind of roulette, as it kept on rotating.

Patient 2

When asked whether the participants preferred the version of the EYEpad on the tablet or on paper, 14 participants preferred the digital version because of the usability and ability to save data.

It is easy to complete, briefly touch and a checkmark appears.

Patient 11

Two participants preferred a paper questionnaire above a tablet; both reported low eHealth literacy. Both participants were females. One female was aged 82 and was accompanied by her daughter, and the other female was 72 years old and accompanied by her partner.

Nurses Five of the 6 nurses provided the EYEpad to all patients, except when the patient did not have a companion or when the patient was very old. However, during the focus group, there was a discussion as to whether a patient could be "too old".

When someone is very old, I don't offer him an EYEpad.

Nurse

But some elderly are very good with tablets, so I think that's no reason to not give it to an elderly patient.

Nurse

Yes, indeed, some elderly are able to handle the EYEpad, and like it very much, so age should not be a discriminator.

Nurse

Some see you approaching them with the piece, and they don't look very happy.

Nurse

Another reason for not providing the EYEpad was the workload experienced by the nurses. The nurses were unanimous that the EYEpad was subordinate to their primary work: treating patients.

Sometimes you need to assist a colleague, or sometimes you are very busy, or something else needs your attention; the EYEpad is then the first to neglect or skip.

Nurse

Five nurses mentioned that they found it hard to give the correct explanation when they provided the EYEpad to a patient. This was caused by different reasons. They referred to the busy schedule and the number of patients around during the provision of the EYEpad. Also, the perceived patient knowledge of the tablet played a role.

If it's very busy, it's difficult to give a proper explanation. You have less time.

Nurse

If the patient is familiar with an iPad, the instructions can be done fast because you don't have to explain how an iPad works.

Nurse

Although nurses were generally positive about the EYEpad usability, they noticed, just like the patients, a few difficulties. First, it was not clear which action was related to the term "*anesthetic drops* " on the second tab of the checklist.

I just still do not understand fully what must be ticked at "anesthetic drops." Is that the moment that we tell the patient they receive anesthetic drops and show which ones? Or is it the moment that we give the anesthetic drops?

Nurse

Second, it was unclear why only "iodine allergy" was in the checklist because other allergies of the patients were also important to know. Finally, they noticed it was not always easy to go back to the top of the checklist when the checklist was finished.

Appreciation of the EYEpad

Patients The EYEpad was well appreciated by patients and companions. Most of the respondents reviewed the EYEpad as *"good"* or *"fine"* (n=12). They especially appreciated the checkpoints. Both patients and companions indicated they felt more involved in the health care process on using the EYEpad.

Well, I thought it is an extra check, for you can't check these things (eg, eye to be operated on) often enough.

Patient 2

We now need to think ourselves, and that was, ehh, you are more involved at least.

Companion 13

Nurses Most nurses did not appreciate the EYEpad for two reasons. The first reason was that the EYEpad caused some agitation for both patients and nurses. According to the nurses, some elderly patients were scared they had to use a tablet. Agitation was also experienced when the patients' companions moved from the waiting room to the preparation room to complete the second checklist.

What I have experienced as troublesome is that the companions of the patients now more often move to the preparation room taking their entire possessions, because they have to complete over there a second list. This is not really the intention and creates a lot of agitation.

Nurse

Yes, indeed, previously the companion came just along to the preparation [room] as a patient had some degree of anxiety, but now they all come in to complete the checklist.

Nurse

The second reason why not all nurses appreciated the EYEpad was because it was time-consuming.

The provision and explanation of the EYEpad still just takes a lot of extra time. It is not always the case that you are there with a short explanation, because most of the patients have several questions about it, such as how it exactly works.

Nurse

They also mentioned positive aspects of the EYEpad. First, the use of the EYEpad improved the reputation of the day center.

It seems luxurious and very modern.

Nurse

Second, they thought it was nice that younger patients were fine with the EYEpad. Third, they were generally positive about the usability. Most of the nurses (n=4) mentioned that the EYEpad was easy to use. Two mentioned that, although they were not completely familiar with a tablet, they always resolved it together with a colleague.

I think it is sometimes still quite a bit of a search, even though I know how an iPad works, but fortunately,you will always bring it to an end.

Nurse

Impact of the EYEpad

Patients Most patients saw no safety benefits associated with using the EYEpad (n=10). They did not know the purpose of the EYEpad. Six patients, however, thought the EYEpad could contribute to safety because of all the extra data checks.

Uh, that the EYEpad would help for safer care, here, in the hospital? Well, no, I really don't see that link directly.

Patient 5

Yes, that would be possible, I think, or yes, I do not really know. What do you [companion] think?

Patient 10

Yes, you know, it certainly can, as long as the nurse still take[s] care of those points [unchecked items on the checklists].

Patient 4

Nurses According to the nurses, the contribution of the EYEpad to safety is not yet known. They felt time they spent on the EYEpad was too short to evaluate its contribution to patient safety. They were still uncomfortable with the EYEpad and felt their explanation to the patients was still suboptimal. The nurses named several impact factors associated with the EYEpad. First, they reported that the EYEpad had a positive influence on the empowerment of patients. The patients were more involved in their care process, more alert, and more conscious of their own responsibility.

The patient is more involved in his or her surgery process by the EYEpad.

Nurse

By the EYEpad the patient becomes more alert and sees more things during the care process.

Nurse

With the EYEpad you make the patient and his or her companion more aware of their own responsibility.

Nurse

Second, the EYEpad had a positive impact on the patients' companions because the companions could use the other functionalities of the tablet to relax. Further, the EYEpad influenced the interaction between patients in a positive manner.

If a patient does not understand the EYEpad or encounters a problem, patients help each other. This creates more contact between patient and companion. Perhaps this also reduces the patient's anxiety.

Nurse

Next, the EYEpad could have a negative impact on patients and their companions because they could get distracted by the EYEpad during intake, get surprised following presentation of the EYEpad, and companions could feel obligated to the patient.

If you give the tablet, people go straight to work with the tablet, therefore people pay less attention to the nurse.

Nurse

Patients do not yet know anything about the EYEpad when they arrive at the day center on the day of their surgery. It can overwhelm them.

Nurse

Some patients often do not dare to say they do not like it [tablet], because we [nurses] offer them from the hospital, and therefore they think that it is obligatory.

Nurse

Companions are more concerned with the iPad [tablet] than with the patient, making the guidance or support falls away.

Nurse

Lastly, the EYEpad may worsen the supportive role of the companion if the companion gives more attention to the tablet than to the patient.

DISCUSSION

Principal findings

This study showed that the use of the EYEpad as a digital patient-led checklist in cataract surgery is feasible. Feasibility has been demonstrated in three ways. First, the EYEpad was well appreciated by patients. Patients were positive about the additional checks and felt more involved in their care processes. Second, we found the EYEpad, beside some practical difficulties, was easy for patients and nurses to use. Third, we found that the EYEpad helped patients feel empowered.

However, there remains room for improvement. The EYEpad, with its current instructions, can increase nursing workload. Furthermore, an improved introduction on the rationale and use of the digital checklist is needed because the purpose of the EYEpad was not always clear to the participants. Improved instructions are likely to further enhance patient experience, increasing patients' abilities to understand and influence their own care. This was suboptimal in this study because some patients participated just because the EYEpad was handed to them and not because they were motivated to use it.

Limitations

This study had several limitations. One limitation was that we held just one focus group with nurses. More focus groups could have yielded more information about the nurses' viewpoints. Moreover, participation in the focus groups was voluntary and in the end, only 6 of the 18 nurses participated. The nurses who participated likely held viewpoints that differed from nurses who did not participate.

Another limitation was that the purpose of the EYEpad was not clear to all patients and nurses at the start of the study. Only 4 patients indicated they understood the purpose of the EYEpad. This may be due to the limited explanation the nurses gave about the checklist. Apparently, a more elaborate explanation is needed to better understand the purpose of the EYEpad, both for patients and nurses. Previous work has suggested the success of checklist implementation largely depends on a clear explanation of the "why" and "how" [22]. A better understanding of the "why" in this study could further improve the feasibility.

Further, although we inquired as to patients' general experiences with the EYEpad; we did not explicitly address electronic health (eHealth) or health literacy during this study. Therefore we cannot be sure that needs related to EYEpad use were specifically addressed.

Comparison with prior work

In our study, the checklist was patient-led instead of team-led. We found this helped to empower the patients in their own care pathways. We suggested two possible explanations for why patients felt more empowered by using the EYEpad. First, patients may feel more engaged in their own care process. Using health technology makes patients feel more involved in their own care [25]. As indicated by Horwitz and Greysen et al, knowledge alone is not sufficient for proper self-care after surgery [26,27]. Hospitals need to facilitate a good transition, and recovery at home will improve, if patients and caregivers jointly explore patient-centered strategies.

Aujoulat et al. described the success factors for patient empowerment. They found that the basics of patient empowerment were to provide reassurance and opportunities for self-exploration on how to manage illness [14]. Second, patients may experience a smaller gap between care professional and patient, which could help them discuss personal questions or issues that may interfere with their treatment.

Besides empowerment, we also found that the EYEpad increased patient participation. Checklists are supplementary tools that encourage critical thinking and conversation [22]. The EYEpad may help patients engage in their own care. It can ease barriers to preventing harm—for example, not speaking up in the case of suspected errors. A study has shown that communication problems are the root causes of wrong IOL implants in cataract surgery [28]. In New York State, wrong implant-related errors account for 63% of the total number of malpractice claims, and data from Veterans Health Administration showed that approximately half of surgical errors were attributed to the use of the wrong implant [29]. Increased patient empowerment and participation using the checklist can prevent IOL-related errors and thereby improve patient safety.

A surprising finding was that nurses experienced the checklist as "extra work" instead of as a supportive tool for their daily tasks. This may be because the goal of the checklist was not clearly explained. Furthermore, not all nurses were involved in the development of the checklist, which may have made them feel less engaged.

Learning points

Before further development of the EYEpad, some hurdles should be addressed. These include providing clear instruction on the rationale for the professionals involved and an improved introduction and explanation of the purpose of the checklist for patients. Communication about the objective of the new digital technology, both with health care staff and patients, is a vital element for successful implementation. It is important to include nurses and other health care professionals from the early idea generation stage,

into development and iteration, to generate support and interest. Communication about the objective of the EYEpad must be clear, both to nurses and to patients. Further, our study showed that the practical implication involved listening closely to the care pathway: Which moments are best for the digital EYEpad checklist to be distributed given the planning of the surgical treatment flow? In the current process the use of the EYEpad sometimes disrupted the existing flow, when it should have contributed to a smoother and high-quality care process.

After these hurdles have been considered, the EYEpad can be further developed and implemented. We found that the EYEpad could encourage learning, for example by conscious information acquisition by patients. We did not give specific attention to eHealth and health literacy of participants. More attention to eHealth and health literacy may improve the level of learning.

Further, the checklist should relate to the various steps of the current care process. The better the checklist is implemented, the more structural value it will add toward patient participation in enhancing safe care. It would be useful to make a connection between the checklist and the patients' records to give the professionals insight into the data in a more accessible way. In addition, future studies should make a connection between the checklist and other patient tools to give patients a more complete overview of their care process.

CONCLUSION

In conclusion, we showed that a digital patient-led checklist during surgery was a feasible instrument in cataract care. Our findings suggest that a digital checklist could increase health literacy and provide enhanced guidance on the day of surgery. Our results also demonstrated the crucial role nurses play in the logistics of technological innovations. Increased patient participation will only improve safety as both health professionals and patients feel empowered to share responsibility and balance power.

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APPENDIX 1. THEMES AND SUBTHEMES

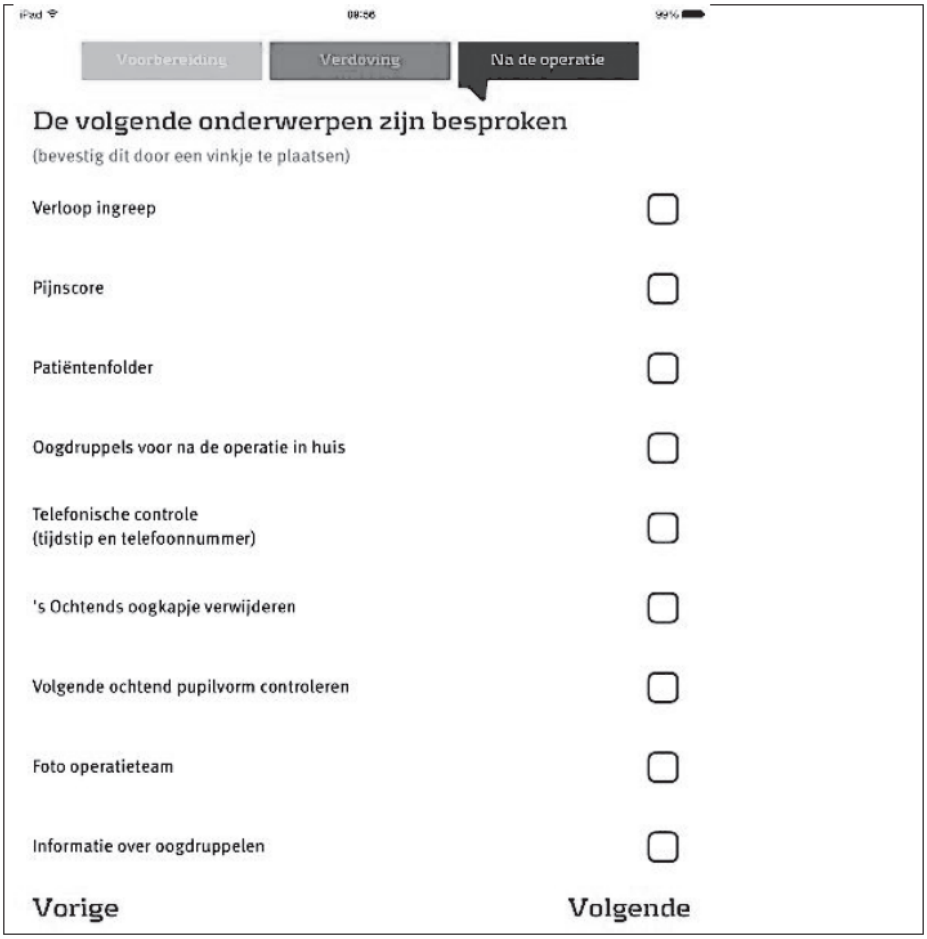
1. Utilization
   - Completed by patient / companion
   - Acceptation of EYEpad
   - Use of other functionalities
   - Experienced difficulties
   - Paper or tablet

2. Appreciation
   - Positive points
   - Negative points

3. Impact - Safety in healthcare
   - Goal of EYEpad
   - EYEpad and safety

APPENDIX 2. 19-ITEMS CHECKLIST (IN DUTCH)


iPad
09:56
99%
Voorbereiding
Verdoving
Na de operatie
De volgende onderwerpen zijn besproken
(bevestig dit door een vinkje te plaatsen)
Time-out
Verdovingsdruppels
Vorige
Volgende


iPad
08:56
99%
Voorbereiding
Verdoving
Na de operatie
De volgende onderwerpen zijn besproken
(bevestig dit door een vinkje te plaatsen)
Verloop ingreep
Pijnscore
Patiëntenfolder
Oogdruppels voor na de operatie in huis
Telefonische controle
(tijdstip en telefoonnummer)
's Ochtends oogkapje verwijderen
Volgende ochtend pupilvorm controleren
Foto operatieteam
Informatie over oogdruppelen
Vorige
Volgende

CHAPTER 4

Effects of clinical parameters on patient-reported outcome in cataract patients: a multicentre study

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ABSTRACT

Purpose

Ophthalmologists tend to evaluate the results of cataract surgery by focusing on the clinical visual and refractive outcomes and the incidence of complications, where patients' main interest might be their ability to perform daily activities. Therefore, there appears to be a need for optimizing effective communication between patients and ophthalmologist about the outcome of cataract surgery. The aim of this multicentre study was to determine the effects of whether the surgery was performed in one or two eyes, ocular comorbidity and per- and postoperative complications on visual function experienced by patients measured with the Catquest-9SF.

Methods

To measure patient-reported outcomes, Catquest-9SF data were collected between 2014 and 2015 in five Dutch hospitals. Data from 870 pairs of questionnaires – completed before and after cataract surgery – were compared with clinical data. Clinical data, retrieved from patients' medical files, consisted of one or two eye surgery, ocular comorbidity and per- and postoperative complications.

Results

Quality of vision improved more in patients who had surgery in both eyes and had fewer postoperative complications (both $p < 0.001$). We found a nonsignificant trend that quality of vision was worse when ocular comorbidity was present. No significant effect of peroperative complications was observed.

Conclusion

Our results emphasize the added value of the Catquest-9SF as a tool for visual function experienced by patients; the additional information can complement clinical parameters to improve patient-centred approaches in clinical practice.

INTRODUCTION

Ophthalmologists tend to evaluate the results of cataract surgery by focusing on clinical parameters such as refractive outcome, postoperative visual acuity (VA) and the incidence of complications. These parameters might be less interesting to patients per se, as their main interest is their ability to perform daily activities [1,2]. These differences in viewpoints may obscure their patient–doctor communication, and thereby, obscure a patient's expectations and satisfaction levels about the outcome of the cataract surgery. As a result, ophthalmologists may be satisfied with the clinical outcomes, whereas patients may not be satisfied with their experienced visual function after cataract surgery. Throughout the manuscript, we apply the term 'visual function' as experienced by the patient, where, in fact, we mean 'vision-related activity limitations'.

To enhance effective patient-centred care, there is a trend towards gathering outcome information from the patient's perspective in addition to the clinical outcomes. As there is interest in patients' side of satisfaction, in terms of outcome, several patient-reported outcome measures (PROMs) have been developed [3]. Several studies have suggested that the use of PROMs has a positive effect on the doctor–patient communication and consequently patients' satisfaction [4]. A validated and short PROM for cataract surgery is the Catquest-9SF, which was developed in Sweden and measures patients' vision-related activity limitations in daily life [5], and has recently been translated into Dutch [6]. It has been shown to be the best-fitting questionnaire to measure the visual function experienced by cataract patients [7].

Several studies have compared patient-reported outcomes measured by the Catquest-9SF and clinical parameters in relation to outcome monitoring [2,9,10]. However, this comparison has not been made for the Dutch situation.

The aim of this study was to determine the effects of whether surgery was performed on one or both eyes, ocular comorbidity (affecting or not affecting visual function) and per- and postoperative complications on visual function experienced by patients measured with the Catquest-9SF. Our research question was as follows: Is the Catquest-9SF a tool that is of added value to clinical parameters in cataract care? We used the Dutch version of the Catquest-9SF at five eye centres in the Netherlands.

MATERIALS AND METHODS

Design

Earlier, we performed a study on the linguistic and clinical validity of the Catquest-9SF for the Dutch situation [6]. The current prospective study on the clinical validity was performed as a follow-up of this study. To determine the clinical validation, that is whether the Catquest-9SF is sufficiently sensitive for various clinical situations, we collected follow-up data in cataract patients. The Catquest-9SF was administered before surgery and 3 months after surgery. This study was approved by the research committee of the Rotterdam Eye Hospital.

Study population

We collected patient-reported outcomes and clinical information of patients undergoing cataract surgery in five Dutch clinics between 2014 and 2015. All patients who had surgery on their first eye during a period of 3 months were invited by care professionals or desk clerks in five clinics; some of these patients had surgery in only one eye, while others had surgery in both eyes. Patients who already had surgery in one eye before the start of the study period were excluded. The participating clinics were as follows: The Rotterdam Eye Hospital, Medisch Spectrum Twente (Enschede), Maastricht University Medical Center, Isala clinics (Zwolle) and VU University Medical Center, Amsterdam.

Patient-reported measures

Visual function experienced by patients was assessed with the Dutch version of the Catquest-9SF, [6]. The Catquest-9SF is a nine-item self-report scale that comprises two parts: the first part contains a global question about difficulties in general to perform daily life activities and a general item about satisfaction with vision. The second part evaluates performances in specific daily activities and patient's general perceptions of difficulties by seven items [3]. Eight items have the following response categories: very great difficulty; great difficulty; some difficulty; no difficulty; can't say. One item, satisfaction with vision, scores: very dissatisfied; rather dissatisfied; fairly satisfied; very satisfied; can't say (Fig. 1). The Rasch scores range from -5.73 to 5.50; where a score of −5.73 suggests the best visual function and a score of 5.50 the worst visual function, in other words, a lower score indicates fewer problems in performing daily life activities, and a higher score indicates more problems in performing daily life activities. The category can't say is treated as missing data in the analysis according to the instructions of the original guidelines [10]. The Catquest-9SF has been recommended as a PROM for use in cataract surgery in a review with 48 PROMS [11]. In addition, the International Consortium for Health Outcomes Measurement (ICHOM) has adopted this questionnaire as PROM as part of their standard set for cataract measurement of risk factors and outcomes [12].

A. Do you find that your sight at present in some way causes you difficulty in your everyday life?

Yes, very great difficulty	Yes, great difficulty	Yes, some difficulty	No, no difficulty	Cannot decide
☐	☐	☐	☐	☐

B. Are you satisfied or dissatisfied with your sight at present?

Very dissatisfied	Fairly dissatisfied	Fairly satisfied	Very satisfied	Cannot decide
☐	☐	☐	☐	☐

C. Do you have difficulty with the following activities because of your sight?

If so, to what extent? In each row place just one tick in the box which you think best corresponds to your situation.

	Yes, very great difficulty	Yes, great difficulty	Yes, some difficulty	No, no difficulty	Cannot decide
Reading text in newspapers	☐	☐	☐	☐	☐
Recognising the faces of people you meet	☐	☐	☐	☐	☐
Seeing the prices of goods when shopping	☐	☐	☐	☐	☐
Seeing to walk on uneven surfaces, e.g. cobblestones	☐	☐	☐	☐	☐
Seeing to do handicrafts, woodwork etc.	☐	☐	☐	☐	☐
Reading subtitles on TV	☐	☐	☐	☐	☐
Seeing to engage in an activity/hobby that you are interested in	☐	☐	☐	☐	☐

Thank you very much for taking part.

Figure 1. The Catquest-9SF questionnaire.

Clinical measures

Clinical measures were derived from patients' records and included gender, age, date of surgery, surgery in both eyes (first eye and second eye), visual acuity before and after surgery and type of implanted intraocular lens [i.e. (toric) monofocal or (toric) multifocal]. Also included were data on the presence of ocular comorbidity. We attempted to distinguish comorbidity affecting and not affecting visual function. Comorbidity affecting visual functioning included the following: retinal detachment, amblyopia, diabetic retinopathy, age-related macular degeneration, glaucoma or macular pucker. Comorbidity not affecting visual function included the following: Fuchs' endothelial dystrophy or previous corneal refractive surgery. In addition, peroperative complications (yes, no) were

noted, if yes: anterior capsule rupture, nuclear drop, zonulolysis ≥3 hr, conversion into extracapsular cataract extraction, anterior chamber bleeding, iris prolapse and other. Also, postoperative complications (yes, no) were registered, if yes: endophthalmitis, cystoid macular oedema (CME), corneal oedema, anterior chamber tingle, posterior capsule opacification, retinal detachment, wound leakage, vitreous haemorrhage and other.

Four of the clinical measures were considered of primary interest: (1) surgery in one versus two eyes, (2) ocular comorbidity, (3) peroperative complications and (4) postoperative complications.

