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PIRKKO SALOKEKKILÄ

Encounters in the Health Care

The Voice of the Patient

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The Voice of the Patient

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ABSTRACT

The consultation is the core event in medicine. Both the physician and the patient have influence on the outcome of the visit. This is a study of the experiences of people consulting their doctors and narratives they have told in the interviews with one researcher based on these experiences.

The participants of the study were people suffering from a chronic pain and disabilities due to osteoarthritis. During the interviews, the interviewees were asked to tell about successful and failed encounters with the health care providers. The respondents were also asked to give their own definitions for "benefit" and "unnecessary visit". Episodic interview technique was applied and no questionnaires were used.

The texts have been analyzed by using the content analysis method. Three main categories were developed based on the concepts that emerged from the data. These were named as *Narratives of survival*, *Quality of care* and *System encounters*. In addition to the qualitative content analysis the Bayesian method was applied because there could have been elements in the data which may have remained undetected if only the content analysis was used. The Bayminer (www.BayMiner.com) non-linear visualization modeling software was used together with B-course classification and dependence model. With these tools it was possible to analyze the data for multivariate probabilistic dependencies which are represented as Bayesian network models.

The main result of the study is that the competent doctor gives face to the system and influences the patient perception towards the whole health care system and makes it more trustworthy and acceptable. Based on the content analysis the predictors of a successful and a failed encounter are presented. A successful encounter included continuity of care, doctor competence, caring doctor, taking the patient seriously, private care, respect and trust in doctor, information giving and perceived benefit together with satisfaction with care. In a failed encounter the predictors were feelings of disappointment, anger and bitterness connected to experiencing indifference and talking to a doctor's back.

The conclusion is that the informants of the study as patients were outcome-oriented. They wanted to gain benefit when they finally had made the decision to consult the physician. Being disappointed with the health care provider had a negative impact on the perception of the health care system. These results are in alignment with the Bayesian network modeling. The model predicted the result with 72% probability. The messages from this study are directed to the decision makers of the medical education and those of the health care system. An innovative and user friendly approach with a strong moral dimension and concern for ethical issues is needed when building the health care system for the next decades.

National Library of Medicine Classification: W 62, W 84, W 85

Medical Subject Headings: Quality of Health Care; Physician-Patient Relations; Referral and Consultation; Physicians; Patients; Patient Satisfaction; Perception; Professional Competence; Pain; Osteoarthritis; Qualitative Research; Bayes Theorem

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TIIVISTELMÄ

Vastaanottotapahtuma on keskeinen käsite terveydenhuollossa. Potilas ja lääkäri rakentavat kohtaamisen sisällön yhdessä ja molemmat vaikuttavat käynnin lopputulokseen. Minun väitöskirjani perustuu omaan tulkintaani niistä tarinoista, joita haastattelemani ihmiset ovat kertoneet minulle liittyen heidän kokemuksiinsa kohtaamisista lääkäreiden kanssa.

Haastatteluvälineeksi valittiin osteoartriittia sairastavia henkilöitä, joilla taudin luonteen vuoksi oli pitkäaikaista kokemusta kroonisesta kivusta ja terveydenhuoltojärjestelmästä palvelujen käyttäjän näkökulmasta. 33 henkilöä haastateltiin joko kodeissaan tai yliopiston tiloissa Kuopiossa tutkijan toimesta.

Haastattelujen aikana osallistujia pyydettiin kertomaan sekä onnistuneista että epäonnistuneista kohtaamisista lääkäreiden kanssa. Samoin pyydettiin heidän omaa määritelmäänsä käsitteille ”hyöty” ja ”turha käynti” terveydenhuollon kontekstissa. Teksti on analysoitu sisällön analyysimenetelmää käyttäen. Kolme pääkategoriaa luotiin perustuen niihin käsitteisiin, jotka nousivat aineistosta. Nämä nimettiin Selviytymistarinoiksi, Hoidon laaduksi ja Vuorovaikutukseksi järjestelmän kanssa. Bayesin menetelmää käytettiin myös analyysissa, sillä aineiston jotkut elementit olisivat saattaneet jäädä huomiotta, jos olisi rajoitettu ainoastaan sisällön analyysiin. Tässä tutkimuksessa käytettiin sekä Bayminerin non-lineaarista visualisaatio-mallinnusta että B-coursen riippuvuus- ja klassifikaatiomallinnusta.

Keskeisin tulos tutkimuksesta on, että osaa lääkäri antaa kasvot järjestelmälle ja vaikuttaa potilaan käsitykseen koko terveydenhuoltojärjestelmästä tehden siitä luotettavamman ja hyväksyttävämmän. Onnistuneeseen kohtamiseen kuuluivat mm. käsitteet hoidon jatkuvuus, lääkärin ammattitaito, lääkärin huolenpito, tiedon antaminen potilaille, potilaan vakavasti ottaminen, luottamus ja kunnioitus lääkäriä kohtaan sekä koettu hyöty yhdessä hoitoon liittyvän tyytyväisyyden kanssa. Epäonnistuneeseen kohtamiseen kuuluvia käsitteitä olivat pettymyksen tunne, vihaisuus ja katkeruus liittyneenä välinpitämättömyyden kokemiseen.

Loppupäätelmä on, että tutkimukseen osallistuneet henkilöt potilaina olivat lopputulos-orientoituneita. He halusivat hyötyä käynnistään, kun he vihdoinkin olivat päättäneet mennä lääkäriin. Toisaalta pettymys hoidonantajaan heijastui negatiivisena suhtautumisena koko terveydenhuoltojärjestelmään. Jos potilas ei kokenut, että käynnistä oli hänelle jotain hyötyä, potilas saattoi arvioida vastaanoton turhaksi. Nämä sisällön analyysin tulokset ovat linjassa Bayesin menetelmällä saadun mallinnuksen tuloksiin. Malli ennusti tuloksen 72% todennäköisyydellä. Tämän tutkimuksen viesti poliitikoille ja päättäjille on, että tarvitaan innovatiivista ja käyttäjäystävällistä lähestymistapaa, jossa on mukana vahva moraalinen ja eettinen ulottuvuus, kun rakennetaan seuraavien vuosikymmenten terveydenhuoltojärjestelmää.

Luokitus: W 62, W 84, W 85

Yleinen suomalainen asiasanasto: terveydenhuolto; lääkärisäkäynti; konsultointi; hoitosuhde; lääkärit; potilaat; kompetenssi; osaaminen; kokemukset; mielipiteet; tyytyväisyys; laatu; kipu; nivelrikko; kvalitatiivinen tutkimus; bayesilainen menetelmä

To My Interviewees

Acknowledgements

I have worked at hospitals and health centres for three decades. In the beginning of the nineties I was given the opportunity to participate in teaching at the department of General Practice and Primary Health Care at the University of Helsinki. Later I was able to contribute to the planning and implementation of a new program in the undergraduate curriculum related to fostering professionalism with a group of enthusiastic and experienced colleagues.

Gradually I started to become more and more interested in the way the patients perceive the consultations with the health care providers and how they assess whether the visit was useful to them. Sometimes new ideas need a long time to mature and life may offer surprises and a complete change of the environment before one can return to the original topic of interest.

This happened to me and when in 2005 during a work-related visit to Kuopio I was fortunate to have a discussion with Professor Esko Kumpusalo, who suggested that I should come and work at the department of Public Health and General Practice in Kuopio as a clinical teacher and finally start to prepare my doctoral thesis, I accepted the offer.

From the beginning the concept of benefit gained from the patient's perspective was central to our thinking and planning of the research agenda. So it was decided to conduct an interview study based on the experiences of the users of the health care services, the patients.

The work for my doctoral thesis has been carried out during six years from 2006 till 2011. I moved back to Helsinki after finishing the interviews in the summer 2006. This field work period has remained as the most memorable and highly appreciated time in my novice researcher's life. I bought an old car to reach the remote villages in the countryside in North Savo and truly enjoyed my visits to these wonderful people, who opened their homes to me to participate in my study.

In Helsinki I have worked during these years at Helsinki City Health Centre and the department of General Practice and Primary Health Care. The weekends and holidays have been the time to write my thesis.

I am very grateful to all those highly respected professionals who have contributed to the preparation of my thesis over the years. First, I want to express my sincere and warm thanks to my principal supervisor Professor Esko Kumpusalo, MD, PhD and my other supervisors Professor Anja Taanila, PhD and Professor Olli-Pekka Rynänen, MD, PhD for all their time and effort, encouragement and valuable advice during the process. I feel gratitude towards professor Olli-Pekka Rynänen, who has introduced me to the world of probabilities, the exciting realm of the Bayesian networks. Professor Anja Taanila has given me practical instruction to carry out qualitative research on many occasions, which I feel most grateful for.

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While working at Helsinki City Health Centre, I have been able to spend two months writing my thesis with the economic support granted by the Health Centre. I want to express my appreciation and thanks for this.

To write a thesis basically at home without the support of the peers can sometimes become almost too lonely. One of the antidotes for these feelings have been my visits to the beautiful old villa owned by my friend Riitta. I wish to express my warmest thanks for the hospitality, outdoor activities and peaceful moments after the sauna by the lake.

I am also grateful to both of my children, Piia and Tuomas, for their strong support, love and understanding during this time consuming process. They have encouraged me to continue when I have felt tired and taken me to the cinema and the concerts to cheer me up.

Tuomas has done the layout of the book and helped me many times with the computer problems, which I feel very much gratitude. His help has been extremely valuable.

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This study would not have been possible without the devoted collaboration of all my interviewees to whom I want to express my most sincere thanks and gratitude.

Helsinki, the 20th of November, 2011
Pirkko Salokekkilä

Abbreviations

CSQ	Consultation Satisfaction Questionnaire
GP	General practitioner
ICD-10	International classification of diseases
OA	Osteoarthritis
PEI	Patient Enablement Instrument
RA	Rheumathoid arthritis
RCGP	Royal College of General Practitioners
SCOC	Sustained Continuity of Care
TKR	Total knee replacement

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1 Introduction

1.1 REVIEW OF THE LITERATURE

The patient voice has traditionally existed as a hidden undercurrent within the health care environment. However, by the 1960s and 1970s a growing interest developed in uncovering the patient experience by social scientists, who began to explore lay concepts of health and illness (Kleinman 1988). This approach lay within a tradition of critiquing the medical model in an attempt to give credit to the voice of the patient and provide a broader perspective on the illness experience. The implications for clinicians were clear: the patient should be listened to and their opinions should be respected. The attitude that professionals know best was now open to significant challenges (Nairn et al. 2004).

Sofaer et al. have written a review about qualitative studies that report how patients define quality. For patients in these studies quality included having their physical and emotional needs met, being involved with their care and decision making about their care, having doctors and nurses who have personal knowledge of the patient, who respect their beliefs regarding health related issues, protect their privacy and confidentiality, give equal care to all and involve the family in the care (Sofaer, Firminger 2005). According to Sofaer et al., there are skeptics who have serious doubts about the patients' ability to assess the technical quality of the health care. In the studies reviewed by Sofaer et al., the patients defined quality as having good health outcomes and an improved quality of life. They were also capable of reporting whether the doctor examined well and thoroughly, observed and listened carefully, worked according to a certain order, first listening, making judgments only after the examination, gave good solutions, knew answers and could tell what patient should expect. The assumptions seem to persist that the technical aspects of care cannot be evaluated reliably by patients themselves. On the other hand, there is little doubt that patients consider good health and functional status outcomes as important aspects of quality.

There should be some kind of joint understanding what kind of actions patients can reliably report and which they cannot. The uncertainty remains whether to believe a medical record or the patient's report on his/her experience. The authors conclude that unless the patients are not being educated, especially those with chronic conditions, about what they should expect from the health care system, their voices continue to be unheard. The growing understanding of the unequivocal importance of the patient experience as a source of information on the quality of health care services is emerging and this should lead to creative ways of eliciting the voice of the patients (Sofaer, Firminger 2005).

When comparing the ratings of physicians and patients on the importance of various determinants of the quality of care, it was found out that both groups rated the clinical skills as the most important determinant. Patients and physicians disagreed significantly about the relative importance of the provision of information, with patients ranking it second and physicians sixth (Laine et al. 1996).

Jung et al. investigated which aspects of general practitioners' behavior determine patients' evaluations of care and whether the views of the general practitioners differ from those of the patients. One part of the study was to examine, which aspects of general practice are prioritized by patients and GPs and if these priorities differ. In general, it appears that patients put more emphasis on the availability and accessibility of general practice care, easiness to speak to GP by telephone, appointment within a short time, health checks being available, acceptance of alternative treatment, and on communication. Telling all about illness and explaining in detail, having enough time to listen are also important issues for

the patients. Patients' main interest seems to be optimizing their possibilities of getting the health care they desire and reaching an understanding of their medical problems.

Patients and GPs stress equally the importance of critically evaluating the benefits of health care provision, usefulness of medicines, advice, medical investigations, and referrals, but GPs unjustifiably believe that avoiding the overuse of medical-technical care is not so important to patients. This is an interesting finding since patients may be better able to contribute to a more appropriate use of health care facilities than GPs might expect. On the other hand, the authors conclude it is possible that patients gave socially desirable answers, when in fact they care less for the prevention of over-use if they consult a GP for a specific complaint (Jung, Wensing & Grol 1997).

According to Campbell et al., quality of care is a concept that is at its most meaningful when applied to the individual users of the health care and they are relied upon in the assessment of its outcomes. The contents of the quality of care can be reduced to only two dimensions: access and effectiveness. The aim of accessing effective health care is to maximize the health benefit for the patient based on the needs.

From the users point of view the most important questions to be asked in the context of the quality of health care are 1. Do users get the care they need? 2. Is the care effective when they get it (Campbell, Roland & Buetow 2000)?

The purpose of the study by McKinstry et al. was to determine whether patient ratings of general practice registrars' consulting skills are associated with 'expert' scoring using the MRCP video assessment protocol. The main outcome measures were rank correlation of Registrars' overall level of attainment on the Royal College of General Practitioner (RCGP) video assessment with mean score on the Patient Enablement Instrument (PEI) and the mean score on the Consultation Satisfaction Questionnaire (CSQ). No meaningful association was identified between Registrars' score on the RCGP video examination and patient assessment via either the PEI or the CSQ. According to the authors this suggests that, with regard to measuring quality in the consultation, one or more of the assessments are invalid or that they measure different attributes (McKinstry et al. 2004).

The incorporation of the patient's perspective into a relationship-centred medical paradigm has been suggested as the approach for the 21st century. To put this into action, it is necessary to revisit the patient-physician relationship very carefully. There should also be a change in the focus of reporting on the quality of the health care through the patient's eyes (Johns, American 2004).

Coulter et al. argue that instead of asking patients to rate their care using general evaluation categories (such as excellent, very good, good, fair, poor), it is better to ask them to report in detail on their experiences of clinical care during a particular consultation. "Were you given information about any side effects of your medicine?", "Were you given a plan to help you manage your diabetes at home?" or over a specified period "Have you had your blood pressure checked in the past 12 months?". These types of questions are designed to elicit reports on what actually occurred, rather than the patient's evaluation of what occurred, and they produce more reliable results. Most patients prefer doctors who have excellent communication skills, but they also want to be assured that their doctor has sound, up-to-date, technical skills. Both attributes are viewed by patients and the public as equally important. A recent public survey carried out for the General Medical Council found that giving good advice and treatment was the factor that most influenced people's confidence in doctors (rated as very important by nine out of 10 respondents), followed closely by good communication skills. Other factors that were highly rated included maintaining confidentiality, respecting patients' dignity, and involving them in treatment decisions (Coulter 2005).

Indicators of quality of general practice care of patients with chronic illness were investigated in a qualitative study with focus group interviews by Wensing et al. This study claims to be a step toward the real involvement of patients in the assessment of the quality of care.

The relevance of the aspects of general practice care for patients was explored through the focus group interviews and the written consensus procedure by the patients and the general practitioners. Patients want doctors who know the most recent developments in medicine and who do not hesitate to refer to a specialist if necessary. The authors argue that the evaluation of health care from the patients' perspective must reflect their views so the indicators that do not make sense for them should be excluded from such studies (Wensing et al. 1996).

In the next chapters the subtitles will be connected to the three main categories of quality assessment: the structure, the process and the outcome first defined by Donabedian (Donabedian 1966). Under the subtitle Structure there will be continuity and access. Under the Process I will include doctor-patient interaction, caring, giving information and the consultation together with competence and trust, the help seeking behaviour of the patient as well as patient participation and decision making. Under the subtitle Outcome will be the outcomes of the treatments as perceived by the patients, satisfaction, dissatisfaction and benefit gained from the encounters with the health care providers.

1.1.1 Structure

Continuity of care

Continuity of care is considered an essential component of primary care and is associated with several beneficial outcomes, including decreased emergency department use and hospitalizations, greater patient satisfaction, and increased use of preventive services. (Gill, Mainous & Nsereko 2000). Prior studies have indicated that many patients and physicians value continuity in relationships. These ongoing relationships are valued for the accumulated knowledge, ease of communication, trust and confidence that develop (Pandhi, Saultz 2006).

Continuity of care has been widely studied during the last few decades and in the context of general practice it is believed to contribute to good quality health care for the patients (Saultz, Albedaiwi 2004). According to Baker et al., continuity does not improve the satisfaction with the care unless the patient will trust the doctor. Consulting the regular doctor, trust and satisfaction with consultations are commonly associated together. Patients who have a high level of trust in their regular doctor and consult that doctor have the highest levels of satisfaction with their consultations. Among patients with relatively low levels of trust in their regular doctor, levels of satisfaction do not vary whether or not they consult the regular doctor (Baker et al. 2003).

Frederiksen et.al have concluded that the combination of recognition with the interpersonal continuity can generate added value in the patient-doctor relationship. From the patients' point of view it is more convenient to visit a doctor who already knows the illness history and the patient does not have to start telling the health problems from the beginning at every consultation. But continuity is not an unambiguous concept. A continuous relationship with the physician provides the patient a feeling of security when meeting the same physician during every visit, and especially patients with chronic diseases express the needs for this. It is not valuable for the patient to have a continuous relationship unless the doctor acknowledges the person in his behavior by attentive listening, showing understanding, confirming and accepting the patient. This can be defined as recognition, which encompasses two dimensions, respect towards the patient and remembering the patient. In order to create and sustainable and satisfying relationship the doctor needs to pursue both. If the patient feels that the doctor is genuinely interested in him or her as a person which is made possible if the doctor knows and remembers the patient, the interpersonal continuity can be especially valuable (Frederiksen, Kragstrup & Dehlholm-Lambertsen 2009).

But does continuity of care improve patient outcomes? Cabana et al. conducted a systematic review of all articles in Medline (January 1966 to January 2002). From 5070 candidate

titles, they examined the full text of 260 articles and found 18 (12 cross-sectional studies, 5 cohort studies and 1 randomized controlled trial) that fulfilled their criteria. Five studies focused on patients with chronic illness like asthma or diabetes. In their results they write that no studies documented negative effects of increased SCOC (sustained continuity of care) on quality of care. SCOC is associated with patient satisfaction (4 studies), decreased hospitalizations and emergency department visits (7 studies), and improved receipt of preventive services (5 studies). Their conclusion is that SCOC improves quality of care, and this association is consistently documented for patients with chronic conditions (Cabana, Jee 2004).

Freeman et al. point out that while the UK government is currently concentrating on offering guaranteed quick access for patients (access to a GP within two working days) it has been silent on the question of helping patients to see a doctor they know. Yet this aspect of patient choice is valuable in spite of the fact that it may conflict with quick access (Freeman, Hjortdahl 1997). The increased freedom of choice for the patients also in the public health care is a major issue in the new Health care law in Finland which is coming into operation in May 2011, and it is regarded as strengthening the role of the patient and his or her freedom of choice.

To find out the association among patient and visit characteristics and extent to which the patient valued continuity of care a study of 4454 consecutive outpatient visits to 138 community-based family physicians was conducted and a 3-item measure of patient valued continuity was used in a study by Nutting et al. Satisfaction with the physician for the visit was greatest among patients who valued continuity and saw their regular physician. Age extremes, the female sex, lower education, a number of chronic conditions and medications, number of visits to the practice, and worse self-reported health status were associated with higher value placed on continuity. Continuity of physician care is associated with more positive assessments of the visit and appears to be particularly important for more vulnerable patients. Health care systems and primary care practices should devote additional effort to maintaining a continuous relationship with these vulnerable patients (Nutting et al. 2003).

Coordination of care was the focus of interest in the study that was conducted by O'Malley et al., to find out the extent to which adults report that their care is coordinated between their primary care physician and specialists and to determine whether visit continuity with one's own doctor and the primary care provider as the referral source for specialist visits are associated with higher coordination ratings. The conclusions were that facilitating visit continuity between the patient and the primary care provider, and encouraging his or her use as the referral source would likely enhance the care coordination (O'Malley, Cunningham 2009).

Freeman et al. argue that interpersonal continuity built on repeated but not necessarily exclusive contacts is important in building trust and respect. People like it when they use craftsmen, go to the hairdresser or send their car to a friendly local garage. Patients also like it when attending the health care system. The opportunity to leave a consultation with unfinished business and perhaps return later if necessary is much valued by patients and means that the often ill-defined problems can be left to evolve and often to resolve. If further review proves necessary, it is most efficiently done by resuming dialogue with the same doctor. The central skill fostered by interpersonal continuity over time is the ability to make and value a multidimensional diagnosis, based on the bio-psycho-social model within the patient's context.

Continuity as prior knowledge can mean both information, for example an available medical record, and a therapeutic relationship where the patient knows the doctor well. Information is important in most medical settings. All over the world there are moves to improve the sharing and availability of patient specific medical data through the use of electronic and/or patient held records. Prior knowledge of a patient is not just about information, even psychological and sociological material. It is also about interaction and relationships,

about feelings, trust and empathy. These aspects of care are more difficult and sometimes even inappropriate to transmit by any form of medical record. They exist in the perceptions of the patient and the doctor and in the degree to which these are shared and recognized. A comprehensive evidence base for interpersonal continuity of care is still lacking.

There is a need for further research to demonstrate the added value of continuity in general practice and the theory behind the elements must be described. It remains to be shown whether interpersonal continuity makes a difference. The authors of this article argue that the answer may be found by turning to the sciences of human behaviour that underpin much of the consulting behaviour in general practice and which will enable researchers to develop and plan theories and hypotheses about behaviours that can be tested (Freeman, Olesen & Hjortdahl 2003).

Personal continuity is a core value for family practice, but policy and performance targets emphasize other aspects of care, particularly waiting times for consultation. The qualitative study by Guthrie et al., examined patient perceptions of the value of personal continuity and rapid access, and the relationship between them. The objectives of the study were to identify whether, how, why and in which circumstances personal continuity and rapid access were valued. The results show that from the patients' perspective, what mattered was access to appropriate care depending on the problem to be dealt with. For a few patients, rapid access was the only priority. For most, rapid access was balanced against greater involvement in the consultation when seeing their trusted doctor, which was particularly valued for chronic, complex and emotional problems (Guthrie, Wyke 2006).

In a qualitative study using grounded theory methodology, Pandhi et al. selected and interviewed a purposeful sample of 14 primary care patients. Audiotapes of the interviews were transcribed and analyzed using open, axial, and selective coding schemes. They state in their results that although the majority of patients were not familiar with the phrase continuity of care, all patients in the study identified comfort with their doctor as important to establishing and maintaining an ongoing relationship. Comfort with a physician was developed in several ways. Patients described their level of comfort with a physician as influencing making and keeping appointments, the likelihood that they would discuss concerns about sensitive issues, their perception that medical problems were resolved faster, and their trust in the physician's treatment plan.

Pandhi et al. concluded that for patients, comfort appears to be an important dimension of the physician-patient continuity relationship. Some patients felt that the comfortable relationship allowed them to trust that their physician was "looking at the whole picture" to put together a diagnosis, beyond what they themselves might notice. Finally, because they were comfortable, some patients stated they were more likely to trust what was being done for them to diagnose a problem and more likely to be compliant with prescribed medication. Interestingly, the results of the study suggest that once patients achieve comfort, they are likely to overlook potential reasons for dissatisfaction such as not having phone messages returned. The findings suggest that patients want physicians to acknowledge them as a whole person, act concerned and caring, and be competent. Patients also appreciate non-medical conversation described as chit-chat, which is similar to the social conversation categorized in the physician-patient communication literature (Pandhi, Bowers & Chen 2007).

Access

Access has become a significant market issue and continues to be an important clinical issue. Murray et al. suggest in their article about redefining the open access to primary care that relying on clinical definitions of good access is no longer useful. Instead they recommend a definition based on the patient's perspective: "The ability to seek and receive care from the provider of choice at the time the patient chooses."

Historically, access has been defined from the perspective of health care providers. Good

access to health care was defined as care delivered within a time frame that met a clinical definition for urgency. It is our belief that this definition is increasingly irrelevant for three reasons. With the exception of certain commonly agreed upon emergency conditions, for example chest pain or trauma, there are few standards for defining urgency. Wide variations in clinical practice make it difficult to standardize access definitions from this highly variable perspective.

Patients as consumers are not satisfied with the waits and delays inherent in these clinical definitions of good access. These definitions do not take into account the non-clinical needs and realities in patients' lives. The author states that many health care organizations have learned an important lesson from other service industries and are re-adopting the premise that access and service must be designed from the customer's perspective (Murray, Tantau 1999).

According to Grumbach et al., few data are available regarding how patients view the role of primary care physicians as "gatekeepers". A cross-sectional survey was carried out and questionnaires mailed in the fall of 1997 to 12707 adult patients who were members of managed care plans and received care from 10 large physician groups in California. The response rate among eligible patients was 71%. The investigators wanted to determine the extent to which patients value the role of their primary care physicians as first-contact care providers and coordinators of referrals, whether patients perceive that their primary care physicians impede access to specialists, and whether problems in gaining access to specialists are associated with a reduction in patients' trust and confidence in their primary care physicians. The questionnaire items addressed 3 main topics: (1) patient attitudes toward the first-contact and coordinating role of their primary care physicians, (2) patients' ratings of trust and confidence in and satisfaction with their primary care physicians and (3) patient perceptions of barriers to specialty referrals. The results showed that almost all patients valued the role of a primary care physician as a source of first-contact care (94%) and coordinator of referrals (89%). Depending on the specific medical problem, 75% to 91% of patients preferred to seek care initially from their primary care physicians rather than specialists. Twenty-three percent reported that their primary care physicians or medical groups interfered with their ability to see specialists. Patients who had difficulty obtaining referrals were more likely to report low trust, low confidence and low satisfaction with their primary care physicians. Managed care policies that emphasize primary care physicians as gatekeepers impeding access to specialists undermine patients' trust and confidence in their primary care physicians (Grumbach et al. 1999).

1.1.2 Process

Patient-doctor relationship

Ridd and co-authors have conducted a systematic review and a thematic synthesis of qualitative studies on patient-doctor relationship from the perspective of the patients. They were able to find 11 studies which they included in the final synthesis. Longitudinal care and consultation experiences, patients' encounters with the doctors, were found to be the main processes by which patient-doctor relationships are promoted. They found four elements, knowledge, trust, loyalty and respect from which the depth of patient-doctor relationship depends on (Ridd et al. 2009).

Street et al. have concluded almost two decades ago in their study that patients' experiences may provide a more useful and relevant measure of the quality of doctor-patient relationship than observer based coding schemes (Street 1992).

Over the decades there has been a shift in the research orientation towards patient-centredness instead of system orientation. One of the pioneers in this field is Moira Stewart whose extensive systematic review of 25 years of research focusing on the doctor-patient

relationship and outcomes of the visit, evaluates the effects of various styles of communication on patient health outcomes. In this review randomized controlled trials and analytic studies were included, 21 studies in total. The outcomes affected were emotional health, symptom resolution, function, physiologic measures (i.e., blood pressure and blood sugar level) and pain control. Most of the studies reviewed demonstrated a correlation between effective physician-patient communication and improved patient health outcomes (Stewart 1995). The patient experience of the consultation very much depends on the level of success in finding a common ground, which includes the patient perception of the interest and respect shown by the doctor during the encounter and to what extent the outcome of the visit coincides with her expectations. The authors state that there was a correlation between a better recovery and emotional health two months later and the perceived patient-centredness. An interesting point in this study was that only the measure of patients' perceptions of the patient-centredness of the visit was associated with improved patients' health status and increased efficiency of care with reduced diagnostic tests and number of referrals (Stewart et al. 2000).

This finding emphasizes the critical role of the patient perceptions in the healing process, which highlight that a person's subjective experience influences biology (Sobel 1995).

To measure patients' perceptions of patient-centredness and the relation of these perceptions to outcomes, Little et al. carried out an observational study using questionnaires at three general practices. Participants were 865 consecutive patients attending the practices. Main outcome measures were patients' enablement, satisfaction, and burden of symptoms. Factor analysis identified five components which were communication and partnership, a sympathetic doctor interested in patients' worries and expectations and who discusses and agrees with the problem and treatment, personal relationship, health promotion, positive approach (being definite about the problem and when it would settle), and interest in effect on patient's life. Satisfaction was related to communication and partnership and a positive approach. Enablement was greater with interest in the effect on life, health promotion and a positive approach. A positive approach was also associated with reduced symptom burden at one month. Referrals were fewer if patients felt they had a personal relationship with their doctor. As conclusions the researchers state that components of patients' perceptions can be measured reliably and predict different outcomes. If doctors don't provide a positive, patient-centred approach patients will be less satisfied, less enabled, and may have greater symptom burden and higher rates of referral. Patient satisfaction with the visit, his or her experience of better coping, enablement and decrease in the symptom burden were connected with the quality of the interaction, partnership building and the positive approach by the doctor in telling the diagnosis and the prognosis (Little et al. 2001).

In a study by Beach et al., investigating the patient perception of physicians' attitudes of respect, it was concluded that patients are able to perceive when they are respected by their physicians although when they are not accurate, they tend to overestimate physician respect. Physicians who are more respectful towards particular patients provide more information and express more positive affect in visits with those patients (Beach et al. 2006).

Petrie et al. argue in the study of the role of illness perceptions on outcomes in patients with chronic medical conditions that the issue of reassurance provided by the physician plays an important role especially following negative diagnostic tests. The reassurance can be ineffective in reducing patients' concerns about symptoms. Patients' existing ideas about their symptoms and illness may not provide a compatible context to allow them to make sense of the diagnostic results. The patient's concerns and symptoms can continue if these are not effectively dealt with during the encounter (Petrie, Jago & Devcich 2007).

An understanding of illness perceptions is essential for effective patient management according to Weinman et al. They argue that the illness perceptions of individuals are highly influential in determining outcomes and adjustment in a number of medical conditions. Pa-

tients' models of their illness are by their nature very private. In medical consultations patients often are reluctant to discuss their belief about their illness because they fear conflict with their doctor or risk being considered stupid or misinformed. Patients are now requesting a more collaborative relationship in which their beliefs and expectations are acknowledged in consultations and treatment. Early exploration and identification of patients' perceptions offers the opportunity of minimizing or avoiding later difficulties such as non adherence to treatment or recommended behavior changes (Weinman, Petrie 1997).

Levinson et al. were able to demonstrate that encouraging the patient to express her own views and opinions as well as checking understanding and giving enough information were connected to less malpractice claims. It was also found out that doctors using humour and laughing belonged more likely to the non-claim group (Levinson et al. 1997).

Experiences shared between patients and physicians may play an important role in the development of a trusting patient-physician relationship. Just seeing the same physician over time does not guarantee a personal relationship or loyalty on the part of the patient. This finding coincides with previous discussions suggesting that the construct of continuity of care needs to be conceptualized in a way that distinguishes contact between patient and physician from the development of personal relationships. The personal relationship has been argued to be more important than simply having exposure to the same physician. Some physicians develop relationships within a short period, whereas others may see patients for years and still not have developed a strong patient-physician relationship. The developing relationship may be tied however, to the successful management of important medical problems and patients having shared experiences with their doctors (Mainous, Goodwin & Stange 2004).

According to Pearson et al., the most commonly described dimensions of physician behavior on which patients are believed to base their trust are competence, compassion, confidentiality, reliability, dependability and open communication. Still, a widely accepted empirical conceptualization and understanding of trust is yet to come (Pearson, Raeke 2000).

To gain further understanding of the components of trust in the context of the patient-physician relationship, 29 patient participants from diverse practice sites were recruited and four focus groups conducted by Thom et al. to explore the patients' experiences with trust. The resulting consensus codes based on a grounded theory approach were grouped into seven categories of physician behavior, two of which related primarily to the technical competence (thoroughness in evaluation and providing appropriate and effective treatment) and five of which were interpersonal categories (understanding the patient's individual experience, expressing caring, communicating clearly and completely, building partnership/sharing power and honesty/respect for the patient). Patients reported trust as being determined by their assessments of physician rapport, compassion, understanding and honesty. Study participants also confirmed the assumption that trust in the physician increases the likelihood of adhering to treatment recommendations (Thom, Campbell 1997).

Patient-physician trust has also been measured by Safran et al., who were interested in studying multiple components of the patient-physician relationship simultaneously. One of the most prominent instruments is the Primary Care Assessment Survey, which consists of 11 unique summary scales and measures seven distinct elements of primary care performance, including trust. The patient trust subscale most highly correlated with patient assessment of the physician's communication (0.75), level of interpersonal treatment (0.73) and knowledge of the patient (0.68). With continuity of the patient-physician relationship the correlation was 0.22. In this study patient-physician trust has been assessed as a predictor of other health outcomes. Although the investigators were unable to demonstrate an independent relationship between patient trust and improved health status, trust was one of the strongest independent correlates of satisfaction and adherence to treatment. Physicians' comprehensive ("whole person") knowledge of their patients and the patients' trust in their

physician were the variables most strongly associated with adherence, and trust was the variable most strongly associated with the patients' satisfaction with their physician (Safran et al. 1998).

Consultation

The patient perception following a visit to a doctor in a primary care unit was studied by Haddad. Randomly selected patients received mailed questionnaires 5 to 7 days following their visit to a doctor. Physician's reassuring attitude and the interest shown were the two attributes of quality related to the interpersonal aspects of care with the highest correlations. From the outcome dimension the attribute lessening of fear and anxiety and from the technical dimension explanation or clarification of treatment and of problem had the highest correlations. The observation in this study was that the outcomes seem to constitute a central attribute when patients are judging quality of care (Haddad et al. 2000).

In the EUROREP study people were asked in 8 European countries about their priorities for primary care services. There were differences among people from various cultural backgrounds but also very similar hopes and needs. Among other things they were very unanimous in wanting to have a general practitioner who listens and provides helpful information about patients' illnesses and their treatment and encourages them to discuss all their problems. Time spent in the waiting room was seen as much less important than the quality of the consultation (Grol et al. 1999).

Taylor has performed a critical review of literature about paternalism, participation, partnership and patient centredness in the context of the current state of consultations in the health care. Taylor's argument is that the consultation is now more important than ever as a point of access, communication, understanding and delivery of health care. The consultation has long been regarded as the focal point of healthcare delivery in general practice. On one level it involves the transaction between two individuals and at the same time it represents the interface between the medical profession and the society. In a relatively short period of time there has been a change from a paternalistic model of communication towards a model with an approach to democratic decision making, shared understanding and empowered individuals (Taylor 2009).

Malterud et al. present theoretical aspects to elucidate the purpose of the general practice consultation from the patient's perspective. An extensive literature review was conducted by Malterud and colleagues to explore presumptions and definitions reported by previous studies. The investigators propose a working definition of the 'purpose' concept. The proposed definition allows multiple purposes for the consultation. They incorporate what the patient hopes to gain (a desire) from the consultation, as opposed to their expectations of the most likely outcome. The working definition aims to identify patients' a priori wishes and hopes for a specific process and outcome, while acknowledging that these may not be voiced and may be modified by the patient during the consultation (Thorsen et al. 2001).

Cromarty wanted to find out what patients think about during their consultations with their doctors. The aim of his study was to describe the range and types of thoughts, which patients have during their consultations. Semi-structured interviews, prompted by video playback and transcript were conducted with 18 patients giving detailed accounts of their thoughts and feelings during a recent consultation. The results confirmed patients' central desire for understanding but also revealed that patients routinely considered their relationship with the doctor, the doctor's willingness, ability and available time, and altered their behaviour accordingly. It is accepted that patients have complex models of illness and that their views are important and that doctors should find them out. However, our understanding of consulting is based upon analyses that largely ignore patient behaviour, tasks and problem solving.

Patients were asked for their recollections of the consultation in three phases: unprompt-

ed, then prompted by video playback, and finally prompted by transcript of their consultation. At each stage, patients were asked to comment freely any topic, which they introduced. Once they had no more to offer, the interviewer probed for the thoughts and feelings underlying each point raised. This process allowed patients to give their own opinions, free of imposed structure. All patients were interviewed at home, within 8 days of their consultation (mean 2.8 days).

Content analysis, characterized by the reflexive and highly interactive nature of the investigator, concepts, data collection and analysis, was used. Not surprisingly, patients thought most about the problems that led them to the surgery, but they also considered their situation, particularly the available time and the behaviour of the doctor. To a much lesser extent, they considered matters that the doctor introduced. Underlying all these thoughts was a continuous reflection and interpretation of a search for meaning. All patients entered the consultation with problems that had been carefully considered in advance and with generally well-defined aims related to those problems. Patients typically wanted three things: understanding, information and a solution of their problems. Once patients' aims were satisfied, the consultation, for them, was at an end. Professional ability was never really doubted and patients assumed automatically that doctors, even trainees, were medically competent. The doctor's time was seen as short and valuable. Patients felt that they themselves actively limited the length of their consultation. Most patients felt guilty while consulting for two reasons: wasting the doctor's time and taking more than their fair share.

Whatever else they were thinking, nearly all patients spent most of their time trying to make sense of their situation. Their search for meaning occurred in all areas of the consultation from the value of treatment to the doctor's motives. Although patients accepted doctors' expertise, they did not accept their advice without first evaluating it in the light of their own understanding.

