

It's your Choice!
A Study of Search and Selection Processes,
and the Use of Performance Indicators in Different Patient Groups.

De keuze is aan u!
Een studie naar zoek- en keuzeprocessen en het gebruik
van prestatie-indicatoren in verschillende patiëntengroepen

Proefschrift

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Summary

In the last few years, the Dutch health care system has undergone the most radical changes since the Second World War. Most people are now aware that competition has become one of the leading principles of the new health care system. A tangible expression of this change came when, on 1 January 2006, all Dutch citizens had to choose a health care insurer. Under the new system, citizens are given more freedom of choice, more choice options and thus more responsibilities for their own choices in health care – not just in their role as insured parties, but also as patients. Most policymakers and scholars are convinced that people are not able to make deliberate choices on the health care market unless they are provided with accessible and understandable information about the price and quality of a particular treatment. However, defining the quality of a health care product has proved to be much more difficult than translating its costs into a price (something with which citizens are not really confronted because of their insurance). As a consequence, great efforts have been in the realms of policy and research to defining relevant aspects of quality, its measurement and the public disclosure of its results. Performance or quality indicators are instruments that are increasingly being used as a means of inducing transparency in health care quality.

This doctoral thesis investigates and answers the question as to the extent to which performance indicators (can) play a role in the search and selection processes of patients who are looking for a health care provider.

Chapter 1 provides an introduction to this research question. It describes recent developments that have changed Dutch health care from a supply-driven to a more demand-driven system, based on the principles of regulated competition. In addition, it reveals the Achilles heel of the health care market – the asymmetrical relationship between patients and their doctors – and stresses the importance of consumer information for patients. This leads to the above research question.

The other chapters of this thesis (apart from chapters 8 and 9) can be divided into three parts:

Part I: Performance indicators and choice processes: an exploration of the phenomenon and the underlying theory

Chapter 2 describes the way in which performance indicators were introduced into health care and discusses their different functions: research, external accountability and internal quality improvement. It then presents an overview of the discussions that are being held about the suitability, usefulness and desirability of performance indicators as an instrument for providing consumer information. Some authors claim that performance indicators are not suitable for this purpose because they merely give an indication of the quality instead of measuring it. Others argue that 'patients' (whoever they may be) do not involve quality information in their decision processes and that it therefore makes no sense to supply them with information on quality. Finally, other authors claim that patients do not want to have to choose at all and that it would only make them unhappy to be given choice options and quality information. However, many of these arguments are too generalistic and are not based on fundamental research. For this reason, chapter 2 concludes that performance indicators may be useful as an instrument for quality information, and that the precise role they play in patients' search and selection processes has still to be studied.

The second part of chapter 2 reports on an inventory of existing health care quality information. The inventory was carried out at the very start of this study (2002-2003). When the existing quality information was compared to patients' stated need for information, it became apparent that most of the existing quality information was not available to individual patients. A second striking result was that most quality information related to the physical locations of health care deliverers, rather than to health care products, which is the level of information that patients are interested in. The third and final conclusion of this study was that while many initiatives were being taken at that time to inform consumers, hardly any attention was paid to the question of which information patients actually want and which search and selection processes lead patients to their health care deliverer.

Chapter 3 reports on a literature review on the search and selection processes of patients with long lasting diseases. It concludes that the lion's share of the existing body of knowledge relates to 'Decision Aids', tools that are used to support patients who have to make decisions during their treatment (e.g. whether or not to undergo breast resection in the case of breast cancer). However, the step that precedes that decision, namely the search for and selection of a doctor, a hospital, etc., has to date not figured in many studies. Despite this, looking at decisions made during treatment, chapter 3 identifies several clusters of factors and actors that influence patients' decisions: socio-demographic characteristics; disease-specific characteristics; consumer information; professional care providers and close relatives and informal caregivers.

Part II: Empirical studies: performance indicators and patients' search and selection processes

In the second part of this thesis, three very different research methods are used to study the search and selection processes of patients with knee arthrosis, chronic depression or Alzheimer's disease, respectively. This section explores the extent to which performance indicators can play a supportive role in these processes.

Chapter 4 uses a Grounded Theory approach (interviews that gradually lead to new insights) to study the search and selection processes of 23 knee patients, 15 chronically depressed patients and 15 patients with Alzheimer's disease and/or their representatives. The results show that there are two basic attitudes towards the search and selection process: an "in-control-consumerist attitude" and a "dependent, passive attitude".

Secondly, chapter 4 points out that several factors and actors influence the search and selection process, depending on the patient's attitude. With this in mind, the third focus in this chapter is on the aspects which determine patient attitudes. Four aspects are identified: the patient's attitude of life; the type of disease from which the patient suffers; the phase or severity of the disease; and the organisation of care.

Using Q-methodology (a hybrid quantitative and qualitative small-sample approach), chapter 5 identifies consumer profiles amongst 45 patients with knee arthrosis, 44 chronically depressed patients and 41 patients with Alzheimer's disease and/or their representatives. In addition, the

dominant factors and actors for each consumer profile were identified. Two consumer profiles appeared to be dominant: patients who focus on health care outcomes (Profile A) and patients who focus on trust in their health care deliverer (Profile B). Both profiles were found among patients with knee arthrosis, although profile A was dominant (60% had profile A and in chapter 6 this figure is as high as 80%). Profile B was the only profile found among chronically depressed patients. Patients with Alzheimer's disease and/or their representatives exhibited both consumer profiles, though again the focus on outcomes dominated (61% and no less than 86% in chapter 6).

Chapter 6 uses three Discrete Choice Experiments (choice simulations with fictitious health care providers) involving 609 patients with knee arthrosis, 368 chronically depressed patients and 421 representatives of patients with Alzheimer's disease in order to show the relative impact of several factors and actors on patient choices.

Patients' preference patterns are different for all three diseases. The search and selection processes of knee patients are mainly influenced by the expected outcomes (effectiveness and safety) of the treatment. For chronically depressed patients, the patient-centeredness (relationship with therapists and continuity of care by the same therapist) is the most important factor. The biggest impact on the choices made by representatives of patients with Alzheimer's disease comes from the provider's expertise and competences in the field of Alzheimer's disease.

There are also important differences between the preference patterns of certain sub-groups: patients with the same consumer profile; patients in the same phase of the disease; and patients with the same background characteristics, such as education level. Patients with a result-driven consumer profile attach more value to the expected results of a treatment or stay in hospital, the scope to participate in treatment decisions and the expertise or competences of the provider. These patients are also prepared to travel further for treatments with better outcomes. For patients with a consumer profile based on trust in the provider, good prior experiences with a provider, continuity of care and the advice of family or friends have the most impact on their decisions. Patients who are in a more advanced stage of their diseases, are more influenced by the interpersonal relationship with the health care provider, and the advice of family or friends. Outcome indicators, travel distance and the advice of a GP become less important when a disease lasts for longer. Finally, the decisions of patients with a higher education level are more often influenced by outcome indicators and the expertise and competences of the health care provider. The GP is of much less importance.

Part III: Methods for developing consumer information for patients

Part II shows that consumer information for patients has to be tailor-made for the specific characteristics of (groups) of patients. The obvious question is therefore what the right ingredients are for consumer (quality) information and how those ingredients can be identified. Part III provides an answer to this question.

Chapter 7 reports on a study that has a dual aim: 1) to identify the appropriate ingredients for quality report cards for geriatric care from the consumer's perspective; and 2) to investigate the **step-by-step approach, based on the availability, continuity and reliability of care, while consumers of institutional care value privacy, respect and autonomy most.** The Concept Mapping method appears to be very useful for identifying the right ingredients for quality report cards. Integration of existing quality information sources and experts in the field of geriatric care supports the validity and feasibility of the content of the quality cards, while integration of consumers supports its appropriateness. Furthermore, participation by all stakeholders helps to build consensus about the building blocks,

Chapter 8 answers the sub-questions that were defined in chapter 1. With regard to the central research question – to what extent performance indicators play a role in patients' search and selection processes – chapter 8 draws the following conclusion:

The empirical results of the study show that publicly disclosed comparative quality information on structure, process and outcome characteristics of health care providers, measured and reported by performance indicators, will empower patients to fulfil their role of critical consumers in a competitive health care environment. Consumer information will however only contribute to patient empowerment if it is made disease-specific and sensitive to patients' choice attitude and the severity of their disease, and differentiates for important background characteristics such as education level. The idea that (quality) information about health care providers would be overruled by what other people (social network or referrers) say, or that patients choose the nearest provider by default is clearly not supported by these results.

Chapter 9 reflects on the meaning of these results in the light of recent literature and of the applied research methods. It also addresses the challenges for the future development and dissemination of consumer information by means of performance indicators, the challenges for future research and finally the challenges for health care policy.

The bottomline advice is that in the short term, outcome indicators have to be developed, measured and publicly disclosed at the level of health care products (e.g. DRGs). This information has to fit the needs of relevant 'segments' of patients and must be disseminated via professionals who refer patients to health care providers (e.g. GPs) or via institutions that allocate care to patients. Only these conditions can help patients to fulfil their roles as a 'change agent' in health care.

For everyone involved in the field of health care, whether patient, doctor, insurer, policymaker, researcher or a developer of consumer information, the same thing applies: the question is not whether patients are able or willing to choose, but when they will start doing this and what you will do to facilitate them: it's your choice!

Chapter 1

General Introduction

1.1. Health care policy 2007-2011: strengthening the position of the citizen

The Dutch Ministry of Health, Welfare and Sport (VWS) has formulated three key objectives for health care for the period 2007 to 2011 inclusive (VWS, 2007, p. 57):

1. *The position of the citizen in the care system has been strengthened;*
2. *Care providers provide the kind of care that citizen want;*
3. *Health care insurers offer all citizens an affordable package of insured basic care.*

The Ministry of VWS is seeking to achieve these objectives by '*providing transparent information*' to enable citizens '*(...) to choose on the basis of quality, accessibility and affordability of the care provider and the health care insurer. This will provide an incentive for providers and insurers to deliver/purchase safe, effective and client-centric care*'. The Ministry wishes to achieve this '*by striving for the provision of transparent information to citizens*' (...) (ibid).

The fact that VWS takes the first policy objective seriously is evident from the financial resources it has set aside for its achievement for the period 2008-2011: a total of almost EUR 14 million (VWS, 2007, p. 59). Among other things the Ministry wishes to develop a set of '*indicators for curative care (EUR 1.8 million) in order to increase the transparency of first-line and second-line care*'. To achieve this, VWS regards it as necessary that:

- *Performance indicators are developed for each provision in order to make the professional quality measurable;*
- *A consumer quality (CQ) index is developed in order to ascertain the opinions of consumers and patients;*
- *A set of 'shop window' information is developed. Performance indicators will also be developed for the diabetes care chain in 2008¹.*

In addition to the development of indicators in the curative care sector, VWS is also funding the development of information across the whole care sector in order to help consumers choose their care (EUR 4.2 million). The idea here is that '*a strong consumer is able to make a choice from the*

¹ In the budget for 2008, VWS set itself the goal of developing the first specific, measurable objectives using 'performance indicators'. This gives rise to an unusual 'Droste-effect': the progress in the development of performance indicators is measured using a performance indicator: '*For 80 diseases, citizens will be able to see what quality hospitals deliver by visiting www.kiesbeter.nl*'

care available, influence the delivery of care by care providers and the purchase of care by health care insurers. Usable products will be developed which enable the consumer to make better choices in practice and to exert more influence over the care delivery. Examples of such products are the CQ-index questionnaires and quality information on the website kiesBeter.nl!

VWS is also encouraging the development of 'reliable and comparable quality information for the entire health care system (EUR 2.4 million). Care providers provide reliable and comparable quality information on care delivery and also provide an insight into the experiences of consumers themselves. Relevant products here are case-mix corrections, databases, comparative research and the development of the CQ-index questionnaires'.

The above objectives and interventions demonstrate that the Ministry of VWS is serious in its desire to equip the citizen to secure a more powerful position in the care market. *Performance indicators* appear to play an important role here as a source of comparative quality information. But how certain is it that patients will develop into critical consumers as a result of transparent consumer information? If we are to believe the well-known American economist Barry Schwartz, patients do not want to have 'endless choice', and health care is precisely an area where increasing the freedom of choice would reduce rather than increase people's quality of life. It would involve a great deal of time, organisation and worry, and would moreover create uncertainty, doubts and anxiety (Schwarz, 2004). In that case, the position of the citizen in the care market would not be strengthened, and experienced care providers and health care insurers would not be incentivised to deliver and purchase safe, effective and client-centric care.

1.1.1. Topic of this thesis

This thesis is concerned with the extent to which this 'transparent, comparative quality information' (or more specifically, 'performance indicators') can be successfully used to support the search and selection process of citizens² who are in search of appropriate care for their disease or disability.

² The term 'citizen' is used as the broadest possible collective term for consumers, patients and/or their representatives. Terms such as (choosing) care user, client, etc., are also used. Where it is the intention to draw a distinction between these categories, this is stated explicitly.

1.1.2. *Layout of chapter 1*

Before looking in more detail at the goals and questions addressed in this thesis, it is important to clarify the administrative background against which phenomena such as ‘consumer information’ and ‘performance indicators’ have been able to grow to such prominence, and why this is seen by many as such an important, not to say crucial part of the functioning of the care market. This chapter therefore begins with a brief discussion of recent developments in Dutch health care policy and places them in an international perspective (§ 1.2). Section 1.3 explores the theory underlying these developments; section 1.4 then shows to what extent these concepts have been put into practice over the last 30 years in the policy on the quality of Dutch health care. Section 1.5 problematises these recent developments, an exercise which culminates in the objective of this study, namely the scope of these developments and the problem definition (§ 1.6). The methodological design of the study is the subject of section 1.7. The structure of the entire book is described in the concluding section (§ 1.8).

1.2. **Administrative context: from regulated supply to market forces**

The basis for the health care policy described here was laid more than 20 years ago. The most tangible ‘milestone’ in this process was the report by the Dekker Commission (1987), which observed that the regulation of supply in the health care sector up to that point had led to excessive bureaucracy and inefficiency. Moreover, the delivery of care was out of line with the changing and diverse needs of the population. The Commission proposed three themes for change: *regulated competition* (health care insurers and care providers had to be given scope for entrepreneurship); a *demand-led* structure (with the needs of the patient at the centre); and *care renewal* (the place where care is given and the way in which it is delivered had to be made more flexible). The report was very well received everywhere. During the years that followed the system of regulated supply was modernised, competition between health care insurers was encouraged and there was more regional cooperation. Confusingly, however, these three pathways for change were followed in a muddled and inconsistent way, with the result that there was no clear change in course in the supply-driven system in the 1990s (Van der Grinten & Kasdorp, 1999).

It was to take until 2001 for the first contours of the long anticipated new care system to begin to take on more tangible form. Apart from the adaptation of the health insurance system (which is not

discussed further here), a start was also made on modifying the running of the care system. A policy document on supply and demand in the health care system (“Vraag aan bod”; VWS, 2001a) assigned a modest but framework-setting role to the government, standing in the midst of what was as far as possible a self-regulating market whose players, within a suitable system of checks and balances, are given the freedom to deliver good, efficient care which meets the wishes of citizens (figure 1).

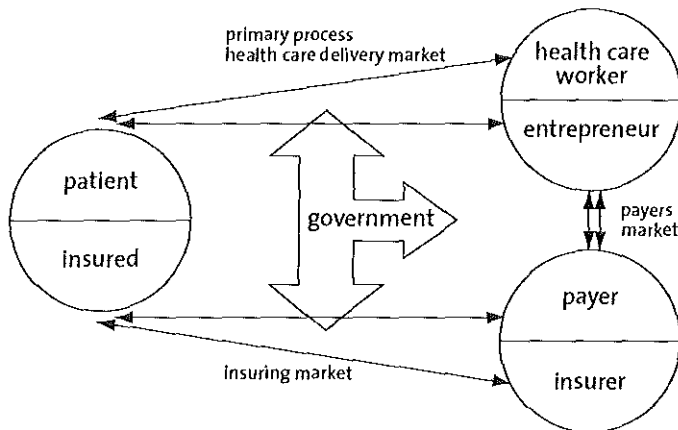


Figure 1. Actors and forces in changing health care markets (Based on: VWS, 2001a; Post, 2005)

Essentially, the new role division is as follows (VWS, 2001a; RVZ, 2000):

- A critical attitude by insured parties and patients to the price and quality of the service delivered (both by insurers and providers);
- Health care insurers protect the interests of their policyholders in competition with each other and buy in care on the basis of value for money;
- Care providers deliver care of good quality in an efficient way which meets the needs of the patient as closely as possible. Their products and services are transparent in terms of pricing and can be assessed for their quality. In order to offer care users sufficient choice, care providers are given greater entrepreneurial scope and access to the market is made easier for new entrants;
- The government withdraws further, takes on a supervisory role and sets the frameworks from a distance.

The new care system came into force on 1 January 2006. The competition on the *insurance market* immediately got off to a good start, as borne out by the genuine price war between insurers and the high degree of mobility on the part of insured parties (Schut, 2007). The scope for competition on the *payers market* is still limited. Although the contracting freedom has increased, the prices are still largely regulated (apart from less than 10% of Diagnostic Treatment Combinations which can be freely negotiated in hospital care). Moreover, the competition in this market segment still revolves mainly around pricing and service and takes little or no account of quality. Hardly any health care insurers set themselves apart through the quality of the care purchased, and insured parties are not yet making choices based on quality. Schut (ibid., p 196) argues that a key bottleneck here is the lack of insight into the differences in quality of care. *“As long as the quality is not transparent, there is a risk that insurers will primarily seek to buy the cheapest possible care. Moreover, insured parties will remain distrustful of insurers who contract selectively: are the selected care providers good as well as cheap?”* And further on in his argument: *“The development of adequate, standardised performance indicators which has begun in recent years is therefore an essential condition for a properly functioning care purchasing market. Another step that is at least as important is to translate these performance indicators into publicly accessible, understandable and reliable consumer information”*. This need is explored in more detail in sections 1.3 and 1.4. Although the taking office of a new government slowed down the introduction of regulated competition in hospital and general health care, the trends that have begun appear irreversible, especially in an international perspective. The dynamic of the health care delivery market has become a much less frequent subject of study in the context of the new system (Groenewoud, 2005). This study, however, investigates in detail the extent to which patients are able to play the role assigned to them in this market segment.

The developments described here are not unique to the Netherlands; other Western countries have also more or less a recently introduced radical reforms in their health care systems (Groenewoud et al., 2006), and comparable trends can be observed in Australia (Hilles & Healy, 2001; Colombo & Tapay, 2003), Denmark (Bech, 2004; Busse & Schlette, 2003; Vraengbek & Ostergren, 2004), Germany (Green & Irvine, 2002; Thomson & Dixon, 2006) and the UK (RVZ, 2003; Appleby et al., 2003; Department of Health, 2003). Faced with a need to reduce the collective costs of health care, a period of government involvement and regulated supply was followed in these countries, too, by the introduction of market forces such as competition between providers, free

choice for patients and insured parties and making the quality of care delivered measurable and transparent. The United States is a partial exception to this; this country has traditionally had a predominantly private health care system (Sultz & Young, 2004), involving an interplay of different market elements. Health care costs are spiralling out of control in the United States, too, but recent discussions are less preoccupied with cost shifting and cost reduction but try to focus on improving health and health care value for patients (Porter & Teisberg, 2007).

1.3. The health care market's Achilles heel: the problem of product uncertainty

But is health care really a market (Schut, 2003)? Can patients simply switch to behaving as consumers? Are care providers willing to 'market' their services in a value for money way? And what is needed in order to achieve this? These are questions that have occupied both scientists and policymakers for many years.

Given its free-market traditions, it is not surprising that the Achilles heel of a market-driven health care system was exposed in the United States. An article written in *The American Economic Review* by the renowned economist and Nobel Prize-winner Kenneth Arrow in 1963, entitled "*Uncertainty and the welfare economics of medical care*" aroused a good deal of interest (Arrow, 1963). In this article Arrow demonstrates the imperfections of the care market. One of the most striking imperfections is what he calls 'product uncertainty': the uncertainty concerning the effect of the service used (does it improve?), but above all the unequal relationship between user (patient) and care provider as regards knowledge and information about the service or product: the information asymmetry. As will become clear below, this lies at the heart of the usefulness of and need for consumer information via performance indicators, the subject of this study.

The information asymmetry between care users and providers need perhaps not be such a problem if the care delivered by different care providers was the same in terms of content and also *quality*. However, it is becoming ever clearer that this is anything but the case. The American Institute of Medicine (IOM) recently shook the health care system worldwide in two highly critical reports on the quality and safety of American health care. In "To Err is Human" (Kohn et al., 1999) it was estimated that between 44,000 and 98,000 American citizens die each year due to avoidable

medical mistakes, making this the eighth most common cause of death in the United States. In “Crossing the Quality Chasm” the IOM put forward proposals for bridging the gulf that has arisen between what can be achieved by medical science on the one hand and the functioning and organisation of the care system on the other. The report makes clear that health care workers will continue to fail, regardless of their efforts, unless the organisation of the health care system is drastically redesigned (Committee on the Quality of Health Care in America, 2001).

In their book “Redefining Health Care”, Michael Porter and Elizabeth Olmsted Teisberg take the standpoint of the IOM a step further (Porter & Teisberg, 2006). In order to change health care from a “zero-sum game” into “positive-sum competition”, three principles are crucial: 1) the goal is value for patients; 2) medical practice should be organized around medical conditions and care cycles, and 3) results – risk-adjusted outcomes and costs – must be measured. On this latter principle they write: *“There is simply no way to achieve large and sustained improvements in value for patients without measuring results: the set of risk-adjusted outcomes of care for each medical condition, together with the costs of achieving those outcomes”* (Porter & Teisberg, 2007, p. 1106).

Donald Berwick (2003), one of the best-known thinkers on quality in modern health care, also stresses that quality measurement and the public disclosure of health care outcomes is crucial in achieving the ultimate goal of improving the quality of health care. According to Berwick, equipping patients to choose the best care available is only one of the two pathways in the drive towards achieving an upward quality spiral (figure 2). He describes this process as follows: *“The mechanism is simple: if you need heart surgery, you can select the surgeon whom (you predict) will give you the best odds of the outcome you want. To accomplish that requires three tasks: (1) Identify the outcomes of importance to you (2) Learn the performance levels of surgeons with respect to those outcomes (3) Choose your surgeon”*. Reality often proves more resistant, as Berwick also acknowledges. He identifies several barriers to the selection process (pathway 1); the availability, the accessibility and the understandability of good quality outcome measures being one of them. Chapter 2 looks in more detail at Berwick’s conceptual model.

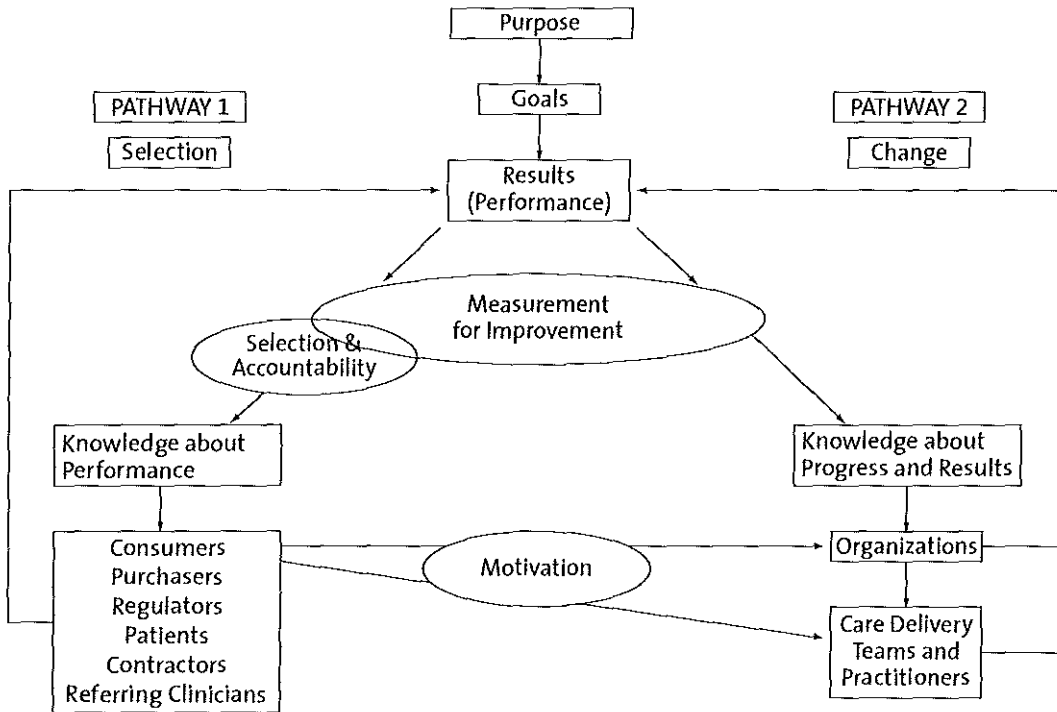


Figure 2. Two pathways to quality improvement (Berwick, 2003).

1.4. Quality policy in Dutch health care

Until a few years ago, the idea dominated in the Netherlands that the quality of health care was good – very good, in fact. The government repeated this statement time and again in all manner of documents (Van der Grinten & Kasdorp, 1999). Recently, however, it has become increasingly clear in the Netherlands, as in other countries, that the quality and safety of the care delivered sometimes leaves something to be desired and that there are wide differences in quality between different care providers. After initially having extrapolated the figures from “To Err is Human” for the Dutch situation, a study was recently carried out on avoidable deaths in Dutch

hospitals. This revealed that around 1,750 people die unnecessarily in hospital each year (Wagner & De Bruijne, 2007). But even before this, examples were known which revealed wide variation in medical treatment and care outcomes (see e.g. the annual reports “*Het resultaat telt*” (‘The result counts’) from the Dutch Health Inspectorate on the performance of Dutch hospitals; IGZ, 2004, 2005, 2006).

1.4.1. *Quality cannot be taken for granted*

In recent decades it has gradually become clear that quality cannot (any longer) be taken for granted, but must be monitored, ‘fought for’ and promoted. Quality no longer coincides with the application of the knowledge and skills of well-trained doctors and other health professionals. The government, care providers and patients all have their own views on quality (Van der Grinten & Kasdorp, 1999). The fact that this raising of awareness has taken place in recent years is no coincidence, because the process is closely related to the reforms in the administrative context of the Dutch health care system as described in § 1.2. In addition, the health care system can do much more in 2008 than 50 years ago, for example. The increased medical possibilities have also led to a growing need for certainty and control (Schepers & Nievaard, 1995). *Attention, commitment and effort remain important in health care, but when it comes to results, assessment of those results and of the continuing expertise of those who process them is more important* (Van der Grinten & Kasdorp, 1999, p.36). On top of this, results are becoming increasingly dependent on teamwork (Van Wijngaarden, 2006), and health organisations are becoming ever larger (Fabbricotti, 2007). Another reason for the increased attention to quality of care is the fact that the doctor-patient relationship has changed radically in recent decades. Patients have become more assertive, are increasingly independent (both individually and collectively) in their relationship with their doctor and place demands on the care delivered (Van der Kraan, 2007). Finally, society is also increasingly demanding accountability for the way in which collective resources are spent in the health care system. This makes value for money a pressing need (Van der Grinten en Kasdorp, 1999) and care providers are expected to be open about this.

1.4.2. *Recent developments in quality policy*

All these developments have ensured not only that the notion of quality has come to be interpreted differently in recent years, but also that the quality policy has undergone a great change over that period. Until midway through the 20th century, quality policy was primarily

government policy, at least in theory. Based on its constitutional duty to promote public health, the government regarded it as its task to standardise and monitor the quality of care and thus to protect patients. In practice, however, the government relied entirely on the self-regulating capacity of the professional field and the quality of care was left almost entirely to the professional organisations (ibid).

The introduction of the Care Institutions (Quality) Act (1992 bill) was based on the view that it was not the government but those directly involved who should establish the quality standards: self-regulation instead of government regulation. In fact, the Act offered only one substantive criterion, namely that the care provider must offer adequate care (care which was effective, efficient and patient-centric).

The Care Institutions (Quality) Act was an expression of the 'new thinking on quality' in the Dutch health care system which had been ushered in shortly before this by the Dekker Commission (see also § 1.2). This Commission stated that: *"Quality control and assessment is in the first place the responsibility of health care professionals. Competing care providers have a commercial interest in ensuring the quality of the care they provide."* Dekker also argued that institutions and doctors should in the future be certified: a sort of quality mark for health care, as was common practice in industry. This was a new idea, because for 150 years the government had supervised quality in the health care system. However, it fitted in well with the prevailing ideological climate of more market and less government. It also fitted in with the perspective of the European market, in which the European Commission felt that consumers must be able to rely on the quality of products and services within Europe. In the first place, this meant that manufacturers had to improve their internal quality policy. European standards were also adopted for independent external certification. The idea was to limit the certification as far as possible to an assessment of the functioning of the internal quality policy of manufacturers. The scope of the external supervision was thus limited (ibid).

In the early 1990s, actors in the health care sector were convinced that they were following the right course, but there was as yet no consensus on the precise details (did competition or, conversely, more regional cooperation generate more positive incentives? Free entrepreneurship or standardisation of care?). It was decided to join forces in order to develop a new quality policy for the years ahead. This took place in 1989 and 1990 during what later came to be known as the

'Leidschendam conferences'. These conferences resulted in a large number of agreements based on four themes:

- the responsibilities of the individual parties;
- the criteria for assessing quality in health care;
- the systems for promoting, safeguarding and verifying the quality of care;
- the means to create and guarantee a good quality policy.

In fact these agreements reaffirm the chosen role division between the government and the professional field: *'The government does not in the first instance formulate quality standards itself, but can indicate the areas for which those standards must be formulated. The government formulates the standards if the field fails to arrive at a practicable package of quality standards'* (ibid, p. 42). In 1995 a committee of the Council for Public Health and Health Care (RVZ) carried out an assessment of the status quo. It was clear that the professional groups and care institutions were actively working on quality projects. Some were aimed at the development of standards and protocols, others at eliminating practical bottlenecks, yet others at developing an internal quality system. It was also clear that a great deal still had to be done. In the end, the main agreement made in 1995 was that efforts would continue and that a new evaluation would be carried out in 2000.

In the first years after the turn of the millennium, the government opted for a slight adjustment (or was it an acceleration?) of the course pursued to that point in respect of quality policy. The main reason for this was the approaching system change (see § 2.1) in combination with the ultimately disappointing progress made by the field itself in formulating quality standards (see previous paragraph). The reasoning was that a government which is seeking to play more of a backseat role needs access to adequate means of supervising the quality of care delivered. There was also a realisation that transparency of the quality delivered is crucial in a care system based on regulated market forces (because of the problem of information asymmetry and product uncertainty). The description and adoption of working processes, the building of internal quality systems and their accreditation, was replaced by a focus on care outcomes: effectiveness, safety, patient-centricity and efficiency. From that moment onwards, many different actors in the Dutch health care system, at all levels and with as many different objectives, developed performance indicators in order to make (the quality of) care transparent (see also chapter 2). In curative care, the Dutch Health Inspectorate formulated a basic set of performance indicators which were made compulsory for all hospitals from 2003 (Berg et al., 2005). This obligation was later extended to care for the elderly, care for the

disabled and mental health care, where indicator sets were also developed (Berg et al., 2006). The Ministry of VWS quickly had in place a Balanced Scorecard for the Dutch care system (Delnoij et al., 2002). Benchmarking also took place on a large scale (first per sector but later also benchmarking of super-sectoral care processes such as the CVA care chain (Huijsman et al., 2003)). Transparency of the quality delivered had become one of the core focuses of quality policy in Dutch health care.

1.4.3. *The patient as the focus of quality policy in 2008*

Initially, transparency of the quality of care delivered was regarded mainly as a necessary condition for the introduction of market forces in health care (combating information asymmetry and product uncertainty). Today, however, it is seen much more as a means of improving quality. The Ministry of VWS wishes to provide citizens with *'transparent information (...) to enable them to choose on the basis of quality, accessibility and affordability of the care provider and health care insurer. This will provide an incentive to providers and insurers to deliver/purchase safe, effective and client-centric care'* (VWS, 2007). Just as in Berwick's concept of the 'two pathways to quality improvement through transparency', the citizen is now seen as a core focus of the quality policy.

This construct is the result of a process spanning many years. Initially the main idea was to give patients 'power' by giving them an individual and collective say and representation in their health care at micro, meso and macrolevel (Van der Kraan, 2007). Contemporaneously with the government policy document on supply and demand in the health care system ('Vraag aan Bod'; VWS, 2001a; see § 2.1), 2001 saw the publication of a parallel policy document, "Choosing with Care". This states that *"the care user or insured person is being given greater and greater scope to make his or her own choices. In the years ahead the Ministry of Health, Welfare and Sport's policy will seek to support care users so that they can themselves make what they want clear to care providers and insurers. The policy will concentrate on what are described as five levels of equipment:*

1. *A satisfactory legal position for care users;*
2. *Up to date, accessible and reliable information on the basis of which care users can get an idea of the quality of the services provided in the health care sector and by health care insurers;*
4. *Independent, reliable and low threshold forms of advice and guidance;*
5. *Individual and collective purchasing power;*
6. *The presence of collective negotiating power that is representative of the care users and operates in a transparent manner (VWS, 2001b, p. 4).*

As regards the second 'level of equipment', the report notes that *"it is necessary to ensure that a system of comparative information becomes available. This is information about the quality of the care products and services provided, the accessibility of care health providers, and also comparative information about insurers' prices and packages, contract policy, services and acceptance policy. Information that becomes available in the future from benchmark studies of health care providers and health care insurers comes into this category (VWS, 2001b, p. 25).*

From the publication of this document, the government worked hard to develop *"transparent quality data for health care and to achieve a tangible and sustainable consumer information structure, for example in the form of quality cards for care"* (ZonMw, 2003). In response to these 'transparency initiatives', data rapidly became available which could be used to equip citizens for their role in the new care system. New initiatives were also launched, aimed at generating quality information to support choice. This took place at the initiative of the Ministry of VWS, as part of a research programme specially setup for this purpose, "Choice in Health Care", developed by the Institute of Health Care Research and Medical Science (ZonMw). Among the projects carried out within this programme in recent years is the development of 'shop window information' on care providers (factual information about the care provided, as well as the facilities and services), quality cards on the Internet (kiesBeter.nl) and performance indicators for a number of commonly occurring diseases. The research project which is central to this thesis was also not only carried out in the context of this research programme, but has also from the beginning made a substantial contribution to shaping it.

1.5. Performance indicators for patients: Columbus' egg or Pandora's box?

Performance indicators, then, are now widely used as a source of consumer information on the quality of care with a view to equipping citizens to take on their role as critical consumers and ultimately to raise the quality of care to a higher level. At first sight, they appear to be a usable and adequate tool for this. At both national and international level, however, criticism has been levelled at the *suitability, desirability* and *usefulness* of using performance indicators for transparency purposes in health care, with the result that it is unclear whether the initiative should be regarded more as a Columbus' egg or as a Pandora's box. Chapter 2 looks at this criticism in more detail; here, a few points of criticism are highlighted.

According to some observers, performance indicators are not *suitable* for measuring and comparing the quality of care. Because indicators by definition only give an 'indication' of the delivered quality, these critics argue that they present a one-sided and distorted picture of reality and could give rise to undesirable behaviour, such as fraud or selection of favourable patient groups. In this sense, the use of performance indicators could actually have a negative impact on quality of care.

There is also a fundamental ethical criticism of the *desirability* of equipping patients via comparative quality information based on performance indicators. Some argue that quality differences in health care should never be the subject of competition and that patients actually become less happy if they have to make choices themselves and in order to do so have to immerse themselves in different options.

A third argument against providing performance indicators for care users is that it is not *useful*. Increasingly, it is claimed that patients in practice make no use whatsoever (or are unable to do so) of performance indicators. Some researchers attribute this to the lack of choice in care, others to the fact that care users attach much greater importance to things such as 'word-of-mouth' recommendations from friends or acquaintances, trust in the expertise and knowledge of their referring GP and/or attending physician, the distance to be travelled, or 'loyalty' to the care provider they have always used.

1.5.1. *Limitations of existing research*

The existing research on the use of comparative quality information in support of choice by patients is broadly characterised by four limitations. It is therefore not possible to say with certainty that patients will not incorporate choice information based on performance indicators in their choice processes. In fact there is an argument that they probably would do this if reliable and accessible information were available.

A first limitation is that the research in question studies 'the care user' in a general sense, without drawing a distinction between the different roles that a care user can fulfil: the role of an insured party, individual consumer of health services, a more or less dependent care user in a doctor-patient relationship, a statutory representative or part of a representative collective (e.g. a patient organisation). Similarly, no distinction is drawn between different types of patients with different diseases and (personal) characteristics. This creates a rather narrowly focused picture of patients' decision processes, as it is frequently based on one single disease, medical decision or setting. Yet it may be imagined, though this has so far not been studied, that a young, well-educated chronic

patient will wish to make use of choice-supporting performance information, whereas this is less likely for an older care user with an acute disorder.

A second problem relates to the way in which patient choice processes are generally studied in practice. Many studies investigate patients' decision-making behaviour at a macro-level, for example by following admissions to, or market shares of bad and well performing providers (Baker et al. 2003; Mukamel, and Mushlin 1998). Yet, the problem with such an approach is that it does not disclose the black box of the micro-level decision making process and conceptualisations of the decision process are mostly not embedded in the wider *social context* in which patients and their systems deal with health care systems. They often see patients' health care decisions as an economic concept of rational choice, conceptualising the patient as synonymous with *homo economicus* (McDonald et al. 2007). There are several disadvantages of such an approach. It tends to obscure the underlying relationships involved (Light, and Hughes 2001; McDonald et al. 2007). In other words: it focuses on rational trade-offs, based on 'product-characteristics' in a laboratory-setting. This results into only a partial understanding of patients' decision processes, ignoring the role of crucial contextual actors and factors (what happens if physician B performs excellently but the patients' general practitioner refers to someone else?). Besides, the reasoned choice approach does not take into account that patients' preferences might change during the decision process or as the illness proceeds (Mol 2006).

A third problem relates to the research methods used. Many study results are of limited use, as these studies simply ask participants how important certain aspects are to them in case of the need for a health care provider (for example by scoring the their relevance on a five point scale). This sort of results leave trade-offs between factors unidentified and often leads to results that hardly differentiate and over-value the relative weight of certain aspects, since many patients find it difficult to prioritise using scales.

The fourth and final limitation relates to the sometimes limited suitability of the material used in some studies (but also in practice) as choice-supporting information. (Berg et al., 2005; Jewett & Hibbard, 1996).

1.5.2. *How this thesis fills the 'gap' in current knowledge*

Based on present knowledge, a definitive answer cannot be given to the question of how far comparative quality information based on performance indicators can support patients in their choice processes when going in search of care.

The foregoing has made clear that there is a need for comparative research into the choice processes of patients with *different diseases* and *different profiles*. For this reason, the empirical part of this study was carried out among three differing groups of care users. In selecting the target groups, a deliberate decision was made to dovetail with current developments in the area of consumer information and transparency of care. At the start of this study, consumer information was developed as part of the “Choice in Health Care” programme of the Institute Health Care Research and Medical Science (ZonMw) in the curative care sector (hospitals), the mental health care sector and care for the elderly (nursing homes, homes for the elderly and home care). Within these sectors we looked for a limited number of large patient groups whose decision processes may be seen as exemplary for many others. In the field of elective clinical surgery, for example, total knee arthroplasty (replacement) or osteotomy for patients with *knee arthrosis* is one of the largest volume care trajectories (besides hip replacement, which is a very similar condition) (Poos & Gijzen, 2003). In mental health care, long-lasting or *chronic depression* is the disease with the highest prevalence and the search for a therapist may be comparable to the search and selection process in other mental diseases (Poos, 2005). Finally, care for the elderly is an area in which family members play an important role (Wackerbarth, 1999) and where the decision to institutionalise a family member is usually taken only as a last resort (Cheek & Ballantyne, 2001). Because dementia is a high volume disease in this area, we chose the decision process of patients with *Alzheimer’s disease* (the most prevalent form of dementia (De Lange, 2007)) and their families as our third focus of study. Furthermore, in our sampling strategies we tried to select a variety of patients with different characteristics so that we were able to look for differences and similarities between decision processes of patients with different ‘profiles’.

A second aim of the present study is to attempt to open the ‘black box’ that constitutes the *choice process* of patients by studying it not in a ‘laboratory setting’, but by *placing it in its social context*. In this study, this was attempted by taking the way in which patients arrive at a particular care provider and attending physician as a starting point and scrutinising this choice process closely from beginning to end. It is by no means certain in advance that choice-supporting information plays a role in this process, but all factors and actors which influence the choice process according to patients are described in detail (Grounded Theory approach in chapter 4). The social context in which decisions are taken, such as the influence of close relatives but also of referring doctors, receive extensive attention.

Thirdly, it emerged from the foregoing that new research into the choice processes of patients and the role that consumer information plays in the process needed to adopt a diversity of methods. Preferably, the choice process should not only be described in qualitative terms, but a more model-based insight should also be obtained into the preferences of patients. This would have to bring out the trade-offs that people have to make in real choice situations. This can provide an insight into the *relative importance* of the many factors and actors that influence the choice process of patients. This study meets this requirement by applying two methods that are ideally suited to identifying differences in the preference structures of divergent groups (Q-methodology in chapter 5) and to ascertaining the relative importance that different groups attach to choice-determining factors (Discrete Choice Experimentation in chapter 6).

Finally, there appears to be a need for suitable *methods* for developing reliable, valid but also understandable consumer information that supports choice. Both research on the use of this information and the (policy) practice in which, say, quality cards for care are *developed*, would benefit from such a method. This thesis meets this need by putting forward a methodology for developing 'quality report cards' for health care consumers (Concept Mapping in chapter 7).

1.6. Objective and problem definition

1.6.1. Objective

This study aims to explore the applicability of performance indicators for equipping the 'choosing care user' and, by analysing the choice behaviour of care users, to identify the desirable and appropriate (quality) information for the right target groups. Finally, this study seeks to offer substantive and methodological guidelines for the development of choice-supporting (quality) information in health care.

1.6.2. Scope

The scope of the research is determined in three ways. First, the study is limited to the *care delivery market* (see figure 1). The aim here is to fill the gap observed earlier in the knowledge about the (potential) effect of the mechanisms of the new care system – a gap which is much less evident in the other care market segments. Secondly, the study targets the processes that take place in modern what Berwick (2003) refers to as 'pathway I'. This means that the study does not extend to the field of internal quality

improvement (processes) or the use of performance indicators in that regard. As a third limitation, the present study is concerned within 'pathway I' only with the search and selection process of care users themselves, not with that of regulators, purchasers, contractors or referring clinicians (the influence of these actors is considered only in so far as they influence the choice process of patients).

1.6.3. Problem definition

This study looks for answers to the following central research question: "*To what extent can performance indicators be used as an aid to support the search and selection process of patients who need a care provider or doctor?*".

In order to be able to answer this central question and thereby help to close the 'gap of knowledge' in existing research, the following constituent questions are addressed:

Part I: Performance Indicators and Choice Processes: Theory and Orientation

1. What are performance indicators?
2. Which discussions take place in relation to the suitability, usefulness and desirability of performance indicators and as a choice-supporting tool?
3. Which performance information is available for the choosing care user and how does it compare with the information that care users would like to have?
4. What is found in the literature about the choice processes of patients?

Part II: Performance Indicators and Patients' Search and Selection Processes: Empirical Studies

5. Via which choice processes do patients with knee arthrosis, Alzheimer's Disease or chronic depression end up with a particular care provider or doctor?
6. What is the (potential) role and desired content of choice-supporting information in that process?
7. Can differences be observed within and between the patient groups referred to in terms of the choice processes, choice-determining factors and actors and the (potential) role and desired content of choice-supporting information?

Part III: Developing consumer information: a methodology

8. What would be a suitable method for developing choice-supporting (quality) information for care users?

1.7. Design and methods

1.7.1. Design

The ensuing chapters of this thesis are arranged in a layered structure: from generic to specific and, for chapters 4 to 6 inclusive, from qualitative to quantitative. Each chapter provides input for the subsequent chapter and helps define the research field more closely. This can be visualised as follows:

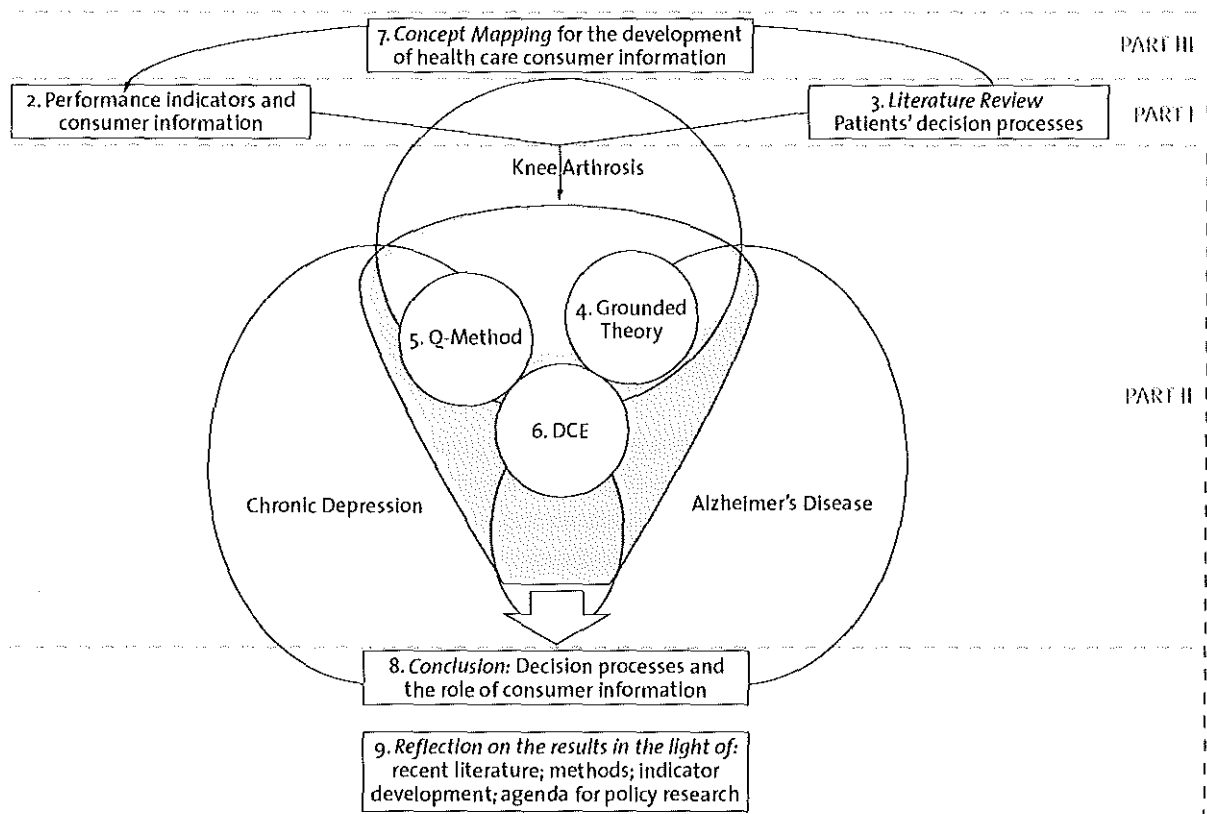


Figure 3. Study design and arrangement of chapters

1.7.2. *Methods*

In view of the different constituent questions addressed in this thesis, a total of five research methods are used. Each individual chapter looks in detail at the methods used; here, therefore, the methods are discussed only in broad outline.

A literature search and document analysis are used to explore the phenomenon of performance indicators and the discussions on their applicability and to compile an inventory of desired and existing choice-supporting information for care users (chapter 2). In addition, a systematic literature review is carried out to ascertain what is already known in the literature about the choice processes of patients who are looking for appropriate care for their disease or impairment (chapter 3).

A grounded theory approach with semi-structured interviews is used to explore the choice process via which patients with knee arthrosis, chronic depression or Alzheimer's Disease end up with a particular care provider or doctor, and what role choice-supporting information may play or could have played in that process (chapter 4).

In order to cluster and rank all the choice-determining factors and actors found and reduce them to the essence, and also in order to identify the profiles of different types of care users, *Q-methodology* is used (chapter 5). This is a hybrid qualitative/quantitative research method that provides a foundation for the systematic study of subjectivity, a person's opinion, beliefs, attitude, and the like.

To explore the relative importance (different groups of) patients attach to the actors and factors that influence health care decisions three *Discrete Choice Experiments* are conducted in different patient groups (chapter 6). A DCE is a popular method for quantifying consumers' preferences for commodities or services by analysing their choices in hypothetical choice situations. It is built on the assumptions that health care interventions, services or policies can be described by their characteristics (called attributes) and that a person's valuation depends on the levels of these characteristics.

In chapter 7, *Concept Mapping* is presented as a promising approach for building feasible and valid quality information from a consumer's perspective. Concept Mapping was first introduced in 1989 as a type of structured conceptualization which can be used by groups to develop a conceptual framework which can guide evaluation or planning. Over the last 15 years, Concept Mapping has also been used in areas other than evaluation and planning, e.g. for defining and assessing quality of care.

1.8. Structure of the thesis

In parallel with the classification of the questions addressed in this study, this book – apart from the introduction (chapter 1), the conclusions and reflection (chapters 8 and 9) – consists of three parts:

The focus in Part I is on the theory and mapping out the present situation. Chapter 2 introduces the phenomenon of performance indicators and their characteristics and looks at the discussions that take place around the suitability, usefulness and desirability of performance indicators as a choice-supporting instrument. It maps out the quality information on health care that patients would like to have and the information that is currently available to them. Part I is based on a background study that was carried out for ZonMw in 2002 and 2003. This study and the research report largely helped shape the Consumer Information and Transparency of Care (Consumenteninformatie en Transparantie van Zorg) programme, part of the Choosing in Care (Kiezen in Zorg) programme. Chapter 3 reports on a literature review of the existing knowledge in relation to the choice processes that patients go through when they are looking for care that meets their needs.

Part II comprises three empirical chapters (4, 5 and 6) in which the choice processes of three very different groups of patients are studied. In the midst of all the factors and actors which influence that choice process, special attention is given to the role that choice-supporting information plays or could play in that process, and to investigating whether this role differs depending on the disease, phase or subgroup of patients. Part II is based on the study “Choice processes of patients with knee arthrosis, Alzheimer’s Disease or chronic depression” (“Keuzeprocessen van patiënten met knieartrose, de ziekte van Alzheimer of chronische depressie”); which was carried out from 2004 to 2007 inclusive for ZonMw in the context of the Preferences and Competencies of Care Users (Preferenties en Competenties van Zorggebruikers) part of the Choosing in Care programme.

Finally, Part III provides methodological pointers for the development of choice-supporting quality information for care users. Chapter 7 reports on a study that was carried out in 2004 for ZonMw in the Consumer Information and Transparency of Care part of the Choosing in Care programme, the purpose of which was to create a quality card for nursing and care homes and home care providers.

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**Performance Indicators
and Choice Processes:
Theory and Orientation**

Chapter 2

Performance Indicators for the Choosing Health Care Consumer?³

³ This chapter is based on two articles:

Groenewoud, A.S. & R. Huljsman, 2005. *Prestatie-indicatoren voor de kiezende zorggebruiker? Een onderzoek naar de mogelijkheden, de stand van zaken en de toekomst van prestatie-indicatoren bij het versterken van de positie van patiënten in de zorgmarkt*. Acta Hospitalia, 2005, 45 (1): 25-49. [In Dutch]

Groenewoud, A.S. & J. Dwarswaard, 2004. *Transparency in Dutch hospital care: Eureka or Pandora's box?* In: Hofstede, G.J., H. Schepers, L. Spaans-Dijkstra, J. Trienekens & A. Beulens. *Hide or Confide? The Dilemma of Transparency*. Reed Business Information, 2004. Chapter 7.4. pp 165-172.

2.1. Introduction

2.1.1. *The changing position of the Dutch care consumer*

A new insurance and funding system came into effect in the Dutch health care system on 1 January 2006. Under this new system, which is characterised chiefly by regulated competition and in which health care is regarded as a market of consumers and suppliers, the roles and responsibilities of market players will change drastically. In summarised form, the envisaged result is “*to strengthen the position of the care user relative to the provider and health insurer; to strengthen the position of the health insurer relative to care providers; and to increase the freedom of manoeuvre for care providers. The role of the government is to provide frameworks and oversee this role division.*” (VWS, 2001a).

Hendrikse and Schut (2004) show what these radical reforms mean for the relationships between health insurers, hospitals and medical specialists. To date, much less attention has been devoted to the changing role of the *care user* relative to these actors. Those on the demand side of the market, whether in the role of policyholders or care users, will in the future have a key role to play in the operation of the health care market. Policyholders will have to take out policies with health insurers that pay for the best care at the lowest premium (voting with their feet). In their role as care users, too, patients will be encouraged to choose the package that offers the best balance between price and quality (Berg, 2004).

However, it is anything but certain whether care users will be able to meet these expectations. After all, it has been known for decades that the health care system has imperfections as an economic market or is perhaps even failing, precisely because of the dependent position of care users vis-à-vis care providers, and the information asymmetry within that relationship (Arrow, 1963; Schut, 2003). In response to this, the Dutch Ministry of Health, Welfare and Sport (VWS) is trying to equip (or empower) care users in such a way that they acquire a more equal negotiating position relative to the traditionally dominant care providers. Five different instruments have been devised to achieve this (VWS, 2001b): giving care users adequate *rights*; ensuring the availability of up-to-date, accessible and reliable *information* on the quality of care providers and health insurers; providing reliable and low-threshold forms of *guidance*; strengthening the individual and collective *purchaser's market*; and finally, creating a collective *negotiation market*. This article is concerned primarily with the second aspect: the role that information about the performance of care providers can play for (potential) care users.

Performance indicators are seen by many as an important tool here, if not *the* tool for generating information on the quality of care to support care users in their choice of care provider. However, it is very debatable as to whether this instrument, which was originally intended for purposes other than supporting consumer choice, is actually capable of fulfilling this function. This article, which contains the findings of a study of performance indicators in the Dutch health care system, accordingly looks first at the suitability, usefulness and desirability of performance indicators for the choosing care consumer. Based on the assumption that performance indicators are desirable, the article then looks at what information needs to be made available to the choosing care consumer. Finally, the article discusses the extent to which this information is already available in the Dutch health care system and what this means for the agenda of policymakers and health care researchers.

2.1.2. *The rise of performance indicators*

The health care system is currently under the spell of performance indicators (Klazinga, 2004). Although appearances can be deceptive, this is not a new phenomenon in. As long ago as 1863, Florence Nightingale counted how many patients died following a leg amputation. During the process, she discovered that good nursing care reduced the mortality rate from 32% to 2% (Bennema-Broos, 2004; Walburg, 2003). In Europe, under pressure from the ever rising costs, attention for performance in the health care system has only really developed since the end of the 1980s. More and more market elements were (and are) built in to the care systems, thus increasing the need for transparency in the performance delivered. While performance measurement itself is not so much a new phenomenon, therefore, a gradual shift is taking place in the function of performance indicators, from serving research objectives to improving care processes and accountability.

Today, initiatives involving performance indicators are sprouting up everywhere in virtually all care sectors and at all levels of the system. For example, the Ministry of VWS has developed a Balanced Scorecard for the Dutch health care system (Delnoij et al., 2002), benchmarking takes place in both the cure and care segments, not only in individual sectors such as home care, but now also in sector-overarching care processes such as CVA care (Huijsman et al., 2003), while a set of basic performance indicators has been developed for hospitals (IGZ, 2004a) and for the entire care sector (Brink-Muinen & Wagner, 2004). Performance indicators are also used in all manner of quality improvement projects (Van Splunteren et al., 2003). For care users, work is currently going

on to develop a set of “transparent quality data on the care and realisation of a concrete supply of consumer information within a sustainable structure, for example in the form of quality cards for care” (ZonMw, 2005). And these are only some of the larger and broadly supported initiatives in the care *provision* market; indicator sets are also being developed in the care *insurance* market and on the funding market, for example in the form of report cards for health insurers and guides with indicators for purchasing care (ZN, 2004). The emphasis in this article is on the care provision market; the care insurance market is left out of consideration.

2.1.3. *Performance*

The meaning given to the word ‘performance’ in the literature is not uniform. Several authoritative bodies and authors use different definitions (JCAHO, 1990; Murray & Frenk, 2000). The differences in interpretations and definitions are largely caused by the characteristics of the notion of performance. An insight into these characteristics is therefore at least as important as the establishment of a uniform definition:

1. It is a subject-specific concept; performance is not an intrinsic quality of an object but exists as an abstract notion in the mind of the observer. The specific interpretation will differ from one actor to another, and is dependent on the *perspective* of the observer and their specific *context* (Donabedian, 1980);
2. The assessment of performance is always directed towards a topic of attention and therefore towards *objects at different levels of aggregation in the healthcare system* (Ibrahim, 2001). This may be the healthcare system of a country, but also of a region, a hospital, a practice or an individual doctor;
3. The assessment of performance is always made up of several *performance aspects* (often not operationalised in the mind of the observer (Donabedian, 1980; Campbell et al., 2000);
4. Performance is a relative concept which is the product of a comparison of an objective or intersubjective *norm* with the *actual achievement* (Donabedian, 1980) or what *could have been achieved* (Murray & Frenk, 2000). In the individual case, the assessment of a performance is the product of a confrontation of *expectation* and *experience* (Parasuraman et al., 1985).

These characteristics correspond with the characteristics of the equally abstract notion of ‘quality’ (Harteloh & Casparie, 2001) or ‘good care’ (Vanlaere & Gastmans, 2002), which many authors see as being synonymous with ‘performance’ (Brook et al. 2000; Campbell et al., 2000; Øvretveit, 2001, JCAHO, 1990). In this article, too, the two concepts are used as synonyms of each other.