Statistical analysis

Descriptive statistics were used to present patient characteristics. Catquest-9SF scores were estimated with a Rasch model, specifically the generalized partial credit model (gPCM) model, using Winsteps 4.0.0 [13]. Generalized partial credit model (gPCM) is a model derived from Item Response Theory that can handle items with ordered categories and takes into account the place on the latent trait and the discriminative value of the items. The person measures estimated by this Rasch model are used in a multilevel regression analysis. Three potential levels were included in the models, institute as upper level, patients as middle level and their two repeated measures as the lowest level. The need for the institute level was tested with a deviance test using restricted maximum likelihood [14]. Time, gender, age, operated on one or both eyes, ocular comorbidity, per- and postoperative complications and their interactions with time were postulated as fixed effects. For answering our research question, the interaction effect of these covariates on the difference between pre- and postoperative Catquest-9SF scores are of primary interest. Gender and age are included as control variables. Cohen's d effect sizes were calculated using the standard deviation derived from the model's variance estimations. Effect sizes >0.20 are considered small, >0.50 medium and >0.80 large [15]. Women at mean age were taken as reference group.

Visual acuity was not included in this analysis as many data were missing in the clinical patient records. Multilevel regression analyses were performed with ibm spss statistics 21.0.1 (Armonk, NY, USA: IBM Corp). As we test the potential influence of four covariates, we applied a Bonferroni correction and considered a level of $p < 0.0125$ significant.

RESULTS

The study population consisted of 870 cataract patients in the five clinics. The majority was female (n = 474, 53%), had surgery in both eyes (n = 509, 59%) and had ocular comorbidity (n = 505, 58%).

Table 1. Patients' characteristics

	Total
Patients (n, %)	870 (100)
Male (n, %)	396 (47)
Age (mean ± SD)	72 ± 9.9
Surgery in both eyes (n, %)	509 (59)
Ocular comorbidity (n, %)	505 (58)
Affecting vision	285 (33)
Retinal detachment	34 (4)
Amblyopia	30 (3)
Diabetic retinopathy (DRP)	25 (3)
Age-related macular degeneration (ARMD)	100 (12)
Glaucoma	97 (11)
Macular pucker	28 (3)
Not affecting vision	35 (4)
Fuchs endothelial dystrophy (FED)	31 (4)
Previous corneal refractive surgery	4 (<1)
Other	311 (36)
Peroperative complications (n, %)	27 (3)
Anterior capsule rupture	10 (1)
Nuclear drop	3 (<1)
Zonulolysis ≥3 hr	5 (<1)
Other	9 (1)
Postoperative complications (n, %)	50 (6)
Endophthalmitis	11 (1)
Cystoid macular oedema (CME)	16 (2)
Corneal oedema	9 (1)
Other	14 (2)
IOL type (n, %)	
Monofocal	651 (88)
Toric monofocal	78 (11)
(Toric) multifocal	10 (1)
Preoperative sum score Catquest (mean ± SD)	−0.43 ± 1.70
Postoperative sum score Catquest (mean ± SD)	−3.33 ± 2.16
Difference pre-post	2.90

Table 1 shows the descriptive characteristics of the study sample. In total, 3% of the patients had peroperative complications (n = 27) and 6% had postoperative complications (n = 50). The most reported postoperative complication was CME (n = 16, 2%). Patients with ocular comorbidity had three times more postoperative complications (7.9%) compared to patients without ocular comorbidity (2.8%). More details are shown in Table 1.

The deviance test pointed out that it was not necessary to apply a three-level model. The two-level model, without the institute level, was not significantly worse ($\chi^2_{(1)}$=3.287, p = 0.07). Pre- and postoperative Catquest-9SF scores had a medium-sized correlation (r = 0.360, p < 0.001).

For all patients, large improvements in Catquest-9SF scores were observed after surgery (Tables 2 and 3 for results with Catquest-9SF Rasch scores). Men and older patients had overall significantly lower (i.e. better visual function) scores at the start of treatment (p < 0.001 resp. p < 0.001) and did not show more improvement after surgery compared to women at mean age (additional Cohen's d = 0.05, p = 0.555; d = 0.00, p = 0.929).

Table 2. Multilevel regression analysis for Catquest-9SF Rasch scores

	Estimates[a]	**95% CI**	**p-value**
Intercept	−0.49	−0.76, −0.23	<0.001
time (this means: after surgery)	−2.67	−3.01, −2.34	<0.001
Male	−0.41	−0.64, −0.19	<0.001
Time × male	0.09	−0.20, 0.38	0.554
Age	−0.02	−0.03, −0.01	0.001
Time × age	0.00	−0.01, 0.02	0.856
Surgery in both eyes	0.28	0.04, 0.51	0.021
Time × surgery in both eyes	−0.97	−1.27, −0.67	<0.001
Ocular comorbidity	0.13	−0.11, 0.36	0.289
Time × ocular comorbidity	0.34	0.04, 0.64	0.025
Peroperative complications	0.46	−0.22, 1.15	0.184
Time × peroperative complications	0.13	−0.74, 1.00	0.775
Postoperative complications	0.21	−0.29, 0.70	0.417
Time × postoperative complications	1.16	0.53, 1.80	<0.001

[a] Catquest-9SF Rasch scores.

Table 3. Estimates pre- and post surgery Catquest-9SF Rasch scores

	Pre-operative	Post-operative	Change	Cohen's d	Additional Cohen's d[a]	p-value
Gender						
Women	−0.49	−3.17	−2.67	−1.60		<0.001
Men	−0.91	−3.49	−2.59	−1.55	0.05	0.554
Ten years older than mean age	−0.70	−3.36	−2.66	−1.59	0.01	0.856
Operated on both eyes	−0.21	−3.86	−3.65	−2.19	−0.58	<0.001
Ocular comorbidity	−0.37	−2.70	−2.34	−1.40	0.20	0.025
Perioperative complications	−0.03	−2.58	−2.55	−1.53	−0.08	0.775
Postoperative complications	−0.28	−1.80	−1.51	−0.90	0.70	<0.001

Estimates are for females at mean age, unless otherwise specified.
p-values are compared to effect for females at mean age, unless otherwise specified.
[a] Compared to women at mean age.

Patients who had surgery in both eyes had significantly worse baseline scores but showed much more improvement in Catquest-9SF scores ($d = -0.59$, $p < .001$).

We found no baseline differences ($p = 0.289$) between the group with and the group without ocular comorbidity. We found a nonsignificant trend that treatment was worse when ocular comorbidity was present ($p = 0.025$, Tables 2 and 3). Of the 550 patients with ocular comorbidity, we were able to classify 285 patients with ocular comorbidity affecting visual function, and 35 patients as having ocular comorbidity that did not affect visual function. We had insufficient information to classify the 311 other ocular comorbidities. The 285 patients with ocular comorbidity that affected visual function reported significantly worse baseline scores ($p = 0.004$, not in Table) compared to patients without ocular comorbidity. No significant relative treatment effect was observed in this group ($p = 0.098$). No significant differences were found at baseline between patients with ocular comorbidity that did not affect visual function ($n = 35$) and patients without comorbidity ($p = 0.983$). They also had no significant treatment effect ($p = 0.409$)

When confronted with postoperative complications, patients showed significantly less improvement ($d = 0.70$, $p < 0.001$).

DISCUSSION

Main findings

The results of this study suggest that the Catquest-9SF is a sufficiently sensitive tool to add a broader perspective on outcome measurement in cataract care. This additional value was demonstrated in several ways. First, surgery led to a large improvement in the visual function experienced by patients. This improvement in visual functioning was particularly strong in patients who had surgery on both eyes.

Second, as was to be expected, we found that postoperative complications had a negative effect on the visual function experienced by patients. More interesting is the absence of an effect of peroperative complications. A possible explanation for this could be that, when a surgeon handles the perioperative complication adequately, there may be no effect on the patient's visual function three months after surgery (the moment when the postoperative questionnaire was completed). Alternatively, only 27 (3%) cases of peroperative complications were observed. This number may be too low to find a significant effect. Comparable low rates of perioperative complications have been reported elsewhere [16]. The perioperative complications found in this Finnish cohort rarely led to long-term complications, which is in line with our [16].

Third, although, on average, older patients reported a better experienced visual function before surgery, we did not observe a differential age-related effect of surgery.

Relationship to previous studies

As previously described for cataract care [8,17], the outcomes of the Catquest-9SF are often closely related to clinical outcomes. Nevertheless, the Catquest-9SF rather adds a broader perspective on outcome measurements in cataract care. It emphasizes the importance of complementing clinical outcome measures with an additional instrument. A recent study [18] suggests that existing instruments such as the Catquest-9SF may even be extended by including negative dysphotopsia complaints, as it seems that these complaints are underreported after cataract surgery.

Many of our findings were in line with those of other studies. We found that patients who experienced good preoperative visual function were more likely to experience less improvement in Catquest-9SF score by cataract surgery [8,9]. We also found that patients who underwent second-eye surgery were more likely to have a better Catquest-9SF score after surgery compared with those undergoing first-eye surgery [17,19].

Ocular comorbidity tended to have a negative effect on the treatment, but this effect was not significant ($p = 0.025$), applying a Bonferroni correction. This trend is in line with the findings of Ronbeck et al. [17], in contrast with the findings of Grimfors et al. [20].

In contrast with other studies, patients in our study with peroperative complications were not more likely to have a worse postoperative Catquest-9SF score [8,9] compared to patients without peroperative complications. Apparent discrepancies in this respect may be due to the fact that other studies only looked into 'capsule complications', and we studied all reported peroperative complications. Alternatively, we may not have found a significant relationship because of the small number of administered peroperative complications ($n = 27$, 3%) in our sample. Furthermore, the other studies were performed longer ago. Therefore, the surgeons in our study may have had access to newer and improved equipment. In addition, new insights into handling peroperative complications may have had an impact on the visual function outcome with a peroperative complication.

Strengths and limitations

The benefit of complementing clinical parameters with the Catquest-9SF score in our study is subject to uncertainties due to various factors including methodological constraints. Although professionals were carefully instructed about our study, ophthalmologist did not always note the visual acuity of the patients before and after the first and second cataract surgery in the patient records. Because of this missing data, it was not possible to better determine the relation with visual acuity.

Another limitation of our approach is that we have no data about the severity of the ocular comorbidities. The type of ocular comorbidities was reported in the patients' records, but not the grade of the severity. As we found that patients with ocular comorbidity more often have postoperative complications, it would be interesting to study whether this relation might depend on the severity of the ocular comorbidity. Additionally, we had limited information to distinguish between vision-related and not related comorbidity, this may have caused a reduced power to find significant effects, for example, patients with ocular comorbidity not affecting vision could have profited more from the operation.

Despite these limitations, a strength of our approach is the availability of data from five hospitals spread across the Netherlands. Thereby, the study population included is a good reflection of the Dutch population of cataract patients.

Implications

Our findings suggest that the Catquest-9SF – because it reflects patients' views – is a valuable instrument for ophthalmologists who want to gain insight into patients'

experiences of outcome after cataract surgery. It is known that patients undergoing elective surgery who have a better preoperative understanding and more realistic expectations report better experiences. Therefore, when informing patients about cataract surgery prior to their surgery, ophthalmologists should include information derived from the Catquest-9SF.

Besides that, the Catquest-9SF can be used to reflect the patients' view, and it can also be used to optimize the cataract care pathway. We found, for example, different starting points in Catquest-9SF score between hospitals. This information may help to answer questions such as follows: which hospitals were doing better, the ones who did surgery in an earlier stage of cataract or the ones who did surgery in a later stage? Even though we have not answered such questions in this study, it would be interesting for ophthalmologists and policymakers to discuss how to deal with such issues.

Further, the Catquest-9SF can enhance the communication between patients and ophthalmologists about the results of cataract surgery. Knowledge of the experiences of previous patients in relation to outcome can support, for example, a better understanding of ophthalmologists regarding patients' expectations, help patients to make better informed decisions and have more realistic expectations about the care they will receive. The subjective measurement by the Catquest-9SF is important to gain understanding of patients' perspectives on the effects of cataract surgery; it can give more information about patients' satisfaction than more objective clinical parameters such as postoperative visual acuity or incidence of complications.

Although the Catquest-9SF appears to be a promising instrument for use in clinical practice, several barriers remain related to its use. First, Catquest-9SF data should be collected on regular base in all cataract patients and added to the medical files of patients. Implementation of such regular patient-reported data collection and addition to medical files seems difficult in practice.

In the Netherlands, data about outcomes for cataract surgery are collected by the Dutch ophthalmic society (NOG), a professional association of ophthalmologists. However, these data are not for public use, but for internal use by members of the NOG. The second barrier, therefore, is finding a way to use the data for public use. The Swedish National Cataract Register which collects nationwide data on cataract surgeries seems to be a successful example of how data seem to improve knowledge about trends and results [21].

CONCLUSION

This study emphasizes the added value of the Catquest-9SF as a measure for visual function experienced by patients. In summary, we conclude that the additional information from the Catquest-9SF to clinical parameters as we have reported here can improve patient-centred approaches in clinical practice.

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PART 2

Multistakeholder perspectives

CHAPTER 5

Multi-stakeholder perspectives in defining health-services quality in cataract care

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ABSTRACT

Objective

To develop a method to define a multi-stakeholder perspective on health-service quality that enables the expression of differences in systematically identified stakeholders' perspectives, and to pilot the approach for cataract care.

Design

Mixed-method study between 2014 and 2015.

Setting

Cataract care in the Netherlands.

Participants

Stakeholder representatives.

Intervention(s)

We first identified and classified stakeholders using stakeholder theory. Participants established a multi-stakeholder perspective on quality of cataract care using concept mapping, this yielded a cluster map based on multivariate statistical analyses. Consensus-based quality dimensions were subsequently defined in a plenary stakeholder session.

Main outcome measure(s)

Stakeholders and multi-stakeholder perspective on health-service quality.

Results

Our analysis identified seven definitive stakeholders, as follows: the Dutch Ophthalmology Society, ophthalmologists, general practitioners, optometrists, health insurers, hospitals and private clinics. Patients, as dependent stakeholders, were considered to lack power by other stakeholders; hence, they were not classified as definitive stakeholders. Overall, 18 stakeholders representing ophthalmologists, general practitioners, optometrists, health insurers, hospitals, private clinics, patients, patient federations and the Dutch Healthcare Institute sorted 125 systematically collected indicators into the seven following clusters: patient centeredness and accessibility, interpersonal conduct and expectations, experienced outcome, clinical outcome, process and structure, medical technical acting and safety. Importance scores from stakeholders directly involved in the cataract service delivery process correlated strongly, as did scores from stakeholders not directly involved in this process.

Conclusions

Using a case study on cataract care, the proposed methods enable different views among stakeholders concerning quality dimensions to be systematically revealed, and the stakeholders jointly agreed on these dimensions. The methods helped to unify different quality definitions and facilitated operationalisation of quality measurement in a way that was accepted by relevant stakeholders.

INTRODUCTION

While many definitions of health-service quality have relied on objectively defined descriptions, others have argued that it should be considered subjectively [1]. Subjective definitions may be based, for instance, on expectations, perceptions, demands and values [2, 3]. Various health-service stakeholders may hold different views on health-service quality and perceive different defining dimensions and corresponding indicators [4]. In the Netherlands, this situation is illustrated by the distinct quality-measurement systems of professional societies, insurers and patient federations concerning cataract care [5–7]. The absence of an overall consensus in defining quality is not limited to ophthalmology; rather, it applies to many other fields, such as oncology [8, 9], urology [10] and geriatric care [11]. Dissent among stakeholders may complicate the measurement and improvement of health-service quality [12].

The importance of stakeholder involvement in indicator development has been increasingly recognized [13]. Delnoij *et al.* [14] concluded that stakeholder involvement is the only way to balance information needs, increase consensus and benefit from transparency. However, scientific literature offers few methods to systematically identify and involve relevant stakeholders [13]. Conversely, current contributions, often involve only stakeholder subsets, resulting in different perspectives and a multitude of variables. Hence, there is a need to compress the variables into a manageable number and measurable form [15, 16]. The variation among stakeholders is especially relevant in this process, as dynamic stakeholder interactions influence the priority attached to the various quality dimensions in practice [17, 18].

The current study aimed to develop and test a method for identifying health-service stakeholders and to develop a multi-stakeholder quality perspective that accounts for differences in viewpoints among stakeholders. We present a general method to establish a framework of quality dimensions that incorporates multi-stakeholder views, without involving a priori quality definitions or dimensions but discussing them afterwards. This reveals variations in the importance attached to these dimensions. We apply the method to cataract care. This is particularly suitable as a first case study, since cataract care represents a mature and well-outlined procedure for a highly prevalent condition that possess many quality indicators (see also the corresponding conclusions).

METHODS

Stakeholder investigation

We conducted this mixed-method study between 2014 and 2015. To include multiple stakeholders that are highly relevant for cataract care, we started our study with a systematic identification and classification of stakeholders based on stakeholder theory [16]. As a first step in the stakeholder selection, the researchers compiled a list of putative stakeholders in cataract care in the Netherlands based on the literature and experience.

Second, stakeholders identified by the researchers as potential participants were invited to participate in our study. Seven out of sixteen accepted the invitation, namely a general practitioner (GP), an optometrist, an ophthalmologist specialized in cataract care in a peripheral hospital, a medical advisor at the largest insurance company in the Netherlands, a doctor/advisor at the central governmental body in healthcare called the Dutch National Healthcare Institute (Zorginstituut Nederland), a director of a private clinic in ophthalmology and a cataract patient. The other potential participants refused, namely the Ministry of Health, Welfare and Sport (Ministry of VWS), a professional association of ophthalmologists called the Dutch Ophthalmic Society (NOG), the consumer association Consumentenbond, the ANBO branch organization for seniors, the Dutch Patient Federation (NPCF) and health insurers. Two of the invitees declined because they were involved in an initiative that they considered comparable. The Ministry of VWS suggested that the more-specialized Zorginstituut Nederland should represent the government as a stakeholder in our study.

Next, the seven initially involved stakeholder representatives filled out an online questionnaire to identify and classify stakeholders. This consisted of the list of putative stakeholders, proposed by the researchers as well as additional stakeholders suggested by the initially involved stakeholder representatives. The questionnaire asked each of the representatives to score the three classical stakeholder attributes—power, legitimacy and urgency—using a 4-point Likert scale (1 = not at all, 4 = absolutely) [19]. When at least half of the participants granted a putative stakeholder a score of at least 3 on an attribute, the stakeholder was viewed to possess this attribute. Following stakeholder theory, stakeholders were subsequently classified based on their attributes as definitive stakeholders (possessing power, legitimacy and urgency), dormant stakeholders (only power), discretionary stakeholders (only legitimacy), demanding stakeholders (only urgency), dominant stakeholders (lacking urgency), dangerous stakeholders (lacking legitimacy), dependent stakeholders (lacking power) and non-stakeholders [19].

Based on the obtained initial stakeholder classification, we complemented the initial group of stakeholder representatives to include additional potentially relevant stakeholders. Thus, 24 more stakeholder representatives were invited to participate, of which 11 accepted the invitation, namely a GP, an optometrist, three ophthalmologists specializing in cataract surgery (one in a general hospital and two in a specialist hospital), a medical advisor at the second largest insurance company in the Netherlands, four cataract patients, and a board member from a categorical hospital. This recruitment resulted in a final group of 19 stakeholder representatives. The representatives declining the invitation to participate (three ophthalmologists, eight patients and two health insurer employees) mentioned lack of time and health problems as the most common reasons for their refusal. Figure 1 provides a flowchart detailing the participation of stakeholder representatives at each stage of the study.

	Identifying stakeholders		Brainstorm quality items		Sorting and rating		Interpretation session	
Stakeholder	n	Non respons	n	Non respons	n	Non respons	n	Non respons
General practioner	1		1		2		2	1
Health insurer	1		1		2		2	1
NPCF	1	1	1	1	1		1	1
Ophthalmologist	1		2	2	4		3	
Optometrist	1		1		2		2	
Patient	1				5	1	5	3
Provider	2	1	2	1	2		2	1
National Health Care Institute	1		1		1		1	

Figure 1. Flowchart of the participants: stakeholder representatives in the different stages of the study.

Consensus building among stakeholders

The group of 19 stakeholder representatives defined health-service quality based on concept mapping, a type of structured conceptualization that can be used by groups to represent ideas in the form of a map [20, 21]. There is no strict limit to the number of participants that should be involved in concept mapping, although the inclusion of 10–20 participants is advised [20]. The number of stakeholder representatives was in this

range, and all stakeholders but one were included in the definitive, dependent, dormant or weak category. Researchers often employ interviews or Delphi-like approaches. However, concept mapping, which is designed to measure complex constructs and has a participatory nature, has several notable advantages over these other approaches. Most notably, it consolidates variables using well-defined, reproducible, quantitative methods [20–23].

Concept mapping starts with the generation of items. In this study, items (quality indicators) were generated through a systematic search of the scientific and grey literature in Embase, PubMed, Scopus and Google that took place from September 2013 to January 2014. We were interested in published studies that included data about the indicators. The search terms were 'questionnaire', 'benchmark' and 'health or healthcare quality' in combination with 'cataract' or 'phacoemulsification' and additional Medical Subject Headings. Moreover, snowball techniques were employed by manually searching the reference lists in the primary selected studies to identify further research that was likely to fulfil the inclusion criteria. The initial search yielded many papers. After the duplicate papers were removed, the remaining titles and abstracts were manually reviewed. Papers that did not consider any quality indicators were removed. Moreover, the search results were complemented by quality indicators discussed in a digital brainstorm involving the researchers and the group of stakeholder representatives. Items in English were translated into Dutch. Items were removed if the researchers agreed that they were clearly irrelevant to the quality of cataract care. For the remaining items, duplicates were eliminated and closely related items were merged to create a final consolidated list.

As a next step, each stakeholder representative individually sorted the items into groups of items considered to be related and labelled each pile. They also individually rated each item according to importance for the quality of cataract care (5-point Likert scale: 1 = absolutely not important, 5 = extremely important compared to all other items). Since non-medical stakeholders had some difficulties in understanding the medical terms in the items, we provided additional information about those items.

After the sorting and ranking tasks, data were analysed by the researchers using Concept Systems Global MAX [24]. Items were represented in maps via multivariate statistical analyses of multidimensional scaling (MDS) and hierarchical clustering [21]. Based on a similarity index, all items were placed on a 2D point map in relation to each other, items sorted together frequently were close to one another on the map. A stress value statistic was calculated to reflect the goodness of fit of the MDS map with the dissimilarity matrix; for each pair of indicators, this displayed how often stakeholder representatives placed them in the same pile [25]. Cluster maps were generated from the point map

to visualize how items could be organized into clusters using hierarchical clustering [20]. Rating maps were created to show the differences in importance per cluster, and bridge maps were generated to explore the relative agreement on rating variables between clusters and across stakeholder representatives [20]. Pattern matches yielded insight into the correlation among stakeholder representatives according to the importance of commonly agreed-upon dimensions. The resulting maps and information constituted a visual representation of the stakeholder representatives' perspectives, as well as the organization and relative importance of the perceptions.

Finally, during a 3-h plenary session, stakeholder representatives interpreted the resulting clusters and maps. They discussed the content of the clusters and reached a consensus on the number of clusters in the map that best synthesized the quality of cataract care. Consensus was based on two conditions, as follows: (i) each cluster needed to have a meaningful interpretation and (ii) interpretation could not be improved by further dividing a cluster. To support this discussion, the researchers showed cluster maps with 5–12 clusters that included underlying quality items. Moreover, stakeholder representatives discussed the naming of the clusters and reached consensus on cluster labels. Stakeholder representatives were reimbursed for their time and travel costs.