The main source of discontent was a failure of understanding. Patients rarely achieved as much understanding as they wished, even if they believed their doctor was good at explaining. Much of the problem was patients' reluctance to ask, which most commonly stemmed from lack of time or a wish not to upset a valued relationship. Patients also kept up a running assessment of their doctor during the consultation "Does he have the time? Is our relationship secure? Is he willing? Is he able?"

If patients perceived the answer to any of these questions to be no, then they were unlikely to ask questions and would often alter the course of the consultation. Rather than assume that a doctor could meet their needs, or infer it from his patient-centred behaviour, patients would prefer explicit permission to ask more questions and use more time. Most left somewhat dissatisfied, with questions un-answered, and cited time pressure as the main reason. Yet patients felt it was they who decided when the consultation was over and did not generally feel that the doctors exerted direct pressure to shorten a consultation. This study extends the principle into every aspect of the consultation – not just, "Why me? Why now?" but "Why won't s/he tell me? Why does s/he look so tired?"

Patients searched for meaning in everything and these searches occurred live in the consultation, during conversation and in pauses, and continued afterwards. Patients consult widely before seeing the doctor, and interpret the opinions they receive in the light of their own experience. This study confirms that, however much the doctor is respected, his or her opinion will be subject to a certain degree of interpretation and comparison (Cromarty 1996).

The Finnish study by Kokko and Punamäki was conducted in the clinical setting by interviewing patients before they consulted the general practitioner, who was the other investigator of the study and immediately afterwards. The study relied entirely on the patients' post-consultation accounts of the diagnosis and the nature of the interaction between the doctor and the patient. There was a great diversity in the contents of both positive and nega-

tive consultations. The negative consultations were experienced as lacking human concern and professional skills and the patients often felt neglected. The positive consultations were holistic experiences where the doctor communicated warmth, equality, medical and humane interest and respect for the patient's own explanations and ideas.

The general question of the post-consultation interview, "What happened in the consultation?" made it possible to analyse, how patients construct their experiences. One predictor for a successful consultation was the matching of the patient's and the doctor's diagnosis. To be exact it was the negotiation process, which resulted in matching that was important. The contents of the consultation, which resulted in a shared diagnosis consisted of a thorough examination by the doctor, explicit explanations of the medical findings and the sense of respect for the patient's own diagnosis. This is an example of how the disease and illness frameworks can be successfully integrated at a medical consultation. Another important predictor of the success of the consultation was the character and content of the subjects' illness explanation. The extent of integrating both experiential and biomedical illness explanations by the patient, was critical in predicting the quality of the consultation experience. Subjects whose illness explanations consisted of both biomedical and experiential models, reported more unsuccessful consultation experiences than subjects with either biomedical or experiential model. According to the authors patients often hesitate to share their ideas, feelings and explanations of their illnesses with the doctor. There may be various reasons for doing this like respect for authority and expertise, fear of hurting the doctor's feelings and disbelief in any genuine interest by the doctor. Even if the subject's own diagnosis remains hidden at the consultation, it obviously is present in the evaluation of the success of the consultation (Punamäki, Kokko 1995).

According to McKinley et al. and Williams et al., the core task of the medical consultation is to find out the real reason for the visit and following this, concentrate on finding a solution to the patient's current health problem. Most patients come to the consultation with a particular agenda, which they expect their doctor to deal with. Failure to address this agenda is likely to adversely affect the outcome of many consultations. Almost all patients have requests they wish to make of their doctor or their own ideas about what is wrong, and some of them have considered explanations about why they are unwell. Quite a few people consult because they have reached the limit of their anxiety or tolerance level (McKinley, Middleton 1999, Williams et al. 1995).

To investigate patients' agendas before consultation and to assess which aspects of agendas are voiced in the consultation and the effects of unvoiced agendas on outcomes, Barry et al. conducted a qualitative interview study with 35 patients consulting 20 general practitioners in appointment and emergency surgeries in south east England and the West Midlands. Agenda items most commonly voiced were symptoms and requests for diagnoses and prescriptions. The most common unvoiced agenda items were worries about possible diagnosis and what the future holds. These included patients' ideas about what is wrong and side effects as well as not wanting a prescription. Agenda items that were not raised in the consultation often led to specific problem outcomes, for example, major misunderstandings, unwanted prescriptions, non-use of prescriptions, and non-adherence to treatment. In all of the 14 consultations with problem outcomes at least one of the problems was related to an unvoiced agenda item (Barry et al. 2000).

Patient expectations

Both Rao et al. and Williams et al. have investigated the specific expectations concerning the appropriate roles of the doctor and the patient in the consultation. The patient is likely to have earlier experience from the health care services and these experiences have impact on how s/he behaves and what kind of preconceptions s/he has. The patient brings to the encounter his or her concerns, expectations and possible fears and the health care provider

brings his or her own history, beliefs and attitudes. Responding to the patients' expectations has been shown in many studies to be correlated to a positive experience of the consultation (Rao, Weinberger & Kroenke 2000, Williams, Weinman & Dale 1998). On the other hand patient expectations are shaped by earlier encounters and adapted to the reality of the health care system. So the true hopes and needs of the patient may not be reflected on the expressed expectations (Thorsen et al. 2001).

Unmet expectations for care and the patient-physician relationship were investigated by Bell et al. Patients who perceived an unmet expectation for care also reported less satisfaction with their visits, less improvement, and weaker intentions to adhere. Patients with unmet expectations related to clinical resource allocation had more post visit health system contacts. Unmet expectations were typically reported by a patient whose request for a resource was not fulfilled. Physicians' nonfulfillment of patients' requests plays a significant role in patients' beliefs that their physicians did not meet their expectations for care (Bell et al. 2002).

In a prospective cohort study by Jackson et al., at a primary care walk-in clinic nearly all patients (98%) had at least one pre-visit expectation, including a diagnosis (81%), an estimate of how long the symptom was likely to last (63%), a prescription (60%), a diagnostic test (54%), and a subspecialty referral (45%). Immediately after the visit, the most common unmet expectations were for prognostic information (51%) or diagnostic information (33%). Patients who seek care for physical symptoms and do not leave the encounter with an unmet expectation are more likely to be satisfied with their care and to have less worry about serious illness. According to the investigators diagnostic and prognostic information are particularly valued by patients and may be associated with greater improvement in symptoms and functional status 2 weeks after the visit according to the investigators (Jackson, Kroenke 2001).

A study focusing on unmet expectations among arthritis patients found that they were more common among patients with higher level of pain and perceived helplessness at the baseline (Rao et al. 2004).

The study by Webb et al. aimed to examine the following questions: 1. What decisions do patients expect the general practitioner to make within the consultation, 2., to what extent are these expectations fulfilled and 3., which factors influence patients' expectations and general practitioners' actions with reference to prescribing and hospital referral. The study covered 1080 consultations with 12 general practitioners in two north London practices. Information was collected by self-administered questionnaires from patients before the consultation and from the general practitioners after the consultation. The results showed that 51% of patients expected and 55% received a prescription; 13% expected hospital referral and 10% were referred. Factors related to their presenting problem were most strongly associated with patients' expectation of receiving a prescription. The actions, which the general practitioners took were most strongly associated with patients' expectations. Patients' anxiety about their health problem also appeared to influence their expectations of referral and the doctor's prescribing decision. As a conclusion the authors state that patients' expectation of management and their anxiety associated with the presenting problem may be two of the factors, which influence general practitioners' prescribing and referral behaviour and may explain some of the observed variations in behaviour (Webb, Lloyd 1994).

Patient's help seeking behaviour

Symptoms are an everyday part of most people's lives, yet few are presented to general practitioners. There is a widespread physical and psychological morbidity in the community. Symptoms of ill health are a common part of the daily life of most people (Gijsbers van Wijk, Huisman & Kolk 1999). One theoretical framework, which has been used widely to explain responses to illness is the Health Belief Model. This model identifies four key psycho-

logical characteristics as determinants of an individual's perception of his or her own health and help seeking behaviour. These issues are perceived susceptibility and vulnerability to illness, perceived severity of the symptoms, perceived costs, monetary and other and perceived benefits of action including belief in the efficacy of the doctor. In an individual situation the patient may be influenced by "cues to action" such as advice from others, previous illness in family or friend, and media reports or campaigns.

The Health Belief Model as described by Pendleton, can be applied to patients' use of primary care, and there is evidence for validity of the concepts within the Model. A patient's perceived susceptibility to an illness may also be related to "the locus of control", or the extent to which a person feels that he or she has personal control over his or her health. In discussing perceived severity, it is important to distinguish between the actual severity of a condition (e.g. actual threat to life) and an individual patient's perception of severity. The Health Belief Model proposes that the balance between risks and benefits from seeking care is an important determinant of help seeking behavior of an individual. The benefits relate mainly to the person's belief in the effectiveness of the action, which is likely to be proposed when medical care is sought, balanced against his or her perception of how effective self-care is likely to be. The costs of seeking care may be financial prescription charges, transport costs, lost time from work or physical barriers to care such as access, as well as perceived negative physical outcomes from treatment, e.g. side effects of drugs. The decision to consult a general practitioner is based on a complex mix of physical, psychological and social factors.

Service utilization reflects not only morbidity in the community but also the availability of services and individuals' willingness to use them, although the experience of symptoms is the usual cue that some action is required. The overall prevalence of symptoms in the community is not closely related to general practice consultation rates, and the consulting population is a selected population of those who are in need of medical care. Poor health status, social disadvantage, poor social support and inadequate coping strategies are associated with higher consultation rates. The response of individuals to health problems depends on a wide variety of individual social and psychological factors (Campbell, Roland 1996, Pendleton 1984).

Saint Arnault has developed the theoretical model called the Cultural Determinants of Help Seeking. She argues that culture affects all aspects of health and illness, including the perception of it, the explanations of it and the behavioural options to promote health or relieve suffering. People seek help for their suffering based on the meaning that culture assigns to the suffering. The author of this paper talks about cultural models of wellness and illness as cognitive guides for perception, emotion and behaviour. The collection of social patterns of interpretation and expectations that are provided for people by their prevailing, local cultural ambience are referred to as cultural models. In this theory help seeking is defined as attempts to maximize wellness or to ameliorate, mitigate or eliminate distress. Understanding how a given cultural model might direct attention is a starting point for making predictions about how the sensations within the body, emotions and social situations will be perceived and therefore how health is maintained or distress experienced.

The attention that people give to any given physical or emotional sensation is filtered through cultural models. Causal attributes are attached to symptoms based on the explanations about the cause of wellness or distress provided by the cultural models. Explanatory models allow groups to develop shared and meaningful patterns of need and care. While culture is a system-level phenomenon, it becomes part of an individual's cognition and is therefore enacted at the small group and individual levels. Culture affects health and distress perceptions, interpretation, communication and social support and ultimately all help seeking behaviours (Saint Arnault 2009).

Campbell studied patients' perceptions of medical urgency and decision making about

consulting in Scotland with a questionnaire completed by 5000 patients attending to certain practices in the area. The medical urgency score was calculated from the responses to ten vignettes of cases, which represented common clinical conditions. The perceived seriousness of the symptoms or the feeling of being unable to cope with the symptoms anymore, have been cited as the main reasons for deciding to consult a doctor. Social deprivation was reported to explain at least part of the variation in the urgency scores. It is also emphasized to recognize the importance of contextualizing these perceptions within the conditions prevailing for a given patient at a certain point in time (Campbell 1999).

Patient's own ideas about causation were crucial to understanding patterns of illness action and help seeking behavior according to Calnan. The common strategy was to wait and see what happens as the pain was believed to be a natural part of the ageing process (Calnan et al. 2006). The same author has investigated the reasons why people go to their doctors and his conclusion is that booking the appointment with their physician is not a common event and that they have good reasons for consulting when they do (Calnan 1995).

Mitchell et al. state that patient perceptions about knee pain, especially beliefs about the severity of the knee pain, are factors associated with consulting the general practitioner (GP) and getting referrals to secondary care. In their study nearly half of those who reported knee pain had not consulted their GP. Those who were referred to a specialist were more likely to believe their knee pain was permanent, that it was a serious condition and that it would have major consequences on their lives. They were less likely to believe it would become easier to live with and that it would not affect their life so much. The findings of the study support the view that they did not have a more severe disease but had higher levels of self-perceived handicap and more negative views about their condition. The authors state that no overlap existed between factors predicting consultation with a GP and referral to secondary care. One explanation is that referrals are largely determined by the GP, who assesses the severity of the problem and the impact it has on the patient, whereas seeking help from the GP is a decision made by the patient. The authors argue that it is surprising that neither pain nor stiffness appeared in the regression analysis. Findings indicate that beliefs relating to consequences were important in connection to consulting the GP and being referred to secondary care (Mitchell, Carr & Scott 2006).

Patient participation

Patient participation in medical encounters depends on a complex interplay of personal, physician, and contextual factors. Although more educated patients tended to be more active participants, the strongest predictors of patient participation were situation-specific, namely the clinical setting and the physician's communicative style. Physicians could more effectively facilitate patient involvement by more frequently using partnership-building and supportive communication (Street et al. 2005).

Patient activation interventions can be conveniently and successfully delivered just before the consultation as it was shown in a study by Cegala et al. With respect to patients, successful patient activation interventions are those that promote the legitimacy of the patient's involvement in care, provide information about the patient's health condition and treatment options, and offer specific communicative strategies like writing down questions and concerns before the visit for their interactions with physicians. It was shown that patients in the intervention group were more actively participating in the interaction during the consultation and asking more questions (Cegala et al. 2000).

Effective communication is a critical component of quality health care, and to improve it health care providers must understand its dynamics. The study by Street et al. examined the extent to which physicians' and patients' preferences for control in their relationship meaning shared control versus doctor control were related to their communications styles and how they responded to the communication of the other participant. They rated 10 doctors

as patient-centered physicians (5 male, 5 female) and 10 doctor-centered physicians (5 male, 5 female) each of whom interacted with 5 to 8 patients, roughly half of whom preferred shared control and the other half of whom were oriented toward doctor control. Audiotapes of 135 consultations were coded for behaviors indicative of physician partnership building and active patient participation. The main results indicated that patients who preferred shared control were more active participants (i.e., expressed more opinions, concerns, and questions) than patients who were oriented toward doctor control. Physicians' beliefs about control were not related to their use of partnership building. The physicians used more partnership building with male patients. As a conclusion the authors state that communication in medical encounters is influenced by the physician's and patient's beliefs about control in their relationship as well as by one another's behavior. The relationship between physicians' partnership building and active patient participation is one of mutual influence such that increases in one often lead to increases in the other (Street et al. 2003).

Patients at an academic medical center were investigated by Schattner et al. Consecutive patients (n = 274) indicated their first and second priority for a change or improvement in their medical care out of a mixed shortlist of 6 issues. Getting more information from the physician and taking part in decisions was the most desirable patient choice, selected by 27.4% as their first priority. Being informed by their doctor and shared decision-making is a top patient priority (Schattner, Bronstein & Jellin 2006).

Doctor competence

The Competence framework called the CanMEDS initiative of The Royal College of Physicians and Surgeons of Canada was originally applied to the professions of medicine, occupational therapy, physical therapy, and nursing. The framework identifies the core competencies common to learners in health care, which are a professional and health advocate, an expert, a scholar, manager, communicator, and a collaborator. CanMEDS dimensions are based on the population perceptions of the desired characteristics of medical professionals. Implementing this competency framework to the development of an outcome-based curriculum in medical education has been a major task in many countries in the recent years (Frank, Danoff 2007).

According to Richard Baker the consultation is the single most important event in clinical practice and based on this, the central target of the revalidation should be the assessment of consultation competence focusing on what the practitioner actually does. It is argued that a competent doctor does not necessarily put his or her skills into practice meaning that the performance may be less than optimal (Baker 2001).

From the patient's perspective, having a skilled practitioner is crucially important according to Anderson et al. When asked to rate their experiences in the health care, patients often describe the key qualities that influence their perception of the consultation and predict their satisfaction. Doctor competence is embedded in these assessments: how the doctors relate to their patients and how they provide care that meets the needs and expectations of their patients. The skill level of the physician, the technical competence, thoroughness of examination and overall treatment approach of diagnosis, treating and following up on results are included in the ratings of high quality healthcare by the patients (Anderson, Barbara & Feldman 2007).

Based on the findings of their study, Chapple et al. argue that patients cannot assess the quality of the technical skills of the medical practitioner but instead they are perfectly capable of judging the communication skills of their doctors (Chapple et al. 2002).

Patients' preferences for technical versus interpersonal quality when selecting a primary care physician while using computerized report cards was investigated by Fung et al. Participants were told that the purpose of the project was to learn more about how patients choose a new doctor. The participants were instructed to imagine that they had moved to

a new city. With the help of family, friends, and co-workers, they had narrowed their list of new primary care physicians to two that were equal in all respects, except for the information contained in the health care report cards provided to them by a trustworthy nonprofit organization. The report cards contained the following categories of evaluations of physicians 1. limited sickness or injury care (acute care) 2. care for ongoing health conditions (chronic care) 3. preventive care 4. communication 5. courtesy and respect and 6. promptness. The first three categories were identified as Technical Quality and the last three categories as Patient Experiences, which represented the concepts of interpersonal quality and getting care quickly.

The principal findings from the study were that participants used both technical and interpersonal quality ratings when selecting the primary care provider and that the majority clearly favors technical quality of care, but not to the exclusion of interpersonal quality. Two-thirds of the sample chose the physician who excelled in technical care three or more times out of five, demonstrating an overall preference for technical quality of care. However, one third of the sample chose the physician who excelled in interpersonal quality at least three times of five, suggesting that interpersonal quality was important for a substantial number of people in the study sample (Fung et al. 2005).

The study by Mainous and David examines the attitudes and perceptions of patients regarding the clinical competence of family physicians. The study design was a telephone survey employing probability sampling (random-digit dialing). The setting was a sample of adults living in Kentucky, US. The data came from a sample of 650 completed calls with a 64% response rate. Patients generally agreed that family physicians are clinically competent to handle common medical problems. Of 11 investigated conditions, depression and heart disease were the conditions with the lowest reported patient confidence. A stepwise logistic regression model indicated that the quality of care provided by one's primary care physician was the only significant predictor of patient confidence in the competence of family physicians. According to the researchers these results suggest that patients believe family physicians are competent to treat a wide variety of common medical problems (Mainous, David 1992).

Patient perception of the quality of the consultation was investigated in a study by Mercer et al. with a qualitative focus group design in an area of high social deprivation in Scotland. Based on the results people want doctors who understand the realities of life in such areas and whom they can trust as both competent and genuinely caring. Competence included references to the doctor's technical competence, including medical skills, knowledge and training. Perceptions of competence were also influenced by the patients' image of the doctor as an individual, including appearance and mannerisms. In general, the participants, especially the older ones, assumed doctors to be technically competent. The doctor's competence would be questioned in circumstances where somebody had experienced an inaccurate diagnosis or there was lack of examination or treatments, which did not result in improved health outcomes. In these occasions the patients were often critical, forusplacng judgments especially on the doctor's medical skills and knowledge (Mercer, Cawston & Biker 2007).

1.1.3 Outcome

Satisfaction and dissatisfaction

These issues are dealt here based on the writings of Susan Linder-Pelz, "Towards a theory of patient satisfaction". Among the various probable determinants of a patient's satisfaction with health care are his or her attitudes and perceptions prior to experiencing that care. Linder-Pelz is referring to the work of Fishbein and Ajzen, their theory of attitudes. The ideas related to job satisfaction are also on the background in her theory building.

“A person’s attitude toward an object is related to his or her beliefs that the object possesses certain attributes and his or her evaluations of those attributes”. A belief is one type of perception. She also states that an attitude, like patient satisfaction, which is a positive attitude, is based on two distinct pieces of information: belief strength and attribute evaluations (Linder-Pelz 1982).

Over the past 20 years consumer satisfaction has gained widespread recognition as a measure of quality in many public sector services. The model commonly used in satisfaction work has been termed the “discrepancy model” (Williams 1994). The discrepancy theory makes the assumption that satisfaction is the result of the perceived discrepancy between that which an individual desires and that experienced as a proportion of those factors. There is variation in the meaning of ‘desires’, since they are sometimes treated as ‘expectations’, or what is ‘important’ and sometimes as what ‘should be’.

Williams argues that the concentration upon areas of expressed dissatisfaction is more valuable than obtaining consistency of expressed satisfaction. According to him patient expectations are the key to understanding the reasons for expressed dissatisfaction. A factor common to many patient satisfaction surveys is that very few patients express dissatisfaction or are critical of their care. The main reason why satisfaction studies fail to emphasize the importance of the technical quality of the care delivered is that patients assume a basic level of competence in medical procedures undertaken upon them. According to the discrepancy model satisfaction is entirely relative, defined in large part by the perceived discrepancy between a patient’s expectations and actual experience.

Williams further refined the theory to assume that dissatisfaction is only expressed when an extreme negative event occurs. If dissatisfaction is expressed then there is likely to be something wrong with the service provision. According to the investigator to be able to fully understand the views of service users we must first discover what rights and obligations they sense they have and what they perceive their role to be.

Quantitatively measured expressions of satisfaction tend to be high while qualitative reports reveal greater levels of concern. The possibility exists therefore that the reductionism necessitated by the quantitative methodology has caused satisfaction results which lack much of the meaning they were intended to express. If future questionnaires are to rise to the challenge, then more qualitative research is required to inform the design and the interpretation of the satisfaction questionnaires. Based on Williams Consumerism relies on three fundamental and basic factors:

- 1) The existence of consumer opinion
- 2) A belief (by the consumer) in the legitimacy of that opinion
- 3) Willingness to engage in an expression of that opinion.

Consumerism is dependent on a refusal to accept paternalism; it relies on the existence of consumers and not passive patients. Consequently satisfaction data can only be useful if patients leave passive roles behind and actively evaluate and criticize. The expression of satisfaction may not necessarily mean that a critical evaluation has taken place; it might just as well be an expression of the non-existence of opinion and an acceptance of medical paternalism (Williams 1994).

According to Linder-Pelz it is this taking for granted that is relevant. The expression of satisfaction might simply reflect the latter rather than any active evaluation. What needs to be known is when and under what conditions patients take the quality of particular aspects of services for granted. Without knowledge of this it is impossible to accurately interpret satisfaction survey results. In Linder-Pelz’s study the most important preceding social-psychological variable was found to be expectations. It is important to note that patient expectations were found to have an independent effect on satisfaction i.e. irrespective of their fulfillment. The implication of this finding is considerable. It suggests that beliefs about doctor conduct prior to an encounter play a significant role in determining subsequent evaluations

of the doctor conduct, irrespective of what s/he actually does or is perceived to be doing at the consultation.

As a result, relatively minor considerations such as the manner of the attending staff and the comfort of the surroundings assume a dominant importance. However, if the medical procedures are found to be deficient, this is associated with patient complaints, a clear indicator of dissatisfaction with a service. Linder-Pelz argues that the concept of patient satisfaction can be regarded in the wider context of the rise of consumerism in the Western medical practice but that the concept has suffered lack of formal attention to its meaning. Perhaps the greatest weakness is that theoretical work has concentrated on the development of models, which explain the results of satisfaction studies, rather than questioning the theoretical foundations on which the concept satisfaction and its measurement are based. This may in large part be due to patient satisfaction being adopted as an indicator of health care quality by provider institutions under pressure not only to monitor and improve performance, but to include patients' views in the audit process.

According to Linder-Pelz deprivation and dissatisfaction result from comparison processes, different objects or levels of comparison are involved in the process. Social comparisons affect the formation and evaluation of opinions. The individual's value system is a culturally transmitted set of standards of value orientation. So there is the cultural determination of individual satisfaction, similar to social influence and social comparison theories of attitude formation developed by social psychologists (Linder-Pelz 1982). In this way a positive response in a satisfaction survey should not be interpreted as indicating that care was good but simply that nothing extremely bad occurred (Sitzia, Wood 1997).

Crow et al. state in their review of literature that there is little standardization, low reliability and uncertain validity of satisfaction measures. Satisfaction can be defined as fulfilling expectations, needs or desires. It does not imply superior service, only adequate or acceptable service and it is a relative concept what satisfies one person may dissatisfy another. In most quality of care assessment studies patient satisfaction is the predominant indicator (Crow et al. 2002).

In the context of the primary care patients, understanding the illness perceptions of the patients is relevant, when assessing satisfaction. In particular uncertainty about their symptoms and emotional distress about the illness have been shown to be significant predictors of lower patient satisfaction with the consultation (Petrie, Jago & Devcich 2007).

In a survey which was completed online by Anderson et al., the patients were asked to evaluate their physicians on several dimensions of healthcare experiences and provide comments about aspects of care that were excellent or most in need of improvement. A total of 24 qualities of healthcare associated with patient satisfaction or lack thereof were identified. Among these seven thematic clusters were found which were access, communication, behaviour of the provider such as the extent of the physician being supportive, caring and compassionate, quality of care processes such as diagnosis and treatment, care continuity, making referrals, the health care facilities and office staff.

One specific dimension in the category of outstanding communication skills was listening. Patients value providers who are excellent listeners and who take patients' concerns seriously. These qualities convey caring and giving attention to the patient's concerns. Trust is an essential quality of excellence in healthcare according to the authors of this survey. It is a result of believing that the provider is sincere, puts the patient's interest first and is very knowledgeable.

In the outstanding medical care category, comments on the doctor's excellence in competence were the most frequent type of praise. Competence defined by the patients includes facets of treatment approach and outcomes. Thoroughness and conscientiousness are mentioned as qualities related to technical competence. Patients value providers who monitor their health conditions and follow the path of care, look after referrals and the opportunity

to seek second opinion when needed. Providers, who work hard on the patients' behalf, are highly thought of and receive the solid trust of their patients. It is concluded that patients may like their doctors as persons but they are judging them for their bedside manners. So the suggestion is that patient satisfaction ratings are not measures of mere friendliness or "likeability" but are closer to measures of the quality of the healthcare processes. The authors state that a notable strength of the study is the large number of comments online they had more than 50 000 respondents in this survey (Anderson, Barbara & Feldman 2007).

A Finnish study by Punamaki et al., investigating the predictors of consultation experience, argues that even if most of the satisfaction studies are based on the overall satisfaction expressed by the respondents, such a research can hardly contribute to a deeper understanding of how patients construct their health care experiences (Punamäki, Kokko 1995).

Persons who are in general rather dissatisfied, will also show greater dissatisfaction with the general practitioner, irrespective of other characteristics that influence the doctor-patient relationship. Improving the interaction process between patient and health care worker might also affect variables related to the patient satisfaction, like adherence to the treatment at the patient level (Sixma, Spreeuwenberg & van der Pasch 1998).

To explore whether responses to questions in surveys of patients that purport to assess the performance of general practices or doctors reflect differences between practices, doctors, or the patients themselves, Salisbury et al. conducted a second level analyses using multi level modeling at practice, doctor and patient level. The three level hierarchical structure means a design where patients are clustered within doctors and then within general practices. The authors conclude that measures of patients' satisfaction discriminate poorly between practices or doctors because random error and differences in people's perceptions account for more than 90% of the variance. The finding that patients' characteristics influence responses to questions about experiences of health services as well as satisfaction raises the question about whether this reflects different expectations or differences in the care provided to different types of patients within the same practices. If patients' experience is related to expectation rather than to performance of the practice, then failing to adjust practices' scores for the characteristics of the population of patients could lead to systematic misrepresentation of the performance of practices that cater for particular patient groups (Salisbury, Wallace & Montgomery 2010).

For a patient-centred consultation to take place, "patients' a priori wishes" should be identified in the pursuit of the reason for the encounter. Patients' desires mean what is perceived by the patient as desirable and wishes regarding medical care, in contrast to patient expectations, take into account a valuation, a perception that a given event is wanted. In the case where the expectations are not very high based perhaps on earlier experiences, being satisfied does not necessarily mean that the care has been excellent. There may be a gap between what patients hope to gain during the consultation versus their expectations of the most likely outcome (Malterud, Hollnagel & Witt 2001).

Expressing dissatisfaction and criticism appears to require justification, accounting and detailed explanation. Coyle, in a grounded theory study of dissatisfaction, found that her respondents were unwilling to describe themselves as dissatisfied without offering elaborate justifications and intricate explanations of attributions, causes and responsibilities for the untoward experience. She found that respondents' accounts of disappointment were based on three recurring themes: 1. dehumanization 2. disempowerment and 3. devaluation.

Dehumanization refers to a sense of being objectified, treated as non-persons, with little recognition given to individual experiences, knowledge and feelings, and the perception of being negatively stereotyped by practitioners. Disempowerment relates to patients' perceptions of having little control over their bodies or treatment, frustration at being unable to gain access to care, being unable to carry out social roles or assert "authentic" personal identity. Finally, devaluation refers to a sense of being unvalued or having one's social

worth undermined. Coyle argues that “personal identity threat” is a key concept delineating the grounds for patients’ dissatisfaction with health care, and is better able to capture the complexity of patients’ experiences, feelings and values than the less theorized concept of satisfaction. “Personal identity threat” and the categories which underpin it would seem a useful starting point for developing a framework to understand more fully the contradictory attitudes, feelings and beliefs that patients express about their health care. According to Coyle, it is likely that changes to services will stem more from the limited number of studies of complaints than the large number of satisfaction surveys being carried out. However, complaint studies cannot be relied on alone since many people may willingly express dissatisfaction and yet not make any form of complaint. If this “silent” group of patients is to be heard and services changed then a re-examination and re-conceptualization of “dissatisfaction” is required. The acceptance of mitigating circumstances for a behaviour or service failing makes expressing dissatisfaction less likely (Williams, Weinman & Dale 1998, Coyle 1999). Therefore, expression of dissatisfaction will involve very detailed justification, which includes assessments of guilt and responsibility (Coyle, Williams 1999).

Benefit

Benefit implies some change from an earlier situation, in the context of health care some positive change in the health status of the patient. If nothing happens as a result of a clinical encounter, the patient has gained no benefit.

The non-existence of relevant studies emerging when using as a key word “benefit” was evident while performing extended search processes in Medline, Ovid Nursing Database, Psych INFO and EBM reviews. When the key words were benefit, patient perception or experience and consultation or office visit, the outcome was not a single relevant publication.

According to Porter the shift in the healthcare paradigm should be from limiting services to maximizing value for the patient over the entire care cycle. This kind of thinking is in alignment with value-based medicine approach according to which the efforts of the health care should bring some “added value” to the patient to be effective (Porter 2006). This coincides with the current trend of enthusiasm here in Finland over the so called “chronic care model” where the objective is to produce health benefit to the users of the health care system. This model is based on the earlier work of Wagner where he introduced the health benefit model. In this model one of the essential ideas is that every visit emphasizes and confirms the realization of the treatment plan and some positive change in the patient’s health (Gensichen et al. 2006).

The patient experience of the quality of the consultation was the focus of interest in a study conducted by Kekki in Finland among users of the public health centre doctor services. Developing primary health care services requires collaboration with the population. As the true financiers of the public sector healthcare the population should receive the kind of health services which coincide its needs. The perceptions and assessments connected to the whole health care system are often based on the experiences encountered at the medical consultations, interacting with the health care provider.

The study design was a telephone survey for the population living at the catchment area of four health centres in Finland. The research assistants conducted the interviews using a structured questionnaire. The participants were asked to assess the interest shown by the doctor, the respect shown by the doctor, the thoroughness of the examination and the taking into account the patient’s opinion. The patient assessments of the qualities of the doctors had a strong correlation with each other. “Interest shown”, “taking into account the patient’s opinion” and “thorough examination” correlated with “respect shown by the doctor”. Therefore respect was chosen to describe the quality of the practice of the doctor. The respondents, who did not perceive any benefit during their last visit to the health centre, rated more often the respect shown by the doctor at that consultation negatively than the

patients who experienced gaining benefit.

In the analysis from all the variables used, the experience of benefit and the age of the respondents best predicted the grades given for the physician services. The benefit means some positive change in the health of the patient as a result of the consultation. The outcome of the treatment is a central indicator of the quality of the care. The patient experience of benefit is an essential factor in her perception of the quality of the doctor performance. This result gives support to the conclusion that the consumer perception of the services received is an important indicator of the quality of the health care (Kekki 1995).

The aim of a Swedish study was to describe and understand patients' positive and negative experiences of general practitioners (GPs). Forty-six consultations were videotaped in four primary health care centres in Sweden. Afterwards the patients were asked to comment on the recorded consultations. The comments were categorized and analyzed using an exploratory qualitative approach. An image of the "good" GP emerged that had two major characteristics: that of being a caring human; an individual who listens, understands, and is concerned. At the same time, the good GP acts like an ordinary person and treats the patient as an equal. The personal relationship with the GP also influenced the choice and course of medical interventions. According to the authors, for the patient, the manner in which an intervention is seen is linked to whether the GPs treats the patient with respect or not. A typical experience of a "bad" GP was that the GP appeared unreachable as a person. An example of this is when the patient feels that the GP is not taking his or her symptoms seriously. Another characteristic of the bad GP is a failure to communicate his or her view on the issues raised during the consultation to the patient (Arborelius, Timpka & Nyce 1992).

1.2 THE BACKGROUND OF THE STUDY

The meeting between the patient and the doctor is always unique and intimate. The consultation between a layperson and a health care provider takes place in all societies every single day in millions of visits throughout the world although the contents and the structure, as well as the level of professional expertise may vary a lot in different sociocultural, geographic and political contexts. The individual experiences symptoms and s/he gets worried about them at some point determined by his/her own health beliefs which again depend on the cultural context s/he is living in. First s/he may ask advice from his/her closest family members, some trusted friend or some wise and respected person. It is known, that only a small minority of symptoms are brought to the knowledge of the health care personnel and people with medical problems may rate their general health as good despite the existence of a disease (Malterud, Hollnagel 2004).

According to Pendleton, the consultation in general practice is defined as the encounter, which takes place between the patient and the physician. The consultation is the core event in the health care and it has various tasks. The doctor meets the patient and works together with him or her to achieve the objectives of the consultation. The main objective is connected to solving the present problem of the patient and taking care of that. In addition to this there can be other objectives and opportunities to influence the health status of the patient during the consultation. The duration of the consultation limits the number of topics that can be dealt with at one visit. By listening attentively and giving the patient space to tell his or her worries without interruption, the doctor conveys caring and this helps building a trusting patient-doctor relationship (Pendleton 1984).

Anton Chekhov (1860–1904) dealt in many of his short stories and plays with various phenomena as encountered in everyday medical practice in late 19th century Russia. In *A Case History* (1898) Chekhov illustrates the physician's many positions in relation to his patient. In his story Chekhov describes how the patient was at first addressed solely from a medical point of view, without any relief to her suffering. Only when the physician was able

to shift his position in a manner which offered the patient an opportunity to be heard as a person was she able to express the true nature of her illness and to find new ways for palliation and cure (Puustinen 2000).

Puustinen discusses the idea of multivocality in his article about the task of the physician to apply a general medical theory of health and illness to a particular patient's situation. These situations are penetrated by the voices of all those related to this particular event, voices as expressed points of view, opinions, convictions, beliefs, fears, or any other human ways of interpreting the reality within which we live. All this emphasizes the nature of the consultation as an active event and non-existence of a "pure" expression since meaning is being constructed as part of the dialogue. Everything that is experienced and told earlier is present in the inner dialogue where the person tells her story. It is interesting how experience time after time is invited alive in speech and narrative. The narrative remains alive since it keeps receiving new meanings and new view points from other people. The past experience is possible to be told as part of the continuing dialogue, the living stream of meanings which is not going to stop when the tape recorder is shut. It goes on first in the interpretation of the researcher and further as somebody reads the research report and in the future dialogues of this person (Puustinen 1999).

When I was conducting a search in the Medline Databases, the number of doctor-patient communication literature rises to hundreds of thousands. While using as search words "communication skills" or "patient-provider relationship" or "doctor-patient relationship" as search words the number of references found was over 100 000. Based on browsing these references, the research activity around the consultation has focused during the decades mainly on the doctor-patient relationship and how to improve the communication skills of the physicians to meet the expectations of the patients and increase their satisfaction towards the health care services.

Training programs have been introduced, video cameras have been brought into consultation rooms and endless instruments have been developed to measure different dimensions of interaction taking place between the patient and the care provider. Most of the published research reports describe the doctor behaviour during the consultations. In the results we read analyses about patient-centred or doctor-centred interviewing style, partnership building and other characteristics that have been reported by the researchers and videotapes of the encounters to assess the quality of the communication during the consultations (Roter et al. 1995, Roter et al. 2006).

According to Ridd et al., studies that focus on the patient's subjective experience of the consultation and her own interpretations of the benefit gained, are much fewer in number. To derive a conceptual framework of the factors that define patient-doctor relationships from the patient perspective, Ridd et al. conducted a systematic review and a thematic synthesis of the qualitative studies. In the final synthesis 11 studies were included, which examined the patient-doctor relationship generally, in terms of loyalty, personal care, trust and continuity. Continuity of care and the experiences of the actual encounters with the doctors were found to be the main processes by which patient-doctor relationships are promoted (Ridd et al. 2009).

"People are potentially unknowable. After all interpretation, they remain others". I happened to hear this statement in the beginning of my research journey at a workshop in Tampere and it has remained on the back of my mind ever since. "One can never know how things really are" (Guba, Lincoln & Cuba 1989). The message of these thoughts makes one humble and gives perspective to my expectations to learn to know the informants of my dissertation. It is not possible to know other people but in optimal circumstances some new understanding about the viewpoints of other people may emerge.

The main focus of interest in this study is the person's experience of the quality of the consultation with the health care provider. What kind of feelings and expectations individu-

als as patients attach to the consultations with their doctors and the experiences connected to the clinical encounters. The interpretation of an unnecessary visit and the concept of benefit from the patient viewpoint were included in the topics of interest. I wanted to make sure that the people involved would get their voices heard as authentically as possible. That is why I decided to use in-depth interviews with the participants and audiotape the discussions. My plan was to visit the interviewees at their homes to give them the advantage of being at a place familiar to them while telling me their stories and where I as a researcher was a visitor. Most of the interviews took place at the informants' homes but some interviews were conducted at the university in my office based on the preference by the informants.