1. Define actor and his perspective: e.g. the choosing health care consumer;
2. Then, specify the actor's goals and the reason for using indicators

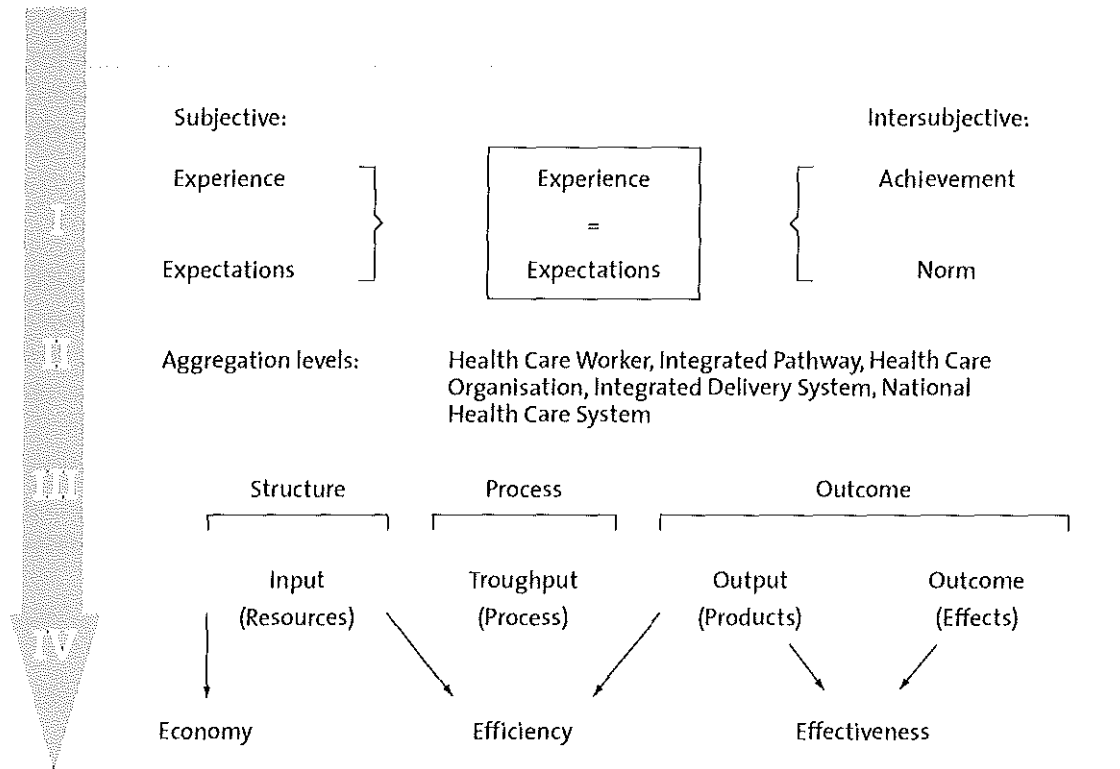


Figure 1. Conceptual model for performance and performance indicators

Based on the literature on the characteristics of the notion of 'performance' or 'quality', a model was constructed (see figure 1) which was used as a conceptual framework in the study for ranking performance and performance indicators.

The order in which the characteristics of the notion of performance were discussed above is not arbitrary, but mandatory. The model shows that performance or quality *aspects* (IV and V) can only be

specified once (the perspective of) the assessor is known (I) and there is clarity as to the object whose performance is being assessed (II). Only then can specific norms or expectations be formulated (III). Formulating performance aspects in advance is possible only at a fairly abstract level.

The classification into performance aspects devised by Donabedian (1980) is perhaps the most basic and widely used. It states that there is no more direct source of information on quality of care than the (primary) *process* of care provision. In addition, he argues that quality of care can be deduced from indirect quality aspects, namely the *structure* of the care and the *outcomes* (IV). Donabedian defines the structural aspects as “*the relatively stable characteristics of care providers; the materials and resources they have available and the physical and organisational setting in which they operate*”. He defines the outcome as “*a change in the existing versus the future health status, which can be ascribed to the health care provided*”. Other authors adopt a more business-oriented approach and see an object in the health care system (e.g. a hospital) as a production process (Harteloh & Casparie, 2001; Janssen et al., 1996). In this approach, resources (input) are transformed via processes (throughput) into products (output) which are ultimately intended to generate a certain effect (outcome). They regard the input, through port, output and outcome as constituent elements whose performance can be assessed.

Finally, there are authors who argue that ‘performance’ can also refer to the relationships between the production phases referred to (V). This is described as the Economy-Efficiency-Effectiveness (EEE) model of performance measurement (Van Helden, 1997; Hatry et al., 1990; Haselbekke et al., 1991). ‘Economy’ refers to the optimisation of the acquisition of production resources and in particular to the prices paid for the production resources needed for the transformation process. The ‘efficiency’ refers to the relationship between the deployment of resources (input) and the products (output). The ‘effectiveness’ reflects the relationship between the products (output) and the envisaged effects (outcome) (Sicotte et al., 1998).

According to some, this broad interpretation of the notion of performance is in danger of undermining its meaning and diverting attention from what is ultimately the most important consideration: the outcomes. This has led to the emergence of an ‘outcome movement’ (Walburg, 2003), in which attention moves away from structural and process aspects to a focus on outcomes. However, we believe that for a balanced assessment of performance in the health care system, *each* of the performance aspects discussed above is relevant. Performance measurement should be focused simultaneously on the different performance aspects in a *balanced* way, though with an emphasis on the structural, process *or* outcome aspects, depending on the user or their purpose or orientation (Rubin et al., 2001; Mant, 2001).

2.1.4. *Indicators*

The flipside of such a broad interpretation of performance is that it becomes virtually impossible for an actor, and especially for the individual care user, to obtain a simple and uniform insight into the performance of objects in the health care system. A limited set of indicators is needed for this, which provide a reliable and clear picture of the performance of such an object. 'Performance indicators' are seen by many as an adequate aid in this connection.

There are many definitions in circulation of the notion of performance indicator, with different authors applying different accents (see e.g. Casparie & Hommes, 1997; Brook et al., 2000; Kerklaan et al., 2000; Berg & Schellekens, 2003). The central characteristic which is common to all definitions, however, is that an indicator provides information which is *possibly* a reflection of the performance or quality of an object in the healthcare system (Casparie & Hommes, 2001; Harteloh & Casparie, 2001; Øvretveit, 2001). As the term itself indicates, performance indicators give an *indication* of the performance or quality, and thus suggest a direction or provide a signal for further research or (in the case of the care user) experience (Kazandjian et al., 1993). Some authors therefore prefer to speak of 'signal indicators' (Casparie & Hommes, 2001). This distinguishes an indicator from a 'criterion' or a 'variable', where there is a clear 'one-to-one' causal relationship between the phenomenon being measured and the actual quality or performance (Øvretveit, 2001). Based on this and on the characteristics of the notion of performance referred to above, performance indicators can be defined as "*key figures which give an indication to an actor of a number of crucial (for that actor) aspects of the performance of an object in the health care system*".

2.1.5. *Functions and use of performance indicators*

The literature contains descriptions of several functions of performance measurement and performance indicators, with each author once again applying their own emphases. A functional classification which has been widely used in recent years is the division into internal *improvement* in and external *accountability* for performance (Casparie & Hommes, 1997; Rosky & Gregory, 2001; Freeman, 2002; Berg & Schellekens, 2002; De Bruijn, 2002). A third function is sometimes added to this: *research* (Solberg, 1997; Øvretveit, 2001).

Both the 'performance paradigm' (Berg & Schellekens, 2002) and the demands placed on performance indicators vary according to the purpose for which they are to be used. Collopy (1999), for example, describes how an American hospital evaluates unplanned secondary surgery. The cases of two older patients who had taken aspirin prior to the operation in order to prevent

cardiovascular complications proved to be striking. This information led to the formulation of a new policy, which banned the intake of aspirin for one week prior to surgery. This is an example of the *internal improvement function* of performance measurement. Based on the indicator 'unplanned secondary surgery', it is possible to see whether the accompanying care process is adequate or requires improvement. The performance paradigm here is 'good - better' (Berg & Schellekens, 2002). According to Solberg et al. (1997), in such a case it will be the care providers themselves, the management and possibly a quality care department that will be the main users of this performance information. They also establish the (internal) indicator(s) themselves and gather the necessary data fairly simply and over a relatively short period via a small sample. This need not be representative and correction for possible distortion is not necessary. The data collectors are after all themselves the users of the outcomes and can easily interpret any deviating findings because they are in the midst of the primary process.

The situation is different where a *patient* is looking for comparative information on the risk of unplanned secondary surgery in various hospitals. In order to be able to select the best hospital (the performance paradigm changes to 'good - bad'), the patient requires precise and valid information on the (external) indicator which in this case is established by independent third parties. This information is obtained by gathering data from comparable hospitals in a uniform way, over a longer period and corrected for distortion. The quality assessment must not depend on case-mix differences or the fact that a hospital specialises in high-risk operations. When it comes to research, the demands placed on data collection and the selection of indicators are even more stringent, because they will be used among other things to implement best practices and evidence-based interventions in care processes.

Berwick (2003) states that the ultimate goal of performance measurement and the use of performance indicators in health care is *quality improvement*, whether the indicators are used internally or externally. This goal should be achieved via two different pathways: the act of *selection* and the *change* of processes (see figure 2).

The first pathway, *selection* of the best hospital, can be followed by people or organisations that are in a position to make choices between hospitals: consumers, purchasers, regulators, patients, contractors and referring doctors. In this context, the meaning of selection goes beyond 'in-or-out choices' and can also include aspects such as reward, recognition, punishment, payment, etc. Selection by itself will not change the distribution of performance. It can nonetheless improve

the quality of delivered hospital care at macro-level, by shifting business to the caregivers with better outcomes. In pathway II, hospitals, medical specialists and hospital staff achieve improved performance, guided by measurement, through *changing the processes* of work. Unfortunately, especially in complex systems like hospitals, the intrinsic motivation of doctors and hospital staff does not provide enough of a boost to overcome the status quo. Organizations resist change. This is where both pathways connect (see figure 2: 'motivation'). The more positive (higher payments, greater market shares, praise), or negative (threat of deselection, reduced payment, losing markets, criticism or embarrassment) actors in the left side of the figure are, the greater the impact on the hospitals (their self-interest), doctors and medical staff (their self-awareness).

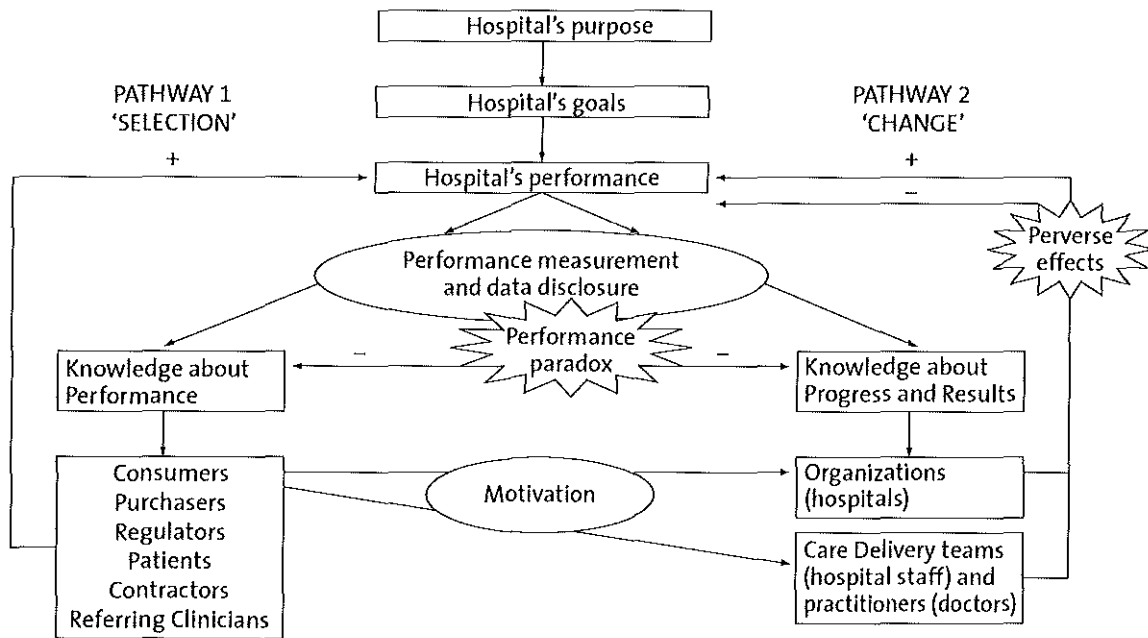


Figure 2. Two pathways from public disclosure to improvement and some unintended consequences. (Based on Berwick, 2003)

The examples given above, and Berwick's model, show that both internal improvers and external assessors may be interested in the same performance indicators, but that an indicator cannot

simultaneously fulfil both an internal improvement and an external accountability function. Internal indicators are too specifically geared to the local situation to be used externally, which means they cannot be compared and provide overly detailed information. By contrast, external indicators are usually too general for internal use, because they offer insufficient scope for translation to the local primary care process and its improvement.

It is very important to apply the distinction between internal and external indicators strictly (Berg & Schellekens, 2002). If internal indicators are used for (public) external purposes, this will lead to all kinds of undesirable effects, such as the performance paradox and perverse effects (see figure 2). This is discussed in more detail below.

2.2. Performance indicators for the choosing care consumer?

The limited applicability of certain types of indicator leads to the question of whether performance indicators are actually *suitable* for supporting the choices of care users. There are all manner of reasons for questioning the *usefulness* of performance indicators: Will patients actually make use of performance data on care provision? Any potential (side-) effects of performance indicators also ultimately determine the *desirability* of using performance indicators for supporting choices by care users.

2.2.1. (Un)suitability of performance indicators for the choosing care user

A frequently heard argument against publishing performance indicators for care users is that they are not suitable as a means of supporting their choices. Indicators do not reflect reality, but provide an indication of an underlying phenomenon, problem or trend. The precise meaning of a deviating value of an indicator itself is rarely clear, therefore requires extra research and according to these critics is consequently not an adequate basis for choice (Schellekens et al., 2003). But do the arguments cited fully legitimise this radical rejection of performance indicators for selection or choice purposes? Comparable mechanisms, such as car tests or quality cards in education, are for example used by many as an important guide in the selection process, in addition to other information (sources) and further investigation of the background to the product or service.

Yet others call for a strict limitation of the performance data that are made available to the public. Their argument is that care users benefit only from the performance information which they themselves are able to assess when they experience the care personally. This argument builds

on the principle described above that performance assessments by individuals are the result of a confrontation of expectation with experience (figure 1). Indicators on the medical effectiveness and quality of medical treatment, for example, are for this reason regarded by some as unsuitable for care users, whereas indicators of service and the way care users are approached are suitable. This standpoint is however purely theoretical and is not substantiated by its advocates with results from research on the information requirements of care users.

2.2.2. *Usefulness or uselessness of performance indicators for the choosing care user*

The main argument against making available performance indicators for care users is that they are not *useful*. The majority of studies show that in practice patients (are able to) make no use of them at all (Schneider & Lieberman, 1997, 2000, 2001; Schneider & Epstein, 1998; Lieberman, 2000; Luft et al.; Marshall et al., 2000). The modern health care system is still largely characterised by *lack of choice* (Schut, 1997). This is due for example to shortages in care provision leading to long waiting lists, to the fact that in many cases referring doctors select the care for their patients (referral function), to the market structure which (partly because of mergers) provides little in the way of diversity of supply, or to characteristics of the patient and/or their disorder. Moreover, there are strong indications that if choices are available, care users are not guided by rational considerations and performance information provided specifically for this purpose. Rather, factors such as the geographical proximity of a care provision are found to play a major role for many patients. For example, patients more or less consciously choose a hospital that is close by because it is practical in terms of travel or because they consider it natural to do so (Edgman-Levitan & Cleary, 1996; Salisbury, 1989; Bates & Gawande, 2000; Stoop & Berg, 2002). In addition, the risks of making a wrong choice are reduced by many care consumers via 'risk reduction methods' (Engel, 1990). Examples might be 'brand loyalty' towards known care providers (Salisbury, 1989; Vladeck, 1989, Consumentenbond, 2002), word-of-mouth information on other people's experience of the quality of care (Salisbury, 1989; Bates & Gawande, 2000, Isaacs, 1996) and trusting the knowledge, expertise and skills of the care professional (Nillesen, 1993).

Against this lack of inclination on the part of care consumers to use performance indicators, it is sometimes argued that collectives which buy care (in the Netherlands, health insurers or in the future possibly patient organisations), referring doctors and intermediaries *will* make use of them (CPB, 2003). Empirical research appears to refute this, however: only 1% of care purchasers use performance data (Gabel et al. 1998), while Dutch GPs do not use waiting

list data when referring patients (Stoop & Berg, 2002). The information is however used in a different way, namely by care purchasers who use the performance information to encourage care providers already contracted to *improve* the quality of care (Maxwell et al., 1998; Schauffler et al., 1999). A by now familiar example is the publication on the Internet of risk-weighted mortality figures for coronary bypass operations in New York State (Millenson, 1997). These figures were made public right down to the level of individual surgeons, with the result that within the space of a few years the mortality figures fell by 40%. Some people were convinced that the reason for this was that the health institutions and professionals, shaken into action by the poor figures, addressed the care processes. However, no causal connection has yet been demonstrated, either in this or other studies, between the publication of performance indicators and an improvement in quality.

However, two critical comments need to be made in respect of the apparent finding that performance indicators are not useful for care users. First, the study in question looks at 'the care user' in a general sense, without making a distinction based on the different roles that the care user can fulfil: that of the insured, the individual consumer of health care services, a more or less independent care consumer in a doctor-patient relationship, or a part of a representative collective (e.g. a patient organisation). Furthermore, no distinction is drawn between patients with different disorders or between groups of patients with different personal and other characteristics. Yet it may be imagined, though this has so far not been studied, that a young, well-educated chronic patient will wish to make use of choice-supporting performance information, whereas this is less likely for an older care user with an acute disorder. A second weakness in most current studies is that they fail to place the relevance of performance information in a dynamic future perspective. At present, the majority of care consumption is concentrated in a generation of (a largely older) people who were not brought up with the idea that there are choices in care and that they themselves can exert an influence. This *attitude*, in which trust and dependency play a key role, will change in the coming years with the arrival of a new generation of care users, who are more assertive and self-reliant. Moreover, there are major opportunities for the dissemination and use of choice-supporting information via new media, with which this new generation of care consumers is familiar. In particular the *Internet* appears to offer major, sometimes as yet undiscovered possibilities for such purposes. In 2003, for example, the number of regular Internet users among the over-65s rose from 13% to 25% (Trendbox, 2004).

2.2.3. (Un)desirability of performance indicators for the choosing care user

For some opponents of performance indicators for care users it is not just the unsuitability of these indicators, but above all their *undesirability* which is a major objection. As a rule, this objection is based on more principled and ethical considerations. The literature produces the following points of criticism.

In the first place, the opponents argue that performance aspects such as effectiveness, expertise and safety of care should never be used as a basis for competition, because they are considered to be present as a matter of course, as basic conditions of care. Patients do not wish to be 'bombarded' with all kinds of figures on this, but simply want to be assured that those conditions are met (Schellekens et al., 2003). And a situation is indeed preferable in which the patient can rely on good quality of care, without having to go in search themselves for the best performing care providers. However, the problem is that such a minimum standard of quality is not (yet) being achieved everywhere. Several studies have shown that there are wide quality differences between specialisms in hospitals, for example (IOM, 2001). Ignorance of these quality differences among care users, and the lack of inclination on the part of care providers to change this situation, are in fact therefore an argument in favour of making available performance information for the choosing care user.

Secondly, some (Hirschman, 1970; Schellekens et al., 2003; Tonkens, 2003; Schwarz, 2004; Trappenburg, 2005) regard the responsibility that is associated with freedom of choice as very burdensome for people, all the more so because that choice quickly acquires something of a mandatory character. Increasing freedom of choice does not therefore automatically improve quality of life. Instead, it is argued, it involves a great deal of time, organisation and worry and also brings uncertainty, doubt and fear. In the event of lack of clarity or dissatisfaction about the quality of care, these critics accordingly advocate debate and dialogue on personal preferences rather than individual choice and 'voting with the feet'. Self-connection, loyalty and voice are advocated to a much greater extent than this 'exit option' (Hirschman, 1970). Ultimately, these authors believe that this has a much greater impact on the quality of care, especially when it takes place collectively (Tonkens, 2003). As a corollary to this, they argue that clients would be helped much more by internal quality systems or a sector quality mark than by all manner of detailed quality data (Schellekens et al., 2003).

The burden of choice that these authors regard as such a problem need not however be problematic at all, as long as an extensive choice process does not become compulsory, including

for those who are unable or unwilling to make such a choice. Choice must be something that can be exercised, not something that must be exercised. Conversely, the inability or unwillingness to use performance indicators by one group of care users should not be allowed to prevent other patients who do wish to use them from doing so. Moreover, a timely exit option 'at the front door' is less burdensome for the less assertive patient than a voice option once inside the front door. If a patient learns at an early stage of an extremely high complaints percentage for a particular specialist, for example, that patient can then save themselves having to go through a lengthy and difficult complaints procedure by simply choosing a different specialist. Voice mechanisms and quality systems have also to date failed to prevent or eradicate quality differences between care providers. Making these performance differences public could provide an extra incentive for care providers to take action to improve the quality of care (Berwick, 2003). Moreover, many are convinced that creating transparency in the performance of health care services funded from public resources is "just the right thing to do" (Roski & Gregory, 2001). The risk with this argument, however, is that performance indicators could become an end in themselves, rather than a means to strengthen the position of patients.

A third fundamental objection is the dilemma that could face *health professionals* if their performance is made public and becomes a 'bargaining chip' in a negotiating process with the patient. Such a development would deny the task and responsibilities of professionals in general, and the position of trust and the duty of care of health professionals in particular. The balance between the logic of the free market (consumerism), the logic of professionals (professionalism) and the logic of bureaucracy (managementism) could be jeopardised if professionals are assessed on their performance and this performance information is passed to the care consumer. Defensive medicine could be the result (Tonkens, 2003). However real the danger of this situation is, the new health care system, which is based on market principles, demands a strengthening of the position of the care user relative to the care provider. This could be achieved with the help of performance indicators, provided these form part of (the establishment of) the doctor-patient relationship.

Finally, reference is often made to the undesirable effects of the use of performance indicators in general, and for the health care sector in particular (Van Thiel & De Leeuw, 2003; De Bruijn, 2002; Groenewoud & Dwarswaard, 2004). On the one hand there is the performance paradox, which influences the *knowledge* about performance; on the other hand there are the potential perverse effects on the *primary process* of care provision. The *performance paradox* means that the performance reported may be better or worse than the actual performance. There can be four

reasons for this. First, there is the positive learning effect. Those whose performance is reported to learn from those reports and will improve their performance. This leads to an increase in the general quality level and a blurring of the mutual differences. The performance indicators used lose their ability to identify poor performance and thus lose their power. A second cause is the selection mechanism that is associated with performance indicators. Since good performers are selected (by clients, referrers, care buyers or authorities who choose the best care provider or reward them in some other way), the average quality level will increase, again reducing the power of the performance indicators. The third cause is 'perverse learning', or 'gaming the numbers': knowledge about the object of measurement can be used to influence the measurements without bringing about an actual improvement in the quality. Fourthly, the performance paradox may be caused by ignoring or hiding poor performance.

Perverse effects influence the primary process. They can lead to blocking of the innovative capacity and ambitions of care providers, because they become focused solely on the target performance to be achieved; changes and innovations would have a negative effect on the (short-term) results. This phenomenon is also referred to as 'myopia', or short-sightedness. Another danger is that care providers begin selecting the 'best' patients in order to minimise the risk of negative results. This is described variously as 'cherry picking' or 'cream skimming'. Performance measurement could also jeopardise the professional attitude of care providers; measuring only the quantifiable aspects of the quality of care brings the danger that other aspects come to be seen as less important by professionals. Finally, there is a risk that performance measurement and comparison will prevent professionals from sharing best practices. This could slow down the dissemination of knowledge and innovation in the field of health care and thus hinder the development of quality.

2.2.4. *An interim review: are performance indicators for care users the future?*

As elsewhere, efforts are under way in the Dutch health care system to find a suitable set of performance indicators which inform care users about the quality of care offered. The above analysis makes clear that there are opportunities to meet the social need to publish care performance figures for care users.

Although it is still unclear whether there are groups of care users who would actually make use of performance indicators in practice when searching for a care provider or practitioner, given the developments so far it is very plausible that this will increasingly become the case in the

near future. Moreover, there is some evidence that publication of performance figures leads to improvements in quality by breaking through the status quo among care providers. Based on these observations and the need to equip the consumer for the new, market-based care system, the introduction of performance indicators for care users who wish to use them appears to be both a *useful* and *desirable* intervention. It is important to ensure that performance indicators are something that can be discussed in the doctor-patient relationship without that relationship being transformed into a purely businesslike transaction between consumer and supplier. It is also important that the size of the set of indicators should be such that it remains manageable and clear whilst on the other hand creating a sufficiently nuanced and balanced picture of the performance in various areas. The conceptual model presented in this study could serve as a starting point here.

In addition to the presumed benefits (which have still not been adequately studied), a number of major drawbacks and less desirable (side-) effects have also clearly emerged. According to some authors, however, those side-effects can be at least partially avoided provided adequate measures are taken (Berg & Schellekens, 2003; Van Thiel & De Leeuw, 2003; De Bruijn, 2002). In particular, the performance paradox and the perverse effects on the primary process deserve attention when setting up and maintaining a system of performance indicators for care users. First, a sharp division must be maintained between internal and external indicators (see Introduction). The use of internal indicators for external purposes and vice versa will inevitably give rise to the performance paradox and perverse effects. Secondly, the performance paradox occurs less readily with indicator sets which are drawn up by an independent body and subsequently frequently and systematically adjusted. The data should preferably also be collected by an external party. Perverse effects such as cherry picking can be prevented by correcting scores properly for distorting factors, such as the composition of the patient population. As many of the side-effects cited in the literature appear in principle to be readily manageable and controllable, this argument for abandoning the development of performance indicators for care users completely can be refuted..

The observation that performance indicators definitely do appear to have a future for care users does not however provide any clarity on how their development and implementation should be achieved. Based on the insights obtained into the suitability, usefulness and desirability of performance indicators, a study was therefore performed to ascertain the information requirements of care users and an inventory was drawn up of which performance information already exist in the health care field. The rest of this chapter is devoted to reporting on this study.

2.3. Study of the information requirements of care users and the availability of performance information

The study, which took place in 2002 and 2003, sought to provide an answer to two questions:

- a. Which performance information do care users want when choosing their care provision?
- b. Which performance information is currently already collected and used in the Dutch health care system?

The purpose of the study was to create an agenda for the future development of performance indicators for the choosing care consumer based on correspondences and differences between their information requirements and the information available.

2.4.1. *Methods*

Since little was known about the topic, the study was exploratory and descriptive in design. Three methods of data collection were used: a literature survey, semi-structured interviews and document analysis.

An extensive *literature survey* was carried out in order to answer the first study question. Owing to the exploratory nature of the study, no research was carried out among care users themselves at this stage. The literature survey was also used to search for any existing (sets of) performance indicators. A search was carried out in the following databases for Dutch or English-language literature published between 1995 and 2002: PubMed (Medline), PiCarta, Web-of-Science, Fulltext journals/ e-books from the Erasmus University Medical Centre, Online Contents and Online Publications Catalogue (POPC) Erasmus University Rotterdam. The search was carried out on key terms such as performance indicators, performance measurement, healthcare, care consumer, care user, patients, choices and choosing. In addition to combinations of these terms, both the English and Dutch equivalent terms were searched. During the search the synonym 'quality' was also used in addition to the concept 'performance'. The 'snowball method' was applied to search the articles and books found via the references given. This was repeated several times, until no new hits were found.

Two research methods were used to answer the second question about existing performance indicators: *semi-structured interviews* (N=27; see table 1) and *document analysis*. The respondents were key figures in patient organisations (N=11) and sector and professional associations of care providers (N=16). Two selection criteria were used here: distribution across the subsectors within

the Dutch health care system (general (curative) healthcare, nursing and care, care for the disabled and mental health care) and mapping out both the supply and demand side per sector.

Table 1. Patient organisations, umbrella organisations and professional associations consulted.

Sector	Patient organisation (N=11)	Umbrella/professional association of providers (n=16)
General Health Care	<ul style="list-style-type: none"> • NPCF (Federation of Patients and Consumer Organisations in the Netherlands) • Dutch Consumers' Association (Consumentenbond) 	<ul style="list-style-type: none"> • NVZ (Dutch Hospitals Association) • VAZ (Association of Teaching Hospitals) • Order of Medical Specialists (Orde van Medisch Specialisten) • NIAZ (Dutch Hospitals Accreditation Institute) • ZN (Zorgverzekeraars Nederland) • NMT (Dutch Association for Promotion of Dentistry) • KNGF (Royal Dutch Society for Physical Therapy) • LHV (National Association of General Practitioners)
Nursing and Care	<ul style="list-style-type: none"> • Client & Quality Foundation (Cliënt & Kwaliteit) • LOC (National Organisation of Client Councils) • NPV (Netherlands Patients' Association) 	<ul style="list-style-type: none"> • Arcares (sector organisation for the care of the elderly) • LVT (National Home Care Association)
Care for the Disabled	<ul style="list-style-type: none"> • Perspective Foundation (Stichting Perspectief) • FVO (Dutch Federation of Societies of Persons with Intellectual Disabilities and their Families) • Chronic Diseases and Disability Council (CG Raad) • LSR (National Centre for Disability Client Councils) 	<ul style="list-style-type: none"> • VGN (Dutch Disabled Care Association) • SOMMA (umbrella organisation for social educational services)
Mental Health Care	<ul style="list-style-type: none"> • LPR / Kwadraad (National Patient and Residents' Councils) 	<ul style="list-style-type: none"> • GGZ Nederland (Dutch Mental Health Care Association)

Each of the respondents was also asked to supply extensive documentation, which was then analysed. The analysis focused on the vision of health care of the organisation in question, the role of patients and the instruments people were developing and using for performance measurement, assessment and possibly improvement, often complete with the sets of performance indicators used.

2.3.2. Analysis

The *literature* found was ranked and analysed on the basis of the performance or quality aspects it contained which care users consider important when choosing a care provider. A count was performed to ascertain how often quality aspects in publications proved relevant. This means that the frequency with which these aspects occur in the literature was interpreted as an indication of the importance attached to them by care users. Since the same aspects recur in different publications using different words and with differing degrees of detail, overlapping aspects were placed in the same category if the differences were merely semantic. For example, 'coordination of care and liaison or cooperation' was placed in the category 'continuity and integrity of care', while the category 'accessibility and availability of care' included aspects such as 'waiting times, (telephone) accessibility and the ease with which appointments can be made'.

The interviews, combined with the documents obtained, were analysed on the basis of the following topics: the *purpose* of performance indicators within the organisation (e.g. quality systems, certification, benchmark, quality tests, etc.); the *development* of the indicators (parties involved, method used); the *status* of the indicator development; the *(sets of) indicators* used and the *actual use* of the indicators (purpose, users, availability to patients). These analyses were then sent to the respondents for comments and additions; in most cases no more than minor amendments were made.

The same analysis as that used in the literature survey was then applied to the sets of performance indicators found for the care provider and care user organisations. The performance aspects and indicators were catalogued and ranked by the frequency with which they occurred. Once again, performance aspects and indicators which corresponded in terms of content but differed semantically were placed in the same category.

Indicators and performance aspects were then categorised in accordance with the conceptual framework according to whether they were structural, process, output or outcome indicators. Finally, the 'performance information wishes of care users' were compared with the currently

existing and available performance information. This enabled conclusions to be drawn for an agenda for the development of performance indicators for the choosing care consumer.

2.3.3. Results

a) Which performance information do care users want?

Based on the literature survey we could concur with other authors (Edgman-Levitan & Cleary, 1996) in concluding that very little was known at that time about what care users, faced with making choices, would like to know about the performance of the care provision. The small amount of literature that did exist consisted mainly of descriptions of quality aspects which users of (healthcare) services *in general* consider important. Even less was known about the information needs of care users on specific *care settings*. Virtually no studies were found which looked at the need for performance information among specific groups of patients when choosing a care provider. Although a great deal had been written about providing information on specific treatments in the context of informed consent (among other things on side-effects and risks), this was not the kind of choice-supporting *performance* information which was the central focus of our study at that time.

The research that had been carried out into performance aspects that care users consider important was almost always concerned with a specific form of *care provision*, in particular GPs (Consumentenbond, 2001; McGlone et al., 2002; Harteloh & Verweij, 1995; Salisbury, 1989) and medical specialists in hospitals (Consumentenbond, 2001). More literature was found on performance aspects which users of (health care) services *in general* consider important, and which they therefore probably also consider important when they have to make choices from those services (Parasuraman et al., 1985; Zeithaml et al., 1988; Babakus & Mangold, 1992; Clemes et al., 2001; Isaacs, 1996; Post et al., 1993; Picker Institute, 2004; Coulter & Cleary, 2001; Edgman-Levitan & Cleary, 1996). Since the available literature proved to be largely general in nature (and therefore not patient or provision-specific), it was only possible to create a general list of the ten performance aspects most commonly cited in the literature which patients consider important when assessing health care services (see table 2, column 1). The most frequently found aspects related to accessibility of care, quality of the medical treatment and information on what a care provider offers (specialisms, facilities, etc.). It should be noted here that these results explicitly did *not* show the relative importance that care users attach to these quality aspects; this would require performance measurement among care users, which fell outside the scope of the exploratory study at that time, but was carried out later on (see chapters 5 and 6).

b) Which performance information already exists in the Dutch health care system?

Based on the interviews and the literature survey, a total of 60 sources of performance indicators were identified; 33 on the demand side and 27 on the supply side of health care.

The 33 demand-side sources were instruments that were used for testing the care provision from a patient perspective. Many of the performance aspects had been worked up into questionnaires and checklists. These tests were mostly performed at the request of the care providers by patient organisations which administer these instruments. Together, these 33 indicator sets produced approximately 140 quality or performance aspects. Through clustering of substantively similar performance themes, this number was reduced to approximately 30. A count was then performed to ascertain which of these 30 aspects occurred most commonly in the 33 indicator sets. Ultimately these analyses led to a list of the ten most important performance or quality aspects (from a care user's perspective) on which information then was available in the Dutch health care system (see table 2, column 2). Insight was obtained primarily into the way in which patients were approached by care providers, the independence of patients and how great a say they had in the quality of the information provision.

Of these 33 indicator sets, only four were designed to inform the (choosing) care user. Since two of these four indicator sets were still being developed at the time of the study, there were only two sets of indicators that were actually available for care users at that time: the hospitals comparison published by the Dutch Consumers' Association (*Consumentenbond*) and a guide to choosing care for the elderly (*keuzegids ouderenzorg*). The other sets were available only to the patient organisations carrying out the tests. They did not compare the tested care providers on the measured performance, but informed them individually of the performance results.

The indicator sets found that were produced by care providers could be divided into a) indicators used as part of a quality system or quality assurance activities; and b) other sets of performance indicators, including from sectoral benchmarks.

The inventory of indicator sets on the supply side also produced a top ten of the then existing performance aspects (see table 2, column 3). Care providers mainly gathered information on waiting times and waiting lists, staff illness and turnover and complaints.

Wide correspondences were found between the desired and existing performance information (compare column 1 in table 2 with columns 2 and 3). The exceptions were indicators which reflected the continuity, integrity and coordination of care, and indicators of the quality of support for family, next of kin and informal carers.

Once again, a number of caveats needed to be mentioned with regard to the *availability* of performance data. Of the 27 sets of performance indicators on the supply side, two were accessible to parties other than the care providers themselves: the hospital waiting list data published by the Dutch Hospitals Association NVZ, and the annual Elsevier survey. The other 25 sets consisted in the first place of indicators that were used in connection with quality systems. They also included indicators that were used for peer review, inspection visits, certification and accreditation, and finally performance indicators used within the national benchmarks in home care, nursing and care homes, mental health care and the disabled sector.

Table 2. Overview of performance information desired by care users and existing performance information on the demand and supply side

Performance information desired by care to user	Top 10 existing performance information at patient organisations	Top 10 existing performance information at care providers
1. Accessibility & availability, including waiting times	1. Approach to patient	1. Waiting times and lists (hospitals)
2. Quality of medical treatment/ skills/experience of care provider (specific disorders)	2. Voiced for patient	2. Staff illness and turnover
3. Care provision offered (e.g. specialisms) and accommodation	3. Information (provision)	3. Complaints (recording and handling)
4. Doctor-patient relationship (trust)	4. Skill of professional	4. Negative medical outcome data (complication records, incidents, decubitus, physical restraint etc.)
5. Information (willingness) and communication	5. Care provision accommodation	5. Evaluations of care plans
6. Approach to patient	6. Obtaining support from care provider	6. Positive medical outcome data (reduction of complaints, disorders, etc).
7. Continuity/cooperation 1st/2nd line/integral care	7. Accessibility of care/provision)	7. Information and communication to patients and next of kin
8. Care outcomes	8. Organisation	8. Production figures (of institutions and departments)
9. Support for informal carers, family and friends	9. Safety (feeling safe) and hygiene	9. Efficiency
10. Own responsibility/ independence	10. Patient/client independence	10. Customer satisfaction (general) and staff satisfaction.

Structural, process, output and outcome indicators

The performance indicators found on the demand side of health care were unevenly distributed across the segments of the conceptual model described earlier: 79% of the indicators were process indicators, including 3% quality assurance indicators; 16% of the total were structural parameters; virtually no output or outcome indicators were found: a combined total of 5%. On the supply side, the distribution appeared to be somewhat less skewed: 64% are process indicators (including 9% quality assurance indicators); 8% were care output indicators (production parameters), 8% were structural or input indicators and 21% were outcome indicators.

2.4. Conclusion

The literature survey and our own study produced a varied picture of the phenomenon of performance indicators for the choosing care consumer and the underlying social trends. Moreover, many points for discussion and even contradictions were identified on which too little research had been carried out at that time to enable a uniform conclusion to be drawn. Based on the conceptual model that we developed, we precisely chose those contradictions as a theme for reflecting on the results of the study as a whole. Following these conclusions a number of proposals were put forward for a research and implementation agenda for performance indicators for care users. In the years 2004 – 2007 we were able to carry out most of the research that was proposed by this agenda. These studies are reported in the chapters 3 - 7.

2.4.1. *Contradiction 1: Existing information not available*

This early study showed that although a good deal of the desired performance information existed, it was not available and accessible for care users in practice. The care providers and patient organisations which often held this information shielded it from the outside world and did not (publicly) compare the quality of care providers. The main reason they gave for this was based on performance paradigms: the main purpose of the then available tests carried out by patient organisations and by care providers themselves was to bring about an improvement in the quality of care, not to make that quality public. The two paradigms of performance measurement (internal improvement and external assessment) were considered to be in conflict with each other and the measured performance was therefore deliberately not made public.

The consequence was that there was a marked lack of consumer information on process and in particular outcome aspects such as (patient) safety, hygiene, quality of the medical treatment or skill of the health professionals (with the exception of hospitals), quality of the information and communication, the way in which patients are approached by care providers (with the exception of hospital specialists), continuity and integrity of care, support for family, next of kin and informal carers, and last but not least the care outcomes. What was available at that time, was summary information on structural and (to a lesser extent) process aspects such as accommodation guides in the nursing and care homes sector, waiting times for specialisms in Dutch hospitals and a comparison of a few hospitals on the grounds of service, the way in which patients were approached, expertise, patient-friendliness, cooperation and management.

2.4.2. Contradiction 2: Lots of initiatives, but information needs and choice processes largely unknown

At the time of our study there had been an explosive increase in the number of initiatives for the development and implementation of indicator sets. At the same time, however, there was great uncertainty about which groups of care users (are willing and able to) use performance information in their choice processes. It was also unknown what those groups would like the information to contain. The available research was largely general in nature and did not describe the information needs of specific groups of care users. This had been studied to a limited extent for users of the services of GPs and medical specialists, but for the majority of the health care system nothing was known about this.

2.4.3. Contradiction 3: Transformation from demand-driven care to performance measurement is institution-specific

The performance information on health care was closely tied to specific sectors and institutions. At first sight this appears logical: the consumer wants information on a particular hospital or home care organisation; on the other hand, it conflicted with the idea of demand-driven care and integration of the care provision. Trends such as these appear to demand performance information for specific groups of patients, to support their progress through the entire care chain (regardless of the individual institutions involved), rather than performance data on specific parts of those care chains being offered in a fragmented way.

2.5. Recommendations for implementation

The inventory study indicated that there was a sort of impasse in relation to performance indicators for the choosing consumer. Measurements were carried out, a good deal was known in certain areas, but (almost) nothing was compared and even less was made public and accessible to individual consumers. The outline of developments to date justified the conclusion that it was not self-evident at that time, that this impasse would be broken by the field itself, either on the providers' or the patient side, and that external pressure might be needed to achieve a breakthrough (the Health Care Inspectorate in particular started to play more active role here). A pattern appeared to be emerging in which care providers tried to 'incorporate' or 'absorb' every step in the direction of openness about performance (Van Herk, 1997). The ongoing introduction of a market system and competition appeared if anything to be strengthening rather than breaking down the impasse. This government-driven intervention in the health care system was at odds with the commitment of that same government, led by social trends towards more consumer sovereignty, demand-driven care and public-political views on 'health care governance', towards greater transparency, comparison and external assessment of the performance of care providers. In our view, all this required more control, reflection and supporting research on the effects and implementation of performance indicators for the choosing consumer.

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Chapter 3

Patients suffering from Long Lasting Diseases; a Review of the Evidence on Revealed Decisions and Choices⁴

⁴ This chapter is based on a paper that has been submitted for review to Social Science and Medicine as: Foets, M., M. Berg, R. Huijsman & A.S. Groenewoud. Patients suffering from Long Lasting Diseases; a Review of the Evidence on Revealed Decisions and Choices.

3.1. Introduction

In most health care systems in industrialised countries, strengthening the position of patients by enhancing their role as consumers is increasingly subject of health care policy. Such policy assumes that more active participation of consumers, or even the perceived chance that they will do so, will foster competition in health care and thus enhance the quality of care and reduce costs (Berwick 2003, Hibbard 2005). Also, patient's rights to influence care are increasingly recognised and the traditional provider-patient relationship in which patients are passive recipients of provider's decisions is questioned. The introduction of personal budgets in a number of countries is one policy instrument of patient empowerment. Reducing the information asymmetry between health care providers and patients is another important method. Therefore efforts are made to provide patients with relevant information on their disease and treatment alternatives by means of decision aids, which can include brochures, videotapes or interactive computer programs, and comparative information on quality of care, by means of quality report cards. Decision aids intend to facilitate patient decision making by presenting information required to consider when multiple treatment alternatives are available, and when the benefits versus risks are not clear, in order to make choices consistent with personal values (O'Connor 1999; Charles 2005). Besides, a proliferation of consumer reports, guides, report cards and performance reports has been observed in recent years, covering information on health care providers.

Patient decision-making is especially relevant in the case of long lasting, usually more serious diseases, for a number of reasons. First, due to the long lasting character many patients have much experience with the course of their disease, and thus have more clear wishes regarding their needs, not only with respect to disease treatment and management, but more in general regarding the quality of their life. Second, opposite to the situation in which one is confronted with an acute health problem, there is often more time to consider different treatment and provider options and to collect information to make more conscious choices. Third, due to the ongoing contacts between patients suffering from long lasting diseases and their health care providers, the former have more clear ideas regarding aspects of quality of care they consider as important, and there may be trade-offs between quality and quantity of life. Finally, at least for some diseases, e.g. some cancers, alternative treatment options are increasingly available without clear differences regarding medical outcomes and quality of life, and whereby patient values and

preferences thus are increasingly important. For some other diseases, e.g. some rheumatologic disorders, no definite cures are available, so choices have to be made between different alternative treatments.

Long lasting diseases cover a wide range of conditions. Many are irreversible, of which some are degenerative, progressively worsening (e.g. COPD, dementia), some are life threatening (e.g. some cancers), some have an intermittent course whereby better and worse periods alternate (e.g. rheumatoid arthritis), and yet others may be treated at a given point in time in order to stop further deterioration (e.g. hip or knee arthrosis). Due to differences in disease course, appeal on formal health care may concern different health care sectors, such as long-term care, elective interventions in hospitals, rehabilitation, surgery and medication.

These long lasting diseases are not directly fatal, and patients have to live with them. Among other things, this means that they have to deal with many choices regarding the health care they want. Contrary to what is the case in acute illness, a long lasting disease can be considered as a process consisting of different stages, whereby decisions have to be made in each stage. As a consequence, patients usually don't need a single medical intervention, but both cure and care during a longer time. Preserving as much autonomy as possible then becomes extra relevant.

Research on patient decision making until now roughly follows four directions. First, an extensive body of studies focuses on the question to what degree patients desire to be involved in clinical decision-making, varying from a completely passive role to the wish to be informed and to participate in the management of the disease (see: Guadagnoli 1998, Robinson 2001, Charles 2005). A second group of studies concentrates on the development of decision aids and report cards, and on their evaluation, e.g. whether consumers understand the information, whether they consider it as useful or whether they would prefer other information, and finally whether patient knowledge indeed increases (Hibbard 1996; 1997; Schneider 1998). In the third places, many studies exist evaluating the impact of decision aids on choices and decisions of patients, but often in an indirect way, by looking at decisions of so-called proxy patients or in fictitious treatment dilemmas (hypothetical scenarios) (see e.g. Goel et al 2001), and easily generalised to real-life decisions. The external validity of this research – do patients make the same choices in reality as they state in a hypothetical context – often remains uncertain. A fourth body of research includes the assessment of effects of report cards (for reviews see e.g. Marshall et al 2000 and Schauffer et

al 2001). These studies usually focus on more remote effects e.g. on quality outcome indicators or on the behaviour of health care providers, rather than on patient choices and decisions. The latter are assessed indirect by impact on market shares (e.g. Mukamel 1998; Wedig & Tai-Seale 2002; Dennis et al 2002), or they merely focus on the choice of health care plans.

Systematic information on the effect of providing information on *revealed* treatment and provider choices of patients suffering from long-lasting diseases is not systematically available, possibly because most research is specific to particular conditions (Leys 2003) and therefore published in many different, often disease-specific journals.

It is therefore difficult to draw more general conclusions regarding the effects of autonomy enhancing initiatives, or regarding the factors and considerations that influence patient choices and decision processes in general. We therefore decided to conduct a review of the literature regarding empirical evidence on the revealed choices and decisions patients suffering from long-lasting diseases make, and on the considerations they take into account as well as on the factors influencing their decisions. We thus focus on the actual content of the decisions and on the underlying considerations, rather than on decision styles or on preferences in hypothetical situations or without relation to real choices. Part of this review will aim to assess empirical evidence on the effects of information support on decisions and choices of patients.

Our research questions are:

1. What types of revealed decisions made by patients suffering from long lasting diseases are subject of empirical investigations? To what degree do they concern treatment choices and to what degree do they concern patient choices of health care providers?
2. With what factors are patient choices and decisions associated and which considerations do they take into account? Are there differences according to disease characteristics? And more specific: what influence has the providing of information on actual choices and decision-making?

3.2. Methods

Computerised searches have been conducted in Medline, PsychInfo and Sociological Abstracts for the years 1995-2006. We used the following keywords, which can be categorised in four groups:

1. Group 1 includes the following two keywords: “choice” and “decision”, always in combination with one of the keywords belonging to one of keywords in the two following groups (2 and 3).
2. Group 2 includes the following keywords: “client”, “patient”, “health care user”, and “health care consumer”.
3. Group 3 includes the following keywords: “health care”, “health care supply”, “health care provider”, “doctor”, “medical specialist”, “hospital”, “elective surgery”, “elderly care”, “home care”, “residential care”, “nursing care”, “mental health care”, “psychiatric care”, “revalidation”.
4. Because of our second aim, we separately included a 4th group of keywords: “report cards”, “league tables”, “performance information”, “performance reports”, and “quality information”.

Keywords in group 2 and 3 are only included in combination with the terms in group 1.

Key words were searched in the titles of publications by means of free text.

Part of the thus selected publications, covering other subjects than required for the aims of this study, has been excluded. In order to make this exclusion process as transparent as possible, we describe it in some detail. First, it was not possible to eliminate automatically choices/decisions not made by patients but by health care providers or insurance companies on behalf of their patients. We excluded them manually on the basis of the title and abstract if possible, and on the basis of the entire article, if necessary. Studies in which it was not possible to disentangle the role of patient and caregiver in the demand for health care also were excluded. Finally, combination of keywords from group 1 and 2 in both Sociological Abstracts and PsychInfo did not allow to exclude some articles outside the health care field: these were removed manually.

The remaining articles were still characterised by a large heterogeneity, and it was necessary to exclude part of them, as they did not fit with the aims of this review. A detailed explanation is offered as an appendix to this chapter. This exclusion process was the result of discussion between the first and second author of this review.

We included both quantitative and qualitative studies. Quantitative studies are expected to inform us on more objective factors associated with choices patients make. Qualitative studies may inform us on the more subjective accounts of patient choices. Moreover, choices patients make entail decision processes, and to gain insight in these processes qualitative methods are in general more appropriate. Also, their focus is on the more experiential aspects of decision-making.

We subsequently review the evidence of the qualitative and quantitative studies, as far as relevant to our study questions. Detailed results can be found in two tables, which include also some information on the aim, design and methods of the studies included.

3.3. Results

3.3.1. *Qualitative studies*

We identified 21 articles using qualitative research methods (see table 1), covering 20 studies: two publications concerned the same study, and largely described the same results (Hudak 2002 and Clark 2004). One study was part of a larger study using also quantitative methods (Scott 2003). In the majority of these studies data were collected by unstructured or semi-structured interviews, three made use of focus groups. We distinguish between two categories of studies. A first category covers 11 studies including only patients who choose for one out of more alternatives; patients choosing other alternatives thus were not included. A second category includes nine studies in which patients were included making different choices.

Within the first category (In table 1 marked by first authors in italic) four studies dealt with decisions towards cancer treatment, usually surgery. Results showed a strong desire to survive and avoid recurrence: patients chose for therapy and not for non-treatment, reason why information on risks and side effects was not important in the decision making process. Information was however important regarding other aspects and for other purposes, e.g. to remain in control over their lives, to reduce anxiety and to change their behaviour whenever this might be helpful. Also, the choice for treatment was a means to maintain hope; life extension was a first priority, followed by pain reduction (Charles 1998, Bywater 2001, Henman 2002). The study by Kelly-Powell also merely included besides cancer patients, also other possibly life threatening conditions such as renal failure and heart disease (Kelly-Powell 1997). She also found that non-treatment was not a real option. She further found that treatment decisions were the result of a process in which past family and personal experiences were taken into account, as well as experiences of others. The sustaining of the current sense of self as an individual was important, as well as the anticipation of the future by choosing treatment that would maximize life chances.

Two studies concerned decisions that were somewhat or completely negative from a professional point of view, the postponement of hip or knee replacement (Hudak 2002 and Clark 2004), and the stopping of cancer treatment in children (Chao-Hsing 1999). In these studies one common factor was the lack of adequate information combined with problems in the physician-patient interaction. Furthermore, the amount of pain was an important factor: the level of pain due to arthritis was not perceived to be as yet serious enough, resulting in

the postponement of surgery, whereas pain as a consequence of the treatment, led to cease treatment in children.

In a study among patients using anti-hypertensive drugs, positive experience with physicians was important, as well as attitudes towards medication (Benson 2002). In a study on choice for complementary medicine among patients suffering from inflammatory bowel disease (IBD), the personal context (e.g. health beliefs and social support) influenced illness experience and subsequent decisions, as well as illness impact. Using complementary medicine often started when conventional treatment failed or when one wanted to avoid side effects or surgery. Patients were actively searching credible information, but not from their physicians (Scott 2003).

Finally, two studies on decisions to place a relative into residential care showed that this was related to functional consequences of the disease resulting in the impossibility to provide care at home (Lundh 2000, Armstrong 1999). In the study by Lundh, also professional influence was strong, not only in the decision to do so, but also in the actual choice of a home (Lundh 2000).

Only three of the foregoing studies paid attention to the process of decision-making. The postponing of hip or knee replacement was a process in which arthritis patients continuously decided not to undergo surgery (Hudak 2002; Clark 2004). Also, patients on anti-hypertensive drugs were continuously balancing whether or not to take these drugs (Benson 2002). Finally, Scott showed how decision-making regarding complementary medicine in patients suffering from IBD was continuously affected by health beliefs, perceived social support and impact of the disease and information seeking (Scott 2003).

The second category includes studies of patients making different choices. High attenders of cardiac rehabilitation more often considered a healthy life style as an important disease cause, they experienced less actual disease consequences and less embarrassment regarding participation in rehabilitation, and they were more confident in their care providers (Clark 2004). Patients choosing for hospital based cardiac rehabilitation were not convinced of own self-discipline, expressed more need for supervision, needed the comradeship of a group, and were willing to make travelling arrangements. Those preferring home-based rehabilitation wanted it to fit into their lives and expressed practical concerns (Wingham 2006).

Three studies on complementary and alternative treatments (CAM) provided congruent insights at least to some degree. Opinions on regular treatments and CAM were important in decision-making, as well as (prior) experience with CAM (Boon 2003, Caspi 2004 and Jørgensen 2005). In

the study on rheumatologic disorders, CAM was also associated with experience and opinions of close associates (Caspi 2004). Furthermore, prostate cancer patients declined CAM on request of their physician, as a consequence of psychological incongruence, and out of fear for adverse effects and/or drug interaction, while the seeking of control directed them towards CAM. Disease stage was also an important factor (Boon 2003). In the study on asthma and allergy patients choosing classical homeopathic therapy considered the disease as curable, while general practitioners (GP) patients did not. Asthma and allergy patients choosing for regular GP treatment also had a better relationship with their GP than patients choosing for classical homeopathy (Jørgensen 2005). A study on patients suffering from migraine or chronic daily headache focussed on the stages prior to the actual decision: assessing severity (pain) and other disease characteristics, followed by evaluating treatment alternatives. This evaluation was based on experiences of own previous management strategies, but also experiences of other individual preferences. Besides, information was gathered of other treatment possibilities from professionals, family, friends, media and specialised migraine associations. These studies concluded that most patients did not choose for one or another treatment, but use a combination of strategies (Peters 2003). A study on patients with chronic fatigue syndrome and fibromyalgia revealed that the function of information seeking on causes, diagnosis and treatment was to influence health care providers so that they offered what patients wanted from them (Åsbring 2004). A study in HIV patients showed that decision-making is a continuous process of interaction between patient and health care provider (Marelich 2002). Harcourt (2004) found that most patients facing the choice for or against immediate breast reconstruction (BR) made instant decisions at the moment of consultation, whereby information was selected afterwards to confirm this decision, while a minority first sought information and decided subsequently. Finally, a study, mainly concerning patients suffering from severe mental illness, revealed that the most important influence on their decisions to seek treatment was an immediate need for care. Besides, patients mentioned negative experiences in acute and outpatient services (DeCoux 2005).

3.3.2. Quantitative studies

We have identified 31 articles using quantitative methods, covering 30 studies (see table 2). They can be distinguished in two large categories. A first category specifically aims (among other things) at evaluating the effect of instruments to facilitate decision-making (decision aids and

quality report cards) on actual choices of patients. Most of these studies have a more or less experimental character. A second category aims at studying more general factors associated with patient choices; the latter have observational designs.

Ten studies evaluated the effect of decision aids by means of randomised controlled trials (RCTs) or quasi-experimental designs. Four of them investigated the influence of such an aid on the decision whether or not to start a therapy. Whelan (2003) did not find differences between the experimental group and a control group receiving usual medical care regarding the choice of adjuvant chemotherapy in breast cancer. However, Peele (2005) found that women with less severe tumours received less adjuvant therapy of any kind in the experimental group as compared to a control group receiving only an informational pamphlet. Also, in the latest study younger women and women under treatment in university cancer centres were more likely to receive adjuvant therapy. Deyo (2000) investigated the effect of a video plus booklet versus a booklet only, on the decision of back pain patients to undergo surgery and found that results were different according to type of diagnosis (details in table2). Finally, Montgomery (2003) studied the effects of three modes of additional information as compared to usual care on the decision whether or not to start with antihypertensive drug therapy, and did not find differences between the groups.

Three studies investigated the influence of decision aids on the choice between breast conserving therapy (BCT) and mastectomy (MAS). Molenaar (2001) and Wilkins (2006) did not find differences between the group with and without a decision aid, whereas Whelan (2004) found that BCT was more frequent in the experimental group. In an earlier study, making use of a pre-test post-test design, Whelan (1999) found that the number of women choosing BCT decreased after introduction of the decision aid. Subsequent analyses of all patients from the Molenaar study showed that treatment preferences were highly predictive of treatment decision, besides age, education, having children at home, and being employed (Molenaar 2004).

Morgan (2000) studied the effect of an interactive videodisc in patients suffering from ischemic heart disease and found small differences between both groups in their choice between elective revascularisation and ongoing therapy. Man-Son-Hing (1999) examined the effect of a booklet, together with a worksheet and audiotape versus usual care on the choice between anti-thrombotic treatment by means of warfarin or aspirin in the case of atrial fibrillation. In the experimental group more patients made a choice for aspirin.

Only one – observational -study investigated the influence of provider reports (Schneider 1998).

Merely one in five patients admitted that risk-adjusted in-hospital ratings of hospitals providing cardiac surgery had any (moderate or major) impact on their decision-making.

Next, we found nine cross-sectional observational studies in cancer patients, of which five concerned breast cancer. In a study by Stanton (1998), again older women more often choose MAS. Women choosing BCT clearly had different expectations: they expected that BCT would promote cure and prevent recurrence, and that MAS would have a negative impact on their femininity, physical appearance and sexuality. Both groups did not differ regarding the amount of support from their physician and from their partner. Mastaglia (2001) investigated the choice between BCT and MAS from another point of view, by investigating which factors patients themselves considered as important in their choice. Women choosing BCT rated surgeon's preference as a more important factor than patients choosing MAS; they also more often took into account the lack of difference in survival. No association was found between choice of therapy and the use of 10 information sources. Three sources were important for both groups: surgeon, family and GP. Pusic (1999) included three choice options: BCT, MAS alone and MAS with BR. BR patients were better educated and more likely to be Caucasian. No difference between lumpectomy and MAS alone patients was found. Ananian (2004) investigated the choice between MAS alone or MAS with BR in women about to undergo MAS, as well as the timing of BR (immediately or later). Women opting for BR more frequently recognised the importance of discussing matters with surgeon and partner, and more often realised that their body image was important. Fear for surgery prevented some women from opting for BR. Women choosing immediate BR had benefited more frequently from discussions with the physician, and also were characterised by a poorer health state (appetite loss and breast symptoms); a higher BMI was negatively associated to this preference. Grunfeld (2006) investigated decisions regarding chemotherapy in women with advanced breast cancer. In this study the oncologist was the person most of influence on the decision, followed by family members. The main considerations of these patients were that chemotherapy would control the disease, that it was their last hope, and that it would cure the disease.

Two studies investigated cancer patients making use of alternative therapies. The first one assessed factors predicting the degree in which cancer patients made use of CAM (Shumay 2002). Heavier CAM use was related to being female, Caucasian, having more education, having breast cancer, suffering more from nausea and vomiting, less satisfaction with the doctor and higher disease

severity perception. The second study investigated differences in choice between standardised or individualised unconventional treatment (Kimby 2003). The likelihood to choose individualised unconventional treatment was greatest among women, patients with more school education, patients seeking relief for symptoms, information and improvement of general condition, among patients with breast and gynaecological cancer, as well as among patients with less metastatic spread. The likelihood to choose standardised treatment was greatest among males, patients with less school education, among patients seeking recovery, among patient with other cancer types and among patients with more metastatic spread (Kimby 2003).

In a study by Salkeld (2004) colorectal cancer patients were asked to rate decision aspects according to importance. Trust in the surgeon was most important, followed by emotional support, followed by a desire to get treatment as quickly as possible and to keep the GP informed, followed by information and communication and by surgeon's specialisation and availability of a patient support group.

Finally one study investigated difficult decisions of parents regarding continuation of treatment or life sustaining care for their children and adolescents suffering from cancer. The information and recommendations of health care professionals were the most important factor in their decisions. The decisions to discontinue treatment occurred more frequently when parents conclude that the child would not get better (Hinds 1997).