RESULTS

To achieve our goal of examining a multi-stakeholder perspective on health-service quality using the newly developed approach described above, we first classified the stakeholders (Table 1). Seventeen stakeholders were identified, of whom seven were considered definitive stakeholders because they were perceived to have all three attributes power, urgency and legitimacy. These definitive stakeholders were ophthalmologists, optometrists, GPs, healthcare insurers, private clinics, the NOG and hospital boards. Patients were categorized as dependent stakeholders because they were perceived to lack power. In contrast, the Ministry of VWS, the Dutch Healthcare Authority and Zorginstituut Nederland were classified as dormant stakeholders because they were considered to lack legitimacy and urgency. Seven stakeholders were classified as discretionary because they only scored high on legitimacy; these stakeholders included the Dutch organization for cataract patients, the NPCF, informal caregivers (relatives and volunteers) and anaesthetists. Finally, 13 representatives were identified as non-stakeholders. The inclusion of scores from stakeholder representatives who scored their own stakeholder groups did not influence the results.

Table 1. List of possible stakeholders

	Power	Legitimacy	Urgency
Definitive stakeholders	+	+	+
1. Dutch ophthalmic society NOG	3.14	3.43	3.00
2. General practitioner	3.33	3.50	3.17
3. Health insurer	3.60	3.00	2.67
4. Hospital board	2.71	3.57	2.86
5. Ophthalmologist	3.67	4.00	4.00
6. Optometrist	3.33	3.83	3.67
7. Private clinic board	3.00	3.20	2.83
Dependent stakeholders	–	+	+
8. Patient	2.50	3.50	3.33
Dormant stakeholders	+	–	–
9. Dutch healthcare authority	3.17	2.67	2.00
10. Ministry of VWS	3.33	2.83	2.17
11. Dutch National Healthcare Institute Zorginstiuut Nederland	3.20	2.80	2.40
Weak stakeholders	–	+	–
12. Anaesthetist	2.71	3.00	2.57
13. Dutch organization for cataract patients	2.29	3.43	2.86
14. Dutch patient federation NPCF	2.57	3.00	2.57
15, Patient counsel of a hospital	2.29	3.14	2.57
16, Relatives of patient	2.29	3.00	2.57
17. Volunteers	2.14	2.86	2.43
Non-stakeholders	–	–	–
18. Bank	2.00	1.67	1.83
19. Board of trustees of a hospital	2.33	2.33	2.17
20. Foreign provider of cataract care	2.43	2.33	2.17
21. Geriatrician	2.50	2.83	2.67
22. Grant provider	2.50	2.17	2.33
23. Guarantee fund for the healthcare sector WFZ	2.33	2.00	2.00
24. Healthcare inspectorate	3.17	3.17	2.83
25. Investor	2.17	1.67	1.83
26. Medical liability insurance	2.50	2.50	2.33
27. Municipality	1.83	1.67	1.67
28. Politics: spokesman care	2.50	2.17	2.00
29. Senior association ANBO	1.80	2.33	2.00
30. Supplier (equipment, instruments, etc.)	2.57	2.43	2.14

Values are mean scores and were calculated by excluding scores in which a stakeholder rated his/her own stakeholder group. For example, when a patient (participant) rated the power of a patient (possible stakeholder), the score was excluded.

As a next step, 125 items were determined to measure the quality of cataract care; these items appear in Appendix 1 with their identifying numbers and average importance ratings. Stakeholder representatives sorted the items into an average of 10 piles (mean [*M*] = 9.8, standard deviation [SD] = 2.7) with a mean importance of *M* = 3.79 (SD = 0.54), suggesting high overall importance.

During the plenary meeting, the MDS map with the seven-cluster solution was chosen as final. One stakeholder representative completed the sorting and rating assignments after the plenary session due to illness. These results had a slight effect on the concept map. Subsequent adjustments were communicated to and approved by all stakeholder representatives. The stress value for this MDS map was 0.27, indicating a satisfactory fit [25, 26]. The clusters are visualized in Fig. 2; considering the clusters in a clockwise fashion, their agreed-upon labels were as follows: patient centredness and accessibility, interpersonal conduct and expectations, experienced outcome, clinical outcome, process and structure, medical technical acting and safety. According to the stakeholder representatives, the horizontal axis in the MDS map represented a time axis, ranging from condition to outcome, while the vertical axis ranged from supply (technical acting, clinical aspects and structures) to demand (processes, experiences, service outcomes and patient values).

The average bridging values for each cluster in the final MDS map, indicating the relative agreement on rated items, are presented in Appendix 1. Average bridging values ranged from 0.15 for the most homogeneous cluster (cluster II, interpersonal conduct and expectations) to 0.73 for the least homogeneous cluster (cluster V, safety).

The importance ratings of the stakeholder groups were strongly correlated (Tables 2 and 3). On average, however, the correlation coefficients associated with the optometrists were considerably lower than those of other stakeholders (0.45 versus 0.70 or higher). Conversely, valuations by the NPCF and Zorginstituut Nederland yielded the largest average *R* values (0.98). When distinguishing the representatives of stakeholders directly involved in health-service delivery from the others, the correlation within the distinguished groups was larger than that between groups.

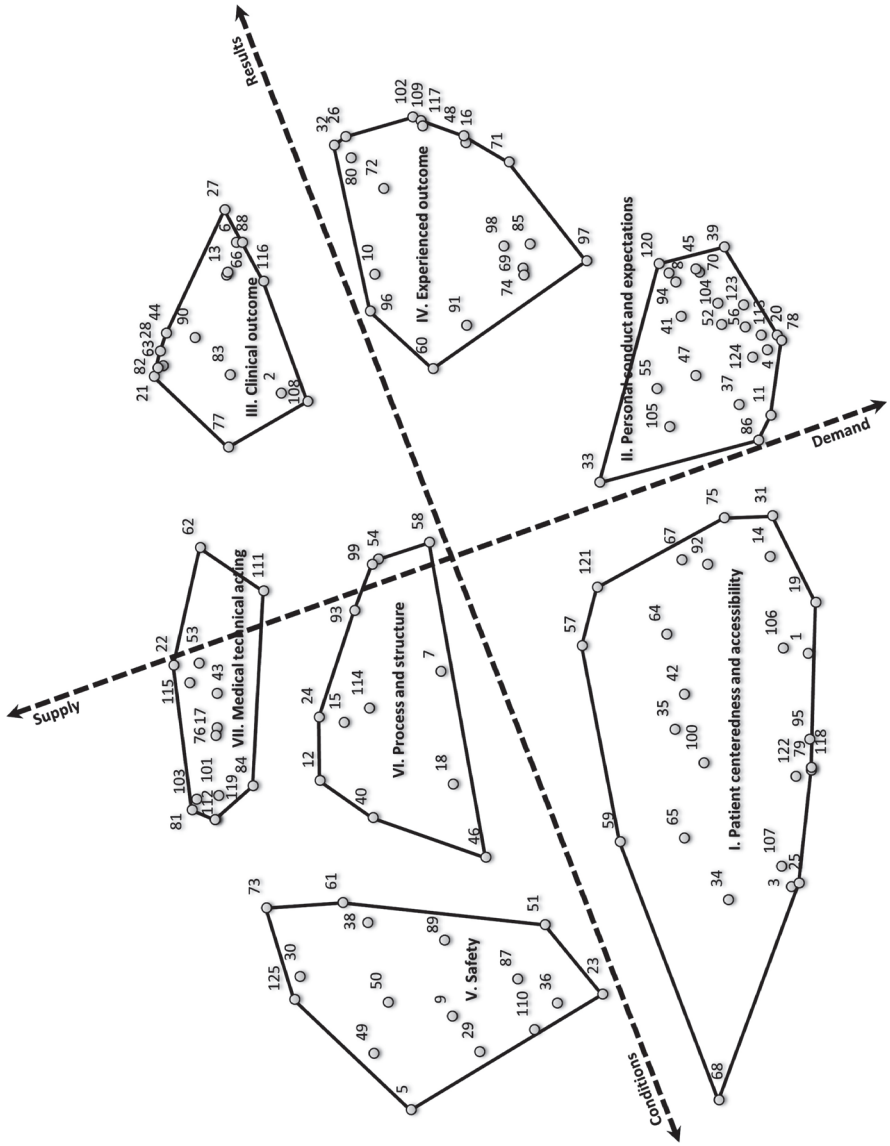

Figure 2. Concept map with seven clusters.

Table 2. Importance score per cluster per stakeholder

Clusters	Ophthal-mologist	GP	Optometrist	Patients	Zorg instituut Nederland	Health insurer	Care providers[a]	NPCF
I Patient centredness and accessibility	3.21	3.62	2.80	3.61	2.80	3.12	3.64	4.00
II Personal conduct and expectations	4.13	4.13	3.70	4.47	3.87	3.98	4.80	4.90
III Clinical outcome	3.44	4.31	3.06	3.86	4.00	4.31	4.59	5.00
IV Experienced outcome	3.79	4.13	3.00	4.41	3.63	3.82	4.47	4.75
V Safety	3.66	4.09	3.88	4.18	3.88	4.00	4.34	4.78
VI Process and structure	3.77	3.83	3.21	4.08	3.50	3.83	4.13	4.67
VII Medical technical acting	2.75	3.46	3.29	3.45	3.50	3.18	3.79	-

[a] Hospital board and private clinic board.

Table 3. Absolute difference (left triangle) and correlation (right triangle) between stakeholders

	Ophthalmologists	GPs	Optometrist	Patients	Zorg instituut Nederland	Health insurers	Care providers[a]	NPCF	All
Ophthal-mologists		0.71	0.39	0.95	0.44	0.67	0.78	0.62	0.85
GPs	1.62		0.27	0.72	0.75	0.94	0.91	0.92	0.84
Optometrists	2.55	2.43		0.44	0.61	0.39	0.46	0.52	0.45
Patients	0.84	1.36	2.01		0.53	0.65	0.81	0.63	0.89
Zorginstituut Nederland	2.69	1.27	1.86	2.25		0.86	0.84	0.98	0.70
Health insurers	2.00	1.04	2.55	1.60	1.09		0.89	0.97	0.80
Care providers[a]	1.52	0.80	2.35	1.34	1.29	1.18		0.93	0.91
NPCF	2.40	1.20	1.86	2.05	0.66	1.14	1.16		0.75

[a] Hospital board and private clinic board.

DISCUSSION

In this study, we examined methods for identifying health-service quality concerning cataract care through a multi-stakeholder approach. While our study is far from the first in this domain, it appears to be the first that has explicitly and systematically developed inclusive multi-stakeholder health-service quality dimensions for cataract care in the Netherlands.

Another recent and well-known initiative is the International Consortium for Health Outcome Measurement (ICHOM) [16], which is comparable to our study, as both ICHOM and our approach aimed to create a minimum set of indicators using a multidisciplinary method. However, our study is also different from the ICHOM initiative in several ways. First, while ICHOM only included patient, provider and registry perspectives, we included stakeholder perspectives using a systematic approach without excluding stakeholders beforehand; this resulted in a broader group of stakeholder perspectives. Second, ICHOM only focused on outcome indicators, while we also were interested in process and structure indicators, which seemed to be important to our stakeholders. Third, ICHOM used a Delphi approach, whereas we used concept mapping to create a consensus among stakeholders. We preferred concept mapping because this approach can be employed not only to create consensus but also to quantify and visualize differences among stakeholders, which contribute to equate the contribution between different stakeholders.

For validation of our approach, we considered how the resulting dimensions related to existing classifications. The World Health Organization (WHO) distinguished six domains in their definition of health-service quality, namely effectiveness, efficiency, accessibility, patient centredness, equity and safety [27]. The effectiveness domain translates to the two outcome clusters in our study, while the WHO domains of accessibility and patient centredness combined into one cluster in our study. The WHO safety domain mapped directly to our safety cluster. Equity did not seem to play a role in the current investigation, as all Dutch citizens have mandatory insurance that fully covers the cost of cataract care. Our study identified several clusters that did not map to the WHO domains; these mostly involved health-service provisioning, including the following: interpersonal conduct and expectations, process and structure and medical–technical acting. Our analysis lacked a cluster that could be considered a natural counterpart to the WHO efficiency domain. This was partly the result of our item list, which was based on existing lists that apparently contained few items relating to efficiency. Moreover, stakeholder representatives did not add efficiency items to the list. Nonetheless, efficiency was discussed extensively during the plenary meeting of stakeholder representatives, as it was perceived to be missing. The stakeholder representatives debated whether efficiency is a quality dimension or

whether it should be considered separately (cost versus quality). In this respect, the specific consensus of Dutch cataract care stakeholder representatives differed from the WHO view. Similar observations can be made when comparing the results with the six aims of improvement established by the Institute of Medicine in the United States [28]. In contrast to chronic care, cataract care is a relatively straightforward intervention with a short pre- and post-operative trajectory. This might have influenced the participation of stakeholders and their perspectives in our study. The differences in perspectives that emerged support the proposition that health-service quality is subjectively defined and varies among stakeholders, countries and conditions [2, 3].

Somewhat surprisingly and counterintuitively, our research revealed that most Dutch cataract care stakeholder representatives viewed patients as lacking power. Thus, patients are not classified as definite stakeholders. This appears to contradict the commonly held view that patients were the ultimate stakeholder. Our results signal that current Dutch (and international) efforts to improve patient centredness are required to empower patients and position their patient values as the basis for decision making [29, 30].

There was considerable consensus among the GP, Zorginstituut Nederland, insurer, provider organization and NPCF stakeholders concerning the importance of quality dimensions and items. At the same time, this consensus was not fully aligned with the viewpoints of representatives directly involved in the process of health-service delivery, namely optometrists, ophthalmologists, and most notably, patients. Since we found that ophthalmologists and optometrists were in line with patients in their perspectives towards quality, they can promote the patients during clinical decision making, and thereby support patient empowerment. We note too, however, that stakeholder classifications are not steady states; current policies and changing values may lead to increases in patients' power over time.

A major strength of this study was the panel of stakeholder representatives, which was systematically selected based on of stakeholder theory. If identification of stakeholders is unsystematic or poorly structured, valuable stakeholder groups can be missed [13]. The methods used ensured that all stakeholders considered relevant by other stakeholders took part in the concept mapping; hence, their views were systematically included in our analyses. However, we note that the NOG, the professional association for ophthalmologists in the Netherlands, acknowledged as a definitive stakeholder, did not accept our invitation to participate. Considering that the NOG represented ophthalmologists, we obviated this setback by inviting more ophthalmologists.

Another strength was that the concept mapping was initiated through an exhaustive literature search to ensure that the most timely and reliable information about health-service quality indicators available was included. Moreover, the indicator list was complemented by a digital brainstorm involving the researchers and the group of stakeholder representatives. This approach provided a structured starting point for the stakeholder representatives, forming a systematic and sound basis for further involvement of the stakeholder representatives, and strengthening the internal validity and feasibility of the concept-mapping process.

The size of our panel was consistent with the recommended size for concept mapping. Further increases in the number of participants are expected to hamper discussion. However, it is possible that due to the small size of each subgroup, caution is needed when comparing results between subgroups. Based on the large within stakeholder-group agreement in sorting and rating the quality items, our findings indicate that the effect on internal validity is limited.

CONCLUSION

The globally felt urgency to improve health-service quality has led to extensive debate and considerable complexity because of differences in viewpoints on its definition and measurement. We have proposed a systematic approach to develop a condition/treatment-specific multi-stakeholder consensus-based definition of health-service quality. The consistent results obtained in the case study on cataract care confirmed the applicability of the methods. They enabled a commonly agreed definition to be developed, in which differences in viewpoints were expressed in relation to differences in importance valuations of the indicators defining the dimensions. Not only has this resulted in seven dimensions to define the quality of Dutch cataract care (which we further operationalize in future research), but it has also revealed that stakeholders presently perceive patient power to fall short of national policy aims. In practice, this may be compensated for through a general agreement on quality with other stakeholders involved in service delivery.

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APPENDIX 1. ITEMS AND CLUSTERS DERIVED FROM THE CONCEPT MAP, ALONG THEIR RATING AND BRIDGING VALUES.

	Clusters and indicators	Rating value	Bridging value	References
Cluster 1: Patient centeredness and accessibility		**3,34**	**0,41**	
121	The patient receives information about what to do after surgery in case of emergency	4,50		Brouwer, W. (2006); Faber, M. (2012)
106	Patient experiences problems in reaching ophthalmology department or clinic by telephone	3,94		Brouwer, W. (2006)
75	Needs assessment and decision for cataract surgery is based on the wishes of the patient	3,89		Brouwer, W. (2006); Zichtbare Zorg Ziekenhuizen (2009)
100	Consultations and preoperative examinations take place on the same day	3,83		Faber, M. (2012); Zichtbare Zorg Ziekenhuizen (2009)
92	Patient has contact with the same ophthalmologist during consultations	3,72		Brouwer, W. (2006)
64	Patient has the same ophthalmologist during consolation and surgery	3,67		Faber, M. (2012); Damman, O.C. (2012)
25	Cataract surgery was fully reimbursed by health care insurer	3,59		Brouwer, W. (2006)
79	Patient has experienced problems with the ophthalmologist that he/she wanted to visit because they had no contract with his/her health care provider	3,56		Brouwer, W. (2006)
65	Preliminary tests for cataract surgery take place in one day	3,56		Brouwer, W. (2006)
95	Patient has experienced problems with the permission of the health insurer with respect to cataract surgery	3,50		Brouwer, W. (2006)
59	Provider has a separate cataract care pathway for patients referred by their GP or by the optometrist	3,41		Holmes, K. (2013)
42	Manner of informing about the day and time of cataract surgery	3,39		Brouwer, W. (2006)
67	Amount of time for explanation of surgery to the patient	3,33		Zichtbare Zorg Ziekenhuizen (2009)

Clusters and indicators		Rating value	Bridging value	References
57	Way of 1st day monitoring (e.g. by telephone, in hospital, by patient)	3,28		OCCUR
122	Patient needs permission of health insurance with regard to cataract surgery	3,24		Brouwer, W. (2006)
19	Patient experiences problems after referral to get an appointment with the ophthalmologist as soon as he/she wants	3,24		Brouwer, W. (2006); Damman, O.C. (2012)
107	Ophthalmologist prescribed medications that were fully reimbursed by the health insurer	3,19		Brouwer, W. (2006)
3	Cost of cataract care for patient (i.e. cost not / partially reimbursed by health insurer)	3,06		Brainstorm
118	Patient wanted to visit an ophthalmologist for the purpose of cataract surgery that has no contract with his / her health insurer	3,00		Brouwer, W. (2006)
68	Actual costs of cataract surgery	3,00		Lundström, M. (2009)
34	Waiting time for the cataract surgery	2,94		Brouwer, W. (2006); Damman, O.C. (2012); Zichtbare Zorg Ziekenhuizen (2009); ECHIM (2011); Conner-Spady, B.L. (2004)
14	Ophthalmologist helps the patient within fifteen minutes after agreed time	2,83		Brouwer, W. (2006)
31	Average length of a consultation with the ophthalmologist according to the patient	2,69		Brouwer, W. (2006)
35	Time of meeting ophthalmologist who performs cataract surgery and patient with cataract	2,53		Zichtbare Zorg Ziekenhuizen (2009)
1	Distance to hospital	2,41		Damman, O.C. (2012)
Cluster II: Interpersonal conduct and expectations		**4,24**	**0,15**	
56	Ophthalmologist takes the patient seriously (from patient perspective)	4,72		Faber, M. (2012); Brouwer, W. (2006)
41	Ophthalmologist provides information about the risks of surgery (from patient perspective)	4,56		Faber, M. (2012); Brouwer, W. (2006); OCCUR

	Clusters and indicators	Rating value	Bridging value	References
52	Ophthalmologist is willing to talk with the patient about things who are not well expired (from patient perspective)	4,56		Brouwer, W. (2006)
8	Patient receives information about possible symptoms after surgery	4,50		Faber, M. (2012); Zichtbare Zorg Ziekenhuizen (2009); Brouwer, W. (2006)
123	Ophthalmologist explains things in an understandable way (from patient perspective)	4,50		Faber, M. (2012); Brouwer, W. (2006)
20	Ophthalmologist attentively listen to patient (from patient perspective)	4,44		Brouwer, W. (2006)
124	Ophthalmologist is polite to patient (from patient perspective)	4,39		Brouwer, W. (2006)
86	Ophthalmologist has enough time for patient (from patient perspective)	4,39		Faber, M. (2012); Brouwer, W. (2006)
70	Decision for cataract surgery is based on the ophthalmic examination by an ophthalmologist and taken by the patient in consultation with the ophthalmologist	4,29		NOG (2013)
45	Ophthalmologist, nurses and other hospital staff explained potential side effects in an understandable way to the patient	4,28		Brouwer, W. (2006)
39	Nurse / optometrist / TOA explains things in an understandable way to the patient (from patient perspective)	4,28		Brouwer, W. (2006)
104	Nurse / optometrist / TOA attentively listen to patient (from patient perspective)	4,28		Brouwer, W. (2006)
120	Patient receives information about which activity can and cannot after cataract surgery	4,28		Brouwer, W. (2006); Zichtbare Zorg Ziekenhuizen (2009)
55	Type of explanation to the patient about surgery on the first eye	4,24		Zichtbare Zorg Ziekenhuizen (2009)
113	Nurse / optometrist / TOA is polite to patient (from patient perspective)	4,24		Brouwer, W. (2006)
105	Care is aligned with other care providers (optometrist, nurse, general practitioner, etc) from patient perspective	4,11		Brouwer, W. (2006)
94	Patient received information about the consequences of cataract surgery for the use of glasses	4,11		Brouwer, W. (2006)

Clusters and indicators		Rating value	Bridging value	References
4	Ophthalmologist takes specific requirements of the patient into account (from patient perspective)	4,11		Brouwer, W. (2006)
78	Patient can choose between different lenses	4,06		Zichtbare Zorg Ziekenhuizen (2009)
47	The ophthalmologist informs the patient during surgery about what is happening (from patient perspective)	4,00		Faber, M. (2012); Brouwer, W. (2006)
37	Ophthalmologist and other health care workers give conflicting information to patient (from patient perspective)	3,76		Brouwer, W. (2006)
11	Patient has talked to anybody about the necessary help at home after cataract surgery	3,67		Brouwer, W. (2006)
33	Perception of ophthalmologist about the priorities of a patient to get a cataract surgery	3,65		Pager, C.K. (2004)
Cluster III: Clinical results		**3,88**	**0,22**	
44	Complication posterior capsule rupture	4,50		Damman, O.C. (2012); Zichtbare Zorg Ziekenhuizen (2009)
90	Complications during cataract surgery	4,47		Lundström, M. (2012); OCCUR; ICHOM (2014)
28	Postoperative complication: persistent corneal oedema	4,19		Lundström, M. (2012); ICHOM (2014)
21	Postoperative complication: uncontrolled elevated intraocular pressure	4,19		Lundström, M. (2012)
63	Postoperative complication: uveitis requiring medication	4,13		Lundström, M. (2012)
88	Corrected distance visual acuity (CDVA)	4,06		OCCUR; ICHOM
2	Outcomes of treatment be mirrored with other providers	4,00		Brainstorm
6	Best corrected visual acuity (BCVA)	3,94		Hahn, U. (2011); Hahn, U. (2012)
82	Postoperative complication: posterior capsule opacification that disrupts vision	3,88		Lundström, M. (2012)