The researcher's background

My own background is very strongly connected to the primary health care. I have worked as a full time general practitioner at a semi-rural health centre 30 km north from Helsinki for almost 15 years. I am also familiar with the British family practice after working there in 2001 and 2002. In the recent years I have been working as the head of two health stations at the Helsinki primary health care organization.

The primary care context contributes to the encounters being so unique since the patients themselves, as lay persons, make the decision to consult their GP with their worries, problems and concerns at a particular and individual point in time during their illness process. One certainly cannot predict all the problems that will be presented to a general practitioner during a working day.

During my clinical work I have frequently encountered patients with osteoarthritic pain. The problems of these patients are familiar to all general practitioners. There is not much to offer other than encouragement for weight loss and regular physical exercise. When this is not enough some painkillers and physiotherapy treatments are recommended. The situation is slowly deteriorating and at the follow-up visits the patient with all the disabilities getting worse over time can make the physician feel helpless and irritated.

Since the early nineties I have had the opportunity to work as a clinical teacher at the department of general practice and primary health care at the University of Helsinki and later at the University of Kuopio. The consultation process and the doctor-patient relationship has been the main focus of my interest throughout the years. I was introduced to the ideas that communication skills can be taught and learned and doctors can improve their interaction with their patients by applying more patient-centred interviewing style (Roter et al. 1995, Aspegren Knut 1999).

There has been an emphasis on learning communication skills in the development of the medical undergraduate curriculum during the past fifteen years. I have been involved and contributed to the development of the program "Becoming a physician" at the University of Helsinki Medical School. The study program has been running since the early nineties and aims at fostering professionalism. In this context I have worked with actors who are performing as simulated patients at the consultations with the undergraduate students. This program gives the student doctors a valuable opportunity to learn about the interaction with the patient in a safe environment and a chance to get immediate feedback from the actor patient from the patient experience of the consultation, which is much appreciated by the students.

The Pilot study

I have written into my logbook after conducting six pilot interviews that the interviews have been very pleasant experiences to myself and the participants have been willing to tell me about their experiences related to the health care providers. The informants in these six pilot interviews were the first six persons who replied to me and expressed their willingness to participate in my study. In the narratives of the interviewees there has been an emphasis

on positive, good experiences. Negative things seem to have occurred to some other people whom my informants sometimes tell me about. The openness and friendliness towards me as the researcher and the obvious interest in this study approach have been the most remarkable observations for myself.

I have reflected my own role as a researcher in these pilot interviews. According to my notes I seem to have taken a more active role than my pre-assumption was. I have been talking more during the interviews than I had planned in advance but I had noticed the informants need a little bit more encouragement and prompting to bring out their opinions and perceptions about the events than I had expected.

I may have been more formal and nervous during the interviews in the beginning of this project. I have written how it is very exciting to drive long distances in the countryside of North Savo where I have never been before and then finally arrive at the yard of some remote farm or a detached house and meet the people living there. It is easy to see they have been waiting for me with some curiosity and they are well prepared with coffee and buns laid on the table. This travelling alone in my old car and visiting people's homes is not that unfamiliar to me since I have worked as a general practitioner in home care for many years in the past and been used to making house calls. My innate curiosity and interest in people also made it relatively easy for me to meet strangers so I have been really excited according to my field notes during the weeks in the spring 2006.

2 *The theoretical framework*

2.1 ONTOLOGICAL BACKGROUND

Ontology is to answer the question what exists. The ontological background for this research consists of the subjective experiences of my informants that have taken place during the consultations with their doctors. My respondents belong to a group of people who have been diagnosed with the hip or knee osteoarthritis, which causes them chronic pain and disability. The research process is about trying to understand and interpret the narratives being constructed of these experiences in the interaction between the informants and the researcher during the interviews. According to Heidegger "Understanding is being in the world" (Heidegger 1978). Since we as human beings exist in the world we can never escape our own historicity, in other words, our situationality.

In the ontological sense this means that the situation also is essentially part of the human being (Rauhala 2005). This is the philosophical background for taking the interviews of the informants about their experiences with the health care providers as a construction of a reality in that particular time and context. This relativist approach admits and respects the multiple constructions of realities (Guba, Lincoln & Cuba 1989).

2.2 EPISTEMOLOGICAL BACKGROUND

Epistemology is to answer the question "How do we know what exists?" In the field of epistemological theories, in this dissertation, the understanding of knowledge is compatible with the approach of social constructionism. There are always a variety of socially constructed realities available instead of one objective truth to be found out there. I share the idea of the relativistic perception of truth with the social constructivists. The knowledge is always built by the knower and only those truths are kept, which most people in a social group agree with. Knowledge is situated and contextual and aims at partial interpretations or situated versions of reality (Berger, Luckmann 1967).

The basic statement of knowledge building in this study is that all knowledge is constructed, based on earlier knowledge, experiences and interaction with other people. The fundamental idea in this approach is that human knowledge is a human construct, "the truth is made". Constructionism abandons the claim that cognition is "true" in the sense that it reflects an objective reality. Instead, it only requires that knowledge be viable in the sense that it should fit into the experiential world of the one who knows (Flick 2006).

The world of medicine is very much based on the agreements of various classifications. The International Classification of Diseases (ICD-10), which is used for indexing medical diagnoses for various purposes and in various contexts, defines osteoarthritis of the hip under the code M16 and osteoarthritis of the knee under the code M17. The medical knowledge building relies on the diagnostic criteria which include the symptoms of the patient, clinical examination and radiological findings in classifying the degree of severity of the osteoarthritis (ICD-10).

The reality studied by qualitative research is not a given reality. Instead it is, constructed by different actors. Subjects with their views on a certain phenomenon construe a part of their reality; in conversations and discourses, phenomena are interactively produced and thus reality is constructed. The qualitative researcher may rely on understanding social realities e.g. through the interpretation of texts. Texts are the basis of reconstruction and interpretation. First there is the translation of the reality into the text and after that the re-

translation of the text into the reality by the researcher. After that comes the interpretation made by the readers of the research report. (Flick 2006) According to Bakhtin "our words are always the words of others". (Puustinen 1999) The practice of interpretation counts for more than the correct application of procedures of interviewing in qualitative research. It is very strongly linked with a specific attitude based on the researcher's openness and reflexivity (Finlay 1998).

According to Bruner Narrative imitates life and life imitates narrative. Life in this sense is the same kind of construction of the human imagination as a narrative is. It is constructed by human beings by the reasoning similar to constructing narratives. When someone tells you his life it is always a cognitive achievement rather than a one-to-one recital of something unequivocally given". An interpretation is made from the perspective of a symbolically produced world of a prior but not necessarily existing world, which itself has already been subject to interpretation (Bruner 2004).

The interactive nature of the knower known dyad, is discussed by the authors of *The Fourth Generation Evaluation*. According to them to suppose it is possible for a human investigator to step outside his or her own humanness, one's values, experiences and constructions is to believe in magic (Guba, Lincoln & Cuba 1989).

2.3 THE CONCEPT OF HUMAN NATURE

The concept of human nature in this study is based on the studies by Lauri Rauhala (Rauhala 2005). The existential phenomenology developed by the philosopher Martin Heidegger has approached the problem of human nature which is called the existence. According to this approach the human being is realized in various forms of being. These basic forms of being, which the humans are attached to during their lifetime are called the situational, bodily and cognitive dimension. The meaning of the situation is central to Heidegger and it is included in his concept "in der Welt sein". The word situationality refers to the part of the world or the reality that one person is related to. A person exists in relation to the world through his or her situationality. This encompasses the entity of all the phenomena, objects and states that are included in the realization of the bodily and cognitive being of one single person. These components consist of genetics, family and educational influences, culture, social and geographic factors together with values and norms. The situation is always individual.

Bodily (organic) and cognitive dimensions can only exist in the situational dimension. The human being who is being made real this way forms an entity. This wholeness is called the existence or a situational circuit of adjustment according to Rauhala. In the ontological sense this means that the situation also is essentially part of the human being. The environment in all its various aspects is not something that concretely and spatially surrounds the human being but instead it is a primary factor of his existence.

2.4 SYMBOLIC INTERACTIONISM

The tradition of symbolic interactionism is concerned with studying subjective meanings and individual meaning making (Flick 2006). According to George Herbert Mead, who represents American pragmatism, people's selves are social products but at the same time these selves are also purposive and creative (Blumer 1986). Herbert Blumer, who was a student of Mead's and a devotee, coined the term symbolic interactionism for studying subjective meanings and individual meaning making within sociological and socio psychological research. In this research approach the focus is on a particular concept of interaction, which stresses the symbolic character of social actions. Blumer argued that people act towards things based on the meaning those things have for them and these meanings are derived

from social interaction and modified through interpretation. Thus, human interaction is mediated by the use of symbols and signification, by interpretation. Blumer came up with three core principles or “root images” to his theory as expressed here.

- 1) Human beings act toward things on the basis of the meanings that the things have for them.
- 2) The meaning of such things is derived from or arises out of the social interaction that one has with one’s fellows.
- 3) These meanings are handled in and modified through an interpretative process used by the person in dealing with the things he encounters.

Another central assumption in this tradition of symbolic interactionism is the so-called Thomas’s theorem: It claims that when a person defines a situation as real, the situation is real in its consequences, and this leads directly to the fundamental methodological principle of symbolic interactionism which states that researchers have to see the world from the angle of the subjects they study. This means for the research situation that the different ways in which individuals invest objects, events and experiences and so on with meaning form the central starting point for research in this approach.

Symbolic interactionism researchers investigate how people create meaning during social interaction, how they present and construct the self or identity. One of the central ideas is that people act as they do because of how they define the situations (Blumer 1986). The focus of interest in this dissertation study is not how the health care system itself describes its’ functioning but the way people perceive its’ contents and quality and what kind of interpretations they make. For this reason the perspectives and methodological approach of symbolic interactionism are compatible with theoretical framework of the study. Symbolic interactionism researchers focus on the subjective aspects of social life, rather than on objective, macro-structural aspects of social systems.

2.5 THE STUDY OF THE EXPERIENCE

What is an experience? According to Perttula an experience is a cognitive way to give meaning to the realities the individual is related to. The research of the lived experience is challenging since the experience cannot be reached directly but only through various descriptions which already include an interpretation. The experiences need to be told verbally first (Perttula, Latomaa 2008).

It is only in relation to something that the human experiences can emerge. A human being cannot develop to a person without a connection to other people. It is only in the relationship to the world and to her self, that a human being can create meanings. Preconceptions are involved in all understanding (Berger, Luckmann 1967). People construct narratives about their experiences in their minds. According to Bruner the narratives of the experiences do not take place in the real world but are constructions created by people to make sense and give meaning to the life situations they find themselves at (Bruner 2004).

Scientifically the challenge is how one can study the experience based on the assumption about its existence (ontological background) and how it is understood (epistemological background). According to Perttula the basis for a scientifically sound outcome lies in the thinking skills of the researcher, in the rigour of his or her determination to complete the research consistently with his or her thinking process. Also important to the study of the experience is to what extent the topic under study is possible to attain as it exists from the point of view of the research questions (Perttula, Latomaa 2008).

As a general rule in the study of the experience it is argued that the researcher should be able to see him/herself as a similar human being experiencing things just like her inform-

ants. The experiencing characteristic of the researcher is a key to understanding the research process. This understanding is constructed in the conscious relationship of the researcher with his or her data and because of this the research process is already interpreted by the researcher and subjective in itself. The preconceptions of the researcher may both limit and enhance the process. The researcher cannot totally be separated from the objects of his or her study. According to Gadamer "The important thing is to be aware of one's own biases so that the text can present itself in all its otherness and thus assert its own truth against one's own fore meanings" (Gadamer 1975).

When different meanings are related to each other, networks of meanings are being created and for this entity Rauhala uses the concept the subjective worldview, the wholeness of the human experience. In our experiences we are always connected to our own history. Subconscious experiences also play an important role in our subjective worldview (Rauhala 2005).

2.5.1 The hermeneutic approach

The process of studying the experience can be examined as a hermeneutic approach. The hermeneutic research tradition assumes that the person interprets her experiences again and again. The interpretative nature is seen as an essential way for human beings in the construction of experiences. The word hermeneutics itself is based on the legend of Hermes who was the messenger of the gods to the humans. The word also implies to the task of interpretation when the will of the gods was revealed to people. Gadamer writes about understanding the other person. Understanding is always interpretative in nature (Gadamer, Nikander 2004).

He argues that the basic model for all mutual understanding between people is a dialogue. Understanding is impossible if the persons involved are not willing to have an honest discussion. In the course of the dialogue a mutual understanding is being constructed and both parties have influence on the outcome. The opinion of one person is not just added to the opinions of the other but instead the dialogue changes the opinions of both.

Interpreting people's experiences can be seen relating the particular to the universal, part to whole and episode to totality. Interpretation occurs through the fusion of the horizons. Gadamer defines a horizon as the range of vision that includes everything that can be seen from a particular vantage point. But he also claims that horizons are always temporal; a person does not have a closed horizon, it is always in motion. The process leading to the fusion of horizons is a willingness to open yourself to the standpoint of another so that you can let their standpoint speak to you and influence you.

In the hermeneutic research approach the task of understanding is to show how a fusion has occurred in research writing. This will happen by showing the way in which the researcher participates in generating data, describing the expressions of the informants, their voices in the social context in which the events took place and then showing how the horizons of the interpreter and the one to be interpreted are fused. Meanings are made and they emerge as the text and the interpreter, the researcher, engage in a dialogue. The aim of telling stories and creating a research product out of this is to gain another or a different understanding of the events (Koch 1998).

The hermeneutic circle describes the process of understanding a text. It refers to the idea that one's understanding of the text as a whole is established by a reference to the individual parts and one's understanding of each individual part by a reference to the whole. Neither the whole text nor any individual part can be understood without reference to one another, and hence, it is a circle. The task of the researcher is to perceive, what kind of social context the study environment represents and it needs to be seen as the framework for the interpretation of the experiences.

Gadamer presents a positive concept of prejudice and argues for its need of hermeneuti-

cal rehabilitation. He states that prejudice is not something negative we should try to eliminate but that instead we only have access to the world through our prejudices. They are only the conditions by which we encounter the world as we experience something. We take prejudices, value positions, with us into the research process and these assist us to understand (Gadamer 1975). Very similar analogy is present in the statement of Merleau-Ponty who explains that it is not necessary to see the light, but only what it illuminates. However, without the light, nothing would be seen (Merleau-Ponty 1962).

2.5.2 The narrative approach

The process of studying the experience can be conducted using the narrative research approach. In the narrative approach the topics of the experiences described stretch both in time and context very widely. There lies a built-in idea that a human being is creating a sound and well-analysed form to her experiences (Perttula, Latomaa 2008). The narrative approach includes the holistic idea of the human beings' existence in the world interwoven with her experiences. Narratives are an important way of constructing meanings from the life experiences and they enable the audience to hear the voice of the narrator. Both the hermeneutic and the narrative research approach assume that the empirical study of the experience is interpretive by nature. The aim is to understand the experiences of the narrator and not to show the facts in the story to be true. The narrative approach takes the point of view of the narrator as the starting point. The reality is understood as being situational and flexible, it is being constructed together in the context where the narrative is being told and listened to by the researcher.

The ability to tell about past experiences is based on the memory. One can argue that people forget things and they may remember incorrect. The very content of any given memory is a social product. One has to accept that it is not the past, only a representative of the past that any memory is about. When remembering, people are engaged in active remaking of the past. The memories piece together, delete, edit and select effectively various items (Bochner 2007). A narrative researcher needs to deal with the relational context in which all stories are constructed (Seaton 2008).

2.5.3 The phenomenological approach

In the phenomenological research approach the researcher wants to give space to the own voice of the informants. There is a defined goal to reach neutrality in the study situation. In the phenomenological approach the researcher tries to exclude him or her self from the study context as completely as it is possible. According to the theoretical explanation, this gives the researcher an opportunity to be present passively, not being forced to take any socio-cultural position. According to the founder of the phenomenology, Edmund Husserl, the experience of a person is real but it is not objective. It is not the goal of a phenomenological oriented research activity to prove right any theories but instead to study and describe the way an individual experiences the world, as s/he sees it. The researcher is aiming at reaching to understand the meanings people give to their experiences. The research question can be "what is it like...?". This question is answered by means of phenomenological reduction, bracketing in trying to find out the essence of the experience. The representation relies upon using the actual words of the informant who has had the experience and the practice of bracketing out the researcher's world and preconceptions (Koch 1996). In the phenomenological research orientation it is seen as an advantage if the researcher knows the world s/he is investigating. The researcher should be able to surpass his or her natural attitude and try to maintain openness and sensitivity in relation to her research object. One should be able to recognize one's own attitudes and keep up a continuous reflexive orientation towards the phenomena of the lived world.

The phenomenological method is related to the activity of the researcher during the in-

vestigation. The aim of the method is to make the research more objective and at the same time keep distance to the subjectively understanding element of the research. The researcher is positioned in a way, which is believed to enable certain objectivity in relation to the informant (Perttula, Latomaa 2008).

The critical issue here is whether this kind of bracketing is possible. Husserl's student Martin Heidegger extended Husserl's philosophy to what is described as existential phenomenology or, following his student, Hans Gadamer, philosophical hermeneutics. In the philosophical hermeneutic approach the argument is that nothing can be encountered without reference to the person's earlier experiences, the history of life events. A researcher having the existential phenomenological orientation can ask the same question, "what is it like...?". In the analysis the data generated from the informants are merged with the background, preconceptions and the experiences of the researcher. The interpretation becomes a joint construction. The researcher brings to the analysis his/her own prejudices and values. According to the philosophical hermeneutic approach it has to be accepted that a value-oriented approach, which also contains a pre-understanding based on the researcher's historical context is the only possible in the study of the experience (Rauhala 2005).

2.6 METHODOLOGICAL FOCUS

The experiences of the people with severe osteoarthritic pain connected to the consultations with the health care providers are the object of my dissertation. The long lasting chronic pain is a common denominator for this group of people and they are all familiar with the use of the health care system as patients. The informants in my study belong to the group of patients whose disease has been officially classified and diagnosed as osteoarthritis. The Finnish word for osteoarthritis refers to the joint being broken. "Worn-out" is another concept used in this connection to describe the degenerative state of the joint. The definition is illustrative and may be interpreted as reflecting the general attitude of the health care providers towards this group of patients who consult repeatedly because of the constant pain and the disabilities that the progressive joint disease is causing them over a long period of time.

My research agenda is to study the narratives they share with me in the interviews about their experiences with their doctors. The encounter with the health care provider is the phenomenon I am interested in. First there is the experience, then follows the interpretation by the individual of his or her experience. The human memory plays an important role in the process of remembering past experiences and finally the individual will tell the story connected to the experience during the interview with the researcher.

The philosophical hermeneutic approach has influenced my thinking particularly in the sense how I position myself as a researcher. The research needs to be translated, interpreted and brought into social context. In my understanding this process is social, situated and contextual. In our experiences we are always connected to our own history. Since we as human beings are living in the world we can never escape our historical context (Heidegger 1978, Gadamer 1975). One cannot completely separate the researcher from the research object and the researcher is having influence on the research process at many levels starting from generating the data to the writing of the report of the results. The most important instrument of the researcher is him/herself, his or her own reflexive way to act and the world of experiences through which s/he tries to understand the object of the study and which his or her own preconceptions and prejudice can either limit or enhance (Perttula, Latomaa 2008).

In this kind of research process the issue of rigour, trustworthiness of the study, and the issue of representation, meaning whose voice is being heard, are of central importance. The Heideggerian-Gadamerian position is that the interpreter participates in generating the

data. Co-constitution demands that primary data need to be regarded as contextualized life events, with the informant's and the researcher's perspectives specified. Stories are told by self-interpreting people who have brought with them their pre-understandings. At the same time the researcher brings his or her pre-understandings and prejudices to the research process. It is important for the researcher to maintain a reflexive attitude throughout the process and adapt transparency in describing her role. As Gadamer puts it "The hermeneutic attitude supposes only that we self-consciously specify our opinions and prejudices and qualify them as such and in doing so strip them of their extreme character" (Finlay 1998, Gadamer 1975).

3 *Aims of the study*

Using the episodic interview method the aim of this study is to find out and understand the patient perception of the quality of the clinical encounters and the benefit gained based on the subjective experiences of the hip and knee osteoarthritis patients in the ambulatory care.

The specific aims are

A) To find out which factors predict the perception of the quality of the consultation based on the subjective experience of the patient

More exactly, the aim is to find out and understand

- 1) Patient experiences of the treatment and management of her illness at the consultation
- 2) Patient experiences of the physician behaviour at the consultation
- 3) Patient perception of the benefit gained
- 4) Patient perception of the unnecessary visit

B) By listening to the patients' voice the aim is to be able to contribute to the process of constructing a more customer-oriented service design in the health care context

- 1) To be able to give recommendations to the patient-centred development of the quality of the treatment process of the osteoarthritis patients in the ambulatory care
- 2) Using evidence-based knowledge about the patient experiences at the consultation when further developing the patient-centred approach in the medical undergraduate curriculum

4 *Participants and research methods*

4.1 PARTICIPANTS

As the interviewees of this dissertation study it was decided to include people who met the following criteria: They were living in North Savo and had a history of chronic pain because of their hip or knee osteoarthritis. At this point of their illness they had been referred to the out patient clinic at the university hospital by their general practitioners to discuss the treatment options with the orthopaedic surgeons. Since the osteoarthritis is a long-term chronic disease and it takes years or decades to develop, the patients were likely to have made quite a few visits to their general practitioners and other health care professionals during this period. The aim of this dissertation was to find out how these people with severe chronic pain had experienced their interaction with the health care system and how they had perceived the quality of the consultations with their doctors.

The osteoarthritis and the disabling symptoms connected to this disease have been the common denominator through which the patient experience of the health care encounters has been studied. The study population came from the group of people who had been referred to the orthopaedic consultation at the university hospital outpatient-clinic and to whom during the last week of March, April and May 2006 the letter about the appointment time from the hospital had been sent. The information letter about the possibility to participate in this study was included in the same envelope. All together 65 letters were posted since persons with known dementia or speech difficulties were excluded. After reading the summary about the objectives of the research and the detailed information about the study process they could contact me by sending a reply letter. When I had received the letter, I called the person and we discussed on the phone more about the details of the study and s/he could ask me questions. If after this conversation s/he agreed to participate in my research we arranged a meeting where the research interview took place. There was a choice to be interviewed either at the university campus in Kuopio or at the participants' home according to their own decision. Nine out of the 33 informants were interviewed at the university and the rest were interviewed at their homes in various municipalities around the catchment area of the Kuopio University Hospital in North Savo and also in Kuopio.

During the spring 2006 these invitation letters were sent from the hospital orthopaedic surgery outpatient-clinic. The mailing of those letters was stopped temporarily because of the approaching summer holiday period. I made the decision at that point to stop collecting the data since I had already received 33 letters of consent and I was advised by my supervisor at the time, professor Kirsti Lonka, that for a qualitative research project the number of respondents was sufficient based on her experience in the interview studies. This is a convenience and purposive sample that I have used.

I was also aware of professor Rosaline Barbour's views about the use of the ambiguous concept "saturation" in the context of qualitative data generation. In her opinion it is very difficult to reach the saturation of themes since human experiences are so versatile and unique. I learnt this when participating her workshop on qualitative research methods at Tampere University autumn 2005. So the decision was made unanimously by the research group at the end of May 2006 that I would not be including any more invitation letters to participate in the study when the mailing for new appointment times would start after the summer holiday period.

My research plan was officially accepted by the Ethics committee at Kuopio University hospital.

Figure 1. Background information about the participants.

participant	occupation	OA symptoms / years	comorbidity
1 Female 80	farmer(r)	<5	none
2 Female 75	auxiliary nurse(r)	5-10	cervical syndrom
3 Female 71	factory worker(r)	>10	ischias syndrom
4 Male 67	builder(r)	5-10	hypertension
5 Female 86	nurse(r)	>10	joint operations
6 Female 69	entrepreneur	>10	none
7 Male 62	farmer	>10	none
8 Male 76	bus driver(r)	>10	ischias syndrom
9 Female 67	clerk(r)	<5	hypothyroidism
10 Female 55	non-skilled worker(r)	<5	depression
11 Female 58	clerk(r)	>5	rheumatoid arthritis
12 Male 56	forest worker(r)	>10	diabetes
13 Female 74	factory worker(r)	>10	coronary heart disease
14 Male 58	skilled worker(r)	>10	spinal injury as young
15 Male 50	permanent staff(r)	>5	none
16 Female 58	clerk(r)	>5	hypertension
17 Female 60	kitchen maid(r)	<5	rheumatoid arthritis
18 Female 83	auxiliary nurse(r)	<5	dizziness
19 Female 66	farmer	<5	asthma
20 Female 78	farmer(r)	<5	diabetes
21 Male 60	supervisor(r)	>10	back pain
22 Female 63	home carer(r)	>10	ischias syndrom
23 Female 63	cleaner/cook(r)	>10	rheumatoid arthritis
24 Male 62	farm worker(r)	<5	back pain
25 Male 58	warder(r)	5-10	diabetes
26 Male 69	lorry driver(r)	<5	coronay heart disease
27 Male 75	entrepreneur(r)	>10	coronary heart disease
28 Male 69	skilled worker(r)	5-10	prostate problem
29 Female 68	auxiliary nurse(r)	<5	none
30 Female 55	farmer	>10	none
31 Male 50	entrepreneur	>10	none
32 Female 75	farmer(r)	<5	hypertension
33 Male 51	factory worker	>10	ischias syndrom

r = retired

1 female 80 = code for a woman, 80 years old

OA = osteoarthritis of hip or knee

comorbidity = one illness / symptom, respondent's subjective report

4.2 RESEARCH METHODS

4.2.1 The interviews

The topics to be discussed during the interviews were which things are considered the predictors for a good quality encounter and what determines the failure of a consultation from the patient's viewpoint. The participants were asked to explain how they interpret gaining benefit at the consultation from their point of view. I was also interested in the patient perception of a visit being unnecessary for them in the context of their health care service experiences. Unnecessary visits have been studied from the organization's viewpoint meaning consultations, which have been assessed by the medical professionals as trivial and not justifying the use of health care resources. I wanted to find out the patient perspective on this topic.

I did not have any written questionnaires for my interviews and I decided to use an episodic interview format. According to Flick, in the episodic interview the informant is asked, to tell about his or her own experiences, which s/he finds important and relevant to the topic of the study. It starts from the episodic elements of the experiential knowledge. Both the form and the selection of narratives, can be chosen by the interviewee according to the aspects of subjective relevance. The starting point for the episodic interview is the assumption that subject's experiences of a certain domain are stored and remembered in the forms of narrative or episodic and semantic or conceptual knowledge. Whereas episodic knowledge is organized closer to the experiences and linked to concrete situations and circumstances, semantic or conceptual knowledge is based on assumptions and relations, which are abstracted from these and generalized. The researcher using this method is trying to collect and analyze episodic knowledge using narratives and the semantic knowledge is made accessible by concrete focused questions by the interviewer.

Episodic interviews yield context related presentations in the form of a narrative. In the episodic interview one tries to take advantage of the best parts of both the narrative and the semi-structured interview techniques. The episodic interview uses the interviewee's competence to present experiences in their course and context as narratives. Episodes as an object of such narratives allow a more concrete approach than does the narrative of the whole life history. The interviewer has more options to intervene and direct the situation through some key questions. By linking the narratives and question-answer sequences, this method realizes the triangulation of different approaches as the basis of data generation.

The theoretical background of studies using the episodic interview is the social construction of reality during the presentation of experiences as narratives. Since there are people who have greater problems with narrating than others, the advantage of an episodic interview is that the interviewee is not requested to produce a single overall narrative but rather to construct several limited narratives. This approach emphasizes the interviewer's ability to handle the situation and to stimulate narratives instead of answers to the questions from the interviewees. As with any other interviewing technique, the episodic interview does not give access to any activities or interactions. They can only be reconstructed from the participants' viewpoints (Flick 2006).

In the beginning of each interview I asked the interviewee kindly to start telling me anything s/he wanted to share with me connected to his or her illness process. I let them talk without interruption for 5 to 10 minutes and in this early phase they normally gave me the overall picture of the beginning of the hip or knee joint symptoms, how the pain had affected their daily activities, and how they had sought help and what kind of treatment was given to them. This part was very similar in most of the interviews and sounded to me like something they had rehearsed beforehand, to be prepared and to please me by showing they can express themselves fluently. Maybe it was also connected to their knowledge of me being a physician myself. In the beginning of the interviews we often discussed about

my background. I told them I didn't know Kuopio region at all, how I was new there and had not done clinical work in the area. I also expressed clearly that I did not know any of the doctors working there at the health centres, private clinics or at the university hospital either. I also told the people something about my previous work history at the health centre in Tuusula and my teaching work among the medical students.

After the interviewees had finished their opening monologue I asked them to tell me in more detail about some topic they had raised in their narrative or to explain something I had not understood in the story. If they used adjectives like good or bad, I requested them to describe what they meant by these words. I always wanted them to open up the adjectives and other expressions they used which could have various interpretations. I made them to operationalize the concepts they used.

I told my informants in the beginning of the interview that I am interested in their own experiences of the encounters with various physicians over the years, both successful and failed ones. They were able to tell me both primary health care and specialized care experiences. I asked them to explain to me what makes the consultation a positive, satisfactory experience for the patient and when s/he feels disappointed. I didn't have any questionnaires to give to the interviewees. The opening question was often "What would you like to tell me about your experiences with this illness?" To obtain more in-depth responses, probes such as "Could you tell me more?" and "What do you mean by that?" were used. The goal of the interviews was to allow the respondents to speak freely about their experiences and bring out those issues they found important and meaningful without the researcher interfering much. The interviewees were also requested to explain to me their interpretations of the two concepts I was interested in first, benefit gained during the consultation and second, unnecessary visit from their point of view in the context of the encounter with their doctors. In addition to this they were encouraged to raise any issues connected to their illness process or their experiences with the health care system they felt important to share with me during the interview.

The average interview lasted around 60 minutes. Some were longer, almost 120 minutes. When the interview took place at the informant's home, I was always shown very friendly hospitality. The table was laid and I was served coffee and buns wherever I went. We often discussed a little while about my journey to their house, whether I had had some difficulties in finding the place, which was often the case since I was totally unfamiliar with the area. I sensed some sort of appreciation and approval for making the effort to come and talk to them, which made the ambience relaxed and pleasant in my interpretation.

Before we switched on the tape recorder I explained once more the core issues of the interview from my point of view. At some places we had coffee before we started the interview, sometimes we had it while we were talking and some people preferred having coffee after the job was finished. The coffee drinking and sitting together at the table was a very important part of these encounters. I always stayed with my interviewees some 15 to 30 minutes after the tape recorder was switched off so that we could end our meeting by talking about some other topics, look around at their gardens, admire the pets or pictures of grand children or some medals won in the sports when young. Some interviews took place in my office at the Kuopio University if the person preferred coming there.

The attitude of my informants towards this study was very positive. They expressed how they felt it was important that the patients were asked about the topics related to the health care system and their experiences with the care providers. They told me they appreciated the opportunity to participate in this study and have the opportunity to make their voices heard. My experience of conducting these interviews is that people took this opportunity to tell their stories, their patient views and experiences very seriously and sincerely.

The actual interviews were all conducted by one researcher myself. The whole data of interviews was audiotaped and later transcribed verbatim by a very conscientious and ef-

ficient research assistant Tuula Aira. N-Vivo version 7.0 a software program for qualitative data analysis, was used to organize transcripts, excerpts, codes, categories and themes (Richards 2005).

4.2.2 Methods for the qualitative analysis

4.2.2.1 The Content analysis

The data have been analyzed using the content analysis (Silverman 2006, Krippendorff 2004). Through the iterative reading process I have constructed the coding framework and identified the categories, subcategories and emerging themes that encompass the informants' perceptions, feelings and attitudes in the context of the encounters with their doctors. The interview data consist of the subjective experiences of the osteoarthritis patients with their health care providers and the patient perception of the quality of these encounters. The analyses of my data have been an iterative process, which has taken a long time to complete. I started reading the texts in the autumn 2006. I had more than 500 pages of text based on the interviews that had taken place in North Savo during the spring and early summer 2006.

Content analysis is being used as the basic method of analysis traditionally in qualitative research projects. The data based approach and the inductive content analysis was chosen as the means of analysis for this dissertation. Content analysis makes it possible to observe the meanings, consequences and connections of the topics and events discussed by the informants. The main focus of the content analysis is to concentrate the text either inductively, meaning based on the data or deductively based on earlier theory or research framework for categories. At the first stage of content analysis one has to choose the unit of analysis. This can either be a word, a phrase or a sentence or a thought. Generally the aim and the objectives of the research influence this selection. In my dissertation study the unit of analysis has been a thought entity, which can sometimes be a word, part of a sentence or even two or three sentences. The final themes are significant concepts that link substantial portions of the various interviews together. The interviewees do not necessarily use the actual words of the identified themes but rather reiterate stories about these topics throughout the interviews (Krippendorff 2004).

The program N-Vivo provides the possibility to code documents to gather material by topic. The container for references to this material is called a node. There are different types of nodes in N-Vivo and I chose to use the Tree Nodes. They are nodes that are catalogued in a hierarchic structure moving from a general category at the top, the Parent Node, to more specific categories, Child Nodes. Based on my iterative reading of the texts I decided to create the Parent Nodes for doctor related concepts, patient related concepts and separate from this the patient related negative concepts and system related concepts.

At this stage I started adding Child Nodes, concepts, under each Parent Node. The concepts were based on the repeated reading process of my original texts and the summaries I made from each interview. While reading, I was highlighting the attributes, expressions and statements used by my interviewees. This was followed, by writing and re-writing lists of concepts that to me captured the essential ideas, topics and meanings in the single interview. Then I made the decision under which Parent Node it was most appropriate to place the concepts I had on my final list.

Under each Child Node I coded the excerpts from each interview, which I found related to this concept. Finally I had a total of 85 concepts on my hierarchical Tree Node construction in N-Vivo. There was certainly some overlapping between my concepts and it was a process of reassessing and relocating the references under various nodes. Every interview transcript has been carefully read many times and quotes have been entered under the matching nodes in N-Vivo. My other supervisor professor Anja Taanila has assisted me in reading my interviews and coded herself some of them. When we have compared our work

the compatibility between our coding has been outstanding.

I constructed The Original Coding table (Appendix 1), where I entered all my informants and the parent and child nodes from the N-Vivo software. I wanted to make a gradation of the concepts to be able to demonstrate how they were expressed by my informants. This is why I chose to code the numbers 1, 2 and 3 in every box to describe whether the tone of the expression was neutral (1), positive (2) or negative (3) in my interpretation.

4.2.2.2 The Bayesian method

The content analysis has been accompanied by the Bayesian network modeling. Professor Rynnänen introduced me to the Bayesian method and under his supervision we decided to use this method for the analysis of my data. The reason for this decision was that in the data there might exist elements which can be left without interpretation if only one method is being used. To increase dependability it has been argued that combining various methods would be beneficial and this is called triangulation (Aira, Seppä 2010). In these analyses the Bayesian method was used as a means of triangulation to reveal the varied dimensions of the phenomenon of patient perception of the encounters with their doctors, and to build up new information to provide as rich a description of the relevant topics as possible.

The Bayesian method is named after an amateur mathematician Thomas Bayes (1702–1761) whose work was posthumously published in 1763. It is an approach based on probability calculations to control inaccurate information found in complex systems. The Bayesian networks are high-level representations of a probability distribution over a set of variables that are used for building models of the problem domain. The Bayesian modeling can be seen as a method to model the change in our perception over some topic as we gain new knowledge related to this (Myllymäki 1998).

The aim of the experiment of using the Bayesian method in the analysis was to investigate how the relatively small qualitative data would fit into the Bayesian networks and what kind of dependencies might emerge. In this study the Bayminer (www.BayMiner.com) non-linear visualization modeling software is applied as it is capable of analysing both linear and non-linear dependencies between variables under investigation. The advantage of the Bayminer program is that it gives the opportunity to demonstrate the subgroups of the observational units and to make comparisons between them and the whole data or between various subgroups (Myllymäki 1998).

Bayes's theorem is a formula that shows how existing beliefs, formally expressed as probability distributions, are modified by new information. From the health care a familiar situation to which this theorem can be applied, is diagnostic testing. A prior belief by the doctor about whether a patient has a particular disease based on knowledge of the prevalence of the disease in the community and the patient's symptoms will be modified by the result of the test.

The Bayesian networks present a joint probability distribution of the data as a product of conditional probabilities. The joint distribution is "known" to the network. There is a probability to all possible events. It is possible to calculate the probability distribution of any set of variables given any other set of variables. The standard method how Bayesian networks "learn" is that they try to find the most probable alternative. A Bayesian network is constructed by explicitly determining all the direct dependencies between the random variables of the problem domain (Nokelainen, Ruohotie 2009). There is nowadays an increasing need to use methods, which allow modeling the uncertainties that come with the problem, are capable of dealing with missing data, allow integrating data from various sources, and at the same time explicitly indicate statistical dependence and independence and allow integrating biomedical and clinical background knowledge. With the wide availability of sophisticated and cheap computing equipment the exploitation of models to support clinical decision-making has become a practical option.

The Bayesian networks, which are a type of graphical network, offer a general and versatile approach to capturing and reasoning with uncertainty in medicine and health care services research. There are always some initial assumptions about the model that have to be made. In Bayesian statistics these include assumptions about the prior probability distribution and the way in which prior information is updated based on observed evidence.

The Bayesian modeling is beginning to emerge as a method for discovering patterns and regulatory processes in biomedical data with complicated nature. The Bayesian modeling is also being used as a basis for the representation of the uncertainties underlying clinical decision making (Lucas P 2004).