In addition to the many studies in cancer patients, nine observational, cross-sectional studies on patients with other diseases have been included in this review, of which one study has been published in two articles. Cox (1996a) studied the decision to discharge dementia patients to home or to a nursing home. Those discharged to a nursing home were more severely cognitively impaired, which corresponds with the most important factor caregivers take into consideration when making a decision. The likelihood to take patients at home was associated with the availability of informal help, and this was even stronger in African Americans, while in white patients this also depended on the availability of formal support (Cox 1996b). Karlawish (2002) found that disease severity was the major predictor of patient or caregiver's participation in treatment decisions. Sales (2005) studied factors affecting choice between different types of residential care. Functional status appeared to be an important factor, besides age, marital status, educational level and memory and behaviour problems. Also restrictiveness of policy regarding life in residential care also was an important factor.

Previous experiences and future expectations are important factors and considerations patients take into account. In benign prostatic hyperplasia not choosing for surgery was associated with negative expectations (Barry 1995), while choosing for renal transplantation was related to the expectation for a better quality of life, and not choosing for transplantation was associated with negative previous experiences (Holley 1996). In IBD patients choosing for complementary therapy was related to negative experience with regular treatment (Hilsden 1998). In all three foregoing examples disease severity also played a role.

A study among diabetes patients investigated the decision to use aspirin in order to reduce cardiovascular risk. Patients using aspirin were at higher risk for cardiovascular disease, knew more about benefits of aspirin and less about the risks, and placed high value on preventing cardiovascular events than on avoiding aspirin side effects. Main reasons for non-use were intolerance and lack of provider recommendation. All patients perceived their provider and the diabetes association as having more influence than family members or other patients (Montori 2003).

A study among multiple sclerosis patients investigated the choice to forgo or discontinue β -interferon treatment, a treatment plagued by high discontinuation, although the first to prevent further relapses and delay disease progression. More risk-seeking patients were less likely to be on treatment compared with more risk adverse patients. For those discontinuing treatment, the explanatory variable of significance was severity of side effects (Prossner 2002).

Finally, in a study investigating sources influencing medication decisions in HIV, patients report their physician as most important source of influence; this was even more the case among white men than under white women and among African men and women (Meredith 2001).

3.4. Discussion

This paper reviewed studies assessing decisions and choices of patients suffering from long lasting diseases. Regarding the first research question, we first may conclude that most studies related to choices with respect to cure and care, whereas choices between health care providers or institutions were addressed in only one study. One should keep in mind that we only included studies investigating the influence of report cards on patient choices of health care providers in case of *long lasting* diseases. Most studies on the influence of report cards are carried out in the United States, and often concern the choice of health care plans of consumers, usually employees,

thus not (yet) suffering from long lasting diseases, as appeared from a recent review by Fung et al (2008). Since 1999, this review only found five studies on the effect on hospital selection, and another five on the effect on individual provider selection, most of them assessing it by changes in market share and not on factors affecting patient decisions (Fung et al 2008). Longo also concluded that, even without our restrictions, there is little empirical evidence on the effect of report cards on consumers, but that there is influence on health care providers (Longo 2003).

The majority of the studies dealt with patients suffering from cancer. Only five studies explicitly dealt with long term care facilities, when decisions have to be made regarding placement of a relative into residential care e.g. in the case of dementia. Two studies dealt with rehabilitation, and only one study in the field of mental health (care) was included.

In the majority of the qualitative studies (12 of 21) only patients choosing for one option were included as research subjects. As a consequence they provided no information on the considerations of patients choosing for another alternative, which restricts the possibility to draw conclusions.

Furthermore, in spite of the extensive list of exclusion criteria, the included studies still show an enormous variety regarding their focus, making it difficult to address especially the second research question. Indeed, the studies included dealt with very different choices, ranging from decisions regarding drug use to decisions regarding placement in nursing homes. Moreover, even when studying the same decision regarding the same health problem, methodological differences remained such as divergent in- and exclusion criteria.

Taking into account these limitations, we now proceed to the main conclusions. We may distinguish six large categories of factors affecting choices and decisions: socio-demographic factors, disease characteristics, psychosocial characteristics such as health beliefs -including expectations, previous experiences and trust in professional caregivers - social support and information.

Regarding the role of *socio-demographic characteristics*, younger age seemed to be important when women have to choose between MAS and BCT (B8, B9, and B26) and in the choice to undergo adjuvant therapy (B28). Younger age also was associated with deciding for renal transplantation (B2), and in choices regarding CAM treatment by cancer patients (B19). Age was not associated with choice for prostatectomy in patients suffering from benign hyperplasia (B1). Not being eligible for a treatment because of age, may urge patients towards alternative treatment, as was the case in

prostate cancer (A12). In the case of dementia age and sex of the patients were not important in two studies (B3, B18), but in another study age was important (B29). As far as the role of educational level was investigated, it was related to choice of alternative/complementary therapy (B19, B20) and choices in breast cancer (B9 and B26), but not the decision for a renal transplantation (B2), nor the decision for prostatectomy (B1) or decisions on medical care of dementia patients (B18).

Regarding *disease characteristics*, first we may conclude that the role of co-morbidity has not been assessed, except in the study on renal disease, where the presence of diabetes did not affect the decision (B2). Many studies seemed to indicate that disease severity is important, and that it interacts with *psychosocial* factors. Which aspect of severity is important, depended at least in part of the type of disease.

In the case of chronic mental disease, the most important factor in the decision to seek treatment was an acute crisis (A20). In the case of the possibly life-threatening disease cancer, decisions often have to be made in an acute phase of the disease. Both qualitative and quantitative studies showed that survival and prevention of recurrence then were the dominant considerations; other considerations such as side effects were hardly important. Patients were inclined to make use of all existing possibilities, also in order to maintain hope (A2, A6, A8) even when cancer was advanced (B30). Eventually they seek CAM treatment, e.g. when suffering from nausea and vomiting and in case of high degree of disease severity perception (B19). A similar result was found among patients suffering from heart disease and renal failure (A1). Patients didn't take risks, in a sense of not making use of all treatment possibilities (A1, A2, A6, A8, and A12). Especially positive expectations thus seemed important, if not hope on cure and avoidance of recurrence, then on life extension and pain avoidance (A8, B30), or at least hope on amelioration or control of the condition or relief of symptoms (B5, B30). In the case of breast cancer, other expectations were also important, such as preservation of femininity, physical appearance and sexuality (B8, B11, and B25). Expected side effects did not play a role in patients suffering from cancer (A6, A8). The two studies on cancer in children related to decisions in later stages of the disease and showed a different picture: whether or not to continue treatment depended on the degree of pain the children suffered from, and whether some hope remained. In this situation, negative expectations such as lack of chance on recovery guided the decisions of the parents (A3, B5).

In progressively degenerative diseases, increasing severity seemed to urge patients and caregivers to undertake some action. This was especially clear in the decisions of caregivers for the care of

dementia patients, where increasing dependency and/or cognitive impairment were important factors. (A4, A5, B3, B18 and B29). Increasing severity may also lead to decisions to change treatment, by choosing for CAM treatment in combination with regular treatment, as was the case in IBD patients (A13, B6).

In many long lasting (sometimes slowly progressing) diseases, treatments are to some degree elective. In these situations the role of *psychosocial factors* in decision-making seemed to be larger, besides disease duration and impact on daily functioning.

In patients suffering from hip/knee arthritis, there seemed to be a process of adaptation resulting in postponing of treatment. Pain and disability level were considered as not being sufficient, and as normal part of ageing (A9, A15). In asthma, the opinion on the incurability of the disease was associated with homeopathic treatment instead of treatment by a GP (A19). In rheumatologic disorders, the willingness to experiment made some patients suffering from rheumatologic disorders choose for alternative treatment only (A16).

Negative expectations may keep patients from treatment, as was the case when patients suffer from prostatic hyperplasia that postponed surgery out of fear for sexual dysfunction, although symptom severity enhanced decision to undergo surgery (B1). Also the anticipation of side effects influenced patient decisions. Not taking antihypertensive drugs was related to an expected risk of addiction (A7), not taking aspirin to prevent cardiovascular disease in diabetes patients related to avoiding side effects (B20). Similarly, the perception of corticosteroid treatment as risky by IBD patients made them choose for alternative treatment (A13; B6) as did fear for adverse effects of regular treatment and for drug interaction in prostate cancer patients (A12).

Previous experiences – personal or by other patients – may influence patient expectations, and subsequent patient choices and decisions. Previous positive experience may favour decision to undergo certain treatment e.g. in the case of heart disease, renal failure and cancer (A1). Previous negative experiences were associated with the decision not to undergo a treatment e.g. renal transplant for a second time (B2), not to seek help by patients suffering from mental disease (A20), with the decision to stop treatment when children with cancer (A3) and with the discontinuation of treatment in multiple sclerosis patients (B17). Failure of conventional treatment influenced decisions toward alternative treatment in IBD patients (A13) and even prostate cancer patients were guided towards CAM in case of adverse effects of conventional treatment (A12). Also, experiences of friends affected decisions, as in the case of arthritis patients (A15) and migraine patients (A11).

Finally the existence of waiting lists also deterred patients from seeking help (A20).

Presence or absence of trust in professional caregivers also influences patient decision-making. Trust in the physician, especially in his knowledge was important in decision-making of cancer patients (A6, A8, B27, B30, B77), in decisions of patients suffering from rheumatologic disease to choose for allopathic and not for alternative treatment, while lack of trust lead to use of alternative treatment (A16). Lack of trust made HIV patients (A10) and IBD patients (A13) change doctors. Finally, lack of empathy by professional caregivers was a reason for patients to stop cancer treatment in children (A3).

In studies assessing patient choices in (quasi)-experimental studies on decision aids, where patient were offered additional *information* besides or instead of regular care, one should in principle not expect large differences in patient choices between experimental and control groups. Indeed goal of these aids is to facilitate decision-making in situations where more than one treatment is available, of which benefits and risks are not clear, rather than influencing decision-making in a certain direction. In 5 of these studies indeed no differences were found, but in 4 other there were. Results were even unequivocal when studying the same decision, e.g. in the case of BCT or MAS (B11, B16, B24 and B31) and in the case whether or not to choose for adjuvant therapy (B23, B28). It remains unclear how this can be explained, although differences in the design of these studies might be part of the explanation. In the only study on quality report cards, its influence was limited because patients were not aware of the existence of the report card (B7).

From the non-experimental studies, it appeared that, in more acute stages of a possibly life threatening disease as cancer, the role of information as such was not decisive (A2, A6). In these studies patients dealt with information in a selective way, by disregarding less favourable information or by interpreting it in a more positive way. Patients take information into consideration, but it did not affect their final decision, as survival was their most important consideration (see above). Another study in breast cancer patients showed that most patients decided quickly regarding immediate BR, whereby information was only used as confirmation (A18). Still another study revealed that breast cancer patient did not really recall the information received from the care provider regarding the different options (B9). Nevertheless, discussion with their doctor was important in the decision for immediate BR (B25) and the surgeon and GP were important sources of information in the choice between BCT and modified radical MAS (B15). Information seemed to be important as a means of gaining control in a study among

different types of cancer patients, rather than actually influencing decision making (A8), while a study among patients with prostate cancer showed that conflicting information may result in control loss (A12). However, parents deciding on their child suffering from cancer indicated to rely heavily on information by the physicians (B5). Lack of information on surgical possibilities was characteristic for patients postponing surgery in the case of arthritis (A9, A15), and also of patients not choosing for CAM (A12), and to non-use by diabetes patient of aspirin to reduce cardiovascular risk (B20).

HIV patients considered their physicians as the most important source of information (B14). Recommendations of health care providers were also important in the decision to use antihypertensive drugs (A7). Advice of professionals was also important in the decisions regarding long term care for dementia patients, when their situation is aggravating (A5, B3, B4 and B18).

A few studies focused on the role of active seeking of information by patients. This was the case in a study on patients choosing for CAM treatment; in this case it was not surprising that patients searched for information from other sources than their regular care provider (A13). In the study by Peters (A11) migraine patients also actively searched for information on treatment alternatives, using various sources of information. In another study on CAM more active searching resulted in the choice of other types of alternative treatment (B22). Furthermore, active searching of information was used as an instrument to influence the health care process in chronic fatigue patients (A17). In this study seeking information sometimes resulted in change of health care provider or turning to an alternative treatment. Active searching for information was also the case in some but not all HIV patients, who became more actively involved in their receiving of particular antiretroviral treatments under influence of the information gathering (A10). Finally, a small group of women having to decide on immediate BR actively searched for information (A18).

This chapter provided a review of studies investigating choices and decisions of patients suffering from long lasting diseases. They were characterised by a vast heterogeneity, both with respect to the precise aims as with respect to the chosen methodology. The factors associated with decision making and the considerations patients take into account, were seldom included based on more theoretical grounds, but rather on an ad hoc basis or based on personal interests of the researchers. Therefore, it sometimes may be questioned whether some researchers did not just find what they were looking for. In general, sociodemographic characteristics e.g. were seldom assessed, whereas personality characteristics were never included. Moreover, choices and decisions that

were investigated were very diverse, and it can be expected that relevant characteristics affecting these choices, depend on the nature of the decision. E.g. it is not unlikely that the choice to (dis)continue a specific treatment in MS is fundamentally different from the choice to end cancer treatment in children. Because of this heterogeneity in many respects, the relative importance of each of the six groups of characteristics cannot be estimated. Future studies should include factors based on theoretical grounds, i.e. theories on factors influencing decision-making. Finally, whereas many studies assess the influence of decisions aids on patient choices, only one study was found assessing the impact of quality cards on revealed patient decisions in patients with chronic disease. This field thus remains open for research.

Table 1. Qualitative studies, in order of publication date

First author Publication date Country	Condition	Sample	Setting	Data collection
A1. Kelly-Powell 1998 United States	Heart disease, renal failure, cancer	18 patients (6 cancer, 3 coronary heart disease and 9 renal failure patients) selected by physicians and nurses	Large urban teaching hospital, outpatient kidney dialysis centre and rural area family practice, all Midwestern U.S	Open-ended interviews soon after treatment decision and subsequent interview among 15 patients 1 month later (in order to explore evolution)
A2. Charles 1998 Canada	Breast cancer (stage I or II), after surgery	Purposive sample of 20 women	Regional cancer centre	Open-ended, in-depth interviews
A3. Yeh 1999 Taiwan	Cancer in children	19 primary care givers selected from register	Childhood cancer foundation	Structured in-depth interview
A4. Lundh 2000 Sweden	Elderly needing nursing care due to several diseases (dementia, stroke and other)	Purposive sample of 14 spouses having placed partner in home for older people	Participants were selected by assistance of the local authority social services department	Semi-structured interviews
A5. Armstrong 2000 United Kingdom	Dementia	4 Relatives or carers	Unclear	Semi-structured interviews

Focus	Main results
Treatment decision-making experiences	<p>Respondents make decisions to accept treatment by:</p> <ol style="list-style-type: none"> 1. Interpreting the past (family and cultural history, past personal experiences and experiences of others) and applying it to their present situation. 2. Sustaining the current sense of self as individual and in relation to others (maintaining normal life schedules / conform personal characteristics). 3. Anticipating the future by choosing treatment that would maximize life chances. <p>Most respondents did not seriously consider a non-treatment option.</p>
Experience of treatment decision-making regarding adjuvant therapy after surgery	<ol style="list-style-type: none"> 1. Treatment choice was often presented in the form of "something versus nothing". Option to do nothing is not perceived as of equal value. This is associated with the need for hope, the assurance that everything has been done to avoid recurrence. 2. Assessing treatment benefits and risks. Scientific information in the form of probabilities of recurrence and survival often was interpreted in a more positive light.
Reasons for parent decision on drop out from cancer treatment	<p>In order of importance:</p> <ol style="list-style-type: none"> 1. Severe pain due to treatment and adverse side effect. 2. Desire for better and less painful treatments. 3. Adverse effect of other patients' experience. 4. Seeking alternative disease explanations after prolonged denial of diagnosis. 5. Lack of empathy from health care professionals. 6. Misinterpretation of improved prognostics.
Decision making of care home placement by spouses	<ol style="list-style-type: none"> 1. Decision usually not the consequence of an acute health crisis. 2. But of growing awareness not to be able to continue to care. 3. Possibility often first raised by others (home help, children). 4. Usually with an important role of professionals, which is part of legitimation. 5. Decision most often experienced as negative, as often not experienced as a real choice. 6. Feelings were less negative when placement occurred after hospital discharge.
Reasons to decide placing relative into residential care	<p>Important factors leading to consider placing are: wandering, aggression, incontinence, physical dependency. Also: stress associated with Christmas.</p>

First author Publication date Country	Condition	Sample	Setting	Data collection
A6. Bywater 2001 United Kingdom	Cancer / bone marrow transplantation candidates	7 Bone marrow candidates out of 10 invited to participate	Unclear	Unstructured interviews, one month before the scheduled transplant date
A7. Benson 2002 United Kingdom	Hypertension	Maximum variety sample of 38 patients selected from all receiving antihypertensive drugs	2 urban general practices	Qualitative interviews
A8. Henman 2002 Australia	Different types and stages of cancer	20 women randomly selected from participants in RCT	4 teaching and 2 regional base hospitals	Semi-structured interviews by telephone 2 weeks after first consultation
A9. Hudak 2002 Canada	Confirmed hip or knee arthritis	Purposive sample of 17 patients probably unwilling to undergo total joint arthroplasty (TJA) surgery, identified in prior population-based survey	Population based survey	In-depth face-to-face interviews

Focus	Main results
Decision to undergo bone marrow transplantation	<ol style="list-style-type: none"> 1. Patients assess their position in the light of information provided by care providers, but decide to undergo treatment because they see it as the only possible cure, which had highest priority (although it may not be the best choice in terms of survival). Information on possible complications or after-effects was not taken into account (avoiding knowing too much). All felt they had received sufficient information. 2. Gut instinct (not purely instinctive, but including a form of situational analysis) and personal beliefs. 3. Unfulfilled personal aims and wish to go back to normal. 4. Maintain hope 5. Trust in professionals' knowledge, expertise and good intent: accepting this was considered as a rational decision strategy.
Considerations to use antihypertensive drugs	<ol style="list-style-type: none"> 1. Reasons to take antihypertensive drugs: positive experience with doctors (including their advice), perceived benefits, pragmatic considerations. 2. Reservations about drugs in general (28 patients) (best avoided/unnatural, unsafe, risk of addiction, signifies ill health). 3. Reservations about antihypertensive drugs specifically (17 patients). 4. Majority (22 patients) balance between reservations and reasons to take the drugs.
Important considerations in decision-making with special attention for the role of information	<ol style="list-style-type: none"> 1. 15 women wanted as much information as possible, because of 4 reasons: (a) to have control, irrespective of eventual use of knowledge in decisions (b) to reduce anxiety (c) to change own behaviour and (d) to make the future more predictable. 2. Critical factors in decision-making (a) specialist knowledge (b) feeling to be included in decision-making, with variation regarding to the degree (c) trust and confidence as important aspect of their relationship with the doctor. 3. Women's priorities in decision-making; (a) extending life and avoiding pain (b) no further treatment is not a real option, treatment is necessary even if uncomfortable.
Subjective accounts of decision-making process regarding TJA	<ol style="list-style-type: none"> 1. Deferral: for majority decision-making is ongoing deliberation of surgical option often resulting in deferral of treatment option. 2. Assumptions constraining decision-making: <ul style="list-style-type: none"> - Considering arthritis not as a disease but as normal part of ageing. - Believing that level of pain and disability is not sufficient. - Expecting more authoritative advice of physician. 3. Moreover: many patients showed poor information on or trust in TJA.

First author Publication date Country	Condition	Sample	Setting	Data collection
A10. Marelich 2002 United States	HIV/Aids	39 HIV positive patients receiving antiretroviral treatment	Recruitment via advertisement in HIV/Aids publication and directly from an HIV/Aids clinic	4 focus group interviews
A11. Peters 2003 United Kingdom	Migraine and chronic daily headache	Convenience sample based on theoretical sampling 13 participants	Via personal contacts, posters in 2 supermarkets and letter to 20 members of migraine association	Semi-structured interviews
A12. Boon 2003 Canada	Prostate cancer	Maximum variety sample 29 participating men	Variety of settings, in which patients were asked to participate in a study on CAM	5 focus groups

Focus	Main results
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<p>Process of antiretroviral treatment decisions</p>	<ol style="list-style-type: none"> 1. Degree of participation varied: <ul style="list-style-type: none"> - Some patients reported playing a very assertive role (pushing) in obtaining particular regimens. - Other patients first listened to the recommendations of the providers, and then chose themselves. - Some patients changed doctor or clinic, when they felt not receiving optimal care. 2. Some patients were first rather passive (especially when newly diagnosed), but became more involved over the course of time (e.g. based on experience and information). 3. Most patients strongly inclined to information gathering from several sources (HIV positive peers, friends, family, professionals and media).
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<p>Factors involved in patients' decision-making (e.g. medication, consultation)</p>	<p>Four stages of decision-making to adopt, maintain or discontinue treatment:</p> <ol style="list-style-type: none"> 1. Onset and severity were starting point of decision-making. 2. Evaluation (awareness, assessment and balancing of options), serving as justification of: 3. Decision 4. Adoption, maintenance or discontinuation of behaviour.
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<p>Decision-making regarding CAM vs. conventional treatment (CM)</p>	<ol style="list-style-type: none"> 1. Core of decision-making: fear and lack of control as a result of diagnosis or recurrence; loss of control also due to volume and conflicting nature of information. 2. Fixed decision-making factors (which patient cannot change): age and other medical conditions resulting in not being eligible for surgery, pushing to exploration of CAM; disease stage influencing decisions to undertake more aggressive CM, unless the disease was progressed to far, again resulting in exploring CAM. 3. Flexible decision factors (which may change over time): <ul style="list-style-type: none"> - Perception of CM as more aggressive and as having significant adverse effects, versus perception of CAM as more gentle and safer resulting in decision to use (only) CAM. Sometimes CAM was used in addition to cope with adverse effects of CM. - Absence of reliable information on CAM sometimes was the reason not to use CAM. - Fear of adverse effects and drug interaction. - Psychological (in)congruence. - Negative experience with conventional physicians or with CAM practitioners. - Fulfilment of conventional physicians' wishes - Perceived need for control.
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First author Publication date Country	Condition	Sample	Setting	Data collection
A13. Scott 2003 Canada	Inflammatory bowel disease (IBD)	Sample size was determined by theoretical saturation. 14 participants	Second stage of a study, of which the first stage was quantitative (see table 2 below)	Interviews, partly guided by results from quantitative part and partly free
A14. Clark 2004 West Scotland	Patients eligible for a cardiac rehabilitation programme, covering a wide range of CHD diagnoses.	Purposive sample 44 participants	District general hospital	8 focus groups: separately with: - Patients with high attendance - Patients with high rates of attrition - Patients not attending
A15. Clark 2004 Canada	Moderate to severe hip and knee arthritis	Purposive sample of 17 appropriate but unwilling candidates for total joint replacement	Toronto; sample generated from a previous large-scale population-based study	Qualitative interviews, using a semi-structured interview guide

Focus	Main results
Factors affecting decision to use complementary therapies	<ol style="list-style-type: none"> 1. Contextual issues influencing illness experience and subsequent decision-making: <ul style="list-style-type: none"> - Symptoms causing the greatest impact are different from person to person. - Health beliefs (=personal assessment of risk and disease severity, perceived benefits of actions, self-efficacy) determine action / all participants perceived that risk of complementary medicine is less than risks of corticosteroids. - Perceived level of social support influences impact of IBD. 2. Impact of illness experience on the individual as well as social effects. 3. Actions to manage illness: using complementary medicine often starts when conventional treatment failed or when one wanted to avoid side effects or to avoid surgery. Personal responsibility is important. Patients were actively searching credible information, but not from their physicians.
Patients' beliefs and decision-making about cardiac rehabilitation attendance	<ol style="list-style-type: none"> 1. Differences in opinions on causes of CHD: full attenders also considered sedentary life style, high alcohol intake and high blood pressure as risk factors; the other patients put greater emphasis on stress and were more sceptical regarding smoking as a risk factor. 2. Full attenders spoke about the effect of CHD on their daily life in the past, while the others considered it as ongoing while the future remains uncertain. 3. High attenders see themselves as more active, the others see themselves as rather helpless regarding CHD. 4. High attenders considered the group as a major factor in confidence, motivation and fitness. The other patients considered participants as old, illness-focused and 'needy'. They lacked belief in the benefits of the programme.
Understanding patient unwillingness for total joint replacement	<ol style="list-style-type: none"> 1. Symptoms (pain and disability), often defined as not sufficiently severe to consider joint replacement. 2. Perception of lack of efficacy regarding pain of joint replacement. 3. Most participants claimed not to have received good or complete information from their physician. Especially information from peers was important and influence on decision-making depended on the experience of these peers.

First author Publication date Country	Condition	Sample	Setting	Data collection
A16. Caspi 2004 United States	Confirmed chronic rheumatologic disorders, such as osteoarthritis, rheumatoid arthritis and fibromyalgia	Purposive sample of 12 patients, 3 groups; - Only considering CAM (group 1) - Combining CAM and allopathic medicine (AM) (group 2) - Only using AM (group 3)	Health centres and alternative practices	In-depth, open-ended qualitative interviews
A17. Åsbring 2004 Sweden	Chronic fatigue syndrome and fibromyalgia	Maximum variety sample 25 patients selected by member of staff on care units, of which 1 withdraw - 12 women diagnosed with chronic fatigue syndrome - 13 women with fibromyalgia	2 hospitals	Semi-structured interviews
A18. Harcourt 2004 United Kingdom	Breast cancer	93 women admitted for MAS, (56 mastectomy alone; 27 mastectomy with immediate reconstruction) 65 completed 3 interviews	3 hospital centres	Semi-structured interviews, one prior to surgery, two 6 and 12 months later.

Focus	Main results
Decision-making regarding CAM or AM: - What processes are used? - What information is central? - Similarities and differences between 3 groups	Differences between three groups of patients relate to: <ol style="list-style-type: none"> 1. Provider trust is most important in group 3, personal role is relatively passive (external locus of control; group 1 patients sometimes refer to previous failures of AM). 2. Disease severity and prognosis: least important in group 1, very important in group 3, where severity and disability perceptions did play major role. 3. Willingness to experiment with many treatments, especially large in group 1, before making definite decision (used as justification). 4. Intuitive/spiritual factors, also especially in group 1. 5. Outcome evidence; seeking information during a longer period of time was common in group 2 (not in group 1 and 3), whereby scientific information was more important than personal testimonies.
Using knowledge to influence health care process (prescriptions, referrals)	<ol style="list-style-type: none"> 1. Seeking knowledge to: (a) clarify causes (prior but also after diagnosis) (b) finding a possible diagnosis and disease characteristics (c) find adequate treatment (d) being able to plan one's own health care process. 2. Results in: <ul style="list-style-type: none"> - Possibility to assess competence of doctor, resulting sometimes in dissatisfaction when doctor seems to know less and does not act: patient has to find himself adequate contacts for referral. - Knowing what one wants before going to the consultation, and thus influencing health care providers in order to be successful. 3. To obtain such influence patients made use of strategies during the consultation: exiting (eventually changing health care provider or turning to alternative medicine), non-compliance, confrontation, persuasion, making demands and demonstrative distancing.
Decision on immediate breast reconstruction	<ol style="list-style-type: none"> 1. Three ways of decision-making <ul style="list-style-type: none"> - Group 1 (76 women): quick instant decision-makers at consultation; information is used as confirmation; women are certain about their decision. - Group 2 (14 women): sought further information before deciding; information seeking was selective and women were certain about their decision. - Group 3 (3 women): hesitated until surgery; information was confusing; women were highly anxious and unsure.

First author Publication date Country	Condition	Sample	Setting	Data collection
A19 Jørgensen 2005 Denmark	Asthma and allergy	6 patients from GPs and 11 patient from classical homeopaths (CH) - from the CH patients, 3 had terminated their treatment	GP and classical homeopath practices	Semi-structured interviews
A20 DeCoux 2005 United States	Severe mental illness	Purposive sample of 10 adult patients suffering from severe mental illness and a chronic medical disorder	2 residential crisis programs providing short-term mental health care	Semi-structured interviews, medical records and observation
A21 Wingham 2006 United Kingdom	Myocardial infarction	17 patients who experienced myocardial infarction and were still in hospital	Hospital	Semi-structured interviews before rehabilitation programme

Focus	Main results
Patients understanding of and reflections on their own reasons for choice (including continuation and termination) of GP or classical homeopathic treatment and termination of treatment	<ol style="list-style-type: none"> 1. Experience with conventional treatment: adverse events were assessed as necessary evil by GP patients and as unacceptable by CH patients. All GP patients experienced effect as satisfactory (including improvement), but CH patients as too little and too short-lasting. CH patients experienced their treatment as symptom-relieving or adding to their well-being. Finally GP patients experienced a good relation with their GP, but CH patients did not. 2. GP patients had a sceptical attitude toward alternative treatment, whereas CH patients were attracted to it, because CH is harmless and they were convinced that treatment would work. 3. GP patients tried to ignore their disease and to consider it as incurable, while CH patients actively tried to work with their disease and did not consider it as incurable, but want to recover. 4. Pressure from friends and family was also reason to seek CH; someone of circle of family or friends is homeopath.
Influences on treatment decisions (not limited to mental health care)	<p>Most important influences was the immediate need for care (crises). In case of subacute complaints no care was sought because participants expected that these complaints would not be taken seriously.</p> <p>Positive reinforcement for emergency use was reported, and deterrents to seek care in acute and outpatient settings (e.g. waiting lists, uncaring attitude etc).</p> <p>The role of enabling factors was more diffuse.</p>
Factors considered by the patients in their choice between hospital or home-based cardiac rehabilitation	<p>Ten patients chose the home based programme and 7 the hospital based programme.</p> <ol style="list-style-type: none"> 1. Patients choosing for the hospital based programme had an emphasis on supervision during exercise, needed the camaraderie of a group, were willing to make travel arrangements and believed they had lack of self-discipline. 2. Patients choosing for the home-based programme believed that their rehabilitation should fit in with their lives rather than the reverse, and considered themselves as self-disciplined; they disliked groups and expressed practical concerns (transport, timing).

Table 2. Quantitative studies, in order of publication date

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B1. Barry 1995 United States	Benign prostatic hyperplasia	373 men, without prior prostatectomy or benign prostatic complications	3 hospital based urology practices	Written questionnaire. Patient followed three months after educational program to assess whether they underwent surgery
B2. Holley 1996 United States	End-stage renal disease	95 patients	Medical Centre, Dialysis Unit	Written questionnaire during routine dialysis session or clinic visit.

Decision / choice under study and determinants' or considerations in the decision	Main results
<p><i>Choice between (elective) prostatectomy and "watchful waiting"</i></p> <ul style="list-style-type: none"> - Symptom state - Prospect of postoperative complications (sexual dysfunction) - Consistency with preferences 	<p>43 (10.7%) underwent prostatectomy.</p> <p>Choice of prostatectomy was predicted by negative ratings of current symptom state and negatively predicted by by prospect of postoperative sexual dysfunction. Age, education and marital status were not associated with the choice.</p>
<p><i>Choice to be listed or not for renal transplantation</i></p>	<p>44% on waiting list; 56% refused.</p>
<p>Demographic differences</p>	<p>Listed patients are younger, fewer years of end-stage renal disease and more likely to be on home dialysis therapy. No differences in gender, race, educational level, marital status, children, diabetes mellitus, previous transplant experience, religious beliefs in white patients. African patients with strong religious beliefs were less likely to be listed.</p>
<p>Reasons of patients</p>	<p>Most frequently reported reason pro transplantation: hope for better quality of life. Of those declining transplant, 92% with previous experience mention discouragement; 59% without previous experience reported the experience of other patients in which transplant failed.</p>

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B3. Cox 1996 United States	Dementia	179 caregivers of hospitalised dementia patients	Five large acute care hospitals Washington DC	Interviews by telephone at time of discharge decision
B4. Cox 1996 United States	Dementia	179 caregivers of hospitalised dementia patients: 99 African- Americans and 80 white	Five large acute care hospitals	Interviews by telephone

***Decision / choice under study
and determinants'
or considerations in the decision***

Main results

Decision to discharge dementia patients home or nursing home

1. Differences between both groups according to socio-demographic characteristics of patients and caregivers.
2. Differences regarding support caregivers receive
3. Factors caregivers consider as important in their decision

90 discharged at home; 73 to nursing home.

1. No differences in gender, age, race and income of the patients. Those discharged to nursing home were more severely cognitively impaired. No differences in gender, marital status, relationship to patient, age and employment status of caregivers.
2. No difference in satisfaction with help of informal supports and nurturing aspects of these relationships. Caregivers receiving more informal help were more likely to take patients at home, as those having an alternative caregiver when necessary. Having more hours of formal help was also associated with patients being discharged home.
3. Most important factor influencing decision was the cognitive status of the patient. Furthermore, important were also the recommendations received from healthcare professionals. Especially in the case when discharge is to a nursing home, the role of the social worker is considerable.

Decision to discharge dementia patients home or nursing home

Differences between white and African Americans

Choice for discharge home for African Americans is strongly affected by the availability of an informal caregiver, while in white patients this also depends on the availability of formal support.

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B5. Hinds 1997 United States	Cancer in children and adolescents	39 parents	Paediatric oncology institution	Retrospective descriptive Semi-structured interview by telephone
B6. Hilsden 1998 Canada	Inflammatory bowel disease (IBD)	134	Database including patients of university affiliated and community gastroenterologists	First phase: cross-sectional survey (structured mailed questionnaire) Second phase of this study has been reported elsewhere and is qualitative (see above)

**Decision / choice under study
and determinants
or considerations in the decision**

Main results

*Decisions of parents regarding continuation of treatment or
life sustaining care*

1. Most difficult decisions

2. Factors influencing decision making according to
parents

1. Most frequently reported difficult decisions:
 - 1) Deciding between phase I drug study or no further
treatment
 - 2) Maintaining or withdrawing life support
 - 3) Giving more chemotherapy or giving no further
treatment.

2. Information and recommendations of health care
professionals are the most important factor in their
decisions.
Decision for no further treatment occurs more
frequently when parents conclude that child will not
get better.

Decision to seek complementary therapies

1. Factors associated with complementary therapy use

2. Reasons for seeking complementary therapy

- Complementary therapies had been used by 51% of
patients in the previous 2 years. Current use among 33.3%,
of whom ½ for IBD.
1. Disease duration and history of hospitalisation were
independent predictors of complementary therapy.

 2. Main reasons were:
 - 1) Avoiding serious side effects of corticosteroids
 - 2) Perception that conventional therapies are not
helping.

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B7. Schneider 1998 United States	Patients that had undergone coronary artery bypass graft	474 eligible patients random sample of larger list provided by surgeons	4 hospitals listed as having average mortality rates	Telephone survey, retrospective
B8. Stanton 1998 United States	Stage I or II breast cancer	76 patients receiving surgical treatment	2 hospitals	Questionnaires before or at preoperative visit in which the decision had to be finalised

**Decision / choice under study
and determinants'
or considerations in the decision**

Main results

Use of a consumer guide providing risk-adjusted in-hospital mortality ratings of hospitals providing cardiac surgery

1. Use assessed by
 - Knowledge of mortality rate of hospital, surgical group or surgeon
 - Whether there was discussion of ratings with physicians or other health care providers
2. Barriers to use of consumer guide

Choice between radical MAS MAS or breast-conserving treatment (BCT)

1. Expectancies (of a particular consequence) and values (importance of that consequence) of MAS and BCT
2. Believing one has a choice
 - Perceived difficulty of the choice
 - Degree of distress

1. Of the 56 patients aware of the report before the surgery, 18 knew the rating of their hospital, and 7 the surgeon rating. 6 reported discussion with a physician.

Of these 56 patients, 11 indicated that the ratings had any effect on their choice.

2. Important barriers to use were: shortness of time to decide and perceived distance to hospital. 63 chose BCT, 37% MAS.

Women's positive expectations of the consequences of treatment options, along with age, correctly classified 94% of the sample with regard to the choice.

- Being older was significantly correlated with a choice for MAS.
- Important contributors to choice for BCT (as opposed to MAS): perception that MAS would not enable preservation of femininity, physical appearance and sexuality, and a positive expectancy for cure.

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B9. Pusic 1999 Canada	Stage I or II breast cancer	267 patients	Hospital registries (3 hospitals)	Written questionnaire after surgery
B10. Man-Son-Hing 1999 United States and Canada	Atrial fibrillation	287 patients already participating in a trial were randomised: - 139 experimental group - 148 in control group	14 Atrial Fibrillation centres	RCT Written questionnaire
B11. Whelan 1999 Canada	Stage I or II breast cancer	175 patients	7 Surgeons working in community practices and in university teaching hospitals	Before / after design

Decision / choice under study and determinants' or considerations in the decision	Main results
<i>Choice between lumpectomy with radiotherapy, MAS alone and MAS with BR</i>	Among BR patients, 67,6 % had immediate reconstruction.
Comparison with respect to demographic characteristics (age, marital status, race, education)	BR patients are younger, better-educated and more likely Caucasian, but no differences regarding marital status. No difference between lumpectomy and MAS patients regarding these characteristics. Preoperative counselling of the three options was not recalled by many patients, but this result should be interpreted with some caution (selective recall, not all patients were elective for each treatment option).
<i>Choice (at the end of participation in a trial) between aspirin and warfarin as anti-thrombotic therapy (stroke prevention)</i>	Effects a few days after meeting with physician: In the control group more patients choose warfarin (11% vs. 8%). Previous warfarin use was an independent predictor of choosing warfarin as first choice.
<i>And: Adherence to decision after 6 months</i>	Adherence after 6 months: little change.
Effect of a decision aid (consisting of a booklet, worksheet and audiotape) provided a few days before meeting with physician, versus usual care only <i>Choice between MAS and lumpectomy plus radiation</i>	BCT decreased after the introduction of the decision board (88% versus 73%).
Effect surgical decision board	Main considerations: avoiding radiotherapy and less concern with body image. Unexpected result remains unexplained, but may be related to the design.
Considerations	

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B12. Deyo 2000 United States	Back pain	393 elective surgery candidates including 3 diagnostic groups (spinal stenosis, herniated disks and other diagnoses). 1 year follow-up: 353	2 sites; HMO and fee for service academic practice	RCT Questionnaires at baseline, at 3 months and 1 year after enrolment.
B13. Morgan 2000 Canada	Ischemic heart disease amenable to elective revascularization and ongoing medical therapy	187 patients considering revascularization: - 90 in experimental group - 97 in control group	Hospital	RCT
B14. Meredith 2001 United States	HIV	202 patients	Local HIV ambulatory clinics	Structured interviews

Decision / choice under study and determinants' or considerations in the decision	Main results
<p><i>Lumbar spine surgery</i> <i>(in most cases an elective treatment)</i></p>	<p>Trend towards lower surgery rates in video risk group. Important differences among diagnostic sub-groups:</p> <ul style="list-style-type: none"> - Herniated disks: those watching video chose significantly less surgery - Spinal stenosis: those watching video chose surgery slightly more often.
<p>Effect of video program plus booklet versus booklet alone <i>Treatment decision revascularization</i></p>	<p>Small difference non significant difference in percentages that underwent revascularisation after six months: less in experimental group.</p>
<p>Effect of interactive video disc versus usual care</p>	
<p>Medication decisions</p> <p>Sources influencing these decisions according to patients Does importance of source vary by patient and disease characteristics? Is choice of most important source associated with use of antiretroviral therapy?</p>	<ol style="list-style-type: none"> 1. 60.4% reports physician as most important source; 11,4% considered prayer as most important. Other sources were selected by fewer than 6% of respondents. 2. Physician as most important source: more among Caucasian men than under Caucasian women and among African men and women. Africans more likely to consider prayer as most important than Caucasians. 3. Reporting physician as most important source and being Caucasian were independent predictors of antiretroviral treatment.

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ^a
B15. Mastaglia 2001 Australia	Stage I or II breast cancer	Consecutive sample of 175 patients: - MRM: 70 - BCT: 93	Cancer registry	Descriptive correlational study executed after surgery (0 to 8 months)
B16. Molenaar 2001 The Netherlands	Stage I and II breast cancer	180 consecutive patients: - 92 in experimental group - 88 in control group	3 hospitals	Quasi-experimental pretest/protest design
B17. Prosser 2002 United States	Relapsing-remitting multiple sclerosis	62 patients	MS clinic (out patient)	Survey / written questionnaire

Decision / choice under study and determinants' or considerations in the decision	Main results
<p><i>Choice between lumpectomy with radiotherapy (breast conserving therapy BCT), modified radical MAS ((MRM)</i></p> <ol style="list-style-type: none"> 1. Factors considered as important in their decision 2. Which information sources women use to assist in choice? 	<p>Lumpectomy: 57.1%; MRM: 34.5%; both: 7.1% and no surgery: 7.1%.</p> <ol style="list-style-type: none"> 1. Two important factors influencing decision making in both groups: <ol style="list-style-type: none"> 1. Knowing preference of surgeon 2. Fact that there is no difference in survival Both were more important in BCT group. The BCT group believed that they had more of a choice in comparison to the RM group. 2. Most important sources of information: surgeon, family and GP (in both groups). The MRM group named family as a more frequent source, the BCT group the GP.
<p><i>Choice between BCT and MAS at 3 months</i></p> <p>Effect of CD-Rom as a supplement to standard care</p>	<p>No difference in treatment decision, most patients in both groups chose BCT (75% in experimental, 68% in control group; difference not significant).</p> <p>See Molenaar 2004 for other predictors of choice.</p>
<p><i>Choosing to forgo or discontinue β-interferon or glatiramer acetate treatment. Treatment choice included four categories: never on treatment, discontinued treatment, on treatment with good compliance and on treatment with perfect compliance.</i></p>	<p>More risk-seeking patients were less likely to choose treatment compared with more risk aversion patients. For patients with discontinued treatment, the explanatory variable of significance was severity of side effects.</p>
<p>Role of risk attitudes</p>	

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ?
B18. Karlawish 2002 United States	Possible or probable Alzheimer's disease	74 patients and caregivers	University clinic	Written questionnaire filled out by caregivers. Clinician completed rating of AD stage
B19. Shumay 2002 United States	Cancer patients	143 patients	Hawaii Tumor Registry	Mail survey questionnaire and oral interview
B20. Montori 2003 United States	Diabetes	206 patients	Tertiary care diabetic clinic	Cross-sectional survey in waiting room Clinical information from medical records

Decision / choice under study and determinants or considerations in the decision

Degree in which decisions about medical care are made by patients or caregivers

Role of caregiver characteristics:

- Disease severity
- Experience
- Age / education
- Relationship with patient
- Depression
- Subjective burden

Degree of CAM use (quantity, intensity, frequency and duration of use)

Sociodemographic characteristics, disease site, quality of life, satisfaction with health care (conventional treatment, physicians, information), perceived severity of illness

Choice whether or not to use aspirin to reduce cardiovascular risk

Characteristics and preferences affecting decision making

Main results

Caregivers have a key role, except in very mild dementia.

Dementia severity (assessed by mental state and clinical dementia rating of dementia severity) was the only significant predictor in patient's participation. No independent effect of other variables (such as age, gender, race and education of caregiver and of patient, relationship).

20% were non-users, 20% light users. 31% moderate users and 29% heavy users.

Female gender, Caucasian ethnicity, having higher education, having breast cancer. More symptoms of nausea and vomiting, higher perceived severity, and lower satisfaction with the physician were significant predictors of greater degree of CAM use.

67% used aspirin.

Patients using aspirin are at higher risk for cardiovascular disease, know more about benefits of aspirin and less about risks, are more certain about their decision; place higher value on preventing cardiovascular events than on avoiding side effects of aspirin.

Patients not using aspirin place equal value on prevention of cardiovascular events and on side effects of aspirin; main reasons for non-use are intolerance and lack of provider recommendation.

No difference between both groups in interest in shared decision making and in perceiving care provider and diabetes association as important external influences on their decision, rather than family or other diabetes patients.

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B21. Montgomery 2003	Hypertension (sustained raised blood pressure)	Patients not yet on anti-hypertension medication (199 at 3 month follow-up): - Usual care (52) - Video/leaflet only (51) - Decision analysis only (48) - Decision analysis and video/leaflet (48)	Patients recruited in 21 general practices	Factorial RCT Written questionnaires
B22. Kimby 2003 Denmark	Cancer	441 consecutive patients using unconventional treatment	43 therapists and clinics practising unconventional treatment	Part of larger explorative prospective 5 year study Data: - From 2 written questionnaires. - Medical records

Decision / choice under study and determinants' or considerations in the decision	Main results
<p><i>Treatment choice: started drug therapy or not (secondary outcome at three month follow-up)</i></p>	<p>About 67% started drug therapy.</p>
<p>Difference between patients receiving simple (information video/leaflet) and complex (decision analysis) decision aids</p>	<p>No difference between the groups.</p>
<p><i>Choice of different modes of unconventional / alternative treatment:</i></p> <ul style="list-style-type: none"> - Standardised treatment (characterised by equal treatment to all cancer patients) - Individualised treatment (based on individual needs of the patient as assessed merely by the therapist) 	<p>52% chose individualised treatment, 48% standardised treatment.</p>
<p>Relationships with user characteristics:</p> <ul style="list-style-type: none"> - Sociodemographic factors - Treatment orientations - Cancer status 	<p>Probability to choose individualised unconventional treatment is greatest among women, patients with longer school education, patients seeking relief for symptoms, information and improvement of general condition, among patients with breast and gynaecological cancer, as well as among patients with less metastatic spread. Probability to choose standardised unconventional treatment is greatest among males, patients with shorter school education, among patients seeking recovery, among patient with other cancer types and among patients with metastatic spread.</p>

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ³
B23. Whelan 2003 Canada and United States	Lymph node negative breast cancer	176 women, candidates for adjuvant chemotherapy: - 83 patients received medical consultation and decision board - 93 receive only medical consultation	8 cancer centres	Randomised trial without blinding
B24. Whelan 2004 Canada	Stage I and II breast cancer	201 women, of which 201 agreed to be evaluated - 94 decision board - 107 usual practice	20 surgeons	Cluster RCT
B25. Ananian 2004 France	Primary breast cancer	181 women about to undergo MAS for primary breast cancer	3 regional cancer centres and private hospital	All patients informed in a similar way (consultation and leaflet) Self-administered questionnaires after decision, but before operation

Decision / choice under study and determinants' or considerations in the decision	Main results
<i>Choice for adjuvant systemic therapy (chemotherapy)</i>	Majority chose adjuvant chemotherapy.
Effect of decision board	No statistically significant difference between two groups in the number choosing for adjuvant therapy.
<i>Choice for MAS or BCT</i>	Patients making use of the decision aid were more likely to choose BCT (94% vs.76%).
Effect of decision aid	
<i>Choice between MAS alone or MAS with BR</i> <i>And</i> <i>Choice of time of reconstruction (immediate or later)</i>	<ol style="list-style-type: none"> <li data-bbox="713 780 1362 956">1. Majority chose for BR (81%). Those choosing for BR more frequently recognise importance of discussing with surgeon and partner, more often realised the importance of body image. Some women were prevented to choose for BR out of fear. <li data-bbox="713 987 1362 1189">2. A majority of women choosing for BR chose immediate BR (83%). This group had benefited more frequently from discussions with the physician, and also was characterised by a poorer health state (appetite loss and breast symptoms); a higher BMI was negatively associated to this preference.
Factors affecting choice (sociodemographic, medical, psychological) Shared decision making	

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ²
B26. Molenaar 2004 The Netherlands	Stage I and II breast cancer	172 patients	3 hospitals	Written questionnaire before treatment decision and before decision aid was provided to an experimental group
B27. Salkeld 2004 Australia	Colorectal cancer	175 (220, post-resection, adjuvant therapy completed, not undergoing any treatment or palliation) 80%	2 teaching hospitals	Written questionnaire
B28. Peele 2005 United States	Breast cancer	386 women, after completion of their primary surgery treatment	14 oncology practices including 56 oncologists	Randomisation of practices in usual care (general informational pamphlet) group and decision aid group. No blinding of physicians nor patients

Decision / choice under study and determinants' or considerations in the decision	Main results
<p><i>Choice for BCT or MAS (MAS)</i></p> <p>Factors affecting choice:</p> <ul style="list-style-type: none"> - Sociodemographic - Treatment preference - Decision aid - Quality of life - Patients' concerns regarding treatment outcome - Decision style - Perceived preference of physician 	<p>Majority decided to have BCT (72%).</p> <p>Having had the decision aid was not associated with treatment choice (see above)</p> <p>Treatment preferences were strongly predictive for actual decisions.</p> <p>Higher age, being employed, having to care for children, and higher educational level were predictors of a choice for MAS.</p>
<p><i>Important aspects of the treatment decision process</i></p>	<p>Important: 1) trust in surgeon (expertise and concerned) 2) emotional support by GP, family, friends and other patients 3) desire to get treatment as quickly as possible (less than half wanted second opinion) and to keep the GP informed 4) information and communication 5) surgeon's specialization and availability of patient support group.</p>
<p>Relation between importance and patient characteristics</p>	<p>Three associated patient characteristics: educational level, employment status and marital status.</p>
<p><i>Choice for adjuvant therapy</i></p>	<p>Among women with low tumor severity those in the experimental were less likely to choose adjuvant therapy (results regarding women with high tumor severity were not reliable).</p>
<p>Effect of decision aid</p>	<p>Additionally younger women and women in university-based practices were more likely to choose adjuvant therapy.</p> <p>Marital status, race, education had no significant effect.</p>

Study: First author, publication date, country	Condition	Net population size	Setting	Design and method of data collection ^a
B29. Sales 2005 United States	Persons placed by State Aging and Adult Services Administration and Home and Community Services Division, excl. those with developmental disabilities or mental illness	<ul style="list-style-type: none"> - 269 residents new to any of three residential care settings - 237 informal caregivers for these residents - 184 owners or managers - 115 direct care providers 		Extraction of data from state and Medicaid database Personal interviews at enrolment

**Decision / choice under study
and determinants'
or considerations in the decision**

Main results

Choice of type of residential care setting

- *Assisted living (AL)*
- *Adult residential care (ARC)*
- *Adult family home (AFH)*

Effect of resident (demographic characteristics, functional status, health status, cognitive status, memory and behaviour, influences on the decision, availability of informal caregiver, role of case manager) and facility characteristics (policy on types of residents to admit, services available, restrictiveness regarding residential life, attractiveness as scored by the interviewer.

Choosing AL as compared to AFH:

- Older age associated with increased likelihood of choosing AL
- Married respondents more likely to choose AL
- Not having informal caregiver associated with choosing AFH
- Higher education, higher need for assistance with ADL and more behaviour problems associated with less likely to choose AL.
- Less restrictive policy was associated with increased likelihood to choose

Choosing ARC as compared to AFH:

- Being married and having an informal caregiver were related to increased likelihood to choose ARC.
- Having more education, more need for assistance with ADL, less mental health were associated with decreased likelihood to choose ARC.
- Less restrictive policy was associated with increased likelihood to choose ARC
- Attractiveness was associated with decreased likelihood of choosing ARC

Choosing ARC as compared to AL:

- Persons with higher ADL scores were less likely to choose ARC
- Attractiveness was associated with less likely choice for ARC

Especially functional status appeared to be a factor in the choice between the three facilities; health and cognitive status were less important.

Restrictiveness also appeared to be important..

B30. Grunfeld 2006 London region	Advanced breast cancer	Consecutive series of 102 women, choosing for chemotherapy	two cancer centres, comprising 16 oncologists	Semi-structured questionnaire; part of the questionnaire was also analysed in a qualitative way, not leading to other results
B31. Wilkins 2006 United States	Stage I and II breast cancer	101 patients: - 49 non video group receiving written and oral information - 52 video group; also received written and oral information	Cancer clinic	Prospective controlled design including experimental and control group without randomisation

¹ Some studies included other dependent and independent variables, not relevant for this review, and thus not included in this table

² Only measurements necessary for the part of the study include in this review are mentioned

Choice for chemotherapy

Persons and factors influencing this choice

Choice for BCT or MAS (MAS)

Effect of an educational video

Persons influencing decision:

1. Oncologist was mentioned by 74% of the women
2. Family members were mentioned by 39%

Factors:

1. Control of cancer, mentioned by 45% of the women
2. Last hope, mentioned by 28%
3. Desire to be cured, mentioned by 10%.

25% of the experimental group chose MAS versus 14% in the non-video group; however this difference was not statistically different.

Appendix: exclusion of manuscripts

- Those dealing with choices not related to long lasting diseases, e.g. of persons suffering from acute diseases and accidents and everyday illnesses; choices regarding dental care, plastic surgery when not related to a long lasting disorder, preventive health care, pregnancy and finally regarding end of life decisions.
- Those studying participation styles of patients by means of questionnaires, those assessing patient involvement during a single encounter with a care provider, both empirical (whether patients are actively participating, factors influencing active participation), and methodological (such as the development of measures to assess patient views on actual participation in decision-making during the consultation) and those studying satisfaction with participation in decisions.
- Those studying preferences without examining real choices and decisions, including studies in which preferences were compared with actual treatment as decided by a physician (for a review see Montgomery 2001).
- Those dealing with patient choice of a general practitioner or another physician as primary care resource, thus not for a specific long lasting condition, as well as those where it remained unclear whether information was used by patients or (referring) physicians.
- Those concerning the role of consumers and patients in the health care organisation at a policy level.
- Those concerning other choices and decisions patients have to make, e.g. regarding work and insurance, and whether or not to participate in clinical trials. Research on the choice of coping strategies was equally excluded.
- Those only reflecting opinions of individuals, mostly clinicians or ethicists, not reflecting empirical evidence; including those in which the limits of patient decision making are evaluated in the light of laws, and those describing one case, a patient, usually by a health care provider.
- Those purely describing choice alternatives, and their, merely medical, (dis)advantages for a given condition.
- Those dealing with the process of developing decision aids and report cards, as well as those evaluating their quality in terms of capacity to enhance decision-making (e.g. understanding by patients; employability) and in terms of correspondence with gold standards.

- Those dealing with information needs of patients without a relationship to actual choices and decisions, both those providing empirical evidence as those dealing with methodological issues e.g. a how to measure information needs. Equally, studies on the information patients actually obtain, as well as on the amount of information they can absorb are excluded when there is no relationship with actual choices.
- Those dealing with the consequences of information provision on medical outcomes, on (health-related)-quality of life, on patient satisfaction and on economic outcomes such as change in market shares.

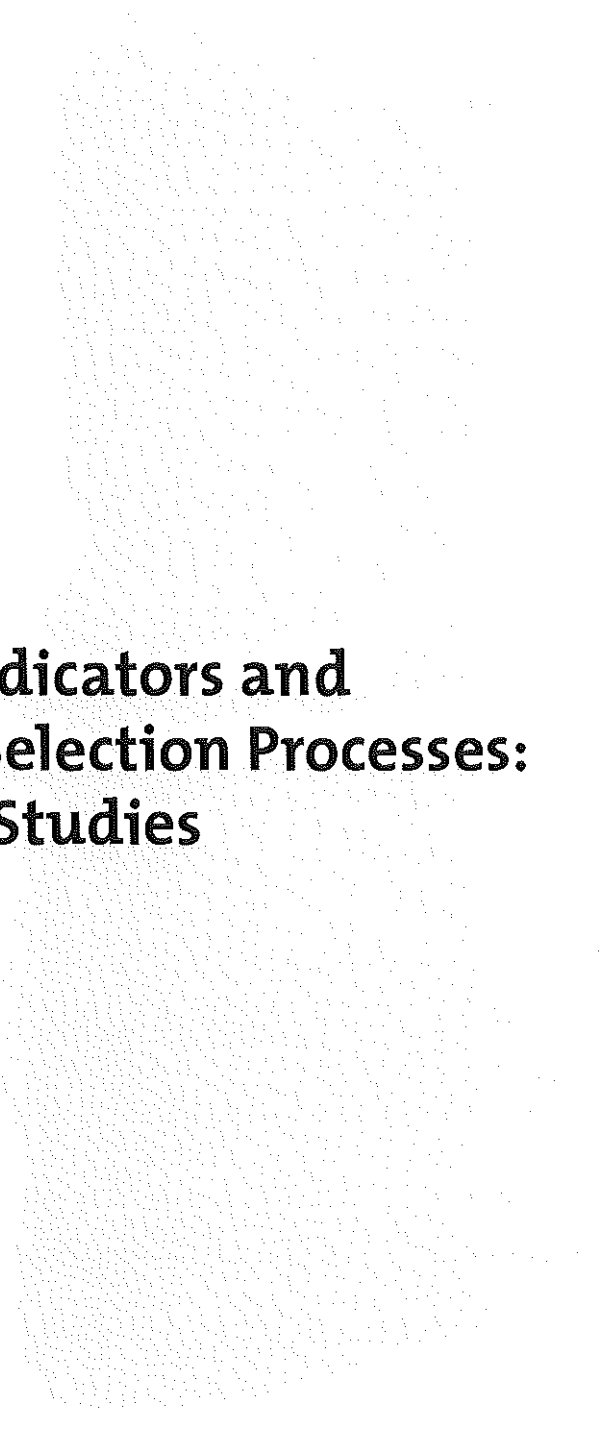
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**Performance Indicators and
Patients' Search and Selection Processes:
Empirical Studies**

Chapter 4

Patients' Decision Making Processes in the Search for and Selection of their Health Care Providers: Findings from a Grounded Theory Study⁵

⁵ This chapter is based on a paper that has been submitted for review to *Sociology of Health and Illness* as: Groenewoud, A.S., R. Huijsman & M. Berg. Patients' Decision Making Processes in the Search for and Selection of their Health Care Provider: Findings from a Grounded Theory Study.

4.1. Introduction

One of the central debates in medical sociology has always focused on the doctor-patient relationship and the (process of) decision-making within this relationship. Over the past five decades many different conceptualisations of the doctor-patient relationship have been developed, revealing a fascinating intellectual history. It starts with Talcott Parsons' characterisation of the doctor-patient relationship as one marked by an asymmetry of knowledge, competence and authority, resulting in professional dominance (Parsons, 1951; Silverman, 1987). Szasz and Hollender's model of 'activity/passivity', 'guidance/cooperation' and 'mutual participation' (Szasz & Hollender, 1956) can be seen as a next step, followed by the concept of 'informed consent' (Rockwell & Peitone-Rockwell, 1979) and then by more recent concepts of 'patient participation' (Meredith, 1993), 'patient-empowerment' (Crossley, 1998) and even 'consumerism' (McDonald et al., 2007; Wiles & Higgins, 1996).

In the field of health policy, an analogous evolution can be seen. In most Western countries traditionally organised, supply-driven health care systems are being reformed into demand-led systems where patients are no longer seen as a passive party but as an important countervailing force against the traditional actors involved (Kraan, 2006). Governments are implementing measures to equip patients and enable them to fulfil such a role. In most countries this began with the codification of patients' rights in patient acts, and was then further expanded by giving patients low-threshold advice and counselling (mostly through patient organisations). The latest stage in the history of liberal reform efforts towards more patient-centred medicine provides support for patient choice by disclosing up-to-date, reliable and accessible (comparative quality) information for patients (Hibbard et al., 2005; Meredith, 1993; VWS, 2001) and by giving patients more freedom of choice, for example in the event of referrals (Appleby & Dixon, 2004; Burge et al., 2004; Burge et al., 2005; Day, 2007; DoH, 2004).