	Clusters and indicators	Rating value	Bridging value	References
66	Uncorrected distance visual acuity (UDVA)	3,88		OCCUR; ICHOM (2014)
27	Refractive outcome	3,81		Lundström, M. (2012); Hahn, U. (2011); Hahn, U. (2012); OCCUR
116	Percentage of readmissions (related to the operated eye) within 28 days of discharge after cataract surgery, for 6 months	3,76		AHRG (2013)
83	Patient is operate on the same eye again after cataract surgery within 3 weeks	3,56		Brouwer, W. (2006)
13	Uncorrected near visual acuity (UNVA)	3,56		OCCUR
108	Number of cataract surgeries in patients over 50 years	3,06		Zichtbare Zorg Ziekenhuizen (2009)
77	Percentage patients having a discharge intention of one day, who have an overnight admission following cataract surgery, during the 6 months' time period	3,06		AHRG (2013)
Cluster IV: Experienced results		**3,98**	**0,43**	
80	Visual function according to the patient / Patient Reported Outcome Measure, PROM (there are several instruments to measure visual function the Catquest-9SF is recommended)	4,41		McAlinden, C. (2011)
109	Good distance vision, e.g. recognizing people across the street (from patient perspective)	4,39		Lundström, M. (2009); Brouwer, W. (2006)
26	Patient is satisfied / dissatisfied with current sight	4,33		Lundström, M. (2009)
117	Good medium distance vision, e.g. reading subtitles on TV (from patient perspective)	4,22		Lundström, M. (2009); Brouwer, W. (2006)
96	Recording of visual acuity prior to cataract surgery	4,18		NOG (2013)
71	Participation in traffic (from patient perspective)	4,06		Brouwer, W. (2006); OCCUR
74	Score for the ophthalmologist given by patients	4,06		Faber, M. (2012); Brouwer, W. (2006)
98	Score for the hospital given by patients	4,00		Faber, M. (2012); Brouwer, W. (2006)

Clusters and indicators		Rating value	Bridging value	References
16	Patient experiences obstacles in everyday life by the current vision	4,00		Lundström, M. (2009)
60	Registration of limitations in visual function prior to cataract surgery	4,00		NOG (2013)
97	The provider shares its own complication rate and patient satisfaction about cataract surgery with the patient (on the website and in the patient flyer)	4,00		Brainstorm
102	Good near vision, e.g. reading newspaper (from patient perspective)	3,94		Lundström, M. (2009); Brouwer, W. (2006)
85	Patient would recommend hospital / clinic to friends and family	3,94		Brouwer, W. (2006)
91	Provider uses PROM (patient reported outcome measure)	3,88		Brainstorm
69	Score for the nurse / optometrist / TOA given by patients	3,83		Brouwer. W. (2006)
48	Good very near vision, e.g. handwork (from patient perspective)	3,82		Lundström, M. (2009); Brouwer, W. (2006)
10	Registration of the opportunity to improve visual acuity and visual function prior to cataract surgery	3,78		NOG (2013)
72	Degree of pain patients experienced during surgery	3,67		Faber, M. (2012); Brouwer, W. (2006)
32	Not dependent of glasses after cataract surgery	3,06		Levy, P. (2010)
Cluster V: Safety		**4,01**	**0,73**	
29	Ophthalmologist, nurses and other hospital staff ask patient or he / she is allergic to certain medicines	4,76		Brouwer, W. (2006)
9	Ophthalmologist, nurses and other hospital staff ask patient or he / she is allergic to iodine	4,71		Brouwer, W. (2006)
125	Theatre room meets the nationwide standards in respect of the prevention of infection when a cataract operation is carried out under local anaesthesia	4,65		NOG (2013)
30	Complications of surgery are discussed in collegial consultation and, if necessary, improvement plans drawn up and implemented	4,61		Brainstorm

	Clusters and indicators	Rating value	Bridging value	References
38	With disappointing performance of treatment or a significantly greater number of complications, the scientific society is called for an audit or a working visit is scheduled at a better performing clinic	4,47		Brainstorm
5	Each cataract surgery is recorded and, in event of a complication, the video is discussed in a collegial consultation for learning	4,44		Brainstorm
49	Healthcare provider uses a perioperative surgical checklist	4,41		Kelly, S.P. (2013)
61	Experience of the surgeon performing the cataract surgery	4,24		Brainstorm
23	Provider is accredited	4,11		Menachemi, N. (2008)
73	For anaesthesia use is made of ASA (risk assessment anaesthesia)	3,94		OCCUR
87	Presence of formal logistics for information transfer between employees	3,82		Brainstorm
51	Presence of formal process which takes account of urgency when planning cataract surgery	3,65		OCCUR
50	Patient is monitored during surgery by an anaesthesiologist	3,41		Faber, M. (2013); Zichtbare Zorg Ziekenhuizen (2009)
89	Position of the person who assists during cataract surgery	3,24		OCCUR
110	Care provider qualifies drop anaesthesia as OK or as outpatient surgery	3,00		Brainstorm
36	Place where cataract surgery takes place (OK / day treatment centre)	2,59		OCCUR
Cluster VI: Process and structure		**3,82**	**0,53**	
114	Participation in nationwide registration system which include complication registration	4,24		IGZ (2013)
18	Level of care professional who performs the examinations on hospital location in the patient with cataract	4,18		Zichtbare Zorg Ziekenhuizen (2009)

	Clusters and indicators	Rating value	Bridging value	References
40	Physician determines systematic risk (e.g. COPD, dementia, deaf)	4,13		OCCUR; Faber, M. (2012); Brouwer, W. (2006)
99	Registration of the presence of cataract prior to cataract surgery	4,06		NOG (2013)
15	Function of doctor performing the surgery (e.g. pool, resident)	4,06		OCCUR
54	Percentage of patients who have had cataract surgery on both eyes, and in whom a check has taken place before the second eye was operated from 1 week after surgery of the first eye	3,81		NOG (2013)
12	Manner outpatient follow-up after the first check (e.g. return as complaints, 2nd eye surgery, sue for old pathology, sue for pathology prosecute by surgery)	3,78		OCCUR
7	Number of cataract surgeries per hospital location by specialism ophthalmology	3,71		Zichtbare Zorg Ziekenhuizen (2009)
24	Premium intraocular lens (multifocal, accommodating, toric IOLS)	3,63		Lundström,M. (2012)
58	Patient has been still in consultation after cataract surgery	3,53		Brouwer, W. (2006)
93	Percentage of patient who have had cataract surgery on both eyes, and in whom was at least 2 weeks between the two successive surgeries	3,44		NOG (2013)
46	Care professional who performs the 1st-day control in patients with cataract (e.g. ophthalmologist, resident, optometrist)	3,25		Zichtbare Zorg Ziekenhuizen (2009); OCCUR; Faber, M. (2012); Van Vliet, E.J. (2010)
Cluster VII: Medical technical acting		**3,27**	**0,20**	
43	Difficulty of surgery (e.g. small pupil, dense cataract, corneal opacities, previous vitrectomy, patient movements, floppy iris)	4,44		Lundström,M. (2012); ICHOM (2014)
76	Applied surgical technique for cataract surgery	3,63		OCCUR
84	Type of anaesthesia (drop, overall, retro bulbar, subtenon)	3,44		Lundström,M. (2012); OCCUR; Brouwer, W. (2006)
53	Location of IOL implantation (sack; sulcus; anterior chamber; no)	3,44		OCCUR

Clusters and indicators		Rating value	Bridging value	References
17	Applied phaco technique during cataract surgery	3,35		OCCUR
62	Keratometry K1 and K2	3,25		OCCUR
22	Cumulative Dispersed Energy (CDE) during surgery	3,25		OCCUR
81	Postoperative medication (dexamytrex, lopidine, other)	3,19		OCCUR
103	Type of intraocular lens material	3,19		Lundström,M. (2012); OCCUR; Zichtbare Zorg Ziekenhuizen (2009)
111	Duration of surgery (minutes)	3,18		OCCUR
112	Incision (corneal (22 mm), corneal (28 mm), limbal, scleral, incision is enlarged, OCCI)	3,06		OCCUR
115	number of sutures after cataract surgery	2,88		OCCUR
101	Viscoelastic (progel, provics, other)	2,88		OCCUR
119	Location of incision (steepest axis, 100 degrees, temporal)	2,63		OCCUR

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CHAPTER 6

Multi-stakeholder perspectives in defining health services quality indicators and dimensions: a concept mapping based comparison for cataract care between Singapore and The Netherlands

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ABSTRACT

Objective

This study aims to advance understanding of globally valid versus country-specific quality dimensions and indicators, as perceived by relevant stakeholders, in particular for cataract surgery.

Design

A mixed methods case study comparing Singapore and The Netherlands

Setting

Singapore (2017-2019) and The Netherlands (2014-2015)

Participants

Stakeholder representatives of cataract care in Singapore and The Netherlands.

Intervention

First, stakeholder representatives of cataract care in Singapore established a multi-stakeholder perspective on quality of cataract care using a concept mapping approach. This yielded a multidimensional cluster map based on multivariate statistical analyses. Consensus-based quality dimensions were subsequently defined during a plenary session. Thereafter, Singaporean dimensions were matched with dimensions obtained in The Netherlands to identify commonalities and differences.

Main outcome measure

Health-services quality dimensions of cataract care

Results

19 Singaporean stakeholders representing patients, general practitioners, ophthalmologists, nurses, care providers, researchers, and clinical auditors defines health-services quality of cataract care in the following eight clusters: clinical outcome, patient outcomes, surgical process, surgical safety, patient experience, access, costs and standard of care. Compared to the Dutch results, 61% of the indicators were allocated to matching dimensions (clusters labels for the two countries and importance of clusters also corresponded largely). At the same time, we found considerable differences in the composition of the dimensions and importance of indicators.

Conclusions and relevance

This study on cataract care in Singapore and The Netherlands shows that cataract care quality measurement instruments can share a common international core. At the same time, it emphasizes the importance of taking a country-specific multi-stakeholder approach to quality definition and measurement. Complementing an international core set with country specific measures is required to ensure the included the dimensions and indicators adequately capture the country specific quality views.

INTRODUCTION

Standardised measures are important to measure, monitor, analyse and improve the quality of health service delivery. The International Consortium for Health Outcomes Measurement (ICHOM) proposes global minimum sets of outcome measurements for health services to standardise outcomes and improve processes globally [1]. While having received much recognition, the value of the ICHOM sets has also been debated. The implementation of such international standards remains a major challenge, for instance, for the globally most common surgical procedure cataract [2]. While the use of large electronic registries allows for large-scale tracking [3], adherence to the proposed standardised sets is limited [2]. Currently, the outcome measures of cataract surgery vary across countries and hospitals [2].

ICHOM characterises the proposed global set for cataract care as a compromise between the usefulness of data and the practicalities of data collection [1]. The set is developed using a Delphi method. The Delphi panel, however, may not have fully included all salient stakeholders as it predominantly consisted of ophthalmologists while failing to represent, among others, health insurance providers and policymakers [4]. Moreover, it remains unclear whether country-specific characteristics are appropriately accommodated, reducing the validity as perceived by local stakeholders. This is especially relevant as quality definitions and dimensions are evidenced to vary across countries [5,6].

This study aims to advance understanding of globally valid versus country-specific quality dimensions and indicators, as perceived by all relevant stakeholders. It focuses on patient level dimensions and indicators and has engaged and involved patients as an important stakeholder, ensuring that their needs and preferences are included, in alignment with the principles of people-centred health services [7]. We conducted a case study comparing cataract surgery between Singapore and The Netherlands. The Netherlands has topped the rankings of the European Health Consumer Index from 2008 to 2016 and can be viewed as a leading representative of a Western healthcare system [8,9]. Singapore's health system is similarly considered as leading and has been identified as the best performing health system outside of Europe by the WHO [8].

The high quality health systems of both countries provide accessible cataract care. In The Netherlands, all citizens are mandated to purchase statutory health insurance from private insurers which covers cataract surgery [10]. In Singapore, the reimbursement system is anchored in the twin philosophies of individual responsibility and affordable healthcare [11]. Singaporean patients are required to provide a copayment for cataract surgery of approximately 30% from their medical savings account [12]. In addition to

health system differences, the organizational cultures and attitudes towards health also differ essentially [13,14].

Cataract surgery is one of the most cost-effective and frequently performed surgical procedures worldwide, as cataract is still a leading cause of blindness globally [15]. The resulting importance of advancing a comprehensive understanding of quality measures for cataract care has already motivated the development of several global registries [16-20].

METHODS

Study design

We conducted a concept mapping study between 2017 and 2019 in Singapore to define quality dimensions of cataract surgery and to systematically compare results with those obtained in The Netherlands between 2014 and 2015 [4]. Below, we present the Singaporean study process and the methods used to identify the commonalities and differences between the quality dimensions of the two countries. We begin with a brief description of concept mapping and a summary of the Dutch data and results [4,21]. Written informed consent obtained from all participants prior to participation. Participants were reimbursed for their time and travel costs.

Concept mapping

Concept mapping is a structured group conceptualization designed to integrate input from multiple stakeholders with different expertise or interests on a set of items. It results in a visualised clustering of the set of items which represents the integrated input [12,13]. Concept mapping is a well-defined and reproducible mixed method that allows for both qualitative and quantitative comparisons, which is a relative strength over other approaches such as Delphi studies [22-25]. Through its participatory nature, it combines group processes with multivariate statistical analyses. There is no strict limit to the number of participants that should be involved in concept mapping, although the inclusion of 10–20 participants is advised [22]. We invited participants representing all relevant stakeholders following a stakeholder theory-based protocol [4,26], while ensuring equivalence between stakeholders of the two countries as much as possible. To include all relevant stakeholders of cataract care in Singapore, we initially selected a Singaporean counterpart for each of the stakeholders included in the Dutch study, and then subsequently added stakeholders considered relevant by the researchers or stakeholders already included. Next, representatives of all identified stakeholders were invited to participate in our study.

For this study, quality indicators for cataract care formed the items of interest. The set of items was obtained by combining all indicators included in sets obtained through systematic search of scientific and grey literature and allowing researchers and stakeholders to add or delete items in case of consensus, as described in [4]. This list involved health service quality indicators relevant at the patient level. Quality indicators at the population or national level, such as those included in the global action plan of the WHO, were excluded [27].

Following the concept mapping methods, each participant individually sorted the items into groups according to similarity, and then labelled each pile and rated the importance of each item on a 5-point Likert scale. These data were analysed using Concept Systems Global MAX [28], which uses multivariate statistical analyses and hierarchical clustering [23]. The resulting clusterings and maps were interpreted by participants in group discussions, reaching consensus on a minimal number of well-defined clusters for which cluster labels were agreed.

Table 1. Participation of stakeholder representatives during different stages of the study in The Netherlands and Singapore

	The Netherlands			**Singapore**		
	sorting	**rating**	**meeting**	**sorting**	**rating**	**meeting**
Patient	3	4	2	3	4	1
Patient federation	1	1	-	-	-	-
General practitioner	2	2	1	4	3	1
Ophthalmologist	4	4	3	3	3	2
Optometrist/ nurse	2	2	2	-	-	2
Care provider	2	2	1	1	1	1
Health insurer	2	2	1	-	-	-
National health care institute	1	1	1	-	-	-
Researcher Health Services	-	-	-	2	2	2
Clinical auditor	-	-	-	1	1	3
Total	**17**	**18**	**11**	**14**	**14**	**12**

Preceding study in The Netherlands

After a systematic inclusion process, the following stakeholders were included in the Dutch study [4]: patients, the patient federation, ophthalmologists, general practitioners, optometrists, hospitals, private clinics, health insurers and the national healthcare institute (which represented the government), see Table 1. Dutch data were collected in 2014–2015. The resulting consensus-based clustering into quality dimensions in The Netherlands can be found in Table 2.

Study process in Singapore

To include all relevant stakeholders of cataract care in Singapore, we initially selected a Singaporean counterpart for each of the stakeholders included in the Dutch study, and subsequently added stakeholders considered relevant by the researchers or stakeholders already included. This resulted in the inclusion of patients from Chinese, Indian and Malaysian origin. Next, representatives of all identified stakeholders were invited to participate in our study. Further details are provided in the results section.

Between-country comparison

We used a descriptive approach for the cross-country comparison between Singapore and The Netherlands [21]. First, we listed all items per cluster for Singapore and The Netherlands. Second, we compared clusters between the two countries and matched clusters based on item and label commonality. More specifically, we first calculated the number of items in common for each pair of clusters from Singapore and The Netherlands. Next, we formed cluster pairs consisting of one Singaporean and one Dutch cluster, with the objective to maximise the sum of the numbers of items that these paired clusters had in common, while also taking cluster labels into account. For the resulting pairs, we then described similarities and differences between the two countries regarding the items in the paired clusters and the importance ratings of these items.

Throughout the manuscript, we apply the cluster labels defined by Singaporean participants unless specified otherwise. The interpretation of the similarities and differences is left for the discussion.

RESULTS

Participants in Singapore

The seven stakeholder groups of cataract care in Singapore were represented by 19 participants: patients, general practitioners, ophthalmologists, care providers, optometrists/nurses, researchers in health services and management/auditors. Patients were of Chinese, Indian or Malaysian origin. Out of a total of 19 participants, 14 participants conducted the digital sorting and rating tasks, and 12 attended the group meeting. The Singaporean optometrists and nurses only participated in the group discussion. Table 1 provides an overview detailing the participation of stakeholder representatives at each stage of the study. The researchers were included as representatives of the Singaporean government, which was identified as a salient stakeholder but chose not to participate.

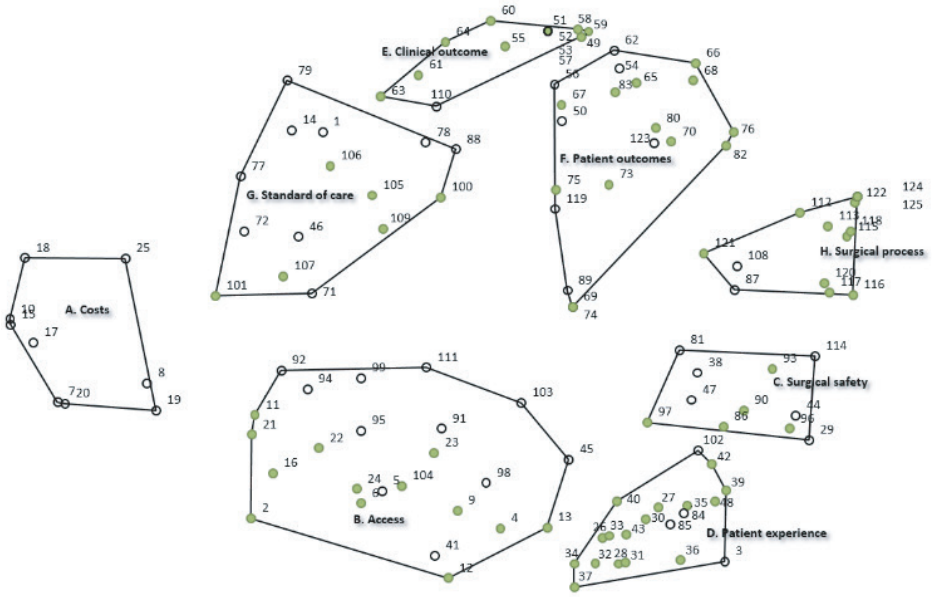

Figure 1. Multidimensional scaling (MDS) map for Singapore with eight clusters (matching items with Dutch MDS map in green).

Consensus building among stakeholders in Singapore

Singaporean stakeholder representatives sorted the 125 items into an average of 10 piles (mean (M)=10, SD=4.8) and rated them with a mean importance of M=3.75 (SD=0.38), suggesting a high overall importance of the items. The items and their average importance ratings can be found in online supplemental Appendix 1.

Stakeholder representatives reached consensus during the plenary meeting that the multidimensional scaling (MDS) map with eight clusters provided most meaningful quality dimensions. Considering the clusters clockwise as presented in Figure 1, the agreed-upon labels were as follows: clinical outcomes, patient outcomes, surgical process, surgical safety, patient experience, access, costs and standard of care. One participant completed the sorting and rating assignments after the plenary session. These additional data had only very minor effects on the resulting concept map. Subsequent adjustments were communicated to and approved by all participants involved.

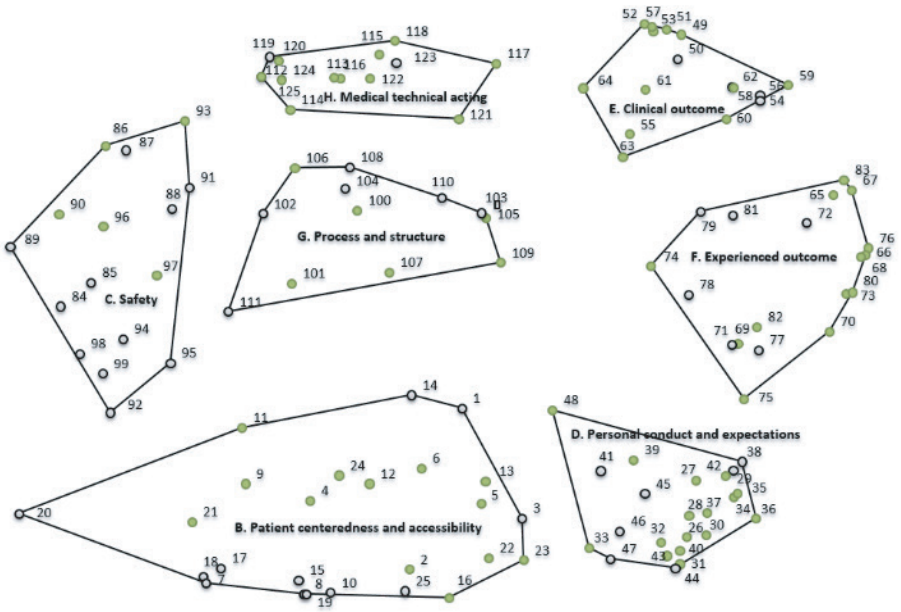

Figure 2. Multidimensional scaling (MDS) map for the Netherlands with seven clusters (matching items with Singapore MDS map in green).

The 'stress value' for the final MDS map was 0.29, indicating that the model demonstrated a satisfactory fit (concept maps have an average stress value of 0.2829). The average bridging values per cluster, which are indicative of the relative agreement on rated items, are presented in Table 2. These bridging values indicate that stakeholders demonstrated strong agreement on the grouping of outcomes and experiences (clusters D, E, F), and weaker agreement on indicators clustered as standards of care (cluster G).

Between-country comparison

As shown in Table 2, the Dutch and Singaporean MDS maps consisted of seven and eight clusters, respectively. Comparing item commonality and labelling between clusters of The Netherlands and Singapore reveals that clusters D through H can be straightforwardly mapped identically (D to D, E to E and so on) between the two countries (see online supplemental appendix 2). The overall matched number of items is maximised by matching B to B and C to C, and leaving the Singaporean cluster A (costs) unmatched. Alternatively, when allowing for one Dutch cluster to be matched to two Singaporean clusters to accommodate the difference in number of clusters, the Singaporean clusters A (costs) and B (access) can be matched to Dutch cluster B (patient centredness and accessibility).

Table 2. Dutch and Singaporean multidimensional scaling maps

THE NETHERLANDS							SINGAPORE		
Cluster	**Labels**	**Mean rating**	**Rating clusters**	**Bridging values**	**Items**	**Number of items**	**Labels**	**Mean rating**	**Rating clusters**
A	N/A	-	-	-	-	0	Costs	3.35	8th
B	Patient centeredness and accessibility	3.34	6th	0.41	1-25	25	Access	3.59	7th
C	Safety	4.01	2nd	0.73	84-99	16	Surgical safety	3.94	2nd
D	Interpersonal conduct and expectations	4.24	1st	0.15	26-48	23	Patients experience	4.05	1st
E	Clinical outcomes	3.88	4th	0.22	49-64	16	Clinical outcomes	3.89	3rd
F	Experienced outcomes	3.98	3rd	0.43	65-83	19	Patient outcomes	3.82	4th
G	Process and structure	3.82	5th	0.53	100-111	12	Standard of care	3.56	6th
H	Medical technical acting	3.27	7th	0.20	112-125	14	Surgical process	3.70	5th

NL, The Netherlands; SG, Singapore.