In a Bayesian network each node represents one of the observable features of the problem domain and the arcs between the nodes represent direct dependencies between the corresponding variables. Each node has to be provided with a table of conditional probabilities, where the variable in question, is conditioned by its immediate predecessors in the network. The Bayesian networks can be used for computing the predictive distribution on the outcomes of possible actions. This means it is possible to use decision theory for risk analysis. The Bayesian networks have been found to be very robust in the sense that small alterations in the model do not affect the performance of the system dramatically. They deal with lacking information by "jumping over". In practice the Bayesian method uses the value of the priori in that case. Entering the priori values into the model gives the method the ability to tolerate mistakes.

In the Bayesian modeling expert knowledge can be coded as prior distributions, meaning that the probability distributions are defined before and independently of processing any possible sample data. Unlike neural network models, all the parameters in the Bayesian networks have an understandable semantic interpretation. The Bayesian networks also can handle several different types of variables at the same time. From the probabilistic point of view all the basic entities are distributions which means that all the different variable types fall into the same unifying framework (Myllymäki P 2003).

The Bayesian analysis includes three parts. First, there is a preconception of the knowledge, which is called a prior. The prior can be thought of as summarizing all external evidence about the topic. One source of a prior distribution is the pooled subjective opinion of informed experts. Secondly, the new observations produce a conditional probability, the likelihood. And thirdly, by combining the prior and the new observation we will get a novel understanding of the nature of the topic, the posterior. The Bayesian analysis is a kind of meta-analyses about earlier knowledge and all the data that have been gathered (Spiegelhalter et al. 1999).

If the data were extremely large, the Bayesian method would behave like logistic regression. Naïve Bayes, the definition of which comes from the assumption that all the variables in the data are independent, is functioning in a way similar to logistic regression, one dependent variable is being predicted by a group of independent variables. The definition naïve comes from the assumption that all the variables in the data are independent. The differences between Bayesian method and logistic regression are, among other things that Bayes is functioning with smaller data and it can take advantage of the prioris, which is improving the predictability and allows for better tolerance for mistakes and missing information. It is easier to demonstrate the Bayesian networks and there are less demands connected to the normal distribution, missing information, outliers and the dependence between independent variables and non-linear dependencies (Lucas P 2004).

By using the Bayesian method it is possible to work with the data that are much smaller than the traditional frequentist statistics require. One of the benefits is also that from a very complex group of a large number of variables where everything depends on everything else, it can bring out the most essential. The Bayesian method is less sensitive to sparse data than logistic regression analysis (Greenland, Schwartzbaum & Finkle 2000). The method can

even do better than logistic regression when working with small data (Dietterich, Becker & Ghahramani 2002). The Bayesian method provides a means to express skepticism about large treatment effects and it can be used in cautious interpretation of results that seem “too good to be true” (Spiegelhalter et al. 1999).

Predicting with the dependence modeling

B-course is a free online data (dependence) analysis tool and the B-course service (<http://b-course.cs.helsinki.fi>) can be freely used for educational and research purposes. With B-course it is possible to analyse the data for multivariate probabilistic dependencies, which are represented as Bayesian network models. B-course tool is implemented as an Application Service Provider, which means there is no downloading or installation of software and it can be used with most web-browsers. B-course tool requires only that the user data have to be a text file with data presented in a tabular format.

In dependence modeling one tries to find dependencies between all the variables in the data, which means in this context modeling the joint probability distribution. Dependencies can also be used to speculate about causalities that might cause them. Dependence models can be used to infer probabilities of any set of variables given any other set of variables.

In order to make the task of creating dependence models out of data feasible, B-course makes two restrictions to the set of dependence models it considers. Firstly, it considers models only for discrete data and it discretizes automatically all the variables that appear to be continuous. Secondly, B-course only considers dependence models where the list of dependencies can be represented in a graphical format using the Bayesian network structures.

Using the Bayesian approach provides a way to recognize a good model when the software finds one, which means in this framework a model with a high probability. In the beginning of the search process with B-course the data file is sent to the server and this is followed by the model search phase. The search method is a combination of a greedy and a heuristic, trial and error one. Greedy means that the algorithm is searching for more variables to better explain the outcome but with the cost of “overfitting” the model. In the classification model where naïve Bayes is being used, one has to determine the dependent variable before hand and the others are independent variables similar to the logistic regression analysis.

After the search is completed, the final report shows the best dependence structure found. When there are many models that have approximately the same probability as the most probable model, those other models should also be consulted when predictions are made and the contribution of each model should be proportional to the model’s probability. The final model is the most probable model B-course could find given the time used for searching. The user is also given a report on strengths of the pairwise unconditional dependencies, i.e., arcs in the constructed Bayesian network of the model. Nevertheless, in non-linear models it is not easy to give strengths to arcs since the dependencies between variables, are determined by many arcs in a complicated manner. Fortunately, it is possible to get a relatively simple measure of the importance of an arc by observing how much the probability of the model is changed by removing the arc.

B-course also provides interactive tools called “playgrounds” that allow the user to perform inferences on the constructed Bayesian network. The requirement is a Java-enabled browser called the Java playground. Inferring causality from statistical dependence is an issue of some ambiguity and debate. There also remains the question of the direction of the causality. This is not always possible to know but sometimes the model is such that the co-existence of dependencies cannot be explained without a certain causal relationship.

B-course uses discrete, discontinuous variables meaning that the set of dependence models B-course considers, expects the variables to be categorical e.g., gender, favourite colour etc. The variables may be numerical like age or the values have some natural order like the

so-called Likert scale. In such cases B-course will categorize the variables and continuous numerical variables are discretized into intervals. The main reason for such a discretization is that for categorical variables one can build models that capture more complex non-linear relationships between variables.

As opposed to many classical estimation procedures, no Bayesian analysis is ever nonviable due to too little data. The Bayesian analysis takes into account all the data available and there are no preset sample sizes that have to be satisfied to be able to perform the dependence analysis. If the database is small, the dependencies are weaker and the best model found may not be very much better than the second best. B-course tool handles missing data as ignoring it, jumping over it. The calculation of the probabilities of the models is essentially based on the frequency of different patterns of data in the database. When calculating these pattern frequencies, B-course ignores the patterns that contain missing data.

The performance of the B-course tool's model construction algorithm has been studied based on simulating the future prediction tasks by reusing the data available, e.g., with cross-validation methods. The main purpose of the tests with larger networks have been to find out whether the model search produces wrong dependencies meaning that it adds dependencies which only reflect the "noise" in the data. According to the results, in this respect B-course is behaving very well since it almost never adds a dependence where there should not be one and prefers simpler models in connection to smaller data sets (Myllymäki et al. 2002).

While using the Bayesian method, inferences about the effects of the variables on the occurrence of an event of interest are based on a mean of the posterior distributions of the set of identified models, weighted by their posterior model probabilities. On the contrary, in logistic regression analyses, a stepwise strategy is often adopted to choose a subset of variables and inferences about the predictors are made based on the chosen model constructed of only those variables retained in the single model. In a particular case when the sample size is small or the event rate is low, there can emerge a problem of choosing the most relevant subset of variables for the analysis that will predict which individuals are at the highest risk of an outcome.

5 Results

Results of the content analysis

In this figure (Figure 2) I will present the main results of the study based on the content analysis. The predictors of a successful encounter and a failed encounter are described and grouped to patient, doctor and system related concepts. All the elements of the quality assessment procedure are represented in this picture. At the successful encounter private care and continuity, belong to the structure, seriously taken, doctor caring, doctor competence, information giving and trust in doctor belong to the process and satisfaction and benefit belong to the outcome. At the failed encounter waiting lists and economic issues belong to the structure, indifference and talking to doctor's back and unnecessary visit belong to the process and disappointment, feeling anger and bitterness are feelings that the indifferent behavior has given rise to. Treatment failure belongs to the outcome.

In the following I have summarized my interpretation of the topics the interviewees talk about under the concepts connected to a successful encounter.

Doctor competence can be perceived in good diagnostic skills, the doctor knows immediately what is wrong. S/he has a holistic approach to the patient's problem, takes the patient as a whole person. There is a smooth flow in the treatment process, even the role of the intuition is mentioned, which gives rise to admiration among the patients. The competence consists of trusted professionalism, good technical skills and communication skills together. The competent doctor has the ability to listen attentively, to find out the real reason behind the symptoms and s/he always performs a careful examination.

Caring doctor shows true concern for the patients' s problems. S/he is available for the patient and there seems to be a 100% presence at the consultation. There is also the promise to call if needed. All the relevant procedures are taken care of, the doctor is looking after the patient's best interest, showing kindness, empathy and encouragement. The doctor gives advice and support to the patient, gets into details and does not leave anything unfinished. There are signs of stubborn perseverance, to get into the heart of the matter. All this gives to the patient the feeling of being in good hands.

Patient need to be taken seriously includes that the doctor is listening attentively, s/he tells the patient what is going to happen in the treatment process and takes the patient's worry seriously. S/he believes the patient, gives assurance the patient has not made the appointment unnecessarily, communicates that the patient has a legitimate right to visit. The doctor gives justification for the consultation by starting the investigation immediately, not only after the patient returns many times. The patient is expecting good interaction at the encounter, straight and honest discussion and getting into details. Concern over the whole person and not only a symptom, a holistic approach is expected.

Respect towards the doctor implies that the patient is willing to show admiration towards his or her doctor because of the competence and expertise. Many of the good doctors are perceived as being top professionals, especially the surgeons. Respect seems to be based on technical skills evaluation, which is connected to experiencing excellent outcomes as a result of some treatment. There is gratitude towards the doctor for finding the right medication and knowing the correct diagnosis immediately.

Trust in doctors is described as essential, there is no alternative but to trust in doctors, it is in the patient's best interest to trust and obey the doctor to make sure the outcome of the treatment is best possible. Previous good experiences enhance the trust for now and in the future. The expert status gives the doctors the authority to decide what is best to do in the patient's case. For some patients there can be equal trust in all doctors independent of being

Factors that predict the patient perception of the quality of the encounter at the health care context

A SUCCESSFUL ENCOUNTER

CONCEPTS THAT ARE CONNECTED TO THIS

1. **satisfaction with care for the patient**
 - “I have been extremely satisfied and glad since the medication helped me.”
 - “At least we have received all the service in time what we have needed so we cannot complain at all.”
2. **benefit perceived by the patient**
 - “Well, yes, when you get some help for your problem it certainly feels nice and you think the visit was beneficial.”
 - “When you are having a lot of pain and swelling (in your joint) so it will obviously be beneficial to have something injected into to the joint.”
3. **patient need to be taken seriously**
 - “One should really listen to the patient carefully and find out what is behind the pain, what could cause it and not treat it as something insignificant.”
4. **respect towards the doctor**
 - “He is such a great gentleman, there is no other like him.”
 - “At K hospital the doctors are of the best quality, one needs to raise a hat for them.”

patient related concepts

1. **doctor caring for the patient**
 - “Young doctors these days are so lovely and in a very different way. They are radiating caring and concern.”
2. **doctor competence**
 - “The doctor at the rheumatologic out patient clinic was very competent and professional when he took me so seriously.” (found out the kidney problem just by listening to the family history).
3. **trust in doctor**
 - “In my opinion it is the doctor who should decide.”
4. **doctor information giving**
 - “There are papers and test results which he takes out and tells me to sit next to him so we can look at them together.”

doctor related concepts

1. **private care experience**
 - “At least the staff is competent there when you visit a certain doctor whom you know to be an expert on that topic.”
 - “I felt they paid more attention to my problem, got into details.”
2. **continuity of care**
 - “Of course it is nice to have the same doctor if you need to visit frequently, it feels more safe to go.”
 - “Well I do prefer to visit the permanent doctor since he already has the kind of touch, that is why I visit him.”

system related concepts

A FAILED ENCOUNTER

CONCEPTS THAT ARE CONNECTED TO THIS

1. **feeling anger**
 - “He said he will not start dealing with this since there is only a fifteen minutes appointment time allocated for me. So I stood up and left.”
 - “It is just that if only the symptoms are looked after, nobody trying to find out the cause, it makes me angry.”
2. **disappointment**
 - “What hurt me most was that I felt so exhausted and she was just enjoying the beginning of her summer holiday and I left for home to bleed.”
 - “I suppose even I could check the drug name from the Pharmacy book and then make the prescription, tell the name of the medication and say goodbye.”
3. **bitterness**
 - “So I happened to meet a doctor who tells me she doesn't know anything about my problem.”
 - “How can you detect with eyes only the prolapsed disc in the back? I don't think anybody can.”

1. **indifference**
 - “He took me as if I only was of secondary importance, made me feel like 'poor you, why did you come to bother him, you should have gone somewhere else.’”
 - “Then I was told this belongs to aging, this knee problem of mine, nothing else.”
2. **talking to doctor's back**
 - “But sometimes it happens that the doctor is facing his computer and the patient is left looking at his back.”

3. **treatment failure**
 - “The joint was not inflamed since the tendons were torn. That was it all about.”
 - “I was surprised they did not find out more what was wrong with me. They just sent me home with my chest pain and advised to take nitroglycerin if needed.”

1. **waiting lists**
 - “Our doctors prefer performing operations at the private clinics.”
 - “These waiting lists are far too long even now.”
2. **economic issues**
 - “I don't know whether times are so bad since they don't seem to like giving you a referral to any tests, blood tests or any other.”
 - “One does think that they run out of resources, there are so many sick people queueing.”
3. **unnecessary visit**
 - “This was a sort of unnecessary visit since I did not get any help.”

Figure 2. Factors that predict the patient perception of the quality of the encounter at the health care context

familiar with them. Confidence in the whole health care system increases when the patient trusts the doctor. The trust is not affected negatively if the doctor does not know the diagnosis but will consult a colleague. There is great trust in surgeons who can perform miracles. The prevailing attitude is that orthopaedic surgeons are allowed to do whatever they want to as long as they can make the hip/ knee painless, it is in their hands, the patients do not question their decisions. It is from the health care system that the help has come before so the people believe the same will happen again.

Information giving is very important for the patient to be able to receive honest, understandable explanations from the doctor. The doctor should give health promotion, too and encourage the patient to look after himself. There needs to be easiness in the communication so that the patient can ask more. Creating a relaxed atmosphere is seen important for the patients' questions to be raised. Much improvement has happened in receiving information during the consultation compared to the past.

Continuity of care makes it is easy to talk about all topics with the doctor whom one knows, feels more safe, preference for an own GP. The familiar doctor has "insider" knowledge, which is seen as an advantage in taking care of the patient. The lack of continuity is seen as negative. Sometimes a very long lasting relationship can grow into some sort of friendship, save time at the consultation and give chance to social talk, which is appreciated. An open interaction with the doctor makes it easier to talk about sensitive matters, too. It is seen as a mutual benefit when the doctor and the patient know each other well. Continuity in the doctor patient relationship makes things easier since one does not have to start from the beginning of illness history at every consultation. It is obvious that continuity where one visits the familiar doctor over a long period of time is one of the elements of a successful encounter. When the doctor has time to listen to the patient attentively and is able to show real concern for the patient's situation, which is known to the doctor from previous visits, it gives the feeling of security and that one is taken care of by a true professional.

Private care experience is described as good and positive when it is based on trust that one's own doctor will always provide some help and give the patient the feeling of being in the hands of a true professional. S/he has good manners, thoroughness of examination, and stays focused on finding the real reason behind the symptoms. The doctor is able to come home and will call afterwards about the progress, not leaving anything unfinished. S/he is treating the patient friendly, seems to have enough time and the cost-benefit ratio is optimal since one can meet an expert. Good communication skills and open interaction with one's own doctor make it easy to consult by telephone. The patient feels very loyal towards the doctor. There is the fast track opportunity when money can buy easy access and one gets value for the money. During the examination the doctor gets into the heart of the matter without delay, things start to happen immediately. It is important to have the freedom of choice from the patient's point of view.

Benefit is gained when the treatment outcome is positive and the patient is getting well and everything in the care process takes place, as it should. The first task is finding out the cause behind the problem and then treating it accordingly. An early diagnosis of a serious illness can also be beneficial for the patient since the problem can be taken care of in the incipient stage. As long as the surgeons perform successful operations, the quality of life is increased. When there is a joint agreement on planning the treatment process and follow-up visits, competent treatment procedures and immediate access when having a severe pain, the patient is gaining benefit from the health care providers and the whole system. It will also be beneficial for the patient if the doctor is taking the responsibility for looking after the health problem and is able to convey a 100% presence at the consultation.

Satisfaction with care is obvious when the patient feels s/he is receiving good quality care continuously. There is a positive experience of an acute stomach pain episode which prompted all the investigations to take place very quickly. Satisfaction is expressed after

successful operations and with the follow-up system of the chronic illnesses which makes sure that nothing can develop unnoticed and this gives the patient security. A satisfied patient is grateful to the friendly GP who has taken good care of everything and managed to get all the needed walking-aids for her patient. Satisfaction is expressed over right medication, which cured the illness completely. There is gratefulness over the fast progress of the care process which has resulted already in being on the waiting list for the knee operation. There is satisfaction over a fair and trusting treatment relationship with the occupational health care doctor who gave sick leave when the knee was too painful to walk up and down the stairs at work. A long-term relationship with the family doctor with whom everything gets done in mutual understanding without any delay gives satisfaction.

During a successful encounter the doctor listens to and takes the patient seriously, examines thoroughly, refers to x-rays, ultrasounds and to the specialists if needed. S/he is kind, friendly, caring and easy to talk to. One notices the difference immediately from the first handshake and the first words that are spoken whether this is a good doctor who has the right kind of attitude towards the patient, or not. The doctor is able to give the impression that there will be as much time as is needed, the patient feels free to tell all her problems and she is not hurried away. Still, the consultation doesn't last a very long time. It is just the feeling of being there for the patient, which the competent doctor can create.

One important characteristic for the doctor at a successful consultation also seems to be the ability to communicate the feeling of being "one of us" in a sense that one cannot tell whether s/he is a very learned person meaning they behave like ordinary people. They don't come across as arrogant, superior or distant, instead they are perceived as equals, caring and humane people. For the encounter to be successful, the doctor should take the patients seriously, listen to them and believe in them and at the same time perform a thorough examination to find a cause and a right treatment, which is the ultimate goal of a successful consultation.

My interpretation is that the concept of satisfaction with care in the narratives of my informants is very closely connected to the concept of benefit. I am arguing that the patient perception of benefit is clearly related to the outcomes of care and in this way to the quality of the health care services as perceived by the users themselves. These comments by the respondents are spontaneous expressions of gaining benefit.

"Well, yes, when you get some help for your problem it certainly feels nice and you think the visit was beneficial."

"It was beneficial at the rheumatoid out patient clinic when they discovered the renal insufficiency... even if it was bad news it almost felt like good news since they caught it then instead of much later."

"There is benefit when the medication is correct and it has been effective."

There are plenty of examples of right medications, successful operations and investigations performed without any delay and thoroughly. So the patient focus with satisfaction seems to be connected to the good quality of the care received.

During the examination the doctor pays attention to the patient's symptoms, is thorough, gets into details, communicates the need to find out the real reason behind the problem. The patient is taken seriously, not treated in an indifferent way. The patient can perceive the real presence of the doctor, s/he is there for you and a sense of having all the time in the world is created at the encounter. Even if the patient knows there are other patients waiting, the doctor is able to avoid the feeling of being in a hurry.

At a successful encounter the doctor's competence is shown in the ability to find out the right diagnosis immediately. S/he also finds the right and most effective medication at one go. When the patient makes the choice of whom s/he wants to consult, there is a certainty that the doctor is an expert on this field and it gives the patient confidence and security.

According to the findings, successful encounters are based on interaction with doctors,

who are friendly and helpful and show real concern over the improvement of the patient's condition and give a follow up call to check how things are progressing. After the consultation a promise to contact the doctor by calling to a given number is regarded as building trust. Doctors are seen to be simultaneously at a service profession and at an expert position. The image of a competent doctor is being one of us, an ordinary person, not somebody who is showing off his or her learned background. Understanding the patient's situation has a very high priority in the assessment of the quality of the encounter. The doctor should also know how to manage the problem effectively and without delays. When all this is happening, satisfaction after the successful treatment outcome is guaranteed.

The respected doctor involves the patient when going through the test results and they look at them together and discuss the meanings of the values in the patient's context. The doctor explains very clearly what is happening in the treatment process and gives all the information the patient wants. S/he also gives advice and support when needed. Being on the same wavelength with the doctor is seen as a very positive sign, it makes the communication easy and allows the patient to open up and discuss even more sensitive issues with the doctor. A very satisfactory consultation also includes some humour and it is appreciated if the doctor can respond to the patient's humorous remarks and jokes.

In the following text I have written a summary of my interpretation of the topics the interviewees talk about under the concepts connected to a failed encounter.

Doctor indifference is present when the doctor seems to be ignoring the patient, makes no eye contact. The patient can sense a non-emphatic attitude, even irritation and annoyance. It can happen, that the doctor is not paying attention to the patient, gives the impression of being in a hurry, not taking seriously the patient's complaints. There may be poor understanding of the situation and insensitivity for the circumstances by the doctor. When no real concern is expressed by the doctor at the consultation the interpretation by the patient can easily be that s/he is just a routine case. The doctor can openly ignore the patient's worry, communicate a couldn't-care-less attitude and even suggest the patient has come for nothing. Making unfriendly jokes during the consultation shows indifference to the patient's feelings.

Bitterness includes a sense of unfairness, feelings of being neglected by the system. During the consultation the patient may feel that s/he is exposed to unfriendly behaviour by the doctor. The patient may think s/he has to tolerate injustice from the part of the health care system. The memory of some arrogant and unkind utterance made by the doctor, can cause bitterness together with negativity and resentment towards the health care providers in general and lack of trust in a fair treatment process.

Disappointment can be caused by an arrogant and cold behaviour shown by the doctor at a moment when the patient is feeling particularly vulnerable. When there is no recovery after an operation, the situation being similar to the preoperative state with no improvement or the care process turns out to be very slow, a disappointment follows. The same is true if only symptoms are treated for too long instead of finding the real cause of the problem. If the computer gets more attention than the patient at the consultation or the attitude of the doctor towards a joint problem is indifferent as expressed in the statement "this is just part of the aging process", disappointment is bound to follow. Also when no action is taken for many years, and the reason behind the symptoms turns out to be a neglected blood pressure problem which is solved only when the patient herself becomes assertive and demands some treatment, frustration is expressed.

The patient can become disappointed when no appointment time is arranged when she has finally decided to consult the doctor. The experience with the doctor can be unsatisfactory since the patient was not met as a whole human being, just a sore throat or an aching foot. If no sense of humour from the part of the doctor is shown, there is a risk that the whole encounter can end in a sense of failure and disappointment. This happened to be the case

where the odd behaviour of a doctor caused an unpleasant experience to an old lady when the doctor misinterpreted the situation and started shouting at the patient who, according to her own interpretation, was just telling a harmless joke.

Feeling anger is a concept used when someone is full of resentment towards public sector doctors who seem to have time to run their private practices during the day. The patient can feel betrayed when a promise given by the surgeon to be able to ask possible questions about the operation from the other surgeon beforehand is broken. Anger is also provoked by the extremely negative prognosis given by a doctor in an insensitive way connected to the patient's walking ability and an abrupt comment by another doctor about the topics, which can be discussed during the phone call. Dissatisfaction over three operations performed for the knee joint and achieving no improvement of the situation are causing anger. Difficulties in access to the health centre by phone to make an appointment make one angry. Disbelief about the workload since often no patients seem to be around at the surgery can be a cause of resentment and the insurance company's decision making and the power of the insurance doctor over the local GP are sources of anger.

Treatment failure is perceived when the patient feels that the doctors have not been following the clinical guidelines in the case of his health problem, and this has caused a life-threatening situation for her/ him. There have been wrong medications for the health problems, an artificial plastic joint partly dissolving and causing severe pain for years. The real problem remains undetected for a long time and can cause disability for the patient. The recurrent occurrence of prescribing antibiotics without any investigation for common colds makes the patient suspicious and reluctant to take the medications. In the past somebody was given strong pain killers for her stomach pain as injections during the work days at the hospital ward without a diagnosis and no action was taken by the local doctor even if the x-ray showed gall stones and the situation evolved so that she finally became yellow and was rushed to another doctor by her husband. The cleaner lady at a primary school having chronic foot pain was diagnosed repeatedly with strain injury. Only after a few years the radiography taken at a private clinic showed severe osteoarthritis together with rheumatoid arthritis.

Waiting lists are referring to the long waiting period at the public sector. To avoid this and instead of waiting for a few years, the patient can go to the private sector if s/he can afford and have the operation in three months. Even though there is a guarantee for treatment since 2005, the public sector doctors seem to prefer operating at the private sector. There are complaints about too long waiting times, the situation of the patient can get worse during the long waiting period and one worries over own health a lot. There are feelings of hopelessness, it is so terrible just to wait while the situation is getting worse for the joint and also some other disorders like diabetes and hypertension can deteriorate because of immobility.

Economic issues explain the suspicion there seems to be for lack of money in the municipalities and the influence this may have on the decision-making about laboratory tests and also getting a referral to the specialist consultation. There is a continuous complaint in the health care about shortage of money to employ doctors to the hospital. The resources seem to fall short when there should be investigations on what is wrong with the patient and this gives the impression the doctors try to save money by not referring the patient to the specialist. Some senior doctors may think locums are just spending the money unnecessarily by making referrals, and there is also suspicion of age racism, according to which old people are not getting proper treatment because of their age. The GPs try to delay referrals to hospitals and save the municipality's money this way.

Unnecessary visit takes place when the patient is not able to talk about matters that s/he really feels concerned and worried about, the whole visit seems useless and unnecessary from the patient's viewpoint. The doctor's indifferent attitude, which can result in not getting any help and no questions answered, makes the visit unnecessary. Some follow-up vis-

its in a stable chronic disease ordered by the doctor may seem unnecessary, but the patient still feels it is good to know everything is under control. For a worker it feels useless to get a two-day sick note when one is really ill and has a job demanding physical labour. The health care providers should be more efficient in planning all the tests and investigations, there should be more collaboration so that the patient does not have to make many visits unnecessarily on succeeding days. The patient perception is that not any sensible person ever visits unnecessarily and there is always some problem that needs medical attention. There are feelings of frustration and wasting time on unnecessary visits when trying to explain the joint problem getting worse and the response is repeatedly that it belongs to aging and the patient should learn to live with it. It is unnecessary to book a doctor's appointment if the supportive discussion is enough for the patient. Doctor consultation is too expensive a treatment for the society to be used for psychological problems. At the private sector they may treat people unnecessarily just because of the money. If there is really nothing wrong and still the person makes the appointment, then it is an unnecessary visit for the system. If the patient is telling her problem and expressing herself clearly and there is no response to this from the doctor, the visit is unnecessary from the patient's viewpoint. After a long waiting period when one gets to see the doctor, it feels useless if nothing is examined and no diagnosis given. The patient may have a certain agenda, worry or concern, which s/he wants to be dealt with at the consultation and if this is not happening, the visit seems unnecessary from the patient's point of view.

At the failed encounter the patient may be left looking at the doctor's back as s/he enters information on the computer at the same time when asking questions. The doctor may have too little time for the patient and s/he seems to be insensitive and indifferent to the patient's needs and sometimes can even get angry with the patient. The informants also talk about bad management of some situations, not making a proper physical examination and not being aware of the working conditions of the patient when signing them on sick leave.

The informants seem to take very seriously every single cue, which they can read from the doctor's behavior. They make assessments whether it means the doctor believes they really have severe pain and some acceptable reason to be there asking for help or whether s/he thinks they are exaggerating their pain and think the patient has come for nothing to waste the precious appointment time. The worst scenario from the patients' s point of view seems to be the fear that the doctor may think the problem is totally "between the ears".

The informants in my study also believe that sometimes the GPs do not give them referrals to specialists just to save the municipality's money. The economic situation is perceived getting worse all the time within the health care, less money and resources are available and this is seen to have influence on the doctors' decision making. They also believe it is the lack of resources when the doctor does not seem to find out the cause of the problem but only treats the symptoms. There is no real saving if the patient is not getting the referral to the specialist care since the situation will deteriorate, more sick days are spent and one should also think about the cost of all pain and suffering that the patient has to put up with. It is a question of values in the society whether looking after the weak and the sick people is regarded as important and given a priority which their experiences seem to contradict. The politicians want to undermine the position of the hospitals and the health centres by not allocating enough resources according to the interviewees.

When the patient is experiencing an indifferent attitude at the consultation, maybe looking at the doctor's back most of the time and the doctor is not paying attention to the patient's problem, the consultation most likely is going to fail from the patient's perception. If the doctor shows a couldn't-care-less attitude and s/he gives the impression of being in a hurry, the patient feels neglected and not taken seriously, and the whole visit is assessed as useless by the patient.

Meeting an unfriendly, impolite and arrogant doctor who does not show any interest in

finding out the real reason behind the patient's symptoms is seen as a total failure. If the doctor lacks any sense of the situation from the patient's point of view it may lead to a disappointing outcome like when a doctor was happily telling about her summer holiday which was due the same day and the patient felt worried and tired after a long period of bleeding problems. The health care system is seen as too fragmented, nobody is interested in the whole person, just different illnesses get treated. Also there seems to be a general mistrust to the system, especially to the equality in health care issue. Politicians and their families are thought to get better treatment.

Resources are believed to be too scarce and very limited and this can influence the willingness to refer patients to hospital examinations or laboratory tests. The decline in public services is taken for granted and it colours the attitude towards the whole health care system. The access is perceived as too difficult, the patient can feel insulted not to get an appointment when s/he wants it. Doctors are seen to be in a hurry with too short consultation times. The patient can only complain one symptom since the doctor will not listen to any other ailments because the appointment was made only for this one cause.

Often the preconception of the patient is negative based on some earlier experiences and it may affect the interpretation of all communication during the present encounter. The informants as patients seem to be very sensitive to any doubts expressed from the doctor concerning the seriousness of their symptoms. If the doctor fails to communicate a justification and reassurance for the legitimacy of the visit, the patient can interpret the situation very negatively and be afraid of the doctor thinking there is no real reason for the visit.

This kind of attitude is very common in the narratives of my own informants. They seem to be relieved when a real reason is to be found behind their complaints, which gives them a legitimate status as a patient and also makes it evident the problem is not between their ears. If the patient has a specific agenda, meaning some particular idea or worry s/he wants to get an answer to and then this happens to remain unsolved, the encounter is easily assessed as unnecessary and useless with no benefit at all by the patient. After a failed encounter the patient may feel s/he did not receive any help, and that the advice was not any better compared to his or her own knowledge. The patient may also experience the encouragement how "to learn to live with the problem, since it belongs to the aging" very negatively and excluding the right to have treatment for the problem.

In the Content Analyses Table (Appendix 2), I was able to generate three main categories emerging from the data during the study process. Under the main categories I have created the subcategories, which consist of the concepts from my original coding of the interview texts.

The main categories are

- 1) Narratives of Survival
- 2) Quality of Care
- 3) System Encounters

In Narratives of Survival there are two subcategories Endurance and Coping.

In Quality of Care there are two subcategories Competence and Benefit.

In System Encounters there are three subcategories: Unfair suffering, Patient perception of Health care system related interactions and Understanding.

Finally, the three themes have been generated to illuminate the patterns and relationships based on my interpretation and understanding of the results of the content analyses.

- 1) Survival despite the suffering of the chronic pain (Endurance)
- 2) Struggle against "the system"

3) Trust towards the expert doctors who will provide good quality care

All the narratives that emerged in the interviews were about people enduring, suffering, coping with a chronic illness, interacting with the health care system to get help, to get better, to be cured. Unfortunately they were also about a constant struggle against the faceless system. Still the bottom line was the fundamental trust in experts of the health care profession who will provide the good quality care needed by these people.

1) Survival despite the suffering of chronic pain (Endurance)

The severe and constant pain made it difficult to move around even at the house. When going to the toilet one had to lean on the furniture since the joints were so painful. One lost interest in everything since the pain was intensively present all the time. Feeling uptight and tense made one crave for alcohol too. Suicidal thoughts could emerge, there could be a temptation to take all the pain killers at one go and get away from the pain. Sex life was affected since it was difficult to find any positions which were not painful. Sometimes a deep hopelessness hit hard because the pain had often lasted for several years, even more than a decade.

The osteoarthritic pain could be seen as one's destiny and there was even acceptance of having a wheel chair in the end to be able to move around. Constant pain and agony was described as eating you up, it was hard to cope with. Giving up social events and hobbies was difficult and sad but inevitable since one could not sit still at one place for a long time. The pain was there 24 hours a day. At work the situation was hard to tolerate especially when one was not able to have sick leave in the last working years because the pension was dependent on the amount of all income, extra work included. One had to go to work even when the knees were swollen and painful. The causality between starting to work very young at physically demanding jobs and the development of severe joint problems in early middle age was emphasized.

Sometimes no visible reason for a severe pain was found out for a long time and this made the patient worry the doctor may think the problem was between the ears, which seemed to be the worst scenario in the patient's mind. Most of the time pain killers were avoided as much as possible since it was understood they could only ease the pain, but did not have any positive effect on the real cause behind the symptoms. Also it was seen almost dangerous to try to mask the painful situation of the damaged joint and possibly make things even worse. The pain had to be severe enough to make one sweat to justify taking of the pain killers.

The example and memory of own parents coping with all sorts of illnesses and poor health had increased the threshold for seeking help for own health problems. One respondent referred to the Finnish "sisu", the guts, to bite the lip and just soldier on, to endure.

The participants described very vividly their suffering.

"This is like hell on Earth, to live with this pain."

"It makes one yell when starting to walk. One has to curse out loud sometimes when it hurts so much."

Their tolerance seemed remarkable and they adapted to the life circumstances they found themselves in.

"When there is a good day and there is less pain, one feels that everything is in control. But then there are times when it seems you cannot stand, cope or tolerate this at all."

"So why didn't you visit the doctor earlier? Well it is my own stupidity, the Finnish guts, that's what it is."

"The constant pain and agony, it does eat you up. I had to tolerate the severe pain for the last few working years since my pension was dependent on the income level of these last years."

They also talked about their ways of coping and getting on with their lives.

"Since there are means, drugs to ease the pain so why shouldn't we use them when necessary?"

"One should not let life get to the depressive mood. There has to be humour, this is merely life." (laughing).

"I am walking every day, short distances, to keep the muscles fit."

"I will get the boat and go fishing, it is a very good pastime. The problem is getting on the boat."

The importance of a supportive family was emphasized and many informants were grateful to their children who took good care of their needs and tried to help in many ways.

"My children have tried to get me all sorts of things to make life easier for me."

"Of course I trust my children, they take extremely good care of me."

The participants in this study wanted to make it clear that although they had severe pain and disabilities they would not visit the doctor unless they really had to, when they could not tolerate the situation anymore.

"I always try to postpone the visit to the doctor as long as I can cope somehow."

"I am too shy to make an appointment for every symptom so I prefer to tolerate the pain for some time."

"One does not go and visit the doctor easily, one tries to persevere as long as possible."

Some of them had even tried alternative medicine treatments and supplements to ease their joint pain.

"I have been taking the fish oil capsules, I am not sure whether they will lubricate my joints." (laughing).

"I was mixing and preparing myself some ointment from herbs and flowers (laughing) and all kinds of compresses."

In these excerpts people talk about their long lasting pain experience, the suffering and their amazing tolerance for a chronic illness. In the narratives there is lots of perseverance, resilience and strong will to win the obstacles in those dire circumstances these people find themselves often for many years. They described their periodic hopelessness, also their ways of coping with the chronic illness and the support and help given by their family members. They also emphasized their own responsibility to look after themselves and their health. They didn't seem to lose their fundamental hope for a better future at any circumstances.

2) Struggle against the "system"

"The patient has to be tough and persistent and to go on complaining."

"I will not ring or sing. I just go to the health centre reception and tell the receptionist I definitely need an appointment right now."

"Well it wasn't easy even after that. A tough struggle was needed."

These excerpts describe the attitude of some of the informants about the role of the patient when interacting with the health care system. They emphasize the assertiveness shown by the patient and the ability to express own needs clearly to the professionals.

People talked about the unfairness they have encountered in the health care system. In their narratives they have dealt with concepts like bitterness, disappointment, feeling anger, doctor indifference, patient talking to doctor's back and fragmented care.

"I don't know whether he suspected I was trying to avoid going to work... Did you get that sort of impression? Yes I did."

"He was always repeating to me that I am not allowed to have pension."

"How can we have these doctors working at the public sector and who are still ready to leave their full time posts in the early afternoon to work at the private clinics?"

"The treatment was not rude but it was indifferent, no attention was paid to me."

"I have now seen it twice, there has been this couldn't-care-less-attitude."

They suspected whether a physician who is healthy can really relate to the patient's pain experience. They wanted to remind that doctors are for the patients but that for someone who is not experiencing the pain himself it may be difficult to grasp the difficult situation the patient is living with and feel true empathy.

"The doctor, if he is not experiencing some pain himself, does not know how miserable this can be."

"I was so exhausted then so I felt unable to give any feedback. It requires some strength to be able to express your own views to the doctor briskly."

"I was surprised they did not find out more what was wrong with me. They just sent me home with my chest pain and advised to take nitroglycerin if needed."

The informants also emphasized their view on timing of the treatment procedures for the joint problems.

"It would be so much better with these osteoarthritis cases to get the right treatment in time."

"Is the pressure too hard so as to influence to the willingness to take the patient seriously?"

"The patient has to be tough and persistent and to go on complaining."

"So I told to this chief doctor at the health centre I cannot cope anymore, something needs to be done now."

"Well it wasn't easy even after that. A tough struggle was needed."

"It depends a lot on the patient's own activity."

"It would decrease these congestions and costs and also bring savings if the doctors were allowed to do right things to right patients."

They expressed their concern of the co-ordination of the care processes and the difficulties in getting access to the system.

"Everyone of them is looking after one ailment or some problem but not anybody is looking after me."

"I assume the own GP system operates the way where some sort of preliminary examination is performed by the GP and then you are thrust into a tube and after that s/he is not interested anymore what will emerge from the other end."

"There should be more collaboration between the public and the private health care system, since it is so difficult to make an appointment at the health centre."

In these narratives connected to the difficulties of access are the experiences of long waiting lists.