In countries that have introduced patient choice as an important principle in their health care reforms, intense debates take place about patients' abilities and willingness to choose their health care provider. Most of these discussions focus either on the more fundamental question of whether patients can act as critical consumers (McDonald et al., 2007), or on the suitability of specific sources of information for consumers (Marshall et al., 2002), sometimes even on the level of individual performance indicators (Hibbard, 1998; Hibbard & Jewett, 1997; Hibbard et al., 2003;

Rigby et al., 2001). This paper's objective is to contribute to this debate by exploring decision-making processes in their social contexts by patients who need a health care provider. How do they end up with a provider, do they deliberately choose between different options, and what role (if any) does comparative information about the quality of different providers play, where such information is available?

4.2. Review of the literature

Given these developments, we might reasonably expect a growing body of literature on health care decision-making from the patient's perspective. And indeed, when we look at research on medical decision-making, we see a parallel trend. Such research used to concentrate on the decision-making abilities of medical practitioners (Bornstein et al., 2000; Dawson & Arkes, 1987; Detmer et al., 1978), and then on decision-making processes in the patient-physician encounter (Charles et al., 1999; Clark et al., 2004; Flynn et al., 2006; Hirschman et al., 2005; Lambert et al., 2005; Whitney et al., 2004). In addition to the latter group of studies, research is also available on how patients can be supported in making such treatment decisions ('decision aids') (Charles et al., 2005; O'Connor et al., 1999). Interestingly, however, far less attention has been paid to decisions patients make in the earliest days of their illness. This is surprising, given that the choice of a particular health care provider determines much of what follows and is pivotal to much current health system reform (Bornstein et al., 2000).

Below, we first present an overview of the most important patient-physician (shared) decision-making models (4.2.1). Although our focus is more on patients' choices prior to treatment decisions, these studies do also address patients' decision-making. We then discuss the few studies that have been performed on patients' choices of health care providers (4.2.2), resulting in the research question for the present study.

4.2.1. *Decision-making processes within the patient-physician encounter*

It was only recently that literature started to focus on decision-making processes in the physician-patient encounter during a course of treatment or hospital stay. Charles et al., 1997; and Charles et al., 1999 provide a framework based on a paternalistic, shared and informed decision-making

model. The framework distinguishes three stages in a patient's decision-making process: information exchange (information flow, direction, type and amount), deliberation and decision. Stages develop differently in all three models. Table 1 summarises the framework.

Table 1. Models of treatment decision-making (Charles, Gafni & Whelan, 1997;1999)

Analytical stages	Paternalistic	Shared	Informed
Information Exchange			
Flow	One way (largely)	Two way	One way (largely)
Direction	Physician → patient	Physician ↔ patient	Physician → patient
Type	Medical	Medical and personal	Medical
Amount	Minimum legally required	All relevant for decision-making	All relevant for decision-making
Deliberation	Physician alone or with other physicians	Physician and patient (plus potential others)	Patient (plus potential others)
Deciding on treatment to implement	Physicians	Physician and patient	Patient

Although the Charles, Gafni & Whelan model is probably the most frequently cited decision-making model (apart from the very similar but less recent model developed by Emanuel & Emanuel, (1992), it is limited in its ability to accurately reflect actual practice because it does not allow the components of the decision-making process to vary within patients and over time. Charles et al., (1999) acknowledge this, as they draw the analogy that shared decision-making is a process in which it 'takes two to tango'. 'When the music changes to another type of dance, the patient may take over the lead'. Lupton (1997, p.373) also rejects a static approach of the medical encounter as she empirically demonstrates that '*in their interactions with doctors and other health care workers, lay people may pursue both the ideal-type 'consumerist' and the 'passive patient' subject position simultaneously or variously, depending on the context*'. Continuing this dynamic approach, Flynn et al., (2006) formulate an alternative model that labels patients who want to be offered many choices 'deliberative' and, conversely, calls patients who do not want many choices 'non-deliberative'. Patients who want to make important decisions themselves are called 'autonomists' and those who prefer the doctor to make important decisions are labelled 'delegators'. These typologies are dynamic and may change over time. Figure 1 visualises the Flynn model.

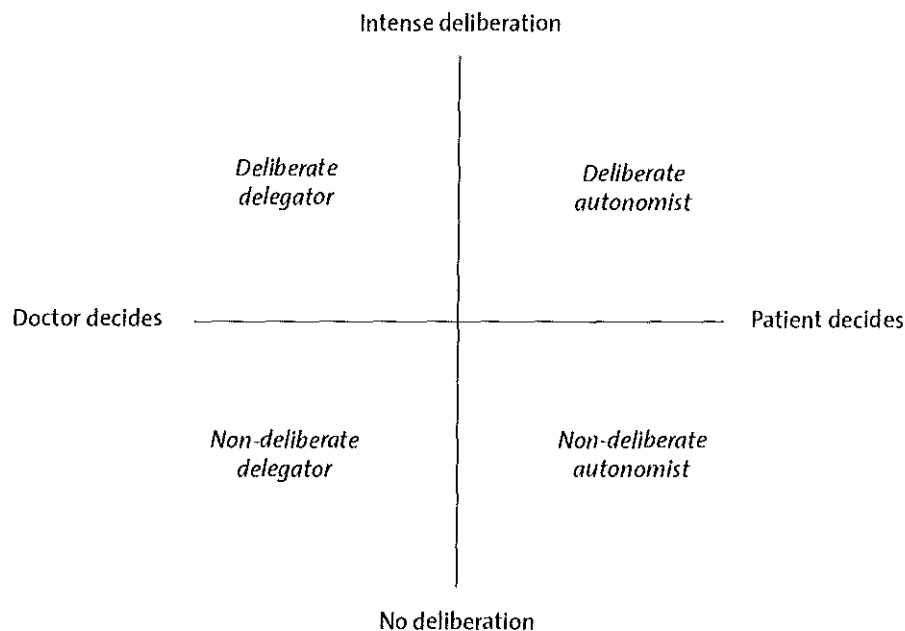


Figure 1. Typology of preferences for participation in health care decision-making (source: Flynn et al, 2006)

The former models and typologies are limited because they are based on only one disease or health care setting. Although the frameworks refer to ‘the patient’ in general, it is difficult to generalise them to all types of other diseases and settings. McDonald et al., (2007, p. 436) for example, claim that *‘for (...) UK citizens, visits to their local general practice can be said to follow certain routines and patterns which are (...) predictable’*. The question, however, is whether this holds for all patients and for all types of health care consumption. As an alternative, the model by Whitney et al., (2004) should solve this problem. They distinguish simple consent, informed consent and shared decision-making, depending on the type of medical decision (the latter can be certain or uncertain, depending on the number of alternatives and high or low risk). Figure 2 visualises the ‘Whitney model’. Although it is more dynamic and case-specific than other models, it still takes the *medical decision* as its starting point rather than the patient’s disease and their demand.

As regards the decision-making models relating to the patient-physician encounter, four concluding remarks can be made. First, most of them do not take into account the fact that patients' preferences for decision participation may vary for different diseases or may change over time as diseases progress. Second, they are all based on – and therefore limited to – one disease or health care setting. Third, they all assume that only two parties are involved in the decision-making process (patient-physician), whereas in practice many parties and (contextual) factors play a part (Berg, 1992; Charles et al., 1999). Fourth, they all focus on the decision-making

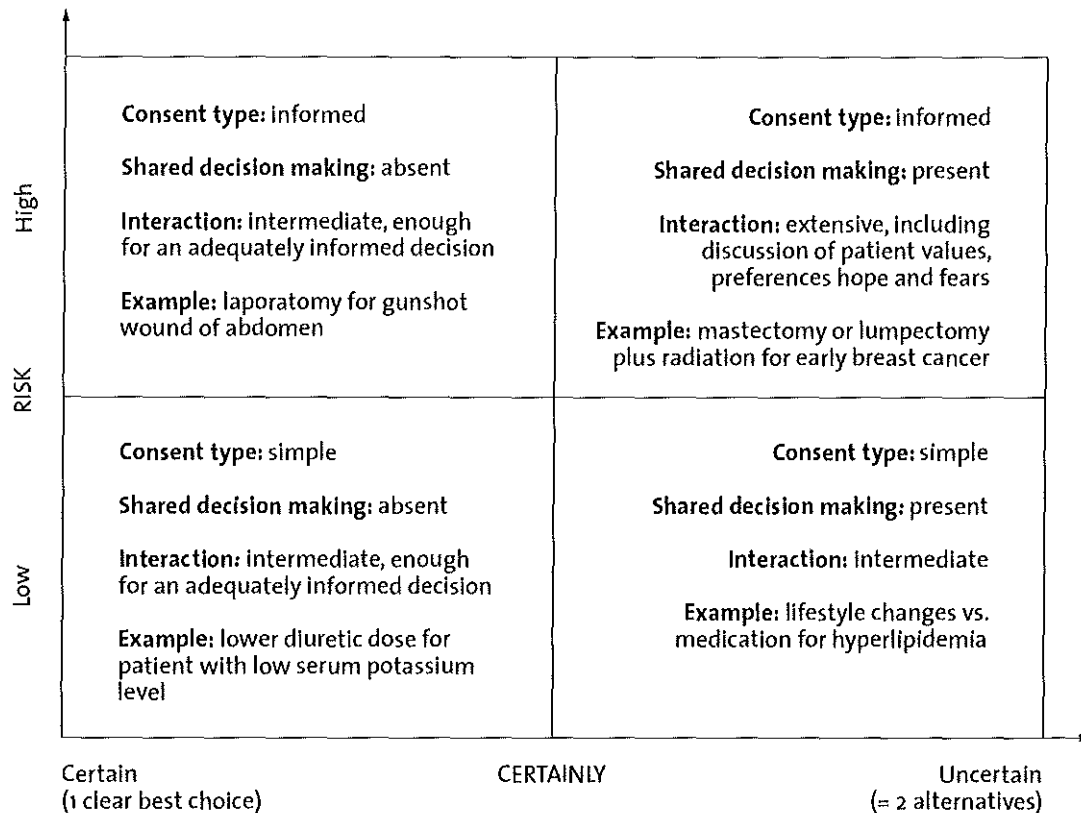


Figure 2. Decision plane showing the distribution of simple consent, informed consent, and shared decision-making within 4 types of medical decisions (Whitney et al, 2004).

process *during* treatment, *within* the patient-doctor relationship, and not on the preceding search and selection process. Since the latter is the focus of this paper, it remains to be seen to what extent the former models and typologies can be used to help provide an understanding of these other decision processes.

4.2.2. *Decision-making processes when choosing a health care provider*

Given the developments described above (towards a more demand-driven health care system with patient choice and all types of consumer-empowering interventions), it is remarkable that so little attention has been paid to the decisions patients make when choosing a health care provider. The few available studies can roughly be divided into two groups: enquiry into patients' *stated preferences* (what *seems* to influence their decision process according to what they say in a fictitious choice situation?) and into their *revealed preferences* (what *did* actually influence their decisions in a real choice situation?).

Stated preferences studies mainly use survey or choice experiment designs to answer the theoretically driven question of whether patients tend to actively choose or switch between health care providers, which aspects they value most in such a choice situation and whether this pattern differs for different patient characteristics. In addition, a few studies employ qualitative methods to answer these questions or to examine patients' attitudes towards the use of publicly disclosed quality information when making choices. All in all, these studies give a discursive picture of what influences patients' decision processes and whether they would be inclined to use comparative quality information if it were available.

A survey by Salisbury, (1989) showed that patients do not actively choose their primary care physician, but go to their doctor out of habit: 'their families have been going there for years'. Bornstein et al., (2000) used a survey to ask health care consumers what types of information they would like to know when choosing a primary care doctor. The authors were more interested in what people would like to know 'when choosing a doctor today than in what they actually did consider in choosing their current doctor'. The variable that participants deemed most important to their choice was whether or not the doctor was board certified. In general, variables relating to the doctor's professional expertise were rated highly, while factors relating to the doctor's individual characteristics (e.g. gender, religion, marital status) were considered relatively

unimportant. Harris, (2003) shows that a small minority of patients actively search for a physician. Within this group, the degree of consumer activism varies across subgroups of patients (nature of patient-doctor relationship, health status, racial and ethnic factors). Tai et al., (2004) discovered that certain groups of patients tend to bypass their closest rural hospital, depending on their age, medical conditions, prior experiences with care and current patient-doctor relationship. A discrete choice experiment by Fung et al., (2005) revealed that most patients attached more value to aspects of technical quality when they are asked to fictitiously choose for a physician, although interpersonal aspects are important as well. Marshall et al., (2002) used qualitative focus groups to examine the attitude of patients to the publication of quality report cards in general practice. They found that patients are more inclined to trust their own expertise or that of friends and family than to trust comparative (quality) data.

Studies of stated preferences see patients' health care decisions as an economic concept of rational choice (Lancaster, 1966; Louviere et al., 2000) and conceptualise the consumer as synonymous with *homo economicus* (McDonald et al., 2007). The literature puts forward several disadvantages of such an approach (the survey and choice experiment designs in particular). First, it tends to obscure the underlying relationships involved (Light & Hughes, 2001; McDonald et al., 2007). In other words: it does not embed patients' decisions in their social context, but focuses on rational trade-offs, based on 'product characteristics' in a laboratory setting. This results in only a partial understanding of patients' decision processes, ignoring as it does the role of crucial contextual (f)actors (what happens if physician B performs excellently but the patients' general practitioner refers them to someone else?). Secondly, the rational choice approach does not take into account the fact that patients' preferences might change during the decision process or as the illness progresses. Mol, (2006) splendidly illustrates this problem with the case of a patient who seems to have made a well-considered choice for diabetic self-management, but gives up due to factors that were not foreseen when the choices were made.

Perhaps Mr. Homer did not quite understand the explanation the diabetes nurse gave about measuring three weeks ago. She tries again. Perhaps she finds the measurement machine she provided him with was too small for his large fingers, or too big to carry to work. The numbers on the display are hard to read. Perhaps he doesn't like pricking his finger or squeezing out blood. He is afraid of blood. Or maybe he works as a builder: The only private place is the toilet,

which isn't anywhere close to clean. And going there five times during a working day may not be what one's colleagues consider acceptable. The devil may be in all these details – and in many more. It is part of the professional skill of a good clinician to find out which of the various details is relevant and then to do something about it. All kinds of things may be done. Almost every single variable in the complex cluster of Mr. Homer's life with diabetes – and with treatment – is open to change. Even the technological bits that seem so fixed where 'decisions' are to be taken are fluidly adaptable. Why not measure once every day, Mr. Homer, instead of five times on a single day?

Other, more technical deficiencies of the aforementioned designs are also reported by McDonald et al., (2007): they use starkly contrasting choice options, which might disrupt patients' preference patterns; they exclude apparently inconsistent responses from the data and they have few, if any, opportunities for collecting background information to assist in the interpretation of the data.

Only a few studies focus on patients' *revealed decision* processes and take into account both the social context and changes in patients' preferences over time. McAuley & Travis, (1997) and McAuley et al., (1997) studied the nursing home search and selection process and found that older people often have little opportunity to participate in the decision-making process. During the crisis of hospitalisation there is pressure from hospitals for sponsors to make quick decisions on nursing home placement. Families face severe limitations to their abilities to carry out deliberate, objective nursing home search and selection processes. Other authors (Nolan et al., 1996; Reed & Morgan, 1999) also point out that rapid decisions often have to be made where families have no clear criteria on which to base these decisions, and that there is enormous pressure to make hurried decisions with little assistance.

Wackerbarth, (1999) developed a dynamic model that describes the decision process of spousal caregivers of family members with dementia, facing decisions throughout their caregiving experience. An important theme in her model is the 'tolerance line': the degree to which the caregiver feels a sense of control over the situation. This feeling is influenced by many factors, of which the most important is 'the progression of the disease'. A second consequence of the progression of the disease is the 'status' of the caregiver: how well is he or she able

to provide care? This situation can become a 'decision event'; a theme that forms the third element in Wackerbarth's model. She describes a variety of decisions (involving providing care, nursing home placement, community relocation, limiting the care receiver's freedom etc.), which are all made because caregivers a) plan ahead or b) react to a crisis. In addition to the model, Wackerbarth identifies five decision-making styles: caregivers who plan ahead; those who take it one day at a time; those who have difficulty implementing decisions; those who receive support from service providers; and those who feel that caregiving decisions are made by others or the disease itself. Each category of caregiver needs a different type of support.

Cheek & Ballantyne, (2001) performed an exploratory, descriptive study that examined the search and selection process for an elderly care facility following discharge of a family member from an acute care setting. Reporting on the family's perceptions of the process and the effect it had on them, they describe five major themes: good fortune ('feeling lucky and grateful that it all worked out in the end'); wear and tear on the sponsor (feeling guilty for 'doing this' to a family member); dealing with the system ('fighting a battle to find your way'); urgency ('being forced to move on'); and adjusting (both family and residents). The authors claim that these insights should be used to a) inform and assist families and health professionals working with families in this situation; b) make 'the system' more accessible and c) make the search and selection process more efficient in terms of time and effort.

4.3. Objective

As stated in the introduction, this study's aim is to contribute to the discussion about the desirability and usefulness of developing comparative quality information about health care providers for (future) patients. To do this, we have to explore the 'black box' of patients' decision processes in their search for and selection of a health care provider, in order to see whether there is any place in those processes for such information. After all, *'a better understanding of the factors that influence people's choices of health care providers would potentially provide them with the resources to make better choices in this arena and consequently attain greater satisfaction with their health care status'* (Bornstein et al., 2000; Hibbard et al., 1997; Lubalin & Harris-Kojetin, 1999)

An overview of current literature on decision processes a) in the patient-physician encounter and b) as reported by patients choosing a health care provider, justifies the conclusion that the literature presents a rather *narrowly focused* (frequently based on one single disease, medical decision or setting) and *static* (not changing within a person or as diseases proceed from one phase to another) picture of patients' decision processes. In addition, these decision-making models are not embedded in the wider *social context* in which patients and their systems deal with health care systems. Studies that investigate c) patients' revealed decision processes are rare and focus predominantly on the search for and selection of long-term-care facilities.

This paper explores and describes decision-making processes as *revealed* by patients in *various phases* of three very *different diseases*: knee arthrosis, chronic depression and Alzheimer's disease (the 'Methods' section explains why these three diseases were chosen). It describes these decision processes in their *social contexts*, as it focuses not only on provider characteristics but also takes into account factors and actors from patients' social systems. This enables us to see whether patients would include consumer information in their decision processes if it were to become available. Study results can be used to guide health service delivery and to sensitise providers of health care (information) to the patient's decision process in order to aid in planning intervention strategies and to assist in the development of (decision-supporting) policies, procedures and interventions that are responsive to patients' needs.

4.4. Methods

4.4.1. Design

We chose a grounded theory approach because this methodology enables us to 'fill the gaps' in the existing knowledge about patients' decision processes with new (theoretical) insights that are grounded in systematically gathered and analysed data from the empirical world (Creswell, 1998; Patton, 2002). Besides, it allows us to build on relevant literature and models that were explored above, by elaborating and modifying existing (grounded) theories as incoming data are meticulously played against them (Boyatzis, 1998; Strauss & Corbin, 2000).

4.4.2. *Three diseases*

A grounded theory study starts with the selection of one or more homogeneous samples of individuals (Creswell, 1998). Only later, after developing the beginning of a theory, is a more heterogeneous sample chosen (see sampling strategy below). Since the aim of this study is to shed light on patients' decision processes in their search for and selection of a health care provider, we looked for a limited number of large patient groups whose decision processes may be seen as exemplary for many others. In the field of elective clinical surgery for example, total knee arthroplasty (replacement) or osteotomy for patients with *knee arthrosis* is one of the largest volume care trajectories (besides hip replacement, which is a very similar condition) (Poos & Gijsen, 2003). In mental health care, long-lasting or *chronic depression* is the disease with the highest prevalence and the search for a therapist may be comparable to the search and selection process in other mental diseases (Poos, 2005). Finally, care for the elderly is an area in which family members play an important role (Wackerbarth, 1999) and where the decision to institutionalise a family member is usually taken only as a last resort (Cheek & Ballantyne, 2001). We therefore chose the decision process of patients with *Alzheimer's disease* and their families as our third focus of study.

4.4.3. *Sampling procedure*

Where quantitative research is concerned with representativeness, qualitative research sampling seeks to enhance the richness of information. Our choice of participants was therefore based on their abilities to contribute to the understanding of emerging concepts; a process that is called theoretical, or theory-based sampling (Creswell, 1998). Once critical concepts became clear, we purposefully stratified our samples in order to capture major variation for criteria that might be relevant to our research question (Patton, 2002). Figure 3 shows the sampling strategies that were followed for the three different diseases.

For all three groups we used gender as a starting selection criterion because this might influence a patient's decision process. This has been done before by other authors (Wackerbarth, 1999). Only for Alzheimer's disease did we start with some additional characteristics: relationship to the patient and phase of the disease. These concepts had emerged from literature and from earlier interviews with patients suffering from the two other diseases. We used the location of the care receiver as a proxy for the phase of the disease (Wackerbarth, 1999). Figure 3 shows that as the interviews progressed, additional characteristics were identified that may influence decision

Knee arthrosis

5 interviews: members of SPO	
Men	3
Women	2

Emerging concepts:
- membership patient organisation
- phase of disease / treatment

5 interviews: non-members		
	<i>Before operation</i>	<i>After operation</i>
Men	1	2
Women	1	1

Focus Group I: 6 members of SPO		
	<i>Before operation</i>	<i>After operation</i>
Men		1
Women	2	3

Focus Group II: 2 members of SPO		
	<i>Before operation</i>	<i>After operation</i>
Men	1	1
Women		

Focus Group III: non-members		
	<i>Before operation</i>	<i>After operation</i>
Men	1	
Women	4	

Depression

3 interviews: call on internet forum	
Men	2
Women	1

Emerging concepts:
- patient visiting support point
- phase of disease
(proxy: (non)institutional care)
- religious indentity provider

6 interviews		
	Men	Women
Religious provider		1
Visiting support point		1
Clinical setting	2	2

Focus Group I: call on internet forum	
Men	
Women	3

Focus Group II: via patient support point	
Men	1
Women	2

Alzheimer's disease

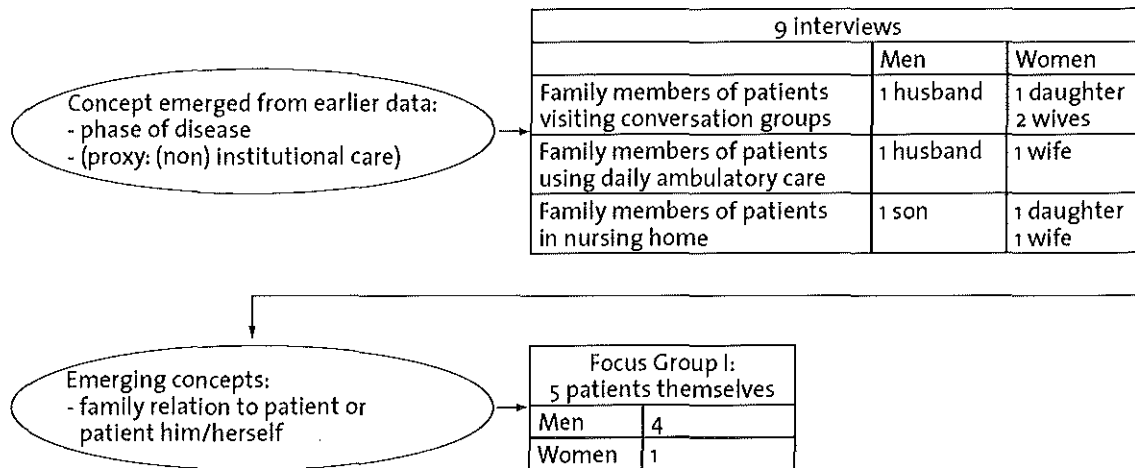


Figure 3. Sampling strategies for three diseases

processes. For knee-patients it became clear that (non-) membership of a patient organisation played a role (members being more critical) and that patients in different phases of their disease (before and after knee replacement or osteotomy) might think and act differently. The same goes for those who are chronically depressed. Again we used the location of the care receiver as a proxy for phase, seeing clinical care as care for patients who are further advanced in the disease or more ill, and patients who use ambulatory care or no care at all as less ill. Two more characteristics seemed to play a role here: the frequency of visits to mental health care support facilities and the religious identity of patients and providers. After the initial interviews, remaining informants for both interviews and focus groups were purposely selected to enrich understanding rather than to determine the distribution of such characteristics (Guba & Lincoln, 1989).

4.4.4. Data collection strategies

Patients' narratives about their decision-making processes were accessed in three different ways. The first mode of data collection was achieved by way of 28 individual semi-structured in-depth-interviews with patients (ten with patients with knee arthrosis, nine with chronically depressed patients and nine with (relatives of) patients with Alzheimer's disease; see also table 2).

Table 2. Sample characteristics

	Knee Arthrosis (23)		Chronically Depressed (15)		Alzheimer's Disease (15)	
	Interviews (10)	Focus Groups (13)	Interviews (9)	Focus Groups (6)	Interviews (9)	Focus Groups (6)
Men	6	4	4	1	3	5
Women	4	9	5	5	6	1

The interviews were audio-taped and transcribed in the same week as the interview was conducted. To help the informants' abilities to remember, each interview started with the question: *'Could you please describe when the first signs of the disease were recognised and what you or your relatives did then?'* For each important decision that was mentioned, we asked: *'Why did you make that choice?'; 'Who or what influenced your decision?'; 'Did you have enough information?'; 'What information would have been helpful for you or your family to make a better choice?'; 'What would you do, or what would you advise future patients to look at when making the same choice (again)?'*

The second way in which data were gathered was by conducting six focus groups (three with patients with knee arthrosis, two with chronically depressed patients and one with patients with Alzheimer's disease; see table 2). We opted for focus groups in addition to interviews because we recognised that patients' decisions are made in a social context, often growing out of discussions with other people. During the meetings, participants were able to hear each other's responses and to make additional comments beyond their own original responses as they heard what other people had to say (Patton, 2002). Concepts that emerged from the in-depth interviews were clarified and elements of preliminary results were tested in the focus groups.

Third, data from the interviews and from focus groups were set against the background of conversations that were held with representatives of patient organisations in the areas of knee replacement (SPO), depression (Steunpunt GGZ) and Alzheimer's disease (Dutch Alzheimer's Association). During the phases of data collection and analysis, we asked them what questions patients have when they initially start looking for health care. They also provided us with patient information documentation that enabled us to understand what information is currently available for patients and their relatives.

4.4.5. Verification: triangulation

Multiple sources of evidence were sought and the data collected were triangulated. Both the data collection methods and sources were triangulated (collection through literature, interviews, focus groups and documents). In addition, we performed a triangulation of the analysts in order to overcome the intrinsic bias that comes from single-method, single-observer, single-analyst and single-theory studies (Denzin, 1989; Patton, 2002). The latter is explained in the following section.

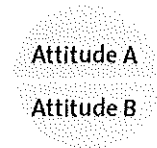
4.4.6. Analysis

Consistent with grounded theory methodology, analysis took place on three levels (Creswell, 1998; Patton, 2002; Strauss & Corbin, 2000; Walker & Myrick, 2006). On the first level all the transcripts and documentation were read by two members of the research team, who separately developed categories of information (open coding). These categories were then discussed, compared and interconnected in the phase of axial coding. Third, after comparisons had been drawn between emerging themes, the final step involved the abstraction of these themes into the conceptual groupings which constituted the core categories (selective coding). The same procedure was repeated after each series of interviews and after each focus group (see figure 3), until theoretical saturation of themes was reached (Patton, 2002). This analytical approach has been previously used and reported in studies that examined the search and selection process for facilities for care for the elderly (Cheek, 1997; Cheek & Ballantyne, 2001).

Where material is cited in the following sections, we will number quotations and give some details about the participant's background characteristics in order to distinguish them from each other. The following abbreviations will be used to make clear who is talking: I = the interviewer; P = the patient; H = the patient's husband; W = the patient's wife.

4.5. Results

4.5.1. *Two basic attitudes*



An overarching finding, incorporating all other themes, which emerged from the data was the finding that in all subgroups there were patients who showed comparable basic attitudes during their search and selection processes. Inspired by prior research (Charles et al., 1999; Flynn et al., 2006; Lupton, 1997; McDonald et al., 2007; Wackerbarth, 1999; Whitney et al., 2004), we observed two basic attitudes, which can be seen as extremities on the same sliding scale: a) patients who take up an *'in control'* or *'consumerist'* position towards their potential health care providers, and b) those who act as *'dependent, docile or passive patients'*. Of course, between the extremes of these two archetypes there is a wide range of alternative patient attitudes towards choosing a health care provider.

The following quote illustrates the consumerist attitude. It was taped during an interview with a 62 year-old lady who tells what she and her husband did when her orthopaedic specialist told her that she required an operation on both legs instead of just on the painful one.

1. So then it was off back home. We were completely thrown at being told it would be both legs. Then you went looking on the Internet; that's how we found Linda (*the patient organisation -1*).
2. Yes; first I trawled through all those university libraries.
10. Because at that time you both agreed that the alternative operation should go ahead, is that right? Or were you still exploring the options?
11. I was so flabbergasted about it being both legs; I thought I might have to have it done, but not there. Never.
12. We had heard the news, and then the alternative seemed much better to us; but then we thought: now we'd like a lot more information

The dependent, passive attitude is very well illustrated by a quote we took from an interview with an 82 year-old man whose wife had Alzheimer's disease and had to be institutionalised when he himself was struck by a cerebrovascular event:

1. I was in hospital for fourteen days. (...) And then Ms S. (*social worker, -I-*) arranged for us to stay living together.
2. *How did you (...) come into contact then?*
3. My son did everything. I had no interest in life at all. What had happened... It all goes over your head. He'd phoned the GP and he'd referred him to them. And (...) then the social worker came. And she said that they had a room there for two people. Because L. (the patient's wife) would have had to go to the Sterrenlanden nursing home. Everyone knew she couldn't stay alone anymore. I would then go to the Amstelhuis nursing unit for the treatment.
4. *So did you have to be admitted to the Amstelhuis or would you be a day patient?*
5. Straight from the hospital. I couldn't move; I couldn't do anything, and I was in a wheelchair

4.5.2. Different attitudes: different (f)actors in decision processes



Beyond this typology of basic attitudes, the data showed clearly that each attitude is associated with different factors, actors or institutions that play a part in patients' decision-making processes. 'In-control consumerists' seek support from their general practitioners (or other primary health

care workers); nonetheless they see them as sparring partners rather than experts who decide for them. This is shown by the quotes of a 55 year-old and a 43 year-old man who report that they asked their GP to support them in their quest for a different orthopaedist:

1. And what role does your GP play?
2. He plays a facilitating role. He helped in thinking about the best way forward, and if I ask I'll be referred to the orthopaedist.

And:

1. And how did the GP function in this regard?
2. Oh, he supported me. He was at a loss too after all that time.

Furthermore, 'in-control consumerists' actively search for information on the Internet, in libraries or via patient organisations. Besides information about the cause, course and treatment options, they are especially interested in expected outcomes, safety and risks and the expertise or experience of a clinic or doctor:

1. (...) what kind of booklet?
2. It's a genuine medical booklet. If you go to the UMC university library here in Utrecht, it is one of the few proper medical books that's accessible to a non-specialist reader. I had already bought it. I had begun to immerse myself in it more and more. I'd got to thinking, no more rough treatment and not yet again. There are some specialists who are relatively quick to decide they want to start cutting. I was perfectly well aware that every operation, even if you only open up the knee and don't do anything else, affects the quality of your knee.

At the other end of the spectrum, docile or passive patients accept, or even expect that their general practitioner or other primary care worker will be dominant, especially in the event of a referral. This is shown by a quote from a 45 year-old man with chronic depression:

1. I hear that it did help you.
2. I should have received a lot more support.
3. Yes, if we stick to you for the moment. You should have received much more help?

4. Yes
5. You feel that the GP is primarily responsible for taking up your case?
6. Yes, I do

They use words such as 'trust' or 'faith' to explain how they ended up with, or what they value in, their doctor:

1. I think trust is the most important thing. You just have to have faith in the specialist and trust them to give you proper information and to ..
2. But you don't read that in a folder. You don't read it in the consumer guide. You don't hear it in the patients' association.
3. But that he draws conclusions from what you have told him and gives you the best information and helps you move forward. I once had it with a GP, I had doubts about the advice he was giving me and he said, now I want you to trust me; otherwise we can't work together. I thought about it carefully then and said yes, I will trust you.
4. And do you find the same thing when you go to a specialist?
5. I think so, yes.
6. But of course you don't know that when you go for the first time.
7. Yes. I think you do. If you have the feeling during that first contact that he's not really listening, that you can't express your own opinion, that there is no "click" between us, then I won't go there again.

Passive patients' own prior experiences with an institution or an existing relationship with a doctor (either good or bad) are also deciding factors for subsequent steps, as well as accounts from family or friends.

Some of them even refuse to use consumer information for orientation, even if it were available. A 63 year-old ex-postman told us:

We can get information everywhere, from the Internet. I don't have a computer, and I don't want one; we're a bit old school. We can go to the library, we can look at teletext. It's as if people are becoming more and more stupid, I think, but also more and more anxious. The more information people have to store away, the more anxious they become.

When these people were interested in comparing quality information about providers, they would look at how other patients report on the interpersonal treatment they experienced. This was clearly put into words by two women (22 and 37 years old) who suffer from depression:

1. That authoritarian attitude, especially, that's something that I can't deal with. Those two psychotherapists I had in the group, and one of whom I'm still with, they were human beings. You could call them by their first names. They were just like you and you felt you were being understood. But if someone sits writing a letter with that authoritarian style, I think, I just don't need that. If I have to make choices in health care, then I'll look for someone who treats me with the basic human dignity. Who is prepared simply to talk about things with me.
2. Do you have an idea of how you could translate that into information for a future client?
3. I really think they have to pay attention to the way they approach you. It would be nice if you were able to say something about that beforehand. You can talk to people with experience about that, too. People who've been there. They can share their experiences,

4.5.3. What 'drives' a patient's attitude?

Now that we have identified different patients' attitudes towards choice and gained an insight into the role and content of consumer information in their decision processes, our next challenge is to identify situations in which a certain attitude is dominant. This will enable us to make more precise statements on the desirability and usefulness of providing health care consumer information. In the remainder of this section, we therefore define and label themes or 'drivers' that determine a patient's attitude towards choice and the factors they include in their decision process. We start first with a very general 'driver', that is not disease or care specific, but cannot be omitted.

A. Attitude to life

As has been discussed in depth by other authors (Blaxter & Paterson, 1982; Lloyd et al., 1991), one of these 'drivers' is a person's attitude to life and their personality, perhaps both influenced by (sociodemographic) personal characteristics. For example, we asked one of the participants, whose knee replacement had resulted into severe complications, whether he would choose an alternative hospital if secondary surgery were to be needed in the future. He stated:

No, I stayed with Dr. B in the end. I never give up something once I've begun. The more people know, the more they grumble. People complain too much. We're so lucky in this country. I've never seen the inside of a church, you know, but we should be glad that we have enough to eat and to drink. (...) Mistakes are made everywhere. Whoever works there. If you don't work you can't make mistakes. Then you have to stay at home sitting on the sofa. And if someone has operated on me properly and I have full confidence in them, then I'll go back to see the same man; that's why I always like to have Dr. B.

Attitude
to life

Attitude A

Attitude B

(F)Actors
influencing
patients
decisions

And the son of an Alzheimer's patient said:

You can want everything just as you like it, but that's not how the healthcare system works. We are in the phase where not everything is possible. As a client, you also shouldn't demand everything. The same applies in times of plenty. You can never please people completely. If you can't live with limitations then your life will be difficult. The same is true in society. If you want to be able to do everything, well it's just not possible, (...) people have their limitations. You also have to keep your feet on the ground a bit. And of course some nursing homes will be worse than others. But in hospitals, too, people are sometimes given the wrong medication. It's then

a good thing if people think for themselves. But if it becomes a structural thing, something has to be done about it. You can try for perfection, but you shouldn't have the illusion that it will be perfect.

Other participants showed a different attitude to life, and therefore towards searching for and selecting a health care provider. They are very critical and act in a business-like way, as real consumers. A lady who needed knee replacement told us:

1. So then I go to the Maartenskliniek hospital to ask for information. I do that with lots of things. I don't just go into things blind. I always want proper information first...

Sometimes, assertiveness almost seems to tend towards aggression. For example, a 70 year-old ex-bank manager defines himself as a very assertive patient:

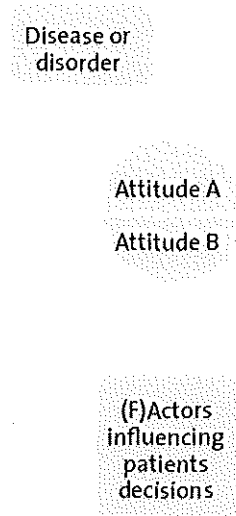
(...) and I'm as assertive as the devil. If someone does something to me that is clearly wrong, then I'll drag them in front of the disciplinary board. (...) if I choose a specialist together with my GP, we both have confidence in that person. My GP is savvy enough and knows me well enough to know better than to send me to someone with a past. Because then I'll grab them by the scruff of the neck; after all, that's a big blow to our relationship of trust. But if he's made a mistake with me for whatever reason, I'll have him. (...) and you really have to do your homework yourself. I can't say that often enough to people.

We shall not go into any further detail on the themes of personality and attitude to life here, but will proceed instead to our major themes. After all, our interest and focus extends to disease and care-related themes rather than to in-depth psychology.

Analysis of the interview transcripts revealed the emergence of three major themes that are determinants for patients' attitudes towards choice and their selection processes: *disease or disorder, phase or stage* and *organisation of care*. Each of these themes will be discussed in detail below. The themes should not however be considered as mutually exclusive and collectively exhaustive (MECE), nor as a balanced, static model or theory that provides a causal explanation for patient attitudes or behaviour. They merely reflect the direction in the analysis that makes

most sense given the available data, and are intended to shed light on the 'black box' of patients' decision processes.

B. Disease or disorder



The analysis of the study material revealed a relationship between a patient's attitude towards choice and their search for and selection of a health care provider on the one hand, and the (characteristics of the) disease or the disorder from which the patient is suffering on the other.

Knee arthrosis is a long-lasting disease with a deteriorating course, normally without any acute events. Patients (who are mostly aged over 50 years), experience increasing pain and physical and social inconvenience caused by the cartilage in the knee, which is either caused by age or by (overly) intensive use of the knee joint, for example in sportsmen and women. The latter group in particular are very much engaged in and concerned with health and making healthy choices.

1. It was winter and it was icy... We were going on an outing. And suddenly I took a dive. And there I lay. Maybe that was the straw that broke the camel's back... I think I then

started messing about. And also partly because I started fitness training again. I can remember, I was using a rowing machine. I thought, this is no good; I need to chase it up. (...) So I came home (*after she had visited her doctor –I-*) and told my husband; he was still a full-time trainer.

2. Yes, I know something about anatomy, because I also trained Karl Verheyen, Dutch ice skating champion, and Thomas. So I got the books out; I said, I think this is a bit of a strange operation for something like this. And that's quite an operation... I thought, let's investigate a bit further.

It can however take many years from the first complaints until surgery (knee osteotomy or arthroplasty) is needed or allowed (only in older patients). During this period, patients have time to gather information about the cause, course, possible therapies and therapists, especially when a diagnosis is given at younger age. In the years preceding their knee surgery they are able to grow more and more assertive:

1. ... had you also read and looked up all kinds of things?
2. No, no, I wasn't like that then. I'm much more like that now than I was then.
3. So you would do that now?
4. Oh yes. I wasn't so assertive in the past, you know. Because what went wrong in '89 with that first knee operation with the anaesthetic, is something that man didn't need to try with me. I'd have hung him from the highest tree. It went completely wrong with my epidural, so I won't ever have another one of those. But then I was more of, well it can sometimes go wrong; but now I'm so assertive.

A woman who participated in one of the focus groups told us:

Meanwhile, when I had heard about that wear and tear, I went looking on the Internet myself at www.knie.nl, and I believe that's also how I ended up here (*patient organisation –I-*). All kinds of hospitals in Germany and what they had to offer. And I also rang them here (*patient organisation –I-*) for information. And it turned out that the orthopaedic surgeon I got was known to the association. He had a good name there and so I went to him. I made a deliberate choice for that orthopaedic surgeon.

Some patients even deliberately postpone surgery, which is possible because their condition is not acute or life-threatening. Patients sometimes use this extra time to gather information and to gain time for better orientation (Clark et al., 2004; Hudak et al., 2002). A 55 year-old man declared:

1. What I want to know is (...) what is the likely prognosis with my knee the way it is now? I'm 55 years old now and I want to know the prognosis for when I'm 60, 65, 70. And I also want to know what more I can do to prevent deterioration and put off an operation for as long as possible. I also really don't want an artificial knee as long as I'm working, so I want to wait for least 10 years.
2. So you don't want an operation?
3. No, not at all. If it were to get worse in the near future, I would start looking around for a technique where the cartilage is injected with a kind of acid, which then replaces the cartilage.

Or a 62 year-old lady:

1. I won't do it, not until I'm 80. And then they won't do it any more.
2. I notice that you are mainly concerned with avoiding having to have artificial knees in the future.
3. Yes, that's the way I'm keeping it. (...) An artificial knee isn't everything! There's a woman from round here who has an artificial knee, it was done here in Amersfoort, but it hasn't gone too well. But then, it's down to the person as well, of course. Some people are more assertive than others. The doctor also says 'defer it'. He says, in that regard you're our ambassador. Don't do it, he said.

Sometimes, patients have suffered from arthrosis before. They might even suffer from other diseases of the locomotory apparatus as well, making them experienced health care users.

I went to my GP first, who referred me to my physiotherapist. The physiotherapist wasn't sure at first whether it really was my meniscus. I said, I don't have any doubts at all, that's what it is.

Because I had felt the left-hand side and, based on that, I said the same thing is going on here. And that proved to be the case, and it was even worse, because it had damaged the socket ... of the knee.

Besides, their constraints are mostly physical and not mental, which enables them to think over and weigh up alternatives and, perhaps even more important, to discuss their disease and treatment options with others. In other words, their decision process is not covered with a veil of embarrassment as might be the case with other diseases. For example, a 50 year-old man told us:

Perhaps I should say two things in this regard. In the past we sometimes had those great big meetings, with the whole patient association in a room with 40 or 50 people. I remember a meeting at which experiences were exchanged.

And the reaction of the 65 year-old ex-postman:

1. So you spoke to sportspeople, footballers...
2. Yes, that was back then, but it has deteriorated since. People have become more assertive. I've heard the story several times now. Then, six or seven years back.
3. They were people who told you that off their own bat?
4. Yes, those footballers from Kozakken Boys and so on. From Werkendam, or from Wijk en Aalburg, who came with those stories that they had also been operated on themselves. You will be helped more quickly there, or there... And arguments like he would be seen to more quickly or that there is a top doctor there...

The foregoing indicates that patients with knee arthrosis are (potentially) assertive and that many of them behave as genuine 'in-control consumerists'. This picture is further reinforced by the fact that there is a relatively high risk that a wrong decision in the search and selection process may have unpleasant and sometimes life-threatening, irreparable consequences. Theory suggests that this should lead to an extended selection and alternative evaluation process (Engel et al., 1990), which is also supported by our data. One of our respondents, for example, told us how he switched to another doctor after his surgeon had made a mistake:

(...) So then I went to a colleague of Dr. B. and he made a really serious mistake. He left one of those threads that they stitch you up with, well he left one in. And my knee couldn't take it anymore, and I was in so much pain (...). And after six weeks I had to go back. And he picked up a pair of tweezers and pulled it out just like that, and it was just like taking out a rotten tooth. But by then, of course, I'd completely lost confidence in him. So I said to my GP, I'm never going back to that man. And then I ended up with Dr. B. and I'm still with him. I'm still with him.

There are however also some disease characteristics that point in the reverse direction, towards a more passive role for patients with knee arthrosis who are seeking help from a consultant in a hospital. Firstly, knee arthrosis mostly becomes manifest in older age, and it is known that older patients are less assertive than their younger counterparts (Lupton, 1997). Secondly, before surgery takes place, patients have already undergone much investigation and (non-)surgical therapies, not only for their knee arthrosis, but often also for other problems with their locomotory apparatus. If there is a need for an orthopaedist, these patients might tend to trust their own experience and go to the doctor they know or were referred to, rather than going through a new search and selection process.

1. It was just before Christmas, and I couldn't lift my head up any more. Rheumatism, acute rheumatism. And so I ended up going to see a rheumatologist at hospital X. And then the knee came back again, too, and it swelled up enormously. I thought, what's up with my bike again now. Back to the physiotherapist. Tried to help, but no joy. Then the rheumatologist said, go and see the orthopaedic surgeon.
2. And then? You were referred to the orthopaedist in the same hospital?
3. Yes, because he is there in that same building. But he operates in hospital Y in Amsterdam.

All in all, we can conclude that patients with knee arthrosis are likely to become critical, in-control consumers as time goes by. Personal characteristics such as age or (growing) experience with care may accentuate the degree of assertiveness. In the next section we will therefore investigate the various stages of a decision process in more detail.

One would expect *chronically depressed* people to be passive, dependent patients and not assertive 'in-control consumers'. This assumption is underpinned by most of our data. A good example is the account given by a 42 year-old lady with whom we had a very difficult conversation:

1. But really I allowed myself to be led by others, because I didn't show any initiative. (...) in those days I did very little in the way of finding books to read myself about it or going off in search myself to find out what was wrong with me. I also gave myself too little time to spend on myself. I left that to the carer, but I myself read very few books.
2. Throughout the entire period when you were receiving help, did you play an active part in that? Did you genuinely engage in dialogue?
3. I let it all wash over me.
4. And did that change during your period at the psychiatric centre?
5. No.
6. You had an intake interview there, as well?
7. Yes, I had an intake interview and discussions there, too. I just let it wash over me. I was glad they'd decided I could go there, though. But the diagnosis didn't become any clearer. At a certain point I received a paper saying what the diagnosis was, but they didn't talk about it. I thought they were paying very little attention to it, but then I could have asked about it myself. (...) but because the I just let everything wash over me I didn't play an active part. I had more the idea of, they know what they're doing.

A chronically depressed patient's passive and dependent attitude is even more pronounced during crises that occur from time to time. During these periods, one cannot speak of 'choice' or 'decision'; not even by approximation:

1. Of course, when you're found with an overdose of pills and along comes a...
2. Then you say, action is needed here?
3. Yes, I've had crises in my life. Then someone simply has to act.

Another important characteristic of depression is that, in contrast to for example knee arthrosis, there is a taboo about being depressed and about searching for a therapist. This greatly complicates the search and selection process, because patients feel embarrassed to talk about their problems. The lady quoted earlier told us:

My problems were really quite severe at the time yet I simply couldn't talk about them. (...) Then she referred me to a psychiatrist who lived in Waddinxveen. Then I followed the advice of the psychologist again. (...) I stayed there for a long time, until 1997.

Although the three former characteristics are very dominant in the 'search and selection process' of people who suffer from chronic depression, there are some disease-related aspects which indicate that there should be at least some activity and assertiveness. Firstly, the prevalence of depression (and dysthymic disorder) is highest in patients aged 20 to 45 years (Poos, 2005), and it is known that younger persons are more often actively involved in choosing their health care provider than older people (Lupton, 1997). Besides, it is a well-known phenomenon that patients who suffer from mental disorders are often ambivalent towards therapy and their therapist, resulting in switching behaviour between alternatives (Mokkenstorm, 2000). Finally, the intermittent course of the disease presupposes the alternate presence and absence of a willingness to choose.

We can legitimately conclude that the patients who are chronically depressed are predominantly dependent, docile and passive. This picture might change, depending on a patient's personal characteristics and their inclination to switch therapists. Since assertiveness might change over time, we will explore patients' attitudes towards choice in more detail below, as we focus on the different stages of a disease.

It is very difficult to give one overall typology of the user's attitude during the complex multiple-stage search and selection process in the case of *Alzheimer's disease*. However, if an attempt were to be made to do this, it would be characterised as a mix between both the docile, passive patient and the assertive, in-control consumer. The disease has a degenerative course that gradually affects the mental capabilities of patients. As a consequence, choices have to be made either in the early stages of the disease by patients themselves (see different stages below) or by patients' representatives. This is an important notion, since it is known that representatives have different preferences from patients themselves (Castle, 2003). Our data suggest that children of patients with Alzheimer's disease tend to be more assertive and 'in-control consumerists' than for example partners of patients or patients themselves. This is shown by the remarks of a 52 year-old son of a man with Alzheimer's disease:

(...) you don't make that choice behind your PC, that seems clear. I'd never do that. Go and look, walk into one of those departments, go and talk to a few people. Talk to residents if possible. If you spend an hour or so doing that, you get to know quite a lot. We went to look in the town of D and visited a number of homes. Some of them dropped out because they had waiting lists of the year.

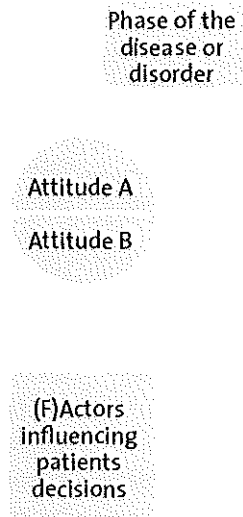
On the other hand, it is also a well-known phenomenon that patients and their families deny the severity of the disease and the potential need for professional help (Sevush & Leve, 1993). Patients and close family therefore tend to act passively and expectantly regarding the choice and selection of professional help (especially in the early stages of Alzheimer's disease, but we will come to this later). For example, a 39 year-old woman whose father has Alzheimer's disease said:

My mother looked after my father on her own right up to the end. And things at the end were fairly dramatic. Because we three children, three daughters, we of course knew about his illness. My mother had a great deal of difficulty in accepting that my father might be suffering from Alzheimer's disease. In fact she hid it for us a bit, especially towards the end. She looked after my father at home for six years, until he started wandering. Then my mother telephoned us regularly and asked what she ought to do.

This attitude often leads to a crisis, which is a totally new situation with its own dynamics and choice and decision patterns, which also impacts on the usefulness and desired content of consumer information. This shows again that there is another important dimension to take into account, namely 'phases of the disease'. We will therefore move on to see how patients' (and their representatives') attitudes towards choice and the search for and selection of a provider differ throughout the different stages of the disease.

C. Attitudes vary per phase

A few studies report that a patient's attitude or self-image may change over time (Arora et al., 2005; Nevitt & Hutchinson, 1996). This is supported at great length by our finding that patients' attitudes towards choice and the (f)actors that influence their decisions are not stable and static, but vary as the disease progresses. Our data show four different stages throughout the three diseases in each of which patients are more or less assertive and willing to include (comparative)



consumer information in their decisions. In addition, the desired content of the information differs in each of the stages (see table 3).

During the *first stage*; from the emergence of the first complaints until a diagnosis is given, patients are often overwhelmed by the fact that something is wrong with them, and uncertain about what it is. This tends to lead them into a dependent, more passive position (depending on what type of disease they are suffering from, as we showed above). This is especially true for depressed patients who are experiencing a crisis and for patients with Alzheimer's disease and their family members who deny complaints because they are ashamed about what is happening (see quotations above). If patients wish to be informed at all, they would like to learn more about the disease, its cause and its course. They usually go to their general practitioner as a first step and expect him or her to start up the whole process, to reach out to them. The GP's initial referral is decisive during this first stage and has important implications for subsequent stages. For example, in most cases diagnostic examination of the knee is carried out by an orthopaedist who will then tend to remain the patient's 'first choice' doctor in the following stages.

Table 3. Attitudes and information in different disease-stages

Stages:		Knee arthrosis	Chronic Depression	Alzheimer's disease
First complaints → Diagnosis	Attitude:	Passive	Passive	Passive
	Information:	What do I have?	What do I have?	What has patient?
Diagnosis → Treatment 1	Attitude:	Active	Passive	Passive
	Information:	How to postpone? What treatments? Who is the best?	What treatments?	What therapies?
Treatment 1 → Cure / recidivism / deterioration	Attitude:	Passive / active	Active	Passive
	Information:	How to rehabilitate	Treatment alternatives	Slow down deterioration
Recidivism / deterioration → Treatment 2 / care	Attitude:	Passive / (very) active	Passive / Active	Passive / active
	Information:	active New techniques Who is the best?	Treatment type Approach / vision	Waiting time What facility fits best?

1. How did you end up there?
2. On the advice of the GP. How else do you get to see an orthopaedist. (...) it started in '65 with the left knee, first the meniscus. Then in '67 the right knee. The meniscus again. Then it all went quiet again until 12 December 1988. I was walking with a colleague in the town of Zutphen and all of a sudden it swelled up to twice its normal size. Now, the usual story: off to the GP, who referred me to the orthopaedic specialist. In January '89 I had an exploratory operation.

After a diagnosis has been given (*second stage*), patients, their doctor or therapist or both together will then more or less actively search for and select the most appropriate therapy or treatment. Sometimes this decision process also covers the selection of the best provider to deliver the care that is needed. Here, some users may develop (suddenly or gradually) from passive, docile patients into in-control health care consumers. Many patients with knee arthrosis, for example, become actively involved in the search and selection process during this second stage. Over a longer period of time (up to 20 years) they have several contacts with their initial orthopaedist;

sometimes with one or more preliminary operations. This gives them the opportunity to think over their initial 'choice'. Some patients take this very seriously, not least because this period will result in the most definite and irreversible form of therapy: total knee replacement. Information that patients would like to be provided with during this stage covers treatment alternatives, ways of postponing knee replacement for as long as possible and comparable quality information about orthopaedic surgeons and hospitals; especially on outcomes and safety.

1. I made a decision based on other people's good experiences.
2. I'm curious to know about those experiences. What made you decide? Did people say to you that it was a nice man or woman?
3. No, they had had good results.
4. What do you mean by results?
5. Successful operation. Mobile again; knee back to normal. The people could move again properly.

Most depressed patients are passively guided through this second stage, usually by the health care worker who performed the initial intake or the professional who set up a care plan. In many cases, their advice to the patient is very directive (especially during a crisis). If patients are interested in receiving information at all in this phase, they would prefer information about the treatment that is to be given. A 27 year-old depressed woman answered our question as follows:

1. What kind of things would you want to know if you had to choose again?
2. Perhaps that they clearly explain the different disciplines. For example psychotherapist, psychologists and socio-psychiatric nurse. What exactly the difference is between them and what exactly you should do in those sessions. What do they have to offer in terms of treatment capacity? And what about people with different areas of expertise? What kind of discussion or treatment methods do they offer?

Patients with Alzheimer's disease or their representatives are still puzzled during this second phase, entering a world of care facilities with which they are not familiar. In their search for group or individual therapy or other low-threshold, ambulatory forms of care, they mostly rely on their general practitioner or social worker. Information given during this phase should explain the care

trajectory and, at most, possible therapies. A 63 year-old wife of a man with Alzheimer's disease told us about this stage:

We submitted ourselves to the advice of the nurse in the hospital. If you can't cope any longer there is a social worker to deal with the social side of the family situation. And in the hospital they are there for the medical side. She made a clear distinction between the two. At first I didn't know exactly where to report to. Then at a certain point they told me in the hospital that they were handing everything over to the Grote Rivieren home, including the medication.

The *third stage* is a period of health improvement or of rapid or gradual deterioration. Some people start looking actively for information to facilitate their recovery process or prepare themselves for the next step in their health care consumption. Others remain rather passive and take further developments as they come. Many patients with knee arthrosis follow rehabilitation as part of a larger programme and therefore do not actively choose their rehabilitation provider. There are however patients who choose a therapist of their own preference. Most chronically depressed patients develop into more or less active consumers during this phase. After a first series of treatments they start searching for information about treatment alternatives. Eventually, they either stop treatment or switch to a different therapy and/or therapist. Other helpful information during this stage should preferably cover experiences of other patients, waiting times, views on treatment and continuity of care. A 37 year-old man with long-standing depressive complaints recounts:

1. Would you also like to see things like this compared? In other words what the effect is with different providers? Or do you think that would be going a bit far?
2. There are so many variables, I really wouldn't know. You can't judge expertise in advance. What you can do is enquire of other people who had the same thing about a particular doctor or whatever. The informal circuit is very important.

Most patients with Alzheimer's disease and/or their representatives refrain from thinking about the further development of the disease and about future choices that have to be made. In this respect they remain rather passive and will at most seek information on possible ways to slow down the deterioration. As the 70 year-old wife of a former schoolteacher with Alzheimer's disease recounts:

I get good support there and I think they keep a very good eye on him and probably observe me as well. I have full confidence in them; I don't think there's any need to look anywhere else. I don't know what else is available. We don't live far from institution B. it's a genuine nursing home. If I wanted to I could go and have a look, but it's completely unnecessary. I don't look that far ahead. But then there's absolutely no need to.

When more severe care or a second treatment is needed (*fourth stage*) the picture is less unambiguous than it was in stage one. A patient's earlier experiences and the cause of the repeated need for treatment appear to be decisive here. Knee patients who need another operation (second knee or repeat surgery on the first), for example, are either passive (they automatically return to their first provider), or highly motivated to find someone else, depending on their earlier experiences. In the latter situation, they are especially interested in information about new treatment techniques and about comparative quality information on different providers. Again, the expected effectiveness and safety of an operation are dominant topics of interest. A 41 year-old man reports that if he had known everything before his operation, he would have been more critical regarding its (expected) outcome:

1. The result was not the best, because I could only bend my leg through 30 degrees; more just wasn't possible. Yes, I had a time that I could bend it through 45 degrees, but that didn't go well.
2. Because they didn't want to insert a new prosthesis?
3. No, but I wish they had done so. Then I would have been able to move it through 90 degrees now. And the muscles are completely cramped up. So technically I can bend my knee but because I've been walking so stiffly for such a long time I can't do it anymore. If I'm under anaesthetic and they relax the muscle, then I can bend it. But now I can't.

Depressed patients who go through a (repeated) crisis and need renewed therapy or even hospitalisation are not able to make deliberate choices, but in the case of mild depression they either return to their own therapist or use the knowledge they have gathered to choose their new therapist with care.

Many representatives of patients with Alzheimer's disease who need to be institutionalised actively search for a good facility for their relative. After all, it is a long-term decision since a patient will

spend the rest of their life in such an institution. Many factors are considered, such as expertise, travelling distance, waiting time and ambience. Sometimes, representatives automatically 'choose' a facility with which they were already familiar because their family member has already received care from its ambulatory division. However, in many cases the constant denial of the disease leads to a crisis during which patients and their representatives have to be guided through the system. Representatives told us that after such a crisis, when their family member had been placed in a rather arbitrary facility, they became critical consumers who would like to be given a second choice option. When we asked a 66 year-old woman whether she had actively chosen her husband's nursing home, she answered:

I know exactly what you mean. But it's like this. In a crisis something has to be done immediately. You don't have time to think. It's only once someone has been admitted that you want to know precisely what is going to happen. And then you sometimes make a choice, because you then do start chasing it up. Let's say that someone has ended up somewhere where you absolutely don't want them to be. As a sort of trial period. Because I don't want it, you go looking to see if there is another option. Then you really do need the help of the professionals, because you'll never get through it on your own.

D. Organisation of care determines decision process

According to our data, the organisation of care is a third theme that influences patients' attitudes towards the search for and selection of a health care provider. In other words, the way in which health care is organised enables, and sometimes even forces people to become 'in-control consumerists' or, on the contrary, turns them into passive, dependent patients.