SINGAPORE			Corresponding items			Non-corresponding items			
Bridging values	**Items**	**Number of items**	**Number of equal items**	**% NL**	**% SG**	**Number of items only in NL**	**% NL**	**Number of items only in SG**	**% SG**
0.48	7-8, 10, 15, 17-20, 25	9	0	0	0	-	-	9	100
0.49	2, 4-6, 9, 11-13, 16, 21-24, 41, 45, 91-92, 94-95, 98- 99, 103-104, 111	24	13	52	54	12	48	11	46
0.44	29, 38, 44, 47, 81, 86, 90, 93, 96-97, 114	11	5	31	45	11	69	6	55
0.21	3, 26-28, 30, 31-37, 39, 40, 42-43, 48, 84-85, 102	20	16	70	80	7	30	4	20
0.17	49, 51-53, 55, 57- 61, 63-64, 110	13	12	75	92	4	25	1	8
0.31	50, 54, 56, 62, 65-70, 73-76, 80, 82-83, 89, 119, 123	20	13	68	65	6	32	7	35
0.70	1, 14, 46, 71-72, 77-79, 88, 100, 101, 105-107, 109	15	6	50	40	6	50	9	60
0.42	87, 108, 112-113, 115-118, 120-122, 124-125	13	11	79	85	3	21	2	15

As a result, 76 of 125 items (61%) are in matched clusters in both countries—85 (68%) when allowing the Singaporean clusters A (costs) and B (access) to be matched to the Dutch cluster B (access). Items in cluster D (patients experience), cluster E (clinical outcomes) and cluster H (surgical process) corresponded most between The Netherlands and Singapore. Items in cluster C (surgical safety) and G (standard of care) corresponded least.

In addition to appropriately matching clusters on items, the matching also resulted in matching labels to corresponding ones. For example: safety versus surgical safety and experienced outcomes versus patient outcomes. The eighth cluster that exists in Singapore but not in The Netherlands is labelled cost (discussed extensively below). Figures 1 and 2 show the MDS maps of Singapore and The Netherlands. To aid visualisation of the similarity between those MDS maps, points that represented the 76 items that were sorted in a corresponding cluster between countries are coloured green.

Stakeholder representatives of both countries rated clusters C (surgical safety) and D (patient experience) as most important. Furthermore, cluster D (patient experience) contains the most items rated in the top-10 in The Netherlands and Singapore.

DISCUSSION

Main findings

This study showed that while health-services quality dimensions and indicators for cataract surgery—as well as their importance—are largely shared between The Netherlands and Singapore according to relevant stakeholders, there are also important differences. We found that considerable inter-country similarities exist in labelling health-service quality dimensions. On the other hand, we found that the resulting dimensions and valuation of the indicators are less uniform between countries. To appreciate the differences, we interpret the results per cluster below, from the least to the highest level of correspondence.

Costs

In The Netherlands, the mandatory health insurance fully covers cataract surgery [10], whereas there is a copayment of 30% in Singapore [12]. This may explain why cost is a separate cluster in Singapore but not in The Netherlands. Consequently, many of the items included in the Singaporean cost cluster are found in the patient centredness and accessibility cluster as identified in The Netherlands.

Standard of care

Standard of care is another cluster with much difference between The Netherlands and Singapore. The Dutch nationwide registration, which contains complications, may have reinforced the importance the Dutch attach to standards—a phenomenon not found in Singapore. By contrast, public hospitals in Singapore are subjected to annual patient experience surveys by the Ministry of Health, which is not the case in The Netherlands. This might explain why Singaporean stakeholders sorted related items (eg, items 71, 72, 77, 78, 79) under standard of care, whereas The Dutch sorted them under patient outcomes.

Surgical safety

Surgical safety is found to be of high importance in both countries. Several items clustered under surgical safety by Singaporean stakeholders—for example, the provision of information and choice options for patients (items 29, 38, 44)—are included in the patient experience cluster in The Netherlands. This might be due to cultural variations in which Dutch respondents believe patients should be well informed and engage in shared decision-making on equal terms, whereas the Singaporean patients might believe the ophthalmologist should take responsibility for risks, safety and decision-making [13].

Access

The concern for costs in Singapore appears to translate to a limitation of patient choice regarding cataract surgeon, medication and type of intraocular lenses. Freedom of choice implies a higher copayment. The corresponding items related to, for example, the choice of specific cataract surgeons, prescription of medication or the type of intraocular lenses, may therefore be associated with access by Singaporean stakeholders, whereas this was not the case from the Dutch perspective.

Further, Singapore has begun only recently to adopt a model of care already established in The Netherlands. In this model, the role of the ophthalmologist is reduced and the role of others, such as optometrists and nurses, is increased. In The Netherlands, several of the items that relate to such care models (eg, 91, 104, 98, 111) ended up in clusters surgical safety and standard of care, whereas Singaporean stakeholders considered these items in the access cluster.

Patient outcomes

Despite the present discussion on value-based healthcare which emphasises the importance of patient-reported outcome measures (PROMs), the cluster patient outcomes scored fourth out of eight on average in Singapore, and the corresponding cluster scored third out of seven in The Netherlands. The PROM items 65, 66, 67, 68

were rated as relatively important by Dutch stakeholders but less so by the Singaporean stakeholders. Other clusters and indicators, particularly surgical safety and patient experience, were perceived as more important in defining the quality of cataract care.

Patients experience

In terms of average importance score, the patient experience cluster scored highest in both countries. However, patient engagement and patient involvement differ between Singapore and The Netherlands. Communication to patients and information provisioning have been institutionalised in The Netherlands for several years, while bodies such as patient councils in hospitals have not been introduced until recently in Singapore. This may explain why several items related to informing and empowering patients (eg, items 29, 38, 41, 45, 46) are clustered in the patient experience cluster by Dutch stakeholders, while the Singaporean stakeholders sorted them mostly under surgical safety.

Surgical process

The surgical process cluster overlaps by 80% among the two countries. Similar to the clinical outcomes cluster, this is likely because of the technical nature of these items, which are subject to long lasting international discussion [1,3,7,8].

Clinical outcomes

The clinical outcomes cluster shows little difference between The Netherlands and Singapore. Clinical outcomes might be relatively easy to compare globally as they are hardly affected by cultural variations across countries. The global consensus may result from the long-lasting international discussion of clinical outcomes via the scientific literature, textbooks, international ophthalmological bodies and organisations like the WAEH (World Association of Eye Hospitals). Moreover, both countries have well-established registries for clinical outcomes which are linked to international registries.

Relationship to previous studies

As previously described [1], the ICHOM cataracts standard set focuses on clinical outcomes, patient-reported outcomes and surgical techniques—indicators which are relatively straightforward to measure. The cluster clinical outcomes covers many of the indicators included in the ICHOM set. Although PROMs are included in the important cluster patient outcomes, in The Netherlands, the PROMs included in the ICHOM were not among the 10 indicators perceived as most important in The Netherlands or Singapore. Stakeholders in our study have selected other patient-related dimensions as more important in defining quality, as for instance related to communication and information provisioning. None of these highly important items are part of the current ICHOM cataracts standard set.

At the country level, our study confirms that differences in cultures and health systems result in differences in quality perspectives and comparability [21]. It confirms that existing international standardised sets such as the ICHOM cataracts standard set [1] can serve as a basis yet need refinement to adequately capture the quality perspectives of local stakeholders [2]. Appreciation of these local perspectives requires rich contextual information and can subsequently translate to country-specific quality dimensions and measures which have broad stakeholder consensus. Indeed, the current study emphasizes the importance of blending globally prioritised quality dimensions and indicators with country-specific ones. Moreover, when it comes to practical implementation in a country, it is important to compose an appropriately-sized set of indicators which are reliable and valid in the context of the country, and for which data collection is feasible. Based on stakeholder input and consensus, this set may include additional indicators [4].

Strengths and limitations

The benefits of using concept mapping to create consensus across stakeholder perspectives also come with some methodological limitations. Although participants were carefully instructed regarding the approach, participants appeared to have some difficulties with its open-ended nature (eg, the process of labelling clusters). As a result, many questions were raised during the plenary meeting regarding methodology, leaving less time for discussion and interpretation of the MDS map. In future research, more time could be allocated to explaining the theoretical background and method of concept mapping in advance. Moreover, in both countries the government was unwilling to be directly involved. While solutions were found in both countries, the lack of direct government representation is a limitation of our study.

Despite these limitations, our method of concept mapping has advantages over the Delphi method previously used to define a set of quality indicators for cataract care among stakeholders [1]. Concept mapping can better synthesise and cope with input from a broad and diverse set of stakeholders. It weighs the individual contributions provided prior to the plenary meeting equally, and subsequently creates consensus on dimensions without having to compromise on differences. Further, it gives quantified and visualised insight into dimensions and the subsequent similarities and differences between countries.

CONCLUSION

This study shows that while many similarities exist between the identified quality dimensions and their perceived importance in Singapore and The Netherlands, there are also clear differences between the two countries. Together with the differences among stakeholders per country, the findings demonstrate the importance of taking a

country-specific multi-stakeholder approach to quality definition and measurement. The implementation of country-specific quality measurement sets can be based on a common international core yet requires identifying country-specific measures to effectively reflect the quality perspectives of local stakeholders.

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APPENDIX 1. ITEMS AND CLUSTERS DERIVED FROM THE MDS MAP SINGAPORE, ALONG THEIR RATING AND BRIDGING VALUES.

Clusters and indicators		Rating value	Bridging value	References
Cluster A: Costs		**3,35**	**0.48**	
15	Patient needs permission of health insurance with regard to cataract surgery	3,57		Brouwer, W. (2006)
10	Patient has experienced problems with the permission of the health insurer with respect to cataract surgery	2,86		Brouwer, W. (2006)
7	Cataract surgery was fully reimbursed by health care insurer	3,79		Brouwer, W. (2006)
18	Cost of cataract care for patient (i.e. cost not / partially reimbursed by health insurer)	3,86		Brainstorm
17	Ophthalmologist prescribed medications that were fully reimbursed by the health insurer	3,21		Brouwer, W. (2006)
8	Patient has experienced problems with the ophthalmologist that he/she wanted to visit because they had no contract with his/her health care provider	3,43		Brouwer, W. (2006)
20	Actual costs of cataract surgery	3,79		Lundström, M. (2009)
25	Distance to hospital	2,79		Damman, O.C. (2012)
19	Patient wanted to visit an ophthalmologist for the purpose of cataract surgery that has no contract with his/her health insurer	2,86		Brouwer, W. (2006)
Cluster B: Access		**3,59**	**0.49**	
13	Amount of time for explanation of surgery to the patient	3,71		Zichtbare Zorg Ziekenhuizen (2009)
45	The ophthalmologist informs the patient during surgery about what is happening (from patient perspective)	3,36		Faber, M. (2012); Brouwer, W. (2006)
103	Registration of the presence of cataract prior to cataract surgery	3,64		NOG (2013)
23	Average length of a consultation with the ophthalmologist according to the patient	3,43		Brouwer, W. (2006)

Clusters and indicators		Rating value	Bridging value	References
4	Consultations and preoperative examinations take place on the same day	2,93		Faber, M. (2012); Zichtbare Zorg Ziekenhuizen (2009)
91	Experience of the surgeon performing the cataract surgery	4,07		Brainstorm
9	Preliminary tests for cataract surgery take place in one day	3,43		Brouwer, W. (2006)
98	Care provider qualifies drop anaesthesia as OK or as outpatient surgery	3,64		Brainstorm
22	Ophthalmologist helps the patient within fifteen minutes after agreed time	3,14		Brouwer, W. (2006)
24	Time of meeting ophthalmologist who performs cataract surgery and patient with cataract	3,21		Zichtbare Zorg Ziekenhuizen (2009)
11	Provider has a separate cataract care pathway for patients referred by their GP or by the optometrist	2,79		Holmes, K.
5	Patient has contact with the same ophthalmologist during consultations	3,93		Brouwer, W. (2006)
111	Care professional who performs the 1st-day control in patients with cataract (e.g. ophthalmologist, resident, optometrist)	3,64		Zichtbare Zorg Ziekenhuizen (2009); OCCUR; Faber, M. (2012); Van Vliet, E.J. (2010)
104	Function of doctor performing the surgery (e.g. pool, resident)	3,93		OCCUR
21	Waiting time for the cataract surgery	3,86		Brouwer, W. (2006); Damman, O.C. (2012); Zichtbare Zorg Ziekenhuizen (2009); ECHIM (2011); Conner-Spady, B.L. (2004)
41	Care is aligned with other care providers (optometrist, nurse, general practitioner, etc) from patient perspective	4,00		Brouwer, W. (2006)
16	Patient experiences problems after referral to get an appointment with the ophthalmologist as soon as he/she wants	3,57		Brouwer, W. (2006); Damman, O.C. (2012)
99	Place where cataract surgery takes place (OK / day treatment centre)	3,79		OCCUR

Clusters and indicators		Rating value	Bridging value	References
12	Manner of informing about the day and time of cataract surgery	3,14		Brouwer, W. (2006)
92	Provider is accredited	4,29		Menachemi, N. (2008)
95	Presence of formal process which takes account of urgency when planning cataract surgery	3,50		OCCUR
6	Patient has the same ophthalmologist during consolation and surgery	3,86		Faber, M. (2012); Damman, O.C. (2012)
94	Presence of formal logistics for information transfer between employees	3,50		Brainstorm
2	Patient experiences problems in reaching ophthalmology department or clinic by telephone	3,71		Brouwer, W. (2006)
Cluster C: Surgical Safety		**3,94**	**0.44**	
97	Position of the person who assists during cataract surgery	3,57		OCCUR
86	Theatre room meets the nationwide standards in respect of the prevention of infection when a cataract operation is carried out under local anaesthesia	4,50		NOG (2013)
90	Healthcare provider uses a perioperative surgical checklist	4,00		Kelly, S.P. (2013)
81	Registration of the opportunity to improve visual acuity and visual function prior to cataract surgery	3,64		NOG (2013)
96	Patient is monitored during surgery by an anaesthesiologist	4,00		Faber, M. (2013); Zichtbare Zorg Ziekenhuizen (2009)
38	Patient receives information about which activity can and cannot after cataract surgery	4,43		Brouwer, W. (2006); Zichtbare Zorg Ziekenhuizen (2009)
47	Patient has talked to anybody about the necessary help at home after cataract surgery	3,29		Brouwer, W. (2006)
114	Type of anaesthesia (drop, overall, retro bulbar, subtenon)	3,71		Lundström,M. (2012); OCCUR; Brouwer, W. (2006)

	Clusters and indicators	Rating value	Bridging value	References
93	For anaesthesia use is made of ASA (risk assessment anaesthesia)	4,21		OCCUR
44	Patient can choose between different lenses	3,71		Zichtbare Zorg Ziekenhuizen (2009)
29	Patient receives information about possible symptoms after surgery	4,29		Faber, M. (2012); Zichtbare Zorg Ziekenhuizen (2009); Brouwer, W. (2006)
Cluster D: Patients experience		**4,05**	**0.21**	
30	Ophthalmologist explains things in an understandable way (from patient perspective)	4,36		Faber, M. (2012); Brouwer, W. (2006)
31	Ophthalmologist attentively listen to patient (from patient perspective)	4,29		Brouwer, W. (2006)
26	Ophthalmologist takes the patient seriously (from patient perspective)	4,21		Faber, M. (2012); Brouwer, W. (2006)
27	Ophthalmologist provides information about the risks of surgery (from patient perspective)	4,36		Faber, M. (2012); Brouwer, W. (2006); OCCUR
33	Ophthalmologist has enough time for patient (from patient perspective)	4,07		Faber, M. (2012); Brouwer, W. (2006)
85	Ophthalmologist, nurses and other hospital staff ask patient or he / she is allergic to iodine	4,21		Brouwer, W. (2006)
36	Nurse / optometrist / TOA explains things in an understandable way to the patient (from patient perspective)	4,07		Brouwer, W. (2006)
32	Ophthalmologist is polite to patient (from patient perspective)	4,14		Brouwer, W. (2006)
28	Ophthalmologist is willing to talk with the patient about things who are not well expired (from patient perspective)	3,86		Brouwer, W. (2006)

Clusters and indicators		Rating value	Bridging value	References
84	Ophthalmologist, nurses and other hospital staff ask patient or he / she is allergic to certain medicines	4,21		Brouwer, W. (2006)
43	Ophthalmologist takes specific requirements of the patient into account (from patient perspective)	4,00		Brouwer, W. (2006)
48	Perception of ophthalmologist about the priorities of a patient to get a cataract surgery	3,50		Pager, C.K. (2004)
102	Physician determines systematic risk (e.g. COPD, dementia, deaf)	3,50		OCCUR; Faber, M. (2012); Brouwer, W. (2006)
35	Ophthalmologist, nurses and other hospital staff explained potential side effects in an understandable way to the patient	4,14		Brouwer, W. (2006)
40	Nurse / optometrist / TOA is polite to patient (from patient perspective)	3,93		Brouwer, W. (2006)
42	Patient received information about the consequences of cataract surgery for the use of glasses	4,07		Brouwer, W. (2006)
34	Decision for cataract surgery is based on the ophthalmic examination by an ophthalmologist and taken by the patient in consultation with the ophthalmologist	4,29		NOG (2013)
3	Needs assessment and decision for cataract surgery is based on the wishes of the patient	4,07		Brouwer, W. (2006); Zichtbare Zorg Ziekenhuizen (2009)
37	Nurse / optometrist / TOA attentively listen to patient (from patient perspective)	3,93		Brouwer, W. (2006)
39	Type of explanation to the patient about surgery on the first eye	3,86		Zichtbare Zorg Ziekenhuizen (2009)
Cluster E: Clinical Outcomes		**3,89**	**0.17**	
53	Postoperative complication: uveitis requiring medication	4,07		Lundström, M. (2012)
52	Postoperative complication: uncontrolled elevated intraocular pressure	4,29		Lundström, M. (2012)

Clusters and indicators		Rating value	Bridging value	References
51	Postoperative complication: persistent corneal oedema	4,21		Lundström, M. (2012); ICHOM (2014)
57	Postoperative complication: posterior capsule opacification that disrupts vision	4,07		Lundström, M. (2012)
58	Uncorrected distance visual acuity (UDVA)	4,07		OCCUR; ICHOM (2014)
59	Refractive outcome	4,00		Lundström, M. (2012); Hahn, U. (2011); Hahn, U. (2012); OCCUR
49	Complication posterior capsule rupture	4,29		Damman, O.C. (2012); Zichtbare Zorg Ziekenhuizen (2009)
55	Outcomes of treatment be mirrored with other providers	3,93		Brainstorm
64	Percentage patients having a discharge intention of one day, who have an overnight admission following cataract surgery, during the 6 months' time period	3,31		AHRG (2013)
60	Percentage of readmissions (related to the operated eye) within 28 days of discharge after cataract surgery, for 6 months	3,79		AHRG (2013)
61	Patient is operate on the same eye again after cataract surgery within 3 weeks	3,79		Brouwer, W. (2006)
110	Percentage of patient who have had cataract surgery on both eyes, and in whom was at least 2 weeks between the two successive surgeries	3,57		NOG (2013)
63	Number of cataract surgeries in patients over 50 years	3,14		Zichtbare Zorg Ziekenhuizen (2009)
Cluster F: Patient Outcomes		**3,82**	**0.31**	
62	Uncorrected near visual acuity (UNVA)	3,50		OCCUR
54	Corrected distance visual acuity (CDVA)	4,14		OCCUR; ICHOM
56	Best corrected visual acuity (BCVA)	4,14		Hahn, U. (2011); Hahn, U. (2012)
83	Not dependent of glasses after cataract surgery	3,46		Levy, P. (2010)

Clusters and indicators		Rating value	Bridging value	References
65	Visual function according to the patient / Patient Reported Outcome Measure, PROM (there are several instruments to measure visual function the Catquest-9SF is recommended)	3,77		McAlinden, C. (2011)
66	Good distance vision, e.g. recognizing people across the street (from patient perspective)	4,07		Lundström, M. (2009); Brouwer, W. (2006)
50	Complications during cataract surgery	4,29		Lundström, M. (2012); OCCUR; ICHOM (2014)
68	Good medium distance vision, e.g. reading subtitles on TV (from patient perspective)	4,00		Lundström, M. (2009); Brouwer, W. (2006)
67	Patient is satisfied / dissatisfied with current sight	4,14		Lundström, M. (2009)
123	number of sutures after cataract surgery	3,29		OCCUR
80	Good very near vision, e.g. handwork (from patient perspective)	3,79		Lundström, M. (2009); Brouwer, W. (2006)
74	Registration of limitations in visual function prior to cataract surgery	3,71		NOG (2013)
69	Recording of visual acuity prior to cataract surgery	3,93		NOG (2013)
73	Patient experiences obstacles in everyday life by the current vision	3,71		Lundström, M. (2009)
82	Degree of pain patients experienced during surgery	3,64		Faber, M. (2012); Brouwer, W. (2006)
89	Each cataract surgery is recorded and, in event of a complication, the video is discussed in a collegial consultation for learning	3,93		Brainstorm
76	Good near vision, e.g. reading newspaper (from patient perspective)	4,00		Lundström, M. (2009); Brouwer, W. (2006)
75	The provider shares its own complication rate and patient satisfaction about cataract surgery with the patient (on the website and in the patient flyer)	3,57		Brainstorm

Clusters and indicators		Rating value	Bridging value	References
119	Postoperative medication (dexamytrex, lopidine, other)	3,50		OCCUR
70	Participation in traffic (from patient perspective)	3,71		Brouwer, W. (2006); OCCUR
Cluster G: Standard of care		**3,56**	**0.70**	
88	With disappointing performance of treatment or a significantly greater number of complications, the scientific society is called for an audit or a working visit is scheduled at a better performing clinic	4,00		Brainstorm
100	Participation in nationwide registration system which include complication registration	3,36		IGZ (2013)
78	Provider uses PROM (patient reported outcome measure)	3,50		Brainstorm
105	Percentage of patients who have had cataract surgery on both eyes, and in whom a check has taken place before the second eye was operated from 1 week after surgery of the first eye	3,31		NOG (2013)
106	Manner outpatient follow-up after the first check (e.g. return as complaints, 2nd eye surgery, sue for old pathology, sue for pathology prosecute by surgery)	3,50		OCCUR
71	Score for the ophthalmologist given by patients	3,50		Faber, M. (2012); Brouwer, W. (2006)
109	Patient has been still in consultation after cataract surgery	3,57		Brouwer, W. (2006)
101	Level of care professional who performs the examinations on hospital location in the patient with cataract	3,50		Zichtbare Zorg Ziekenhuizen (2009)
107	Number of cataract surgeries per hospital location by specialism ophthalmology	3,36		Zichtbare Zorg Ziekenhuizen (2009)
72	Score for the hospital given by patients	3,15		Faber, M. (2012); Brouwer, W. (2006)
14	Way of 1st day monitoring (e.g. by telephone, in hospital, by patient)	3,79		OCCUR
79	Score for the nurse / optometrist / TOA given by patients	3,14		Brouwer. W. (2006)

Clusters and indicators		Rating value	Bridging value	References
77	Patient would recommend hospital / clinic to friends and family	3,57		Brouwer, W. (2006)
46	Ophthalmologist and other health care workers give conflicting information to patient (from patient perspective)	3,43		Brouwer, W. (2006)
1	The patient receives information about what to do after surgery in case of emergency	4,71		Brouwer, W. (2006); Faber, M. (2012)
Cluster H: Surgical Process		**3,70**	**0.42**	
124	Viscoelastic (progel, provics, other)	3,36		OCCUR
125	Location of incision (steepest axis, 100 degrees, temporal)	3,50		OCCUR
122	Incision (corneal (22 mm), corneal (28 mm), limbal, scleral, incision is enlarged, OCCI)	3,57		OCCUR
118	Cumulative Dispersed Energy (CDE) during surgery	3,36		OCCUR
115	Location of IOL implantation (sack	4,00		OCCUR
121	Duration of surgery (minutes)	3,29		OCCUR
120	Type of intraocular lens material	3,86		Lundström,M. (2012); OCCUR; Zichtbare Zorg Ziekenhuizen (2009)
112	Difficulty of surgery (e.g. small pupil, dense cataract, corneal opacities, previous vitrectomy, patient movements, floppy iris)	3,86		Lundström,M. (2012); ICHOM (2014)
113	Applied surgical technique for cataract surgery	3,93		OCCUR
116	Applied phaco technique during cataract surgery	4,07		OCCUR
117	Keratometry K1 and K2	3,71		OCCUR
87	Complications of surgery are discussed in collegial consultation and, if necessary, improvement plans drawn up and implemented	3,85		Brainstorm
108	Premium intraocular lens (multifocal, accommodating, toric IOLS)	3,71		Lundström,M. (2012)

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APPENDIX 2. NUMBER OF ITEMS IN COMMON BETWEEN SINGAPORE AND THE NETHERLANDS

	The Netherlands →								
Singapore ↓	Cluster A	Cluster B	Cluster C	Cluster D	Cluster E	Cluster F	Cluster G	Cluster H	**Total SG**
Cluster A	×	9	0	0	0	0	0	0	**9**
Cluster B	×	13	6	2	0	0	3	0	**24**
Cluster C	×	0	5	4	0	1	0	1	**11**
Cluster D	×	1	2	16	0	0	1	0	**20**
Cluster E	×	0	0	0	12	0	1	0	**13**
Cluster F	×	0	1	0	4	13	0	2	**20**
Cluster G	×	2	1	1	0	5	6	0	**15**
Cluster H	×	0	1	0	0	0	1	11	**13**
Total NL	**0**	**25**	**16**	**23**	**16**	**19**	**12**	**14**	**125**

Note: Arced cells indicate matching clusters between Singapore and The Netherlands

CHAPTER 7

Explaining valuation of health service quality using prospect theory: a case study in cataract care

Revised for Social Science and Medicine:
Stolk-Vos AC, Arthur EA, Michelle M, van de Klundert JJ. Explaining valuation of health service quality using prospect theory: a case study in cataract care.