"It is twelve months since I visited the health centre and now finally I am having the appointment time with the orthopaedic surgeon and when will I get the operation, if ever."

"I find it so terrible just to wait, I don't know."

There was a fear of cuts in the funding of the health care services and general shortage of resources.

"It must be the decline at the health centres that we ordinary people keep noticing, that's what we feel, the decline of services."

"I don't know whether times are so bad since they don't seem to like giving you a referral to any tests, blood tests or any other."

"One does think that they run out of resources, there are so many sick people queueing."

"Has the morale of the human kind stooped to killing old people when they no longer are useful?"

The inequality issues were dealt with in the responses. Many informants had strong opinions about the fairness and equal opportunities for everybody in the health care services.

"Everybody knows that those who have the money and can visit the private doctors get better quality treatment than those who cannot afford this."

"I am just criticizing this system since when you are old you are not getting anywhere."

"The system will take care of the politicians and their family members, they know this."

"Everybody should get help just during the right moment so that the future life would be better."

The communication at the consultation was seen difficult and dysfunctional sometimes.

"If one argues anything they (the health professionals) will be so terribly hurt."

"That exactly may be the problem, one is not capable of making demands."

"There could be some of this customer-centredness present at the consultation."

"I think the doctor should listen to the patient, what s/he has to tell and one should not be in such a hurry."

The patient perception of health care system related interactions includes concepts such as continuity of care and access to care, assertiveness shown by the patient, being one's own advocate, patient perception of public and private care, experience of operations, waiting lists, leadership in the health care and societal values connected to health care.

The interviewees talked about unnecessary visits from the patient perspective. In their opinion the visit was unnecessary when one did not get any help, nothing happened to make things better with one's illness or problem. They have dealt with patient decision-making and customer attitude, doctors being at a service profession and discussed power struggle between doctors as well as between doctors and patients.

People have described very clearly the problems they have encountered and experienced while interacting with the health care system. Their experience is that too much time is allotted to the PC during the consultation, the doctor sometimes does not even look at the patient who is just talking to the doctor's back.

"If the patient will express clearly the situation and how s/he is feeling and then getting no response, I think it certainly is an unnecessary visit."

"It was an unnecessary visit. Just as well, I could have asked a man in the street what I shall do with my knee and he could have told me I just have to learn to live with it."

They expressed doubts about economic issues interfering with referral policy from the health centres and some of the interviewees suspected that patients will get treatments they don't even need if they use the private system.

"On the private sector it has become more business like, I just mean these unnecessary patients."

They accused the politicians who were not giving enough resources to the health care to look after all the sick people and they expressed their worries how things will be in the future.

"Money is needed but there is no money. It is the same thing out there in the industry, it is just being strangled."

3) Trust in expert professionals who will provide good care

Despite the negative and failed encounters there are plenty of narratives where the participants described good and rewarding experiences with the health care providers when they had received excellent care. Here people talked about their satisfaction and the benefit they had gained while visiting their doctors.

"I have experienced a remarkable benefit from this brain circulation medicine ever since I was referred to the investigations and the dizziness stopped. In the mornings I used to get up holding the doorframe."

"So maybe I have been so lucky to have understanding doctors who have taken me seriously and decided this man is not complaining for nothing."

"She gave me such an effective pill (for blood pressure) that I have needed no other. It was the first time right, she was such a clever doctor."

Doctor competence was defined as having expert knowledge, ability to find the right diagnosis and provide appropriate treatment. They also defined doctor competence to include the qualities of attentive listening, empathy, caring attitude and holistic approach, which included respect and interest towards the patient as a whole person and taking the patient seriously.

"You can ask, if it is your throat that's bothering you or some other reason, those first, but I would expand the context and ask how things are in general."

"Young doctors these days are so lovely and in a very different way. They are radiating caring and concern."

"The doctor will say, tell me what's on your heart and what is the problem."

"It seemed that he was able to solve the problem almost automatically."

"The doctor takes the patient seriously and listens to her and a good doctor-patient relationship"

develops where one can trust to receive help."

"In K there are so many top doctors and surgeons that one has to raise one's hat."

"I think that the kindness, paying attention to the patient, getting into details and the feeling of not being in a hurry even if he was short of time, all these things were important."

There were narratives about doctors who just touched the painful joint and immediately knew what was wrong.

"Yes, he could immediately tell what was wrong." (the orthopaedic surgeon).

The interviewees talked about doctor decision-making, information giving and responsibility of finding the right diagnosis.

"I think that the doctor should decide because s/he is the professional... that's how I say to my hair dresser when she asks me something." (laughing).

"He will be very professional and deal with the patient topics and explain things to me and tell what the situation is."

"When you tell your symptoms to the doctor, you expect the doctor to be able to diagnose the problem."

"He can take the patient, go in to details in a different way compared to some ordinary doctor at the health centre."

"So they went in to details, they wanted to find out what is wrong here."

Trust in doctors, comparisons of the professional competence between private and public sector doctors, easiness to get a referral to the specialist care when needed were also among topics discussed.

"One does trust the doctor and his words so much more."

"Well, one has to have trust in doctors. Nothing else will help."

"If the doctor does not understand the situation himself he should refer the patient to someone who does. That's what I think."

"The doctor could say like this: this is not my field of expertise but I can consult a colleague, and so avoid making a possibly wrong diagnosis."

"My own GP has always made the effort to look after the matter and then put the referral forward if needed."

Doctors using humour at the consultation and the feeling of being at the same wave length were concepts under this theme too.

"The young woman had complained how expensive it is, the artificial insemination and then the doctor had replied, I would have taken care of this without any cost."

"It is surprising you still live (the doctor said). I said to that, it is touch and go."

The respondents referred mostly to private orthopaedic surgeons when they described their experiences at the private sector. These professionals were mainly described in a very positive way. For the patient the experienced surgeon represented a kind of hero, a rescuer, in their long lasting ordeal with the chronic pain and disability.

"The private orthopaedic surgeon told me to contact him and he promised to look after me."

Some participants told about good experiences at the local health centre but my interpretation is that the core message expressed by the majority of my informants seemed to be to go private and find the best available professional when the patient really needs expert medical help and more demanding care. The exception here was the competence of specialists at the public sector hospitals, which seemed to be highly appreciated by most of the informants.

They also emphasized that the general practitioners should be more willing to refer a patient to the specialist care when s/he is not capable of solving the problem and does not have the competence to help the patient in the best possible way and this should happen without any delay.

There were comments about the young doctors who seemed to be very different from the older ones. They were described as showing interest and being empathetic, caring and

radiating concern for the patients.

The good doctor-patient relationship as well as the trust in the doctors were seen as very important elements together with the sufficient information giving by the doctor in a successful encounter. The doctor should decide what needs to be done. There were hardly any interviewees who mentioned they would want a more active role in negotiating the treatment decisions. They stated that the doctor is the expert and s/he should decide what is best for the patient.

"It is in their hands, what they decide to do with my hip."

So there was not much support for the concept of partnership and joint decision-making among these patients. Some of them did emphasize it is important to tell the patient what is going on and what the treatment choices were but in the end they didn't expect to participate in the decision making since the doctor knows best and they trusted in his or her professional judgment.

"I have not thought I would be able to say what to do (laughing). Better to trust the doctor."

This kind of attitude may be connected partly to this particular group of patients I have been involved with. All my informants were people who had long suffered from a severe disability in their hip or knee joint and now they were willing to have a total arthroplasty to get rid of the pain. On the other hand, during the interviews the respondents talked about various illnesses and encounters with the doctors and they seemed to have this same approach even in those situations.

The Interaction-Outcome table

The Interaction-Outcome table (Figure 3) is my interpretation of how my informants as patients evaluate the encounters with their doctors. The patient is very outcome oriented. I am arguing that s/he wants results, some benefit for the visit. After conducting the content analyses of the narratives of my respondents, I have come to the conclusions that are described in this table.

The explanation for this table is that patients in the lower left box make complaints and are dissatisfied with their treatment since the outcome and the interaction with the doctor have both been poor. The patients in the upper left box are reasonably satisfied and do not make complaints since the outcome for their visit is good even if the interaction may have been dissatisfying. The fact that the interaction with the doctor was not optimal particularly in some acute problems is not so important to the patient when s/he is worried about her symptoms and anxious to find out what is wrong and what should be done. Getting an explanation, a diagnosis for the problem and a right treatment, affects more to his or her satisfaction than the quality of the communication.

In the lower right box are those patients who are not satisfied with the outcome but who find the doctor very nice and well known to them since many years. In this situation the patient seems to be willing to understand and explain to herself why the doctor didn't know the right diagnosis or give the right treatment. In the upper right box the situation is the best possible from the patient's point of view. The benefit gained is maximal since the outcome is good and the interaction with the doctor is very satisfactory.

Based on my results I am arguing that patients do understand the technical quality connected to the outcome from their own context and when related to some concrete procedures taken place during the care process and they can evaluate to what extent their needs and expectations have been met. They are capable to assess whether they have gained any benefit.

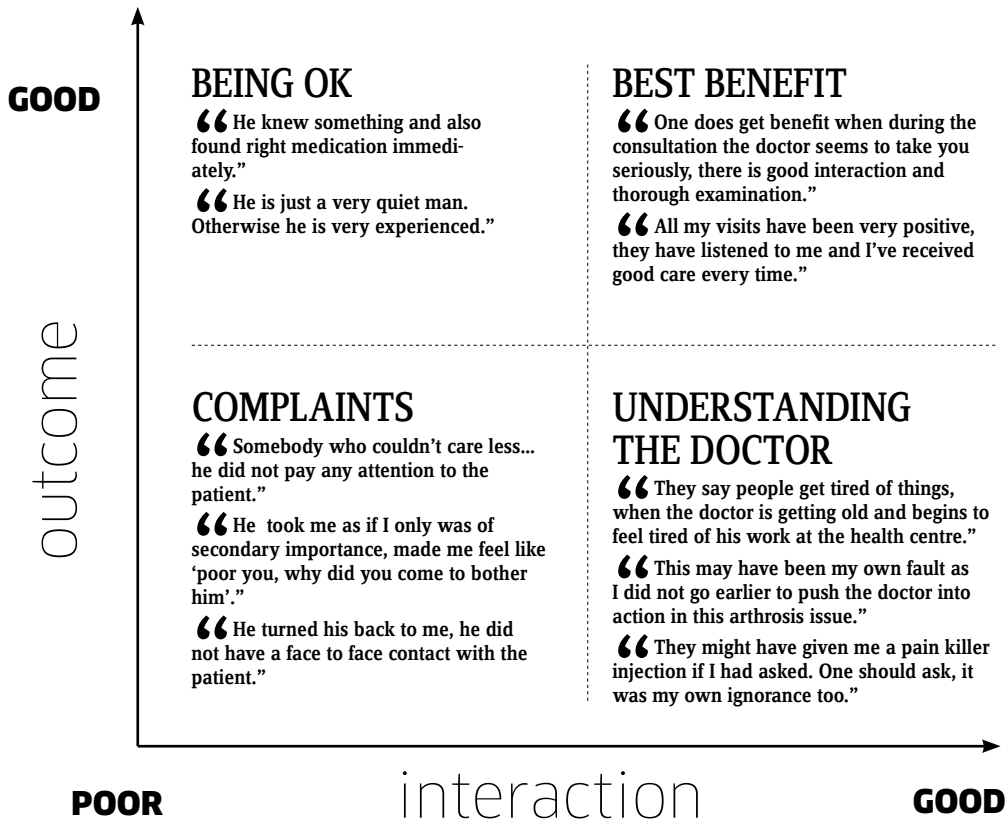


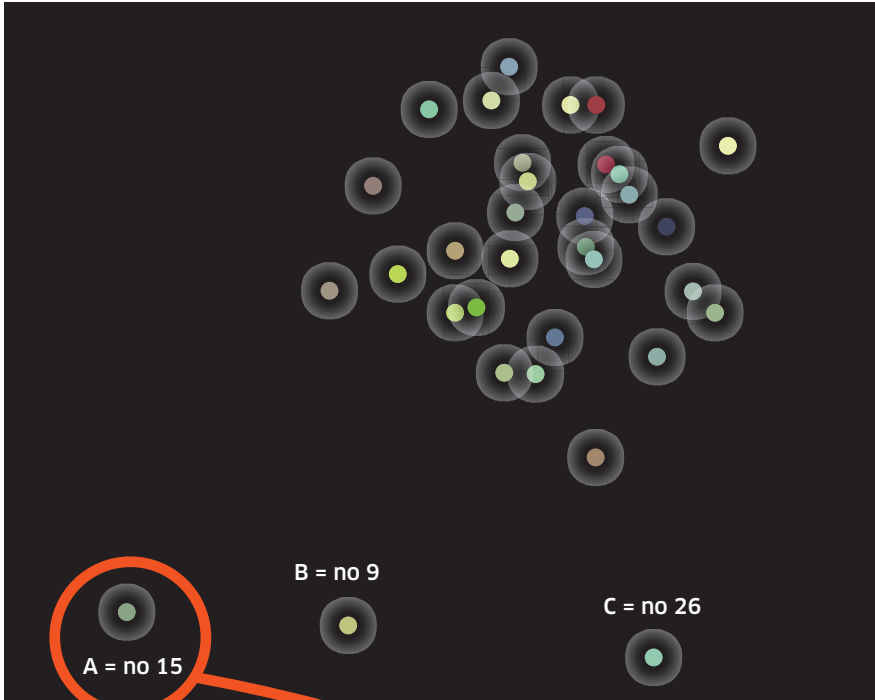
Figure 3. Interaction-Outcome table.

Bayminer cloud

These qualitative data about the interviews of the osteoarthritis patients based on their experiences of the doctor consultations have also been analyzed by the Bayesian dependence modeling B-course, and visualized by using the Bayminer cloud (Figure 4). The Bayminer cloud tells about the data. It is searching from the data individuals and places them either next to each other or far away based on various characteristics. If the persons agree on some topic, they will be near neighbours and if they disagree there will be a distance between them. One can rotate the cloud and change the variables and find out whether the individuals will be located very differently in relation to some other variable. In the Bayminer cloud the locations of the dots represent the posterior probabilities of the variables. They are described as geometric distances in relation to the whole data. There are no axes in the model but instead a 3D space.

The cloud tells about the characteristics of the data. It is possible to capture some individuals at a time and compare how their opinions and attitudes relate to the opinions of all the other informants in the data. The outliers in the data are clearly depicted and their deviant profiles can be analysed. In the picture the columns connected to each variable are described. The Bayminer cloud can be rotated in the 3-dimensional space and observed from different angles to display the shape of the clusters. The cloud can also be coloured by the different values of the variables to show groups, which differ from each other based on

The Bayminer Non-linear Visualization Modeling



In this study the application used is **the Bayminer (www.BayMiner.com) non-linear visualization modeling software.**

In the Bayminer cloud the locations of the dots represent the posterior probabilities of the variables. They are described as geometric distances in relation to the whole data.

Conditional probabilities can be shown as a graph, the three dimensional Bayminer cloud. This graphic model encodes the joint probability to a vast number of variables. Bayesian modeling is a convenient means to manage uncertainty and it is highly applicable to human sciences where the research problems often are connected to people's opinions and attitudes and how to model them mathematically.

Variable values
 1 = neutral 2 = positive 3 = negative
 na = no answer

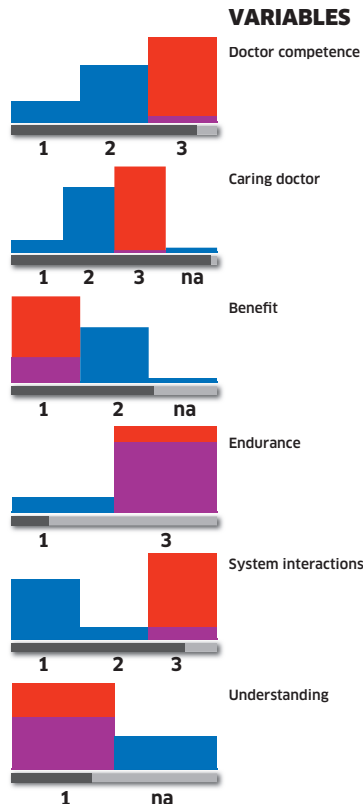


Figure 4. Results from the Bayesian modeling of the data.

their opinions about a specific topic. In the analysis three persons, two men and one woman, emerge as the outliers in the cloud when compared against all the variables included in the data. I have told their stories under the subtitle bitter life stories. They are Mr A (patient number 15), Mrs B (patient number 9) and Mr C (patient number 26).

Bitter life stories

Mr A

I have had problems with both of my knees for years. There have been some accidents where I have hurt one of my knees in the woods. The very unfortunate situation where my future pension was depending on how much I was earning during the last few years made me ignore the severe pain and other symptoms in my knees and neglect the treatment opportunities since I was unable to take any sick leave. My illness history is very long and it includes lots of pain and suffering. There is no way of hiding my frustration and disappointment towards the health care system, particularly the occupational health care doctor.

During my working days I was able to witness how easy it sometimes seemed to get to the university hospital radiology department for MRI. I myself had to go to the GP who only gave me painkillers and sometimes took the fluid out of the knee joint when it was badly swollen. I know I would have needed the MRI for my knee problem but to get the investigation I should have needed to go privately and pay for it myself. All this turned out to be an enormous disappointment towards the public health care system, which I feel has totally betrayed me. I used to talk about the health centre as a guessing centre since when I made an appointment I was only asked how many days I want sick leave.

I suspect that the GPs don't take the patient seriously during the first visit and they will just give some symptomatic relief to get rid of him. Only if the patient is persistent enough to revisit because of the same problem, they may start to consider the situation in more detail and that it is worth some proper investigations. I believe there can be patients who just pretend to be sick and that has made doctors suspect everybody faking the severity of their symptoms. I think it is so frustrating to be given some medication and not knowing the real cause of the pain. I would appreciate if the doctors would say I will try to ease your pain but at the same time let's find out what is causing all this trouble.

At the moment I am extremely worried that the situation with both of my knees is deteriorating very rapidly. This makes it hard to cope with the waiting period for the potential operation. I am afraid that the better knee will suffer too much and get worse when I cannot use the other knee normally and soon I will need artificial joints for both my knees.

My business is suffering since I have been forced to cancel many booked tours because my knees are just too painful for hiking long distances in the wilderness. The knee joints are swollen from time to time and they take the fluid out. I also need pain killers all the time even if I think it cannot be good to use them. I am very grateful to my partner who has been active in arranging the consultations with the private doctors to get investigations and find out about the real reason behind the symptoms and treatment choices. She is constantly looking after my health and wellbeing. I have lost weight after my working days since she cooks me healthy food to keep me going. I just feel the time is running out and I should be having the knee joint operation as soon as possible.

Mrs B

I am 63 years old and I retired almost three years ago. I haven't been happy with my life recently since my knee has caused so much pain and discomfort. It started quite suddenly about three years ago, no trouble before that. The knee just became very painful after I had been standing a longer time and then it was swollen. For some days I could not walk at all. I decided to make the appointment to the health centre and I was given some medication. The next time I visited they took the x-ray and said there is osteoarthritis in my knee.

I am extremely dissatisfied with the public health care system. After the retirement I had to give up a privately run occupational health care system and start using the local health centre for economic

reasons. The most annoying thing to me is the attitude of my GP. It feels like all the negative issues that have taken place in my treatment are connected to this particular doctor. I don't have any appreciation of her and also I know other people have complained about her. She once said to me I don't know at all what is wrong with you. So I just had to accept I had consulted a doctor who doesn't know anything. It took a long time to get a referral to an orthopaedic surgeon because of my joint problem. The GP seemed to be very reluctant to write it. I had to ask about it many times and make her believe I have severe pain in my knee. Not everybody has the problem between their ears.

My experiences in general connected to the public sector doctors have been quite negative. I have had many mistakes and failures that the GPs have been responsible for when they have tried to treat me. I can tell you how I went to see the GP when I was feeling very tired and had constant pain in my throat for a long time. I was diagnosed having tonsillitis and given an antibiotic. But my condition did not improve, and I was lying in bed all my summer holiday. Then I decided to visit my occupational health care doctor at a private medical clinic since I was not able to go back to work. That doctor understood what it was all about and I finally started getting the right investigations and the correct medication for my problem. I am very grateful to her, I felt they really took me seriously and wanted to find out what was wrong with me. I am feeling negative and sad because I had waited for a long time to be able to retire and do all the things I would have wanted to when I am not working anymore, but then my knee started to hurt and give severe symptoms which have prevented me totally from travelling and even make my daily living very difficult and also extremely painful. It also feels humiliating that as a woman I cannot bend on my knees in my own kitchen to take items from the lowest drawers and I am not able to do the hoovering under the bed.

I spend my days sitting at home, watching tv and reading. Also I have to take the painkillers regularly. My husband has been ill too, but he has now made some recovery. It affects the relationship because we are both disabled to look after the home and manage the domestic duties and also since we feel somehow betrayed by life when we cannot enjoy the retirement time together the way we had planned. It is not easy to talk about these things since there is such deep disappointment inside me that I find it difficult to talk more about this situation at the moment.

Mr C

I am a 69 year old entrepreneur. My doctor is a private GP whom I find very humane and easy to communicate with. This doctor treats all people as equals and he is always friendly towards me. My joint problems started about two years ago. First the knee was very painful and it became difficult to walk with. Then the pain moved to the hip joint. Even the slightest wrong movement gives a very sharp pain at the moment. At the local health centre they took the x-rays from my hip and the knee. I remember it was in the autumn during the elk-hunting season since I was not able to go with my mates, the leg was so painful. I was told there is osteoarthritis and I was surprised how the joint can be broken since there has not been any accident. (The word osteoarthritis in Finnish implies that the joint is broken).

But I want to tell about an incident many years ago when I was experiencing throat symptoms and some sort of shortness of breath, which had already lasted for some time before I decided to visit the local health centre. The symptoms mainly bothered me during the nights when I was at work driving the lorry. I myself was worried that an old abscess in my throat had somehow been reactivated. My mother had told me there had been some serious trouble with an abscess in my throat when I was a very young child. When I first visited the GP and told about my symptoms I was given some cough medicine and no investigations were made. I tried to cope with my symptoms which persisted and I always had some hot tea and aspirin with me in my lorry. They seemed to help a little bit even if I felt guilty for taking the aspirin regularly since it was not prescribed for me by the doctor.

One night I suddenly had a more serious pain in my throat and chest while driving and I had to get into the hospital immediately which I luckily managed to do. There I was diagnosed as having a heart attack and it also turned out that I had some older changes on my heart film, which confirmed that there had been a myocardial infarction sometime in the past. During the recovery period there

was an unpleasant event which I remember very clearly. I had some problems after the by-pass surgery with the wound not healing as it should have and I was having a long sick leave, which was planned to lead to the retirement. The sick leave was supposed to be continued at the health centre before the hospital out patient appointment but somehow the GP decided not to continue the sick leave.

This procedure was very humiliating and disappointing to me and also cost me some money since the retirement process was interrupted. I believe that the doctor at the health centre made a mistake by not writing the sick leave and he was not working for my best interest. I can also remember how in the old days the company occupational doctor always used to make jokes about how my lungs seemed to demand cigarettes. I really did not like the doctor's attitude when he tried to be humorous about my smoking. I found the doctor's behaviour very upsetting and even now after many years it is difficult to talk about this and it makes me feel bitter.

B-course dependence modeling

In the Bayesian network modeling using B-course tool the model can predict the values of the end variable related to an individual. Dependence models can be used to infer probabilities of any set of variables given any other set of variables. This will lead to "a game" where the model can be examined interactively by probing it (Figure 5). An open node shows all its possible values and their probability distributions as predicted by the browser. By clicking and choosing a new value, the probability distribution of the open node changes, reflecting the observations that were specified by fixing the values. It will be possible to see how the dependencies cause the knowledge on some things affect the probability of other things. This way we can also observe the strengths of the dependencies.

If we fix Doctor competence with the alternative b, meaning that competence was mentioned in a positive way by all the informants, it affects the concept System interactions so that only 14% of the informants speak negatively about the health care system. This is very different from the results when we fix Doctor competence with c, meaning that competence was mentioned in a negative way by every informant. This causes 62% of informants talk about the health care system interactions in a negative way.

Benefit is also affected when different values are given to Doctor competence. When Doctor competence is fixed to b, Benefit is mentioned in a neutral way by 28% of respondents and in a positive way by 65%. If Doctor competence is fixed to c, Benefit is mentioned in a neutral way by 56% and positively only by 39%.

The patient experience of the doctor competence can be separated from his or her interpretation of the interactions with the health care system as a whole. But the impact of the perceived competence of the doctor is so strong that it colours the perceptions of the system interactions. This is demonstrated in the alternative where the option b (positive perception) of doctor competence predicts the probability for the option c (negative perception) of system interactions in 14%, compared to the alternative where option c in doctor competence predicts an increase in the probability of negative perception in system interactions up to 62%.

These alternative predictions and the direction of the changes can be seen as a trend. The successful doctor experience affects the patient perception of the whole health care system and also has influence on the experience of gaining benefit. The data were also entered in the classification model of B-course. The method that has been used in this analysis for the predictive accuracy of the classification model is called "Leave-one-out cross-validation. It predicts the accuracy of the classification model by removing the data vectors one in a time from the data matrix containing N vectors and feeds the classification model with N-1 vectors. This process is called training and it is repeated N times. The end result will give the estimate of the classification accuracy of the model. In the case of these data the model predicts the result with a 72% probability.

The themes that were left outside are Endurance, Caring doctor and Understanding the doctor.

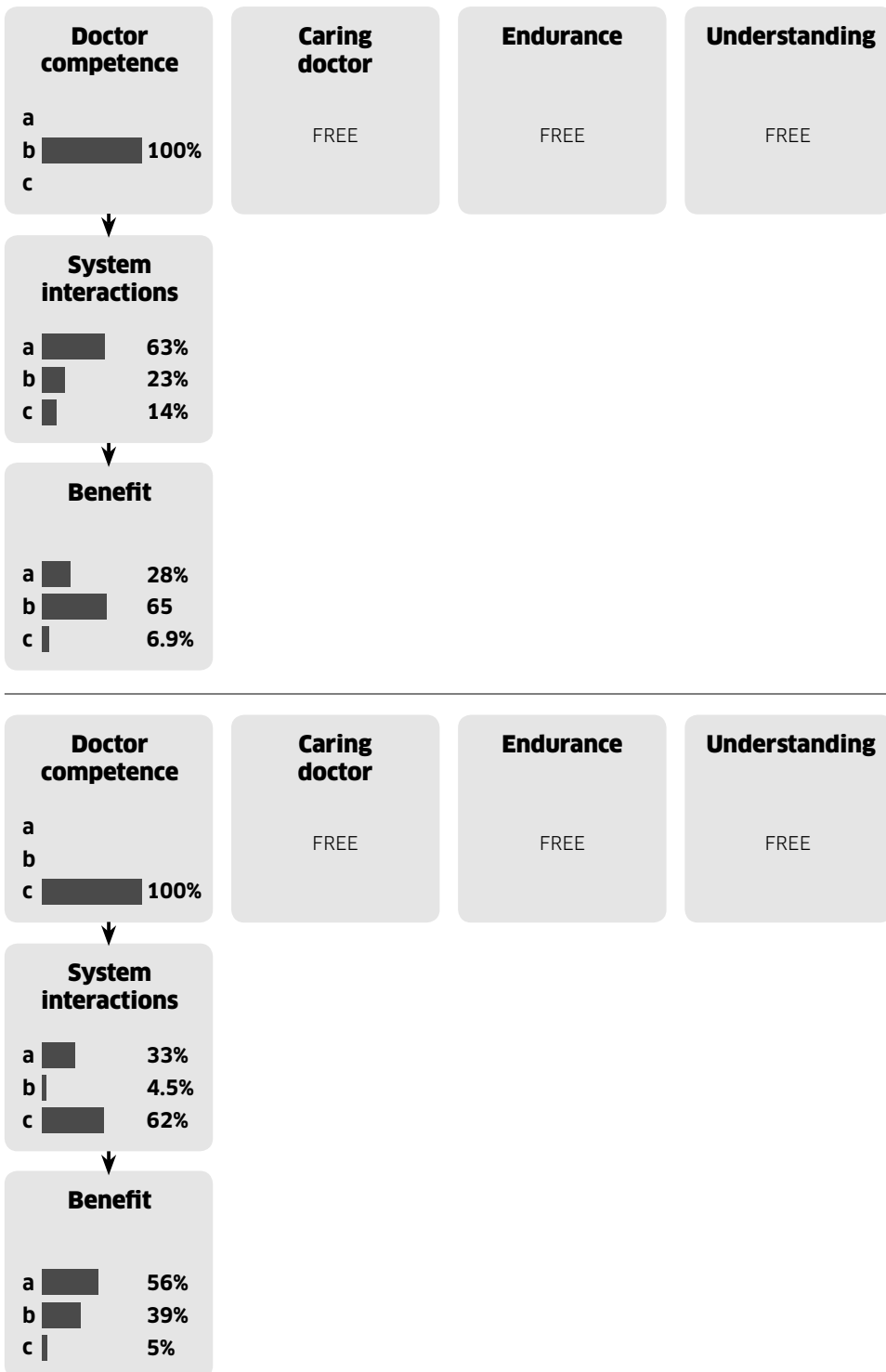


Figure 5. B-course fixation tables. In these two pictures we can see the three concepts that were left in the final model, Doctor competence, System interactions and Benefit and there is dependency between competence, benefit and system interactions.

Among the concepts which belong to these three themes are the experience of chronic pain and suffering, coping, disappointments in the treatment process and also empathy and caring shown by the doctor as well as attentive listening and patient need to be taken seriously. The data are not big enough to bring out the very small bias in the opinions. The lack of contrast in the results is the explanation why Endurance, Caring doctor and Understanding the doctor are left outside the model in B-course. Every informant has too similar experiences for the subtle differences to become visible.

Comparison of the results of the content analysis and the Bayesian network modeling

It is interesting to compare the results of the content analyses with the results of using the Bayesian method in B-course to find out the dependencies in the data. The interpretation of the probabilistic networks is that doctor competence, benefit gained and interactions with the health care system are interrelated.

The Bayesian analysis makes it possible to observe some trends and gives new perspectives to this complex entity of the narratives constructed through the interviews. Based on my thorough knowledge of the data I can agree with the statements about the dependencies visible in B-course. The interviewees emphasized in their stories the importance of the competent doctor who knew immediately what the problem was and what needed to be done. They trusted in expert doctors who were able to provide them with the state-of-the-art treatment. All these positive experiences influenced the patient perception of the whole health care system and the ones with good doctor-patient relationships felt they always received good quality services when they were needed.

In the content analyses the informants unanimously wanted to be taken seriously by their doctors, they wanted to be heard and listened to attentively. In the same way all the respondents had experiences of chronic pain and difficulties in everyday living circumstances; they did not differ in these aspects. Since these things were important to everybody, in the Bayesian analyses these topics did not cause differences between the participants. All the interviewees had experienced severe chronic pain, disappointments, showed endurance along the patient's path, and on the other hand they all had encountered caring doctors so these issues did not separate the participants in the model enough.

In the analyses of these data, the Bayesian method has been used to reveal the varied dimensions of the phenomenon under study, the patient perception of encounters with their doctors, and to build up new information to provide as rich a description of the relevant topics as possible.

The dependencies shown by the Bayesian B-course analysis are compatible with the interpretation based on the content analyses of the data. In the final stage the concepts that were left in the model in B-course were Competence, Benefit and System Interactions. This means that there is a dependence between these concepts connected to the patient's perception of doctor competence, the benefit s/he has gained during the consultation and the patient experiences of the health care system encounters.

My interpretation based on the analyses of my study is that individuals as patients are fundamentally very outcome oriented. They want results when they finally make the decision to consult the doctor.

As one of the interviewees expressed this: *"If the doctor's services are used for giving support and just listening to the people's worries, it is too expensive care for society."*

Getting benefit out of the consultation and reaching a positive outcome lies in the heart of the whole encounter from the patient's point of view.

6 The reliability and the validity of the study

6.1 THE RELIABILITY OF THE STUDY

In the context of the quantitative data validity and reliability are the concepts to be dealt with when discussing the dependability of the study. Reliability refers to the degree of consistency with which instances are assigned to the same category by different observers or by the same observer on different occasions. In qualitative research the main problem in this respect lies in the reliability.

The same weakness is also true in connection to my dissertation which needs to be openly admitted. My aim has been to understand and interpret the phenomenon under study, the informants' subjective experience of the encounters with their physicians through their narratives as thoroughly and authentically as possible. During the study process I did frequently go back to my previous coding and category building to double check the results. The outcome was very satisfactory and I was able to confirm consistency in my coding.

The generating of the data in a qualitative study needs to be explained in a way that makes it possible to check what is a statement of the informant and where the researcher's interpretation begins. The research process needs to be documented in detail to increase the reliability of the whole process (Flick 2006). I have aimed at transparency in this study by saving all the documents and notes from my interviews, my reflections on them and the various stages in the development of the coding process.

According to Silverman interviews do not give direct access to "facts" or tell about people's experiences but instead they offer indirect "representations" of those experiences. An interview produces a particular account of an individual's views or opinions. When people talk about the world they live in to somebody, they take into account who the other is and where this other is in relation to him or herself. Together the interviewee and the interviewer construct some version of the world appropriate to the context of the situation. Interviews are interactions in which both speakers are engaged and collaborating in making meaning and producing knowledge. People are active narrators who create appropriately located stories. Interview responses need not to be heard simply as true or false reports on reality. Instead, they can be treated as displays of perspectives and moral forms which draw upon available cultural resources (Silverman 2006).

6.2 CONCEPTS USED TO DEFINE THE VALIDITY OF THE STUDY

In the context of qualitative research, validity receives more attention than reliability (Flick 2006). The concept of validity is described by a wide variety of terms in qualitative studies. The terms adopted by many researchers, include rigour and trustworthiness. Rigour in the meaning of exact and precise often appears in reference to the discussion about reliability and validity. In the qualitative paradigm there has to be developed a re-conception of rigour by exploring subjectivity, reflexivity and the social interaction of interviewing (Golafshani 2003).

The concept of trustworthiness or dependability can be used when discussing the validity of qualitative research. Dependability can be increased by a very detailed and thorough description of the methods used and how the analyses were performed and the participation of more than one researcher in the analyses. In my dissertation study the other supervisor, Professor Anja Taanila, has participated in the analyses and there has been a mutual agreement over the concepts and categories used.

In the qualitative research tradition trustworthiness is an essentially relevant property (Guba, Lincoln & Cuba 1989). The starting point is openly to admit the subjectivity of the researcher. Because of this the researcher him or herself forms the central criterion for the trustworthiness of the research and the assessment of trustworthiness includes the whole research process and how it is described. It is also important to pay attention to the significance, adequacy and exhaustiveness of the data.

When assessing the trustworthiness of qualitative research it is essential to emphasize the correspondence between the data and the reality that has been investigated (Guba, Lincoln & Cuba 1989). The issue here is the compatibility between the reality observed and the concepts and categories in the analyses of the data and the interpretation of the findings.

Trustworthiness may be examined through triangulation. The main theoretical perspective, social constructionism makes it feasible to use both qualitative and quantitative approaches, as constructionism values the multiple realities that people have in their minds. Triangulation is a strategy for improving trustworthiness of research as it strengthens the study by combining methods (Barbour 2001).

This mixed methods study involves both qualitative and quantitative research approaches. The Bayesian method was chosen to be used together with the content analysis to reveal elements in the data which otherwise might have remained undetected. As opposed to many classical estimation procedures, no Bayesian analysis is ever non-viable due to "too little data". The Bayesian analysis takes into account all the data available and there are no preset sample sizes that have to be satisfied to be able to perform the dependence analysis. If the database is small, the dependencies are weaker and the best model found may not be very much better than the second best (Myllymäki et al. 2002).

Using the Bayesian method, inferences about the effects of the variables on the occurrence of an event of interest are based on a mean of the posterior distributions of the set of identified models, weighted by their posterior model probabilities. On the contrary, in logistic regression analyses, a stepwise strategy is often adopted to choose a subset of variables and inferences about the predictors are made based on the chosen model constructed of only those variables retained in the single model. In a particular case when the sample size is small or the event rate is low, there can emerge a problem of choosing the most relevant subset of variables for the analysis that will predict which individuals are at the highest risk of an outcome.

In a comparison study by Wang and co-authors, the aim was to compare the Bayesian methods approach with the stepwise procedures for selection of predictors and predictive performance in logistic regression using original data from the Framingham Heart Study. The results from these studies have shown that using Bayesian methods improves predictive performance, by factors ranging from modest to substantial and the predictors of the coronary heart disease provide further evidence that Bayesian model averaging predictively outperforms the stepwise method (Wang, Zhang & Bakhai 2004).

Sakai et al. used Bayesian network modeling in predicting the diagnostic accuracy of appendicitis diagnosis with a data of 169 patients. They compared the diagnostic accuracy with other diagnostic models, such as an artificial neural network model and a logistic regression model. The authors conclude that the error rate was the lowest in the Bayesian network model. The area under the receiver operating characteristic curve analysis also showed that the Bayesian method provided the most reliable results (Sakai et al. 2007).

To evaluate the performances of popular predictive models for estimating morbidity probability after heart surgery a study was conducted by Cevenini et al. According to the authors the experimental results indicated that all models provided acceptable discrimination in test data and satisfactory generalization in the illustrative example of the study. The Bayesian model required the smallest set of predictor variables, only three and provided results, which were similar or better than those obtained with logistic regression models.

Because of the small number of predictors needed, the Bayesian model enabled an explanatory interpretation of the results obtained in the example. The Bayesian modeling offers a good compromise between complexity and predictive performances and can therefore be a convincing alternative to other much more extensively used predictive models such as e.g. logistic regression models (Cevenini et al. 2007).