The care delivery process for patients with knee arthrosis can be characterised as 'loosely coupled'. Patients can discuss their referral to an orthopaedist with their general practitioner, and once they have been examined or treated there they return to primary care to rehabilitate with a physiotherapist whom they can choose themselves. As soon as a new problem occurs or their current disease deteriorates, patients are free to go anywhere to obtain help. Such a system repeatedly holds patients responsible for the choices they make, and encourages them to act as 'in-control consumerists'.

Organisation
of care

Attitude A

Attitude B

(F)Actors
Influencing
patients
decisions

On the other hand, the trajectory through which chronically depressed patients go can be compared with a carousel that covers all the steps from beginning to end and leaves little freedom of choice. Patients are usually referred to a regional institute for mental health care. From intake until therapy and sometimes hospitalisation, patients are 'led by the hand' by health care workers who all work for the same organisation:

1. Yes, that's well known. He read that everywhere. First from the RIAGG [*Regional Institute for Outpatient Mental Health Care*]. You read that in every newspaper about the RIAGG, now they have a new building, with different disciplines, nurses, occupational therapists. Not just the psychologist and psychiatrist; they're all there.
2. Did you also feel at that time that you had options?
3. No, but the advantage is that you have different disciplines there. The disadvantage is that you have to wait a very long time.

In the case of Alzheimer's disease, patients are referred to an ambulatory geriatric unit in a hospital for a diagnosis. In parallel with this, they are brought into contact with a social worker from either a regional organisation for mental health care or an institution for care for the elderly, which

accompanies patients and their relatives as the disease progresses. When group or individual therapy and, later on, institutionalisation is required, the choices are also generally made for patients by professional health care workers.

One would expect that the above processes would develop in such a way that the timing and the level of decision-support match patients' abilities and desire to maintain their autonomy on the one hand and to be helped when needed on the other. However, our data reveal a number of important mismatches. An example of such a mismatch was already given above, when it became clear that after a 'cooling off' period, relatives of an Alzheimer's patient who has been placed in a facility would like to be given a second option to make a definitive choice of institution.

The following quote gives another example of a system mismatch. It was taped during a conversation with a 39 year-old lady whose father had been institutionalised in a nursing home because of his Alzheimer's disease. She recounts that at a certain point she wanted to place her father on the waiting list for the facility they all preferred. Unfortunately she was told that she would have to wait for an official referral by the competent body. This referral could not be given before her father's problems had become so acute as to require immediate institutionalisation. When that happened, the preferred facility was full and the man was placed elsewhere.

1. And there is a waiting list?
2. Yes, then there is a waiting list. Whereas I'm thinking, my mother wants to find something good for my father; she doesn't want to put him just anywhere. Then I think it's very important that we are able to choose now he still knows what's going on. Not later. And once it gets to the stage where he no longer recognises her, that'll be a great shock for her. Then you don't have time to think, because he has to be taken away immediately. But (...) I can't put my father on a waiting list until the moment that he really knows nothing any more. You have to have an explanation; an indication that he has lost his way completely. Once you get to that point, you can start looking. I think that's terrible.

Besides situations in which people are prevented from acting as in-control consumers, there are also system mismatches that force patients to act as assertive consumerists in situations where they are not able to do so. The quote below was taken from a chronically depressed

woman who recounts that she was no longer given therapy sessions and had to search for follow-up care by herself:

Until we were told that (...) no more than fifty treatments could be given to patients. Five years and 45 weeks. (...) That caused us quite a shock. They then started looking (...): What do you think you still need? Would you like to go to a different group, a short-term group? Or would it be worth while carrying on individually? Or is support better and no actual therapy as such?

4.6. Discussion and concluding remarks

The objective of this study was to shed light on patients' decision processes in the search for and selection of their health care providers, in order to show whether they would include comparative quality information in their decisions if such information were available.

Consistent with earlier findings (Charles et al., 1997; Flynn et al., 2006; Lupton, 1997; Wackerbarth, 1999), two basic attitudes towards the search and selection process for health care providers emerged from the data: the 'in-control consumer' versus the 'passive, docile patient'. The consumerist attitude corresponds with what Flynn et al. (2006) call 'deliberate autonomists', with Wackerbarth's (1999) (spousal) caregivers who 'plan ahead' and with Lupton's (1997) 'ideal-type consumerist'. Compared to the typologies by Charles et al. (1997, 1999), these patients search for all relevant medical and personal information before making a decision. The flow and direction of the information are not straightforward. The process of information-seeking is interactive, involving the patient, physicians and other sources (family, Internet, scientific literature, second opinions, etc.), and is to be seen as an ongoing process. There is quite an extensive period of deliberation before the patient finally chooses a certain provider. In both the deliberation and the decision phase, the patient is 'in control' and actively involves others in the deliberation and decision-making process (other physicians, experts, consultants from patient organisations, family members, etc.). The dependent, docile patients at the other end of the continuum seem to fit in with Flynn's (2006) 'non-deliberate delegator', with Wackerbarth's (1999) family caregivers who 'feel that care giving decisions are made by others or by the disease itself', the paternalistic decision-making model by

Charles et al. (1997; 1999) and with Lupton's (1997) typology of the 'passive patient'. Information about the disease, therapies or possible choice alternatives is largely one-way in nature (given by the physician and received by the patient). Both deliberation and decision-making are carried out by the physician without involvement of the patient.

In addition to these corresponding insights, our participants' stories show that it is impossible to generalise about *the* search and selection process of *the patient*. Patients' attitudes towards the search for and selection of a health care provider are not static, but vary depending not only on the patient's basic attitudes to life, but also on the type of disease, the stage of the disease and the organisational context. Just as patients' attitudes differ, so does their potential interest in decision-supportive information. These findings support study results by Harris (2003) and Wackerbarth's (1999) contention that different family members of patients with dementia '*will undoubtedly want different information based on their decision-making style and also their place in the decision process*'.

The more detailed exploration of the (f)actors that are involved in patients' decision processes show a less unanimous similarity with prior research. Whereas Salisbury (1989) and Marshall et al. (2002) claim that patients 'choose' their physician out of habit and trust their own experiences or that of friends and family more than comparative quality information, our participants told us that at certain times they would certainly have been helped by accessible and reliable information on providers' performance, to enable them to make deliberate choices. This information might cover all kinds of topics, depending on a patient's attitude towards choice, the type of disease or disorder and the disease stage. Depending on their early experiences with their initial orthopaedist, many patients with knee arthrosis, for example, gradually become interested in the more technical aspects of quality (outcomes and safety) and seriously consider their choice in the event of knee arthroplasty. This supports the findings of a discrete choice experiment by Fung et al. (2005) and the study by Tai et al (2004) mentioned earlier. As regards the search and selection process by representatives of patients with Alzheimer's disease and chronically depressed patients, we found both similarities and new insights with respect to earlier research. Our data confirmed that these choices often have to be made under great pressure and without clear criteria, as was also reported by McAuley et al (1997), Reed & Morgan, (1999) and Nolan et al. (1996). On the other hand, participants told us that in the event of (repeated) institutionalisation they would be interested in comparing facilities' expertise

in cases of Alzheimer's disease, and other patients' experiences with interpersonal treatment in cases of depression. The former finding was also reported by Bornstein et al (2000), who found that a providers' professional expertise was rated highest by patients.

We can thus legitimately conclude that there is substantial scope in patients' decision processes for comparative quality information about health care providers, depending on the type of disease, the disease stage and the way in which health care is organised. Elaborating on this conclusion, four concluding remarks can be made that might be useful to policymakers in the field of patient empowerment, to future developers of consumer information, to health care providers in assisting patients and their families during periods of deliberation, and to researchers in the area of consumer behaviour in health care.

First, decision-supporting patient information should be carefully designed and should preferably be tailor-made in terms of its timing and content. This was also recommended by Arora et al., (2005), who suggest that *'To move people from precontemplation towards action in participating in medical decision-making, interventions (...) should balance advocacy for an active patient role with individual patients' preference for participation'*. Our data showed that patients with long-lasting diseases who need elective surgery, such as knee arthrosis, seem willing to include comparative quality information at a relatively early stage of their disease compared to intermittent mental diseases such as depression or diseases with a regressive course such as Alzheimer's disease. In other diseases or in earlier stages, people might be much more interested in information about the disease itself, its prognosis or the treatment options.

Second, many patients with chronic depression or Alzheimer's disease (and their families) end up in an acute situation where professional assistance has to be given immediately. In our opinion many of these situations could be prevented if future decisions were talked through at an early stage of the disease. Both patients' embarrassment and denial behaviour have to be overcome, but this would nonetheless lead to fewer acute situations and put patients and their representatives more in control of their own decision process.

Third, the mismatches mentioned above between patients' abilities to behave as critical consumers and the degree to which 'the system' allows them to choose, show that improving patient

choice need to be achieved not only through better consumer information but also through a better organisation of the entire care process, and especially the timing and support in choice situations. Patients who have been institutionalised in an acute situation, for example, should be offered a second (final) choice of institution, preventing them from ending up in a facility that makes them unhappy.

Finally, we believe that further research will be needed if these suggestions are put into practice. Although our aim was to select three 'prototypical' diseases, it remains to be seen how 'similar' patients' decision processes are in 'similar' diseases. In addition, future studies should identify and define different 'patient profiles' or 'market segments' throughout and within other patient groups. Furthermore, the results of the current study need to be refined by gaining insight into the way in which different segments trade off different (f)actors that influence their decision processes. So far, we have only been able to identify the main influential (f)actors, but we remain uncertain about patients' behavioural changes due to changing circumstances. Tailor-made consumer information, however, requires more precise insights into how patients value different kinds of information in relation to other influential, perhaps contextual (f)actors.

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Chapter 5

“Quot Capita, tot Sensus?” An Investigation of the Choice Processes of Patients seeking for a Health Care Provider, using Q-Methodology⁶

⁶ Quot capita, tot sensus: “There are as many opinions as there are heads”. *Terentius, Roman poet (190 B.C - 159 B.C)*

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5.1. Introduction

In the last two decades, many Western countries have introduced market principles into their health care systems in pursuit of cost containment and quality improvement (IOM 2000, 2001; Porter, and Teisberg 2007). As a result of these reforms, governments are retreating and insurers become more dominant; both in the health insurance market and in the allocation of resources in the funding market.. In the health care delivery market, patients are challenged to become an important countervailing power towards providers; both collectively as purchasers and individually as critical consumers (DoH 2004; Thomson, and Dixon 2006; VWS 2001). However, as Kenneth Arrow already described in the early 1960s, health care has some specific characteristics that may lead to important market failures (Arrow 1963). Asymmetry of information is probably the best known problem, meaning that patients, as lay persons, are far behind health care professionals as regards medical knowledge and thus lack crucial information about the 'product' they are 'buying'. In order to overcome this market failure, governments and private parties try to empower patients, for example by disclosing comparative quality information about health care providers (Dr. Foster 2007; National Institute for Public Health and the Environment (RIVM) 2007; U.S. World and News Report 2007).

These developments have resulted in discussions in health care literature on the question of whether patients tend to act as critical consumers and, if they do, whether they would use comparative quality information during their search for and selection of a health care provider, if such information were available. The existing body of knowledge on this subject gives a rather ambiguous answer to this question. On the one hand there are authors who state that the public disclosure of health care providers' performance does not affect patients' decisions at all (Marshall, Hiscock, and Sibbald 2002; Marshall et al. 2000; Schneider, and Lieberman 2001). Other studies observe (growing) interest among patients in (comparative) quality information, even on the more technical aspects of health care quality and safety (Fung et al. 2005; Harris 2003; Luft et al. 1990).

These diffuse results are probably caused by the diversity in research methods and focuses. Some studies investigate patients' decision-making behaviour at macro-level, for example by following admissions volumes or the or market shares of poorly and well-performing providers (Baker et

al. 2003; Luft et al. 1990; Mukamel, and Mushlin 1998). Yet the problem with such an approach is that it does not disclose the 'black box' of the micro-level decision-making process. Other studies ask participants how important certain aspects are to them when they need a health care provider (for example by scoring their relevance on a five-point scale). This often leads to results that hardly differentiate and which overvalue the relative weight of certain aspects, since many patients find it difficult to prioritise using scales (Devellis 2006). A third group of studies uses (forced) choice experimentation in order to overcome these problems (Burge et al. 2005; Fung et al. 2005), conceptualising the patient as synonymous with *homo economicus* (McDonald et al. 2007). However, the literature puts forward several disadvantages of such an approach. First, it tends to obscure the underlying relationships involved (Light, and Hughes 2001; McDonald et al. 2007). In other words: it does not embed patients' decisions in their social context, but focuses on rational trade-offs, based on 'product characteristics' in a laboratory setting. This results in only a partial understanding of patients' decision processes, and ignores the role of crucial contextual actors and factors (what happens if physician B performs excellently but the patients' general practitioner refers them to someone else?). Secondly, the rational choice approach does not take into account the fact that patients' preferences might change during the decision process or as the illness progresses (Mol 2006).

In contrast to their methodological diversity, the former studies have one thing in common: they all focus on one specific health care setting (for example hospital care or primary care) or on a single disease or treatment (for example coronary bypass surgery). Although results are often generalised to *all* patients, it is not impossible that there is a great diversity in patients' ability and willingness to involve comparative quality information in their deliberations preceding the choice of a provider.

Against the background of the increasing development and public disclosure of comparative consumer information, and the ambiguous views in current literature on the usefulness of such information in patients' decision processes, there is a need for research that provides an understanding of the actors and factors that influence patients' search for and selection of health care providers. Methodologically, such a study should on the one hand take on board diversity among patients, and on the other embed their decisions in their social context. The study presented here aims to contribute to current knowledge in this way. We conducted a Q-methodological study to

investigate the search and selection processes of patients with different diseases seeking a health care provider, in order to identify relevant choice profiles based on differences and similarities in the importance these patients attach to a range of actors and factors that play part in their search for and selection of a health care provider.

5.2. Methods

5.2.1. *Three diseases*

We decided to focus on knee arthrosis, chronic depression and Alzheimer's disease for three reasons. Firstly, there is a lack of disease-specific knowledge about patients' choices and their decision processes. At the same time, it would be of great value if disease-specific insights could be generalised to other, comparable groups. Knee arthrosis and its therapies arthroplasty or osteotomy, for example, can be seen as exemplary for other diseases that require elective surgery (hip, cataract). The search and selection process in the case of chronic depression might be largely comparable to that of other mental (mood) disorders, and decisions in the event of Alzheimer's disease are likely to match with choices of other people who need geriatric or psychiatric care for the elderly (McAuley, and Travis 1997; Wackerbarth 1999). Secondly, hospital care, mental health care and care for the elderly are the domains in which the Dutch government first started developing comparative quality information. We therefore believe that research into the decision processes of the above patient groups would have the greatest added value and social relevance. Given these areas, a third consideration was to select only high-prevalence diseases. In the Netherlands, knee arthrosis is one of the highest volume causes of problems with the locomotor apparatus (Poos, and Gijsen 2003). In mental health care, long-lasting or chronic depression is the disease with the highest prevalence (Poos 2007), while 73% of people with dementia suffer from Alzheimer's disease (Lange, Gijsen, and Poos 2007).

5.2.2. *Sampling procedure*

As preliminary research (see below) had shown that (the factors and actors that influence) patients' decision processes might be associated with the stage of a disease, this became our primary sampling criterion. During January and February 2007 we included patients with knee arthrosis who were on a waiting list for knee arthroplasty or osteotomy or underwent such an

operation in the year 2006. Participants were invited via the Dutch Association of Orthopaedic Patients (SPO), via a primary care physician's practice and via orthopaedic departments at two general hospitals.

For chronically depressed patients and for patients with Alzheimer's disease and/or their representatives, we took the type of health care provider as a proxy for disease stage. Both ambulatory and institutionalised depressed patients were included via several providers of mental health care. Patients also enrolled after we had advertised on the website of the Dutch National Depression Centre.

Patients with Alzheimer's disease and/or their representatives were invited via ambulatory geriatric care facilities at a university hospital and a general hospital, ambulatory care facilities at two mental health care providers and the ambulatory and intuitional departments of a nursing home. We also recruited patients and/or representatives during Alzheimer Cafes (low-threshold walk-in meetings that are frequently held in homes for the elderly).

5.2.3. Study design: Q-methodology

In order to answer our research questions we conducted a Q-methodological study. Q-methodology is a hybrid qualitative/quantitative research method that provides a foundation for the systematic study of subjectivity, a person's opinion, beliefs, attitude, and the like (Brown 1980; Exel, and Graaf 2005). Although it has been around for over 70 years (Stephenson 1935), it is a relatively novel method in health services research (Exel, Graaf, and Brouwer 2007; Risdon et al. 2003; Stenner, Cooper, and Skevington 2003; van Exel, de Graaf, and Brouwer 2006). During a Q-methodological study, participants are presented with a sample of statements on a certain subject (here: factors and actors that may play a part in patients' decision processes in their search for and selection of a health care provider), called the *Q-set*. Respondents, called the *P-set*, are asked to rank the statements from their individual point of view, according to their preference, judgment or feeling about them and, subsequently, to explain their ranking of the statements. By Q-sorting the statements, people assign a subjective significance to the set of statements, and so reveal their subjective viewpoint (Smith 2001; Cross 2005). The Q-sorts are then subjected to factor analysis to produce a limited number of corresponding ways in which the statements have been sorted by respondents.

The Q-set

Prior to the Q-study, we conducted semi-structured interviews with 23 purposefully sampled patients with knee arthrosis, 15 chronically depressed patients and 15 patients with Alzheimer's disease and/or their representatives. Following a grounded theory approach in both the data collection and analysis phases (Patton 2002), we derived three long-lists of statements (300+ for each disease type) regarding (f)actors that may play a role in patients' decision processes when searching for and selecting a health care provider. These long-lists were structured according to themes that emerged from the transcribed interview data. Next, the structured long-lists were condensed to sets of manageable size by stripping out duplicate and comparable statements and by selecting the most frequently mentioned (f)actors within each theme. The final sets of statements - 46 for patients with knee arthrosis, 45 for chronically depressed patients and 48 for patients with Alzheimer's disease and/or their representatives (see tables 2 to 4) - are considered representative for the issues raised during the interviews. Finally, the statements were edited, randomly assigned a number and printed on cards.

The P-set

Respondents for the Q-sort interviews were purposively selected according to the same sampling criteria as used for the earlier interviews described above. The aim was to include between 40 and 45 respondents in each group. Q-methodology is a small sample methodology; "Q does not need large numbers of subjects as does [regular survey analysis], for it can reveal a characteristic independently of the distribution of that characteristic relative to other characteristics" (Smith 2001). A Q-methodological study can thus reveal the main viewpoints on a particular subject within a population, but will not inform about the distribution of these viewpoints in the larger population (Brown 1980). For this, regular survey analysis in a representative population is necessary.

Q-sorting

Respondents were asked to rank the statements using a quasi-normal distribution (see Figure 1) and in accordance with the following condition of instruction: *Because of your health complaints as a consequence of [knee arthrosis; chronic depression; Alzheimer's disease], you are seeking care. How important are these factors in your decision process when searching for and selecting a health care provider?*

These composite sorts were used to interpret and describe the choice profile reflected in each factor. A first interpretation of a factor is based on the characterising statements of that factor, i.e. those with a rank score of “+4”, “+3”, “-3”, “-4” in the composite sort (columns 9, 8, 2 and 1 in Figure 1). Differences between the factors are highlighted using the distinguishing statements; those with a statistically significantly different rank value on that factor as compared to all other factors. Similarities are described using the consensus statements; those that do not distinguish between the identified factors. Finally, the remarks made by respondents during the post-Q-sort interview to explain their rankings of the statements were used to assist in the interpretation of the statistical results and the description of the choice profiles in the results section. Q-analysis was conducted using PQMethod 2.11 (Schmolck & Atkinson 2002; statistical method: centroid factor analysis with varimax rotation).

5.2.4. Measures

The main outcome measures are the choice profiles of patients searching for and selecting a health care provider. In addition, information was collected on the following variables: *personal characteristics* (age, gender, education level and relation to patient); *disease stage* (current health care setting, period since diagnosis and severity of the disease); and *search and selection behaviour*. Among patients with chronic depression or Alzheimer’s, disease severity was assessed using a visual analogue scale ranging from 0 (no complaints at all) to 10 (the worst conceivable complaints). Among patients with knee arthrosis, disease severity was assessed using two visual analogue scales, one for the degree of pain and one for the limitations they experienced from the disease. Finally, as an alternative measure of patients’ search and selection process, a scale was developed consisting of six statements (see Annex for details).

5.3. Results

A total of 130 persons completed one of the three disease-specific Q-sorts: 45 patients with knee arthrosis, 44 chronically depressed patients and 41 patients with Alzheimer’s disease and/or their representatives. Table 1 shows the (sub)sample’s main characteristics.

Analysis of the Q-sorts for each disease group revealed two choice profiles within the group of patients with knee arthrosis and those with Alzheimer’s disease and/or their representatives, and one dominant profile within the group of chronically depressed patients. We now present the

Table 1. Sample characteristics

	Knee Arthrosis (N=45)	Chronic Depression (N=44)	Alzheimer's Disease (N=41)
Relationship to patient			
Patient him/herself	100 (45)	100 (44)	7 (3)
Partner			25 (10)
Child			61 (25)
Other			7 (3)
Age Average (Range)	56 (27-82)	43 (17-66)	61 (38-92)
Gender			
Female	60 (27)	81 (36)	85 (35)
Male	40 (18)	19 (8)	15 (6)
Education			
High	42 (19)	43 (19)	24 (10)
Middle	27 (12)	37 (16)	22 (9)
Low	31 (14)	20 (9)	54 (22)
Current / most recent health care setting or therapy*		ITH 25 (11) AC 52 (23) IC 5 (2) Other 36 (16)	IC 40 (16)
Period since diagnosis given			
Average (Range)	9.5 (0-31)	9.1 (0-36)	3.7 (0-15)
Disease severity			
Average (Range)	Pain: 4.5 (0-10) Limitation: 5.4 (0-10)	5.3 (1-8)	5.0 (2-10)
Search behaviour score			
Average (Range)	13.6	11.0 (6-15)	11.0
Choice profile when searching for and selecting a health care provider			
"focus on outcomes"	60 (27)	- (-)	61 (25)
"focus on trust"	40 (18)	100 (44)	49 (16)

* Several options could be chosen at the same time. *Chronic depression*: ITH=Independent Therapist; AC=Ambulatory Care Facility; IC=Institutional Care Facility. *Alzheimer's Disease*: IC=Institutional Care Facility (nursing home or home for the elderly);

choice profiles operant within each disease group, and the similarities and differences between them. Similarities and differences in profiles between the disease groups are addressed in the discussion section.

5.3.1. *Knee arthrosis*

Two major choice profiles emerged among patients with knee arthrosis. Profile A is described by 27 (60%) patients, profile B by 18 (40%). Together, these two profiles account for 52% of the variance in the Q-sorts.

People with choice profile A attach most value to the expected outcome of a treatment (table 2, aspects 4;21): *“that I am relieved of my complaints and can do everything 100% again”*, or: *“it is very important that I am left free of pain after an operation”*. They are therefore highly interested in the expertise of both the hospital and the specialist who will be treating the knee arthrosis (29;37): *“I want the best specialist, but the team behind them is also important”*, *“if the therapist is good, you can be almost certain that it will turn out all right”*, or: *“of course mistakes are made, so you want someone who is as expert as possible”*. In addition, these patients with knee arthrosis attach great value to the advice of their specialist regarding a specific therapist (43), *“because I trust the ability of the specialist to give me good advice”*, and to whether the treatment is paid for by the health insurer (41): *“it’s ‘free’. That’s a nice feeling, despite the fact that I pay the health insurer and hefty premium”*, or: *“because I can’t afford it myself”*. The urgency, in terms of pain and the limitations experienced due to the disease (39;45), also plays an important role in the care selection process: *“every day spent living with pain is very tiring and limiting”*, or: *“you have to stand/walk on your legs all day, so the less pain you have, the better you can function”*.

People with choice profile B emphasise the importance of a good relationship with their doctor (table 2a, 2;7;16;27;30), their specialisation and experience (29), the information provided by the therapist (12) and how much say they have in the treatment chosen (15). On involvement (2) they say the following: *“that is very important; you feel you’re not alone”*; *“in many cases you are just a number; as soon as the patient knows who you are he also knows your problem”*. On good personal contact (16): *“it’s important for me that it really clicks with my therapist. If it doesn’t, the operation will go wrong”*, or: *“I always have to have the feeling that I can trust the person that I’m likely to be spending many months with; they have to be interested in my account, be prepared to talk, arrive*

at a solution together, be professional, take the time. You feel supported, accepted, and that means you'll deal with the operation better". On trust (27): "when it comes to medical interventions, you have to have a 'good feeling' about the person treating you; they have to be someone who exudes confidence in the broadest sense", or: "I have to feel I can trust my therapist". On specialisation (29): "for me, the expertise is the most important thing,, because I think that gives you the best chance of a good outcome of the therapy (whether or not it's an operation)", "that the therapist has the experience and expertise to take the right decisions and therefore minimises the risk of errors", or: "the outcome depends on it, and in my experience the differences are a wide". On having a say in the treatment (15): "it's my body, my future"; "I want to have the feeling that the solution chosen is one that's right for me". Finally, these people feel that the expected outcome of the treatment is important (4;21): "the outcome is my future", "the only thing that matters to me is that after the operation I can do at least the same as before it. I sometimes see people who have had pain-free outcomes but who can't walk another step", or: "of course you want to be very sure that everything will be done to make sure the operation is as perfect as possible; you want to be treated as if you were the Queen".

Based on these descriptions, choice profile A was labelled "focus on outcomes" and choice profile B "focus on trust". Figure 2 presents brief descriptions of both profiles. People in both profiles shared an interest in the expected result of the treatment (4,21), the specialisation and experience of the therapist (29), and to a slightly lesser extent the specialisation and experience of the hospital (37). By contrast, both groups attach little importance to advice from their employer (20), from medical programmes on television (5), or from people in their social network who play a lot of sport (9) or who have early experience with the same therapist or hospital (42). In fact, all aspects of the choice relating to "referral/advice" are considered fairly unimportant. Whether the hospital is a general or university hospital is also of subordinate importance (9), as is the question of whether a therapist or hospital is one which also treats top sportsmen and women (3).

Comparing the background characteristics of respondents with the different attitudes shows that people with a 'focus on outcomes' are better educated than people with a 'focus on trust', have often already undergone a number of treatments, received their diagnosis of knee arthrosis earlier and suffer less pain but comparable limitations from their disease (all $p < 0.10$). Outcome-focused persons also show more extensive information search behaviour than those who tend to trust their doctors more ($p < 0.10$).

Knee Arthritis	<p>Choice profile A: Focus on outcomes</p> <p>The most important thing for me is the feeling of safety and security for clients in a care home or nursing home. There must be enough expert staff, who devote enough time and attention to the personal care of the residents, to helping them with eating and drinking, and to putting them at their ease. Having a say in the care and sticking to agreements are also important.</p>	<p>Choice profile B: Focus on trust</p> <p>Trust and getting on with the staff on a personal level are the most important things for me. It is good always to have the same caregivers. The expertise of the care or nursing home, the waiting time for admission and the support they give to the client in continuing to live at home for as long as possible, are also very important.</p>
Chronic depression		<p>Choice profile C: Focus on trust</p> <p>Having confidence in the person and the expertise of the therapist is the most important thing for me. If that confidence is there, we can discuss which treatment is the best for me and take the right decision so that after treatment I can function as well as possible again without pain in everyday life.</p>
Alzheimer's disease	<p>Choice profile D: Focus on outcomes</p> <p>The specialisation and experience of the therapist and the hospital are the main priority for me; an expert team is the best guarantee of a good outcome. Enabling me to function without suffering pain is what the treatment is ultimately about.</p>	<p>Choice profile E: Focus on trust</p> <p>Trust and getting on with the staff on a personal level are the most important things for me. It is good always to have the same caregivers, who give me attention and are concerned with me and my problem. Without trust there's no point in starting the treatment</p>

Figure 2. Choice profiles of patients searching for and selecting a health care provider

5.3.2. Chronic depression

Chronically depressed people appeared to have one dominant choice profile (C in figure 2). It covers 45% of the variance in Q-sorts. People with this choice profile attach most importance to

the relationship (of trust) with the doctor (table 2b, aspects 14;26;34;35): *"The therapy stands or falls on trust in the therapist. Trust in the care provision is also essential, otherwise you should steer well clear"*. And: *"Trust is very important for me. It's a condition for making it possible to talk about my problems openly"*. The expertise of the therapist (33) and the expected outcome of the treatment (39) are also important, but come in a clear second place: *"I was looking for help/support just to be able to carry on with my life at that time, without 'setbacks' knocking me out of my rhythm again; in other words, to be able to maintain my life the way of was"*. And: *"If I know what to expect, I can prepare myself for it. It gives a feeling of certainty and control"*. Finally, respondents say that they attach importance to the waiting period between the initial contact and the commencement of care (32) and the way in which intake is conducted (4). On the waiting time (32): *"Getting help quickly is crucial in depression; every day that you have to wait is full of misery and suffering"*. And: *"The waiting time should be as short as possible, because the more time elapses, the more difficult the road to recovery is"*. On the intake and treatment plan (4): *"I think it's very important because in principle, I don't come with very clearly defined complaints"*. All kinds of provider characteristics such as religious identity (7), the location and size of the care facility (31,37) and the atmosphere of the buildings and rooms (45) are subordinate to the former aspects. This also applies for advice on care provision from the social network (11), from employers (25), fellow clients or fellow sufferers (15, 28), a confidential counsellor (23) or other health professionals (8, 44). Based on the above description this choice profile, in line with the results for people with knee arthrosis, can be labelled "focus on trust" (see figure 2 for description).

5.3.3. *Alzheimer's disease*

For patients with Alzheimer's disease or their representatives, two basic choice profiles emerged from the Q-data. Profile D was found in 25 persons (61%) and profile E in 16 respondents (39%). Choice profiles correlated fairly well (0.67), but the differences between profiles were significant, together accounting for 47% of the variance in the Q-sorts. People with profile D emphasise the importance of feeling at home in a care facility.

Feeling safe and secure within the care facility, and the supervision of safety by the facility, is thus very important (table 2c, aspects 1;33): *"my mother is suspicious and distrustful, so feeling safe and secure is very important for me"*; *"Alzheimer's disease can cause enormous anxiety, the feeling of being completely alone and that nothing is safe any more."* Following on from the foregoing,

they also emphasise the expertise and availability of staff (12; 24), the way they approach the client and the attention they give them, for example as regards personal care and (help with) eating and drinking (11;17;47), and the result of the help (43). On having sufficient and sufficiently expert staff (12;24): *"We leave our loved ones behind with trust, which means we place their care in their hands": "To achieve this you need people who dedicate themselves to providing care at home,; well-trained staff with lots of respect and patience"*. On the approach of the care facility and the attention it gives to its clients (11;17;47): *"despite being disabled, being treated with dignity", and "Personal attention is extremely valuable, especially in this degrading phase of their lives"*. On the expected result of the care (43): *"the expected outcome is important because it takes time. If you see acceptance and a reduction in anxiety, this is evidence for the 'healthy' party that they have made the 'right' choice. Or: 'it is sad when someone dies from malnutrition in a wealthy country"*. People with this choice profile also feel it is important to have a say in the care that is provided (38): *"as far as possible I want to determine my own life"; "very important because you want the best for the person concerned"*.

People with choice profile E attach most value to the relationship with the therapist; their attitude to clients (11; see quotations above), whether they trust the therapist (31), whether things 'click' with the therapist (45), but also whether they always get to see the same therapist (48). On trust in the therapist (31): *"you need trust because it makes the patient calmer", and: "because my partner quickly becomes nervous and consequently confused, having trust in people and the environment is important"*. On the personal 'click' between the patient and the therapist (45): *"because my partner quickly becomes nervous and consequently confused, having trust in people and the environment is important"; 'it's important that it clicks on a personal level, because otherwise the patient is restless and uncertain."* On continuity of care (48): *"People with dementia need familiar things/the same faces/trust. Recognisability is important"; "not continually having to explain everything"*. In the choice of a care facility, people with choice profile E attach great importance to the advice of the specialist (8): *"the specialist is aware of the possibilities and can therefore give the right advice"; "someone who knows what he's talking about in a world that is confusing"*. In addition, people regard the expertise (specialisation and experience) of the care facility with Alzheimer's disease (12) and the waiting time (39) as very important. On expertise: *"the quality of staff in nursing and care homes is below par; more attention needs to be paid to this"*. On waiting times: *"before the actual diagnosis is established you've already gone through a long and difficult period; care and*

help are then needed quickly"; "because it often takes a long time for the pieces to fall into place. And because it is a very emotional step to ask for help". Finally, people attach importance to the availability of a fixed point of contact for the client and/or their representative (2) and attention for communication by the care facility with the partner and children of the patient (35): "this is to provide a patient with better support and to give the carer(s) a better understanding of what has happened to the patient's mental condition"; "trust is the foundation of the therapy". People with choice profile E feel it is important that the care provider makes an effort to enable clients to continue living at home for as long as possible (5): "I think it's important that my father can continue living at home in his familiar environment and with my mother for as long as possible", "I'd really rather continue living at home because then I can have private conversations with friends, especially on the 'phone". On the basis of participants' explanations of their arrangements, the two choice profiles can be labelled in accordance with the profiles of patients with knee arthrosis: 'focus on outcomes' (D) and 'focus on trust' (E). Figure 2 gives a more precise description of the two choice profiles.

The strong correlation between the two choice profiles (0.67) is reflected by the relatively high importance people in both profiles attach to the expertise (specialisation and experience) of the care facility with Alzheimer's disease (12), but also the way in which clients are approached by the therapist (11). By contrast, people in both these choice profile groups attach little importance to recommendations for a specific therapist or care facility by people with the same complaints (37), or people in their social network who have heard good or less good accounts (18), people who work in the medical world (40), or people who have less good experiences with a particular therapist or care facility (42). Advice from others is thus considered relatively unimportant, with the exception of advice from the specialist (8), for people with choice profile 'focus on trust' as are earlier experiences they or others have gained with the care facility (3,15). It is also striking that people with both choice profiles attach little importance to (quality) information on achievement, therapist or care facility from various sources (7,14,20,23). Also of subordinate importance is whether the facility is a university or general hospital (6), and – in particular for people with choice profile 'focus on trust' – what the religious identity of the care facility is (9).

Comparing the background characteristics of respondents with the different attitudes indicates that – in comparison with trust-focused participants – outcome-focused persons were given a

diagnosis longer ago, suffered more severely and were sons or daughters of the patient with Alzheimer's disease (rather than the patient themselves or their partner), were younger and were more often institutionalised in a facility for geriatric care (all $p < 0.10$). Information search behaviour did not deviate statistically significantly from zero.

5.4. Discussion

The aim of our study was to identify choice profiles based on differences and similarities in the importance patients seeking a health care provider attach to a range of actors and factors that play a part in their search for and selection of a health care provider. The study was conducted against the background of increasing availability of comparative quality information on health care providers and the ambiguous views in current literature on the usefulness of such information in patients' decision processes. Based on our data, two main conclusions can be drawn.

A first important finding from our study is that *the* patient does not exist. On the other hand, not all individual patients show a unique individual choice pattern when searching for and selecting their health care provider. The study shows that within three very different patient groups (people with knee arthrosis, people with Alzheimer's disease and people suffering from chronic depression), who come into contact with three different areas of the health care system (hospital care, geriatric care and mental health care), only two distinguishing choice profiles emerge: "focus on outcomes" and "focus on trust". Since not only differences were found between these profiles in the importance of different aspects, but also considerable correspondences with regard to a number of other aspects, the word *focus* was chosen. The choice profile "focus on outcomes", apart from the shared basis, places the emphasis mainly on trust and security in the relationship between the care recipient and the care provider, whether this is a therapist, a nurse or a care institution.

Second, our data show that across choice profiles, treatment results as well as interpersonal aspects of care are important to patients. This supports the findings of earlier studies which found that patients value both technical and interpersonal quality (Jung et al. 1998; Wensing et al. 1998). On the other hand, it was found that there is a substantial group of patients who place the

highest value on the technical aspects of health care quality (results and outcome measures) and less importance to interpersonal skills and service aspects. In this respect, our findings support the work of those who found that patients have a strong preference for providers of high technical quality (Fung et al. 2005). But as our study also shows, this is not the complete story.

5.4.1. Methodological reflections

In this study we investigated patients' choice profiles using Q-methodology. One of the advantages of Q-methodology is that it enables us to identify the different types of patients we may encounter and the similarities and differences between these types. More conventional methods, for instance using a Likert-type scoring system to evaluate the same set of statements, are more suitable for identifying majority views (see also Groenewoud et al., 2007). In this respect it is relevant to stress that Q-methodology clusters respondents according to their views on the set of statements presented to them, while conventional factor analysis clusters statements according to respondents' ratings. Accordingly, representativeness in Q-methodology does not lie in the sample of respondents, but in the sample of statements. The results of this study are therefore representative of the type of patient profiles one may encounter. Based on this study, however, little can be said about the distribution of these profiles within the different patient groups or about associations between the profiles and the characteristics of, for instance, patients or the severity of their illness. The relationships presented in the previous section should therefore be seen more as hypotheses which need to be confirmed in follow-up research, and for which conventional survey analysis is required. Recently, the short descriptions presented in Figure 2 were included in large surveys of representative samples of the three disease groups (see chapter 6). Respondents were asked to indicate which of the two descriptions best fitted their search and selection process in the event of a need for a health care provider. Initial analysis of the data collected in these surveys (knee arthrosis n=600, Alzheimer's n=400, chronic depression n=350) shows that 80% of patients with knee arthrosis, 86% of Alzheimer's patients and 16% of chronic depression sufferers had a "focus on outcomes", while the remainder (20%, 14% and 84%, respectively) had a "focus on trust".

5.4.2. Implication of the results

The actors and factors that patients with different choice profiles valued most and least give us reason to believe that if accessible and reliable comparative quality information on health care providers were to become available, patients would include it in their search and selection

processes. After all, patients with choice profile A or B attach great importance to the expertise of the therapist and the care institution, in terms of specialisation and experience, to the outcome of the treatment, and to the way in which they are approached by the therapist. The best way to give patients an insight into these topics is through quality indicators (see e.g. Groenewoud et al., 2007). There is also great agreement on the choice aspects that are of subordinate importance. In particular, many of the choice aspects making up the theme “referral/advice” achieve a low score, including both the advice and experiences of people in the immediate setting and information from all manner of media sources. All kinds of character sticks of care institutions, such as religious identity, travel distance and accessibility, and the atmosphere on first impression of the buildings and facilities, also appear to be less important in the choice process. The contention of certain authors who state that (quality) information about health care providers would be overruled either by patients’ own experiences or by what other people (social network or referrers) say (Marshall et al. 2002), or that patients choose the nearest provider by default (Burge et al. 2005; Salisbury 1989) is clearly not supported by these results.

5.4.3. Implications for further (research on) development of decision-supporting consumer information

The study results form a good starting point for the development of consumer information on the quality of health care providers. The identification of different consumer profiles implies that comparative quality information would have most impact if it were tailor-made, taking into account the similarities and differences in types of information that patients with differing choice profiles consider important.

The insights presented may help future developers of (comparative) consumer information to fit the information to requirements, depending on patients’ individual choice profiles and background characteristics. In The Netherlands, for example, our study results will be used to guide visitors smoothly through a web-based quality report card, asking for their specific preferences.

Future research should not only test our findings on different samples of patients, but also investigate the relative weights of the actors and factors which play a part in the decision processes associated with certain choice profiles. This would enrich comparative quality information by giving more weight to aspects that are of greater importance to certain health care consumers. In

addition, it would enable health care providers to predict which 'market' segments would be most attracted by a certain (combination) of health care provision.

Table 2. Choice aspects for knee arthrosis; composite rankings

Choice aspects	Factor		
	1	2	
1 The travel distance and accessibility of the hospital.	0	-3	*
2 The degree to which the therapist is concerned with me and my problem.	2	3	*
3 Whether it is a therapist or hospital where top sportsmen and women go for treatment.	-3	-2	
4 The risk of avoidable complications, infections and mistakes in the treatment.	3	3	
5 Information from a medical programme on television on a specific treatment, therapist or hospital.	-2	-1	
6 Information available from various media (Internet, magazines, newspapers) on a specific treatment, therapist or hospital.	-2	0	*
7 My earlier experience(s) with this therapist.	0	2	*
8 Quality comparisons between hospitals from various media (Internet, magazines, newspapers).	-1	-1	*
9 Recommendation for a specific therapist or hospital by people in my social network who play a lot of sport.	-2	-2	
10 The service (food, atmosphere, care) in the hospital.	0	-2	*
11 Recommendation for a specific therapist or hospital by people with the same complaints.	-1	0	*
12 The information provided by the therapist before, during and after the treatment.	1	2	*
13 My ability to have a say in the type of anaesthetic that is used in the operation.	1	1	
14 The quality of the nursing care after the treatment.	1	1	
15 My ability to have a say in choosing the treatment.	1	2	*
16 The personal 'click' between me and the therapist.	0	2	*
17 The therapist offers several treatment techniques, including new and less invasive options.	1	1	
18 The waiting period from initial contact to treatment.	1	0	
19 My impression of the hospital after a first visit.	0	-1	
20 Recommendation by my employer (via the safety, health and welfare service/company doctor) for a specific therapist or hospital.	-4	-4	
21 The expected outcome of the treatment (degree of bend in the knee, ability to walk, period until new operation needed).	4	3	*
22 Recommendation by my physiotherapist for specific therapist or hospital.	-1	0	*

Choice aspects	Factor	
	1	2
23 Recommendation by the patient organisation for a specific therapist or hospital.	-1	0 *
24 Recommendation by people in my social network who have heard good or less good accounts about a specific therapist or hospital.	-3	-2 *
25 Earlier experience(s) with this hospital.	-1	0 *
26 Recommendation by my health insurer, who mediates on my behalf, for a specific therapist or hospital.	-2	-3 *
27 My confidence in the therapist.	2	4 *
28 My ability to have a say in the date of the treatment.	0	0
29 The expertise (specialisation and experience) of the therapist.	4	4
30 The way in which the therapist approaches me as a patient.	0	1 *
31 Recommendation for a specific therapist or hospital by people in my social network who work in the medical world.	-1	-1 *
32 The chance of cancellations by the therapist within 24 hours before the treatment.	-1	-1
33 The general information provided by the hospital before, during and after the treatment.	0	0
34 The continuity of care, whether I am always treated by the same therapist as far as possible.	1	1 *
35 Whether the therapist always has my current patient details available.	1	1
36 Whether the travel costs are reimbursed.	-4	-4 *
37 The expertise (specialisation and experience) of the hospital in the field of knee arthrosis.	3	2
38 Recommendation by my GP for a specific therapist or hospital.	0	-1 *
39 The pain I experience from my knee arthrosis.	3	1 *
40 My impression based on earlier experiences with the health care system.	-1	-1
41 Whether the treatment is reimbursed by my health insurer.	2	-1 *
42 Recommendation by people in my social network who have good or less good experiences with a specific therapist or hospital.	-3	-2
43 Recommendation by my specialist for a specific therapist or hospital.	2	0 *
44 The efficiency of the organisation of care in the hospital.	0	0
45 The limitations I experience in day-to-day functioning due to my knee arthrosis.	2	1 *
46 Whether it is a general or university hospital.	-2	-3

Note: * distinguishing choice aspect (statistically significant rank scores between factors[$p < .01$]).

Table 3. Choice aspects for chronic depression; composite rankings

Choice aspects	Factor
1 The information provided by the therapist/care facility before, during and after the treatment.	1
2 The type of treatment: individual or group therapy.	0
3 My earlier experience(s) with this therapist/care facility.	1
4 Whether there is an extensive intake interview, on the basis of which the treatment and therapist are decided.	2
5 The availability of therapeutic activities/day-care activities at the care facility.	0
6 The frequency and duration of consultations.	1
7 The religious identity of the therapist/care facility.	-4
8 Recommendation by the RIAGG [<i>Regional Institute for Outpatient Mental Health Care</i>] or another caregiver for a specific therapist or care facility.	0
9 The attitude and approach of the care facility to suicidal behaviour.	1
10 Information available from various media (Internet, newspapers, magazines) on various disorders and possible treatments, therapists and care facilities.	0
11 Recommendation by people in my social network who have heard good or less good accounts about a specific therapist or care facility.	-2
12 Whether there are house rules in the care facility and how strictly they are enforced.	-3
13 The composition of the group; the personal 'click' between me and the other clients.	-1
14 The way in which the therapist approaches me as a client.	2
15 Recommendation by fellow clients for specific therapist or care facility.	-2
16 Whether a clear treatment plan is formulated, with the goals, duration and content of the treatment.	1
17 The travel distance and accessibility of the care facility.	0
18 Information folders (via GP, pharmacist, care facility) on various disorders and possible treatments, therapists and care facilities.	-1
19 The composition of the group, severity of depression comparable with other clients.	-1
20 The personal 'click' between me and the therapist.	3
21 Whether there is a crisis.	0
22 The attitude and approach of the care facility to supervision and the restriction of leisure time.	-1
23 Recommendation by my confidential counsellor for a specific therapist or care facility.	-1
24 The supervision of safe use of medicines by the therapist/care facility.	1

Choice aspects		Factor
		1
25	Recommendation by my employer (via the safety, health and welfare services/company doctor) or school management for a specific therapist or care facility.	-3
26	The continuity of care, always the same therapist .	2
27	The breadth of the care offered by the care facility.	0
28	Recommendation by fellow sufferers for a specific therapist or care facility.	-2
29	Quality comparisons between care facilities from various media (Internet, magazines, newspapers).	-1
30	The philosophy on the basis of which the therapist/care facility works.	0
31	Location of the care facility; in town or the countryside.	-4
32	The waiting time between initial contact and actually receiving care.	2
33	The expertise (specialisation and experience) of the therapist.	4
34	The attention and concern of the therapist for me and my problem.	3
35	My confidence in the therapist/care facility.	4
36	The expectation that I will lose my benefit, work or training if I do not go for therapy.	-1
37	The size of the care facility.	-3
38	Whether the treatment is reimbursed by my health insurer.	2
39	The expected outcome of the treatment (efficacy of medication, state of mind, stepping stones for change).	3
40	The experiences of other clients with the therapist/care facility.	-2
41	The type of treatment; outpatient clinic or admission	-1
42	How safe I feel in the care facility.	1
43	My ability to have a say in the choosing of the treatment.	1
44	Recommendation by my GP for a specific therapist or care facility.	0
45	The atmosphere of the buildings and rooms of the care facility.	-2

Note: * distinguishing choice aspect (statistically significant rank scores between factors[$p < .01$]).

Table 4. Choice aspects for Alzheimer's disease; composite rankings

Choice aspects	Factor	
	1	2
1 Feeling safe and secure in the care facility.	4	0 *
2 The availability of a fixed point of contact at the care facility for the client or their partner/child.	1	2 *
3 My earlier experience(s) with this care facility.	-1	-3 *
4 Recommendation by the patient organisation (Alzheimer Nederland) for a specific therapist or care facility.	-1	-1
5 The efforts by the care facility to enable the client to live at home for as long as possible, and the supervision of this.	0	2 *
6 Whether it is a university or general care facility.	-4	-2 *
7 Information folders (via GP, pharmacist, care facility) on possible treatments, therapists and care facilities.	-2	-1 *
8 Recommendation by my specialist for a specific therapist or care facility.	-1	2 *
9 The religious identity of the care facility.	0	-4 *
10 Recommendation by the care needs assessment officer for a specific therapist or care facility.	-1	1 *
11 The way in which the therapist approaches the client.	2	2
12 The expertise (specialisation and experience) of the care facility with Alzheimer's disease.	3	4 *
13 Location of the care facility, in town or the countryside.	-1	-1
14 Quality comparisons between care facilities from various media (Internet, magazines, newspapers).	-1	-2
15 The experiences of other clients with the care facility.	-2	-3
16 The degree to which the care facility sticks to care agreements.	2	1
17 The attention paid by the care facility to (help with) eating and drinking.	2	0 *
18 Recommendation by people in my social network who have heard good or less good accounts about a specific therapist or care facility.	-3	-4 *
19 The size/scale of the group or care facility.	0	0
20 Information available from various written media (Internet, magazines, newspapers) on a specific treatment, therapist or care facility.	-3	-3
21 The accessibility of the buildings and rooms of the care facility.	0	-1
22 The range of activities provided by the care facility aimed at training brain and body functions.	1	1
23 Information from a medical programme on television about a specific treatment, therapist or care facility.	-4	-2

Choice aspects	Factor		
	1	2	
24 The availability of sufficient staff of a suitable standard.	4	1	*
25 The atmosphere of the buildings and rooms at the care facility.	1	0	
26 The impression of the care facility after a first visit.	0	1	
27 Recommendation by the social worker for a specific therapist or care facility.	-1	-1	
28 The ability to stay together as partners after admission to the care facility.	0	0	
29 The policy of the care facility in relation to end of life issues.	1	-1	*
30 The composition of the group, stage of Alzheimer's comparable with other clients.	0	0	
31 Confidence in the therapist.	1	3	*
32 The burden of the care for partner/children.	0	0	
33 The degree to which the care facility monitors the safety of clients.	2	0	*
34 The limitations I as a client or partner/child experience from the consequences of Alzheimer's.	-2	0	*
35 The attention paid by the care facility to communication with and support for partner/children.	1	2	*
36 The availability of transport to and from the care facility and the supervision of the transport.	-1	-1	
37 Recommendation by fellow sufferers for a specific therapist or care facility.	-3	-2	
38 The ability to have a say in which care is given, how and when.	2	1	*
39 The waiting time from initial contact to actually receiving care.	0	4	*
40 Recommendation for a specific therapist or hospital by people in my social network who work in the medical world	-2	-1	*
41 The travel distance and accessibility of the care facility.	0	-1	*
42 Recommendation by people in my social network who have heard good or less good accounts about a specific therapist or care facility.	-2	-2	
43 The expected outcome of the care (acceptance, reduced and piety, consolation, self-respect).	3	1	*
44 Composition of the group, the personal 'click' with the other clients.	1	0	
45 The personal 'click' with the therapist.	1	3	*
46 Recommendation by my GP for a specific therapist or care facility.	-1	1	*
47 The attention paid by the care facility to the personal care of the client.	3	1	*
48 The continuity of care, whether I am always treated by the same therapist as far as possible.	1	3	*

Note: * distinguishing choice aspect (statistically significant rank scores between factors [$p < .01$]).

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Annex: Search and Selection Behaviour (SSB) scale

In order to discover the extent of search and selection behaviour, we developed the Search and Selection Behaviour (SSB) scale. Respondents were asked to indicate their level of agreement with six statements on a four-point scale (0 meaning completely disagree; 4 meaning totally agree). These statements were:

- 1. It doesn't matter too much to me where and by whom I am treated.*
- 2. I don't want to invest too much time and energy in the choice process.*
- 3. If I need care, I usually go to the therapist/care facility to which my GP or specialist has referred me.*
- 4. If I need care, I usually investigate thoroughly how, where and from whom I will receive the best treatment.*
- 5. I have experience with the health care system and therefore know which therapist or care facility is best for me.*
- 6. I think it's important to weigh possible treatments, therapists and care facilities against each other properly.*

A total of 121 people in the three subgroups assessed the complete set of statements (see Table 2.2). Factor analysis showed that the six statements constitute a scale with one dimension. The first three statements were recoded and the scores for the six items added up to produce a SSB score (possible scores between 0 and 24). A higher SSB score is an indication for more extensive search behaviour in the care choice process. The SSB scale showed high reliability (Cronbach's alpha .67). The average score was 11.4 (95% CI 10.9-11.9; min 4; max 17), suggesting moderate search behaviour. Patients with knee arthrosis had the highest SSB score (12.1), while patients with chronic depression and patients with Alzheimer's disease and/or their representatives both achieved an average SSB score of 11.0. A higher SSB score was associated with a higher education level ($p < .001$) and more limitations from the disease in the case of knee arthrosis ($p < .10$). No correlation was found with age, sex, paid employment or severity of the disease.

Table Annex. 1. Assessment of statements and correlation between statements

Statement	Assessment (%)					Correlation coefficients				
	disagree completely	disagree	agree	agree completely		2	3	4	5	6
1	42	40	12	6	.416**	.229*	-.344**	-.242**	-.245**	
2	33	43	22	2		.119	-.369**	-.083	-.263**	
3	5	26	58	11			-.333**	-.259**	-.283**	
4	2	16	50	32				.266**	.462**	
5	8	36	41	15					.119	
6	2	10	58	30						

Note: Spearman. ** p<.01; * p<.05.

Chapter 6

What influences Patients' Decisions when Choosing a Health Care Provider? Measuring Preferences of Patients with Knee Arthrosis, Chronic Depression or Alzheimer's Disease, using Discrete Choice Experiments⁷

⁷ This chapter is based on a paper that has been submitted for review to British Medical Journal as: Groenewoud, A.S., EA. Stolk, A. Bobinac, N.J.A. van Exel, M. Berg & R. Huijsman. What Influences Patients' Decisions when choosing a Health Care Provider? Measuring Preferences of Patients with Knee Arthrosis, Chronic Depression or Alzheimer's Disease, using Discrete Choice Experiments.

6.1. Introduction

Health care reforms in many countries are aimed at giving a central role to the health care ‘consumer’ (DoH, 2004; Thompson & Dixon, 2006; VWS, 2001) through a focus on patient choice (Appleby et al., 2003; Burge et al., 2005; Steer, 2006), patient empowerment (Wensing, 2000) and decision support (Hibbard et al., 1997). Providing the ‘consumer’ with comparative (quality) information about health care providers is an essential aspect of these attempts. At the root of these efforts is the assumption that patients would act upon this information as critical health care consumers. The evidence base for this assumption is however still weak, which begs the question of whether the resources needed to implement these policies represent money well spent. Recent studies have shown that patients do have an interest in the more technical aspects of quality of care, for example proper high blood pressure care and prescription of medication, and that they would include such information in their decision processes if it were available (Fung et al., 2005; Harris, 2003). These results are however of limited use, as the studies in question simply asked patients to rate or score factors that may influence their choice of provider according to relevance (Cheng & Song, 2004). Results of this nature do not identify trade-offs between factors, and hardly differentiate between factors because many patients find it difficult to prioritise using scales (Devellis, 2006). In addition, most of these studies do not differentiate between patient groups or between individuals within a group of patients (Marshall et al., 2000). What is needed is an approach that reveals the relative importance of factors and actors that influence patients’ decisions and that takes into account the fact that patients’ preferences may change over time and may differ between segments or groups.

The available evidence is not only unconvincing, but the “critical health care consumer” assumption underlying it is also often contested (Marshall et al., 2002; McDonald et al., 2007). The idea that patients do not actively choose providers but just go to the nearest one is widely shared (Salisbury, 1989). At best, patients are seen to be guided by earlier experiences with care providers, their own or those of families and friends (Marshall et al., 2002), or they trust and follow their general practitioner’s advice (Grumbach et al., 1999). In so far as patients are interested in differences between providers at all, they are believed to focus primarily on service and relational quality aspects, which they can observe and judge for themselves (Linder-Pelz, 1982). In this perspective, providing quality information would not empower patients to make better choices (Marshall et al., 2000; Schneider & Lieberman, 2001).

Given these limitations and debates, the present study sought to investigate which actors and factors influence patients' health care decisions, how these preferences differ between and within patient groups, and what the implications are for providing information on the quality of health care providers to patients. To gain a better insight into the relative importance of these aspects of health care for different patients, we conducted discrete choice experiments (DCE) in three patient groups, namely patients with knee arthrosis, chronic depression and Alzheimer's disease⁸. These are high-volume health conditions in most countries, which at the same time represent three typical health care settings for patient decision-making and provider choice.

6.2. Methods

6.2.1. Study sample

Patients with knee arthrosis were recruited in January and February 2007 on the basis of being on a waiting list for knee arthroplasty or osteotomy or having undergone such an operation in 2006. Patients were recruited via the orthopaedic departments of two academic and four general hospitals and via the website and call centre of the Dutch Association of Orthopaedic Patients (SPO). In addition, patients who had participated in the preliminary study (see below) were approached. Paper questionnaires were sent by mail to 806 patients who had indicated their willingness to participate.

Patients with chronic depression were recruited via the Internet. Despite authorisation by the medical ethics committee of our University Hospital, we were not able to include patients via mental health care providers. We therefore worked with an existing Internet panel of Dutch civilians aged 18 years and older who had reported suffering from depression⁹. To confirm this self-reported diagnosis the questionnaire included questions to establish whether a respondent met the DSM-IV-TR-criteria for Dysthymic Disorder, the mildest form of depression. In addition, the severity of the depression was assessed using the Beck Depression Inventory-II scale. (APA, 2000). January 2007 a total of 3,500 panel members were invited by email to participate in the study and to complete the web-based questionnaire.

⁸ The sampling protocols for all three DCEs were authorised by the medical ethical committee of the Erasmus University Medical Centre Rotterdam (EMCR).

⁹ We worked with Survey Sampling International, an international supplier of survey samples.

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Representatives of patients with Alzheimer's disease were recruited in two different ways. First, a number of nursing homes, residential homes for elderly and ambulatory mental health care services were asked to invite their clients to participate in our study. Second, we advertised in a popular weekly magazine for middle-aged women that featured a special issue on Alzheimer's disease in November 2006. A total of 550 representatives expressed their willingness to participate in the study and were sent a paper questionnaire.

6.2.2. Preliminary research

Prior to the current study, the search and selection processes for a health care provider of the above patient groups were investigated in depth. First, we conducted semi-structured interviews with 23 purposefully sampled patients with knee arthrosis, 15 patients with chronic depression and 15 patients with Alzheimer's disease and/or their representatives. Following a grounded theory approach in the phases of both data collection and analysis (Patton, 2002), we derived three long lists of actors and factors that may play a part in the search for and selection of a health care provider. Next, we used Q-methodology (Brown, 1980; Cross, 2005; van Exel & de Graaf, 2005) to identify choice profiles in all three patient groups, based on differences and similarities in the importance these patients attached to a structured sample of the actors and factors identified through the interviews (Groenewoud et al., 2007). A total of 45 patients with knee arthrosis, 44 patients with chronic depression and 41 patients with Alzheimer's disease and/or their representatives participated in this Q-methodological study, from which two main choice profiles among patients emerged: a result-focused and a trust-focused profile, representing different rankings of the actors and factors that influence patients' decision processes. The results of these two preliminary studies supported the current study by giving us a deeper insight into patients' attitudes toward health care choice in general, as well as by generating a pre-selection of actors and factors that patients with different attitudes find important.

6.2.3. Current study: three discrete choice experiments

To explore the relative importance (different groups of) patients attach to the actors and factors that influence health care decisions, we conducted three DCEs in different patient groups. A DCE is a popular method for quantifying consumer preferences for commodities or services by analysing their choices in hypothetical choice situations. The method is based on random utility theory (McFadden, 1974) and Lancaster's economic theory of value (Lancaster, 1966). It is built on the assumptions that health care interventions, services or policies can be described by their characteristics (called attributes), and that a person's valuation depends on the levels of these characteristics (Ryan, 2004; Ryan et al., 2007).