ABSTRACT

Objectives

This study aims to compare the valuation of health service quality by patients and other stakeholders through a case study in cataract care.

Methods

The valuation of health service quality by Dutch patients, ophthalmologists and healthcare purchasers involved in cataract care are elicited by a prospect theory-based measurement task. Respondents stated preferences for probabilities and scores for the clinical indicator Complication (posterior capsular rupture with vitreous loss) and the patient-reported experience measure Information Provisioning (the ophthalmologist provides sufficient information about risks of cataract surgery to the patient). Our subject pool (n=256) consisted of 90 ophthalmologists, 125 cataract patients, and 41 healthcare purchasers employed by health insurance companies.

Results

Following prospect theory, respondents were loss averse, and risk averse for gains. However, utilities differed from prospect theory, especially the concave utility for losses. Patients were significantly more loss averse than the other respondents, more subject to a pessimistic view on losses, and had significantly more concave utility for losses, especially for the clinical quality indicator Complications. For each of the stakeholders, the results differed significantly between the two essentially different quality indicators.

Conclusions

The heterogeneous valuations of patients and other stakeholders invalidate commonly applied cataract care quality assessment frameworks. Incorporating loss aversion, pessimism and concave utility for losses can remedy existing shortcomings. The valuation differences between patients and other stakeholders emphasize the need for communication and shared decision making in patient-centered treatment, purchasing and policy.

INTRODUCTION

Patients and other stakeholders in healthcare increasingly consider healthcare quality indicator scores when choosing and evaluating health services and providers. In many countries, forms of public reporting and ranking have been made available, based on Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs) in addition to clinical and health outcome measures. However, patients attach difference importance to the quality indicators figuring in these reporting frameworks and rankings than other stakeholders, such as physicians, management, health insurance companies, and policy makers [1]. This hampers the validity of current quality frameworks that express healthcare quality as a weighted sum of indicator scores, as for instance used by insurers for purchasing purposes and in quality rankings published to guide patient decision making [2-4]. The methodological shortcomings of the underlying linear additive logics based on expected utility are well documented [5-10], as are the disproportional effects on hospital reputation [11, 12].

This study investigates alternative valuation methods of healthcare quality with higher validity, especially with regard to valuation by patients. To this purpose we conduct a case study investigating quality evaluations of patients receiving cataract care, as well as the evaluations of two other important stakeholder groups of cataract care, ophthalmologists and purchasers employed by health insurance companies (henceforth purchasers). Cataract surgery is selected for our study purposes as it is one of the oldest and most frequently performed surgical procedures worldwide [13]. The condition is still responsible for 5% of blindness in developed countries and 50% of blindness in low- and middle-income countries [13]. Several quality frameworks and indicator sets for cataract care have been developed and are widely implemented by stakeholders across the globe [14, 15].

There is a growing body of evidence showing that the valuation of health outcomes partially follows Prospect Theory (PT, see Box 1) and therefore is not a linear function of health outcomes. These studies have focused on utility and/or probability weighting of health outcomes, such as QALYs and life expectancy, and involved respondents from proxy groups, the general population, and patients [e.g., 16-19]. Instead of such general health outcome indicators, our study considers two commonly adopted indicators which are of specific importance in cataract care quality frameworks.

Box 1. Prospect Theory
In Prospect Theory (PT), every individual has an initial condition for assessment, a *reference point*, which may for instance represent the current status. The valuation of increases above the reference point, called *gains*, and of decreases below the reference point, called *losses*, varies with the proximity to the reference point (reference dependence) [20]. More specifically, PT assumes that the value function is S-shaped with the reference point in the flection [21]. Furthermore, PT proposes a kink at the reference point, reflecting a steeper value function for losses than for gains. This phenomenon is known as *loss aversion* and indicates that losses loom larger than gains of the same magnitude [22]. Finally, individuals tend to transform probabilities into decision weights in a nonlinear fashion, usually underweighting high probabilities and overweighting low probabilities (*probability weighting*). The resulting probability weighting function has an inverse S-shape and may be different for gains and losses [13].

The aim of our study is to provide a deeper and more accurate understanding of the valuations of quality indicators scores by relevant stakeholders and of the differences in valuation between patients and other relevant stakeholders. We therefore conduct a case study on the valuation of cataract care quality involving patients, ophthalmologists and purchasers in the Netherlands. More specifically, our research tests the hypotheses that the valuations of these stakeholders are different and follow PT.

By providing a more accurate scientific understanding of the (differences in) valuation of the quality in cataract care by patients and other stakeholders, the results are intended to contribute to resolving the aforementioned shortcomings of quality frameworks commonly applied in practice and corresponding negative effects on patient centeredness of cataract care.

METHODS

Study design

The preferences of the stakeholders regarding the valuation of healthcare quality measures are elicited by a bisection procedure. In the bisection procedure, respondents are repeatedly asked to choose between two options to elicit their valuations [23]. We now first describe the selection of indicators and subsequently turn to the bisection procedure and the analysis methods.

We selected the indicators and their corresponding levels based on a previously determined list of 125 items to measure quality in cataract care. The 125-item list was generated through a systematic search of the scientific and grey literature in Embase, PubMed, Scopus, and Google [1]. The 125 items were previously clustered into seven quality dimensions using Concept Mapping [1] and their importance was rated on a scale

from 1-5 by all relevant stakeholders. In a first round, indicators were selected from that list according to five criteria:

1. *Interpretability.* All respondents are competent to interpret the indicator. For example, the indicator does not contain medical terminology.
2. *Importance.* The selected indicator must have an average importance score of 4.5 or higher for each of the three stakeholder groups involved (as reported in [1]).
3. *Continuous outcome.* The indicator must be a continuous outcome measure to facilitate bisection.
4. *Variation.* The indicator value can vary across settings, to facilitate realistic differences in values between settings in the choices made during the bisection process.
5. *Data availability.* Empirical data is available for the indicator to construct realistic choice sets.

Nine of the 125 items on the list met the selection criteria. Six of these nine items regarded the quality dimension 'patient experience' [1]. Out of these six items, we selected the item rated as most important within the dimension 'patient experience' [1], which was the PREM addressing the information provision to a patient by her/his ophthalmologist. Of the other three indicators, we selected an indicator of a very different, more technical, nature, from the quality dimension 'clinical outcomes'. This indicator regarding complications relates to treatment effectiveness and is of importance in value-based healthcare [14]. The resulting two selected distinct indicators covering patient-reported data and clinical data are:

1. *Complication: posterior capsular rupture with vitreous loss*
2. *Ophthalmologist gives sufficient information about risks of cataract surgery to patient*

While they are distinct and from different quality dimensions, these two indicators together are not intended to form a proxy of the much wider (seven dimension) construct of quality of cataract care. These indicators are further referred to as 'Complications' and 'Information Provision'.

We investigate preferences over two-outcome lotteries $(x,p;y,1-p)$, giving outcome x with probability p $(0<p<1)$ and outcome y with probability $1-p$. We assume respondents behave according to PT, with reference-dependent preferences with respect to a reference point r. Gains are outcomes that are strictly preferred to r and losses are outcomes strictly less preferred to r. Gain prospects involve no losses, loss prospects involve no gains, and mixed prospects involve both a gain and a loss.

We use commonly adopted parametric shapes to model the utility function and the probability weighting function. For utility, we estimate the power function ($U(x) = x^{\alpha}$ for gains and $U(x) = -(-x)^{\beta}$ for losses), with $U(x)$ the utility of outcome x, $\alpha,\beta > 0$, and $\alpha < 1$ [>1] implying a concave [convex] utility for gains, $\beta < 1$ a convex [concave] utility for losses, while $\alpha, \beta = 1$ implies linear utility.

We model probability weighting with Prelec's [24] one-parameter function: $w^i(p)=\exp\{-(-\ln(p))^{\gamma}\}$, where $w^i(p)$ represents the decision weight given to probability p, $i=+,-$ (i.e., we have separate weighting functions for gains and losses), and γ for gains and δ for losses. For $0 < \gamma < 1$, this function has an inverse S-shape, with overweighting of small probabilities and underweighting of large probabilit ies. For complications, this implies that respondents would give too much weight to a small probability of fewer complications, too little weight to higher probabilities, and that they are not very sensitive to changes in intermediate probabilities. Hence, for $0 < \gamma < 1$, this function causes insensitivity to probabilities in the middle, and extreme sensitivity to changes from impossible to possible (e.g., a slight change from $p = 0$ to $p = 0.01$) and from possible to certain (e.g., from $p = 0.99$ to $p = 1$). Expected utility theory [25] is the special case of this function when $\gamma = 1$, in which case there is no probability weighting.

Loss aversion is modelled by multiplying the utility of losses by the loss aversion index λ. Respondents are classified as loss averse if $\lambda > 1$, gain seeking if $\lambda < 1$, and loss neutral if $\lambda = 1$. Here, $\lambda > 1$ implies that respondents give more weight to deteriorations in Complications and Information Provision than to comparable improvements. Appendix 1 gives a derivation of our regression equations that result from these models.

Data collection

Data collection took place by digital and paper surveys. The digital version of the survey was built using Qualtrics. The survey started with background information explaining the study rationale, indicators, and levels. Sociodemographic data (age, sex) were collected to assess if these factors influenced stated preferences. Completion of the survey took approximately 15-30 minutes.

The draft survey was administered to a sample of ophthalmologists, policy makers of an eye hospital and patients from the patient council of an eye hospital. The resulting feedback on the length, lay out and wording led to adjustments by consensus among the researchers. The piloted draft survey with the background information confirmed the interpretability of the somewhat technical complications indicator by patients.

Our subject pool (n=256) consisted of 90 ophthalmologists, 125 cataract patients, and 41 purchasers (115 women, 141 men) recruited between September 2018 and Augustus 2019. All participants gave informed consent to participate.

Adult cataract patients were recruited at the outpatient clinic of the Eye Hospital Rotterdam by one ophthalmologist (MM). The ophthalmologist handed out envelopes containing an invitation letter, the paper version of the survey, a return envelope and a reimbursement form for a book receipt. 250 patients received an envelope with questions regarding indicator I and 200 patients received an envelope with questions regarding indicator II. The ophthalmologist registered who received an envelope. Patients received a phone call from a research assistant to remind them to complete the survey. Patients were offered a book voucher of €10 for participation.

Ophthalmologists and ophthalmologists in training at the Eye Hospital Rotterdam (n=65) were invited by a researcher (AS). After a presentation about the study during a clinical meeting, they received an email with a link to the survey. They were reminded to participate by email and in person (by AS and MM). All other ophthalmologists in The Netherlands (n=675) were recruited by post letter. The letter contained a QR-code and a short link to fill in the digital version of the full survey. Ophthalmologists were reminded to participate by post letter.

Purchasers employed by health insurer companies were recruited by contacting one or more employees at the health insurer company who subsequently invited healthcare purchasing professionals within their own organization by email with a survey link. Five companies were contacted and willing to participate. The combined market share of the health insurer companies included is around 90%.

Ophthalmologists and purchasers were incentivized to participate by a donation of €10 to Aravind Eye Hospital India made by the researchers for every fully completed survey.

The bisection procedure is a common way to elicit preferences in economic experiments [23, 26]. In short, a bisection procedure elicits indifferences between two options by requesting several iterative choices. One of the options remains fixed throughout the entire list, while the other becomes more attractive or less attractive, conditional upon the previous choice. The resulting indifference point gives an indication of the preferences of the respondent.

The experiments always started with the task on Complications. Since complications are a bad outcome, i.e., people generally prefer to have fewer complications, a reduction in complications is considered a gain, while an increase is seen as a loss. In the task, respondents were instructed to consider two hospitals. One hospital had one full-time ophthalmologist the respondent would see for sure when choosing that hospital. The other hospital had two ophthalmologists both working part-time. When choosing that hospital, the respondent would be assigned to either of these two ophthalmologists depending on chance. The probability p of being assigned to either of the two ophthalmologists equalled the fraction of the week (s)he was on duty.

For each ophthalmologist, a specified number of complications per 1,000 surgeries was given. The instructions mentioned that the national average number of complications was 100 per 1,000 surgeries, which was used as the reference point r. In the gain part, the number of complications was always smaller than or equal to 100 per 1,000. In the loss task the number of complications was always larger than or equal to 100 per 1,000 (with a maximum of 200).

For example, let Hospital A have part-time Ophthalmologist 1 on duty 2 days per week with 50 complications out of 1,000 (a gain of 50 relative to the reference point of 100 complications per 1,000) and Ophthalmologist 2 on duty the other 3 weekdays, with 80 complications out of 1,000 (a gain of 20). The best outcome is to see Ophthalmologist 1, which has probability $p = 0.4$ (2/5). The worst outcome is to see Ophthalmologist 2, with probability $1 - p = 0.6$ (3/5). The alternative choice is to select Hospital B where the respondent sees Ophthalmologist 3 for sure (i.e., $p = 1$). The complication rate of Ophthalmologist 3 in Hospital B varies in the experiment between the complication rates of the two ophthalmologists in Hospital A. In our example, the complication rate for Hospital B varies between 80 per 1,000 and 50 per 1,000 and therefore the gain varies between 20 and 50. Now, the lower the gain in Hospital B for which the respondent would be indifferent between Hospitals A and B, the more risk averse is the respondent. A respondent that prefers Hospital B if it offers a complication rate of 70 per 1,000 (gain of 30) to avoid the risk of being assigned to Ophthalmologist 2 in Hospital A (with complication rate 80 per 1,000) and forego the opportunity to see Ophthalmologist 1 in Hospital A (complication rate 50 per 1,000), is more risk averse than a respondent who only prefers Hospital B if the complication rate in Hospital B is 60 per 1,000 or less (and therefore willing to take the risk of being assigned to Ophthalmologists 2 in Hospital A if the complication rate in Hospital B is 70 per 1,000).

We asked 5 choice questions in the gain part and 5 in the loss part, in both tasks. This number sufficed to enable estimation of the parameters and was not too cognitively demanding.

We elicited fulltime equivalents (FE's) from these binary choices. Both for Complications and for Information Provision, FE's describe the outcome in Hospital B that a respondent accepts to be indifferent between the outcomes of Hospitals A and B. For each question, an FE was estimated as the mean of the largest sure gain that was turned down and the smallest sure gain that was preferred to Hospital A. If all sure gains were chosen, the FE was estimated as the mean of the smallest sure gain of Hospital B and the worst possible outcome of Hospital A. If no sure gain was chosen, the FE was estimated as the mean of the largest gain of Hospital B and the best possible outcome of Hospital A.

The loss part was the same as the gain part except that the two possible outcomes in Hospital A were worse than the national average. To elicit loss aversion, a mixed-prospect bisection procedure was used. Table 1 presents the outcomes offered for the Complications task.

Table 1. Stimuli for the "Complications" task.

Number	**Hospital A (*p,x*; 1-*p, y*)**	**Hospital B**
	Losses	
1	(0.5, 200; 0.5, 100)	CL1
2	(0.5, 200; 0.5, 150)	CL2
3	(0.9, 175; 0.1, 100)	CL3
4	(0.7, 200; 0.3, 100)	CL4
5	(0.35, 175; 0.65, 100)	CL5
	Gains	
6	(0.5, 0; 0.5, 100)	CG1
7	(0.5, 50; 0.5, 100)	CG2
8	(0.1, 0; 0.9, 75)	CG3
9	(0.3, 0; 0.7, 100)	CG4
10	(0.65, 0; 0.35, 75)	CG5
	Mixed	
11	(0.5, CM; 0.5, 150)	100

The design of the Information Provision task was similar to the design of the complications task. Respondents were asked to imagine the same situation with two hospitals, one with one ophthalmologist and one with two part-time ophthalmologists. Now, the outcome was replaced by the relative number of times sufficient information was provided. Again,

five indifferences were elicited, for each of the gain, loss and mixed tasks. Table 2 presents the stimuli for the Information Provision task.

Table 2. Stimuli for the Information Provision task.

Number	Hospital A (p,x; 1-p, y)	Hospital B
	Losses	
1	(0.5, 650; 0.5, 750)	IL1
2	(0.5, 675; 0.5, 750)	IL2
3	(0.1, 650; 0.9, 700)	IL3
4	(0.3, 650; 0.7, 750)	IL4
5	(0.65, 650; 0.35, 700)	IL5
	Gains	
6	(0.5, 1000; 0.5, 750)	IG1
7	(0.5, 1000; 0.5, 875)	IG2
8	(0.9, 950; 0.1, 750)	IG3
9	(0.7, 1000; 0.3, 750)	IG4
10	(0.35, 950; 0.65, 750)	IG5
	Mixed	
11	(0.5, IM; 0.5, 825)	750

Data analysis

The outcomes were normalized to facilitate comparison between the tasks. For Complications, outcomes were divided by 100, resulting in a normalized value in the range [-1,1]. For Information Provision, we divided outcomes by 250.

The parameters of functions 1 and 2 were estimated by nonlinear regression [18]. The gain parameters α and γ were estimated simultaneously using the responses to questions 6 to 10 (from Tables 1 and 2). The same was done for the loss parameters β and δ with the responses to questions 1 to 5 (from Tables 1 and 2). The loss aversion coefficient λ was assessed by means of the indifference value obtained from the responses in the mixed prospect together with the other parameters obtained (see. Appendix 1).

RESULTS

Reference dependence, probability weighting, loss aversion

For all respondents together, Table 3 shows the medians and interquartile ranges for the five parameters $\alpha, \beta, \gamma, \delta, \lambda$ (medians are shown instead of averages because of some outliers). To facilitate interpretation of the results, let us recall that PT hypothesizes $\alpha < 1$, i.e., concave utility for gains and $\beta < 1$, i.e., convex utility for losses. Moreover, it proposes

$\gamma, \delta < 1$, representing overweighting of small probabilities and underweighting of large probabilities, and $\lambda > 1$, reflecting loss aversion.

Table 3. Medians and interquartile ranges (IQR) of parameter estimates for both tasks.

	α	β	γ	δ	λ
Complications					
Median	0.953	**1.321**	**0.400**	**0.254**	**1.356**
IQR	0.671-1.477	0.885-2.052	0.237-0.686	0.032-0.778	0.476-2.788
N	199	193	199	193	186
Information					
Median	1.012	**1.341**	**0.239**	**0.533**	**1.898**
IQR	0.673-1.538	0.912-2.027	0.059-0.738	0.192-0.896	0.167-122.6
N	147	147	147	147	146

*Bold numbers reflect a significant difference from 1 (Wilcoxon signed ranks test)

The results in the first two columns of Table 3 reject the hypothesis that the valuation follows PT. For gains, the utility power estimates of the reference dependent valuations are not significantly different from 1 ($p=0.364$ for Complications and $p=0.227$ for Information Provision). Interestingly, for losses, the estimates are significantly higher than 1 (instead of less than 1), confirming reference dependence yet contradicting PT. Comparing the two tasks, we see that respondents have a more concave utility function for losses for Information Provision than for Complications ($p<0.01$).

Columns 3 and 4 of Table 3 confirm PT regarding probability weighting for gains and for losses for both tasks ($p<0.01$), indicating probabilistic pessimism [27]. Column 5 confirms PT as loss aversion indices are higher than 1 for both tasks ($p<0.01$). Respondents were more loss averse for Information Provision than for Complications ($p<0.01$), while there are no differences in the probability weighting ($p=0.888$ for losses and $p=0.652$ for gains).

Table 4 presents the median parameters estimates for patients, ophthalmologists and purchasers separately. It suggests several differences between patients and the other stakeholders, as is confirmed by statistical tests. Patients have more concave utility for losses ($p<0.01$ for ophthalmologists vs. patients, $p=0.02$ for purchasers vs. patients), are more subject to probabilistic pessimism for losses ($p<0.01$ for both comparisons) and are more loss averse ($p<0.01$ for ophthalmologists vs. patients, $p=0.056$ for purchasers vs. patients). We find no such differences for gains (only marginally significantly higher γ for purchasers, $p=0.072$). Moreover, no differences are observed between ophthalmologists and purchasers.

Table 4. Median parameter estimates per subject group (interquartile ranges in parentheses)

	α	*β*	*γ*	*δ*	*λ*
Complications					
Ophthalmologist (n=77)	0.973 (0.764-1.541)	1.189 (0.901-1.534)	0.383 (0.153-0.740)	0.524 (0.156-0.909)	1.117 (0.427-1.717)
Purchaser (n=37)	0.988 (0.831-1.199)	1.320 (1.018-1.611)	0.483 (0.321-0.720)	0.592 (0.245-0.943)	1.327 (0.774-2.058)
Patient (n=81)	0.891 (0.313-1.733)	1.765 (0.765-16.417	0.297 (0.237-0.686)	0.146 (0-0.433)	2.348 (0.475-45,513)
Information					
Ophthalmologist (n=59)	1.071 (0.654-1.559)	1.320 (0.946-2.011)	0.239 (0-0.663)	0.414 (0.120-0.829)	1.450 (0.158-136.4)
Purchaser (n=34)	0.965 (0.853-1.150)	1.351 (1.143-1.662)	0.399 (0.092-0.709)	0.448 (0.135-0.760)	2.923 (0.679-16.16)
Patient (n=52)	0.961 (0.346-4.922)	1.341 (0.637-6.587)	0.230 (0.071-2.043)	0.673 (0.503-0.898)	1.777 (0-inf.)