According to Myllymäki et al., the perceived problems with the Bayesian approach are mainly concerned with the source of the prior and there remains the question how to produce the priors. There is always some subjectivity involved and the critique has been that prejudices are given a mathematic form. The answer here is to develop means to transparently and openly present how the priors are being formed. The Bayesian network modeling uses variables that only have random dependence on the end variable. The transferability of the model is not good meaning the robustness and the priors try to prevent this. Since the data in my dissertation are selected to include informants with a chronic pain related to the osteoarthritis of the hip and the knee, the findings cannot predict the circumstances of other groups of people with chronic pain. The model can also be "over-fitted", which means that the model includes too many variables and having enough of them, all problems can be predicted but the robustness of the model equals to zero. This is likely to happen if the data are very small and none of the variables is able to predict the outcome very well. A good rule to remember is that the number of independent variables should not exceed 10% of the N of the data. The coding of the data is the fundamental and most important factor in the whole process. Coding is always subjective and includes an interpretative process in itself (Myllymäki 1998).

Credibility and authenticity

Lincoln and Guba identified credibility as an overriding goal of qualitative research, reflecting the relativistic nature of truth claims in the interpretive tradition. Assuring credibility refers to the conscious effort to establish confidence in an accurate interpretation of the meaning of the data (Guba, Lincoln & Cuba 1989).

In the qualitative research the question always remains if the results of the research reflect the experience of the participants or the context in a believable way. There is the need for assurance that interpretations are trustworthy and reveal some truth external to the investigators' experience.

Authenticity is closely linked to credibility in validity and involves the description of the research that reflects the meanings and experiences that are lived and perceived by the participants. Because of the multivocality of an interpretive perspective, authenticity of the person, phenomenon, or situation becomes an important criterion for validity. An attempt to remain true to the phenomenon under study is essential. It is very important that the inquirer exhibits a high awareness of subtle differences in the voices of others since the involvement of the inquirer in the research process can influence the ability to speak authentically for the experience of others, which requires conscious attention to the influence of the inquirer and the perspective of the investigator.

Overall attention to credibility and authenticity is referred to as descriptive and interpretive validity. The credibility of qualitative research is influenced by the extent to which the findings explain the phenomenon under scrutiny, whether alternative models of explanation have been sought after and to what extent the researchers agree about the findings and whether they are parallel to those of previous studies. When publishing the report of a qualitative study it is important to write everything down in such a detailed fashion as to make it possible for the reader to decide if the results are transferable to another context referring to the transferability of the study (Aira, Seppä 2010).

In my own analyses I have aimed at the authenticity of the narratives of my informants by including a large number of direct quotes from the interviews to the content analysis

table showing the subcategories and main categories of the content analysis. My sincere effort throughout the analysis process has been to openly describe and justify my interpretations of the data generated. I have kept logbooks based on every interview I conducted and written my reflections on these occasions. In qualitative research, the researcher is the instrument. The credibility of qualitative research depends on the ability and effort of the researcher (Finlay 1998, Koch 1996).

Criticality and integrity

The differing interpretations, assumptions, and knowledge background of investigators can potentially influence the research process and this requires a devout attention to integrity and criticality. Reflexivity, open inquiry, and critical analysis of all aspects of inquiry contribute to validity in qualitative research. A systematic research design needs to be portrayed that demonstrates evidence of critical appraisal. Ambiguities should be explored and recognized.

Integrity becomes important in the critical reflection and analysis of qualitative research. The subjectivity of the interpretive research values the investigator as a person who may interpret data uniquely yet integrity must be evidenced in the process to assure that the interpretation is valid and grounded within the data. Integrity and criticality are represented through recursive and repetitive checks of interpretations as well as honest presentation of findings. Validity threats of investigator bias, not paying attention to discrepant data, or not considering alternative understandings should be addressed during the research process.

I have written about the need of critical reflexivity at the end of this chapter. Also I have referred to my own role in generating the data at various points of the dissertation. The awareness of my role and influence in the research process has not left me for one moment and I can honestly state that reflexivity has been the guiding light in all my activities connected to this study.

Thoroughness

Thoroughness in qualitative research refers to sampling and data adequacy as well as comprehensiveness of approach and analysis (Popay, Williams & Carol 1998). This does not mean that findings are merely an exhaustive list of themes. Thoroughness implies attention to connection between themes and full development of ideas. The research questions that are posed should be convincingly answered.

Congruence

Congruence should be evident between the research question, the method, and the findings, between data collection and analysis, between the current study and previous studies and between the findings and practice. Study findings should also demonstrate logical congruence as well as congruence with the philosophical or methodological perspective articulated by the investigator. Despite the elusiveness of generalizability in qualitative research, study findings should fit into contexts outside the study situation.

As described in the results chapter of this dissertation I was able to find out and develop understanding about the informants' perceptions of the factors that predict the success or the failure of the clinical encounters. (Figure 2). The participants of the study expressed clearly when they considered the consultation with their doctors beneficial and also the occasions when the visit had not been useful to them. The unnecessary visit was defined as one when the patient did not get any help. According to my interpretation of the findings the competent doctor can "give face" to the whole health care system and influence in a positive way to the perceptions of the users of the health care services.

Based on the opinions and experiences of the participants about how they would have hoped the health care system to be organized to respond to their needs, I may be able to con-

tribute to the discussion of developing a more patient-friendly interface between the users and the world of medicine and the developers of the health policies.

Transferability

Transferability refers to the ability to carry out the research in a different context. It entails the accurate description of the research context so that a judgement of transferability can be made by the readers of the dissertation. I have provided a detailed description of the study context and the participants as well as the research methods in chapter 4.

The bases for data gathering was essentially purposive. The size of the data is small and the extent was defined during the study. Knowledge is context specific, but a theory created as a result of a qualitative study may be generalized. The impact of the researcher on the construction of the results needs to be recognized.

Generalizability

Generalizability refers to the extent to which the account of a particular population or situation can be extended to other persons, times or settings than those, which were directly studied.

Despite the elusiveness of generalizability in qualitative research, study findings should fit into contexts outside the study situation and a theory created as a result of a qualitative study may be generalized. Claims about attempts to generalize the qualitative research findings to other communities or groups of population are rarely made according to my knowledge. Interviews need to be seen as a social situation, which involve a relationship between the interviewer and the informant. It is important to understand the nature of this relationship and how it affects what goes on in the interview and how the informant's actions and narratives could differ in other situations and circumstances.

In my dissertation the phenomenon under study the patient experience of the consultation with the doctor is certainly universal. As human beings we have a lot in common when it comes to emotions, feelings of disappointment or perceptions of respect and caring in the context of clinical encounters. Based on my own experience as a clinician I find it plausible that findings compatible to mine would be obtainable at a different setting with another group of informants.

Sensitivity

Sensitivity as a validity criterion of qualitative research refers to research that is implemented in ways that are sensitive to the characteristics of human, cultural, and social contexts. Ethical consideration in design and conduct of the research should be explicit. Also the participants of the research should benefit in some way. Concern for human dignity and respect of participants should ideally be demonstrated.

My research plan has been officially accepted by the Ethics committee at Kuopio University Hospital. The process was prolonged, since in the beginning there was concern over the idea that patients will be asked to assess the quality of the health care they have received based on their subjective experiences.

Quality in research is dependent on honest and frank investigation processes. Searching for alternative explanations and a self-critical attitude is imperative. Every study has biases and particular threats to validity, all methods have limitations, and research involves multiple interpretations as well as a moral and ethical component inherent in judgments. Validity cannot be assumed, and presentation of research findings must invite the opportunity for critical reflection by consumers. The importance of explicating how we claim to know what we know is as essential as the claim to what we know. (Whittemore, Chase & Mandle 2001)

According to Barbour et al., the researcher is required to interpret data, building up an argument, considering alternatives and exceptions, and to provide a description of how find-

ings were reached. Outcomes cannot be detached from the process of data analysis and the reasoning engaged in by the researcher. The need to present this process transparent creates one of the most important challenges for the qualitative researcher. As long as the researcher provides a description of the process of analysis and developing of analytical categories, it is possible to determine how rigorous or systematic the work has been (Barbour, 2003).

It can be argued that in my dissertation one of the weaknesses may have been my background as a physician and at the same time the only interviewer. It was my decision to honestly explain to my informants my professional training. The main reason for this decision was the focus of my interest, the experiences of the informants as users of the health care services. I felt the respondents needed to know they were talking to a medical professional during the interviews.

Reflexivity in the context of the qualitative research

According to Finlay narrative research approach demands high levels of ethical and critical engagement and the cultivation of a narrative sensibility, in which people are witnessed and read closely as text. Reflexivity and tolerance of ambiguity are critical to such intensive reading. Being reflexive involves disciplined self-reflection. It encompasses continual evaluation of both our subjective responses and our method of research. Through constantly reflecting on, questioning and evaluating the research process, the researcher attempts to distinguish how subjective and inter-subjective elements have influenced on and possibly transformed both the data generating process and the analysis (Finlay 1998).

This I have tried to pursue through the whole study process very carefully. I have kept my logbooks and reflected on everything I have encountered during these six years of being involved in this dissertation project. Also important in this respect have been my contacts, both discussions and e-mails, with the supervisors and other professional friends who have intellectually contributed, guided and participated in the study process.

Reflexivity, which should be an essential component for all research, offers a way to turn the problem of subjectivity in research into an opportunity and it should be exploited as a research tool. According to Blumer, postmodern researchers, who are inclined towards constructivist, interpretive and poststructuralist persuasions want to question the concepts of universal, causal laws. The argument is that reality is socially constructed and that meanings are historically and culturally situated. Qualitative researchers' objective is to understand the complexity and versatility of people's experience. The subjective interpretations are valued and there is emphasis on meanings being negotiated within a social context and also the same event being interpreted in multiple ways since people act towards things based on the meanings the things have for them (Blumer 1986).

In her study Finlay asks, if it is possible to challenge the idea that subjectivity means "bias". The alternative view, adopted by phenomenologists and social constructivists among others, is to recognize the relative, multiple and socially constructed nature of reality and how meanings are negotiated in particular contexts. If multiple interpretations of the same event are possible, from this follows that subjectivity can be positively embraced rather than habitually dismissing it as "bias". The denial of subjectivity undermines the validity of the research. In other words explicit reflexive analysis, which is open to public scrutiny, can increase the trustworthiness of the research.

The limitations of reflexivity are also recognized. Much care, skill and time needs to go into any reflexive analysis. Even when it is performed well, can one be assured that a personal experience is captured adequately? There remain challenging questions about the validity of subjective interpretations and explanations. The researcher's position can become unduly privileged, at the expense of hearing the participants' voices. Within every scientific investigation, the researcher's own thinking, feelings and interpretations should be valued as primary evidence (Finlay 1998).

In the following chapters I have taken the topics Finlay talks about in her study and reflected on them in my own research context.

The influence of the researcher's assumptions

As a medical professional I most certainly have created some assumptions about patients whom I have been meeting during three decades at various health care contexts. I was assuming the informants to be reasonably critical towards the health care system based on my own interaction with patients and stories in media about the occasional treatment failures. So I was prepared to hear strong critique about the health care system. I was hoping I would be able to face it calmly and remain neutral, not starting to defend the system at any case.

The impact of the researcher's expectations

Before the study even starts there are all kinds of expectations being constructed in the mind of the researcher. There was some uneasiness when I contemplated, prior to my visits, the situation at the home of my interviewees. I was worried the people might find the topics I wanted to discuss with them too sensitive and personal. I was also thinking how I would be able to respond if they were very dissatisfied with their care and started making complaints to me. So it must have been that I felt nervous especially during the first two or three interviews.

The researcher's unconscious responses

I have also thought about my own professional background in the context of my interviews. There were discussions before I started conducting them whether I should introduce myself as a researcher from the University or reveal that I am also a physician. I decided to tell my interviewees honestly that I have worked as a general practitioner for decades in Southern Finland. Obviously this has had influence on my informants since physicians have a specific status in the minds of lay people. I can think of two opposing aspects that could result from this knowledge.

First, the respondents may be reluctant to criticize the health care providers they have encountered since they could fear this might have some negative influence on their future care because the interviewer belongs to "them". Secondly, the fact that the interviewer is a physician can have a positive and relaxing influence on the willingness of the informants to tell about their very personal experiences in the health care context since they know they are talking to a "doctor" whom people in general still seem to trust in this society. Sometimes during the interviews I caught myself behaving the way I would do at the consultation room with my patients. I became very much aware of this role adaptation and tried to act very cautiously especially in formulating questions to probe some topics more deeply to avoid history taking-mood of the practitioner. Quite often the interviewees told me "well, you know, being a doctor yourself..." In these occasions I always asked them to explain to me in their own words what they were referring to and not make the assumption that I know it anyway.

I was very conscious of my medical background and took as much trouble as possible to avoid behaving like a general practitioner when I was sitting at the kitchen table or in the living rooms of my informants at their homes. But it cannot be denied that my own background as a practicing clinician is a major part of my identity and unavoidably affects the way I approach the narratives people tell me. Throughout the research process this fact has been very clearly and honestly on my mind and I have tried to be very transparent in my proceedings and reflect on this constantly.

The researcher's behaviour and emotions

The researcher's emotions, attitudes and values are always engaged in the process and it is

impossible to distance oneself to a stereotype of being an objective, rational researcher. My own behaviour has also affected the responses of my informants and thus influenced the construction of the narratives during these interviews. Another researcher in a different context would have undoubtedly unfolded a different story. The research interviews directly affect the interviewer and the informant: interviews augment, make the experience stronger rather than simply reflect it. According to Ruusuvuori et al. they alter meanings instead of just portraying them. Ultimately, any research is a joint product of the researcher, the participant and their relationship, which means that the research is co-constructed (Ruusuvuori, Tiittula & Aaltonen 2005).

7 Discussion

The focus of my research is the quality of the health care encounters as perceived by the informants of my study as patients. The whole study is a tribute to the voice of “the patient” in defining the quality of the consultation with the health care providers.

The theoretical framework that was chosen for the dissertation encompasses the social constructionism and symbolic interactionism. The philosophical hermeneutics approach is referred to especially in defining the role of the researcher in the research process. My original goal has been to find out and listen to people’s narratives about their experiences with their doctors. It was my choice to apply the episodic interview and not to use any questionnaires in generating the data in the interviews. (Ruusuvaori, Tiittula & Aaltonen 2005).

My dissertation is a study about people’s experiences during the clinical encounters with their doctors, which in this case are the experiences of people suffering from a chronic pain caused by the severe osteoarthritis of the hip or knee. The consultation is the core event in general practice. A comprehensive understanding of the scientific approaches including hermeneutics is also needed in defining general practice as an academic discipline (Kumpusalo, Ellonen 1991). The doctor and the patient are constructing a social reality together in the interaction that takes place at the consultation. They come to the encounter with their own histories, prejudices and pre-understandings. They make interpretations from their discussion and they try to reach a mutual, new understanding of the situation. All this is compatible with the ideas of hermeneutics (Gadamer, Nikander 2004) and this is why hermeneutics is in the heart of general practice. As Heidegger put it, “understanding is being in the world”. People can never escape their own historicity and that is why into every encounter, we bring with us our own background, attitudes, experiences and prejudices.

My aim was to find out factors that predict the successful and failed encounters at the consultations. More precisely I wanted to find out and understand the patient experience of the treatment and management of his or her illness at the consultation, the behavior of the physician and the patient perception of benefit gained as well as the experience of an unnecessary visit from the patient’s point of view. By listening to the voice of the informants in the role of the patient the aim was to try to contribute to the process of constructing a more customer-oriented service design in the health care context in the future and be able to give recommendations to a patient-centred development of the treatment process of the osteoarthritis patients in the ambulatory care. Also by using the evidence about patient experiences of the consultation gained through this study, my goal is to contribute to the further development of a patient-centred approach in the medical undergraduate curriculum.

The findings of the content analysis showed that the predictors of a successful encounter were a caring doctor who took the patient seriously, showed competence in finding out the right reason and treatment for the problem and was able to give information to the patient in an understandable way. This led to the perception of gaining benefit and satisfaction with the care process. Also continuity of care and the opportunity to choose the expert doctor in the private health care enhanced the experience of a positive encounter. One of my main findings was that a competent doctor gives face to the health care system meaning that successful experiences with health care professionals can influence the attitudes towards the interactions with the whole health care service system.

In the similar way predictors of a failed encounter were connected to the perceived negative behaviour of the doctor during the consultation. Feelings of disappointment, bitterness and anger were mentioned together with the experience of neglect and indifference. Treatment failures had impact on the negative perception of the encounter. Too long waiting lists

and the feeling of not gaining any benefit contributed to the perception of a failed consultation experience. Unnecessary visits were defined in this context as consultations when no help was received. The economic issues were suspected having influence on not getting a referral to a specialist.

Based on the evidence and new knowledge about the subjective experience of my informants as patients about the quality of the health care encounters, I will pursue to contribute to the discussion of constructing a more customer-oriented service design in the future primary health care context. Hopefully I can give my contribution and recommendations emerging from the findings of my research to the development of a patient-centred treatment process for the osteoarthritis patients in the ambulatory care. In my present work as the coordinator for the training of the undergraduate medical students in the primary health care context and participating in the planning and development of vocational training for young doctors I will be able to share the experiences and ideas of my informants with the medical students and trainee doctors.

Endurance is the concept that I have introduced in the context of the long struggle with chronic pain, the fatigue caused by the constant agony and the burden of disability among the interviewees in my dissertation study. They had developed endurance to be able to cope while waiting for the health care procedures to take place and they certainly were experienced as patients. Based on my results, endurance means persistence, not-giving-up mentality, courage and a realistic but basically optimistic attitude in the middle of the dire circumstances. The idea expressed in this comment describes the common attitude among my informants *“One should not get too worked up, this is merely life.”*

Do the health care system and its rules meet the needs of the suffering patients? The carefully written criteria for various treatments and guidelines to good clinical care may serve the purpose from the system viewpoint but do they work for the patient or against his or her best interest?

The treatment of knee and hip osteoarthritis (OA) according to the Finnish Current care summary is defined as follows. The primary health care system and the occupational health services share the main responsibility for the diagnostics and treatment of OA. The goal of OA treatment is the management and alleviation of pain as well as the maintenance and improvement of functional capacity. With respect to conservative non-drug treatments, appropriate physical exercise represents the basis of OA care. Guided physical exercise as a treatment for OA of the hip may reduce pain and improve functional capacity the evidence is in category C according to the current care guideline. There is no research evidence available on the relative superiority of various forms of exercise. A total knee or hip arthroplasty should be performed if OA pain is not otherwise manageable, the patient's ability to manage everyday tasks is essentially compromised due to OA or there is a significant restriction of motion or a joint malposition. In the guideline text it is mentioned though that every patient's individual needs and expectations should be carefully considered (www.kaypahoito.fi).

The question of timing of the joint operation was essential and extremely important to my informants. *“It would be so much better with these osteoarthritis cases to get the right treatment in time.”* Especially the younger participants argued they would need the total joint arthroplasty as soon as possible to prevent further damage to other joints and related disorders, e.g. diabetes getting worse because of the lack of exercise. They wanted to avoid long waiting times and they demanded action taken as soon as possible at the stage when they had finally made the decision to consult the doctor. This was only taking place after a long period of time during which the individual had tried to deal with and cope with the painful joint independently. The informants in my study wanted to emphasize the active role of the general practitioner to consult the orthopaedic surgeons without any delay.

There seemed to be a contradiction in the views about the timing among the participants

of my study and their doctors although people did understand that there needed to be some prioritization to whom the procedures are performed first. Particularly the younger informants did not want to spend months or even years in the waiting lists. This was shown very clearly also in the opinions of the respondents in one of the earlier studies (Sjoling et al. 2005).

Do the health care professionals take the osteoarthritic pain seriously or do they perceive the pain and disability as something one has to learn to live with when getting older? This is a valid question based on the experiences of some of my informants about the behavior of their doctors during the consultations. The symptoms of osteoarthritis and the findings can remain stable and rather non-dramatic for quite a while and the doctor may find the joint problem almost trivial, not requiring much attention. Despite the seemingly benign nature of the problem, constant pain and suffering were the core concepts that emerged from the narratives of my informants.

The informants went to the clinical encounter with an agenda and they had thought about the visit often a long time before actually making the decision to consult the doctor. They could be very worried and have fears, and the problems may have been invested with lots of meaning and emotions. If the doctor was not able show empathy, to “step into the patient’s shoes”, there remained a chance that the doctor might miss the point, the intense meaning embedded in the narrative his or her patient was trying to tell at the consultation.

My informants as patients needed the assurance that they had a legitimate cause to be at the consultation. It was very important that the doctor did not think they had booked the appointment unnecessarily. By starting to examine the patient the doctor justified the visit. This conclusion coincides with the results of the Finnish study that describes the conversation analyses of 100 video-recorded and transcribed GP consultations (Ruusuvaara, Raa-vaara & Peräkylä 2003). The doctor could easily hurt the patient’s feelings by not responding to his or her needs of assuring the legitimacy. The problem, which the patient was telling to the doctor, could be very mundane in medical respect, and the doctor may have express this not knowingly in his or her response, perhaps non-verbally even. If the doctor could not catch the same wavelength with the patient, the whole consultation might have gone wrong and both parties felt dissatisfied afterwards.

People with a chronic illness experience restricted life due to disability, social isolation and feelings of being a burden to others which is illustrated in this comment made by one of the informants in my dissertation *“Sometimes one gets a kind of feeling of hopelessness that once I said I am tempted to get the package of Tramal and take them all at one go so this would end.”*

I find the concept of dissatisfaction relevant in the context of my dissertation. I have dealt with this concept in more detail in the literature review. In her grounded theory study of dissatisfaction Coyle found that the respondents’ accounts of disappointment were underpinned by the three recurring themes. These are dehumanization, disempowerment and devaluation. She argues that “personal identity threat” is a key concept delineating the grounds for patients’ dissatisfaction with health care and is better able to capture the complexity of patients’ experiences, feelings and values than the less theorized concept of satisfaction (Coyle 1999).

This is a very similar view to my own interpretation of some of the narratives told by the informants. I will introduce the concept of “primal insult” to describe the same idea as Coyle in her personal identity threat approach. According to my interpretation of the data in my study, people can experience something similar to an insult during the consultation if they feel their problems are not taken seriously, and their worries are not listened to and they cannot interpret a justification, a kind of permission for their visit from the doctor’s behaviour. The end result will be that the patients are left in uncertainty about the legitimacy of their cause to be there. A sense of dehumanization, disempowerment and devaluation can be included in the concept of primal insult and it may affect seriously the future interac-

tion with the health care providers.

According to the study conducted by Delany et al., those individuals who seem to have a negative approach towards the public health care system may also be experiencing worse health care services in reality. They can be considered difficult, demanding, heart sink patients as the British GPs call them (Delany 2007). The question remains whether these individuals as patients actually get worse treatment as it is suggested in the study by Salisbury or is it their attitude only that makes them to interpret events during the care process and in the various encounters in a negative way (Salisbury, Wallace & Montgomery 2010). The health care providers are only humans and it is not easy to be empathetic to people who always seem to complain and show a negative, suspicious attitude towards the professionals.

In her writings about a theory of patient satisfaction Susan Linder-Pelz reported already 30 years ago that among the various probable determinants of a patient's satisfaction with health care are his or her attitudes and perceptions prior to experiencing the care (Linder-Pelz 1982).

The real challenge to the health care system is how to organize the services to the dissatisfied and distrusting people who have lost their faith in the system for some reason or another and provide them with an opportunity to constructive, meaningful encounters where they can gain benefit. It has been argued that persons who are in general rather dissatisfied, will also show greater dissatisfaction with the GP services (Sixma, Spreeuwenberg & van der Pasch 1998).

With the Bayminer cloud it was possible to visualize the bitter and dissatisfied individuals in these data. After rotating the cloud to various positions and comparing their values of different variables to the rest of the data, three informants always remained as outliers. I have told their stories in the Results chapter and my interpretation is that they all had experienced disappointments and indifferent attitude in the encounters with the health care providers. It is beyond this dissertation to contemplate the direction of causality between their health care related disappointments and the very obvious negative attitude towards the system and the general bitterness they expressed in their behaviour.

I have written in my logbook during the interviews as my interpretation that people seemed to have an almost fatalistic attitude towards the encounters with the doctors. Sometimes one was able to get a very good doctor and some other time one could meet an incompetent doctor. If this was the case, there was not much hope for any benefit, the whole visit could be useless and because of this also unnecessary. Very seldom though people made official complaints, at least those people I have interviewed. Their attitude seemed to be there is no use complaining, nothing would have happened and the system would have defended its own. With the system they referred most of the time to the public health care. The only opportunity for an individual to exercise some power was to turn to the private health care sector where it is possible to choose the health care provider independently. The participants in the dissertation study were very familiar with the option of using a private doctor in certain occasions. The general opinion among the informants seemed to be very positive mainly due to the easy access and the choice of real expert doctors. But there were also some critical views expressed about charging a big fee for a short visit.

My interpretation is that when the informants were complaining about failed communication skills of their physicians, they were also expressing their disappointment to the whole consultation process. They could perceive there was no benefit gained. My argument is that as patients people are able to assess the technical quality of the consultation from their own context and based on the outcomes they experience. They may feel inadequacy in assessing the medical issues and find it easier to express their disappointment in the failure of the communication skills. In the patient role people are outcome-oriented and want the most effective treatment as soon as possible. They respect a doctor who is a true professional and able to reach the correct diagnosis and provide the right treatment without delay.

This argument is supported by my finding that if the outcome of the consultation was satisfactory even if the interaction was suboptimal, the patient did not complain as explained in my Interaction and Outcome table (Figure 3). S/he respects a doctor who is a true professional and able to reach the correct diagnosis and provide the right treatment without delay. Also in alignment with this are the results from the dissertation of Vuokko Virtanen connected to the quality of the consultation. In her study almost half of the unsatisfied patients perceived the doctor incompetent as well (Virtanen 1991).

Some of my informants were telling me during the interviews that at the consultation it was hard for them to accept if the doctor was not able to find any real cause for the symptoms. They could easily start to worry that the doctor may have been thinking there was something wrong "between the ears", a psychological problem instead of a proper somatic cause.

Based on my results, I am arguing that there still seems to be a stigma attached to a symptom being labeled as psychological if the patient wants to present and describe it as purely somatic. The doctor should be able to communicate with the patient very effectively in a relatively short time and make the patient feel at ease. S/he should find out the real reason for the visit, examine, make plans for further treatment and preferably, cure the patient. Communication skills belong to good clinical practice and they can be learned (Aspegren 1999).

According to the results of the study by Cromarty about what patients think during the consultation they basically want to understand and make sense of their situation. Patients thought most about the problems that led them to the surgery, but they also considered their situation, particularly the available time and the behaviour of the doctor. To a much lesser extent, they considered matters that the doctor introduced. Underlying all these thoughts was a continuous reflection and interpretation of a search for meaning. All patients entered the consultation with problems that had been carefully considered in advance and with generally well-defined aims related to those problems. Patients typically wanted three things: understanding, information and a solution of their problems. Once patients' aims were satisfied, the consultation, for them, was at an end. Professional ability was never really doubted and patients assumed automatically that doctors, even trainees, were medically competent. The patients' search for meaning occurred in all areas of the consultation from the value of treatment to the doctor's motives. Although patients accepted doctors' expertise, they did not accept their advice without first evaluating it in the light of their own understanding. The main source of discontent was a failure of understanding. Much of the problem was patients' reluctance to ask, which most commonly stemmed from lack of time or a wish not to upset a valued relationship. They read the cues very carefully and interpreted the non-verbal communication of their doctor constantly and they were realistic in adjusting to the time constraint. The author states that patients consult widely among lay people before seeing the doctor, and interpret the opinions they receive in the light of their own experience (Cromarty 1996).

I find the conclusions of this study compatible with the results of my own research. The participants of my dissertation had evaluated their situation very carefully before consulting the doctor, they had formed their own interpretations of the problem and they had a specific agenda they wanted to be dealt with at the clinical encounter.

According to Stewart et al., the patient experience of the consultation very much depends on the level of success in finding a common ground, which includes the patient perception of the interest and respect shown by the doctor during the encounter and to what extent the outcome of the visit coincides with her expectations (Stewart et al. 2000). Sobel emphasizes the critical role of the patient perceptions in the healing process arguing that a person's subjective experience influences biology (Sobel 1995). The satisfaction of the patient towards the consultation was connected in receiving a diagnosis and prognosis from the doctor (Little et al. 2001).

In the context of the participants of my dissertation study it is appropriate to refer to the

theory of coherence by Aaron Antonovsky (Eriksson, Lindstrom 2006). The sense of coherence depicts the human ability to understand and control the challenges of life and also find the meaning in them, in other words to cope. This ability to cope is considered to prevent the development of chronic stress and the sense of coherence is seen as a predictor of mental health. My interpretation based on the analyses of these data is that ordinary people with chronic diseases have immense capabilities in themselves and one of the driving forces is the strong sense of being “whole”. The wide social network, friends and family members had an essential role in the coping narratives of all my informants and gave them strength to survive even in very difficult circumstances.

In the past few years, health maintenance and health promotion initiatives have emerged with the paradigm shift from the pathogenetic to salutogenic approach. Miettola has dealt with this in his dissertation from the context of metabolic syndrome (Miettola 2011).

It is important to remember the concept of hope in the context of the chronic pain the informants in my study had suffered for years. People seemed to be able to make adjustments in their lives that were realistic in the present circumstances and they wanted to emphasize how things could be much worse. They wanted to believe they could receive a new life after total joint replacement. They had high hopes for life to become much better and they wanted to believe the orthopaedic surgeons were performing miracles as one of the informants put it. Compared to the vast majority of people living with osteoarthritis the participants in my dissertation study belonged to a small minority willing to undergo the joint replacement surgery. That explained some of their enthusiasm and optimism over the surgical treatment. Many times during my visits I was impressed by the positive attitude and optimism expressed by the informants when they were referring to the coming operation and the expectations of their physical performance afterwards.

In my dissertation the orthopaedic surgeons came out as heroes. Of course this was not so unexpected since the target group of the study were people with a severe osteoarthritis and who were willing to undergo operation. The extent of appraisal and respect exceeded all expectations. The participants in the study appreciated surgeons who are like ordinary people, not showing off their learned expertise. They talked about orthopaedic surgeons who were able to tell the diagnosis just by touching the painful joint and who could perform miracles.

I will discuss the results from qualitative studies that bear similarity in their design and methods to my own research. I am comparing and reflecting the opinions and ideas expressed by the interviewees in my study with the findings and conclusions of these studies. I have taken direct excerpts from the interviews that I have conducted and written them in italics in the text.

Pain, disability and poorer quality of life had been the reality for the participants in my study for such a long time and all their stories and opinions need to be seen in the context of their subjective history of suffering. There were narratives of acceptance of the circumstances and of remarkable determination to continue to live life as normal as possible despite the constant pain and disabilities. *“I won’t compromise anything because of the pain”* is the statement made by an elderly woman living on a farm with her son.

In a research article that highlights the importance of measuring the wider personal and social consequences of osteoarthritis (OA) both at a population and an individual patient level, osteoarthritis patients reported handicap in six areas of their lives functional and social activities, relationships, socio-economic status, emotional well-being and body image. The prevalence was similar to that reported by rheumatoid arthritis (RA) patients. OA patients reported more severe handicap than RA patients in each of the 6 areas. These data suggest that the psychosocial impact of OA may have been underestimated and highlight the importance of going beyond disability diagnosis in assessing the impact of OA (Carr 1999).

Also it is important to realize that my informants represent a small minority among peo-

ple who suffer osteoarthritis globally. According to the Canadian study (Hawker et al. 2001) only about 9 to 15% of those whom the health care professionals regard as being in potential need for joint replacement operation, are willing to go through this.

In my data the inclusion criteria were that these people had agreed to be referred to the orthopaedic outpatient clinic at the university hospital to have a consultation with the orthopaedic surgeon to discuss about the possible joint operation. The respondents in my data did not share the rather common view expressed in other studies that symptoms of osteoarthritis are a natural part of normal aging and something one has to get used to living with. The experience of chronic osteoarthritic pain served as a framework for these people in my study when they constructed their narratives about the encounters in the health care during the interviews. On the other hand, some of the encounters they described in the interviews had taken place years ago, even before they started having problems with their joints. So the narratives encompassed a wide range of patient perceptions of various consultations in different contexts with the health care providers.

“The physician should be part of the same narrative with the patient.” This is a thought that emerged in a discussion with some PhD students many years ago and I have written it down since it gave me a new insight in the approach of trying to understand the interaction, taking place at the consultation. The same idea is described in a study by Haidet et al. who were investigating the complexity of patient participation and lessons learned from patients’ illness narratives. The conclusion was that patients are enacting a story as they deal with their illnesses and that physicians are key characters in these stories. But in reality the culture often positions the physician as a neutral observer somehow existing outside the patient’s narrative. By realizing that they are embedded within the narratives, physicians may be able to create opportunities for patients to adopt more productive illness management strategies (Haidet, Kroll & Sharf 2006).

The qualitative study by Wofford et al. investigating patient complaints about physician behaviours, came up with seven complaint categories. The most commonly identified category was disrespect, followed by disagreement about expectations of care, inadequate information, distrust, perceived unavailability, interdisciplinary miscommunication and misinformation. The meaning of disrespect is discussed in more detail since it is the only category that suggests ill intent on the part of the physician and because of this it may seem surprising that this category is so well represented among the formal complaints. This may be explained by the fact that voluntary formal complaints represent the worst physician behaviour in the patient’s view and thus are most likely to surface in the office that collects such complaints (Wofford et al. 2004). Although the informants in my study had perceived rather disappointing physician behaviour during the clinical encounters, they had made very few complaints about it. Their attitude seemed to be there is no use complaining since nothing will happen even if they do. The respondents did not believe they could influence the system with their complaints “*No dog will step on the tail of another dog*”, was the opinion of one older man among my interviewees.

The informants in my study expressed their views on physician behaviour during the consultations very openly and told about arrogance, showing off the learned background in an impolite way. The sense of injustice could also affect the experience negatively and give the patient a feeling of not getting equal care. The doctor may have hurt the patient also by showing too openly his or her personal feelings. “*What hurt me most was that I felt so exhausted and she was just enjoying the beginning of her summer holiday and I left for home to bleed.*”

A concept of “Left in limbo” is introduced by Preston et al. in a qualitative study about patients’ views on health care across the primary and secondary care interface. The researchers conclude that the concept of progress is central to patients’ views of care. It involves both progress through the health care system and progress towards recovery or adjustment to an altered health state. Patients can experience the treatment process as a clinical and per-

sonal journey, the purpose of which is to make progress and to reach a goal. Sometimes the actual progress may not be delayed but the patient can have a feeling that this is the case, particularly if the interaction with the staff is not satisfying or s/he feels there is not enough information given. This concept of progress may be an appropriate indicator for monitoring health service performance according to the results of this study.

The researchers have named the concept "limbo" meaning uncertainty, anxiety, difficulties in making progress through the system and having an indefinite period of waiting, uncertainty about what to expect or what would happen next. There was a strong feeling of powerlessness and loss of control connected to limbo. Patients accept waiting if they get an estimate of the length of the waiting period and it is not unreasonable compared to their problem (Preston et al. 1999).

These same experiences of uncertainty and indefinite waiting were very strongly echoed in the narratives of my informants as expressed in the following excerpt. *"It was very stressful for years not to know what was the matter with the knee. The uncertainty was gnawing."*

Another theme discussed by Preston et al., is getting in, gaining access to appropriate care and obtaining appointments, being referred, having hospital admission procedures and receiving after care. The need for their problems to be recognized as legitimate, was viewed by the participants as essential in determining the speed with which they gained access to care.

Gaining access to appropriate care was often accompanied by feelings of intense relief in such circumstances when quite serious conditions had been diagnosed. The attitude of the patients seemed to be "Oh, good, I am not wasting the precious time of the doctor!" This kind of attitude was very similar to the narratives of my interviewees. My informants seemed to be relieved when a real reason was found behind their complaints, which gave them a legitimate status as a patient.

In the results of the qualitative study by Teh et al., the participants described the importance of being heard and being understood by the health care providers. They wanted to have a meaningful relationship with their doctors, they wanted them to sympathize with their pain and to understand the psychosocial context in which the patients lived and they wanted to be known as whole persons. Not finding a doctor who understood, could lead to a sense of vulnerability, isolation and the feeling of being left alone with the pain. Being understood is in alignment with the concept of legitimacy. If the doctor shows understanding towards the patient's pain, it will give the signal that the patient has the right to complain and the problem will be taken seriously. "Being heard" is described in this study as being able to tell the doctor anything and not to be interrupted. Not being heard made the respondents feel their doctors were not interested in them and did not care about them (Teh et al. 2009).

These same issues were much emphasized and discussed in the narratives of my interviewees. They described how the patient could sense if the doctor did not take him or her seriously and how the patient could not express herself then but instead would get locked up. My informants also had experiences of very successful interactions with their doctors as this excerpt will illuminate: *"It felt like I was the only one there and she was communicating to me let us now discuss this matter and we are not in a hurry at all."*

In the study by Teh et al., several people reported changing the pain medications on their own without consulting their doctor. They did not like taking painkillers or being reliant on them and instead experimented with taking less medication than was prescribed to them. This kind of thinking is consistent with the opinions of my respondents when they talked about trying to avoid pain medication as much as possible and can be interpreted as being in charge of their own situation. The participants also told about their use of nutritional supplements, vitamins and homeopathic remedies they had discovered on their own (Teh et al. 2009).

The informants in my study seldom reported relying on any alternative treatments. There

was one lady among the interviewees who was making ointments and using various herbs in them. She also took acupuncture for her arthritic knee pain and found it beneficial. One male participant had used ginger and blue mussels products for years and reported very good experiences about these. Fish liver oil capsules, were taken by one man and two ladies had used segmental therapy for their arthritic pain.

When the focus is on older adults with chronic pain it is also essential to understand the extent to which each patient is interested in being involved in treatment decisions. Not everybody wants to be involved in the decision-making when it comes to deciding about various treatment options and several respondents expressed that they preferred a more traditional role. Many people also reported they would never disagree with their doctor because after all "they have the degrees" (Teh et al. 2009).