6.2.4. Attributes and levels

Based on the results of preliminary work (see chapter 5), we identified two important components for the development of the attributes. First, the attribute set should cover aspects concerning the structure (accessibility and expertise/competence), process (advice/referral, timeliness, care process and patient-centeredness) and outcome (effectiveness/safety) of health care. In addition, the attribute set should cover characteristics of the health care provider and the health services provided, but also the different actors involved in the decision-making process (i.e. the social context). For example, we defined “*Provider was recommended by...*” as an attribute and “*your general practitioner*” as one of its levels.

The definition of each attribute and its levels varied across disease groups, depending on disease characteristics and the priorities indicated by the patient groups during preliminary work (chapter 5). Using the interview material and the results of the Q-methodological study as a starting point, the authors condensed the set of potential candidate attributes to a manageable set of 10 attributes for the DCEs among patients with knee arthrosis and chronic depression, and 11 attributes for the DCE among representatives of patients with Alzheimer’s. Three levels were defined for each attribute; in ascending order from worst to best. As far as possible the levels were based on real health care performance data - for example, waiting times and risk of infections - in order to present respondents with situations that may have occurred in the ‘real world’. The design was pilot-tested with a selection of the patients who had been interviewed earlier. The three final sets of attributes and levels are presented in Tables 2, 3 and 4.

6.2.5. Experimental design

The potential number of scenarios associated with these numbers of attributes ($3^{10} = 59.049$ for 10 attributes, $3^{11} = 177.147$ for 11 attributes) was reduced to 27 scenarios per DCE by selecting an appropriate orthogonal array using Sloanes’ ‘Library of Orthogonal Arrays’ (Sloane, 2008). Each scenario was paired to an image, following the strategy as outlined by Street et al (2005). and because evaluating 27 scenarios may lead to respondent fatigue (Ubach et al., 2003) they were split into three sets of nine scenarios over three versions of the questionnaire. Each pair of scenarios was presented in forced choice response mode (see example in figure 1). Together with the questionnaire, participants received an explanation of the meaning of each attribute and its levels.

Imagine: You have been given the diagnosis 'knee arthrosis'. You need to go to an orthopaedist in a hospital and you may possibly need surgery. Which of the two health care providers (A or B) would you choose?

Choice situation 1:	A	B
Number of knee operations performed per month	2	8
Provider was recommended by...	Family or friends	A patient organisation
Travel distance to hospital	50 km	150 km
Type of hospital	General	University
Degree of knee-bending	75°	50°
Waiting time	20 weeks	8 weeks
Information is given...	Written, before treatment	Written and oral before treatment
Prior experience with this doctor	Could not get on with him	You have never been there before
Prior experience with this hospital	Not very good	You have never been there before
Wound infections	2,5% or: 1 per 40	5% or: 1 per 20
Based on this information, I would choose provider...	<input type="checkbox"/> A	<input type="checkbox"/> B

Figure 1. A pair of scenarios

6.2.6. Survey section of the questionnaire

In addition to the evaluation of nine DCE scenarios, the questionnaire asked respondents about a number of personal, disease-related and health care-related characteristics that emerged as potentially relevant during the preliminary work. In addition, respondents were presented with statements about making choices in health care, in order to distinguish between people with passive and active choice behaviour, and with short descriptions of the result-focused and trust-focused choice profiles from the Q-methodological study, in order to distinguish between decision-makers with different attitudes (chapter 5).

6.2.7. Analysis

We analysed the discrete choice data by means of a conditional logit (McFadden, 1974), using Stata 9.2. Although Random Parameter Logit models (RPL) are currently the state of the art in DCE analysis, we opted for the conditional logit model because, in combination with the large size of our experiment, it provided us with enough information on patients' preferences to answer our research questions. Given the assumption of compensatory decision-making, individuals were assumed to consider all the attributes in the choice set, and to trade between them. The conditional logit model assumes that an individual i 's utility of making choice j - represented as U_{ij} - is composed of an observable and an unobservable component:

$$(1) \quad U_{ij} = \beta X_{ij} + \varepsilon_{ij}$$

where X_{ij} as the observable stochastic component defined by the vector of choice attributes $J=1, \dots, j$ (and β the vector of attribute parameters to be estimated) and ε_{ij} as the unobservable random error component which captures elements of U_{ij} that are not represented in X_{ij} . Because U_{ij} is unknown, it is assumed that when individual i chooses alternative j , U_{ij} is the maximum of the utilities for all the J alternatives and the probability that alternative j will be chosen is:

$$(2) \quad \pi_{ij} = \Pr(Y_i = j | I) = \Pr(U_{ij} > U_{ij'})$$

Separate models were specified for each of the three disease groups as well as for sub-groups with divergent characteristics within each disease group. In the results section we compare the sign and the magnitude of coefficients *within* the three disease group models. It is not possible to compare the magnitude of coefficient estimates *between* the main models directly because the stochastic component of utility has different variances in the these models (Hensher et al., 2005).

To make comparison of attribute preferences *between* disease groups possible we expressed the strength of each attribute in terms of waiting time, a common attribute in all models. These marginal rates of substitution (MRS) can be interpreted as a proxy for welfare obtained from different options, since intuitively it makes sense that people may be willing to accept longer waiting times in return for better care. Nevertheless, the MRS should also be compared with caution because the levels of attributes (including waiting time) differ between the models (Schulpher et al., 2004) (see Tables

2-4) and because waiting for care may not be equally acceptable for different disease groups and for different types of care. Comparisons of the attribute preferences between disease groups will therefore be made on the basis of a ranking of MRS, which has also been done in earlier studies.

To explore preference heterogeneity *within* and *across* disease groups we defined sub-groups based on personal, disease-related and health care-related characteristics of respondents and compared preference structures between these sub-groups by plotting their estimated coefficients against each other. This has proven to be a very convenient method to detect differences in attribute strengths between sub-groups (Hall et al., 2006). The null hypothesis that the estimated coefficients were all the same was tested using Fishers's Z-Test (Bernstein et al., 1988); a method that is not yet widespread in health care, but that is regularly applied in psychology studies (Wünsch et al., 2002).

6.3. Results

Completed questionnaires were returned by 616 patients with knee arthrosis (76%), 368 patients with chronic depression and 421 representatives of patients with Alzheimer's disease (77%). As regards the patients with chronic depression, 1,626 of the 3,500 persons who were invited to participate began the questionnaire; 449 of them met the DSM-IV-TR-criteria for Dysthymic Disorder; 368 persons completed the questionnaire (82% of the target group). Table 1 presents the personal, disease-related, and health care-related characteristics of the three samples.

6.3.1. Three disease group models

In the 'knee arthrosis model' (see Table 2), all statistically significant coefficients showed positive signs, indicating that, as presumed, higher levels of attributes were preferred over lower levels. The expected outcome of the operation (represented by the indicator "average before-after degree of bending of the knees that were operated on by a surgeon") had the strongest impact on the search and selection process of patients with knee arthrosis, followed by a good prior experience with the hospital and a personal match with the medical specialist during earlier contact. Travel distance, risk of wound infection and referral by GP were also influential factors, while waiting time was of least importance. Some other attributes and levels, like the type of hospital and the provision of information before treatment, played no part in patients' decisions.

Table 1. Sample characteristics

Characteristic	Knee arthrosis	Chronic depression	Alzheimer's disease
Personal			
Gender			
- Male	229/609 (38)	83/368 (23)	78/421 (19)
- Female	380/609 (62)	285/368 (77)	343/421 (81)
Mean (SD) age (years)	66 (10.5)	41 (10.9)	57 (10.1)
Education level			
- Low	407/607 (67)	72/368 (19.5)	157/406 (39)
- Middle	106/607 (18)	219/368 (60)	136/406 (33)
- High	94/607 (15)	77/368 (19.5)	113/406 (28)
Urbanisation			
- City	189/606 (31)	245/368 (67)	262/418 (63)
- Countryside	417/606 (69)	123/368 (33)	156/418 (37)
Disease-related			
Mean (SD) disease severity (0-10)	4.4 (2.9) pain 5.1 (2.8) limitation	6.2 (2.0) ^a	7.0 (2.0)
Mean (SD) perceived health (0-10)	7.1 (1.3)	4.5 (1.6)	7.6 (1.4)
Mean (SD) period of complaints (years)	12.5 (12.1)	14.6 (9.5)	7.1 (5.1)
Health care-related			
Choice attitude			
- Result-focused	480/598 (80)	58/368 (16)	357/416 (86)
- Trust-focused	118/598 (20)	310/368 (84)	59/416 (14)
Choice behaviour			
- Passive	428/609 (70)	194/368 (53)	132/421 (31)
- Active	181/609 (30)	174/368 (47)	289/421 (69)
Member of patient organisation			
- Yes	31/595 (5)	54/368 (15)	73/419 (17)
- No	564/595 (95)	314/368 (85)	346/419 (83)
Type of current/most recent care ^b	484/596 (81) GH 86/596 (14) UH 13/596 (2.5) OC 13/596 (2.5) Other ^c	186/368 (51) Am 107/368 (29) Psych 81/368 (22) GP 25/368 (7) PH 80/368 (22) Other ^d	111/421 (26) Am 238/421 (57) In 71/421 (17) Cd ^e
Type of treatment	Underwent TKP / Osth 403/616 (65) Yes 213/616 (35) No	-	-

^a Scores on Beck Depression Inventory-II scale: 0 (not depressed): 14/368 (3.8%); 1 (mildly depressed): 78/338 (21.2%);

2 (modestly depressed): 47/368 (12.8%); 3 (seriously depressed): 142/368 (38.6%); 4 (very seriously depressed): 87/368 (23.6%).^b More than one option could be selected.

^c GH: General Hospital; UH: University Hospital; OC: Orthopaedic Hospital. ^d Am: Ambulatory mental care facility; Psych: independent psychologist or psychiatrist; GP: General Practitioner; PH: psychiatric hospital. ^e Am: Ambulatory care facility; In: Institutional care facility; Cd: Client has died.

Table 2. Main model: knee arthrosis

Quality domain	Attributes and levels	β	SE	95% CI	MRS ^a	Rank ^b
Accessibility	Travel distance (km): 150, 50, 10	0.3799*	0.0281	0.3249 to 0.4350	7.31	4
Expertise / competence	# knee operations per month: 2, 8, 10	0.1053*	0.0251	0.0561 to 0.1544	2.02	9
	Type of hospital:					
	general	-0.062	0.0492	-0.1585 to 0.0343	-	-
	university	0.0597	0.0495	-0.0374 to 0.1567	-	-
Advice and referral	Provider recommended by...:					
	family or friends					
	patient organisation	0.0137	0.0492	-0.0827 to 0.1100	-	-
	general practitioner	0.1880*	0.0497	0.0906 to 0.2854	3.62	6
Timeliness	Waiting time (weeks): 20, 8, 2	0.0520*	0.0248	0.0034 to 0.1006	1	10
Care process	Information is given to you...:					
	before treatment, written					
	before treatment, written and oral	0.0908	0.0506	-0.0084 to 0.1900	-	-
	continuously, written and oral	0.1382*	0.0500	0.0402 to 0.2361	2.66	8
Patient-centeredness	Prior experience with hospital:					
	not very good					
	never been there before	0.1637*	0.0512	0.0633 to 0.2641	3.15	7
	good	0.6382*	0.0562	0.5280 to 0.7483	12.27	2
	Prior experience with medical specialist:					
	did not match very well					
	never been there before	0.0610	0.0568	-0.0503 to 0.1722	-	-
	matched well	0.3808*	0.0486	0.2855 to 0.4761	7.32	3
Effectiveness / Safety	Average before-after degree of knee-bending: 30°, 90°, 120°	0.7470*	0.0284	0.6912 to 0.8027	14.37	1
	Risk of wound infections (%): 5, 2½, 1	0.2677*	0.0243	0.2199 to 0.3154	5.15	5

* $p < 0.05$; ^a MRS = Marginal rate of substitution with waiting time, defined as β of specific attribute divided by β of waiting time; ^b Relative ranking of attribute based on MRS.

In the 'chronic depression model' (see Table 3) continuity of care, personal match with the therapist during earlier contact, the possibility to have a say in the care process and a matching vision on treatment were considered most relevant in the choice of health care provider; waiting time was among the least relevant factors. The coefficients for the levels 'medical doctor' and 'no good relationship during earlier contact' showed negative signs, indicating that patients preferred the preceding levels 'social-psychiatric nurse' and 'no relationship yet', respectively, which is a plausible result. In this model, all attributes turned out to be relevant in the choice of health care provider, but not all attribute levels.

Table 3. Main model: chronic depression

Quality domain	Attributes and levels	β	SE	95% CI	MRS ^a	Rank ^b
Accessibility Expertise / competence	Costs per consultation (): 80, 15, 0	0.4468*	0.0327	0.3827 to 0.5108	1.92	7
	Expertise, experience, specialisation:					
	Social-psychiatric nurse					
	Medical doctor	-0.2034*	0.0658	-0.3324 to -	0.87	12
	Psychiatrist	0.1308*	0.0616	0.0744 0.0100 to 0.2516	0.56	14
	Vision on treatment:					
	No clear vision					
	Vision does not match with client	-0.1124	0.059	-0.2290 to 0.0043	-	-
	Vision matches with client	0.5379*	0.0614	0.4174 to 0.6583	2.31	5
Timeliness	Waiting time (weeks): 24, 12, 2 to 3	0.2331*	0.0315	0.1714 to 0.2947	1	11
Care process	Intake and care plan:					
	Limited intake, no care plan					
	Extensive intake, no clear care plan	0.0556	0.0641	-0.0670 to 0.1811	-	-
	Extensive intake with clear care plan	0.3377*	0.0598	0.2206 to 0.4548	1.45	8

Patient-centeredness	Percentage of clients satisfied with <i>interpersonal: treatment: 25, 50, 80</i>	0.2033*	0.0320	0.1407 to 0.2660	0.87	13
	Relationship with therapist:					
	No contact before; no relationship yet	-0.6646*	0.0633	-0.7887 to -0.5404	-2.85	3
	Prior contact; not a very good relationship	0.2546*	0.0624	0.1323 to 0.3768	1.09	10
	Prior contact; good relationship	0.7015*	0.0634		3.01	2
	Continuity of care:	0.8045*	0.0632	0.5773 to 0.8257	3.45	1
	Change in treating professional			0.6807 to 0.9283		
	Fixed team of professionals					
	Always same professional	0.5292*	0.0618		2.27	6
	Participation:	0.6209*	0.0642	0.4080 to 0.6503	2.66	4
	Hardly any possibilities for participation			0.4950 to 0.7468		
	Participation; professional in control					
	Participation; client in control					
Effectiveness / Safety	<i>Expected result: percentage of people reporting good results: 20, 50, 80</i>	0.2873*	0.0310	0.2264 to 0.3482	1.23	9

* $p < 0.05$; * MRS = Marginal rate of substitution with waiting time, defined as β of specific attribute divided by β of waiting time; [‡] Relative ranking of attribute based on MRS.

In the 'Alzheimer's model' (see Table 4) caregiver expertise, travel distance and care delivery in accordance with agreements were the most important factors in the choice of care provider by representatives of patients with Alzheimer's disease. Waiting time was again the least important. All attributes were relevant for the search and selection process and all coefficients showed positive signs.

Table 4. Main model: Alzheimer's disease

Quality domain	Attributes and levels	β	SE	95% CI	MRS ^a	Rank ^b
Accessibility Expertise / competence	Travel distance (km): 60, 20, 5	0.5345*	0.0313	0.4732 to 0.5959	3.62	3
	Expertise of the institution regarding Alzheimer's disease:					
	- Not specialised					
	- A specialised ward/unit	0.5412*	0.0608	0.4221 to 0.6603	3.67	2
	- Institution is specialised	0.6432*	0.0567	0.5320 to 0.7544	4.36	1
Advice and referral	Provider recommended by...:					
	- No one in particular					
	- Family or friends	0.0171	0.0593	-0.0991 to 0.1334	-	-
	- GP or medical specialist	0.1640*	0.0602	0.0460 to 0.2819	1.11	10
Timeliness	Waiting time (months): 12, 8, 4	0.1476*	0.0291	0.0905 to 0.2047	1	11
Care process	# hours of personal care / week: 4, 10, 16	0.3789*	0.0279	0.3241 to 0.4336	2.57	6
Patient- centeredness	Percentage of residents experiencing good <i>interpersonal treatment</i> : 25, 50, 75	0.3362*	0.0299	0.2775 to 0.3948	2.28	7
	Percentage of representatives satisfied with <i>communication</i> with staff: 50, 70, 90	0.1025*	0.0296	0.0446 to 0.1605	0.69	12
Effectiveness / Safety	Percentage of residents <i>feeling safe and comfortable</i> : 50, 70, 90	0.4447*	0.0301	0.3856 to 0.5038	3.01	5
	Risk of <i>pressure ulcers</i> (%): 20, 10, 2	0.2569*	0.0274	0.2031 to 0.3106	1.74	9
	# personnel per 15 residents: 1, 2, 3	0.2979*	0.0290	0.2411 to 0.3547	2.02	8
	Deliver care as agreed:					
	- seldom	0.1041	0.0591	-0.0118 to 0.2200	-	-
- sometimes	0.5089*	0.0585	0.3941 to 0.6235	3.45	4	
	- always					

* $p < 0.05$; ^a MRS = Marginal rate of substitution with waiting time, defined as β of specific attribute divided by β of waiting time; ^b Relative ranking of attribute based on MRS.

6.3.2. Differences and similarities between disease group models

The marginal rates of substitution (MRS) between waiting time and other attributes (see second-last column in Tables 2-4) provide an indication of how much waiting time (in weeks) people were willing to trade off for an improvement in one of the other attributes (by one level). For example, patients with knee arthrosis who needed help from an orthopaedist in a hospital (and possibly surgery) were willing to wait extra for an orthopaedic surgeon with more experience: two additional weeks for a surgeon performing eight rather than two operations per month, or 20 rather than eight.

When looking at the ranking of attributes by their marginal rate of substitution over waiting time (see last column in Tables 2-4), it becomes clear that patients with knee arthrosis were more influenced by the expected effectiveness and safety of a treatment than those who are depressed or represent patients with Alzheimer's disease. Patient-centeredness appeared decisive in the search and selection process of patients with chronic depression but was of much less importance for representatives of patients with Alzheimer's disease, who focused much more on the expertise and competence of the care provider. These differences largely corresponded with the percentages of patients who qualified themselves as 'result-focused' or 'trust-focused' (see Table 1). A striking similarity was the small impact overall of both the waiting time and the advice and referral attributes.

6.3.3. Differences and similarities within and across disease groups

Preferences concerning attributes not only differed between disease groups but also between sub-groups of patients *within* and *across* disease groups. Figure 2 shows scatter plots of the estimated coefficients for sub-groups based on 'choice attitude', 'stage of disease' and 'education level'. If the preferences of sub-groups were identical, the dots would all be on the diagonal; i.e. the coefficient would be identical for people in each sub-group. The nine plots show that in general the preferences between sub-groups were fairly similar. There are however two noticeable types of difference. First, there are coefficients that have a positive sign in one sub-group and a negative sign in another (e.g. dots 6 and 25). Second, there are coefficients that have the same sign in both sub-groups but show considerable and statistically significant differences in size between sub-groups (e.g. dots 1 and 3; see Table 5).

Patients with a result-driven *choice attitude* attached more importance to the expected outcome of a treatment or stay (dots 1, 9, 10; see Figure 2 & Table 5), the possibility to participate in decisions during treatment (5) and the expertise/competence of the provider (6, 7) than those who were driven by trust in their doctor. In addition, result-focused representatives of patients with Alzheimer's disease were more likely to travel a longer distance to find such a facility (8). Patients with a trust-focused search and selection process were much more influenced by good prior experience with a doctor (2), continuity of care (3, 4) and advice from family or friends (11). Higher *severity of disease* (used here as a proxy for a more advanced *phase of the disease*) was associated with higher weight for the interpersonal relationship with the health care provider (13, 14, 15) and advice from family or friends (19), and lower weight for the expected outcome of a treatment (12, 17, 18), travel distance (16) and advice from their GP (20). Finally, a higher *education level* was associated with higher weight for outcomes (21, 22, 31, 32, 33), care provider expertise (23, 27, 30), good prior experience with the hospital or doctor (24, 25), and care delivery according to agreements (31, 32), but less to advice from their GP (34). Furthermore, highly educated patients with chronic depression attached more importance to the therapist's vision on treatment (26) and patient participation during treatment (28, 29); similar relationships were found for representatives of patients with Alzheimer's disease.

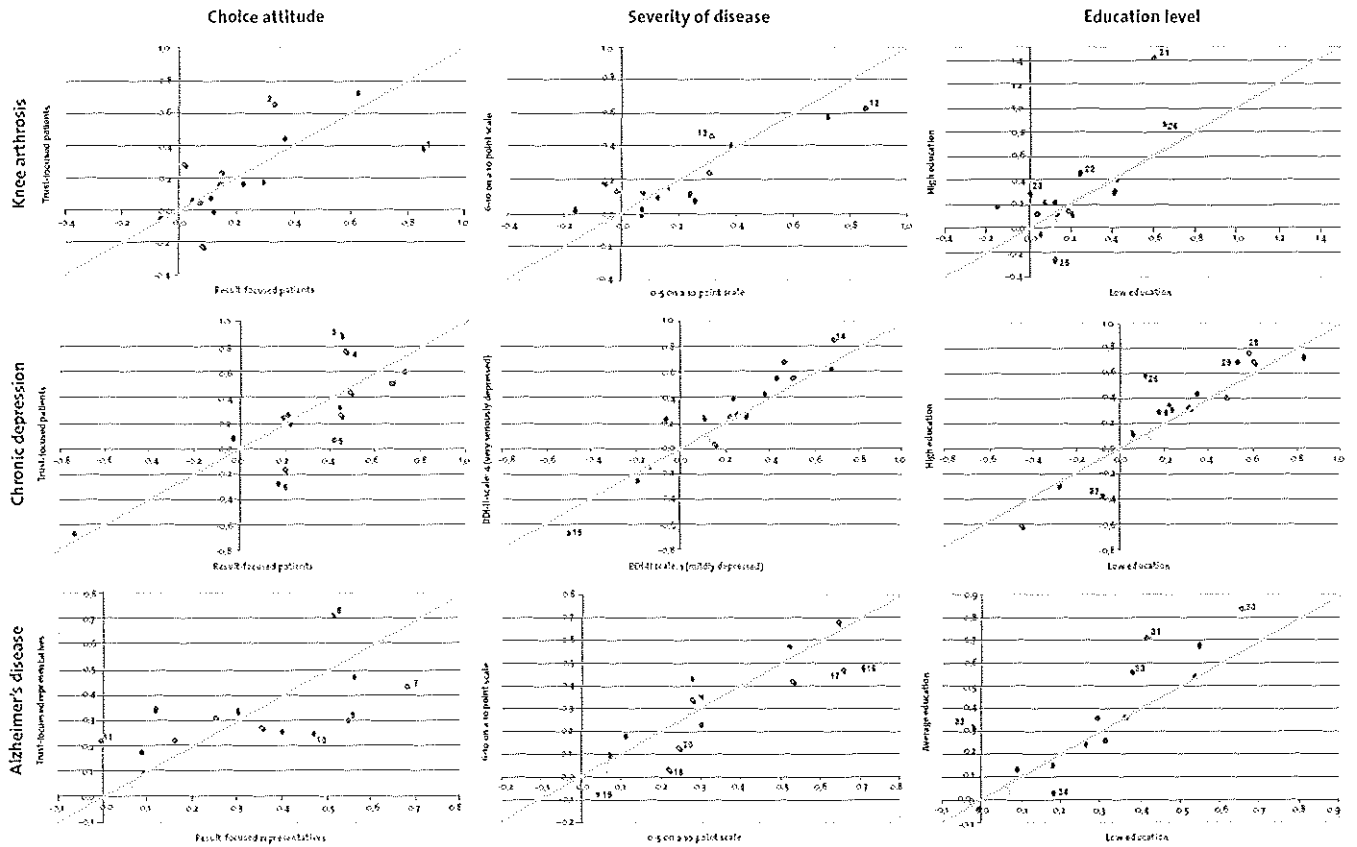


Figure 2. Differences and similarities between sub-groups (numbers correspond to Table 5 and text)

Table 5. Differences between sub-groups (numbers correspond to Figure 2 and text)

Attributes		Choice attitude	Severity of disease	Education level	
Knee arthrosis	Travel distance	-3.405*	-1.034	0.449	
	# knee operations per month	1.296	1.457	-4.995*	
	Type of hospital	- university	-0.554	-8.678*	-11.964*
		- orthopaedic	0.946	-6.926*	-10.257*
	Recommended by...	- patient organisation	11.787*	3.803*	-3.076*
		- general practitioner	2.414	5.986*	0.721
	Waiting time (weeks)		-0.517	2.025	-2.042
	Information given	- before, written, oral	4.736*	2.299	0.306
		- continuous, written, oral	-0.532	0.491	-3.573*
	Prior experience with hospital	- never been there before	-3.484*	9.029*	2.125
		- good	-7.703*	11.106*	-18.616*
	Prior experience with specialist	- never been there before	-10.080*	-11.540*	13.985*
		- matched well	-16.396*	-8.257*	3.953*
Degree of knee-bending		32.282*	25.114*	-∞*	
Risk of wound infections		4.764*	3.414*	-8.724*	

23

13

24

25

2

1

21

22

Chronic depression

<i>Costs per consultation</i>				1.886		-1.944		2.918*	
<i>Expertise, specialisation</i>	- medical doctor			13.454*	6	1.826		8.088*	27
	- psychiatrist			10.988*	5	-8.082*		-3.287*	
<i>Vision on treatment client</i>	- vision does not match with client			11.274*		0.198		0.582	
	- vision matches with client			6.774*		-2.023		-14.117*	26
<i>Waiting time</i>				-1.869		-0.091		-0.141	
<i>Intake and care plan</i>	- extensive intake, no care plan			-3.314*		3.548*		-1.718	
	- extensive intake, clear care plan			3.896*		-0.383		-2.709*	
<i>Interpersonal treatment</i>				0.700		-3.743*		-2.182	
<i>Relationship with therapist</i>	- prior contact; no good relationship			-3.649*		6.996*	15	6.442*	
	- prior contact; good relationship			-1.742	4	-4.781*		-2.242	
					3		14		
<i>Continuity of care</i>	- fixed team of professionals			-14.386*		2.374		-3.114*	29
	- always same professional			-27.699*		-11.575*		7.613*	28
<i>Participation control</i>	- participation; professional in control			7.581*		-4.546*		-6.701*	
	- participation; client in control			6.613*		-8.772*		-8.114*	

Alzheimer's disease

<i>Expected result</i>				6.327*		1.109		-3.627*	
<i>Travel distance</i>				-9.305*		13.447*	16	-0.220	
<i>Expertise institution</i>	- a specialised ward/unit			3.531*		-2.700*		-7.560*	
	- institution is specialised			10.701*	7	-1.790		-15.957*	30
<i>Provider recommended by...</i>	- family or friends			-6.608*	11	4.468*	19	1.238	
	- GP or medical specialist			-1.728		4.690*	20	5.524*	34
<i>Waiting time</i>				-6.893*		-2.609*		0.944	
<i># hours personal care / week</i>				4.675*		-6.774*		0.075	
<i>Interpersonal treatment</i>				2.783*		-2.218		-2.842*	
<i>Communication with staff</i>				-2.511		-0.838		-1.581	
<i>Feeling safe and comfortable</i>				7.503*	10	5.612*		-8.481*	33
<i>Risk of pressure ulcers</i>				-1.693		2.844*		0.798	
<i># personnel per 15 residents</i>				-1.001		-2.324		1.894	
<i>Deliver care as agreed</i>	- sometimes			-0.122		7.437*	18	-12.628*	32
	- always			8.815*	9	10.634*	17	-15.947*	31

* p<0.01 (Fisher's Z-test)

6.4. Discussion

This study sought to investigate which actors and factors influence patients' health care decisions, how these preferences differ between and within patient groups, and what the implications are for providing information on the quality of health care providers to patients. We found that patients' preferences were conditional upon the type of disease, the individual's choice attitude (result-driven or trust-driven), phase or severity of the disease, and some background characteristics such as education level. Some sub-groups of patients attached more importance to measures of outcome, others to measures of process or (infra)structure. This supports findings from earlier studies indicating that both interpersonal and technical quality play a part in patients' search and selection processes (Fung et al., 2005; Harris, 2003). Factors such as advice from family or friends, referral by a general practitioner, waiting time or information during treatment, which have been claimed to be dominant *if* patients were to choose at all (Burge et al., 2005; Grumbach et al., 1999; Marshall et al., 2000), were however found to have much less or even no influence. Finally, these findings suggest that a proportion of patients will benefit from comparative quality information about care providers. We think these results are relevant for policymakers and organisations in the health care sector which are interested in patient preferences in the process of searching for and selecting a care provider, for example because they are involved in developing patient information or quality report cards, or because they purchase or supply health services and want these to be demand-led.

Given *a priori* expectations, the results were plausible and support the theoretical validity of the techniques applied. Nevertheless, there are some limitations to this study that need to be discussed. First, we used forced choice to elicit preferences. This means that respondents had no opt-out option, i.e. the possibility not to choose any provider at all. Although this may be realistic for people needing care - no treatment is not a real option - it may not be realistic in all cases. We believe, however, that by adding the attributes 'advice/referral', 'travel distance' and 'earlier experience', the model offered people the opportunity to behave as (in)actively as they preferred. The relatively low impact of these attributes showed that very few people did not want to choose at all. Second, we used a relatively large number of attributes (10 and 11). This is not uncommon but some have claimed that people can only handle a limited amount of information at a time and therefore recommend a maximum of between five and nine attributes (AHRQ, 2007; Hochhauser, 1998). The

selection of attributes always involves a trade-off between realism – which often demands more attributes and levels - and feasibility for respondents – which usually demands that the number of attributes and levels be limited. Given the response rates in all three disease groups, we do not believe that the number of attributes posed serious problems to respondents. Moreover, the attributes were selected on the basis of extensive preliminary research involving consultation with the target population (see chapter 5), which we regard as a clear strength of this study and which may have contributed to greater realism and appeal of the choice sets to respondents. Third, this study focused on main effects only and thus disregarded possible interaction effects between attributes. Addressing such interdependencies would have required a much larger set of scenarios (or a smaller number of attributes) to be evaluated by respondents, and would have left too little statistical power to identify differences between (sub-)groups of patients, which was one of the primary purposes of the study. Fourth, the sampling strategy may have implications for the ability to generalise results. Women seem to be overrepresented in our sample. However, prevalence data show that far more women than men suffer from knee arthrosis or chronic depression, and it is a well-known phenomenon that informal care for patients with Alzheimer's disease is mostly given by women (especially wives and daughters) (Max et al., 1995). Furthermore, the use of an Internet panel to recruit patients with chronic depression might have biased the sample towards more assertive decision-makers within this disease group. This means that in institutional care settings (which we were not able to include) the group of dependent, passive patients might be larger than in our sample, even though the latter contained a significant group of severely depressed patients. On the other hand, the number of people who regularly use the Internet is growing fast, and future consumer information will mainly be disseminated through this medium. We therefore believe that our conclusions can be maintained for the potential target group of consumer information in the field of depression care. Finally, despite the assertion that Discrete Choice Experimentation “*is likely to be somewhat deficient when judged against its stated aim of eliciting consumer preferences in healthcare contexts*” (McDonald et al., 2007) because “*it does not embed patients' decisions in their social context, but focuses on rational trade-offs, based on 'product-characteristics' in a laboratory-setting*” (Light & Hughes, 2001), DCEs have generally been shown to be reliable and valid (Ryan & Gerard, 2003). Besides, the current situation in Dutch health care provides no opportunities to study the (potential) role of consumer information in patients' *revealed* choices, even if we had preferred to do so. Such a study would only be possible in the hypothetical situation where there are no shortages in the provision of health care and where

patients have sufficient accessible, reliable and understandable information at their disposal, which is not yet the case in the Netherlands. In addition, simulating patients' choices gives control over the experimental design, which not only ensures statistical robustness (Ubach et al., 2003) but also makes it possible to simulate a situation with understandable quality information about care providers across a broad spectrum of aspects.

Notwithstanding these limitations, our findings clearly suggest that publicly disclosed comparative quality information on health care providers will empower patients to fulfil their role of critical consumers in a competitive health care environment. Consumer information will however only contribute to patient empowerment if it is made disease-specific and sensitive to patients' choice attitude and the severity of their disease, and differentiates for important background characteristics such as education level. This is in line with earlier findings indicating that although there is no such thing as *the* patient in this context, there is a diversity of choice profiles which emerges when searching for and selecting a health care provider (see also chapter 5). We therefore argue that the development of effective consumer information requires a tailor-made approach in order to provide groups of patients with convenient and relevant comparative quality information about care providers.

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**Developing Consumer Information:
a Methodology**

Chapter 7

Building Quality Report Cards for Geriatric Care in The Netherlands: using Concept Mapping to identify the appropriate ‘Building Blocks’ from the Consumer’s Perspective¹⁰

¹⁰ This chapter is based on the following article: A. Stef Groenewoud, N. Job A. van Exel, Marc Berg and Robbert Huijsman, 2008. Building Quality Report Cards for Geriatric Care in The Netherlands: Using Concept Mapping to Identify the Appropriate “Building Blocks” From the Consumer’s Perspective. *The Gerontologist* 48:79-92 (2008)

7.1. Introduction

On 1 January 2006 a new Health Care Insurance Act came into effect in the Netherlands. This Act gives the Dutch health care system many features of the American system of Preferred Provider Organizations (PPOs). Citizens now choose their own health care insurer and, if they need care, their own provider. Insurers bid for the public's favor by selectively contracting the best-performing providers (in terms of costs and quality) and offering clients a wider range of insurance and care options. The purpose is to increase competition between health care providers and thus raise quality while constraining costs (Schut & Van de Ven, 2005). Notwithstanding the debate about the benefits and desirability of such a system, most parties agree that its adequate functioning depends on reliable and accessible comparative consumer information on the quality of health care insurers and providers. Information asymmetry is recognized as one of the main deficiencies of the health care 'market' (Arrow, 1963). Therefore, the Dutch Ministry of Health, Welfare and Sport (VWS) has launched the 'Choosing in Health Care' program, which aims to develop quality report cards for insurers, hospitals, providers of mental health care, care for the disabled and geriatric care (defined here as home care, homes for the elderly and nursing homes).

7.2. Current approaches and their problems

The key question when developing a quality report card is what information it should contain, i.e. what the appropriate 'building blocks' are. The literature describes several approaches to developing quality report cards (see e.g. Harrington, O'Meara, Kitchener, Payne Simon & Schnelle, 2003; Mattke, Reilly, Martinez-Vidal, McLean & Gifford, 2003). In the US, for example, preliminary versions of the Centers for Medicare and Medicaid Services (CMS) Nursing Home Compare website (the largest and most well-defined nursing home report card in the United States) were mainly based on the work of researchers at the University of Wisconsin's Center for Health Systems Research and Analysis (CHSRA). They developed a set of nursing home quality indicators from existing items in the Minimum Data Set (MDS); a set of 15 clinical outcome indicators such as

¹¹ In this paper we use "building blocks", "quality themes" and "quality domains" as synonyms. "Building blocks" (such as "ambience and privacy in a nursing home") can be subdivided into quality aspects ("feeling at home" for example) that can be measured by quality indicators ("percentage of clients that say they feel at home when they are asked for").

pressure ulcers and weight loss (Zimmerman et al., 1995; Berg et al., 2002; CMS, 2005). Another way of developing a report card is to look at existing cards (in other countries) (Castle & Lowe, 2005), or ask the public what they want to know about health care quality (Hibbard & Jewett, 1996). Other techniques include Delphi techniques (Normand, McNeil, Peterson & Palmer, 1998), storytelling methodology (Sofaer, Gruman, Connaughton, Grier & Maule, 2000) and the Balanced Scorecard approach (Hall, Doran, Laschinger, Mallette, Pedersen, O'Brien-Pallas, 2003).

All these methods share the same two problems, however. First there is the 'trichotomy' between the quality report card's *technical validity* (do the indicators measure what they are supposed to measure?), its *appropriateness* (does it contain the information consumers need and want?) and its *feasibility* (are measurable data available?). Selecting indicators from the literature, from carefully chosen existing quality report cards or on the basis of expert opinion may guarantee validity and technical adequacy, but will not necessarily fit with consumers' perspectives. On the other hand, giving consumers 'carte blanche' when building a quality report card might lead to a rather utopian set of indicators that is hard to measure or goes beyond common and feasible health policy objectives, and therefore constitutes an undesirable incentive mechanism.

Berg et al. (2005) stress the importance of feasibility of public performance data. They argue that feasibility is the most important prerequisite for public reporting, more than *perfect* technical validity of the indicators, say. The appropriateness dilemma is well illustrated in studies by Arling, Kane, Lewis & Mueller (2005), Castle & Lowe (2005) and Harrington et al. (2003). Arling et al. (2005) critically evaluate nursing home quality indicators used in the United States for measuring and comparing nursing homes, including the CMS' Nursing Home Compare indicators. One of their conclusions is that quality indicator reporting systems should be tailored to specific stakeholder needs, for example to consumers. The second study examined nursing home report cards in 19 US states, and found that the information presented differed substantially. Castle and Lowe (2005) concluded that this variation in types of information, caused by the specific needs of regulators, provider organizations and consumer groups, imposes a considerable limitation on current quality report cards, as it creates a situation where few elderly people are capable of judging report card information. Based on a literature review, Harrington et al. (2003) present a rationale and a framework for presenting comprehensive consumer information on nursing homes through report cards. They find six key information areas: (1) facility characteristics and ownership; (2) resident characteristics; (3) staffing indicators; (4) clinical quality indicators; (5)

deficiencies, complaints and enforcement actions; and (6) financial indicators. Their claim that all these areas are important in informing consumers fully was however not substantiated by testing their findings against consumer preferences.

The second problem with current approaches is the dichotomy between the *'ivory tower strategy'* versus the *'consensus strategy'*. Some report cards are developed by one or a very limited number of parties. These report cards often lack consensus and support, and are consequently rarely fully implemented or have a short lifespan. Castle and Lowe (2005) warn that their 'cross-section' of 19 report cards is based on the opinion of only one research team and that their results should be presented to consumers before any conclusions can be drawn regarding their appropriateness. Other report cards are developed jointly by regulators, providers, insurers and consumers. Such a consensus process usually leads to a greater diversity of information, making it much more difficult for users to understand the information provided, make trade-offs between information items, use the information to prioritize provider organizations, and come to a well-considered decision (Jewett & Hibbard, 1996). In the United States, this problem is well illustrated by the CMS' Nursing Home Compare website, probably the best known example of a consensus-seeking report card development process. From 2002-2004, the National Quality Forum (NQF), developed 16 performance measures that "facilitate standardized comparison of the quality of nursing homes. These quality measures were carefully reviewed and endorsed by a diverse group of stakeholders: consumer and patient groups, health care purchasers, health care providers and health plans, research and quality improvement organizations" (NQF, 2004, p. E1). However, despite the thoroughness of the consensus process, evaluations of the Nursing Home Compare initiative report several problems, including the appropriateness of the indicators for consumers, as well as failure to identify key conceptual dimensions and to aggregate indicators into general categories or domains, which would make it easier for consumers to understand information (Arling, et al., 2005; United States General Accounting Office (GAO), 2002).

What is needed, apparently, is a method for developing quality report cards that strikes a balance between validity, appropriateness and feasibility of content, whilst generating sufficient consensus and support in the development process. In this paper we present an approach to meet this challenge, which was recently developed and applied in the Netherlands.

Objectives

This paper reports on a study conducted to identify the appropriate building blocks for quality report cards for geriatric care from the consumer's perspective, and aims to describe the results of the study - the building blocks - plus the innovative step-by-step approach developed to arrive

at these results. The paper ends with a discussion of the results and methodology, plus some suggestions for future quality report card initiatives and applications of the method.

7.3. Methods

After studying various earlier methods for developing quality report cards and performance indicators and potential innovative approaches (Harrington et al., 2003; Castle & Lowe, 2005; Hibbard & Jewett, 1996; Normand et al., 1998; NQF, 2004; Sofaer et al., 2000; Hall et al., 2003), the authors selected Concept Mapping as the most promising approach for building a feasible and valid quality report card from a consumer's perspective, based on consensus between the main actors in the field.

Concept Mapping was first introduced in 1989 by William Trochim as 'a type of structured conceptualization which can be used by groups to develop a conceptual framework which can guide evaluation or planning' (Trochim, 1989; Trochim & Kane, 2005). Over the last 15 years, Concept Mapping has also been used in areas other than evaluation and planning, e.g. for defining and assessing quality of care (Trochim & Kane, 2005). Concept Mapping can take various forms, such as 'Idea Mapping', 'Mind Mapping', 'Causal Mapping' or 'Cognitive Mapping' (Trochim & Kane, 2005). Here we focus on the form used in the Trochim & Kane study, 'Structured Conceptualization'. This is a mixed-method, participatory, group idea-mapping methodology that integrates well-known group processes such as brainstorming (Bowling, 2002) and unstructured sorting (Weller & Romney, 1988; Coxon, 1999) with a sequence of multivariate statistical methods. From this point forward the term 'Concept Mapping' will be used.

In its most extensive form, Concept Mapping comprises six steps (Trochim & Kane, 2005). The *preparation step* (1) identifies the focus for the mapping project, participants are selected and the project schedule and logistics are determined. The *generation of ideas and statements* (2) often involves some form of brainstorming, and the ideas generated are synthesized into statements. Participants then *sort* the statements and *rate* them (3) according to one or more variables (e.g. importance, feasibility). Multivariate statistical analyses of multidimensional scaling (Davison, 1992; Kruskal & Wish, 1978) and hierarchical cluster analysis (Anderberg, 1973; Everitt, Landau & Leese, 2001) are used for the *representation of the ideas in maps* (4). Next, participants are

involved in the *interpretation* (5) of these maps. Finally, in the *utilization phase* (6), the maps and all associated information are used to define the concepts (e.g. quality themes or purposes of a project).

Table 1 summarizes the Concept Mapping procedure as used in this study, i.e. identifying the appropriate 'building blocks' for quality report cards for geriatric care from the consumer's perspective.

7.4. Results

7.4.1. *Existing quality information about geriatric care*

22 sources for existing quality information were found during the first part of the study; 10 relating to home care (providers) and 12 focusing on institutional care. A list of more than 750 quality aspects, criteria and indicators was retrieved from these sources; over 350 for home care and more than 400 for institutional care. A first review of these quality aspects, criteria and indicators and the underlying themes revealed such dissimilarities that it proved more appropriate to work towards two more focused quality report cards, one for home care and one for institutional care, rather than striving for a single comprehensive quality report card for geriatric care. Analysis of the 22 sources of quality information also showed that only four of them can effectively be used to supplement report card data: two consumer satisfaction instruments and two instruments from the Dutch Health Care Inspectorate. Other sources are not publicly accessible or do not generate data frequently enough to enable report cards to be based on them.

7.4.2. *Ideas and statements*

The Concept Mapping process resulted into two lists of quality aspects, criteria and indicators, some 350 for home care and 400 for institutional care. These were condensed into a 'short-list' of 88 statements for quality of home care and 90 statements for quality of institutional care. A selection of these statements is presented in tables 2 and 3.

Table 1. Using Concept Mapping to identify the appropriate 'building blocks' for quality report cards for geriatric care.

Steps in this study:	Explanation
1. Preparation	
Participants:	Included were:
- Consumers of geriatric care (both elders and their representatives)	- Elders and/or representatives who were receiving geriatric care (residential or home care). They were believed to be better able than people who have not yet chosen a care provider to reflect on their decision-making processes. Both elders <i>and</i> their representatives were involved because the latter play an important role in the decision-making process (Castle, 2003; Lambert, 2005; Wackerbarth, 1999). We did not include representatives as proxies but as the ones who make decisions when an elder is not able to do so. We believe this best reflects the real decision-making process.
- Experts in quality of geriatric care (representatives of patient and sector organizations)	- Experts: representatives of consumer and provider organizations and 'think tanks' concerned either with the development of quality criteria for geriatric care or the assessment of quality amongst providers. Experts were included because they have access to existing information on quality criteria (from the consumer perspective), and could thus make a valuable contribution to the generation of ideas (step 2); were expected to be better able than the average consumer of care to think about and discuss the contents of quality report cards in a more conceptual way; are helpful in generating support for the methodology and the results of the study, which was one of the explicit aims.
2. Generation of ideas and statements	
Inventory of existing sources of care quality information using a combination of data collection methods:	Objective of the inventory: to ascertain what quality data is already collected on a regular basis; to provide a quick and easy starting point and to ensure that maximum use is made of existing information. The intention is definitely <i>not</i> to limit quality report cards to data that are easily available; one of the known pitfalls of using indicators (Boyce, 2002; Giuffrida, Gravelle & Roland, 1999; Thiel & Leeuw, 2002).
a) web search	<ul style="list-style-type: none"> - Dutch websites containing relevant quality information or documents with quality criteria for geriatric care, as well as - Websites of organizations concerned with the development of quality criteria of geriatric care, or which measure quality amongst providers. - Keywords: Dutch equivalents of 'quality' and 'performance' combined with 'indicators', 'criteria', 'measurement', 'check', and 'information' and with the terms 'home care', 'homes for the elderly' and 'nursing homes', 'consumers', 'clients' and 'patients'. - search performed in September - October 2004.

- 22 semi-structured interviews with experts (12 experts on quality of home care and 10 in the field of institutional care);
 - Topics: (i) whether the organization had a set of quality criteria or quality indicators of its own; (ii) which dimensions, criteria or indicators made up the set; (iii) how the set had been developed; (iv) whether and how the set was used for quality measurement; and (v) whether data were (expected to become) available for health care consumers.
- b) semi-structured interviews
- Documents gathered during interviews, containing quality criteria and indicators for providers of home care and institutional care.
 - Topics for analysis: the same topics that were used for the interviews.
- c) document analysis
- All quality aspects, criteria and indicators distilled from a, b and c were gathered in a large database and analyzed by two researchers by:
- Extracting common themes from the database entries and categorizing all entries in accordance with these themes, eliminating overlapping entries and merging highly similar entries and by converting all remaining database entries into statements about the quality of home care and institutional care.

3. *Sorting and rating of the statements*

- Sorting by experts
 - Statements were printed on cards and presented to the experts who had been interviewed earlier (2b) and to at least one colleague in the same organization.
 - Each expert was sent a package by mail containing two sets of cards, a questionnaire and instructions; each expert received a follow-up call to ascertain that the materials had arrived in good order, emphasize the importance of their participation and give them an opportunity to ask questions.
 - Respondents were asked to read the cards carefully, sort them into piles 'in a way that made sense to them' (Trochim, 1989) and provide a label for each of the piles they created.
- Rating by experts
 - Experts were asked to rate the full list of statements according to the following instruction: 'Please tick on the 7-point scale how important you think each statement would be for you if you had to choose a provider of home care or institutional care (where 1 means not important at all and 7 means very important)'.
- Rating by consumers
 - Consumers who attended the focus groups (see 5) were asked to fill out the same rating-questionnaire as the experts. Consumers were not asked to sort the statements, because the cognitive load of such an exercise would have been too heavy for them.

4. Representation of the ideas in maps

- Multidimensional scaling
 - Hierarchical cluster analysis
- Concept Mapping software was used to analyze the sorting and rating data, using:
- *Multidimensional scaling* results on a map, with each statement plotted as a separate point. The more closely statements are positioned to each other on this map, the more likely it is that these statements were sorted into the same pile by the experts.
 - *Hierarchical cluster analysis* groups the statements on this map into clusters. Statements that show a high level of coherence (given their position on the point map) end up in one cluster. Each cluster represents higher-order conceptual groupings of the original set of statements. Not all clusters have the same level of homogeneity. Therefore, a cluster's 'bridging score' (a number between 0 and 1, with 0 representing the highest level of homogeneity and 1 the lowest) shows the 'power' of that cluster. This analysis also constructs map overlays presenting average ratings by point (i.e. the point rating map) or by cluster (i.e. the cluster rating map).

5. Interpretation

- Four focus group sessions:
- Expert panel
 - Home care
 - Nursing home
 - Home for the elderly
- Maps were discussed during expert group meeting. Consensus was obtained regarding the appropriateness of the proposed 'building blocks' for future quality report cards.
 - Consumer focus groups used a mix of three methods: (i) open brainstorming session on quality aspects considered important when choosing a provider; (ii) prioritization of the building blocks generated by the experts using Q methodology; (iii) rating of the statements using the same questionnaire that the experts had filled out earlier.

6. Utilization

- Written report and oral presentation
- Aim of this study was to identify building blocks for quality report cards, not to create them. The results were passed to the developers of the report cards in a written report and through an oral presentation. Besides, the authors assisted a National Steering Group for the development of a national set of quality indicators for geriatric care.

7.4.3. Sortings, ratings and maps

14 experts on the quality of home care and 11 experts on the quality of institutional care participated in the clustering exercise and sorted the statements. These same experts, as well as 13 home care consumers and 17 consumers of institutional care, rated the individual statements.

7.4.4. Cluster analysis

Initial analysis of the clustering of statements by experts revealed 17 clusters for quality of home care and 18 for quality of institutional care. In both cases, the number of clusters was reduced step-by-step using Concept Mapping software¹² (Concept Systems, 2006). Each step was analyzed, taking into account the clusters being grouped together in that step and the content represented by the newly formed clusters. This resulted in 10 clusters for quality of home care (one of which, entitled 'remainder', contained a non-coherent set of statements) and eight clusters for quality of institutional care, as potential 'building blocks' for future quality report cards.

7.4.5. Cluster interpretation

Next, the clusters were presented to the expert panels and discussed with respect to content validity, clarity for consumers, and appropriateness of the proposed labeling. The home care expert panel proposed spreading the statements of one home care cluster ('remainder' cluster 3) over the other clusters. The institutional care expert panel suggested splitting two institutional care clusters (5 and 7) and distributing half the statements in cluster 5 over the other clusters. This left nine clusters (or quality themes) for both home care and for institutional care for the future quality report card. The draft final maps, clusters and aspects were also discussed during focus groups with consumers. No major amendments were required, merely a few changes in wording and labeling to increase their clarity for consumers. Tables 2 and 3 present the final clusters, ranked according to their mean rating by consumers. The tables also show a selection of the five statements that consumers rated highest, the mean statement and cluster ratings by experts and the bridging scores.

7.5. Discussion and conclusions

This paper has a dual aim: to identify appropriate building blocks for quality report cards for geriatric care from the consumer's perspective, and to present the newly developed step-by-step approach based on the 'Concept Mapping' method. Based on this dual objective, we discuss the results and the methodology separately. This section also embeds the study findings in the

¹² Concept Mapping Software licenses can be bought via www.conceptsystems.com

existing body of knowledge from prior studies and current initiatives on report cards for geriatric care. The discussion ends with some future challenges and current developments in health care in the Netherlands and other Western countries that may affect the creation of report cards for geriatric home and residential care.

7.5.1. Reflection on the results

This study showed that, although home care and institutional care for the elderly share many quality themes, separate quality report cards are needed for the two types of geriatric care.

7.5.2. Differences and similarities between home care and institutional care

Early in the study, it was decided to develop two separate quality report cards for geriatric care: one for home care and one for institutional care. This decision was based on the information gathered during the expert interviews, and was reaffirmed later by the differences in content and consumer rating between the quality themes. Availability, continuity, reliability and organization of care (1), waiting time (2), complaints (6) and informal care (8) were defined for home care and not for institutional care (numbers in table 2). Protocols and procedures (5), ambience and privacy (6), quality of rooms (8) and organization of care (9) are unique for institutional care (numbers in table 3). It was found that consumers of home care and institutional care attached different values to corresponding quality themes. For instance, institutional care consumers rated the themes 'privacy, respect and autonomy' and 'participation and choice' higher than home care consumers, while the latter found the themes 'availability, continuity, reliability and organization of care' and 'waiting time' more important. These differences may reflect the differing impacts of having to leave home for a nursing or residential home as compared to caregivers coming into the home setting. People moving to a new environment because of their need for care may be more preoccupied with preserving some autonomy, retaining some privacy and having some say in their day-to-day schedule of care provision, (social) activities, meals, etc. The high rating of 'privacy, respect and autonomy' supports this. People receiving care at home will be more concerned with availability and reliability of caregivers, caregivers keeping appointments, a limited number of different caregivers, and organization of the care provision in such a way that it fits in with their home and family life.

There is a striking similarity in the high rating attached to 'staff expertise' and 'personal care plan and care file'. The underlying reasons appear to differ, however. In home care the staff experience

relates to quality of care, in terms of safety and effectiveness, independence and responsiveness to individual consumer demands. The personal care plan, by contrast, is considered important primarily because it constitutes the person's care entitlements, while the care file is important as a means of communication and coordination between the different caregivers. In the institutional care context, staff experience relates not just to effectiveness and safety of care, but also to the patient-caregiver relationship and caregivers' efforts to promote patient well-being. Quality of care appears to be seen more as a responsibility of the institution than of individual caregivers, and this is also reflected in the themes 'protocols and procedures' and 'organization of care'. Furthermore, both the personal care plan and the care file are mainly considered relevant as a means of communicating with and rendering account to the patient and their family.

7.5.3. *Differences and similarities between consumer and expert perspectives*

The most striking difference between consumers and experts were the experts' expectations that home care consumers would value responsiveness to consumer demands (and would hence give high ratings to 'participation and choice' and 'privacy, respect and autonomy'). In their view, the timeliness and effectiveness of home care would be less important to consumers, because most of the past waiting list problems in home care have now been resolved and consumers were believed to be less involved with the medical (outcome) aspects of care. Apparently, the day-to-day experiences of many home care consumers are different, given the high value they attach to receiving high-quality care from highly qualified health care workers, and at the appointed times.

In the field of institutional care, experts and consumers largely agreed on the most important quality aspects when choosing a provider. A striking similarity was the low rating of aspects of organization of care that are usually propagated as quality performance indicators, such as the availability of a quality system and employee satisfaction.

7.5.4. *Conclusions regarding the results*

The findings show that, although home care and institutional care share many quality themes, separate quality report cards are needed for the two types of geriatric care. Home care consumers attach more value to the availability, continuity and reliability of care, while consumers of institutional care value privacy, respect and autonomy most. This study also shows that, unlike

many other quality report card studies, consumers want information on structure, process and outcome indicators, rating outcome indicators such as effectiveness and safety of care highly, both for geriatric home and residential care.

7.5.5. Reflection on the methodology

This study shows how Concept Mapping can be used to identify building blocks for quality report cards. Integration of existing quality information sources and experts in the field of geriatric care supports the validity and feasibility of the content of the quality cards, while integration of consumers supports its appropriateness. Furthermore, participation by all stakeholders helped to build consensus about the building blocks, and may be expected to facilitate their implementation.

7.5.6. Limitations and suggestions

Some limitations of the current study need to be mentioned, but first it is important to look at a key assumption at the beginning of the study. Developing a quality report card for elderly people presumes that they want quality information and that they will use report cards. While this study did not seek to verify this assumption, prior (and some current) research shows that it does not always hold (Castle, 2003; Cheek & Ballantyne, 2001; Wackerbarth, 1999). Further research is needed in the Netherlands to explore the decision-making processes of older persons and determine how helpful quality report cards would be.

The first limitation concerns the number of respondents rating the statements (and hence clusters): between 11 and 17 respondents participated in the focus groups. This is not so much a problem for the definition of clusters (i.e. quality themes), but does limit the ability to generalize the prioritization of quality themes to larger groups of consumers. On the other hand, a second method that was used to sort the themes; Q-Methodology¹³, revealed support for the ranking of quality themes presented in tables 2 and 3.

A second limitation may be the focus on existing quality information: there might conceivably be quality aspects that are very important to consumers but are not yet measured in any

¹³ Q-methodology was only used as a supportive tool during the focus groups, the method and its results are accordingly not discussed in detail here. Q-methodology provides a foundation for the systematic study of subjectivity, a person's viewpoint, opinion, beliefs, attitude, etc. Typically, in a Q methodological study people are presented with a sample of statements about some topic, called the Q-set. Respondents are asked to rank the statements from their individual point of view, according to some preference, using a quasi-normal distribution. These individual rankings are then subjected to factor analysis, resulting in factors representing operational clusters of subjectivity. In this way, Q-methodology can be very helpful in exploring tastes, preferences, sentiments, motives and goals (Stephenson 1953; Brown 1980; Van Exel & De Graaf 2005).

existing instrument. This was addressed during the focus group sessions, by starting with an open brainstorm session, but this did not reveal any new quality items. Ongoing changes in the market structure and consumer preferences do however mean that quality report cards should be evaluated regularly.

Third, in this study the sorting of statements was performed by experts, while in order to limit cognitive load consumers were only asked to reflect on this sorting (88-90 statements). Though in theory consumers could sort the statements, extensive support was found for the experts' clustering during the focus groups.

Finally, the 'double-barreled' statements and quality aspects in this study may be problematic. For example the items 'the caregiver works independently, efficiently, carefully, and hygienically' are grouped in one quality aspect. This statement might not have meant the same to all respondents. Future research needs to examine the (relative) weight consumers attach to each of these items.

Some suggestions for improvement can be made. Concept Mapping is a consensus method. Here, consensus was created among experts from various parts of the health care field and among consumers, with the two groups reaching this consensus independently of each other. The consensus effect might have been even stronger if experts had discussed the results with consumers. A further improvement would be to ask respondents (i.e. the experts) not only to rate the statements, but also to give a feasibility score. When quality aspects and indicators have to be selected for the quality report card, both the rating and the feasibility score can function as selection criteria (Trochim, 2005; Nabitz, Van den Brink & Jansen, 2005).

7.5.7. *Embedding study results*

Compared to other studies and initiatives in relation to performance indicators for care (see Introduction), the quality themes identified in the current study are less about facts (i.e. aspects of structure such as facilities, residents, deficiencies), such as the Online Survey, Certification and Reporting (OSCAR) data partially fills the CMS' Nursing Home Compare website in the United States, and more about quality (OSCAR, 2006). This is obviously due in part to the aim of this study, which was to define building blocks for *quality* report cards. However, during the focus groups consumers said that quality information on report cards should be supplemented with 'factual' information, an easy task using existing sources of information.

Nonetheless, comparing the quality aspects identified in other studies and initiatives such as

Nursing Home Compare reveals important differences in how quality is defined. For example, Nursing Home Compare assesses quality by means of the MDS. In the current study, however, quality items that can be measured with clinical indicators (such as the aspects within cluster 2 in table 3) are only one side of the 'quality coin'. Most of the quality themes for institutional care (clusters 1, 4, 6, 7 and 8 in table 3) and many quality themes for home care (clusters 5, 6, 7, 9 in table 2), deal with 'quality of life'. This is poorly measured by clinical indicators such as the MDS and has been cited earlier as an important deficiency of the Nursing Home Compare initiative (Arling et al. 2005; Kane et al., 2003).

Other studies ignore outcome measures completely and limit quality assessment to process or structure indicators. However, the current study shows that consumers are interested in a broad range of issues incorporating structure, process and outcome aspects that measure quality (see table 3). As discussed earlier, they assign the highest importance to outcome indicators. Unlike other studies, this study also did not find consumers to be interested in costs and financial performance of care providers. This is probably related to the Dutch health care market structure, with very small user fees and little danger of bankruptcy of providers.