Table 5. Regression estimates (standard errors in parentheses)

Explanatory variable	***α* Comp**	***γ* Comp**	***β* Comp**	***δ* Comp**	***λ* Comp**	***α* Info**	***γ* Info**	***β* Info**	***δ* Info**	***λ* Info**
Dummy Male	0.46 (0.39)	0.14 (0.14)	-0.77 (0.75)	0.12 (0.10)	-2912 (4548)	-0.41 (0.42)	0.22 (0.23)	0.09 (0.76)	-0.19 (0.17)	Inf. (inf.)
Dummy Patient	-0.16 (0.54)	0.26 (0.19)	3.41 (1.06)***	-0.07 (0.14)	15968 (6397)**	1.07 (0.57)*	0.22 (0.31)	1.05 (1.04)	0.21 (0.23)	Inf. (inf.)
Dummy Purchaser	-0.76 (0.54)	-0.13 (0.19)	-0.01 (1.03)	-0.12 (0.13)	-1217 (6165)	-0.47 (0.53)	-0.07 (0.29)	-1.22 (0.96)	0.01 (0.21)	Inf. (inf.)
Age	0.03 (0.02)*	-0.01 (0.01)	0.04 (0.03)	-0.01 (0.004)*	229 (193)	-0.01 (0.02)	0.01 (0.01)	0.01 (0.03)	0.01 (0.01)	Inf. (inf.)

Dependent variable

* Significant at the 10% level. ** Significant at the 5% level. *** Significant at the 1% level.

In addition, interesting differences emerge when comparing the two tasks for each of the respondent groups. For both ophthalmologists and purchasers, we find that utility for losses is more concave for Information Provision (Wilcoxon signed ranks test, $p<0.03$) and loss aversion is higher for Information Provision ($p<0.01$). For patients however, utility of Complications was significantly more concave ($p<0.04$), even though the number of respondents who did both tasks was low (n=13). A between-subjects test in which we could include more respondents did not confirm this finding (Mann-Whitney test, $p=0.34$), although we did find significantly more probability weighting for losses for the Complications task there ($p<0.01$).

In addition to the above, we found a positive correlation between age and loss aversion for Complications ($p<0.05$). Moreover, older respondents have more convex gain utility and more concave loss utility for Complications ($p<0.01$). Older people also have more probability weighting for losses ($p<0.02$ for Complications and $p<0.05$ for Information Provision). No gender effect is present, except for probability weighting for gains in Information Provision, where women show marginally significantly more probability weighting ($p<0.06$).

Finally, we ran ordinary least squares regressions where we combined these explanatory variables in one model (Table 5). The results revealed significant effects for patients on β and λ for Complications. For age there were some marginal effects. This suggests that the significant differences between patients and other respondents were driven by their respondent type rather than by their older age.

Risk aversion

The majority of choices (around 60%) were risk averse for both Complications and Information Provision, both for gains and for losses. However, there were some significant differences in risk aversion within tasks, depending on the probabilities (Friedman tests, $p<0.01$). These differences were consistent with the usual pattern predicted by PT, with more [less] risk aversion for higher [lower] probabilities of the best outcome. This phenomenon is known as the fourfold pattern of risk [22]. Figures 1 and 2 plot the average risk premiums against the probabilities of the best outcomes in the lotteries. Figure 3 and 4 does the same for losses, where the average risk premiums are shown as a function of the probability of the worst outcome of the lotteries.

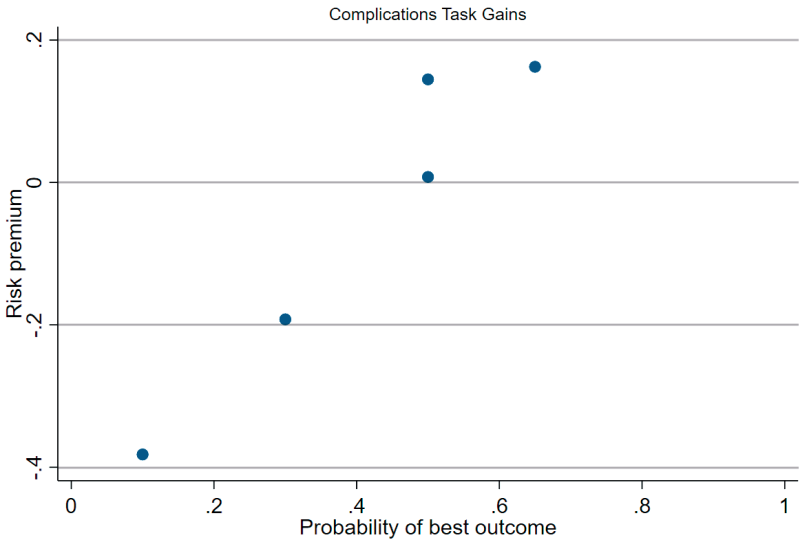

Figure 1. Average risks premiums against probabilities of the best outcomes in Hospital A for Complications

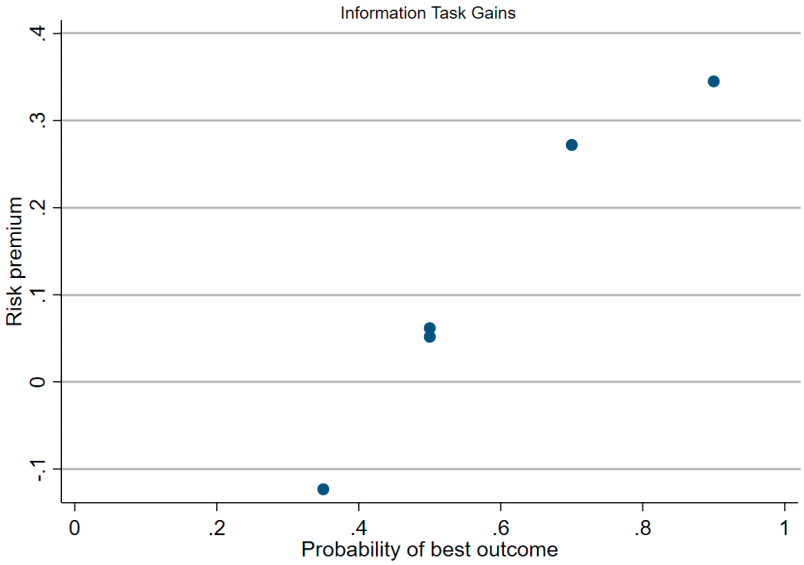

Figure 2 Average risks premiums against probabilities of the best outcomes in Hospital A for Information Provisioning

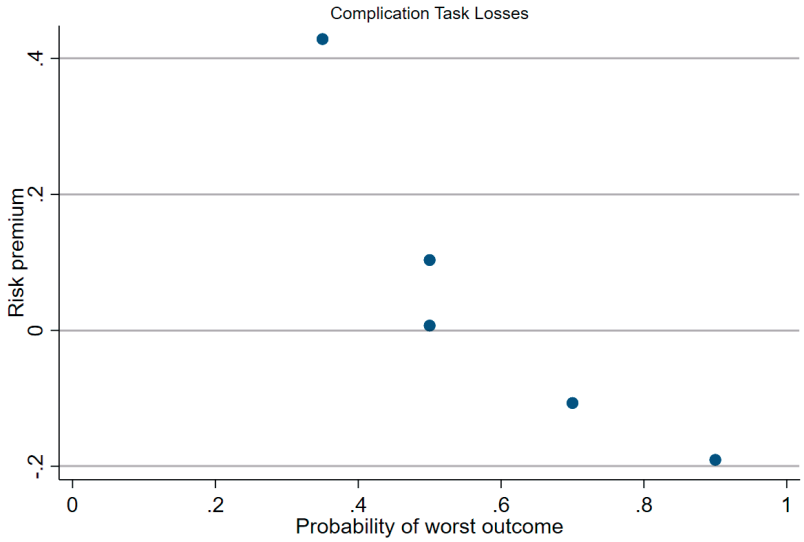

Figure 3. Average risks premiums against probabilities of the worst outcomes in Hospital A for Complications

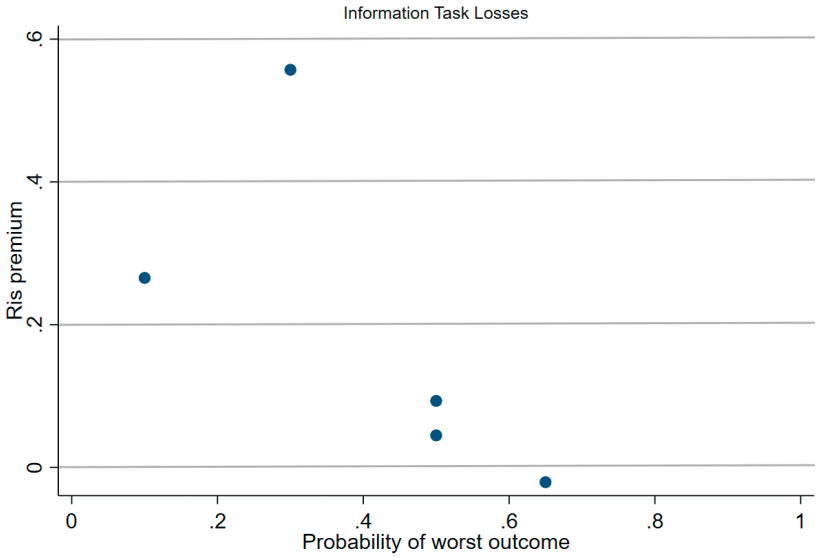

Figure 4. Average risks premiums against probabilities of the worst outcomes in Hospital A for Information Provisioning

DISCUSSION

This study provides the first quantitative estimation of valuation of health service quality by patients and other stakeholders using PT. The stated patient preferences differed significantly from the preferences of ophthalmologists and healthcare purchasers, and partially followed PT. Our results are not the first evidence partly supporting PT in the healthcare domain [16-19]. However, the study is the first to include actual patients and other stakeholders as respondents to evaluate quality indicator scores rather than health outcomes. Moreover, our study is explicit about risk framing and advances beyond additive linear expected utility-based risk modelling as recently called for [38].

A Prospect Theory perspective

In conformance with PT, we found significant loss aversion and an inverse S-shaped function for probability weighting. In contrast to PT however, we found no significant deviations from expected utility for gains and a concave utility function for losses. Moreover, the value functions of the patients differed significantly from those of the ophthalmologists and purchasers. Taken together, our results therefore invalidate existing practical frameworks and expected utility-based models valuing healthcare quality as a weighted sum of indicator scores. Such frameworks tend to disregard nonlinear utility for losses, los aversion, and probability weighting, all of which especially applied to patients.

Our finding of concave utility for losses confirms previous studies in the health domain [18, 30] and provides further evidence that valuation within the health domain is different from valuation in the monetary domain [31-33]. Together with the large loss aversion values found, the concavity reveals that especially patients weigh quality losses increasingly heavily. This is further exacerbated by probability weighting in case variation in quality increases. This risk aversion regarding the quality indicators on the highly standardized treatment cataract surgery contrasts with the risk seeking behaviors found for the progressive disease MS for which no effective standardized cure is presently known [39].

Patients' valuations deviate more from expected utility than the valuations of ophthalmologists and purchasers. Patients gave more weight to losses and were more risk averse for losses, especially regarding Complications. By contrast, ophthalmologists and healthcare purchasers were more loss averse for Information Provision than for Complications. Further research is needed to understand why the valuation of quality differs between stakeholders and indicators, e.g., is it different for clinical outcomes than for PROMs and PREMs [36]?

Empirical findings on perspectives of patients, ophthalmologists and purchasers

The differences found between the risk and quality preferences of patients and other stakeholders emphasize the importance of including the patient perspective in quality assessment and shared decision making [28, 29]. A patient-centered approach requires ophthalmologists and purchasers to make the patient's valuation leading and not to follow their own valuations of quality measures and risks. If, however, one perceives patient valuations to deviate too much from expected utility, then purchasers and physicians need to better inform patients or correct for these biases after learning the patient preferences [16].

Limitations

The strength of including actual stakeholders in our study may in turn bring along some limitations. The complexity of the task may impact the quality of response and lead to bias in respondent groups, e.g., excluding older patients and time-pressed professionals. Another limitation of our method might be that all patients are recruited by one physician at one hospital. A third limitation might be the relatively small number of purchasers included, even though respondents cover almost all Dutch healthcare insurers. To strengthen validity and reliability, we encourage future studies to include patients from multiple ophthalmologists and hospitals and to be conducted in larger and/or multiple countries.

Conclusions

The identified heterogeneity in the valuation of quality indicator scores for cataract care invalidates commonly adopted quality assessment frameworks and therefore has implications for the construction of such frameworks and for cataract care provisioning, purchasing and policy. To be representative of stakeholder quality valuation, and specifically of quality valuations by patients, frameworks need to adopt nonlinear valuations of quality scores which express the loss aversion of patients, concave utility for losses, and the probability weighting of variation in outcomes instead of being solely based on average scores. For decision making on the services provided to individual patients, the results give new forms of support to the importance of communication and shared decision making when aiming for patient-centered care and for the practice to incorporate communication and shared decision making in treatment guidelines, purchasing practices, and regulatory policy.

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APPENDIX 1

Using functions (1) and (2), the utilities of gain prospects were evaluated as follows:

$$(\exp\{-(-\ln(p))^{\gamma}\}) \times (x^{\alpha} - y^{\alpha}) + y^{\alpha}. \quad \text{(A1)}$$

Similarly, for loss prospects we get:

$$\left(\exp\left\{-(-\ln(p))^{\delta}\right\}\right) \times \left(-(-x)^{\beta} + (-y)^{\beta}\right) - (-y)^{\beta}. \quad \text{(A2)}$$

We assume that observable utility U is a composition of a loss aversion coefficient λ and a basic utility u (Köbberling and Wakker, 2005):

$$U(x) = \begin{cases} u(x)\ if\ x \geq 0 \\ \lambda u(x) if\ x < 0 \end{cases}. \quad \text{(A3)}$$

As a result of Eqs. 1, 2 and A3, the evaluation for mixed prospects becomes:

$$(\exp\{-(-\ln(p))^{\gamma}\}) \times x^{\alpha} + \lambda \times \left(\exp\left\{-(-\ln(1-p))^{\delta}\right\}\right) \times -(-y)^{\beta}. \quad \text{(A4)}$$

For gains, an indifference is evaluated by:

$$z^{+\alpha} = (\exp\{-(-\ln(p))^{\gamma}\}) \times (x^{\alpha} - y^{\alpha}) + y^{\alpha}. \quad \text{(A5)}$$

We can solve this equation for Z^{+} to obtain the regression equation:

$$z^{+} = [(\exp\{-(-\ln(p))^{\gamma}\}) \times (x^{\alpha} - y^{\alpha}) + y^{\alpha}]^{1/\alpha}. \quad \text{(A6)}$$

Likewise, for losses we get:

$$z^{-} = \left[\left(\exp\left\{-(-\ln(p))^{\delta}\right\}\right) \times \left(-(-x)^{\beta} + (-y)^{\beta}\right) - (-y)^{\beta}\right]^{1/\beta}. \quad \text{(A7)}$$

Setting equation A4 equal to 0:

$$(\exp\{-(-\ln(p))^{\gamma}\}) \times x^{\alpha} + \lambda\left(\exp\left\{-(-\ln(1-p))^{\delta}\right\}\right) \times y^{\beta} = 0. \quad \text{(A8)}$$

Solving (A8) for λ yields:

$$\lambda = -\frac{(\exp\{-(-\ln(p))^{\gamma}\}) \times x^{\alpha}}{\left(\exp\left\{-(-\ln(1-p))^{\delta}\right\}\right) \times -(-y)^{\beta}}. \quad \text{(A9)}$$

Now, λ can be computed by inserting the four gain and loss parameter estimates, together with the relevant values of p, x and y, into Eq. A8.

CHAPTER 8

General discussion

The best 'oliebollen' rankings have been given up as a result of persistent criticism on the methods used to compose the ranking. Despite receiving comparable criticism, however, quality rankings in the healthcare domain continue to exist. If we believe indeed that such rankings should be provided, we need to advance the methods and our understanding of the quality perspectives of patients and all other stakeholders involved. As described in the introduction, there is a lack of consensus among stakeholders on what constitutes 'quality' in healthcare. This holds for many domains of healthcare, including ophthalmology, which is the domain of healthcare addressed in this thesis. This lack of consensus makes it difficult to compare the quality of care provided by hospitals and to compose hospital rankings. What should be taken into account when measuring 'quality' and what should better be disregarded? Inconsistency, arbitrariness, and lack of clarity in quality definitions and measures are undesirable for patients as well as for other stakeholders such as ophthalmologists, hospital managers and health insurers. Therefore, the aim of this thesis was to identify various perspectives on quality of care in ophthalmology and to systematically address commonalities and differences among the perspectives of patients and other stakeholders.

In this chapter we discuss the main findings of this thesis. We start with conclusions regarding the research aims formulated in Chapter 1. Next, we reflect upon the results and discuss implications for the various stakeholders involved.

Conclusions

The first objective of this thesis was to gain understanding of how patients perceive and evaluate the quality of ophthalmic care. The first part of this thesis showed that patients attach much value to process indicators in addition to the more commonly considered clinical outcomes and patient-reported outcomes. For example, adult patients with chronic uveitis considered five main themes important when evaluating healthcare quality: the process of diagnosis and treatment, disease symptoms and treatment, impact on daily functioning, emotional impact, and treatment success factors (Chapter 2). Two out of those five themes explicitly focused on the process side of healthcare quality. To illustrate, access to a medical specialist familiar with the (rare) disease and its idiosyncratic course appears highly valued by patients. Further, we conclude that simple digital tools, such as the EYEpad, can be helpful in supporting patients to perceive more involvement in their care process and we underline the crucial role clinicians have during implementation of such devices (Chapter 3). Regarding outcomes indicators, we conclude that patient reported outcome measures (PROMs), like Catquest-9SF, are important in gaining insight into patients' perspective on quality. We showed that the information PROMs provide in addition to clinical parameters accounted for a broader view of treatment outcomes and can improve patient-centred approaches in clinical practice (Chapter 4).

The second objective of this thesis was to gain understanding of the commonalities and differences in perspectives on the quality of cataract care between various stakeholders. The second part of this thesis showed that stakeholders agreed on the set of dimensions that constitute cataract care quality (Chapter 5). We found that the identified quality dimensions share a common core between countries yet need to be complemented with different country-specific measures for effective local application (Chapter 6). Moreover, chapters 5 and 6 provide evidence that stakeholders weigh the importance of jointly agreed quality indicators differently. Stakeholders directly involved in the cataract care delivery process, i.e., patients and ophthalmologists, strongly correlated in their importance rating of quality indicators, yet differed from the stakeholders not directly involved in the care delivery process, such as hospital managers and health insurers (Chapter 5). Hence, any weights applied in rankings would represent the views of at most one of the stakeholder groups. Furthermore, we showed that the valuation of the jointly agreed quality indicators by stakeholders significantly differs from the linear additive logic commonly applied in rankings. Instead, it partially follows prospect theory. However, in contrast with prospect theory, especially patients weigh quality losses increasingly heavily and significantly more heavily than other stakeholders (Chapter 7). These findings invalidate the logics applied in existing rankings. Moreover, bringing these findings to practice can improve communication among stakeholders and the decision making in treatment, purchasing and policy. This is especially important as most stakeholders viewed patients to lack power, signaling that patients are not empowered and that the care might not be patient-centered (Chapter 5). Hence the findings support calls to improve patient-centeredness and involve patients in decision making to ensure patient values are leading.

Reflection

The idea of patients being involved in their own treatment as a self-governing and autonomous individual has been encouraged by the World Health Organization for several decades[1]. Patient-centeredness requires that patient views are to be respected, especially when they are different. This amplifies the relevance of our finding that patients weigh quality losses more heavily than clinicians and health insurers (Chapter 7).

One way of looking at the various stakeholders in healthcare is through the lens of stakeholder theory. According to stakeholder theory stakeholders are identified on three relationship attributes: power, legitimacy and urgency [2]. Our finding show that patients are perceived to lack power in cataract care. (Chapter 5). Such lack of power is detrimental for patient-centeredness in cataract care, since power is the probability that one is in the position to carry out their own will despite resistance [2]. Limited power of patients can, therefore, inhibit the will of the patient being carried out by other stakeholders. This lack of power can be overcome through increased patient involvement

of patients by clinicians during the treatment process. This thesis provides examples of tools to help patients engage more with their clinicians and with their own treatment (Chapter 3 and Chapter 4). The use and application of these tools, such as the PROM instruments do not only require time from patients, but also from hospital management (to introduce and implement these tools) and from clinicians (to discuss the outcomes of these tools with patients). However, if properly implemented, PROMs can improve patient-clinician communication, clinician awareness of symptoms, and patient satisfaction [3].

Patient-centeredness is also important as our research reveals that in addition to the commonalities, differences exist in the perspectives on healthcare quality among patients and other stakeholders (Chapter 4-7). Commonalities between patients and clinicians are found in the strong correlation in their rating of which domains are important to define healthcare quality. For example, both patients and clinicians highly valued personalized treatment and patients' experiences (Chapter 5). The commonality between patients and clinicians is also seen in the close relation between clinical outcomes of cataract surgery and the PROM Catquest-9SF. To illustrate, surgery led to a large improvement in the visual function as indicated by patients in their Catquest-9SF outcomes. This improvement in visual functioning measured by the Catquest-9SF was particularly strong in patients who had surgery on both eyes. Postoperative complications had a negative effect on visual functioning (Chapter 4). Nevertheless, the Catquest-9SF has a broader perspective on relevant cataract care outcomes. For example, the Catquest-9SF includes topics related to impact on daily functioning. The use of PROMs such as Catquest-9SF to improve the quality of cataract care has been receiving more endorsement recently in cataract care (see e.g. Zijlmans et al. [4]).

Health insurers were also found to have their own perspective on the quality of cataract care. This is especially relevant for the Dutch health system as they have a responsibility towards patients. Health insurers are expected to act as customer-driven buyers of care on behalf of the people they insure [5,6]. This might be complicated when health insurers' view towards healthcare quality differs from those of patients. Health insurers are more focused on clinical outcomes and safety, whereas patients are more focused on personalized treatment and patients' experiences (Chapter 5). This brings up the question whether health insurers are sufficiently patient-centered in their purchasing decisions if they focus on other domains of cataract care quality than patients do.

The stakeholders not only differ in the weights they attach to quality indicators, but also in how they value indicator scores. We questioned existing logics, as for instance applied in healthcare quality rankings. Instead of the usual linear additive logic, we hypothesized

that prospect theory (PT) applies to healthcare quality indicator valuation [7]. In PT subjective values are modeled by a value function that is convex for losses, concave for gains, and steeper for losses than for gains (loss aversion). Further, the impact of probabilities is characterized by a weighting function that overweighs low probabilities and underweights moderate to high probabilities (probability weighting). Especially in patients these additional characteristics of PT appeared relevant when valuing healthcare quality (Chapter 7). Moreover, the differences with other stakeholders underline the above conclusions to increase patient-centeredness. The obtained results imply that healthcare rankings which determine overall healthcare quality as a weighted sum of indicator scores do not represent the perspective of any set of stakeholders. To have validity and be patient-centered, rankings must more carefully address utility, loss aversion and probability weighting. This holds particularly true for the patient perspective, as patients stood out for the concavity of utility for losses and for loss aversion.

Implications

The outcomes of this thesis have several clinical and practical implications for the stakeholder groups involved. Below, we discuss these implications for patients, clinicians, hospital managers and health insurers.