Some of the participants in my study clearly wanted the doctor to decide what should be done. It also depends on how patient participation in decision-making is defined. My results show that people wanted to be involved in the decision-making process, they wanted to be heard and their ideas and opinions taken into account but most of the time they preferred the doctor to make the final decision about the treatment options; *"The doctor should decide. S/he knows best."*

For the patient the decision about seeking help and actually making the appointment to see the doctor is the most relevant. The participants in my study emphasized in many occasions how they did not make this decision very easily. The situation had to be serious enough before they would seek help from the doctor. In my interpretation this is essential for the health care providers to understand since this does affect the context and preconditions of the encounter.

Preference for handing over control to the physician may be significantly greater for a case involving potential mortality like a major operation than for a case involving mainly morbidity like urinary problems. Still, few wish to hand over decision-making control to their physician since they want to be involved even if they do not wish to be identifying the right answer in the problem solving task (Deber, Kraetschmer & Irvine 1996). It is an interesting observation that much trust as well as lack of trust towards the physician can lead to unwillingness to be involved in the decision making process (Belcher et al. 2006).

If the informants in my study disagreed in their minds with their doctors, they were reluctant to voice this disagreement since they were concerned about jeopardizing their future relationship with the doctor. They seemed to be very careful in weighing how to express themselves not to upset their doctors. One elderly lady said she would never tell her general practitioner (GP) she went privately to have her knee x-ray taken or that she visited the district hospital Accident and Emergency because of dizziness and was diagnosed having a very high blood pressure. Her GP had just previously recommended massage because of tense neck muscles. One of the informants continued the injections for her knee just because she felt she could not hurt the doctor's feelings by telling him they did not help her since he tried to do his best.

Being remembered by the health care provider is important to the patients. It makes them feel comfortable and safe within the medical interaction and about the treatment decisions that are being made. Remembering the patient seems to be a characteristic for a caring and empathetic physician (Teh et al. 2009). This same sense of being known and looked after by the doctor was expressed by my interviewees when they talked about young doctors especially radiating caring and concern. Also they found it easy to talk with a doctor who always discussed even other than health related things, asking also about family members too. Continuity of care was an important element of the patient-provider relationship since this allowed the person to be known and understood much better by the doctor. The informants in my study talked about a mutual respect and a rapport that had been built over the years. *"The next visit is much more familiar because of the continuity which should make the visit*

more rewarding also for the doctor."

There are opposing opinions too, expressed about the continuity as highlighted in a qualitative study by Infante et al. Even if a continuous relationship with a GP was seen important and giving confidence to the patient to express all their needs, some respondents believed GPs may become complacent seeing the same patients for years and felt a second opinion could sometimes be useful (Infante et al. 2004). This kind of attitude was not expressed by any of the interviewees in my study, only very few had ever even thought about changing the physician to get a second opinion. According to Infante et al., there was consensus that a good relationship between the GP and the specialists improved patient care although some believed the GP might lose interest in patients once they had been referred to specialists. Some of my respondents had experienced difficulties in getting referrals to the specialist care and they raised the suspicion there could be economic issues behind the reluctance to refer since it is always more expensive to the municipality if the treatment takes place at the hospital. *"It is certainly a question of economic cost for the doctors here at our health centre when they consider whether to refer somebody to the hospital."*

A profile of a good GP was produced by the participants of the study performed by Infante et al. Characteristics included in the profile were interpersonal skills, clinical skills and being accessible by the telephone and also having time for the patient. The participants wanted their doctors to be up-to-date with medical knowledge and know about various treatments. They found it important that the GP was enrolled in some form of continuing professional development. It was seen as a strength rather than a weakness if the doctor consulted guidelines during the visit (Infante et al. 2004).

A poor GP profile was also described, in the study by Infante et al., as being pressured, with too little time for patients. Some respondents felt that GPs could at times be impersonal and dismissive, particularly with those patients having osteoarthritis. There was a general agreement among the participants that GPs are weak in recognizing and treating the emotional impact of chronic diseases (Infante et al. 2004). The lack of competence when dealing with emotional issues was described in this comment by one of my informants which at the same time showed understanding towards the workload of the GP. *"We never talk like this... face to face about how I am feeling. But he is a general practitioner and has lots of things to look after and maybe I should make an appointment to see a psychiatrist to discuss emotional problems."*

Some of my respondents suspected that a young doctor who has not ever experienced chronic pain himself is unable to fathom the pain intensity and the seriousness of the patient's knee problem.

The involvement of the patients in their own care divided the respondents in the Australian study by Infante et al. Some of the participants considered themselves as expert as their GPs about their own conditions. But there was no consensus since some participants preferred their doctors to take responsibility for their care believing it is the doctor's job to keep them healthy (Infante et al. 2004). Based on the results of my dissertation the respondents seemed to be very well aware of their own role in the coming joint replacement process. They had been given instructions to do certain daily exercise by the physiotherapists, they were joining in the water jogging and they were dieting to lose weight before the operation. Their biggest worry was that because of the severe pain they had to cancel some exercise lessons and even riding the exercise bike at home was sometimes impossible since sitting on the saddle felt so uncomfortable.

Coping strategies preferred by elderly people and barriers to management of chronic pain have been investigated in a study performed by Lansbury. The results show that most popular coping strategies among the respondents were home remedies, massage and topical agents and some informal cognitive coping strategies. Least preferred strategies were the conventional treatments of medication, exercise and physiotherapy. Most people prefer strategies that are convenient, inexpensive, of easy access and those for which they do not

have to make major behavioural changes (Lansbury 2000). According to my findings, the coping strategies and means of dealing with the pain varied from holding on to a ladder to performing dry brushing of the skin standing on one leg (an elderly lady doing the muscle balance training).

Many barriers need to be overcome to achieve relief for the pain such as cost, access to health care, related disorders, attitudes of health professionals, lack of communication and fear of losing independence according to the results of the study by Lansbury et al. Although most participants were aware that a daily general exercise program, such as walking, was beneficial for their health, this was not commonly practiced. Some of the reasons given were that it was not in their usual lifestyle, they were afraid of falling, anxious for their personal safety or that some related disorder like a cardiac condition prevented them from exercising. The reasons for non-adherence to an exercise program were quite pragmatic in many cases (Lansbury 2000).

Campbell et al. have tried to understand non-compliance with physiotherapy in patients with osteoarthritis of the knee and they have asked the question why patients don't do their exercise. From the patient's perspective, decisions about whether or not to comply are rational but often cannot be predicted by therapists or researchers (Campbell et al. 2001). The message of this study emphasizes the decision-making and behaviour of the patient as a true actor in his or her own life. The health care professionals should be able to take this seriously if they want to provide supportive care for their patients instead of just telling them authoritatively what would be in their patient's best interest.

The participants in my study talked about physical exercise in a positive way and they seemed to understand that doing regular exercise is beneficial for them in the light of the approaching joint operation. It is impossible to tell what the reality is and how much of the descriptions were given to please me as a researcher and a physician. They also expressed their worries for not being able to exercise because of the severe pain and the possibility that some other chronic illness like diabetes or a heart disease may deteriorate while they were unable to exercise.

The majority of respondents in Lansbury's study complained that nobody had time to talk to them about their condition. Also many elderly people did not want to "bother" other people especially the busy doctor. As a result their questions about their condition and treatment often went unanswered. Many respondents also expressed a concern about maintaining their independence.

Treatment in the medical system was perceived as a threat to the participants' own control, so it could be that the fact not wanting to bother anyone about their problems may be linked with this fear of losing independence (Lansbury 2000). These thoughts seem to be fairly consistent with the ideas expressed by my interviewees as shown in this excerpt by an elderly lady: *"There is a lot of benefit if one can explain things to the doctor who has time to listen to you."*

The participants in my study did not want to waste the precious time of a busy doctor and they very easily seemed to doubt whether their pain was severe enough to justify a consultation. *"One always ponders (laughing) whether one is complaining for nothing, when it is hard to judge the subjective feeling of pain, how terrible it is now when you experience it all the time."* They also expressed the fear of the doctor thinking they might be exaggerating their pain. But there was one lady who thought there should be enough time for everybody to tell all the problems s/he felt were relevant during that particular visit.

One emerging theme in Lansbury's study was the acceptance by the participants of joint pain being due to old age. This kind of attitude may prevent the patient even trying to find the most appropriate treatment for the osteoarthritis. Some of my respondents were also familiar with an attitude like this, especially one female participant repeatedly heard this from her occupational health care doctor who commented her knee osteoarthritis by saying

it belongs to getting old you just have to learn to live with it.

Unmet needs for joint replacement, were discussed in a qualitative investigation about barriers to treatment among individuals with severe pain and disability of the hip and knee by Sanders et al. The view of arthritis as a natural degenerative condition of older age made respondents pessimistic about formal care and this was also a major factor in making them reluctant to seek care. Younger people were much more determined to get the surgical treatment they felt necessary. Some reluctance to seek care also had its origin in the poor outcomes of people they knew, particularly failures in the outcomes of knee surgery. Their perceptions of the role of the general practitioners in the joint problems were very pessimistic. They did not want to bother the GPs with symptoms for which they considered there was no appropriate treatment. For some, their doctors even had reinforced the perception that nothing can be done and confirmed the lack of effective treatment. The researchers conclude there is obviously a need for information to counter prevalent lay-beliefs that pain and disability are an untreatable and inevitable part of aging. The majority also had not had an opportunity to discuss the risks and benefits adequately with their health care providers (Sanders, Donovan & Dieppe 2004).

The respondents in my dissertation shared some of the negative views connected to the public primary health care, the level of competence of the doctors and the shortage of resources. *"I felt that at the health centre they didn't pay much attention to my painful foot during the years. I did get the impression they paid more attention, got in to details, here at the private clinic."*

The worry and suspicion about declining economic resources to look after all the patients was expressed by many of my interviewees. One old lady felt very upset after hearing the comment of her GP about the expenses her joint operation was going to cause to the municipality.

Sanders and co-authors argue that those who have early surgery get better outcomes than those who have late surgery when they are older with more severe symptoms (Sanders, Donovan & Dieppe 2004). However, this needs to be put into perspective against the risk of prosthesis failure during the longer active lifetime in younger patients.

According to the Finnish Current Care Guideline, survival results for hip and knee prostheses appear favorable during a follow-up period of 10 to 15 years. It is recommended that a total knee or hip arthroplasty should be performed if osteoarthritic pain is not otherwise manageable, the patient's ability to manage everyday tasks is essentially compromised due to osteoarthritis and there is a significant restriction of motion or a joint malposition (www.kaypahoito.fi).

In the study by Hajat et al. to assess the impact on the outcome of total hip replacement of the length of time spent waiting for surgery, 143 orthopaedic and general hospitals provided information about aspects of surgical practice for each total hip replacement conducted between September 1996 and October 1997 for publicly and privately funded operations in five English health regions. In their results the investigators concluded that twelve months after a total hip replacement, the majority of patients experienced substantial improvements in hip-related pain and disability. Those patients who started with a worse Oxford Hip Score before the operation tended to remain worse after the operation. Worse pre-operative score was associated with an increased length of either outpatient or inpatient wait, and this trend remained after the operation. The relationship between waiting time and outcome remained after adjustment for possible confounding variables. Those patients who were socially disadvantaged had a worse score than more socially advantaged patients both before and after the operation. Waiting for surgery was associated with worse outcomes 12 months later. Longer-term outcome needs to be considered to see if this association persists (Hajat et al. 2002).

The concept of deferral is discussed by Hudak et al. who investigated the opinions of potential candidates for total joint arthroplasty (TJA) who were unwilling to undergo the pro-

cedure despite severe disabling arthritis. Although TJA had not been chosen as a treatment option now, the possibility remained that it could be chosen at some point in the future. Many participants seemed to believe they had to be in constant pain and virtually unable to move before they would be considered as a TJA candidate. So they did not feel they were putting off surgery but waiting until the time was right. They also suggested that others are more needy of the procedure, this being a kind of fairness consideration.

It is argued by the researchers that some older patients may have a desire for a more authoritative model of patient-practitioner interaction. Today's elderly patients lack experience for shared decision-making with the health care providers. Given that some elderly persons are heavily reliant on their physicians to advise them on their health, doctors may need to initiate discussions about arthritis and various treatment options including surgery. Sometimes the practitioner sensing a patient's reluctance may fail to initiate or engage in discussion about TJA. The authors ask whose role or right it is to challenge patients' views of arthritis as a normal part of aging and should the practitioners more aggressively pursue treatment of arthritis with elderly. They argue that patients need to know when they have a treatable condition and the specialists should be consulted more eagerly to clarify patients' potential candidacy with respect to TJA. The general practitioners also should consider their role in trying to demystify the surgical intervention and make the patients see it as a health enhancing rather than an "end-of-the-road" treatment (Hudak et al. 2002).

The participants in my dissertation expressed similar views of the doctor as an authority who should know, what was best to do. They did not seem to want a shared decision-making situation since they felt they lacked the expertise and knowledge to make the right decisions about the treatment options for their joint problem. My respondents, who were a purpose-built sample of the osteoarthritis patients willing to consider the total arthroplasty as their treatment option, did not share the view of the arthritis being something that is normal and belonging to old age. Just the opposite, they seemed to think the health care providers should be more active in arranging specialist consultations for the assessment of the patient being suitable for the joint surgery.

Surgery avoidance for hip and knee arthritis has also been investigated by Ballantyne et al. To make decisions about how to manage their condition the participants used previous experiences, especially negative encounters in medical and surgical care, including those from the distant past and those experienced indirectly through some relative or friend. Previous negative experiences combined with the perception, often reinforced by physicians, that doing nothing was a viable option, prevented arthritis-related help seeking in the health care system (Ballantyne, Gignac & Hawker 2007).

Some of my informants had relatives or friends whose joint operations had not been successful but they did not let that affect negatively to their bright expectations about better quality of life after the TJA. One lady who had never been operated expressed herself in a fatalistic way: *"I suppose I will not die on the operating table but if I do, then so be it."*

The role of clinical severity and patients' preferences in determining the need for hip and knee arthroplasty are two separate issues. It is important to distinguish clearly between the prevalence of illness which is often called "potential need" and the preferences of patients, defined as "willingness to have surgery" (Hawker et al. 2001).

Sanders et al. were investigating the experiences of chronic illness, disability and aging with people who had severe osteoarthritis (OA) of hip or knee. The authors talk about meaning as significance and meaning as consequence and how this provides a useful framework to examine the biographical aspects of the symptoms. They found out that older people portrayed their symptoms as a normal and integral part of their biography but they also described the highly disruptive impact of the symptoms to their daily lives. The onset of symptoms for many participants was bound up with their life history and revealed varying degrees of hardship. Most had experienced difficult and physically demanding work condi-

tions. The respondents could be seen referring to a social model of causation in that they highlighted previous aspects of their social history, which they felt had contributed to their osteoarthritis (Sanders, Donovan & Dieppe 2004). This is very similar to the interpretations of the root causes behind their joint symptoms given by my respondents as portrayed in this one excerpt: *"I can tell how the back pain started 28 years ago. I was in a hurry and I was lifting a big milk churn from the cart very abruptly at a one go and I felt a terrible pain in my back."*

In alignment with my results, people in the study by Sanders et al., were reflecting on negative stereotypes of older age and the notion that they were a burden on society and they wanted to distance themselves from such stereotypes. Several respondents spoke about their embarrassment connected to their disabilities and the stigma they felt using aids or a wheelchair. One of my interviewees expressed her attitude towards the possible loss of mobility by saying that if it happens that she will be sitting in a wheel chair she needs to accept even that, moving is just a little bit slower.

The participants in the study by Sanders et al., talked about age-related resource allocation in the health services. They expressed how younger people might be more "deserving" of the treatment than themselves. The differences in meaning of osteoarthritic symptoms for younger people were obvious since they did not refer to their joint problems as being natural and degenerative or as being inevitable. These views influenced their approach to management and their determination to get formal treatment. The issue of diagnosis was very important to them and they did feel a sense of relief at finding a legitimate and treatable cause for their symptoms. This is very much parallel to the opinions expressed by the informants in my dissertation.

The informants in my study talked about the frustrations of coping with pain and disability in their everyday lives and how it made them feel depressed. Some of them even indicated they felt suicidal at times because of the pain. The constant pain and disabilities affected the everyday life very profoundly and two of the respondents expressed suicidal thoughts during the interviews. Even going to the toilet could become an effort.

Several informants of mine, however, did mention their attempts to overcome feelings of being depressed. The accounts of the consequences of symptoms on their daily lives clearly indicated that people perceived things were often quite bad and just getting worse. A common finding was that people compared themselves with others by saying they expected there were plenty worse off than themselves.

Many elderly people demonstrate a stoical attitude towards illness because of their desire to be viewed as independent or successfully old. They may consider illness as a sign of weakness. Consequently, those living with disabilities may "accept and forget" too much and this can lead to a situation where older people with severe joint problems may experience poorer quality of life and have unmet needs for health services.

According to the results of a study by Kravitz et al., perceived vulnerability, past experience and transmitted knowledge influence patient expectations both by affecting the interpretation of symptoms and by establishing an implicit standard of care. These findings highlight the previously recognized gap between the clinician's focus on objective disease and the patient's subjective experience of illness. A better understanding of patients' interpretations of symptoms, perceptions of vulnerability and ways of knowing can enable clinicians to meet patients "where they are" and can lead to more productive clinical negotiation (Kravitz 1996).

This is very clearly expressed by some of my informants since they were having a pressing urge to get to the joint replacement operation as soon as possible. In their minds the waiting period only meant that things were getting worse, the other leg was under much strain and that increased the risk for joint problems in the near future. Also other disorders were expected to get worse. The perception of vulnerability was most concretely expressed by the youngest of my respondents.

Older patients' unexpressed concerns about orthopaedic surgery were the focus of a study by Hudak et al. The researchers conclude that patients only raised half their concerns regarding surgery during the visits with the orthopaedic surgeons. But the authors especially point out that it is important to realize that quite a few of the new patients visiting an orthopaedic surgeon were there for the second opinion. They were not motivated so much by doubts about the competence of the present consultant but by lack of trust in or dissatisfaction with the consultant who provided the first opinion (Hudak et al. 2008). This was not a common situation among the participants in my dissertation study. The informants described how they went to see the specialist to get the professional opinion on what would be the best thing to do. They trusted in this expert view and nobody expressed spontaneously, that s/he would go somewhere else to get a second opinion. In this respect there seemed to be a totally different culture compared to the findings of Hudak's study.

Tallon et al., wanted to explore the priorities connected to symptoms, treatments and research agenda from the perspective of the individual with osteoarthritis (OA) of the knee. According to the results the issues that were the major problems for all participants included pain, disability, depression and anxiety. A striking feature according to the researchers was the psychological impact of the pain and disability. Drugs were seen as helpful though several respondents took drugs as little as possible. They seemed to be aware there are side effects but "if you are in pain, you need them" (Tallon, Chard & Dieppe 2000). The psychological, as well as the physical dimensions of the osteoarthritic pain, were described by the informants in my study, here in the opinion of a 55 year old woman: *"It brings your mood down. Am I really a crippled who cannot go anywhere?"*

Many of my informants expressed their concerns that by taking pain killers they could actually make the situation worse since they would carry on and put too much strain on the damaged joint. The pain was seen very difficult to deal with also among my informants as expressed in this excerpt: *"The constant pain and agony, it does eat you up and it takes all the interest towards anything else."*

Power et al. conducted a focus group study to increase understanding of the fatigue experience in community dwelling people with osteoarthritis (OA). The participants described the mental fatigue as feeling absolutely drained, unable to focus on anything, affecting the clarity of thinking (Power et al. 2008). Emotions and mood, including frustration, anger, stress and depression are additionally linked to fatigue according to Power et al. The impact of fatigue on the respondents' lives was described substantial, all consuming, totally overwhelming. Living with fatigue made them irritable, cranky, frustrated, angry and depressed. Several participants indicated they had to limit or give up activities such as volunteer work, chores and leisure or social activities. Methods of coping with fatigue included resting, taking naps, getting help and using assistive devices. Exercise was also mentioned as a means to reduce fatigue. Being in a cheerful company where one could laugh also made it easier to cope since it was possible to forget the fatigue and the pain. Spouses were the only people mentioned when the respondents were asked, whom they would talk about fatigue (Power et al. 2008).

For the participants in a study by Dosanjh et al., being intimate with their partner was the single most current important limitation in addition to most domestic tasks that were compromised because of the restrictions in movement caused by osteoarthritic pain (Dosanjh et al. 2009).

This is very different from the narratives of my interviewees. Very few of them even mentioned spontaneously the problems connected to intimate relationships. One older lady expressed her feelings of being pleased about the simultaneous impotence affecting her husband since the excruciating pain in the hip prevented her from having sex. Only one male respondent mentioned problems experienced in sex life. *"At least one has to choose the positions. One cannot pursue the way one did when young and also erectile dysfunction started to happen."*

The respondents in the study by Dosanjh et al., talked about the emotional consequences of living with the pain and waiting for the surgery. They mentioned fear they had for their condition worsening, gaining weight, hurting other body parts and possible complications due to the coming surgery. The participants seemed to be very well aware of the different techniques for performing total hip arthroplasty. This may be due to the fact that they did not represent the typical patients being on the waiting list for hip surgery. The cultural influence in California, the relative affluence of the participants their extensive data gathering about hip arthroplasty and the competition for services was not generalizable to any other environment. The respondents talked about minimally invasive techniques, which preserve the anatomy of muscles and tendons. In my data the interviewees were not at all this well informed about the actual procedure of a total joint arthroplasty. Nobody talked about different techniques for the surgery.

Feelings of self-blame, compromised self-image and isolation from others are echoed in the responses of the participants in several of these studies. The core feelings of depressed mood resulting from the limitations and an altered self-image associated with osteoarthritis appear to be experienced very widely across different ethnical and cultural backgrounds and contexts. Modern patients are information seeking to a greater extent than in previous years and industry marketing to patients about implants and less invasive techniques has increased a lot making it important for the future investigators to explore the decision-making process of patients across age, ethnicity, occupation and socioeconomic status.

Personal meanings in the construction of the need for total knee replacement surgery, were investigated by Toye et al. The investigators argue that our social network does not just influence decision-making but actually shapes the decisions that we make. This is based on the writings of Blumer about methodological position of symbolic interactionism (Blumer 1986). According to the authors very few qualitative studies have explored the personal meanings of people with knee osteoarthritis. Their results suggest that the decision to undergo a total knee replacement operation (TKR) is not related to symptoms alone, but also to personal meanings. Most participants adopted the medical model and indicated that a specific medical diagnosis, osteoarthritis, confirmed by X-ray determined the need for a TKR. All agreed that the doctor defines the need for the operation, they expressed faith in the doctor as an expert and that there was no point in seeing an expert if you were not going to take his or her advice (Toye et al. 2006). The adoption of the medical model is clearly visible in this comment from one of the respondents in my study. *"He (the private orthopaedic surgeon) knew immediately what was wrong with me, he was able to say that to me at once."* Also the person's social network has influence in the construction of the need for total arthroplasty. Most respondents in the study by Toye et al. had been given positive reassurance of the operation from friends and the family.

Pain is an important factor determining the need for a joint replacement. Some participants felt the pain can destroy the meaning of life. They talked about difficulties in assessing pain, what was severe enough pain and the need to qualify it with effects such as loss of function or low mood. Functional loss is related to the need for a TKR. Women mentioned more often difficulties in walking and shopping when men discussed the effects on leisure activities. Getting older decreases the functional expectations and this reduces the perceived need for a joint replacement operation. The need of a total joint replacement was directly related to beliefs about the disease progression. The vast majority believed their osteoarthritis would progress. Being "crippled" or being in the wheelchair, was described by some as their worst fear. There were respondents who suggested they would rather be dead than get any worse (Toye et al. 2006).

Priority setting for a knee joint replacement based on the opinions of people on the waiting list for a total knee replacement (TKR), has been studied by Woolhead et al. Some of the respondents said they had been told their excessive weight was a problem, which they felt

was unfair. They thought the doctors did not appreciate the fact that osteoarthritis leads to reduced mobility and therefore to weight gain. They felt they needed the joint replacement in order to be more active and to lose weight. Nine out of 25 had been told they were too young for the joint replacement. The participants felt this was inappropriate and that they should have been offered their surgery earlier (Woolhead et al. 2002).

One of my informants was told at the consultation by the orthopaedic surgeon that he was too young for the operation in a way which left the patient feeling neglected. "He asked me to lay on the examination table, lift my leg and said this is osteoarthritis, we will do nothing for this. If something is done, it will be an artificial joint but since you are not old enough we'll do nothing. Goodbye."

A few respondents in my study thought ageism operated also as to exclude older people. Similar to the participants in the study by Woolhead et al., my informants suspected that knowing or repeatedly bothering the surgeon and excessive complaining could result in earlier treatment. They also raised suspicions that private care meant some patients received unfair earlier treatment. This kind of criticism was expressed in some comments about long waiting lists on the public sector. A fair decision-making process should include factors specific to the patient's circumstances.

Living a life on hold, a metaphor for a continuous struggle against a faceless system while waiting for the surgery, is the main theme of the study by Sjoling et al. The data consist of 9 informants who were interviewed one week after their arthroplasty and 9 other informants whose interviews took place while they were still on the waiting list for the total arthroplasty.

In the background of the study the investigators refer to Eriksson's ontological understanding of the patient as the suffering human being. There are three forms of suffering according to Eriksson: illness-suffering, which is caused by the actual symptoms of the illness, caring-suffering which consists of pain and inconveniences inflicted by examinations and surgery but also discrediting the patient and not believing her and life-suffering related to the disruptive life situation and self-image (Eriksson 1997).

One of the emerging themes that characterizes the interviews is pain as the common problem restricting life activities. The pain is described as dreadful and extremely disabling. This results in isolation and feelings of depression. Most of the respondents had been on the waiting list for more than 12 months and they talked about their life on hold. The most annoying thing was that they were not able to get information about when surgery is due to take place. This uncertainty made them angry and frustrated. The informants talked about a sense of being neglected by the health services system and how this has brought out feelings of unworthiness as a human being. The health care system was seen faceless, nobody listened to them and that made people feel powerless. Living with a disrupted self-image had led to feelings of stigmatization and a sense of not belonging to the society.

One of the positive themes that emerged is the concept of caring needs being met. When it was possible to establish a trusting relationship with health care representatives, this helped the person endure the wait for the surgery more easily. They talked about events where the patient in distress had been seen by the doctor as a person who matters, confirmed as a human being as well as a person with a caring need.

Some of the respondents had been able to carry on living a full life in spite of the pain, disability and uncertainty of the waiting time for the surgery. Also having a sense of underlying support from family, relatives and friends could preserve meaning and continuity in life. People needed to struggle to have their caring needs confirmed but this was a struggle against "a faceless enemy" the system, where there was no one they could turn to and address their frustration. It is argued that people feel victimized when strangers make decisions about them as they are in the system which also threatens them although it is supposed to help them. The authors conclude that there is a need for an attitudinal change

to be made which recognizes the responsibility of the health care professionals in trying to meet the caring needs of these patients and help them to live a full life in spite of their illness. The best medicine could be a face-to-face appointment with an attempt to establish a trusting relationship between "the system" and the person, thereby giving the system a face which may confirm the person's caring needs and make the wait less indeterminate and more worthwhile (Sjoling et al. 2005).

The opinions of my informants reflected very similar attitudes and experiences as the ones depicted in the study by Sjoling et al. *"I was so exhausted then so I felt unable to give any feedback. It requires some strength to be able to express your own views to the doctor briskly."* It was similarly emphasized in the narratives of my respondents that having a sense of underlying support from the family, relatives and friends did help in maintaining continuity and meaning in life.

The uncertainty and unawareness of the length of the waiting time made them angry and frustrated and gave rise to a sense of being neglected by the health care services system. All this brought out feelings of unworthiness as a human being and the opinions about the system as faceless, where nobody actually listened to them but instead made them feel powerless.

The path of the patient is not always smooth and straightforward in the health care system and it requires a lot of endurance from the patient to make progress, to reach positive outcomes and to get the treatments s/he needs. Sometimes it seems almost like a struggle requiring lots of persistence and assertiveness to make things happen, get referrals to the specialists and to be heard. This is not, however, the whole truth of the health care system either. There were plenty of occasions when the respondents in my study had experienced good quality care provided by top professionals and respected experts. The bottom line was the strong trust in the competence of the health care providers. The doctor needs to communicate two major characteristics: that of being a caring and concerned human being and that of treating the patient as an equal partner and with respect (Arborelius, Timpka & Nyce 1992).

The Finnish study by Punamäki et al., to find out predictors of consultation experiences among Finnish primary care patients was conducted in the clinical setting by interviewing patients before they consulted a GP and immediately afterwards. The consultations were all on-call visits for some acute conditions, which may partly explain the central role of the diagnosis in the findings. One predictor for a successful consultation was the matching of the patient's and the doctor's diagnosis. The contents of the consultation which led to a shared diagnosis consisted of a thorough examination by the doctor, explicit explanations of the medical findings and the sense of respect for the patient's own diagnosis. The experiences connected to failed consultations were feelings of neglect, helplessness, insecurity and being hurried through the consultation (Punamäki, Kokko 1995). These findings are compatible with the predictors of unsuccessful encounters as described in the results of my study.

Kukkola and Virtanen both have investigated the clinical encounter between the patient and the physician. The consultation and the interaction, taking place during the visit were the focus of their dissertation studies. Their study designs are more quantitative compared to the qualitative nature of my dissertation. (Kukkola 1997, Virtanen 1991). Despite the different methods used in these studies, there are similarities in the findings of these two dissertations and mine.

According to Kukkola, the outcome after the search for different explanatory models was a regression model, which included factors from the instrumental communication and this model predicted 27% of the satisfaction. The best predictors were the competence and the expertise of the care provider and how understandable the given information was (Kukkola 1997).

Virtanen concludes that the factor getting into details explained the majority 42.9% of the

variance of the interaction between the patient and the doctor. In this factor were included the following topics: interest shown by the doctor, listening to the patient, showing caring attitude, was there enough time, understanding the patient, the chance to discuss the topic the patient was most worried about and taking into account the patient's view related to the treatment. The participants in the study by Virtanen also assessed the competence of the doctors. The competence was evaluated as excellent by 44.8% and 0.3% only thought there was no competence. Of the respondents, whose expectations were fulfilled 64.2% regarded the doctor competent. Those who were not satisfied with the consultation estimated that 48.5% of the doctors were incompetent (Virtanen 1991).

To investigate the users' understanding of the quality of medical knowledge in general practice and find out what lay people mean when they indicate their doctor's medical knowledge as excellent, good, fair or poor, Chapple et al., conducted a study. The participants were encouraged to talk about their past experiences with as little interruption as possible during the interviews. They were asked to explain how they had made the judgment about the medical knowledge of their GPs.

One of the results was that medical knowledge means different things to different people. Some of the respondents perceived it as knowledge of disease and treatments. Others considered that it included knowledge of the whole person within a wider social and personal context. The authors argue that relatively little is known about the quality of clinical care in general practice. Medical knowledge is one aspect of quality but the investigators state that there is reason to be skeptical about the validity of surveys measuring the technical competence of the doctors assessed by the patients. Firstly they criticize that people have different meanings for the concepts used in assessment. Secondly there were respondents who just presumed that their GPs were knowledgeable because the credentials they had acquired through formal training and membership of the medical profession. Thirdly relatively few patients had enough knowledge about their own illness to make an informed judgment about the level of treatment standards of their GP. The authors conclude that patient surveys are of importance in assessing patient perspectives of interpersonal care and access but for assessing clinical care they recommend audit, critical appraisal and outcomes such as health status (Chapple et al. 2002).

In my dissertation the focus was on the patient perception of the quality of the clinical encounter based on his or her subjective experiences. I was not studying how well the patient assessment could be compared to audit results of clinical care or peer evaluation of professional competence of the doctors involved. My aim was not to judge or verify the behaviour of the health care professionals as it is described in the narratives of my informants. I have wanted to listen to the informants, their experiences and evaluations of the quality of the clinical encounters as the users of the health care services.

In the study by Kekki et al., about the experiences of the quality of the consultations at the health centre, the respondents who did not perceive any benefit during their last visit to the health centre rated more often the respect shown by the doctor at that consultation negatively than the patients who experienced they had gained benefit. Respect was chosen as the one variable to describe the quality of the activities of the physician. Interest shown, taking into account the patient's opinion and thorough examination correlated well with respect shown by the doctor (Kekki 1995).

The benefit means some positive change in the health of the patient as a result of the consultation. The outcome of the treatment is a central indicator of the quality of the care. The patient experience of the beneficial outcome of the treatment is an essential factor in his or her perception of the quality of the doctor performance. Despite the fact that Kekki's study was a large-scale telephone survey and my dissertation is a qualitative study, the trend in the results is quite similar. The perception of the patient about the behaviour of the physician at the consultation has great impact on his or her overall picture of the entire healthcare

system. This is also demonstrated in my findings using the Bayesian method where it was shown that there exists dependence between patient perception of benefit, doctor competence and the interaction with the health care system. These findings give support to the argument that the user perception of the health care services received is an important indicator of the quality of the health care.

8 Conclusions

A competent, caring doctor, who takes the patient seriously, represents continuity, and gives information and whom one can trust, predicts the successful encounter. On the other hand, long waiting lists, economic issues seen as obstacles for getting treatment, and patient perceptions of indifference, treatment failures, disappointments, bitterness and feelings of anger are all predictors of a failed encounter.

The mutual dependencies of the themes Doctor Competence, Benefit and System Interactions I have been able to demonstrate with Bayesian modeling, indicate that the subjective experience of the clinical competence of the doctor at the consultation is very meaningful and important to the patient. By clinical competence I mean in this context the skills the doctor is able to show when listening attentively to the patient and examining him or her thoroughly to find out the correct diagnosis and planning the state-of-the-art treatment and communicating all this to the patient at an understandable way.

I have used competence in this study as a synonym to capability, professional expertise, being adequately qualified. The original concepts that I have used in my analysis are doctor competence, caring doctor and doctor behaviour at the consultation. They have all been operationalized in the results. Finally I decided to combine these three concepts under the subcategory "competence" which together with the subcategory "benefit" form one of the main categories "quality of care". I am aware of the use and meaning of the words competence and performance in the context of medical education and revalidation of physicians. Based on the narratives of the informants, I argue that lay persons seem to have an innate perception of doctor competence including all the dimensions of knowledge, skills and attitude.

My interpretation is that people as patients are very much outcome-oriented and they want something concrete to happen that would improve their health as soon as possible. They have thought about consulting the doctor very thoroughly and made the decision only after they have tried to deal with the health problem by themselves. They expect the doctor to be capable to help them and to act professionally according to a high standard without any delays.

I have come to the conclusion that one explanation for the often-repeated statement that patients mostly make complaints based on poor communication and breakdown in the interaction with their doctor is actually based on their disappointment to the whole consultation process, including both communication skills and technical skills executed by the doctor. It may happen that the patient feels s/he did not get the kind of treatment, examination or referral she had expected and because of this unsatisfactory outcome the tension can arise during the consultation. In these circumstances the behaviour and the words of the doctor are very easily heard and interpreted in the most negative way and the breakdown in the communication skills dimension becomes the main culprit and the focus of the failure of all the aspects of the consultation process.

My own observation and interpretation based on the narratives of the informants is that patients seem to value a normal, humane relationship with their doctors, not too detached or artificially official and cold. They would prefer having encounters where they meet the health care professional and can discuss with him or her as two human beings do, honestly and openly and show mutual respect. The patient wants to be seen as an individual, equal as a human being even if s/he does appreciate and recognize the superior professional expertise of the physicians. If the patients experience this, they can forgive some mistakes or failures caused by their doctor. They show understanding towards the doctor just as we do in our relationships in general.

I argue that patients are not that sensitive to the doctor's speech and communication skills when things go smoothly and common ground is found during the consultation about the procedures that should be performed and the patient can feel his needs are met. The interviewees stated very clearly that all they expect from their doctors in the communication front is decent behaviour with basic good manners like greeting them friendly, not being angry and not turning their back when talking to their patients. *"There is not much time for chit-chat since the waiting room is full of patients."* The patient takes very seriously every single sign which s/he can read from the doctor's behaviour and makes an assessment whether it means the doctor believes there is some acceptable reason for him or her to be there asking for help or whether s/he thinks the patient is exaggerating the pain and even worse, if the problem is totally "between the ears" which seems to be the worst scenario.

The participants of the study also believed that sometimes the GPs did not give them referrals to specialists just to save the municipality's money. The economic situation was perceived getting worse all the time within the health care and this was suspected to have influence on the doctors' decision making.

There is a gap between the levels of meaning that both the doctor and the patient invest to different topics. The wider the gap, the more serious can the sense of disappointment and even frustration be in the patient's perception. My interpretation is that from the patient's viewpoint the experience of not being heard and not being taken seriously can be perceived almost as an insult to his or her integrity. The patient is most likely to be dissatisfied if the doctor seems to be indifferent and ignores his or her worry during the consultation. S/he has in most cases thought very carefully beforehand about the visit to the doctor.

The patient has waited for the symptoms to disappear and the problem to be solved spontaneously. In the case of long lasting pain, s/he has most likely used the over-the-counter painkillers, and tried all other means of relieving the pain recommended by his or her family and friends. So if it happens that after plenty of preparation and anticipation, the patient is out of the doctor's office in five minutes with a prescription, s/he may feel abused, betrayed and s/he can perceive the visit as unnecessary, not beneficial. The informants in this study told me about doctors who turn their backs, enter information to the computer at the same time when they ask questions and have too little time for the patient. They have met doctors who seem to be insensitive and indifferent to the patient's needs and who get angry with the patient. They also talked about bad management of some situations, not making a proper physical examination and not being aware of the working conditions of the patient when giving them sick leave. According to my interpretation, there seems to be the subtle undercurrent of resentment in some of the narratives based on several unsatisfactory encounters with the health care providers.