Since consumers were actively involved in the Concept Mapping approach adopted in this study, it was to be expected that it would generate quality indicators that 'fit' consumers' needs for information more closely.

7.5.8. Challenges for the future

As stated, the aim of this study was not to develop the report card itself, but to identify appropriate 'building blocks' from the consumer's perspective. The report card will be created by the Dutch National Institute for Public Health and the Environment (RIVM), which develops all consumer report cards in health care. This increases the similarity of all health care report cards, making them easier for consumers to understand. However, some challenges remain before report cards for geriatric care are ready for use.

First, the most important quality aspects per quality theme need to be selected. The rating of quality aspects by consumers seems to be a reasonable criterion; alternatively, the ratings by the experts could be used, or a mix of the two ratings. The number of aspects per theme could also be varied. For instance, themes with a higher average cluster rating could be assigned more aspects, or more homogeneous clusters (with a lower bridging score) fewer aspects.

Secondly, the reliability of the report card could be increased by a system of 'checks and balances', in which at least one indicator is measured 'objectively' for each aspect (by recording facts such as falls or complications) and one through consumer consultation (e.g. patient experience questionnaires). The inventory of existing data sources in step 2 of this study revealed the indicators that are already measured for each aspect and, more important, the indicators that are actually accessible and useful for filling the report cards. Four data sources were found to be available: two consumer satisfaction instruments and two instruments of the Dutch Health Care Inspectorate. In the next section we discuss current developments in the health care system in the Netherlands and other Western countries that will ensure quality in long-term geriatric care and increase the availability, comparability and reliability of data sources.

Third, the indicators and scores have to be translated into comprehensible, everyday language. Several authors stress the importance of the communicative aspects of report cards (Hibbard, Slovic, Peters & Finucane, 2002; AHRQ/CMS, 2006). The key issue here is the layered construction of the report cards. Information should not be too detailed, but needs to be detailed enough for those who want to learn more about how scores are composed.

Fourth, the Concept Mapping procedure should be repeated regularly to reflect changes in consumer preferences, the market structure and provider performance. Once quality report cards are in use, health care providers are known to begin focusing on the quality aspects that are measured on the report cards in order to improve quality and (perhaps more important in their view) their league table rankings (Zinn, Spector, Hsieh & Mukamel, 2005). This is a powerful and beneficial impulse, but focusing on a limited number of aspects over an extended period might lead to unintentional effects, such as 'myopia', or: short-sightedness (Thiel & Leeuw, 2002). While close correspondence between the core themes of providers' quality policy and current consumer preferences is clearly not a problem, it is worthwhile monitoring trends in quality on aspects that are currently less highly valued by consumers (but which may be of societal value).

7.5.9. Recent developments

Recent developments in Dutch and other Western health care systems create a number of opportunities and challenges for choosing consumers, and hence for the development of quality report cards. An important positive development is the creation of one uniform set of performance indicators for the whole Dutch geriatric care sector. This was recently done by a steering group comprising all stakeholders in Dutch geriatric care, that was led by the Dutch Health Care Inspectorate

and was assisted by the authors of this article. 40 indicators will be measured by health care providers themselves, - by completing MDS-based forms at patient level - (covering cluster 3 in table 2 and cluster 2 in table 3), through consumer consultation, - using uniform questionnaire based on the Consumer Assessment of Health Care Survey (CAHPS) methodology) - (covering clusters 1, 2, 4-9 in table 2 and clusters 1, 3, 4, 6-9 in table 3), and through surveillance by the Health Care Inspectorate (covering cluster 5 in table 3). From January 2007, all Dutch geriatric care providers must use these instruments to measure consumers' experiences every two years, and the MDS indicators continuously or at least once a year. Providers must also report on their quality to the public, both in an annual report and through the national consumer report cards for geriatric care. All in all, this system of 'checks and balances' seems to guarantee the feasibility of consumer report cards for geriatric care in the Netherlands. For the US Nursing Home Compare website a similar procedure, especially the use of consumer experiences (using CAHPS questionnaires that have already been developed for nursing homes) would be extremely beneficial, supplementing the report card with the currently absent quality of life data (Arling et al. 2005; Kane et al., 2003). A good example of what we propose here is the U.S. Ohio report card for nursing homes. This initiative combines both consumer-survey data with MDS-quality indicators and gives visitors a broad overview of what they may expect from a nursing home (State of Ohio, 2006).

Some developments might not facilitate the creation of consumer report cards about geriatric care providers, but rather give cause for critical reflection. First, care for elderly people with a chronic condition is increasingly being redesigned into 'integrated care pathways'. Consequently, people might become more interested in the quality of disease-specific care arrangements rather than in the quality of home care providers. Second, following the liberalization of the Dutch health care market, home care has been split into product groups, enabling the access of different types of providers. For instance, domestic help – the largest segment of home care - can be provided by existing service organizations outside the health care sector. As a result, in the near future people may be more interested in the quality of providers with respect to the individual product groups than in the quality of the total organization. Another consequence of the ongoing liberalization is the emergence of large conglomerates of care providers with local branches that may vary in type and quality of service provision. Such mergers reduce consumer choice and raise questions as to the level at which quality should be reported: organizational or local branch level (given that quality may already vary substantially between caregivers from the same provider, hence the consumer's focus on continuity and expertise).

Table 2. Clusters, aspects, bridging scores and ratings for home care

Cluster ^a	Bridging score	Priority C	E
1. Availability, continuity, reliability and the organization of care ^b	0.43	5.89	5.48
The organization is always (24x7) available (in the event of emergencies)		6.67	6.38
In emergencies a caregiver comes quickly		6.27	6.57
The manager ensures that the caregivers are aware of the (care) arrangements between the organization and the client		6.20	5.00
2. Waiting time ^c	0.57	5.89	4.61
Waiting time from the application for care to the delivery of care		6.23	5.07
The client can contact a manager if he/she is dissatisfied with the care provided or the caregiver		6.14	5.71
Waiting time before the client can talk to the right professional (e.g. designated contact, care coordinator) on the telephone		5.93	4.00
3. Staff expertise and effectiveness and safety of care ^d	0.30	5.82	5.29
The caregiver works independently, efficiently, carefully and hygienically		6.47	6.07
The care provided is skilful, effective, safe and demand-led		6.40	6.07
The client has confidence in the expertise and quality of care of the caregiver		6.40	6.07
4. Personal care plan and care file ^e	0.72	5.77	5.31
On request, the client may always inspect their care plan and care file		6.33	6.07
The organization/caregiver uses a care file for each client in which aspects of the care given are recorded		6.00	5.79
The caregiver uses the care file for reports, coordination and transfer		5.80	5.71
5. Privacy, respect and autonomy ^f	0.37	5.75	5.85
The caregiver acts correctly in physical contact, waits for instructions from the client when providing physical care and responds accordingly		6.31	6.54
During the care provision, the client feels at ease and not intimidated or threatened in any way		6.27	6.50
The client is helped correctly on the telephone		6.27	6.21
6. Complaints ^g	0.60	5.69	5.17
The organization provides good service to the client in the event of complaints about the quality or functionality of medical aids supplied and/or home adaptations carried out		5.80	6.00
The organization handles complaints correctly and always within two weeks		5.80	4.93
The organization operates an accessible complaints procedure		5.47	4.57

7. Participation and choice ^b	0.59	5.55	5.94
Client is able to change the caregiver if he is dissatisfied with the caregiver's approach, work attitude, care provided or if they do not get on with the caregiver		6.20	6.64
The organization, caregiver and client make agreements on what the client himself can / wishes to do in terms of household tasks, care tasks and coordination		5.80	6.57
The care plan is created after consultation between organization and client (with a cooling-off period for the client) about needs and wishes concerning the content and organization (e.g. days and times) of the care		5.79	6.46
8. Informal care ^f	0.52	5.48	5.57
Informal carers are involved in the drawing up of the care plan, with the task division between caregiver and informal carer being discussed		5.69	5.71
The caregiver identifies (the danger of) overloading of the informal carer and gives the informal carer information and expert advice on structural support available in the region		5.50	5.50
The caregiver knows what help the client receives from their informal carer and offers the informal carer occasional support at the latter's request		5.25	5.50
9. Information ^l	0.20	5.43	5.27
The client knows what to do in emergencies		6.20	6.57
The organization provides information to the client on the (telephone) accessibility of the organization and the caregivers during and outside office hours		6.00	5.93
The organization provides information to the client on any waiting times, the designated contact or waiting list manager during the waiting period, and the possibilities of temporary bridging care or replacement care		5.86	5.86

Note: ^a This table lists only the three most important statements per cluster, according to consumers. A list of the aspects covered by the remaining statements is provided with each cluster (in a note). ^b Other: consumers receive care from a limited number of (social) workers; care is delivered in accordance with the agreed content, times and level of expertise of the caregiver, permanent caregiver regardless of illness, holiday periods; client has a fixed point of contact at the organization. ^c Waiting time from the application for (changes to) aids and appliances and/or home adaptations; waiting time before the client can talk to someone from the organization on the telephone. ^d Other: health care workers: are careful with consumers' possessions; know how to use aids (pump, wheelchair, bed etc.); do not exceed their competences, help to prevent accidents in/around the house, contribute to the physical and mental health status of consumers; work with guidelines and protocols and consumers have confidence in them; the caregiver has sufficient expertise with the disorder(s) and the limitation(s) of the client; caregiver contributes to the prevention of incorrect use of medicines. ^e Other: the home care provider puts agreements down in writing within six weeks after they were made and asks the home care consumer's approval by signing; agreements are evaluated twice a year to see whether the delivered care still meets the consumer's needs; care plan reports the aim, content and timing of the care provision and the level of expertise of the caregiver. ^f Other: health care workers: respect consumers' privacy and private life; take sufficient time for their clients; take consumers seriously; confidentiality of client particulars is guaranteed; care provider is friendly, polite, respectful and maintains a correct professional distance. ^g N/A. ^h Other: clients can choose a specific health care worker and a maximum number of substitutes; the organization promotes participation of consumers; consumers are free to choose what aids and adaptations are made in their homes; organization responds flexibly in individual cases to temporary or acute changes in the care need of the client in terms of volume, content and timing of the care provision. ⁱ N/A. ^j Other: the organization provides good, understandable information about: how to change the delivery care (time, amount); the costs; duties and rights; choice options; procedures for complaints; the client board; new technologies in home care; the religious identity of the organization and its mission and vision; organization provides all information to the client, both written and verbal, in a language that the client (or their representative) understands; organization provides a clear explanation and instructions to the client of any medical aids/appliances and/or home adaptations.

Table 3. Clusters, aspects, bridging scores and ratings for institutional care

Cluster ^a	Bridging score	Priority	
		C	E
1. Privacy, respect and autonomy ^b	0.45	6.21	6.41
The care provided contributes to improving the quality of life of clients		6.38	6.09
Caregivers do not take over more tasks from the client than necessary. The client may look after themselves in so far as they wish to and are able to		6.35	6.00
Before and during the care provision, it is explained to the client what the care worker will do or is doing. During the care provision the caregiver talks to the client, not over their head		6.06	6.73
2. Staff expertise, effectiveness and safety of care ^c	0.37	5.94	6.02
Staff make an effort to get to know the client well, display personal attention and patience, are open for questions and also sometimes take the time to chat. The client never has the feeling of being a nuisance		6.76	6.64
Staff accept the client as he or she is, are polite and friendly towards the client and treat him or her respectfully and with dignity (not being condescending or treating the client like a child). Care is taken with the client's possessions		6.35	6.82
Caregivers help the client on toilet visits in a pleasant and expert way using adequate aids. Toilet visits are possible at any time. There are no 'toilet rounds', nor needless use of catheters and incontinence material. After toilet visits, the client is given an opportunity to wash their hands		6.29	6.73
3. Personal care plan and care file ^d		0.66	5.79
The privacy of (confidential) client information is guaranteed	6.53		5.82
There is a good complaints procedure. There is an independent confidential adviser or complaints mediator present. Clients feel that they can make complaints without repercussions, that they will be taken seriously and that they will be dealt with correctly	6.50		5.45
It is laid down in the care file whether the client has made their wishes known regarding care and treatment at the end of life (comfort care only directive, euthanasia directive, refusal of treatment directive, organ donor directive) and who is authorized by the client to take decisions when they are no longer able to do so themselves .	6.13		5.91
4. Participation and choice ^e	0.47	5.74	6.05
The client board in the institution demonstrably looks after the interests of the residents and the recommendations of the client board are taken seriously by the institution. For psychogeriatric clients, designated contacts are represented on the client board		6.19	5.45

The client has the right to choose the (para)medic (including the right to retain their own GP) and to a second opinion where appropriate	6.13	6.00
The client determines their daily rhythm themselves and how they fill their day, such as time of getting up and going to bed, how many visitors they wish to receive and when, whether they wish to withdraw, and what time they leave the institution when going home again. The care is geared to this	6.00	6.36
5. Protocols and procedures^f	0.49	5.68
A bell or personal alarm system is within reach throughout the institution and clients know what to do in the event of accidents, incidents or emergencies.	6.53	5.82
Caregivers know what to do if mistakes are made in the administering of medication (type of drug, prescribed dose or time of administering)	6.29	5.18
The institution contributes to the prevention of accidents in and around the building (e.g. preventing falls, signage, instructions), among other things through a good reporting procedure, registration, evaluation and tackling of accidents and incidents	6.13	5.18
6. Ambience and privacy^g	0.48	5.65
The institution meets the need for spiritual care and helps to enable the client to practice their religion and pursue their philosophy of life as they wish. There is a room for reflection and/or a quiet room; the client is offered the opportunity to attend a church service at least once a week; clients are given an opportunity to pray before and after eating; and the client or their family can call on spiritual care in their own religion, if desired from outside the institution	6.18	5.82
Clients feel at home in the institution, at ease, safe and protected and in no way intimidated or threatened	5.88	6.45
Terminal care provision takes place in accordance with the wishes of the client or their legal representative	5.87	6.64
7. Information^h	0.76	5.52
In the psychogeriatric wards the days of the week, the seasons of public holidays are clearly indicated	5.87	5.45
The institution gives (potential) clients or their legal representative verbal and written information about the admission with regard to the institution's care philosophy, the house rules, policy on the end of life, client rights, the presence and functioning of the client board and the confidential adviser, the division of the day, activities and options for spending the day, who can be approached with questions, the complaints procedure, costs of accommodation (own contribution), of all possible supplementary services and rules and rights relating to measures restricting freedom	5.67	6.27
Clients are kept well informed for relevant events and elements within the institution	5.63	5.45

8. Quality of private and shared rooms¹	0.23	5.40	5.55
The communal areas and toilets are clean		6.53	5.82
The temperature in the client's own room is pleasant and can be regulated by the client		6.41	6.27
The client's living/bedroom is clean and in a good state of maintenance on handover		5.88	6.18
9. Organization of care¹	0.35	5.37	4.94
The efficiency of the institution		6.33	4.00
Staff satisfaction score		6.00	4.55
The institution carries out regular research into client and staff satisfaction, and demonstrably makes use of the results		5.92	5.82

Note: ¹This table lists only the five (or fewer) most important statements per cluster, according to consumers. A list of the aspects covered by the remaining statements is provided with each cluster (in a note).

² Other: Physical privacy is guaranteed during the provision of the care. The client is not treated in the living room (except with eating or drinking). Where personal care is provided in bed, the curtains are drawn. During toilet visits the toilet doors are closed. Terminal clients have a single room where family members can be with them if they wish. ³ Other: The care provided contributes to improving the physical and mental status of clients and preventing unnecessary complications. Staff has experience in helping clients with their aids and medication, caring for the clients (clients look well-groomed), preventing clients from troubling each other etc. and there is a good laundry service. ⁴ Other: Shortly after admission (no longer than six weeks), an individual care plan is prepared in consultation with the client or their legal representative. The plan sets out the content, aims and timing of care provision. Both parties sign for agreement. The care plan is evaluated at least twice a year or whenever the care needs of the client change radically. Within a few weeks of the death of the client, the care provided is evaluated with the family. Care is delivered in accordance with the plan. The professionals use a multi-disciplinary patient record and clients are confronted with a limited number of health care workers. ⁵ Other: There is an adequate response to alarms raised by clients; in balancing risks and restriction of freedom, clients are able to make choices and to have these recorded in the care plan. These choices will be respected. Clients have options for meals, activities, accommodation and rooms (no forced separation of married couples), transport, work, education, hobbies and leisure time; there are enough activities; meals are spread over the day, there is enough time to eat and the quality of the food is good. ⁶ Other: The institution operates in accordance with a recent protocol for the setting out and administering of drugs. The medical team keeps a close eye on (the safety of) the use of medicines (number of different medicines, administering of correct dose at correct time). The introduction of clients into the home is well organized by means of protocols; there are protocols for risky and (health) threatening situations in the home; the home is safe from burglary and fire; and there are protocols for the limitation of clients' freedom. ⁷ Other: Attention is paid to the atmosphere/ambience (tablecloth, serving dishes) and the atmosphere is quiet during meals (TV and radio off). The atmosphere among the residents is pleasant; clients experience warmth and cosiness. Clients (including those without their own apartment) are given sufficient opportunity to be alone, whether or not they have visitors. Staff and fellow residents may not enter the client's living space without their permission. ⁸ Other: The institution keeps (potential) clients well informed of all relevant events and developments in the institution and their consequences are (the daily life of) clients. ⁹ Other: Clients may go where they please inside and around the building; rooms, corridors and the surrounding grounds are easily accessible, large enough and suitable for people with disabilities. ¹⁰ Other: quality, comfort and size of: own apartment and other rooms; rooms and sanitary facilities are cleaned properly; the vicinity of the home; the number of single or multiple rooms and average number of clients per multiple room; the furniture; whether pets are allowed or not. ¹¹ Other: There is sufficient capacity available to provide the crucial elements of care; medicines are available; group areas are supervised by qualified staff; there is sufficient geriatric expertise; and sufficient help/aids are available during eating and drinking; percentage absence amongst employees due to illness; clients who can potentially improve their ability to cope for themselves receive the therapy they need; there is one fixed person clients can talk to; good cooperation with other health care providers (integrated care); the proportion of time spent on clients versus time for other activities; the provider has a quality label; patient satisfaction score; innovation and development within the organization; multidisciplinary staff meetings; quality of technical services; financial soundness of the organization.

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Chapter 8

Conclusions

This final chapter summarises the main conclusions from the foregoing chapters, discusses the constituent questions (8.1 to 8.8 inclusive) described in chapter 1 and finally answers the central question in this study (8.9). Chapter 9 presents a reflection on this.

8.1. Performance indicators: definition and application

The health care system is currently under the spell of performance indicators (Klazinga, 2004). All kinds of stakeholders are endeavouring to pin down difficult to measure phenomena such as quality (efficiency, effectiveness, safety, patient-centeredness, etc.), results of (improvement) activities and the degree to which goals are achieved. Performance indicators are increasingly being used as part of this endeavour, and for a diverse range of purposes. The same can be said for informing and equipping the choosing care user. For many people in the care sector, however, it is unclear precisely what performance indicators are and how and where they can be used. The first question addressed in this thesis is therefore: *What are performance indicators?*

8.1.1. Performance

To answer this question, the two parts of the concept are discussed separately. The meaning given to the word 'performance' in the literature is not uniform. The differences in interpretations and definitions are largely caused by the characteristics of the notion of performance:

1. It is a subject-specific concept; the specific interpretation is dependent on the perspective of the observer and their specific context (Donabedian, 1980);
2. The assessment of performance is always directed towards objects at different levels of aggregation in the health care system (Ibrahim, 2001), (for example a hospital, a division, a ward, a team, or an individual doctor);
3. The assessment of performance is always made up of several performance aspects, which can be broadly subdivided into aspects of structure, process and outcome (Donabedian, 1980), or: input, throughput, output (Harteloh & Casparie, 2001), or: economy, efficiency and effectiveness (Van Helden, 1997);
4. Performance is a relative concept which is the product of a comparison of an objective or intersubjective norm with the actual achievement (Donabedian, 1980) or what could have

been achieved (Murray & Frenk, 2000). In the individual case, the assessment of a performance is the product of a confrontation of expectation and experience (Parasuraman et al., 1985).

These characteristics correspond with the characteristics of the equally abstract notion of 'quality' (Harteloh & Casparie, 2001) or 'good care' (Vanlaere & Gastmans, 2002), which many authors see as being synonymous with 'performance' (Brook et al. 2000; Campbell et al., 2000; Øvretveit, 2001, JCAHO, 1990). In this thesis, too, the concepts 'performance' and 'quality' are used as synonyms of each other.

8.1.2. Indicators

The flipside of such a broad interpretation of performance is that it becomes virtually impossible for an actor, and especially for the patient, to obtain a simple and uniform insight into the performance of objects in the health care system. Therefore there is need for *indicators*; parameters which provide a reliable and clear indication of the performance or quality of an object. There are many definitions in circulation of the notion of performance indicator, with different authors applying different accents (see e.g. Casparie & Hommes, 1997; Brook et al., 2000; Berg & Schellekens, 2002). The central characteristic which is common to all definitions, however, is that an indicator provides information which is possibly a reflection of the performance or quality of an object in the healthcare system (Casparie & Hommes, 2001; Harteloh & Casparie, 2001; Øvretveit, 2001). As the term itself indicates, performance indicators give an indication of the performance or quality, and thus suggest a direction or provide a signal for further research or (in the case of the care user) experience (Kazandjian et al., 1993). This distinguishes an indicator from a 'criterion' or a 'variable', where there is a clear 'one-to-one' causal relationship between the phenomenon being measured and the actual quality or performance (Øvretveit, 2001).

Based on this and on the characteristics of the notion of performance referred to above, performance indicators can be defined as "*key figures which give an indication to an actor of a number of crucial (for that actor) aspects of the performance of an object in the health care system*".

8.1.3. Application

The literature contains descriptions of several *functions* of performance measurement and performance indicators, with each author once again applying their own emphases. A functional classification which has been widely used in recent years is the division into internal *improvement*

in and external *accountability* for performance (Casparie & Hommes, 1997; Rosky & Gregory, 2001; Freeman, 2002; Berg & Schellekens, 2002; De Bruijn, 2002). A third function is sometimes added to this: *research* (Solberg, 1997; Øvretveit, 2001).

Indicators often cannot be used for several purposes at the same time. There is an important distinction between the *internal* and *external* use of performance indicators. Both the 'performance paradigm' (Berg & Schellekens, 2002) and the demands placed on performance indicators vary according to the purpose for which they are to be used. In case of the internal use of performance indicators, the performance paradigm is 'good - better' (Berg & Schellekens, 2002). According to Solberg et al. (1997), in such a case it will be the care providers themselves, the management and possibly a quality care department that will be the main users of this performance information. They also establish the (internal) indicator(s) themselves and gather the necessary data fairly simply and over a relatively short period via a small sample. This need not be representative and correction for possible distortion is not necessary. The data collectors are after all themselves the users of the outcomes and can easily interpret any deviating findings because they are in the midst of the primary process.

The situation is different for the *external use* of performance indicators, for example in a situation where a patient is informed by comparative information on the risk of unplanned secondary surgery in various hospitals. In order to be able to select the best hospital (the performance paradigm changes to 'good - bad'), the patient requires precise and valid information on the (external) indicator which in this case is established by independent third parties. This information is obtained by gathering data from comparable hospitals in a uniform way, over a longer period and corrected for distortion. The quality assessment must not depend on case-mix differences or the fact that a hospital specialises in high-risk operations.

When it comes to *research*, the demands placed on data collection and the selection of indicators are even more stringent, because they will be used among other things to implement best practices and evidence-based interventions in care processes.

8.1.4. Conclusion

A preliminary conclusion would be that performance indicators might be a useful instrument to provide patients with information about the quality of health care services; something that is not easy to measure and understand without some well chosen indicators. On the other hand, we saw that such indicators must be carefully chosen, because their external use imposes a number of important requirements, for example in relation to validity and reliability.

8.2. Suitability, usefulness and desirability of performance indicators for patients

After the first successful applications of performance indicators in health care, however, critical comments were quickly voiced concerning both the phenomenon itself and its application in some fields, as well as concerning the use of performance indicators for equipping care users. Hence the second constituent question addressed in this thesis: Which discussions take place in relation to the suitability, usefulness and desirability of performance indicators and as a choice-supporting tool?

Discussions cover a) the question of whether performance indicators are actually *suitable* for supporting the choices of care users. There are also all manner of reasons for questioning b) the *usefulness* of performance indicators: Will patients actually make use of performance data on care provision? Any potential (side-) effects of performance indicators also ultimately determine c) the *desirability* of using performance indicators for supporting choices by care users.

8.2.1. Suitability

A frequently heard argument against publishing performance indicators for care users is that they are not suitable as a means of supporting their choices. Indicators do not reflect reality, but provide an *indication* of an underlying phenomenon, problem or trend. Yet others call for a strict limitation of the performance data that are made available to the public. Their argument is that care users benefit only from the performance information which they themselves are able to assess when they experience the care personally; for example aspects of service and interpersonal treatment.

But do the arguments cited fully legitimise this radical rejection of performance indicators for selection or choice purposes? After all; indicators are used in many other areas to help people make choices; for example in car tests or school quality cards. Besides, the second argument is purely theoretical and is not substantiated by its advocates with results from research on the information requirements of care users.

8.2.2. Usefulness

Another point of discussion against making performance indicators available for care users is that they would not be *useful* to them. Although there is some recent evidence that patients do have interest in the more technical aspects of quality of care and that they would involve

such information in their decision processes if it were available (Fung et al., 2005; Harris, 2003), the majority of studies show that in practice patients (are able to) make no use of them at all (Schneider & Lieberman, 1997, 2000, 2001; Schneider & Epstein, 1998; Lieberman, 2000; Luft et al.; Marshall et al., 2000). However, four critical comments need to be made in respect of the apparent finding that performance indicators would not be useful for care users:

1. First, these studies look at 'the care user' in a general sense, without making a distinction based on the different roles that the care user can fulfil. Also, no distinction is drawn between patients with different disorders or between groups of patients with different personal and other characteristics.
2. A second weakness in these studies is that they fail to place the relevance of performance information in a dynamic future perspective. At present, the majority of care consumption is concentrated in a generation of (a largely older) people who were not brought up with the idea that there are choices in care and that they themselves can exert any influence. This attitude will probably change in the next few years, with the arrival of a new generation of care users.
3. Third, there are a few methodological limitations to the studies that were cited above: a) they see patients' health care decisions as an economic concept of rational choice (the *homo economicus*), which results into only a partial understanding of patients' decision processes, ignoring the role of crucial social contextual actors and factors; b) they do not investigate the trade-offs patients have to make between factors that influence choices in real life; c) they use experimental consumer information which is often not suitable and understandable for patients.
4. Finally, it has become clear from other studies that, even though the public would not use decision supportive information, publicly disclosed consumer information is used in a different way, namely by care providers who want to *improve* the quality of care. This means that transparency also leads to quality improvement if 'pathway I' (the selection process via the consumer) does not work.

8.2.3. *Desirability*

For some opponents of performance indicators for care users it is their *undesirability* which is a major objection. As a rule, this objection is based on more principled and ethical considerations:

1. In the first place, the opponents argue that performance aspects such as effectiveness, expertise and safety of care should never be used as a basis for competition, because they are

considered to be present as a matter of course, as basic conditions of care. Although no one would disagree with the latter statement, we know that nowadays there are still major quality differences between health care providers. Besides, we have also seen that the public disclosure of comparative performance information improves quality. Therefore, it is not wise to refrain from the development of consumer information for reasons of desired future situation that have not been achieved yet.

2. Secondly, some regard the responsibility that is associated with freedom of choice as very burdensome for people and especially for patients. However, the responsibility that accompanies freedom of choice need not to be problematic at all, as long as choice is something that *can* be exercised, not something that *must* be exercised, which still is the case in health care.
3. The third point of discussion is the dilemma that *health professionals* could face if their performance is made public and becomes a 'bargaining chip' in a negotiating process with the patient. The public disclosure of performance information would harm the logic of professionalism in favour of the logic of the free market (consumerism) and the logic and the logic of bureaucracy (managementism). For this reason it is important to ensure that performance indicators are something that can be discussed in the doctor-patient relationship without that relationship being transformed into a purely businesslike transaction between consumer and supplier. It is also important that the size of the set of indicators should be such that it remains manageable and clear
4. Finally, reference is often made to the undesirable effects of the use of performance indicators in general, and for the health care sector in particular (the performance paradox, which negatively influences the *knowledge* about performance; and perverse effects on the *primary process* of care provision). However, those side-effects can be avoided provided adequate measures are taken.

8.2.4. Conclusion

Although there is no hard evidence yet whether there are groups of care users who would actually use performance indicators in practice when searching for a care provider or practitioner, given the developments so far it is very plausible that this will increasingly become the case in the near future. Moreover, there is some evidence that publication of performance figures leads to improvements in quality by breaking through the status quo among care providers. Based on these observations and the need to equip the consumer for the new, market-based care system,

the introduction of performance indicators for care users who wish to use them appears to be a *suitable, useful* and *desirable* intervention.

8.3. Existing and desired information for health care consumers

The observation that performance indicators do appear to have a future for care users does not however provide any clarity on how their development and implementation should be achieved. In order to make maximum use of existing quality information and to fit in with the wishes of the choosing care user, an inventory study was performed in chapter 2 based on the research question: *Which performance information is available for the choosing care user and how does it compare with the information that care users would like to have?*

Prior to the empirical part of the study, a literature search and document analysis was used to map out the existing information about the quality of care and the information that care users would like to have. The inventory of existing sources of performance information revealed a total of 60 locations of performance indicators; 33 on the demand side and 27 on the supply side of health care. The following table shows the top-10 ranking of information that care users would like to have (left-hand column) and the existing information (middle and right-hand columns) on the quality of care.

The confrontation of the two showed that although a good deal of the desired performance information already existed, it was not available and accessible for care users in practice. As a consequence we established a marked lack of consumer information on process and in particular outcome aspects such as (patient) safety, quality of the medical treatment or skill of the health professionals. What was available was summary information on structural and (to a lesser extent) process aspects such as accommodation guides in the nursing and care homes sector, waiting times for specialisms in Dutch hospitals and a comparison of a few hospitals on the grounds of service and patient-friendliness.

The inventory showed an explosive increase in the number of initiatives for the development and implementation of indicator sets. At the same time, however, there was great uncertainty on how patients' decisions come about and whether there are groups of care users who are willing

and able to use performance information in their choice process. It appeared also to be unknown what those groups would like the information to contain.

Table 1. Overview of performance information desired by care users and existing performance information on the demand and supply side

Performance information desired by patients	Top 10 existing performance information at patient organisations	Top 10 existing performance information at care providers
1. Accessibility & availability, including waiting times	1. Approach to patient	1. Waiting times and lists (hospitals)
2. Quality of medical treatment/ skills/experience of care provider (specific disorders)	2. Voiced for patient	2. Staff illness and turnover
3. Care provision offered (e.g. specialisms) and accommodation	3. Information (provision)	3. Complaints (recording and handling)
4. Doctor-patient relationship (trust)	4. Skill of professional	4. Negative medical outcome data (complication records, incidents, decubitus, physical restraint etc.)
5. Information (willingness) and communication	5. Care provision accommodation	5. Evaluations of care plans
6. Approach to patient	6. Obtaining support from care provider	6. Positive medical outcome data (reduction of complaints, disorders, etc).
7. Continuity/cooperation 1st/2nd line/integral care	7. Accessibility of care/provision)	7. Information and communication to patients and next of kin
8. Care outcomes	8. Organisation	8. Production figures (of institutions and departments)
9. Support for informal carers, family and friends	9. Safety (feeling safe) and hygiene	9. Efficiency
10. Own responsibility/ independence	10. Patient/client independence	10. Customer satisfaction (general) and staff satisfaction.

8.4. Current knowledge about patients' decision processes

In order to fill the observed gap in knowledge on the choice processes of patients, a systematic literature review was carried out in chapter 3 based on the question: *What is found in the literature about the choice processes of patients?*

8.4.1. Dearth of literature on choosing a care provider

The review produced 17 usable qualitative articles and 24 quantitative works. Only one study was about the choice of a care provider. Virtually all studies on the choice processes of patients are concerned with choices *within* a particular treatment setting, for example whether or not to use a particular treatment. Studies on informing patients are mostly concerned with decision aids (supporting choice within a course of treatment). Studies on the use of 'quality report cards' focus on fictitious choice situations rather than the actual choices made by patients. Most studies (18) focused on patients with cancer; only a few (4) dealt with choices relating to institutional provisions in settings such as nursing homes, homes for the elderly and home care. No studies were found on patient choices in mental health care.

8.4.2. Factors influencing patient choices

Although the material found did not entirely match the research question, it was nonetheless analysed on the basis of factors that influence patient choices. Several clusters of choice-determining factors were identified:

1. *Socio-demographic characteristics*: age and gender are found to influence the choices made by patients with breast cancer.
2. *Disease-specific characteristics*: the severity and course of the illness are determinants of choice. Patients with life-threatening or degenerative diseases, for example, take no risks with their decisions. Possible side-effects play no role: survival and avoiding further deterioration are the primary considerations. In the case of long-term diseases, patients adapt to their capabilities and put off treatment for as long as possible.
3. *Information*: patients vary in the extent to which they actively seek information on their choices. The precise influence of information on patient choices is not clear, probably because of the widely differing research methods. Moreover, the influence of information was found to be highly dependent on the severity of the disease (less influence in acute situations).
4. *Professional care providers*: influence patients in a variety of ways: passively (patients trust the professional) or actively (the professional advises or refers). Professionals have a considerable influence on patient choices for particular treatments or decisions not to undergo treatment.
5. *Close relatives and informal carers*: also play a role, depending on the impact of the above factors.

8.4.3. Conclusion

Based on the review of the existing literature, it can be concluded that the research questions in the present study hit upon an important 'fallow' area of research. No studies were found which examine the actual choice process of patients who are looking for and preparing to choose a care provider. Although several groups of choice-determining factors were identified based on the existing literature on decisions made by patients *during* treatment, the literature review provided no clarity on the (relative) impact of these factors on the choice process which precedes the choice of a particular care provider.

8.5. Decision processes of patients with knee arthrosis, chronic depression or Alzheimer's disease

The literature review demonstrates that a better insight is needed into the actual choice processes of patients before the central research question can be answered. A study of this choice process would not only have to take note of whether patients make use of decision-supporting information in their revealed choices, but would also have to objectively identify all choice-determining factors and actors and thus embed the choice process in the social context (see also § 1.5). Chapter 4 reports on that study, in which the choice processes are investigated of three target groups: patients with knee arthrosis, patients with chronic depression and patients with Alzheimer's disease and their representatives. The fifth constituent question in this study, which is addressed in chapter 4, is: *Via which choice processes do patients with knee arthrosis, Alzheimer's Disease or chronic depression end up with a particular care provider or doctor?*

8.5.1. Knee arthrosis¹⁴

Knee arthrosis is a long-lasting disease with a deteriorating prognosis, normally without any acute events. Patients (who are mostly aged over 50 years), experience increasing *pain* and *physical and social inconvenience* caused by the cartilage in the knee, which is either caused by *age* or by (overly) intensive use of the knee joint, for example in *sportsmen* and women.

It can however take many years from the first complaints until surgery (knee osteotomy or

¹⁴ Words in italics in this section are factors or actors which influence the choice processes of patients suffering from knee arthrosis

arthroplasty) is needed or allowed (only in older patients). During this period, patients have *time* to gather *information about the cause, course, possible therapies and therapists*, especially when a diagnosis is given at younger age. In the years preceding their knee surgery they are able to grow more and more *assertive*

Some patients even deliberately *postpone* surgery, which is possible because their *condition* is not acute or life-threatening. Patients sometimes use this extra time to gather information and to gain time for better orientation (Clark et al., 2004; Hudak et al., 2002).

Sometimes, patients have *suffered from arthrosis before*. They might even suffer from *other diseases* of the locomotory apparatus as well, making them experienced health care users.

Patients' *constraints* are mostly *physical* and not mental, which enables them to *think over* and *weigh up alternatives* and, perhaps even more important, to discuss their disease and treatment options with *others (family, general practitioner, peers)*. In other words, their decision process is not covered with a veil of *embarrassment* as might be the case with other diseases. All in all, patients with knee arthrosis (potentially) can be described as a rather assertive patient group.

8.5.2. Chronic depression¹⁵

One would expect chronically depressed people to be passive, dependent patients and not assertive 'in-control consumers'. This assumption is underpinned by most of our data. A chronically depressed patient's passive and dependent attitude is even more pronounced during *crises* that occur from time to time. During these periods, one cannot speak of 'choice' or 'decision'

Another important characteristic of depression is that there is a *taboo* about being depressed and about searching for a therapist. This greatly complicates the search and selection process, because patients *feel embarrassed* to talk about their problems.

Although these characteristics are very dominant in the 'search and selection process' of people who suffer from chronic depression, there are some disease-related aspects which indicate that there should be at least some activity and assertiveness. Firstly, the prevalence of depression (and dysthymic disorder) is highest in patients *aged 20 to 45 years* (Poos, 2005), and it is known that younger persons are more often actively involved in choosing their health care provider than older people (Lupton, 1997). Besides, it is a well-known phenomenon that patients who suffer from mental disorders are often ambivalent towards therapy and their therapist, resulting in

¹⁵ Words in italics in this section are factors or actors which influence the choice processes of patients suffering from chronic depression.

switching behaviour between alternatives (Mokkenstorm, 2000). Finally, the *intermittent course* of the disease presupposes the alternate presence and absence of a *willingness* to choose. We can legitimately conclude that the patients who are chronically depressed are predominantly dependent, docile and passive. This picture might change, depending on a patient's personal characteristics and their inclination to switch therapists.

8.5.3. Alzheimer's disease¹⁶

Alzheimer's disease has a *degenerative course* that gradually affects the mental capabilities of patients. As a consequence, choices have to be made either in the *early stages of the disease* by patients themselves (see different stages below) or later on, by patients' *representatives*. This is an important notion, since it is known that representatives have different preferences from patients themselves (Castle, 2003). Our data suggest that children of patients with Alzheimer's disease tend to be more assertive and 'in-control consumerists' than for example partners of patients or patients themselves.

On the other hand, it is also a well-known phenomenon that patients and their families *deny the severity* of the disease and the potential need for professional help (Sevush & Leve, 1993). Patients and close family therefore tend to *act passively and expectantly* regarding the choice and selection of professional help (especially in the early stages of Alzheimer's disease, but we will come to this later). This attitude often leads to a *crisis*, which is a totally new situation with its own dynamics and choice and decision patterns, which also impacts on the usefulness and desired content of consumer information.

8.6. The (potential) role and desired contents of decision supporting information

The picture that emerges from the inventory of choice-determining factors and actors described above does not enable an answer to be given to the (main) question concerning the extent to which decision-supporting information could support the choice processes of patients. The next constituent question to be addressed – again focused specifically on patients with knee arthrosis, chronic depression or Alzheimer's disease – is therefore intended to narrow the field

¹⁶ Words in italics in this section are factors or actors which influence the choice processes of patients suffering from Alzheimer's disease and their representatives.

down somewhat: *What is the (potential) role and desired content of choice-supporting information in the choice processes of (these) patients?* To answer this question, the *present* role and desired content of that information is first considered (§ 8.6.1). This is based mainly on the insights that emerged from the interviews discussed in chapter 4. The *potential* role and desired content of decision-supporting information is then explored (§ 8.6.2), making use of the results of both the Q-methodological study in chapter 5 and the DCE in chapter 6. Section 8.6.3 ends with a conclusion.

8.6.1. *The present role and content of information in the choice process*

The interviews with patients and/or their representatives looked extensively at the role that decision-supporting information played in their choice processes and what the precise content of such information was. A common pattern was found in the information needs, in the form of the ‘*what, how, where and who*’ of the illness and the treatment. When the first symptoms manifest themselves, patients mainly need information on what is wrong; they then need information on how the symptoms can be reduced or even eliminated, and only after this are they interested in where this should be done and by whom.

As regards the ‘*where*’ and ‘*who*’, it must be said that decision-supporting information often played a less dominant role in the choice processes, though there was wide variation between (groups of) patients (see § 8.7). Other influencing factors, people and organisations played a more prominent role. When asked why this was, many patients reported that at the time they were *not able* to choose due to a lack of adequate care provision, were *not aware* of the choices available and of the importance of choosing (because of quality differences between care providers), or simply did *not possess* reliable and accessible decision-supporting information. Against this background, this study also experimented with offering decision-supporting information to patients in order to see what its possible role and content might be in the future.

8.6.2. *The potential role and content of information in the choice process*

In order to investigate the possible future role of decision-supporting information, a large number of choice and determining factors and actors were submitted to patients. The Q-methodological study explored how important patients consider the items referred to in § 8.5 to be in choosing a care provider or doctor. The DCE then established the relative importance of 10 or 11 of these factors and actors in a fictitious choice situation.

Patients with *knee arthrosis* shared an interest in the expected result of the treatment, the specialisation and experience of the doctor, and to a slightly lesser extent the specialisation and experience of the hospital. By contrast, patients attached little importance to advice from their employer, from medical programmes on television or from people around them who play a lot of sport or have earlier experiences with the same doctor or hospital. In reality, all choice aspects relating to 'referral/advice' are considered fairly unimportant. Other factors of subordinate importance are whether the hospital is a general or university hospital and whether the doctor or hospital in question is one chosen by top sports personalities for treatment. These findings are supported by the results of the DCE which found that the expected outcome of the operation (represented by the indicator "average before-after-degree of bending of the knees that were operated by a surgeon") had the strongest impact on the search and selection process of patients with knee arthrosis, followed by a good prior experience with the hospital and a personal match with the medical specialist during earlier contact. Travel distance, risk of wound infection and referral by GP also were influential factors, while waiting time was of least importance. Some other attributes and levels, like the type of hospital and the quality of information provision before treatment played no part in patients' decisions.

Patients with *chronic depressive disorders* attach most importance to the (confidential) relationship with their doctor. The expertise of the doctor and the expected outcome of treatment are also important, but are in clear second place. Finally, respondents reported that they also attach importance to the waiting time between the first contact and the actual commencement of care, and to the way in which intake takes place. All kinds of provider characteristics such as ideological and philosophical identity, the location and size of the care facility and the 'feel' of the buildings and rooms, are subordinate to the former aspects. This also applies for advice on care provision from friends and acquaintances, employers, fellow-dients or fellow-sufferers, a confidential counsellor or other health professionals. These results largely correspond with the findings in the DCE, where it was found that continuity of care, personal match with the therapist during earlier contact, the possibility to participate in the care process and a matching vision on treatment were considered most relevant in the choice of health care provider, waiting time was among the least relevant factors.

Patients with Alzheimer's disease and their representatives attach a great deal of importance to the care facility's expertise (specialisation and experience) with Alzheimer's disease, but also to the way they are approached by the doctor. By contrast, they attach little importance to advice on a specific doctor or care facility from fellow-sufferers with the same complaints, or from people in

their social network who have heard good or less good accounts, who work in the medical world, or who have less good experiences with a specific doctor or care facility. Advice from others is thus considered relatively unimportant. It is also of subordinate importance whether the hospital is a general or university facility and what the ideological/philosophical identity of the care facility is. These findings again correspond with the results from the DCE study, where it was found that caregiver expertise, travel distance and care delivery in accordance with agreements were the most important factors in the choice of care provider by representatives of patients with Alzheimer's disease. Waiting time again was least important.

8.6.3. Conclusion

It can be concluded that, owing to the lack of decision-supporting information and the lack of familiarity with the available choices and the need to choose, decision-supporting information does not play a prominent role in the choice processes of *existing* patients (see chapter 4). However, chapters 5 and 6 show that many patients do make use of (comparative quality) information on care provision when this is presented in choice situations in an accessible fashion and with clear explanations where needed.

Statistics on the expected outcomes and risks of a given treatment, as well as on expertise (specialisation and experience) are highly valued and are included in the choice process, and therefore lend themselves very well to comparative presentation. It is striking that advice from the patient's social network, the quality of the information provided on the treatment and the waiting time are of subordinate importance to these aspects.

The idea that (quality) information about health care providers would be overruled by what other people (social network or referrers) say, or that patients choose the nearest provider by default is clearly not supported by these results. There seems to be substantial room for consumer information in patients' decision processes.

8.7. Differences and similarities between, within and across different patient groups

The (potential) role played by decision-supporting information in the search and selection process in the case of need for health care can vary from person to person or from group to group. It can for example be imagined that patients with a disease that progresses only slowly (such as knee

arthrosis) will have more opportunities to immerse themselves in the available care provision than patients in need of acute care (e.g. a patient suffering from depression who is in crisis). Not only differences between patient groups appear relevant, but also differences within and across patient groups. In order to be able to establish the (potential) role and desired content of decision-supporting information for the choice process more precisely, the seventh constituent question addressed in this study is: Can differences be observed within and between the patient groups referred to in terms of the choice processes, choice-determining factors and actors and the (potential) role and desired content of choice-supporting information?

8.7.1. Differences between the patient groups

The study shows that the *nature* of the choice process differs widely between patients depending on whether they are suffering from knee arthrosis, chronic depression or Alzheimer's disease. Chapter 4 concludes that patients with knee arthrosis are (potentially) assertive and that many of them behave as genuine 'in-control consumerists'. Patients who are chronically depressed are predominantly dependent, docile and passive. Patients with Alzheimer's disease could be best characterised as a mix between both the docile, passive patient and the assertive, in-control consumer. Their attitude toward choice strongly depends on the relationship with the patient who suffers from Alzheimer's disease. The data suggest that children of patients with Alzheimer's disease tend to be more assertive and 'in-control consumerists' than for example partners of patients or patients themselves.

It is not only the nature of the choice process which varies depending on the disease; there are also important differences between the *factors and actors* which play a dominant role in that process. Chapter 6 showed that patients with knee arthrosis were more influenced by the expected effectiveness and safety of a treatment than those who are depressed or represent patients with Alzheimer's disease. Patient-centeredness appeared decisive in the search and selection process of patients with chronic depression but was of much less importance for representatives of patients with Alzheimer's disease, who focused much more on the expertise and competence of the care provider.

The foregoing means that, regardless of the illness, *decision-supporting information* has an important *role* to play. Apart from the patient's early experiences with a health professional, all the factors mentioned can be measured and compared using performance indicators which can then be translated into understandable consumer information. Another important correspondence

between the three patient groups is that advice from the formal and informal (care) circuit plays a less important role in the choice process than might be expected.

8.7.2. Differences between the phases of a disease

Chapter 4 showed that patients' attitudes towards choice and the (f)actors that influence their decisions are not stable and static, but vary as the disease progresses. The data show four different stages throughout the three diseases in each of which patients are more or less assertive and willing to include (comparative) consumer information in their decisions. In addition, the desired content of the information differs in each of the stages.

During the *first stage* (the emergence of the first complaints until a diagnosis is given), patients are often in a dependent, passive position (depending on what type of disease they are suffering from, as we showed above). After a diagnosis has been given (*second stage*), patients, their doctor or therapist or both together will then more or less actively search for and select the most appropriate therapy or treatment. Sometimes users develop (suddenly or gradually) from passive, docile patients into in-control health care consumers. The *third stage* is a period of health improvement or of rapid or gradual deterioration. Some people start looking actively for information to facilitate their recovery process or prepare themselves for the next step in their health care consumption. Others remain rather passive and take further developments as they come. When more severe care or a second treatment is needed (*fourth stage*) the picture is less unambiguous than it was in stage one. A patient's earlier experiences and the cause of the repeated need for treatment appear to be decisive here.

Chapter six quantitatively underpins these findings as it shows that higher severity of disease (used as a proxy for a different phase of the disease) was associated with higher weight for the interpersonal relation with the health care provider and advice by family or friends, and lower weight for the expected outcome of a treatment, travel distance and advice from their GP.

8.7.3. Differences between 'consumer profiles'

Chapter 4 concludes from the qualitative interviews that in all subgroups there were patients who showed comparable basic attitudes during their search and selection processes. Two basic attitudes were observed, which can be seen as extremities on the same sliding scale: a) patients who take up an '*in control*' or '*consumerist*' position towards their potential health care providers, and b) those who act as '*dependent, docile or passive patients*'.

Beyond this typology of basic attitudes, the data show clearly that each attitude is associated with different factors, actors or institutions that play part in patients' decision-making processes. 'In-control consumerists' appear to seek support from their general practitioners (or other primary health care workers); seeing them as sparring partners rather than experts who decide for them. Furthermore, 'in-control consumerists' actively search for information on the Internet, in libraries or via patient organisations. They are especially interested in expected outcomes, safety and risks and the expertise or experience of a clinic or doctor. At the other end of the spectrum, docile or passive patients accept, or even expect that their general practitioner or other primary care worker will be dominant, especially in the event of a referral. Their own prior experience with an institution or an existing relationship with a doctor (either good or bad) are also deciding factors for subsequent steps, as well as accounts from family or friends.

This basic division based on the qualitative material was examined in greater breadth and depth in chapter 5. It became clear there that there are only two distinctive choice profiles within the three very different groups of patients: 'focus on outcomes' and 'focus on trust'. The profile 'focus on outcomes' places the emphasis, apart from the shared basis, mainly on the result of the treatment, while the profile 'focus on trust' places additional emphasis on trust and security in the patient-caregiver relationship, whether the caregiver is a doctor, a nurse or a care institution. These results were further specified and underpinned by the DCE in chapter six. It shows that patients with a result-driven *choice attitude* attached more importance to the expected outcome of a treatment or stay, the possibility to participate in decisions during treatment and the expertise/competence of the provider than those who were driven by trust in their doctor. Besides, result-focused representatives of patients with Alzheimer's disease appeared more likely to travel a longer distance to find such a facility. Patients with a trust-focused search and selection process were much more influenced by good prior experience with a doctor, continuity of care and advice of family or friends.

8.7.4. Differences between patients with a higher and lower education level

Chapter 5 revealed the first contours of background variables which may perhaps be associated with differences in patients' choice processes. In comparison with trust-focused participants, outcome focused persons were given a diagnosis longer ago, suffered more severe and were sons or daughters of the patient with Alzheimer's disease (instead of patient himself or partner), with younger age and higher education and patients were more often institutionalized in a facility for geriatric care.

This was explored more precisely in chapter 6. Education level was found to show a statistically significant correlation with the nature of the choice process, the choice-determining factors and actors and thus the (potential) role and desired content of decision-supporting information. Higher education level was associated with higher weight for outcomes, care provider expertise, good prior experience with the hospital or doctor, and care delivery according to agreement, but less to advice from their GP. Furthermore, highly educated patients with chronic depression attached more importance to the therapist's vision on treatment and patient participation during treatment; similar relations were found for representatives of patients with Alzheimer's disease.

8.7.5. Conclusion

An important finding from this part of the study is that *the patient* does not exist. On the other hand, not all individual patients show a unique individual choice pattern when searching and selecting their health care provider. Patients' preferences can be predicted on the basis of characteristics which determine the choice process and the role and desired content of decision-supporting information: the disease itself, the phase of the disease, the consumer profile and background characteristics such as education level.

To give an impression of the variables that are dominant in different circumstances, table 2. resents an overview of the choice-determining factors with the greatest impact on the choice process for the various segments.

8.8. Methods for developing decision-supporting (quality) information for health care users

This study shows that in many cases patients do have a need for decision-supporting (quality) information when choosing a care provider or doctor. It is therefore logical to develop quality reports or lists, which patients and/or their representatives can use to compare different care providers. A good deal of experience has been gained in the United States with such 'report cards' and 'league tables' in health care (State of Ohio, 2006). In the Netherlands, report cards for schools have been in use for some time by the Education Inspectorate, and similar cards have recently been developed for use in health care (kiesBeter.nl).

Table 2. Choice-determining factors and actors with the greatest impact on the choice process

	Knee Arthrosis	Chronic Depression	Alzheimer's Disease
General population (top 5)	<p>Efficacy and safety: "Average before-after-degree of bending of the knee"</p> <p>Patient-centeredness: "Good prior experience with hospital"</p> <p>Patient-centeredness: "Personal match with the therapist during earlier contact"</p> <p>Accessibility: "Travel distance"</p> <p>Efficacy and safety: "Risk of wound infections"</p>	<p>Continuity of care: "Always the same therapist"</p> <p>Continuity of care: "A fixed team of therapists"</p> <p>Relationship with therapist: "Not such a good relationship during prior contact"</p> <p>Participation: "Client is 'in control' during treatment"</p> <p>Vision of treatment: "Vision of therapist matches wishes of client"</p>	<p>Expertise of institution with Alzheimer's: "Specialist institution"</p> <p>Expertise of institution with Alzheimer's: "Specialist department"</p> <p>Accessibility: "Travel distance"</p> <p>Meeting care agreements: "Care always as agreed"</p> <p>Efficacy and safety: "% of residents who feel safe and comfortable in institution"</p>
Consumer profile			
'outcome-focused, in-control consumers'	<p>Efficacy and safety: "Average before-after-degree of bending of the knee"</p>	<p>Participation: "Client is 'in control' during treatment"</p>	<p>Expertise of institution with Alzheimer's: "Specialist institution"</p>
'trust-focused, dependent patients'	<p>Patient-centeredness: "Good prior experience with hospital"</p>	<p>Continuity of care: "Always the same therapist"</p>	<p>Accessibility: "Travel distance"</p>

Phase of the disease

initial phase

Efficacy and safety:
"Average before-after-
degree of bending of the
knee"Relationship with
therapist:
"Not such a good
relationship during prior
contact"Accessibility:
"Travel distance"

advanced stage

Efficacy and safety:
"Average before-after-
degree of bending of the
knee"Continuity of care:
"Always the same
therapist"Expertise of institution
with Alzheimer's:
"Specialist institution"**Education level**

high

Efficacy and safety:
"Average before-after-
degree of bending of the
knee"Participation:
"Client is 'in control'
during treatment"Expertise of institution
with Alzheimer's:
"Specialist institution"

low

Patient-centeredness:
"Good prior experience
with hospital"Continuity of care:
"Always the same
therapist"Meeting care
agreements:
"Care always as agreed"

The problem with many existing report cards and league tables, however, is that the quality of the material presented leaves something to be desired. This applies for the validity and reliability of the data presented, the quality aspects included (which often do not match the needs of patients) and the accessibility (physical and cognitive) of the decision-supporting material. Shortcomings such as these are often caused by the application of unsuitable methods in developing the decision-supporting material.

The final question addressed in this study is therefore: What would be a suitable method for developing choice-supporting (quality) information for care users?

In chapter 7, building blocks were defined for report cards for nursing and care homes and for home care. This was done using the 'Concept Mapping' consensus method and 'Structured Conceptualization' (a mixed-method, participatory, group idea-mapping methodology that integrates well-known group processes such as brainstorming and unstructured sorting with a sequence of multivariate statistical methods). Chapter 7 shows that Concept Mapping can be used to identify building blocks for quality report cards. Its ability to integrate existing quality information sources and experts in the field of geriatric care supports the validity and feasibility of the content of the quality cards, while integration of consumers supports its appropriateness.

Furthermore, participation by all stakeholders helped to build consensus about the building blocks, and may be expected to facilitate their implementation.

Apart from the methodological added value of these findings, the substantive results were also found to support the conclusions in section 8.7. Although home care and institutional care share many quality themes, the findings show important differences in the preferences of patients who need institutional care versus the ones who search for home care. Therefore, separate quality report cards are needed for the two types of geriatric care. Home care consumers attach more value to the availability, continuity and reliability of care, while consumers of institutional care value privacy, respect and autonomy most.

Finally, chapter 7 supported earlier results by showing that consumers want information on structure, process and outcome indicators; rating outcome indicators such as effectiveness and safety of care highly, both for geriatric home and residential care.

8.9. General conclusion

The central research question of this thesis is: *To what extent can performance indicators be used as an aid to support the search and selection process of patients who need a care provider or doctor?*

By using a combination of research methods, this study has made clear that numerous factors and actors play a role in the search and selection process that patients go through when they need a care provider or doctor. The *structural* characteristics of the care provider (such as travel distance or available expertise), *process* characteristics (waiting times, patient-centeredness) and *outcomes* and safety of care play a greater or lesser role in that process. All of these characteristics can be very well measured and reported by means of performance indicators.

One striking finding is that for many patients the expected outcome and safety of care play a much more important role in their choice process than, say, travel distance or advice from family, friends or even their GP. The frequently heard argument that ‘the patient’ will automatically go to the nearest hospital based on a referral by their GP and on anecdotal accounts from their social network is thus certainly not confirmed by this study.

It has also become clear that the choice process by which patients arrive at their care provider or doctor varies markedly from patient to patient. Not every individual patient is entirely unique

in this respect; the study has identified a number of 'segments'. For example, the choice process is strongly determined by the (nature of the) disease, the phase of the disease, the patient's 'consumer profile' and (socioeconomic) personal characteristics.

These findings lead to the conclusion that patients have a greater or lesser need for decision-supporting information during their choice process. That need depends greatly on the variables referred to and relates both to knowledge about the disease and possible treatments and to information about quality differences between care providers.

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Chapter 9

Reflection; Implication of the Results

The results of this study are not entirely as might be expected and therefore call for further reflection, explanation and interpretation. This concluding chapter therefore places the research findings in the perspective of recent/current discussions and insights in the literature on performance indicators, without any attempt at completeness (9.1). Partly on the basis of that literature, the chapter then reflects on the methods used in this study (9.2). This gives rise to a number of challenges for the development of performance indicators going forward and for the dissemination of consumer information (9.3). All this culminates in a research agenda (9.4) and a policy agenda (9.5) based on the theme 'the patient as change agent in health care'.

9.1. Reflection in the light of discussions in recent literature

9.1.1. *Current discussions at a glance*

Chapter 2 and section 8.1 have already looked in some detail at the suitability, use and desirability of performance indicators as decision-supporting information for care users. Discussions on these matters are still in full swing today, at both national and international level; new life is breathed into them at intervals by politicians wishing to score points, or they are enriched by scientists with new research results.

In the Netherlands, for example, Professor Roland Bal delivered an inaugural lecture on 29 February 2008 entitled 'A new visibility. Control in times of market forces' ("De nieuwe zichtbaarheid. Sturing in tijden van marktwerking"). One of the (main) lines of argument in his lecture was that transparency and product information are not necessary for the functioning of a market and that transparency in health care has today become a value in itself rather than a means of achieving goals such as quality improvement. If we listen carefully to Bal, we are presented with a somewhat sorry picture of what he describes as 'New Public Management' in health care and what he uses to illustrate the most tangible expression of it: the use of performance indicators. Bal describes a situation in which no one benefits in practice from this form of transparency. In the first place, care providers focus primarily on recording the required indicators better, which does absolutely nothing to improve the quality of the data and does not by definition improve the quality of care (Bal, 2008 p. 16). Secondly, the learning ability of the government (the Dutch Health Care Inspectorate) declines because performance indicators produce only a very limited picture of the quality of care in an institution (ibid, p.17). Thirdly – and this is of particular importance for

this thesis – Bal asserts that patients will not (in large numbers) make choices based on quality information. He not only bases this assertion on his own research among policymakers in Dutch health care, but also makes reference to international authors (Marshall et al, 2002; Hibbard, 2008): *“The quality information offered via the website and in the rankings is not really suitable for making choices; patients do not really trust the information offered and moreover would prefer not to make these kinds of choices at all, as the literature shows”* (Bal, 2008 p.3).