Implications for patients

Patients are advised to further empower themselves to ensure their perspective comes across. Patient empowerment could take place on an individual level, and this thesis showed two examples of how patients take a more prominent role in their treatment process. First, patients can complete PROMs, such as the Catquest-9SF described in Chapter 4, to monitor their disease experiences and explain to their clinicians how they experience their health status. Patients can also pro-actively discuss their PROMs during consultation, as they are important to them. Therefore, the information PROMs additionally provide when compared to clinical parameters can improve patient-centered approaches in clinical practice and enhance patient empowerment. Second, patients can make use of health technology, such as EYEpad described in Chapter 3, to increase engagement in their own care process. Increased patient participation by PROMs and use of health technology can reduce the gap patients experience with clinicians. It can help to discuss personal questions or issues that may interfere with their treatment. Patient empowerment could also be organized groupwise. Patients can for instance join patient organizations which in turn can exert power on the cure and care for their patient group. For example, patient organizations are increasingly involved in process improvement, e.g. when optimizing care pathways. Patient-centeredness can be better embedded in the process (re)design. Growing such initiatives can promote patient-centeredness of cataract care.

As described in Chapter 7, patients especially weigh quality losses more heavily than other stakeholders. In any real intent to improve patient-centeredness, these patient valuation of cataract care quality should become leading. That being said, if patient valuations portray a lack of understanding of the treatment process and outcomes, interventions to better inform and educate patients are necessary.

Implications for other stakeholder groups: clinicians, managers and health insurers

It is important for each stakeholder groups to be aware of the differences between their perspective on quality of cataract care and the perspectives of other stakeholders. Understanding of different viewpoints can benefit the communication and collaboration. For example, as cataract patient generally have high expectations about treatment outcomes, clinician awareness of patient expectations can guide clinicians to informing patients about treatment options and corresponding outcomes, resulting in increased patient satisfaction [8]. PROMs can be valuable instruments to this purpose as discussing PROMs outcomes with patient may help in formulating and designing future treatment.

Hospital managers are more aligned with stakeholders not directly involved in care than with patients and clinicians in their rating of healthcare quality indicators (Chapter 5). Therefore, hospital managers are advised to critically appraise whether these valuation differences with patients and ophthalmologists on processes and outcomes are inhibiting patient-centeredness. At an institutional level, hospital managers can set up the systems which ensure that patients are involved in defining quality, design and evaluation of health services, and last but not least that every patient is systematically informed, involved, and empowered in the decision making on their treatment. For example, hospital managers can promote and implement the use of PROMs, which as noted above, can improve patient-centered approaches in clinical practice and enhance patient empowerment. Hospital managers are advised to involve clinicians during development of supportive tools to improve patients participation. Such clinician involvement is essential for adoption and implementation of such innovations, which might be perceived as 'extra work load' if introduced top-down (Chapter 3).

As mentioned, health insurers are focused on other healthcare quality domains than patients. This brings up the question whether they are sufficiently patient-centered in their purchasing decisions. To actually act as customer-driven buyers of care on behalf of the people they insure, health insurers need to understand and adopt the patient perspective and implement patient-centered procurement practices, in alignment with the principles of people-centred health services [9]. Moreover, health insurers can reward or request that hospitals put systems in place to involve and empower patients in the decision making

on quality in treatment and outcomes in hospitals in their contracting. These systems can operate both on a general level, in the form of patient representation in managerial decision and in process (re)design, and on the treatment level, in shared decision making together with clinicians. Although several initiatives exist to ensure patients' input and agreement, further advancements are recommended as involvement of the patient perspective can increase quality of care (see e.g., Malfait et al. [10]).

Concluding remarks

Overall, we have identified various perspectives on quality of care in ophthalmology by systematically addressing commonalities and differences among the perspectives of patients and other stakeholders. We have shown how patients and other relevant stakeholders differ and overlap in their valuation of quality of care. We have demonstrated this on the level of quality indicators, quality dimensions, and between countries. Our results highlight the importance of empowering patients to improve healthcare quality.

Returning to the thoughts and ambitions that gave rise to this thesis as presented in Chapter 1, we have to conclude that the simple 'oliebollen-lijstjes' are of limited value when it comes to judging hospitals. Therefore, our recommendation is to end these 'oliebollen-lijstjes'-like quality rankings in healthcare. They do not represent the views of any stakeholder or subset of stakeholders and therefore are better abandoned, just like the newspaper 'oliebollen' ranking. Especially the poor representation of the patient perspective stands in sharp contrast with the global advancements on patient-centeredness in which the patient perspective is increasingly leading. When truly aspiring to put the patient at the center of healthcare, the patient perspective should take the central place in healthcare quality frameworks.

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SUMMARY

SUMMARY

Chapter 1 is the introduction to this thesis. It describes how the problems associated with using rankings in healthcare gave rise to the studies presented in this thesis. In evaluating the quality of healthcare, each stakeholder, or stakeholder group will have his/her own perspective on what constitutes quality. These different perspectives have led to a plethora of indicators that consequently cause great variety in rankings of healthcare quality. This problem with defining "the best quality" holds true for many areas in healthcare, including ophthalmic care. Therefore, the aim of this thesis is to *identify various perspectives on quality of care in ophthalmology by systematically addressing commonalities and differences among the perspectives of patients and other stakeholders*. This thesis consists of two parts. The first part of this thesis, Chapter 2 to Chapter 4, consists of studies that focus on the patient perspective within cataract care and chronic uveitis. In the second part of this thesis, the studies described in Chapter 5 to Chapter 7, multi-stakeholder perspectives within cataract care are addressed.

Chapter 2 describes a qualitative study based on focus group interviews with 20 adult chronic uveitis patients. The aim of this study was to determine which factors chronic uveitis patients consider important when evaluating the impact of their disease and treatment. This resulted in a conceptual model with five themes that patients considered important for the quality of their healthcare: disease symptoms and treatment, diagnosis and treatment process, impact on daily functioning, emotional impact, and success factors. This conceptual model can contribute to the development of an uveitis specific set of indicators to measure quality of uveitis care in adult patients.

Chapter 3 investigates the experience of patients and nurses with a digital application for information provision to increase patient engagement during their treatment. A qualitative study with semi-structured interviews with 17 patients and a focus group discussion with 6 nurses was conducted to explore the feasibility of a digital patient-led checklist for cataract patients who underwent surgery in an ambulatory setting. The 'EYEpad' checklist was distributed to patients and their companions during their hospital visit via an application on a tablet. It contained items with regard to necessary information that the patient should have received before or during the surgical preparation (8 items), before anesthesia (2 items), and before discharge (9 items). The results showed that simple digital tools, such as the EYEpad, can be helpful in supporting patients to engage more in their care process and underlined the crucial role clinicians have in the implementation of such devices.

Chapter 4 describes a quantitative study in which the health-related quality of life data reported by 870 patients using PROM Catquest-9SF is compared to clinical data retrieved from patients' medical files. Patient-reported outcomes were collected before and after cataract surgery in five Dutch hospitals. Clinical data consisted of surgery in one eye or both eyes, ocular comorbidity and per- and postoperative complications. This study showed that the additional information from PROMs to clinical parameters accounted for a broader view of treatment outcomes and can improve patient-centred approaches in clinical practice.

Chapter 5 describes a concept mapping study to define a multi-stakeholder perspective on quality in cataract care. First, stakeholder of cataract care in The Netherlands were identified and classified using stakeholder theory. Seven definitive stakeholders were identified: the Dutch Ophthalmology Society, ophthalmologists, general practitioners, optometrists, health insurers, hospitals and private clinics. Results showed that most stakeholders viewed patients to lack power, signaling that patients are not empowered and that the care might not be patient-centered. Second, 18 stakeholders representing ophthalmologists, general practitioners, optometrists, health insurers, managers of hospitals, managers of private clinics, patients, patient federation and the Dutch Healthcare Institute sorted 125 systematically collected indicators. After multivariate statistical analyses resulting in multidimensional cluster maps, they subsequently defined seven consensus-based quality dimensions in a plenary session: patient-centeredness and accessibility, interpersonal conduct and expectations, experienced outcome, clinical outcome, process and structure, medical technical acting, and safety. Importance scores from stakeholders directly involved in the cataract service delivery process correlated strongly, as did scores from stakeholders not directly involved in this process. This study demonstrated the feasibility of unifying different quality perspectives in a way that was accepted by relevant stakeholders.

Chapter 6 advances the understanding of globally valid versus country-specific quality dimensions and indicators in cataract care, as perceived by relevant stakeholders. Following the approach of Chapter 5, 19 Singaporean stakeholders of cataract care representing patients, general practitioners, ophthalmologists, nurses, care providers, researchers and clinical auditors established a multi-stakeholder perspective on quality of cataract care using a concept mapping approach. They defined eight quality dimensions: clinical outcome, patient outcomes, surgical process, surgical safety, patient experience, access, cost, and standards of care. Thereafter, Singaporean dimensions were matched with dimensions obtained in The Netherlands to identify internationally commonalities and differences. This study showed that the identified quality dimensions share a common

core between countries (61%), although need to be complemented with country-specific measures for effective local application.

Chapter 7 explores the valuation of quality indicators by patients, ophthalmologists and health insurers using prospect theory to a case study in cataract care. The preferences and trade-offs of the stakeholders involved were elicited by a bisection procedure. Two quality indicators were selected: ´complication: posterior capsular rupture with vitreous loss´ and ´ophthalmologists provide sufficient information about risks of cataract surgery to patients´. The subject pool (n=256) consisted of 125 cataract patients, 90 ophthalmologists, and 41 persons employed by health insurance companies. This study showed that the evaluation of quality indicators by stakeholders significantly differs from the linear additive logic commonly applied in rankings. We found that especially patients weight quality losses more heavily than other stakeholders.

Chapter 8 is a general discussion and elaborates on how the findings of the studies described in Chapter 2 to Chapter 7 advanced our understanding in how patients and other relevant stakeholders differ and overlap in their definition and valuation of healthcare quality. This chapter concludes that simple rankings are of limited value when it comes to judging hospitals. They do not represent the views of any stakeholder or subset of stakeholders and therefore are better abandoned. Especially the poor representation of the patient perspective stands in sharp contrast with the global advancements on patient-centeredness. When truly aspiring to put the patient at the center of healthcare, the patient perspectives should take the central place in healthcare quality frameworks.

NEDERLANDSE SAMENVATTING

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Hoofdstuk 1 is de inleiding van dit proefschrift. Het beschrijft hoe de knelpunten door het gebruik van ranglijsten in de gezondheidszorg aanleiding gaven tot de studies die in dit proefschrift worden gepresenteerd. Bij het beoordelen van de kwaliteit van de zorg zal elke stakeholder, of stakeholdergroep, zijn/haar eigen perspectief hebben op wat kwaliteit is. Deze verschillende perspectieven hebben geleid tot een veelheid aan indicatoren, die vervolgens voor grote variatie zorgen in de ranglijsten van kwaliteit van zorg. Dit probleem met betrekking tot het definiëren van "de beste kwaliteit" geldt voor veel gebieden in de gezondheidszorg, waaronder ook de oogheelkundige zorg. Het doel van dit proefschrift is daarom om de verschillende perspectieven op kwaliteit van zorg in de oogheelkunde te identificeren door systematisch aandacht te besteden aan overeenkomsten en verschillen in de perspectieven van patiënten en andere stakeholders. Dit proefschrift bestaat uit twee delen. Het eerste deel van dit proefschrift, Hoofdstuk 2 tot en met Hoofdstuk 4, bestaat uit studies die zich richten op het patiëntperspectief binnen de zorg voor patiënten met cataract en chronische uveïtis. Het tweede deel van dit proefschrift, Hoofdstuk 5 tot en met Hoofdstuk 7, behandelt studies over multi-stakeholder perspectieven binnen de cataractzorg.

Hoofdstuk 2 beschrijft een kwalitatief onderzoek gebaseerd op focusgroep interviews met 20 volwassen patiënten met chronische uveïtis. Het doel van deze studie was om te bepalen welke factoren patiënten met chronische uveïtis belangrijk vinden bij het evalueren van de impact van hun ziekte en behandeling. Dit resulteerde in een conceptueel model met vijf thema's die patiënten belangrijk vinden voor de kwaliteit van hun zorg: ziektesymptomen en behandeling, diagnose en behandelproces, impact op het dagelijks functioneren, emotionele impact en succesfactoren. Dit conceptuele model kan bijdragen aan de ontwikkeling van een uveïtis-specifieke set van indicatoren om de kwaliteit van uveïtiszorg bij volwassen patiënten te meten.

Hoofdstuk 3 onderzoekt de ervaring van patiënten en verpleegkundigen met een digitale applicatie voor informatievoorziening waarmee de patiëntbetrokkenheid vergroot wordt tijdens de behandeling. Een kwalitatief onderzoek gebaseerd op semi-gestructureerde interviews met 17 patiënten en een focusgroep interview met 6 verpleegkundigen werd uitgevoerd om de haalbaarheid te onderzoeken van een digitale patiënt-gestuurde checklist voor cataractpatiënten die geopereerd werden in een ambulante setting. De checklist 'EYEpad' werd tijdens het ziekenhuisbezoek aan patiënten en hun begeleiders uitgedeeld via een applicatie op een tablet. De checklist bevatte items met betrekking tot informatie die de patiënt had moeten ontvangen vóór of tijdens de chirurgische voorbereiding (8 items), vóór de anesthesie (2 items) en vóór

ontslag (9 items). De resultaten toonden aan dat eenvoudige digitale hulpmiddelen, zoals de EYEpad, behulpzaam kunnen zijn bij het ondersteunen van patiënten om meer betrokken te zijn bij hun zorgproces en onderstrepen de cruciale rol die clinici spelen bij de implementatie van dergelijke applicaties.

Hoofdstuk 4 beschrijft een kwantitatief onderzoek waarin de gezondheid gerelateerde gegevens over kwaliteit van leven, gerapporteerd door 870 patiënten middels de PROM Catquest-9SF, worden vergeleken met klinische gegevens, verkregen uit de medische dossiers van patiënten. Patiëntgerapporteerde uitkomsten werden verzameld voor en na een cataractoperatie in vijf Nederlandse ziekenhuizen. Klinische gegevens bestonden uit chirurgie aan één oog of beide ogen, oculaire co-morbiditeit en per- en postoperatieve complicaties. Deze studie toonde aan dat de aanvullende informatie van de PROMs op de klinische parameters een bredere blik oplevert op de behandelresultaten en de patiëntgerichte benaderingen in de klinische praktijk kan verbeteren.

Hoofdstuk 5 beschrijft een 'concept mapping'-studie om een multi-stakeholder perspectief op kwaliteit in cataractzorg te definiëren. Eerst zijn stakeholders van cataractzorg in Nederland geïdentificeerd en geclassificeerd met behulp van stakeholdertheorie. Er werden zeven definitieve stakeholders geïdentificeerd: het Nederlands Oogheelkundig Genootschap, oogartsen, huisartsen, optometristen, zorgverzekeraars, ziekenhuizen en privéklinieken. De resultaten toonden dat de meeste stakeholders vonden dat patiënten geen macht hadden, wat signaleert dat patiënten onvoldoende empowerment hebben en dat de zorg mogelijk niet patiëntgericht is. Vervolgens hebben 18 stakeholders, die vertegenwoordigers waren van oogartsen, huisartsen, optometristen, zorgverzekeraars, managers van ziekenhuizen, managers van privéklinieken, patiënten, patiënt federatie en het Nederlands Zorginstituut, 125 systematisch verzamelde indicatoren gesorteerd. Na multivariate statistische analyses, die resulteerden in multidimensionale figuren, definieerden ze vervolgens zeven op consensus gebaseerde kwaliteitsdimensies in een plenaire sessie: patiëntgerichtheid en toegankelijkheid, bejegening en verwachtingen, ervaren uitkomsten, klinische uitkomsten, proces en structuur, medisch technisch handelen en veiligheid. Het gescoorde belang van de indicatoren door stakeholders die direct betrokken waren bij het zorgproces van de cataractzorg correleerden sterk, evenals scores van stakeholders die niet direct bij dit proces betrokken waren. Deze studie toonde de haalbaarheid aan van het verenigen van verschillende kwaliteitsperspectieven op een manier die aanvaard was voor relevante stakeholders.

Hoofdstuk 6 vergroot de kennis van wereldwijd geldige versus land specifieke kwaliteitsdimensies en indicatoren in de cataractzorg, zoals onderscheiden door

relevante stakeholders. Aan de hand van dezelfde aanpak als in Hoofdstuk 5, hebben 19 Singaporese stakeholders van de cataractzorg, die vertegenwoordigers waren van patiënten, huisartsen, oogartsen, verpleegkundigen, managers van zorgaanbieders, onderzoekers en klinische auditoren, een multi-stakeholderperspectief op de kwaliteit van cataractzorg vastgesteld met behulp van de 'concept mapping'-aanpak. Ze definieerden acht kwaliteitsdimensies: klinische uitkomsten, patiënt uitkomsten, chirurgisch proces, chirurgische veiligheid, patiëntervaring, toegang, kosten en zorgstandaarden. Daarna werden de Singaporese dimensies gematcht met de dimensies verkregen in Nederland om internationale overeenkomsten en verschillen te identificeren. Deze studie toonde aan dat de geïdentificeerde kwaliteitsdimensies een gemeenschappelijke kern hebben tussen landen (61%), maar moeten worden aangevuld met land-specifieke indicatoren voor een effectieve lokale toepassing.

Hoofdstuk 7 onderzoekt de waardering van kwaliteitsindicatoren door patiënten, oogartsen en zorgverzekeraars met behulp van prospecttheorie in een case study in de cataractzorg. De voorkeuren en afwegingen van de betrokken stakeholders werden uitgelokt door een bisectie procedure. Er zijn twee kwaliteitsindicatoren geselecteerd: 'complicatie: posterieure kapselruptuur met glasvochtverlies' en 'oogartsen geven patiënten voldoende informatie over de risico's van de cataractchirurgie'. De deelnemers (n=256) bestond uit 125 staarpatiënten, 90 oogartsen en 41 personen die werken bij zorgverzekeraars. Deze studie toonde aan dat de evaluatie van kwaliteitsindicatoren door stakeholders significant verschilt van de lineaire additieve logica die gewoonlijk wordt toegepast in ranglijsten. We vonden dat vooral patiënten het kwaliteitsverlies zwaarder wegen dan andere belanghebbenden.

Hoofdstuk 8 is een algemene discussie en gaat in op hoe de bevindingen van de studies beschreven in Hoofdstuk 2 tot en met Hoofdstuk 7 ons begrip hebben vergroot in hoe patiënten en andere relevante stakeholders verschillen en overlappen in hun definitie en waardering van de kwaliteit van de gezondheidszorg. Dit hoofdstuk concludeert dat eenvoudige rankings van beperkte waarde zijn als het gaat om het beoordelen van ziekenhuizen. Ze vertegenwoordigen het perspectief van geen ene stakeholders of een subgroep van stakeholders en kunnen daarom beter worden losgelaten. In het bijzonder staat de ondervertegenwoordiging van het patiëntperspectief in schril contrast met de wereldwijde vooruitgang op het gebied van patiëntgerichtheid. Wanneer het streven werkelijk is om de patiënt centraal te stellen in de zorg, dient het patiëntperspectief een centrale plaats in te nemen binnen de kwaliteitskaders voor de zorg.

ABBREVIATION

ABBREVIATION

ASC	ambulatory surgical center
CME	cystoid macula oedema
eHealth	electronic health
gPCM	generalized partial credit model
ICHOM	International Consortium for Health Outcome Measurement
IOL	intraocular lens
MDS	multidimensional scaling
Ministry of VWS	Ministry of Health, Welfare and Sport
NEI-VFQ-25	25-item National Eye Institute Visual Function Questionnaire
NL	The Netherlands
NOG	Dutch Ophthalmic Society
NPCF	Dutch Patient Federation
PROM	Patient-reported outcome measure
PT	prospect theory
SF-36	SF-36 Health Survey
SG	Singapore
VA	visual acuity
WHO	World Health Organisation

ABOUT THE AUTHOR

CURRICULUM VITAE

Alida Caroline (Aline) Stolk-Vos was born on July 15th 1987 in 's-Hertogenbosch, the Netherlands. After graduating from secondary school (Gymnasium) at the Jacobus Fruytier Scholengemeenschap in Apeldoorn in 2005, she started her bachelor's in Health Sciences at the Vrije Universiteit Amsterdam. During her Bachelor's, she did a scientific internship at division of Human Nutrition and Health, Wageningen University & Research, which was her first hands-on experience with scientific research. Thereafter, Aline obtained her Master degree in Prevention & Public Health at the Vrije Universiteit Amsterdam, for which she performed a scientific internship at division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute – Antoni van Leeuwenhoek Hospital. This internship resulted in her first academic publication.

In 2009, Aline started her working career as a researcher at GGD Rotterdam-Rijnmond. She participated in a team that worked on the Rotterdam Youth Monitor, a longitudinal youth health surveillance system integrated into preventive youth healthcare in the Rotterdam area. Thereafter, Aline worked as a management consultant at KPMG Plexus, KPMG Netherlands, a leading consultancy in health. She worked on challenging projects across the broad spectrum of the healthcare sector, which aroused her interest in healthcare quality.

In 2013 the opportunity of a PhD-position in quality of ophthalmic care came arose at the Rotterdam Eye Hospital in collaboration with Erasmus School of Health Policy and Management, Erasmus University Rotterdam and the Medical Psychology and Psychotherapy section, Erasmus MC. During her PhD she gave birth to two sons and a daughter and moved back to the place she grew up on the Veluwe. Since 2020, Aline has been working as a policy advisor (Dutch: zorgexpert) at health insurer Menzis, a job where she can apply her expertise and passion for healthcare quality.

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PHD PORTFOLIO

PhD training	Year
General courses	
Oogheelkundige Leergang (Het Oogziekenhuis)	2013-2014
Systematisch literatuuronderzoek in Pubmed (Erasmus MC)	2013
Systematisch literatuuronderzoek in andere databases (Erasmus MC)	2013
Research integrity (ESHPM, EUR)	2014
Biomedical English writing and communication (Erasmus MC)	2016
Specific courses	
Clinical Decision Analysis (NIHES)	2013
Methods of Health Services Research (NIHES)	2013
Qualitative research (IQ Healthcare)	2013
Introduction concept mapping (Concept Systems Global)	2014
Discrete Choice Experiments in healthcare (Maastricht University)	2015
Journal club (Rotterdam Ophthalmic Institute)	2013-2015
Monthly research meetings (Rotterdam Ophthalmic Institute)	2013-2019
Presentations	
Research meeting Rotterdam Ophthalmic Institute (Oral presentation)	2013
Management team Rotterdam Eye Hospital (Oral presentation)	2014
Employee meeting Rotterdam Eye Hospital (Oral presentation)	2014
Visiting la Fondation Asile des aveugles Lausanne at Rotterdam Eye Hospital (Oral presentation)	2014
8th annual meeting World Association of Eye Hospitals (Oral presentation)	2014
European Healthcare Management Association (Oral presentation)	2014
Research meeting Rotterdam Ophthalmic Institute (Oral presentation)	2015
International Forum for Quality and Safety (Poster contribution)	2017
ICHOM conference 2019 (Poster contribution)	2019
(Inter)national conferences	
Symposium Achmea Health Database (Achmea, The Netherlands)	2013
Symposium Science in Transistion (Erasmus MC, The Netherlands)	2014
8th annual meeting World Association of Eye Hospitals (WEAH, India)	2014
Conference DICA (DICA, The Netherlands)	2014
Annual meeting European Healthcare Management Association (EHMA, The Netherlands)	2014
International Forum for Quality and Safety (BMJ Quality and Safety, England)	2017
ICHOM conference 2019 (ICHOM, The Netherlands)	2019
ICHOM conference 2020 (ICHOM, virtual)	2020
Other activities	
Workgroup WAEH	2014
Supervising Bachelor's thesis	2014
Visiting Singapore National Eye Centre	2018

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DANKWOORD

DANKWOORD

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