The argument by the (former) professor Margo Trappenburg follows the same line. Coincidentally or otherwise, but at any rate on the same day as Professor Bal delivered his inaugural lecture, she published a column in the *NRC Handelsblad* national newspaper entitled: ‘The plumber model in the care system’ (‘Het loodgietermodel in de zorg’) (Trappenburg, 2008). In this column, Trappenburg expresses her concerns that health care may be developing into a market where providers specialise and care users can no longer obtain care everywhere without question. This line of thinking by Trappenburg does not come out of the blue; in her inaugural lecture in January 2005, she spoke out explicitly against the phenomenon of increasing freedom of choice for patients. Among other things she argued that *“people are generally not exactly wild about having to make choices, and absolutely not when it comes to health care”*. In response to the question of whether people are not very different in their willingness to make choices and in what they regard as good doctors or good hospitals (we do after all live in a pluralistic society, including in this regard?), Trappenburg states: *“I would venture to doubt that. I think people resemble each other quite closely in their wishes with regard to health care. We want effective medical care, as few unpleasant side-effects as possible, good information and friendly health professionals. It really is not much more complicated than that”* (Trappenburg, 2005, p.19).

What is it that links the view taken by these two scholars of the willingness of patients to choose and the usefulness of consumer information to support that choice? Ideologically this is difficult to discern, and it is therefore more useful to look at the substantiation of their arguments. Broadly speaking, they base those arguments on the same authors and studies.

Bal refers first and foremost to a study of patient attitudes to comparative quality information on general practitioners (Marshall et al. 2002). It is however very much open to question whether the choice of a GP is comparable to the choice of an actual, temporary and reasonably well-defined

care product such as Total Knee Arthroplasty or talk therapy for depression. And the situation will be completely different when it comes to radical lifelong choices such as the choice of a residential care facility for an Alzheimer's patient. A study carried out 20 years ago by Salisbury (1989), for example, revealed little or no willingness on the part of patients to switch their GP, except when moving house; the interpersonal, emotional relationship which has often been built up over a long period creates a strong bond between doctor and patient. Given the uniqueness of this relationship, it is not defensible to draw conclusions about the choice by patients for a GP and then generalise these to choice situations in other areas of health care. It can also not be argued on the basis of this kind of study that patients (in general) will not use decision-supporting quality information in making their choices.

Trappenburg's argument can ultimately also be traced back to a (review) study by Marshall et al. (2000). This study was discussed in chapter 2 and was found to be problematic for two reasons as a substantiation for the claim that patients (in general) do not choose on the basis of decision-supporting information. First, because they look at 'the care user' in a general sense, without making a distinction based on the different roles that the care user can fulfil (...). A second weakness is that they fail to place the relevance of performance information in a dynamic future perspective. And this is despite the fact that it is known that patients are rapidly becoming more assertive and that the Internet is used by many as an important source of information (Adams, 2006).

Another important source for Bal's argument is a recent discussion by Hibbard (2008) of an extensive literature review by Fung et al (2008). That literature review included 45 studies of the impact of public disclosure of quality indicators in health care. Fung and colleagues use Berwick's framework of the two pathways (see also chapters 1 and 2) to describe the impact on the selection of health plans, hospitals and individual providers, their quality improvement activities and the (unintended) outcomes they deliver. Close analysis of this review shows that it certainly does not provide a basis for the conclusion that patients do not (wish to) involve publicly disclosed quality information in their decision processes. Regarding Berwick's pathways Fung and colleagues conclude that "*studies of the effect of public reporting on outcomes provide mixed signals (...). We found additional support for the conclusion that public reporting stimulates hospital quality improvement activity, although studies were mostly descriptive in nature and had low global ratings.*" In their reflections, they put forward the following as a possible explanation

for these mixed results: *“We suspect that “upstream” design and implementation issues affected “downstream” selection and quality improvement pathways and end points (effectiveness, patient safety, and patient-centeredness). Evidence suggests that poorly constructed report cards may impair consumers’ comprehension of these measures and may cause consumers to make decisions that are inconsistent with their goals. (...) It is possible that design and implementation issues, if sufficiently improved, could increase the impact of publicly reported performance data (...)”.*

Hibbard (2008) aligns with this view in her discussion of the review. She puts forward three explanations for the widely varying outcomes of existing research into the use of publicly disclosed quality information: *“First, consumers are largely unaware of the ubiquitous quality problems in health care. Consequently, most consumers assume that the technical quality of care is uniformly high. Second, although research shows that consumers care very much about the quality of medical care, they define “good quality” differently from experts and industry leaders. Consumers’ conceptualization of quality of care differs from the way in which it is measured and reported publicly. Consumers are not likely to make full use of quality information until they understand the measures of quality in these reports. Third, the tasks involved in using public reports (for example, processing a large volume of information, weighing some factors more than others, and bringing all the factors together into a choice) are cognitively burdensome”.* Hibbard thus does not argue that patients (will) make no use of decision-supporting quality information, but concludes that *“we should not interpret the results of Fung and colleagues’ systematic review as an indication that we should give up on consumers as important actors in the quality improvement equation and move on to a new paradigm. Rather, they suggest that we should improve the execution of public reporting efforts and only then reevaluate the effect of public reporting on quality”.* After all, *“inconsistent execution yields variable results”.*

9.1.2. Thesis results in the light of the recent literature

The results of this thesis underpin Hibbard’s analysis above and take away some of the force of the argument of sceptics who claimed that ‘the patient’ does not wish to make use of these kinds of choices at all. Instead it is found that patients, to a greater extent than has been assumed to date, do indeed include decision-supporting quality information in their choice process, provided the right parameters are met.

First, Hibbard attributed the apparent indifference of patients to publicly disclosed quality data to the fact that they do not realise that there are important quality differences in health care. This

line of reasoning is based on the fundamental idea in (health care) marketing that a willingness to choose begins with the presence of 'observed product differences' (Nillesen, 1993). Chapter 4 made clear that many patients interviewed did indeed not realise that they had choices, let alone that the quality of care could differ between different care providers. It was for this reason that explicit attention was devoted in the choice experiment (chapter 6) to the quality differences between care providers. In each choice situation, careful consideration was given to the relationship between the attributes (described using quality indicators or situational descriptions) and their meaning for the quality of care delivered. This working method probably explains why substantial groups of patients in this study did indeed involve decision-supporting quality information in their choices and were guided above all by aspects relating to the efficacy and safety of the care.

Hibbard's second point is closely related to this, namely that patients often have a different understanding of quality from professionals or other experts. They are inclined only to include that information which fits most closely with their frame of interpretation. If we look at the methods used in this study to define the right (comparative quality) information for patients' choice processes, the 'bottom-up' method is immediately noticeable. This applies both for the definition of the attributes and levels for the DCE (chapter 6) and for the development of building blocks for the quality report card for geriatric care (chapter 7). In both cases (group) interviews with patients and experts were combined with a hybrid qualitative/quantitative research method (respectively Q-methodology and Concept Mapping) in order to arrive at recognisable and supported information in support of choice. Using this method provided an optimum match with the real world of patients and the meaning they assign to quality.

Finally, Hibbard argues that the cognitive burden of a choice must not be too heavy or patients will refuse to make it. The choice simulation in this thesis is a good example of this (chapter 6). Care providers were consistently described using 10 or at most 11 characteristics, each with three possible levels. As stated, these characteristics were consistently explained in an accessible manner. This contrasts with many choice-supporting initiatives, in which hundreds or sometimes thousands of care providers are compared with each other in all kinds of complicated league tables using star and points systems.

Not only do the results of our study negate the argument that 'the patient' is not willing to choose based on decision-supporting (comparative) quality information, but it also makes clear that it is impossible to maintain that *"people resemble each other quite closely in their wishes with regard*

to health care. We want effective medical care, as few unpleasant side-effects as possible, good information and friendly health professionals” (Trappenburg, 2005, p.19). In practice, therefore, it absolutely is “more complicated than that” (ibid). This study has made clear that the focus applied by patients when they are looking for care can vary widely from patient to patient. There are patients with a more active and ‘in control consumerist’ profile and those with a more passive, docile patient profile. Chapter 5 shows that these profiles are associated with type, phase and severity of disease, information search behaviour, and education level. Chapter 6 elaborates on these findings and shows that patients prefer higher outcomes and safer care over good information and nice interpersonal treatment, depending on characteristics such as the type and stage of the disease and a patient’s education level. These findings are strongly underpinned by three recent studies that were published in a patient-decision special of The International Journal for Quality and Safety in Health Care in April 2008. Wilkinson et al. (2008) and Duggan & Bates (2008) show that a patient’s diagnose and disease have a significant bearing on his information desires and degree to which he/she wants to play an active role in decision-making. They claim that “it is important for healthcare professionals to identify and understand that patients with different diseases have different desires for information”. Regarding the influence that patients’ education level has on their preference pattern, Davis et al. (2008) found that “less educated or unemployed patients are less willing to challenge healthcare staff regarding the quality of care than to ask healthcare staff factual questions”. These results are in line with the findings that were presented in chapter 6. There we saw that less educated people’s decisions were stronger influenced by factual data and that more educated patients based their choice on performance indicators about the quality (effectiveness and safety) of care.

9.2. Reflection on the methods

9.2.1. Strength of the multi-method approach

The introduction to this thesis (chapter 1) looked in detail at the methodological imperfections of many existing studies. Four important (clusters of) problems with modern research emerged: modern research 1) studies ‘the care user’ in a general sense; 2) investigates patients’ decision-making behaviour at a macro-level, seeing patients’ health care decisions as an economic concept of rational choice and conceptualising the patient as synonymous with

homo economicus without opening the black box of the wider *social context*; 3) leaves trade-offs between factors unidentified; and 4) uses material that is not really suitable as decision-supporting information.

This thesis meets all these objections and requirements by applying five different research methods to the same subject. Moreover, very carefully considered sampling methods were used in each constituent study. For example, the empirical part of this thesis (1) was carried out among three divergent groups of care users: patients with Knee Arthrosis, patients with chronic depression and patients with Alzheimer's Disease and their representatives. This thesis meets the second issue (2) by operationalising 'the choice processes of patients' as 'the way in which patients arrive at their care provider and doctor'. This process was thus studied in breadth and in all its facets and not simply reduced to a single decision moment. It was in no way certain in advance that choice-supporting information would play a role in that process, but all choice-determining factors and actors were included which according to patients influence their choice processes (Grounded Theory approach in chapter 4). Although the choice process was simulated at a later stage and reduced to a single decision moment (DCE in chapter 6), this was done in the light of the preceding analyses of the social context. Another unique feature of this study is that the social context was also involved in the (rational) choice experiment by incorporating aspects from the patient's social network in the vignettes.

Another unique feature is the *combination* of methods used to arrive at a preference model, with a manageable number of choice-determining factors which moreover offers an insight into the trade-offs made by patients when choosing a care provider or doctor (3). In the Q-studies (chapter 5), patients were challenged to make an actual distinction between more less influential factors and actors. Although the Q-method did not make the relative importance of these clear, these trade-offs subsequently became visible in the DCEs (chapter 6).

Finally, the study approach was designed to generate high-quality choice material for the DCEs (4). The vignettes had to consist of recognisable and appealing attributes which matched the world in which patients live. It was therefore decided to use a layered approach involving interviews and the Q-studies among patients, supplemented by the input of subject experts. In addition, chapter 7 presents a method for arriving at supported and recognisable choice-supporting information for patients in a series of steps.

9.2.2. Study limitations

Although it anticipates known objections to existing research as far as possible, this study, too, naturally has its limitations. The specific limitations are discussed in detail for each individual constituent study, and are therefore not repeated here. One important limitation does however merit discussion here, namely the fact that patients' choice processes were perhaps not followed as closely as they might have been. In the qualitative part of the study discussions were held with patients who would be choosing a care provider in the near future or who had done so in the recent past. In the Q-studies, a comparable group of patients were asked about the importance of relevant choice-determining factors. Finally, in the DCEs, (future) patients and representatives of Alzheimer's patients were asked to choose between two fictitious care providers. Although DCEs have generally been shown to be reliable and valid (Ryan & Gerard, 2003), this remains a simulation of reality and there is always a question-mark as to whether what people *say* they do or prefer (stated preferences) corresponds in practice with their actual choices (revealed preferences).

The reason that a study was not carried out for this thesis of patients' revealed preferences is that at the time of the study (2003-2007) insufficient (comparative) decision-supporting (quality) information was available for relevant groups of patients. ZonMw did moot the possibility in mid-2004 of setting up a number of 'trials' in which offering consumer information would enable experiments to be carried out (and therefore also allow discrete research designs to be formulated), but unfortunately this was not carried out. More importance was attached to developing decision-supporting quality information for as many groups of patients as possible and as quickly as possible. Following this line of reasoning for the choice processes that patients go through, research such as that carried out in this thesis was a logical step.

9.3. Challenges for indicator development and the dissemination of consumer information

The study results teach us some important lessons both for the development and dissemination of health care consumer information. This section discusses both elements.

9.3.1. *Indicator development*

Chapter 2 largely consists of a paper that was written in 2004 and published in 2005. It ends with some striking contradictions in the area of performance indicator development. One of these contradictions was: *“The existing performance information on health care is closely tied to specific sectors and institutions. This conflicts with the idea of demand-driven care and integration of the care provision.* The chapter ends with a proposal for linking quality to actual care products, for example Diagnosis Related Groups (DRGs).

In 2008, the results of this thesis confirm this idea. Chapter 4 shows that patients who are confronted with symptoms first ask the question: “What do I have?” The next question is: “What can be done about it?” and finally (if they are sufficiently aware of the existing product differences): “Where is the best place to get treatment?” Following this line, patients will always link their choice of a care provider to the desired therapy or treatment for their disease. It is therefore all the more surprising that many current providers of decision-supporting quality information concentrate on comparing care providers, as for example the Elsevier study of the best hospitals or the AD top-100 hospitals. A much more useful exercise would be to develop indicators for measuring and comparing the quality of care products, such as DBCs. The DRGs produced by different providers can then be compared with each other. A nice recent example of this is the development of indicators for 80 DRGs for the Dutch Ministry of Health, Welfare and Sport. Increasing this number is desirable in the near future, as is extending the initiative to other sectors than hospital care. The same applies for the development of chain-DBC's to expose the (provider-independent) performance delivered by the chain as a whole.

The second thing to be learned from this study is that it is crucial when developing indicators for consumer information to take account of differences between diseases, phases within a disease and background characteristics of patients, such as search behaviour and education level. Profiling or segmentation of patients is extremely important in this regard and ensures a better ‘fit’ between the choosing care user and the decision-supporting (quality) information available to them. To date, the main investments have been in ‘shop window information’ for patients (factual information about facilities, the approach to patients, service and the structural characteristics). Whilst this may meet the information needs of patients with a choice profile that is based on ‘trust’ and ‘relationship’, these patients are sometimes in the minority. For most patients it is therefore of the utmost importance that investments are now made in the near term in good outcome indicators for the effectiveness and safety of health care. Further development of indicators and

consumer information without providing customised choice-supporting information for different 'client segments' will lead to unusable material and to even more (unnecessary) criticism by sceptics of the notion of providing support for the choosing citizen.

9.3.2. *Dissemination of consumer information*

As regards the dissemination of comparative quality information for health care consumers, this study (and a reflection on very recent research) shows that *knowledge transfer on the existence of quality differences in health care* is crucial. Although the public disclosure of performance information can of itself contribute to this awareness, it is also known that this information has the most impact on patients who realise that 'paying attention to quality pays'. A parallel campaign to draw the attention of citizens to the usefulness of quality comparisons would therefore be exceedingly valuable.

Secondly, the research findings show that *allowance must be made for differences in the preferences of different groups of patients* and their next of kin not only in the development of information, but also in its dissemination. A good example of this is the addition of a functionality to quality comparison websites which identifies the 'consumer profile' of the visitor at the start of a search action. By asking a few simple questions, this enables a 'basket of preferences' to be put together, so that care products can be weighed and compared in a more targeted and customised way. Although at the time of writing the first conversations have already taken place with providers of choice sites, based on the present study results, 'customised solutions' such as these are still some way in the future for most compilers of consumer information (owing to government restrictions). This leads to fears of the worst for choice-supporting information that is developed in the coming period. Ignoring the different 'client segments' in health care will lead to unusable care comparisons and thus to even more criticism from 'choice sceptics'.

Thirdly, the results of this study show that some health professionals or organisations impose a heavy stamp on the further course of the disease right from the start of a patient's 'disease career'. While the degree of influence that a GP, a social worker or a social psychiatric nurse, for example, has on the choice process varies depending on the disease, the phase of the disease and the patient's background characteristics, in all cases such health professionals do play *some* role. It is therefore logical that these *health professionals*, but also other bodies which (help) determine patient choices, such as the Care Needs Assessment Centre (CIZ) should *be involved in making*

patients aware of differences in the quality of care and mobilising them to help patients make sound choices for high-quality care.

Finally, it was found to be crucial in this study that the information is presented in an understandable and clear way to the patient. It will remain critical for future choice-supporting initiatives to devote maximum attention to adequate communication. Judith Hibbard (2008) says on this subject that until now, *“the content and format of public reports have been flawed. Reports have been difficult to understand and use, have not adequately communicated what quality of care is, and have not convinced consumers to pay attention to quality”*. Hibbard accordingly calls for improvements in the publicly disclosed information for consumers. In doing so she refers to studies which explicitly devote a good deal of attention to the subject of Report Cards. *“One public report displayed data in a format designed to facilitate use of the information. In that study, public reporting stimulated both quality improvement efforts and improved effectiveness”*.

9.4. Agenda for future research

Before concluding this chapter with a policy agenda, a number of recommendations are given below for future research so that the insights obtained can be further expanded and deepened.

First and foremost, it is important that the choice processes through which patients progress in the search for a care provider/doctor be mapped out for a range of diseases or care needs, and also what the role and desired content of decision-supporting (quality) information might be in that process. This will create a clearer insight into the dilemmas confronting patients who are in search of care and would enable decision-supporting information to be developed in a more targeted way. Chapter 3 clearly demonstrated the importance of such research, all the more so because current research is limited to the choices made by patients during treatment, and excludes the choices in favour of a particular care provider or doctor. In filling this gap with future research it remains important that, as in this thesis, the choice process is not narrowed down to a rational judgment process, but it is investigated within its social context. The methods used in this future research would need to be constantly refined, so that a better insight is obtained into the judgment process that takes place in the social network and in the mind of the patient.

As stated, this thesis did not investigate whether patients actually convert their stated preferences into revealed preferences in practice. To date, only one study has been carried out into both the stated preferences and revealed preferences of patients: the London Patient Choice Project (LPCP) (Burge et al., 2005; Picker Institute, 2005). In this large-scale study, patients who had had to wait more than eight months for elective surgery were given an opportunity to go to an alternative hospital with a shorter waiting time. 82% of the patients said they would consider an alternative hospital (people in paid employment, people with a higher education level and people with a high income were significantly more often inclined to choose an alternative hospital). Ultimately, only 32% of these were offered an alternative. Of these, 67% actually chose the alternative hospital. In choosing an alternative hospital, patients were interested mainly in its location, the length of the waiting time and the travel facilities (for family and friends). 33% of the 'choosers' would have liked more information on follow-up care, the quality of care, the expertise of the surgeons, the surgical success rate, hygiene and safety. One interesting fact was that patients who had made a conscious choice were many times more satisfied with their hospital experience than those who were treated in their local hospital. The researchers ultimately came to the conclusion that market forces only improve the quality of care if patients are able to act as genuine consumers. In order to make clear to them the differences between care providers, patients and GPs need accessible and reliable information on what they may expect in terms of quality of care. In order to give everyone in the country the same opportunity to make choices, people need to be made aware of the choices they have (Picker Institute, 2005). The research results presented in this thesis underpin the earlier findings of the LPCP, which ultimately also investigated patients' revealed choices. While this gives some cause for confidence that the outcomes found here will be translated into actual behaviour, a second recommendation of this thesis is nonetheless that this be thoroughly investigated in future research. Only then can substantiated investments be made in developing suitable choice-supporting information for those target groups that make use of it.

A third recommendation is that the effect of existing and new decision-supporting initiatives be monitored over an extended period both nationally and internationally. The existing research is usually limited to a few overly familiar international settings, whereas the number of initiatives both at home and abroad is increasing rapidly. Fung et al (2008, p121) issue the following warning in this connection: *"If the past 7 years are any indication of what the next 7 years will look like, we can expect more studies about the same few reporting systems and little evaluation of many of the prominent public reporting systems unless better coordinated funding and research strategies are*

implemented". In the Netherlands this would mean that research should as a minimum be carried out into the impact of sites such as KiesBeter.nl, the AD top-100 or the annual Elsevier survey.

This study has shown that the quality of choice-supporting information and the choice setting are very important for the extent to which patients incorporate this information (e.g. performance indicators) in their choice processes. Some of these parameters were discussed earlier, but the purpose of the study was not to ascertain the best principles and conditions for offering consumer information to patients. Research on this (and this is at the same time the fourth recommendation) is desperately needed in order to give present initiatives the best possible chance of success. This is in line with a recommendation by Hibbard (2008, p.161) that *"(...) the content and format of public reports have been flawed. Reports have been difficult to understand and use (...). We should improve the execution of public reporting efforts and only then reevaluate the effect of public reporting on quality"* Fung et al. (2008) recommend that *"research is needed on the effect of report design and implementation on the report's impact"*.

A fifth area of research, and one which is currently virtually untapped, concerns the (causal) relationship that has been demonstrated in some studies between the comparison and publication of quality data and subsequent improvement initiatives and quality improvement. This means not just research into Berwick's 'pathway I' via selection by patients, as has been done here, but also research into the influence of other stakeholders within this pathway (referrers and purchasers) and via pathway II or internal improvement, intrinsic motivation and the driving force of reputation. Fung et al (2008, p.121) also call for this type of research: *"finally, studies should examine empirically the causal pathways through which public reporting influences quality of care"*.

Finally, this thesis makes a plea for the research carried out and the methods used here to be made available and accessible for market research by care providers themselves. Providers operate in an ever more dynamic care delivery and funding market where they have to fight for the favour of patients and their insurers. Knowledge of other market segments and their motivations for choosing or rejecting a particular care provider is crucial for care providers. Just as the market fails if patients have insufficient knowledge about the care product to be delivered (information asymmetry), so there is a risk that the care market will fail if providers have insufficient insight into the motivations of their clients (an example of 'inverse information asymmetry'). The present

study offers important insights and methods to enable care providers to obtain a better picture of the wishes and motivations of various client segments.

9.5. Agenda for health care policy: patients as change agents

This study investigated the choice processes via which patients ended up with a particular care provider in the past (chapter 4), how important various choice-determining factors are for different types of choice (chapter 5) and what the relative importance of these factors is if patients in a simulated choice setting are asked to choose a care provider or doctor (chapter 6). From the findings it was concluded that large groups of patients would like to base their choices on choice-supporting quality information. The great importance that substantial groups of patients attach to indicators of the efficacy and safety of care can be described as particularly striking. An important condition here is that the right parameters are met (such as cultivating a sense of urgency with respect to quality differences, explaining the information properly, presenting clear choice situations). It is useful to end this thesis with an answer to the question: "What do these insights mean for (government) policy in relation to the role of the citizen as a 'change agent' in the care market?"

First and foremost, these research results provide support for the present government policy of allowing citizens to take more responsibility for their own health, including with regard to obtaining the necessary care and support. Provided the government ensures that the necessary parameters are in place, it can indeed withdraw as the dominant party in the care market and instead assign a key role to citizens and patients (both individually and collectively). The Dutch Ministry of Health, Welfare and Sport (VWS), for example, could then focus on issues such as:

- Emphasising the existence of quality differences and the importance of having an insight into them when making care choices;
- Overseeing the development of good (outcome) indicators and ensuring they are measured in a uniform way (e.g. via the Dutch Health Care Inspectorate IGZ);
- Ensuring that comparative quality information on care is accessible for citizens;
- Encouraging 'frontline' primary care workers and care needs assessors to draw the attention of patients to quality comparisons when they have to make care choices;

- Ensuring that patients actually have choices. There must be no absolute scarcity of supply which effectively removes the ability to choose. To achieve this, there will always need to be a slight supply surplus, something which the present Dutch government is in fact aiming for (Capaciteitsorgaan, 2008)

Secondly, the results of this study breathe new life into the discussion on who is the right actor to 'direct' the care market. A view which has held sway with many people since the first discussions about a system change is that health care insurers are the appropriate party to fulfil this role. The argument is that insurers acting on behalf of their clients (in another role: patients) could act as the best 'countervailing power' by contracting good-quality care for them at acceptable prices. Many question-marks have since been placed against this construction, chiefly because insurers have to date not fulfilled their role as selective contracting parties; virtually all health care insurers continue to contract all available care (and even advertise the fact!) without taking into account the (sometimes considerable) differences in delivered quality. Care purchasing is still dictated mainly by price (Schut, 2007).

In one of her articles, Professor Trappenburg welcomes this trend (Trappenburg, 2008): "*Luckily*", she says, "*insurers have decided on our behalf that we are not interested in 'selectively contracted care'. This would mean that, depending on the terms of the policy, a patient would be able to go to hospitals A and B for oncology, C and D for paediatric medicine, X, Y and Z for surgery and F, G and H for GP care. As a rule, health care insurers simply contract all care providers so that we - when we are looking for a GP, a paediatrician, a surgeon or an oncologist - do not have to go through the misery akin to that of spending a Saturday morning looking for a plumber to mend the boiler*".

The results of this study contradict this view, however: patients most definitely *are* interested in the difference between good and less good quality of care and are also willing to take their knowledge about those differences into account in making their choices. If insurers do not take this (fully) into account or even ignore it, there is justification for asking whether they are the appropriate 'change agents' in the care system, or whether a greater role should be assigned to the patient in this regard.

Of interest in this connection is an article by Berg et al. (Berg et al, 2006) in which they claim that the ever-increasing costs of care and the lag in quality (which lead to a 'zero sum game') are caused largely by the fact that competition is taking place at the wrong level, namely between care institutions and between insurers – whereas in practice there are wide quality differences

within institutions and insurers are not capable of differentiating on the basis of quality (in terms of both purchasing and policy). They come to the conclusion that no one (not the insurer, not the care provider and not the patient) benefits from having the care market dictated by the insurers. *“It is virtually impossible for insurers to gain a meaningful grip on the content of the care delivered. Moreover, for the government the dilemma is that giving the lead role to insurers offers no prospect of a controlled development of costs within the basic health care package. There is no other sector where this lead role is assigned to an insurer. Innovation, improvement, renewal and increasing value for money are always driven by providers, encouraged by consumer behaviour. Ultimately, patients are not really interested in institutions or insurers”.*

It has emerged from the present study that patients are mainly interested in an integrated response to their care needs (care products). In this regard it would seem more logical that patients choose a good-quality care provider as soon as they become ill rather than having to consider the quality of care when taking out a health insurance policy whilst they are still in good health.

What Berg et al. (2006) accordingly propose is a system that *“incentivises the patient to search for high-value care, so that providers have to provide better care more efficiently than their competitors. This can be done by linking copayment to value: (i) no copay for patients choosing a high-value provider and (ii) a copay (calculated as a percentage of the product’s costs) for patients who opt for a more expensive and/or lesser quality provider. This would be ‘consumer-driven health care’ at its best: a market revolving around the choices of the patient, guided by a system of meaningful copays. Paying a copay for care that is equally good but more expensive is acceptable; why should society pay for luxury or status, for example, that does not translate in outcomes measured?”*

The research results in this thesis thus fit in seamlessly with a system which assigns a key role to the patient in a relationship with the care provider and uses the patient as the natural ‘change agent’ in the care market. Moreover, this system offers the necessary incentives for patients to adopt a more critical attitude towards the available care provision. The realisation of how important it is to take note of quality differences would increase if financial consequences were attached to the unnecessary use of care of poor quality.

9.6 At last...

This thesis has shown that the development, and dissemination of health care consumer information by means of performance indicators has a large potential impact on patients' search and selection processes. For everyone involved in the field of health care, whether patient, doctor, insurer, policymaker, researcher or a developer of consumer information, the same thing applies: the question is not whether patients are able or willing to choose, but when they will start doing this and what you will do to facilitate them: it's your choice!

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About the Author

Antonie Steven (Stef) Groenewoud was born in Amersfoort, the Netherlands, on 24 May 1977. In 1995 he completed his pre-university secondary education (Athenaeum) at Ichthus College in Veenendaal.

From 1995 to 2000 he studied at the institute of Health Policy and Management (iHPM) at Erasmus University Rotterdam (EUR), where he graduated with a Master's dissertation on integrated care pathways. From 1997 to 2004 he studied Law at EUR and Utrecht University.

Between 1999 and 2000 Stef worked as a business analyst for the Deloitte & Touche health care advisory group. From 2000 to 2007 he was employed as a research fellow at the iHPM/EUR, where he developed a special interest in the field of health care quality, performance measurement and performance indicators. After having carried out several research projects in this field, he initiated the project "Search and Selection Processes of Patients (...)", funded by the Netherlands Organization for Health Research and Development (ZonMw), which led to this PhD thesis. In addition to the research for his thesis, he was also involved in teaching and supervising both Bachelor and Master's students.

Since 2005, the author has been working as a senior consultant at Plexus Medical Group, a leading consultancy serving clients across the broad spectrum of the health care sector. Topics covered in his recent work at Plexus include the development and evaluation of national sets of performance indicators for geriatric care, care for the disabled and forensic care, a benchmark instrument for Frail and Elderly care in hospitals, business process redesign projects in hospital ambulatory care settings and in primary health care centres.

Samenvatting

De Nederlandse gezondheidszorg heeft de afgelopen jaren de meest ingrijpende wijzigingen ondergaan sinds de Tweede Wereldoorlog. Zelfs niet-ingewijden weten dat inmiddels 'de marktwerking' zijn intrede in de zorg heeft gedaan. Zo moesten alle Nederlanders voor 1 januari 2006 een zorgverzekeraar kiezen. Ook niet kiezen betekende in feite een keuze. Maar niet alleen als verzekerde, ook als patiënt krijgen burgers steeds meer keuzevrijheid, keuzemogelijkheden en daarmee keuzeverantwoordelijkheden. De meeste beleidsmakers en wetenschappers zijn er van overtuigd dat burgers in zo'n ingewikkelde omgeving als de zorgverleningsmarkt niet weloverwogen kunnen kiezen, zonder dat zij eerst goed geïnformeerd zijn over de prijs en de kwaliteit van de behandeling en/of verzorging. Het vaststellen van de kwaliteit van een zorgproduct blijkt daarbij veel moeilijker dan het vertalen van de kosten ervan in een prijs (die de burger zelf bovendien meestal niet ervaart). Daarom is er in zowel beleid als onderzoek veel aandacht voor het bepalen van relevante kwaliteitsaspecten, het meten, het publiek maken en het vergelijken van resultaten. Prestatie-, of kwaliteitsindicatoren worden daarbij steeds vaker ingezet als middel voor transparantie.

Dit proefschrift onderzoekt en beantwoordt, met behulp van zeer uiteenlopende onderzoeksmethoden, de vraag in hoeverre prestatie-indicatoren een rol (kunnen) spelen in het keuzeproces van patiënten die op zoek zijn naar een zorgaanbieder of behandelaar.

Hoofdstuk 1 geeft een inleiding tot deze probleemstelling. Het beschrijft de recente ontwikkelingen die het Nederlandse zorgstelsel veranderden van een aanbodgericht in een vraaggericht systeem, gebaseerd op de principes van gereguleerde marktwerking. Het legt verder de achilleshiel van dit systeem bloot, door te wijzen op de asymmetrische kennisrelatie tussen vragers (patiënten) en aanbieders (zorgverleners) en het belang van keuzeondersteunende informatie voor patiënten. Dit leidt ten slotte tot de genoemde onderzoeksvraag.

Het vervolg van het proefschrift bestaat (afgezien van de hoofdstukken 8 en 9) uit drie delen:

Deel I: prestatie-indicatoren en keuzeprocessen: verkenning van het fenomeen en de theorie

Hoofdstuk 2 beschrijft de opkomst van het fenomeen prestatie-indicatoren. Daarna gaat het hoofdstuk in op de functies die prestatie-indicatoren kunnen hebben: externe verantwoording, interne kwaliteitsverbetering en onderzoek. Vervolgens komen de discussies aan bod die gevoerd worden over de geschiktheid, bruikbaarheid en wenselijkheid van het inzetten van prestatie-indicatoren ter ondersteuning van het keuzeproces van patiënten. Sommige auteurs betogen dat prestatie-indicatoren naar hun aard (zij geven slechts een indicatie van kwaliteit in plaats van deze onomstotelijk vast te stellen) niet geschikt zijn als keuzeondersteunende informatie. Anderen stellen dat 'de patiënt' (wie dat ook moge zijn), zijn keuze voor een zorgaanbieder toch niet baseert op kwaliteitsinformatie, zodat prestatie-indicatoren voor dit doeleinde onbruikbaar zijn. Weer anderen betwisten de wenselijkheid van prestatie-indicatoren voor patiënten, omdat, volgens hen, patiënten helemaal niet willen kiezen en hiervan alleen maar ongelukkig zouden worden. Veel van deze argumenten zijn echter sterk generaliserend en niet gebaseerd op gedegen onderzoek, zodat hoofdstuk 2 concludeert dat prestatie-indicatoren in principe bruikbaar kunnen zijn voor keuzeondersteuning, maar dat onderzocht moet worden in hoeverre ze ook daadwerkelijk een rol zouden spelen in het keuzeproces van patiënten, als ze in voldoende mate en op toegankelijke wijze beschikbaar zouden komen.

Het tweede deel van hoofdstuk 2 doet verslag van een inventarisatie van bestaande kwaliteitsinformatie, die werd uitgevoerd aan het begin van deze studie (2002-2003). Vergelijking hiervan met door patiënten gewenste informatie leerde ten eerste dat er destijds veel kwaliteitsinformatie bestond, maar dat dit nauwelijks beschikbaar was voor individuele patiënten. Ten tweede ging de meest kwaliteitsinformatie over zorginstellingen, terwijl patiënten in eerste instantie op zoek zijn naar een zorgproduct (behandeling en/of verzorging). Een derde en laatste constatering van hoofdstuk 2 is dat er destijds veel keuzeondersteunende initiatieven ontstonden, maar dat er nauwelijks of geen aandacht was voor de informatiebehoefte en het keuzeproces waarlangs patiënten bij hun zorgaanbieder of behandelaar komen.

Hoofdstuk 3 doet verslag van een literatuuronderzoek naar de bestaande kennis over de keuzeprocessen van langdurig zieke patiënten. De conclusie luidt dat er vooral veel onderzoek is verricht naar de rol van zogeheten 'Decision Aids', die bedoeld zijn om patiënten te ondersteunen bij keuzes die zij gedurende

de behandeling moeten maken (bijvoorbeeld het ondergaan van een wel of niet borstsparende operatie bij borstkanker). De stap die daaraan voorafgaat; namelijk de keuze voor een specifieke zorgaanbieder, blijkt niet of nauwelijks onderzocht. Desondanks is het mogelijk om, kijkend naar keuzeprocessen tijdens de behandeling, enkele clusters van keuzebepalende (f)actoren te benoemen, die mogelijk ook een rol spelen bij de keuze voor een zorgaanbieder of behandelaar: socio-demografische factoren zoals leeftijd of geslacht; ziekte specifieke kenmerken zoals de ernst; informatie; professionals; vrienden, bekenden en mantelzorgers.

Deel II: empirisch onderzoek naar keuzeprocessen van patiënten en de (potentiële) rol van prestatie-indicatoren daarin

In het tweede deel van deze studie is met behulp van drie uiteenlopende methoden onderzoek gedaan naar de keuzeprocessen van patiënten met knieartrose, chronische depressiviteit of de ziekte van Alzheimer. Verkend is in hoeverre prestatie-indicatoren daarin een keuzeondersteunende rol zouden kunnen spelen.

Hoofdstuk 4 doet verslag van een onderzoek dat met een Gefundeerde Theoriebenadering (interviews die stap voor stap tot inzichten leiden) de keuzeprocessen onderzocht van 23 kniepatiënten, 15 chronisch depressieven en 15 Alzheimerpatiënten. Het onderzoek wijst allereerst uit dat er twee basishoudingen bestaan ten aanzien van het zoek- en keuzeproces dat voorafgaat aan de keuze voor een zorgaanbieder of behandelaar: een “in-controle consumentenhouding” en een “afhankelijke, passieve houding”. Ten tweede maakt hoofdstuk 4 duidelijk dat, afhankelijk van de basishouding, verschillende (f)actoren het keuzeproces beïnvloeden. Interessant is het daarom te bezien waardoor de basishouding van patiënten wordt bepaald. Dit is dan ook het derde wat hoofdstuk 4 onderzoekt. Vier zaken bepalen de houding van patiënten ten aanzien van de keuze voor een zorgaanbieder of behandelaar: de levenshouding; de aard van de aandoening, de fase of ernst van de aandoening en de manier waarop de zorg is georganiseerd.

Hoofdstuk 5 identificeert met behulp van Q-methodologie (een mix van kwantitatieve en kwalitatieve onderzoeksmethoden die geschikt is voor kleine steekproeven), klantprofielen onder 45 kniepatiënten, 44 chronisch depressieven en 41 Alzheimerpatiënten en/of hun vertegenwoordigers. Per klantprofiel en per aandoening worden bovendien de dominante keuzebepalende factoren onderscheiden.

Twee klantprofielen blijken dominant: patiënten met een focus op uitkomsten van zorg (profiel A) en patiënten met een focus op vertrouwen in de zorgverlener (profiel B). Beide profielen komen voor bij patiënten met knieartrose, maar profiel A blijkt dominant (verhouding 60/40; in hoofdstuk 6 blijkt deze zelfs 80/20). Onder chronisch depressieve patiënten komt vrijwel alleen houding B voor (hoewel in hoofdstuk 6 toch nog 14% van de patiënten aangeeft meer op uitkomsten te focussen). Onder patiënten met de ziekte van Alzheimer en/of hun vertegenwoordigers komen opnieuw beide houdingen voor, maar is eveneens de focus op uitkomsten dominant (verhouding 61/39; blijkt zelfs 86/14 in hoofdstuk 6).

Hoofdstuk 6 gebruikt drie Discrete Choice Experimenten (keuzesimulaties met fictieve zorgaanbieders) onder in totaal 609 kniepatiënten, 368 chronisch depressieven en 421 vertegenwoordigers van patiënten met de ziekte van Alzheimer om te laten zien wat de relatieve impact is van diverse (f)actoren op de keuze voor een zorgaanbieder of behandelaar.

De preferentiepatronen die zo zichtbaar worden, blijken te verschillen tussen de drie aandoeningen. Zo blijkt de keuze van patiënten met knieartrose vooral beïnvloed te worden door de verwachte effectiviteit en veiligheid van de behandeling. Voor chronisch depressieve patiënten is vooral de patiëntgerichtheid (goede relatie en continuïteit qua hulpverlener) van belang. Meeste impact op de keuze die vertegenwoordigers van Alzheimerpatiënten maken, heeft de expertise en de deskundigheid van de zorgaanbieder op het gebied van de ziekte van Alzheimer.

Daarnaast zijn er ook belangrijke verschillen in preferentiepatronen van bepaalde subgroepen: patiënten met een vergelijkbaar klantprofiel, een vergelijkbaar stadium van de aandoening en vergelijkbare achtergrondkenmerken, zoals het opleidingsniveau. Zo hechten patiënten met een resultaatgedreven klantprofiel meer waarde aan de verwachte uitkomsten van de behandeling of het verblijf, de mogelijkheden tot inspraak in de behandeling en de expertise en deskundigheid van de behandelaar. Ook zijn deze patiënten bereid verder te reizen voor betere resultaten. Bij patiënten met een klantprofiel dat 'vertrouwen in de hulpverlener' als basis heeft, hebben zaken als goede eerdere ervaringen met een zorgaanbieder, continuïteit van zorg en het advies van familie en vrienden meer impact. Naarmate patiënten in een verder gevorderd stadium van de aandoening komen, krijgen aspecten als de inter-persoonlijke relatie met de hulpverlener en het advies van familie en vrienden meer impact, terwijl uitkomstindicatoren de keuze dan steeds minder beïnvloeden. Ook de reisafstand en het advies van de huisarts worden dan minder belangrijk. Tenslotte blijken hoger opgeleide patiënten hun keuze voor een zorgaanbieder of behandelaar sneller te laten beïnvloeden door uitkomst(indicator)en van zorg en de expertise en ervaring van de behandelaar. De huisarts is voor hun keuze daarentegen minder bepalend.

Deel III: methoden voor het ontwikkelen van keuzeondersteunende informatie voor patiënten

Deel II maakt duidelijk dat keuzeondersteunende (kwaliteits)informatie toegesneden moet zijn op de situatie van (groepen) patiënten. Daarom ligt de vraag voor de hand welke bouwstenen kwaliteitsinformatie voor bepaalde groepen dan moet bevatten, en hoe deze bouwstenen het beste geïdentificeerd kunnen worden. Op deze vraag geeft deel III een antwoord.

Hoofdstuk 7 doet daarom verslag van een studie met een tweeledig doel: 1) het identificeren van de juiste bouwstenen voor een kwaliteitskaart voor verpleeg- en verzorgingshuizen en thuiszorgaanbieders en 2) het verkennen van een stapsgewijze benadering voor de ontwikkeling van consumenteninformatie, gebaseerd op de methode van Concept Mapping. De resultaten maken duidelijk dat er in de ouderenzorg twee soorten kwaliteitskaarten nodig zijn: één voor de intramurale verpleging en verzorging en één voor de thuiszorg. (Potentiële) thuiszorgcliënten blijken meer waarde te hechten aan de beschikbaarheid, continuïteit en betrouwbaarheid van zorg, terwijl (potentiële) cliënten van verpleeg- en verzorgingshuizen hun keuze vooral willen baseren op privacy, respectvolle bejegening en autonomie. De methode Concept Mapping blijkt door de combinatie van bestaande kwaliteitsinformatie en experts op het gebied van kwaliteit van zorg een hoge mate van validiteit en haalbaarheid van de te ontwikkelen keuzeondersteunende kwaliteitsinformatie op te leveren. Door bovendien vanaf het begin patiënten en andere belanghebbenden bij het ontwikkelproces te betrekken, wordt bereikt dat het materiaal maximaal geschikt is en is er optimale zekerheid over een passende invoering van het ontwikkelde materiaal.

Hoofdstuk 8 beantwoordt één voor één de deelvragen zoals die in hoofdstuk 1 zijn gedefinieerd. Ten aanzien van de hoofdvraag; de vraag in hoeverre prestatie-indicatoren een rol (kunnen) spelen in het keuzeprocess van patiënten die op zoek zijn naar een zorgaanbieder of behandelaar, trekt hoofdstuk 8 de volgende conclusie:

De onderzoeksresultaten tonen aan dat vergelijkende kwaliteitsinformatie over structuur-, proces- en uitkomstkenmerken van de zorg, gemeten en gerapporteerd door middel van prestatie-indicatoren, weldegelijk patiënten kan toerusten om hun rol als kritische zorgconsument in een concurrerende zorgmarkt te vervullen. Dit effect zal echter alleen optreden als consumenteninformatie wordt toegesneden op de specifieke situatie van de patiënt. Daarbij moet minimaal rekening gehouden worden met de aard en de fase of ernst van de aandoening, de keuzehouding of het klantprofiel en belangrijke

achtergrondkenmerken van de patiënt, zoals het opleidingsniveau. De veel gehoorde stelling dat 'de patiënt' automatisch naar de dichtstbijzijnde zorgaanbieder gaat en zich daarbij vooral laat leiden door wat de huisarts, familie of vrienden adviseren, is daarmee definitief weerlegd.

Hoofdstuk 9 reflecteert op de betekenis van de onderzoeksuitkomsten in het licht van de meest recente literatuur en van de gebruikte onderzoeksmethoden. Daarnaast benoemt het de uitdagingen voor de toekomstige ontwikkeling en de verspreiding van consumenteninformatie via prestatie-indicatoren, voor toekomstig onderzoek en tenslotte voor het gezondheidszorgbeleid.

In essentie luidt het advies dat de komende tijd voornamelijk uitkomstindicatoren ontwikkeld, gemeten en gerapporteerd moeten worden op het niveau van zorgproducten (DBC's, ZZPs). Deze informatie moet worden toegesneden op de behoeften van relevante klantsegmenten en in ieder geval worden verspreid via verwijzers en toewijzers, zoals de huisarts, de maatschappelijk werker etc. Alleen onder deze condities kunnen patiënten de hen toebedachte, belangrijke rol van 'change agent' in de gezondheidszorg vervullen.

Ten slotte geldt voor alle betrokkenen, of u nu zelf patiënt bent, of dokter, verzekeraar, beleidsmaker, onderzoeker of ontwikkelaar van kwaliteitsinformatie: het is niet langer de vraag of patiënten kunnen en willen kiezen, maar vanaf wanneer zij dat gaan doen en wat u daarbij voor hen gaat betekenen: de keuze is aan u!

Woorden van dank

Toen ik op 10 mei 2000 na de bekende '5 minuten op de gang' weer binnengeroepen werd, had de afstudeercommissie zich nog geen unaniem oordeel kunnen vormen. Het was een 'dikke acht', die een negen kon worden, als ik beloofde mij bij het iBMG verder te bekwaamen in het doen van onderzoek. Voor zo'n cijfer was ik tot heel veel bereid en zo legde ik mij die middag, in ieder geval moreel, voor vele jaren vast. De stap om ook daadwerkelijk te gaan promoveren volgde drie jaar later, toen ik de smaak van het onderzoeken pas echt goed te pakken had gekregen. Het lukte om subsidie te verkrijgen voor een onderzoek naar keuzeprocessen van patiënten. Een proefschrift was geboren. Nog eens vijf jaar later ligt voor u deze nieuwe 'proeve van bekwaamheid' waarover zich opnieuw een commissie van geleerden zal buigen. Omdat de geschiedenis leert dat de loop der dingen daarna heel onvoorspelbaar kan zijn, is dit een goed moment om even stil te staan...

Er wordt wel gezegd dat het schrijven van een proefschrift een zwaar en eenzaam traject is, waarbij veel neerkomt op het doorzettingsvermogen van de promovendus. In die zin lijkt het wel wat op de beklimming van een berg van de buitencategorie met de racefiets, maar er is voor mij één groot verschil. Als ik deze 'Col de la Dissertation' in mijn eentje had moeten overwinnen, was ik nooit boven gekomen, laat staan weer heelhuids beneden! Mijn grote dank gaat daarom uit naar alle mensen die mij hierbij de afgelopen jaren hebben geholpen.

Als eerste mijn beide promotoren. Robbert, jij was het die mij overhaalde om als onderzoeker bij het iBMG aan de slag te gaan. Ik heb het altijd erg gewaardeerd dat jij voortdurend liet blijken 'het met mij te zien zitten' en dat je mij steeds het vertrouwen en de ruimte gaf om mijzelf verder te ontwikkelen. Van onze gesprekken zullen me altijd twee zaken bijblijven: jouw vermogen tot razendsnel conceptueel schakelen en de enorme hoeveelheid energie die jij aan je gesprekspartner weet over te dragen. Als eerste promotor heb je het hele proces van A tot Z aangemoedigd, bijgestuurd, en van je deskundige en praktische adviezen voorzien. Dank daarvoor!

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dat jij daar, voor de Nederlandse gezondheidszorg, baanbrekend werk aan het verrichten was. Na een gezamenlijke studie voor de Consumentenbond was het niet meer dan vanzelfsprekend dat we jou vroegen als tweede promotor. In die rol heb je me altijd voorzien van vlijmscherpe, maar opbouwende kritieken en adviezen. Ik ben er trots op met je te mogen werken!

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Eveneens onmisbaar voor dit resultaat zijn de 1581 patiënten en/of hun vertegenwoordigers, die hebben meegedaan aan dit onderzoek. Hoewel ik hen niet allen persoonlijk kan bedanken, kan ik dit wel doen via de vele professionals die actief zijn geweest bij het leggen van de contacten met al deze respondenten. Zonder compleet te kunnen zijn, gaat mijn grote dank uit naar: Linda Riemens, Stichting Patiëntenbelangen Orthopedie (SPO); Frank van Oosterhout, Beatrix Ziekenhuis Gorinchem; Cor van Vlaanderen, Rivas Zorggroep Gorinchem en Mattijs Numans, Huisartsen Oog in Al Utrecht. De orthopeden van de volgende ziekenhuizen: AMC/UVA, LUMC, AZM, UMCN, UMCU, Medisch Centrum Alkmaar, VieCurie, St. Maartenskliniek, Scheeper Ziekenhuis, West Fries Gasthuis, Medisch Spectrum Twente en het Slotervaart Ziekenhuis. De verpleeghuisartsen en psychologen van Het Parkhuis Dordrecht, Rivas Zorggroep Gorinchem en de SGZZH. De geriaters van de geheugenpoli's van het Erasmus MC en het Havenziekenhuis. De therapeuten en groepsleiders van De Gelderse Roos Ede, Altrecht in Utrecht, Eleos

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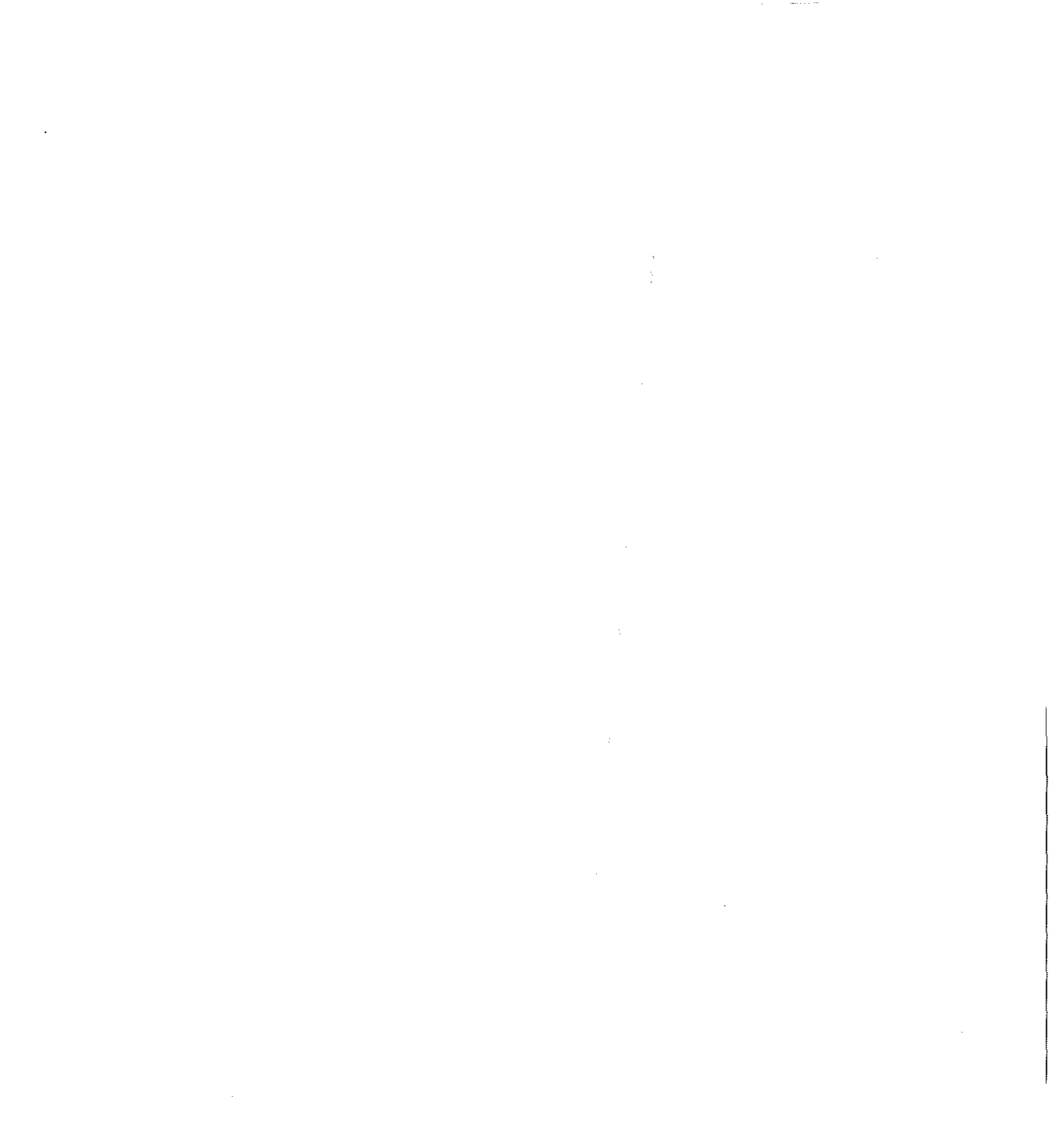
Maurits, Herwin, Henk, Menno en Hans, al sinds de middelbare school zijn wij als vriendengroep bij elkaar. Als jullie op zaterdagmiddag bij mij thuis op de stoep stonden en ik weer achter mijn bureau zat, moeten jullie weleens gedacht hebben dat er een steekje los zit bij die workaholic. En misschien is dat ook wel zo. Met jullie heb ik niet alleen veel plezier, ook mijn wederwaardigheden rond dit onderzoek heb ik met jullie kunnen delen. Hans, ik vind het daarom een eer dat jij vandaag één van mijn paranimfen wilt zijn.

Hendrik, beste zwager, jij bent niet voor niets de andere paranimf. Heel wat keren heb ik bij mooi weer vanachter mijn bureau in Rotterdam naar buiten gekeken en jou benijd om je heerlijke buitenwerk. Wat heb ik een respect voor wat jij kunt maken met groen en voor de manier waarop jij je bedrijf runt!

Lieve familie: Hanneke, Guus en Marloes, Jaap-Willem en Marije, dank jullie wel voor het meeleven tijdens dit proces. Oma, tijdens mijn interviews met Alzheimerpatiënten en hun vertegenwoordigers moest ik vaak aan Opa en u denken. We hebben het daar ook wel over gehad. Laten we hopen dat patiënten en hun naasten in de toekomst nog beter hun weg vinden in zorgland. Pa en Ma Rooz, dank jullie wel voor jullie steun aan mij en aan ons gezin. Vaak heb ik op mijn werk trots verteld over mijn schoonmoeder, die (twee)wekelijks helemaal vanuit Lienden naar Gouda kwam om op de jongens te passen! In dat opzicht wil ik Aletta, Jacomijn en Jacolien ook bedanken voor alle zorgzame uren. Pa, dank voor al je adviezen op het gebied van studie en werk. Jij nam me mee naar Rotterdam en schreef me bij mijn afstuderen: "The sky is the limit". Dat lijkt nog altijd op te gaan. Ma, jij hebt me altijd duidelijk gemaakt hoe bijzonder het is als je de kans krijgt om te studeren. Een deel van dit resultaat is daarom ook voor jou en niet alleen vanwege het oppassen. Wietsze en Sem, de herfstvakantie van 2008 is de laatste die papa aan 'dat boekje' heeft besteed. In die week kwam jij naar boven, Wietsze en je vroeg: "is je boekje nog niet af?" Vandaag kan ik zeggen: "ja het is af!" Lieve Coos, ongelofelijk hoe jij je moederschap en alles wat daarbij komt

kijken, combineert met je coschappen en inmiddels een specialisatie tot huisarts. Daarbij vergeleken is een proefschrift een eitje. Voor je liefde en steun tijdens dit traject, dat voor jou soms ook eenzaam was, ben ik je ontzettend dankbaar. Je hoeft me niet meer te delen met dat onderzoek; ik hou van je.

Tenslotte, collega's in Rotterdam hebben hem weleens zien hangen op mijn whiteboard: de boekenlegger met daarop de tekst uit Psalm 111:10 "De vreze des Heeren is het begin van de wijsheid, een goed inzicht hebben allen die ze betrachten. Zijn lof (die Hem meer dan wie ook toekomt) houdt eeuwig stand".



Stellingen

Behorend bij het proefschrift:

It's your Choice!

*A Study of Search and Selection Processes,
and the Use of Performance Indicators in Different Patient Groups.*

Antonie Steven (Stef) Groenewoud

Stelling 1

De patiënt bestaat niet, maar niet iedere patiënt is uniek; zeer diverse groepen patiënten zijn te typeren in twee klantprofielen: patiënten focussen op “uitkomsten” of “vertrouwen” (Hoofdstuk 5 van dit proefschrift).

Stelling 2

Afhankelijk van hun klantprofiel, laten veel patiënten zich bij de keuze voor een hulpverlener meer beïnvloeden door kennis over zorguitkomsten dan door adviezen van derden, wachttijden of de gemeten kwaliteit van de informatievoorziening door zorgaanbieders (Hoofdstuk 6 van dit proefschrift).

Stelling 3

Het negeren van de verschillende ‘klantsegmenten’ in de zorg zal leiden tot onbruikbare zorgvergelijkingen en daardoor tot nog meer kritiek van ‘keuzesceptici’ (Hoofdstuk 9 van dit proefschrift).

Stelling 4

Productinformatie is cruciaal om patiënten productverschillen te doen waarnemen, wat op zich weer een voorwaarde is voor actief keuzegedrag (Hoofdstuk 9 van dit proefschrift).

Stelling 5

Verbetering van de keuzemogelijkheden voor patiënten vergt niet alleen goede keuzeondersteunende informatie, maar ook een betere match tussen enerzijds het vermogen en de wens van patiënten om te kiezen en anderzijds de keuzemogelijkheden of –verplichtingen in het zorgstelsel (Hoofdstuk 4 van dit proefschrift).

Stelling 6

Na twee decennia vraaggerichtheid en vraagsturing in de zorg, is het een opvallende tegenstrijdigheid dat vrijwel alle beschikbare keuzeondersteunende kwaliteitsinformatie zich nog steeds richt op vergelijking van zorgaanbieders in plaats van zorgproducten.

Stelling 7

Het door Kenneth J. Arrow gedefinieerde begrip 'product uncertainty' kent niet twee, maar drie dimensies. Niet alleen is er bij patiënten sprake van kennisachterstand met betrekking tot de inhoud van een behandeling en onzekerheid over de werking ervan; ook is het onzeker of de effectiviteit, veiligheid en klantgerichtheid bij een willekeurige zorgaanbieder even groot zijn als die bij een andere.

Stelling 8

Als de wereld MECE¹ was, had je een stuk minder te kiezen.

Stelling 9

Het portret van Hare Majesteit Koningin Beatrix in de hal van het Ministerie van VWS kan worden gezien als een verbeelding van de versnipperde kijk van 'de zorg' op een patiënt, daar waar een heel-de-mensbenadering noodzakelijk is.

Stelling 10

Wanneer atheïsten, agnosten en andere 'reli-sceptici' de parabel "The Blindmen and the Elephant"² gebruiken om te betogen dat geen enkele godsdienst mag claimen de waarheid in pacht te hebben, ondergraven zij daarmee direct hun eigen stelling (naar Timothy Keller).

Stelling 11

Om tot grootse prestaties te komen heeft men twee zaken nodig: een plan en net niet genoeg tijd om het uit te voeren (L. Bernstein).

¹MECE is een Engels acroniem dat staat voor *Mutually Exclusive, Collectively Exhaustive*, oftewel wederzijds uitsluitend en gezamenlijk uitputtend. Het is een groeperingsprincipe met als uitgangspunt dat een groep in subgroepen wordt opgedeeld die geen overlap kennen en gezamenlijk de gehele groep representeren.

²John Godfrey Saxe, 1816-1887.