The themes that emerged from the content analysis I have named as "Survival despite the suffering of enduring pain", "Trust towards expert doctors who will provide good quality care" and "Struggle against the system". The key issues connected to these themes are endurance, coping with severe chronic pain, not giving up and trust in expert doctors. But there is a darker side to the interaction with the health care system. The exhausting struggle that is sometimes needed to get help and the persistence to win the obstacles preventing easy access and the opportunity to be heard as a suffering human being. For the person, it is most important to have a justification for his or her decision to consult and use the precious time of the doctor. It seems to be a sensitive issue and makes one vulnerable in pursuit of the physician's approval. By listening and taking seriously the patient's problem, the doctor gives the legitimization for making the appointment.

The decision to use the Bayesian modeling in the analyses was based on the curiosity and enthusiasm of applying a novel way for analysing qualitative data. The Bayesian analyses were able to show the dependencies between the patient perception of doctor competence, gaining benefit at the consultation and the interactions with the health care system. The

results in itself are understandable and in alignment with the outcomes of the content analyses. Also it was demonstrated by the B-course fixation table (Fig.5) that when a person perceives a doctor professionally competent, this assessment has impact on his or her attitude towards the whole health care system.

My conclusion is that a good doctor gives face to the system and makes it more trustworthy and acceptable. On the other hand, being disappointed with the health care provider has very clear negative impact on the perception of the quality of interaction in the health care system.

I want to return to the concept of unnecessary visit from the patient's viewpoint. When a patient with severe osteoarthritic pain makes an appointment to see the doctor and leaves the office with the information about the clinical guidelines, which state that the situation does not fulfill the criteria for joint arthroplasty and he gets a prescription of ibuprofen which he has been taking already for a long time, the interpretation may be that there is no added value for the patient from the visit. This is closely connected to the current discussion of value-based medicine. What is needed is shifting the focus in the health care from false savings and restricted services to efficiently achieved good outcomes where the aim should be increasing value for the patient. If the patient does not perceive that s/he has gained any benefit during the consultation, there is no added value connected to the visit and the patient may assess the visit unnecessary. The patient as an expert of his or her own condition makes the assessment of the value of the outcome connected to the consultation.

There is a task for the training of the future physicians to be able to respond to these issues. An attitudinal change is needed in many levels of medical education. Introducing the bio-psycho-social approach together with system theory thinking into medical education, especially the undergraduate clinical training and at more advanced level in the specialist training, could have a positive impact on the future encounters with patients and their doctors. A more comprehensive view on the whole person is recommended instead of the very fragmented picture available at present, which does not seem to serve the purpose of the current needs of the customers of the health care services.

"There are specialists for the left little toe nowadays but nobody seems to be interested in me, take care of me as a whole person" is a comment made by one of the informants.

"If they could, I am sure they would separate this rheumatoid arthritis to some laboratory and once a month they would send me a post card telling I am fine and enjoying life here with every other rheumatoid arthritis."

The participants in this study have been painting a picture of our primary health care, which is not entirely flattering and desirable. There are narratives which tell us about indifference, arrogance, unfriendly behaviour and lack of empathy and effort to serve the patient right. It is difficult to avoid the interpretation based on the descriptions of the experiences of the informants that the main task of the health care system sometimes is to keep the patients away with their demands and needs by every possible means.

In the present Health Care Law in Finland, which has come into force in May this year, the paradigm shift is obvious. The spirit of the Law is to emphasize the freedom of choice for the patient when choosing the health care professional whom s/he wants to visit and work with (FINLEX). In 2014 the freedom of choice is planned to expand to cover the health care facilities of the whole country whether at the primary health care or at hospital care. The very important reform to take place is that "the money will follow the patient" meaning that the health care unit which gives the treatment to the patient will get the economic resources too.

The messages from this study are directed to the decision makers of the medical education and those of the health care system. From the educational point of view it is important to emphasize the equal approach towards all patients as suffering human beings not depending on the quality of their disease. Since the world of medicine is pathogenesis-

oriented, it may happen that some ailments are evaluated mundane and not very interesting from the scientific point of view. The integrity of the person should not be determined by the ICD-10 classification code of her disease but the humanity.

“The doctor was just briefly examining my knee, twisting it a bit and asking does this hurt. I believe a doctor who does not suffer from chronic pain himself can hardly understand how miserable this can be.”

For the leaders and developers of our health care, the important question to be asked is connected to the existence of the system. What are we here for? What is the ultimate goal of our existence as health care providers? An innovative and user friendly approach with a strong moral dimension and concern for ethical issues is needed when building the health care system for the next decades.

The politicians should support the change towards a new primary health care system with human face and the ability to listen to the voice of the patient.

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SYSTEM RELATED		Health care system related concepts															
0180	Access to services	2	1	3	2	2	1	1	3	2	1	1	1	3	1	1	33M51
0275	Economic issues		3					3							3		32F75
0371	Complaining patients														1		31M50
04M67	Equality in health care		1		2	1	1	3	1	3	1						30F55
05F86	Leadership function		1	3	1												29F68
06F69	Patient teaching student	1			1		2			2							28M69
07M62	Need to please	2	1	1	1		2										27M75
08M76	Private care perception	2	3	1	1	2	1	2	2	2	2	2	1	2	2	1	26M69
09F67	Public care perception	3	2	2	2	3	1	1	3	3	1	2	3	3	1	3	25M58
10F55	Physical environment																24M62
11F58	Values and resources		3	3	2	3	1										23F63
12M56	Waiting lists		1	3													22F63
13F74	Experience of operations	1	1	1													21M60
14M58	Unnecessary visit	1	3	1	3	1	3	1	1	3	1	1	1	1	1	1	20F78
15M50																	19F66
16F58																	18F83
17F60																	17F60
18F83																	16F58
19F66																	15M50
20F78																	14M58
21M60																	13F74
22F63																	12M56
23F63																	11F58
24M62																	10F55
25M58																	09F67
26M69																	08M76
27M75																	07M62
28M69																	06F69
29F68																	05F86
30F55																	04M67
31M50																	03F71
32F75																	02F75
33M51																	0180

Appendix 2

CONTENT ANALYSIS TABLE

QUALITY OF CARE

BENEFIT

Patient perception of benefit at the consultation

“Well it cost me 3000 FiM, the whole operation but I was given 1000 FiM reimbursement and also I had good legs to walk with for many years. Which was the most important thing.”

”Nin tuota, se makso kolmetuhatta markkaa mulle se homma vanhassa rahassa, mutta minä sain tuhat markkaa siitä poikkeaa ja minulla ol vuoskausia hyvät jalat kävellä. Ennen kaikkee.”

“There is benefit when the medication is correct and it has been effective.”

”No sillo esimerkiksi, ko on lääkkeet onnistunu ja ne on vaikuttanu, nin se on tottakai se, kyllä.”

“One does get benefit when during the consultation the doctor seems to take you seriously, there is good interaction and thorough examination.”

”No kyllä siitä sillo hyötyy, kun sen näkköä ja tuntoa ite, että nyt lääkäri ottaa oikeella lailla tämän minun, nämä niinku me jutellaan hänen kanssaan ja hän kyselöö ja on kaikkin ja tutkii.”

Satisfaction with care

“The doctor was so polite and she found out all the things in detail and she managed to get this walking aid for me and she took care of everything.”

”Olj hirveen kohtelias ja otti kaikki asiat ihan tuota juurta myöten hän hommas mulle tuon kärrihommanni, mikä on tuossa ulukona nyt peitteen alla ja kaikki ja se piti huolen.”

COMPETENCE

Attentive listening by the doctor

“It is important to notice that s/he is listening to me just now, s/he has time for me.”

”Se on tärkeätä, että huomaa, että mua nyt kuunnellaan, että sill on aikaa just mulle ”

“One should really listen to the patient carefully and find out what is behind the pain, what could cause it and not treat it as something insignificant.”

”Mut tosiaan kuunnella heitä ja ottaa tarkasti seville, mikä se oikeen, mikä siinä nyt on sitte kipujen takana, mistä se vois johtua, ja ei läpihuutojuttuna.”

Patient need to be taken seriously

“So maybe I have been so lucky to have understanding doctors who have taken me seriously and decided this man is not complaining for nothing.”

”Että onko mulla ollu niin hyvä tuuri, että on ymmärtäviä lääkäreitä ollu, että on otettu tosissaan, että katottu, että ei se nyt turhasta taija märistä.”

“The other (doctor) will say, tell me what’s on your heart and what is the problem.”

”Toinen ottaa ihan, että no kerroppa nyt mikä sulla on sydämmellä ja mistee se vaivoo. ”

Doctor caring

“He was always asking does it hurt and that made me feel he was really taking it seriously and it made me think I was in the right hands.”

”Hän aina kysy, että, että koskeeko, että minusta hän kyl niinku paneutu sillä tavalla tosiaa, että potilas tuns, että nyt on oikeessa käsissä .”

“Young doctors these days are so lovely and in a very different way. They are radiating caring and concern.”

”Nykyiset nuoret lääkärit on aivan ihania ja ihan eri tavalla ihania. Just se, ne myöskin, niissä jotenkin hohtaa se ulospäin se huoli ja semmonen ”

Doctor showing empathy

“He said to me there is no point in you cycling and working in the cold weather, even in the winter outdoors, when you are so wretched.”

”Se sano, että ei siitä tule mittään, että sinä tuota matkoo kulet ja semmosessa kylymässä työssä, kun se ol kylmyee, talavellakkii ulukona ja oot nui vaivane. ”

Doctor showing interest

“He was asking me what sort of work I am doing and

what kind of material the floors are I am cleaning.

“Kysy, että minkälainen työ ja minkälaiset lattiat, onko kovaperäiset ja tämmöiset ja kaikista tämmöisistä, mitkä niinku töissä joutuu tekemään.”

“It is easy to talk and then we discuss even other things than health related.”

”Helppo puhua ja siinä puhutaan muutakkiin, kun vaan terveyvestä, että.”

Doctor showing respect

“He can take everybody as an individual, he has that skill indeed.”

”No se osoo ottoo jokkaisen immeisen sillä lailla, että se yksilönä ottaa immeisen, että sillä on se taito kyllä.”

“How do you think will you notice if the doctor is showing respect towards you? Well, I haven’t thought about it in that way ever but of course I will notice from the way he talks and everything, there is a sense of being taken seriously.”

”Miten teijän mielestä se näkyy, että jos lääkäri teijän mielestä niinku arvostaa teitä, ni miten se näkyy? En minä oo sillä laalla aatellu millonkaa... en, muuta kun sen nyt tietysti huomoo siitä puhheesta ja kaakesta, että on kaekki sillä laalla ottaa vakavasti ja nii.

Doctors being at a service profession

“When you are working, it is easy to forget the customer and just think, bloody hell, I am again sitting here at the health centre this late in the evening.”

”Sitte, ku sitä ollaan työelämässä, ni sitä helposti unohetaan se (asiakas) ja sitten, että hitto, että minä oon taas täällä teekoossa, näin myöhään.”

“That’s what the doctors are for... the patients. The doctor would be out of work without patients.”

”Sitä vartehan ne lääkärit on, että potilasta varten. Ei kai sillä lääkäriillä mittää töitä ois, jos ei ois potilaita.”

“It is both and... a service profession and an expert.”

”Se on sekä että... palveluammatti ja asiantuntija.”

“You have to be friendly and you need to serve the patients and this does not suit everybody. It may suit him better to say hello and goodbye.”

”Sun pitää olla ystävällinen ja sun pitää palvella ja tietenkään ei se kaikille sovi. Se mielummin sopii hänelle sillä tavalla, että päivää ja näkemiin.”

“There could be some of this customer-centredness present, this fine concept.”

”Vois olla semmonen asiakaslähtöisyys, tämä hieno sana.”

“One should think about this when seeking to study medicine that I am dealing with customers.”

”Kyl siinä niinku pitäs miettiä, kun sille alalle lähtee, niin asiakkaitten kanssahan minä oon nyt tavallaan tekemisissä.”

Doctor competence

“The doctor at the rheumatologic out patient clinic was very competent and professional when he took me so seriously.” (found out about the kidney problem just by listening to the family history).

”Oli se reumapolilla sillon siltä lääkäriltä hyvää ammatitaitoo ja hyvää lääkäritointa, että hän niinku paneutu siihen sillä tavalla.”(selvitti munuaissairauden vain kuuntelemalla perheanamneesin).

“This surgeon was so competent when he realized to take the ultrasound since the fluid would not have been visible in MRI and they would have taken me as someone who is complaining for nothing.”

”Oli hyvä just tää kirurki, joka hoksasi tähän ultraääneen, koska se ei ois missään magneettikuvissakkaan se neste näkynä ja minua ois pietty ihan turhaan valittajana.”

“Not everybody can be equally competent even if they would study the same subjects. One doctor knows how to perform and the other one doesn’t.”

”Ei kaikki voi olla samantasosia, vaikka ne lukis kuinka paljon samaa ainetta, ni toinen osaa, toinen ei.”

“It is the doctor’s responsibility to find out the cause since they have the skills and equipments.”

”Kyllä se on niinku lääkärin vastuulla sitte ehtiä se syy, koska heillä on siihen taito ja välineet.”

“It seemed that he was able to solve the problem almost automatically.”

”Tuntu siltä, että hän niinkun keksi jo automaattisesti, missä se vika oikeestaan loppujen lopuksi on.”

Doctor behaviour during the consultation

“Well I think this makes a good doctor when one approaches the customer in a holistic way and at her level.”

”No se musta just tekee sen hyvän lääkärin, että lähestyy asiakasta...laajemmin ja asiakkaan tasolla vähä.”

“The doctor takes seriously the patient and listens to her and a good doctor-patient relationship develops where one can trust to receive help.”

”Lääkär tosiaan panneutuu ja kuuntelee ja on, tulloo semmonen hyvä lääkärisuhde, luottaa ja tuntee aina saavasa apua.”

“There are difficult days in patients’ lives as well, so there can be bad days in doctors’ lives too, they are only humans after all.”

”Niin niitä on raskaita päiviä potilaillaki ja huonoja päiviä, että eihän se lääkärikkään oo, ku ihminen.”

“He is just a very quiet man. Otherwise he is very experienced.”

”Se on vaan semmonen hiljanen mies. Kyllä se muuten asiantunteva on.”

“One person always creates the feeling of being in a hurry and the other one does the same job without any hurry.”

”Toinen ihminen saa niinku itselleen aikaan aina kiireen ja toinen ihminen tekee näennäisesti ne samat työt ilman kiirettä.”

“So that s/he would not suspect that I have come for nothing (laughing).That is so unpleasant.”

”Ei tuta ihan ainakaan epäile, että se ainakaan suotta valittaa (naurahtaa). Että se on ihan tympeetä, jos.”

“I was thinking, oh my god, am I here again, but now he has learned, he examined me thoroughly and found out things.”

"Minä aattelin herran jukara, tuasko minä sotkeevun sen luokse, mutta nyt hän on tullu ihan toisen laaseks... nyt se on oppina jo, kyllä se nyt tutki ja kaikki ja otti se levee, nii."

Respect towards the doctor

"In K there are so many top doctors and surgeons that one has to raise one's hat."

"K:ssa on niin huippuliäkäreitä ja kirunkia nii, että hattua pittää nostooki."

"Well one does respect the doctor more than an average educated person since s/he orders things, s/he knows about human body."

"No kyllä sitä niinku kunnioitetaan lääkäreitä, siis keski-vertoa enemmän, että kyllähän se niinku aika tavalla määräälee, se tietää fysiikasta."

"In the old days when one visited the doctor, he was put on a pedestal, he was raised to be a king."

"Ennen vanahaan tuota mentiin lääkärin luokse... sillohan se ol, lääkäri ol niinku jalustalla jollain tavalla se, se ol nostettu niinku kuninkaaks."

Doctor checking patient understanding

"Well they don't do this, I suppose they take it that the patient will interrupt when it is getting incomprehensible."

"Ei ne semmosta kyllä, ei kyllä ne niinku lähtee vissii siitä että se potilas sitte keskeyttää sillä kohalla, kun menee yli hilseen."

Doctor decision making

"The doctors are clever enough to decide about the job." (the operation for an artificial joint).

"Liäkärit on varmasti sen verran, niin viisaita, että ne päättää varmasti siitä hommasta." (tekonivelleikkauksesta).

"I have the appointment time for an orthopaedic surgeon so he can decide what should be done."

"On meno sitten K:hon, että ortopedin vastaanotolle, että kahtoo mitä ruvetaan tekemää."

"I think that the doctor should decide because s/he is the professional... that's how I say to my hair dresser when she asks me something."(laughing).

"Kyllä mä olen sitä mieltä, että lääkäri päättää, et koska, niin mä sanon kampaajallaki aina, että kun hän kysyy jotakin, et sä oot ammatti-ihminen, että..." (nauraen).

Doctor information giving

"There are papers and test results which he takes out and tells me to sit next to him so we can look at them together."

"On niitä paperia ja kokkeita sun muita, nin hän ottaa ne esille ja sanoo, että tule nyt tähän ni katotaan nämä."

"He will be very professional and deal with the patient topics and explain things and tell the situation."

"Ottaa asiallisesti sen potilaan ne asiat ja asiallisesti selostaa ja sanoo sitte, että minkälaine on tilanne."

"One has to ask him questions since he doesn't talk much."

"Siltä pittää kysellä, se ei paljoo puhele."

"Sometimes it is hard to extract any information from him."

"Kyllähän joskus on lujassa, mutta" (tiedon saanti lääkäriä).

"It is very important to me that things are explained properly."

"On tärkeetä, se ois minusta hyvin tärkeetä, et selitetään kunnolla ja."

Doctor responsibility of finding out the right diagnosis

"When you tell your symptoms to the doctor, one expects the doctor to be able to diagnose the problem."

"Kun sen asian selevittää lääkäriillä, ni tuta sitä vuan, tietysti sitä oottaa, että hän sitten sen ossoo määrillä sitten siinä."

"It is the doctor's responsibility to find out the cause since they have the skills and equipments."

"Kyllä se on niinku lääkärin vastuulla sitte ehtiä se syy, koska heillä on siihen taito ja välineet."

"One should immediately start finding out the reasons instead of just relieving the symptoms."

"Alettas heti niitä syitä selvittää ei vaan tosiaan, ni pyritä niitä oireita lievittämään."

Doctor using humour at the consultation

"There needs to be humour in life and if the doctor is clever and able to pick up from the customer the right mood and give it back the same way."

"Huumoria pitää olla elämässä, ei sitä muuten ja kyllä, jos on fiksu lääkäri, tietenki semmonen, että näkee asiakkaasta, että samalla mitalla takasi."

"The young woman had complained how expensive it is, the artificial insemination and then the doctor had replied I would have taken care of this without any cost."

"Nuori nainen oli sitte valittanu, että kun se niin kalliiks tulee, se keinohedelmöitys, ni lääkäri oli sanonu, että minä oisin ilimaseks sen asian hoitanu" (nauraa).

"It can be difficult for the doctor since somebody may like (the humour) but it could be that somebody really gets angry."

"Onhan se lääkäriilläki varmaan sitte, että joku tykkeis hyvinnii, mutta toinen voi olla, että suuttuu tupsahtaa iha."

"If somebody is visiting because of the pain s/he is not very willing to listen to any jokes."

"Joku kivun takia männöö, ni ei se hyvin paljo siellä (nauraa) ruppee vitsiä kuuntelemaan."

"The doctor should reflect the situation, how the customer is reacting. Not everybody can be said like that."

"Se pitäas tavallaan peilata asiakasta sillan, että miten se reagoi. Ei kaikille asiakkaille voi sanoo sillä tavalla."

Doctors as equals

“One should not feel nervous, just to go in. Aren’t they similar human beings?”

”Ei, mitä sitä passoo jännittee? Eiku vaan männöö. Eiks ne oo samanlaisia immeisiä?”

“After all, they are humans” (laughing).

”Ihmisiähän ne on.” (naurahtaa).

“Well she is a bit like my mate, the doctor is.”

”No, et se on niinku kaveri vähän niinku se lääkäri.”

“Just ordinary, so he is not showing off he has studied to become a doctor.”

”Tavallinen nii, ettei oo semmonen, että hää on käyny lääkäriks tiptop, tarkotan, nii, että hää nyt on vähä, että pittää, että ei näätä sitä, että on lukenut immeinen, nii.”

“Nowadays the doctors have become humans, they are like other people.”

”Nykyisin on lääkärit tulleet ihmisiks, ihan niinku muuttii ihmiset.”

“There are orthopaedic surgeons, professors and all those whom you cannot tell whether they are ordinary people.”

”Täällä on niitä ortopeetiä, rohveessoria ja kaikkia nin eihän niitä voi tavallisista kansalaasista erottaa, joo.”

“It could have been as I was younger that you respected, thought highly of. Now they seem to be so much younger, close to equals.”

”Oisko se nuorempana ollu, että sitä niinku kunnioitetaan, katsotaan ylöspäin. Nyt tavavallaan ne on nuorempiaki aika paljon, lähes samanvertasena...”

GP competence compared to private doctor competence

“At the private gynecologist they told me the GPs don’t necessarily have the expertise needed.”

”Yksityisellä gynekologilla sanottiin mulle, että ei näillä terveyskeskuslääkäreillä oo välttämättä sitä ammattitaitoo.”

“When I went to have better investigations at the private sector they found out there were already severe osteoarthritis and degenerative problems.”

”Ku läksin parempiin tutkimuksiin yksityislääkärille, ni todettiin, että siellä on jo pahat niinku nivelrikoja ja kulumavikoja.”

“I cannot blame the health centre doctor either but somehow it feels as if they took it more seriously when I made the appointment to the private doctor.”

”En sovi moittimaan sitä terveyskeskuksen lääkäriä, mutta jotennii tuntu, jotta minä sain niinku enemmän otettiin kantaa siihe, kun mänin yksityiselle.”

“So they went in to details, they wanted to find out what is wrong here, this is not right.”

”Nii, että silleen niinku syvennyttiin, että tää pittää saaha seleville, että mikä on, tää ei oo oikeen.”

“They never took x-ray from my knee at the health centre. I then did it privately to find out what was wrong with it.”

”Polovee ne ei oo kuvannu millonkaa (tk:ssa). Minä kävin sitte yksityislääkäriässä tään V:ssa maksoin tään poloven, että tiesin mikä siinä on.”

Trust in doctors

“Well it is the doctor who needs to say what can be done and what shall be done.”

”No kyllähän se lääkärs se kuuluu sannoo mittee on tehtävissä ja mittee tehään.”

“One does trust the doctor and his words so much more.”

”Kyllä sitä aina niinkun ihminen luottaa lääkäriin, sen lääkärin oppeihin niin paljon enemmän.”

“I think it conveys trust, this doctor cares about me, s/he wants to take care of this. S/he does not know but will find out.”

”Et mun mielestä antaa niinku semmosen luotettavan kuvan, et joo, hei tää on huolissaan minusta, se niinku haluaa hoitaa tän homman, että joo se ei ite tiijä, mut sepä ottaa selville.”

“Well, one has to have trust in doctors. Nothing else will help.”

”No kyllä se on pakko luottoo (lääkäreihin). Eihän tässä mikkään muu auta.”

Patient feeling free to open up

“Somebody can make you feel at ease immediately so that you feel free to talk but I cannot tell what causes this.”

”Toinen ihminen ehkä tuntuu paremmin sillä lailla heti, että vappaantuu, minä vappaavun puhumaan, mutta minä en ossaa sannoo, mistä se johtuu.”

“One does notice at once, when entering the consultation room whether it is possible to talk freely and naturally with the doctor.”

”Kyllä huomoo lääkäristä heti, kun männöö, että mitenkä tämä on, että onko näin, että voep vappaasti ja luonnollisesti ja kertoo asiasa.”

“It felt like I was the only one there and let us now discuss this matter and we are not in a hurry at all.”

”Ihan silleen niinku tuntu, että eipä oo, sinä olet se ainut siinä ja otetaampa nyt tämä asia ja ei oo minnekkää kiire.”

Being on the same wave length with the doctor

“If it happens to be a doctor who is at the same wave length and who will just slip in something, it makes it easier to open up.”

”Jos se on semmonen lääkäri, joka tavallaan artikuloi samalla aaltopituudella, jotaki heittää mitä tahansa, ni siinä niinku avautuu helpommin.”

“In his case, we just got on very well. Maybe it was based on the acquaintance when he was already like a family doctor looking after the parents and the children alike.”

”Hänen tapauksessa, se vaan synkkas jollain tavalla, että ehkä se tuttavuus teki sitte, kun hän oli jo lopulta perhelääkäri, että hoiti niin lapset, kun isän ja äidin.”

“It is surprising you still live (the doctor said). I said to that it is touch and go.”

”Ihme, että sinä elät (lääkärin toteamus). Minä, että, no siinä se kiikun kaakun on kuule.”

GP readiness to refer to specialist care

“They injected the drug into my knee three times, to improve the function. It didn’t. After that he had to write the referral finally. He took his time with it.”

”Siihen pantiin semmosta, piikillä muka semmosta ainetta siihen poloveen, että se muka vaikuttaa. Ei se vaikuttanu mittää. Kolome kertaa. Sit piti, (kirjoittaa lähete), sain sen lopulta. Ei se ollu oikeen hopukas laittamaanakaan sitä.”

“At least he should refer the patient to a more competent doctor if he is not capable of treating himself.”

”Ainaki lähete antaa viisaammalle, jos ei kerra ite (osaa hoitaa) .”

“Obviously it is the experience that matters and one has to state that the GP does not seem to have this. But s/he should refer the patient forward to an expert who is capable of helping.”

”Kokemushan se on, joka sanoo, täytyy sanoo, että terveyskeskuslääkärillä ei ilmeisesti oo, mutta hänen pitäs lähettöö eteenpäin tutkittavaks semmoselle henkilölle(joka osaa auttaa).”

Easiness of communication
at the consultation

“I will always ask the doctor if I can tell all my worries to her... my doctor is a very nice lady.”

”Minä kyllä aane, jos on mulla ussempi asia, ni minä sitte suanko minä sanoo kaakki vaevat, nii....hyvin on semmonen soma tämä naislääkäri.”

“I find it easy to talk when I am complaining about a real issue so why should it be difficult.”

”Kyllä minusta ainaki on ollu asiasta ku valittaa, ni mikä siit on puhhuissa.”

“We never sit and talk face to face like this, never, it seems that he is always in a hurry, that is a minus.”

”Me ei koskaan niinku tälleen kasvotusten jutella lääkärin kanssa, ei ikinä, et hällä näyttää, et hällä on kyllä aina kiire, että se on miinusta.”

“For me personally it is very easy to approach the doctor since he happens to be my acquaintance.”

”Mulla henkilökohtasesti on heleppo lähestyä, koska tämä lääkäri on tuta vähän niinku muutenki tuttu.”

“Being so outspoken, which we managed to be among this exaggeration and joking was somehow helpful.”

”Mut se suorapuheisuus, mihin se lopulla aina sitten tän sairauden ja leikinlaskun ja karrikoinnin tasollaki päästiin, ni se jollain tavalla autto.”

NARRATIVES OF SURVIVAL

ENDURANCE

Chronic pain experience

“One has to lean on the freezer and the furniture on the way to the toilet, the joints are so painful.”

”Kyllä sitä niinku pakkasii ja muihin nojjaillaan, että piästään vessaan, että ne on niin kippeet .”

“The pain arrives like a big wave. Then it lasts for many hours.”

”Se tulee, ku hyökyaalto se kipu. Se on monta tuntia sitte aina koskee.”

“This is like a hell on the earth, to live with this pain.”

”Tämä on ihan muanpäälaine helevetti kyllä tämän tuskan kanssa ni tuota olla. ”

“It makes one yell when starting to walk. One has to curse out loud sometimes when it hurts so much.”

”Se ärjytyttää ryökäle, ku lähtöö kävelemmään, ni iäneen pittää ärjyvä välin se kääpi niin kippeeks.”

“When there is a good day and there is less pain, one feels that everything is in control. But then there are times when it seems you cannot stand, cope or tolerate this at all.”

”Et sillon kun on hyvä päivä, ni koskee vähemmän tai muuta, ni sillon tuntuu, että kaikki on niinku hallinnassa, mut sitten tulee niitä semmosia kausia, et tuntuu, et ei täst selviä millään, eikä tätä jaksa, eikä pysty olemaan eikä...”

“The constant pain and agony, it does eat you up.”

”Se jatkuva kipu ja tuska, ni se vähän niinku rassaa ”

“And is the pain on a daily basis? Yes, night and day, 24 hours a day.”

”Ja onks se särky ihan päivittäistä, että ihan..? On, on ihan yötä päivee, kaksikymmentäneljä tuntia päävässä. ”

“One always ponders (laughing) whether one is complaining for nothing, when it is hard to judge the subjective feeling of pain, how terrible it now is when you experience it all the time.”

”Aina sitä tulloo aateltua (nauraa), että valittaakohan sitä turhasta, joo, ei ossoo niinku omalta kohaltaan sanoo sitä, että onko se nyt sitte hirvee kipu, kun niit on jatkuvasti.”

Depressive mood

“Sometimes one gets a kind of feeling of hopelessness that once I said I am tempted to get the package of Tramal and take them all at one go so this would end.”

”Joskus tulee niinku semmonen toivottomuuden tunne tietysti, että mä kerran sanoin, et tekis mieli mennä vielä kerran hakee se yks paketti sitä Tramalia, iskee kerralla turpaan ne, ni loppuu tämä. ”

“It brings your mood down, am I really a crippled who cannot go anywhere.”

”Sitte se vie niinku mielialanki sitte alaspäin sitte tota, että onko mä nyt tosiaan tämmönen rampa, että en pääse minnekkään. ”

“Well it certainly affects when the other one is irritable and the constant pain in the hip did influence sex life and other things.”

”No kyllä se vaikuttaa varmaan, ku toinen on kärttynen ja sehän se jatkuva särky tuolla lonkassa, ni sehän vaikutti jo seksielämään ja vaikka sun mihin helekattiin.”

Sex life and joint pain

“At least one has to choose the positions. One cannot pursue the way one did when young and also erectile dysfunction started to happen.”

”No ainakin asennot pitää jo valita. Ei sitä ihan olla niinku nuorena ja siinä ihan erektiovaikeuksia tuli jo. ”

“In the beginning he would have wanted and he did visit the health centre to get help for the erectile dysfunction. But when I explained to him I am now ill this way so could we just lie close to each other.”

”Hän tiesti alakuun oisi halunnu ja kävikii apua tuolta terveyskeskuksesta siihen potenssiongelmaan, mutta sitten, kun minä hänelle selitin, että kuule, että kun minä oon nyt tällä talvalla kippee, että jos vaan, nin ollaan vaan lähellä toisiaan. ”

“One does say (to the partner), go away, it does affect.”

”Kyllä sitä niinku, että mänehä muualle. (nauraa) Kyllä se vaikuttaa. ”

Illness tolerance

“I find this mentally very nasty because I have been physically active.”

”Siis tää on ollu minun mielestäni inhottavaa henkisesti, kun mä oon ollu menevä sikäli. ”

“Of course one complains and somebody may have more pain and whine less, s/he is just biting the lip. But the other one is more sensitive to pain and all this is so much dependent on the personality.”

”Tietysti tulloo valitettua ja toeseen voi koskee enemmän ja toene ee valite, nii se purroo hammasta ja toene on tietysti kipuherkempi, ku toene ja tuota paljohan se siitä on luonteesta kiinni. ”

“There are things which you can do and things you can't do anything about.”

”On niinku asioita, joita voi tehdä ja asioita, joille ei mahda mitään ”

“I don't cope well, I am coping poorly but not well.”

”Minä en pärjee hyvin, mä pärjään huonosti, mut en hyvin.”

“So are you willing to get rid of your pain, the doctor asked. I said, bloody hell I want since I have had this pain for twelve years.”

”Että halluutteko työ piästä niistä kivustanne. Minä sanon, että totta hitossa minä kakstoista vuotta oon pitänä. ”

“You have just been very stubborn and suffered? So I have been forced to, although I guess my wife has suffered even more than myself.”

"Te ootte vaan sinnikkäästi kärsiny?" "No niin sit on pitänä, vaekka enemmän kai se vaemoväki kärsii, kö minä ite."

"I have been thinking this is my destiny and this is how it has to go."

"Minä ainaki oon aatellu, että se on minun kohtalo ja se on näin mäntävä."

Bitterness

"When you have to leave for work very young you harm yourself since you are still half-grown."

"Se ku nuorena pitää lähtee, silloin sitä särköö ihtesä, keskenkasvusena lähtöö."

"They did not give me anything, not any money since I have left home. Such a hard destiny I have had."

"Kotoo ei annettu minkäänlaista, ei minkäänäköstä rahapuolta, ei markallakaan ei annettu, että kun minä oon kerta pois lähteny, niin ei mitään annettu, että se oli niin kova elämän kohtalo."

"Well I have not complained much, I have been so persevering that I haven't groaned."

"No minäpä en paljon oo valittanu, minä oon ollu niin sitkee ihminen, että minä en oo paljon valittanu."

"Ten years is a long time even with this kind (of joint pain)."

"Kymmenen vuotta on pitkä aika tämmösesäkki."

"They laugh how easy it is to get money for booze. When a poor pensioner like me goes and asks support for living costs, I will get nothing."

"Nauravat miten helpolla saapi viinarahaa. Tämmöinen pieni eläkeläinen kun menee ja pyytää vaikka asumistukia, nin ei saa."

"Every half an hour there was a bus to take the privates to the hospital investigations but we who were employees had the occupational health care doctor who was giving us sympathy only."

"Tasalta ja puolelta ja tunnin välein tosiaan meni pikkubussi vietiin tutkimuksiin, ni että me jotka oltiin palakka-työssä, ni sitte pitää mennä tosiaan työterveyslääkäriin, joka antaa vaan myötätuntoa."

Disappointment

"What was it that made it so bad? Well, most of all I would think the disgusting arrogance did it. Even if he is highly educated I have never encountered anybody like him."

"Ni mikä sen teistä teki erityisesti huonoks? No ennen kaikkee semmonen tymepeys, ei se vaikka hän on korkeesti oppinu ihminen, nin emminä oo hänen kaltaistaan tavannu missään täällä."

"To me all the negative things have happened when dealing with her (the local GP)."

"Minun kohalla on kyllä kaikki negatiiv- tapahtunu hänen kohallaan."

"What hurt me most was that I felt so exhausted and she was just enjoying the beginning of her summer holiday and I left for home to bleed."

"Se minuun sattuu kaikkein enimmäin, kun minä olin niin väsynyt ja hän iloitsi siitä, että kun hän pääsee kesälomalle

ja minä vaan läksin kottiin vuotammaan."

"I was so disappointed with the doctor I hope I will never have to consult him again."

"Minä ainakin petyin siihen lääkäriin niin, että ei toivottavasti en tarttis millonkaan."

Activities of daily life

"Maybe I've learned some stubbornness since my mother was coping (with her bad legs) so why shouldn't I."

"Oisko se opettanu sit vähän sitkeyttä, et kun äitikin noin sitkeesti meni, ni kai niinku minäkin."

"It has not always been such a smashing job but you just need to get on with life."

"Ei kai ne nyt nii oo tuota herkkuhommii, mut se on aina vähän semmonen, sitä pitää vähän niinku jotennii vaan selevitä."

"There is so much going on here at home all the time with many children around that you cannot listen to your own mind and perceptions."

"On tämmöstä huisketta aina meillä, kun on tätä porukata, ni ei siinä jouva aina ommoo mieltään kuuntelemaan."

"I am walking every day, short distances, to keep the muscles fit."

"Joka päivä mää kävelen, mut pienissä erissä, että pysys lihaskunto hyvänä."

"After two hundred metres the pain gets so nasty that I have to stop and rest."

"Parisattoo metriä ja sillee, että kai se, se tuo kipu sitten nii tulloo inhottavaks, et sitä pitää huilata sitte."

"I have managed so far but it is getting more painful and I need to take care of the heating with wood and all other tasks in the house."

"Ihan oon selevinny vielä, mutta nyt on kyllä kohta tuskallista, jos ei, kuitenkin puulämmitys ja tämmöset askareet pitää tehä."

"I have been riding a bike a lot but now I dare not since my leg is so stiff."

"Minä oon pyörällä ajana paljo, nii, mut nyt en uskalla, tää on niin könttä."

Working conditions and health

"And the last year while working I was dependent on the pain killers."

"Ja viimeisen vuoen tein töitäkin melkeen särkylääkkeihen varassa"

"I was working with delivering goods for shops so I had to lift and carry lots of heavy things which may have influenced my hip problems."

"Kauppatavaran kuletuksissa, muissa, että paljo nostelemaan, ni siinä kait män mun lonkkanivel."

"I was given petidin injections while I was working so that they just gave me the injection and I continued to work." (at the local hospital ward).

"Petidiiniä pistettiin ja minä olin töissä, ni et kipupiikki laitettiin ja töissä vuan oltiin."

"I had to tolerate the severe pain for the last few working years since my pension was dependent on the

income level of these last years.”

“Piti kärsiä viimeiset työvuo­det näistä kivuista, koska eläke määräytyi näitten viimesten vuosien tulojen perusteella.”

“Does this make any sense when you have pain every­where and after the working day you feel like you have been running a marathon.”

“Onko täs mitään järkee, kun joka paikkaan koskee ja sit työpäivä vaikuttaa niinku suurin piirtein ois maratonin juossu.”

“I started working at the forest when I was 14 years old. In those days one did not spend time watching the videos.”

”Minä lähin metsään töihin jo sillon neljäntoista vanhana, että ei sillon oltu ihan videoihin ääressä.”

COPING

Gratitude towards own spouse

“I need to give credit to my spouse who has been calling and taking care of things when I myself haven’t paid attention much.”

“Pittää tuota avovaimoo ansiota, että se on jaksennu soitella ja hoitaa, että ite vähä niinku liian hällä väliä on suhtautunu.”

“My wife does everything. I haven’t been able to do anything (at the house) and this is even more stressful for me.”

”Vaemo tekköö kaikki. En oo pystyny tekemää mittää ja tämä rassoo minua vielä henkisesti.”

“My husband saw how difficult it was for me to walk and then he even tried to do my tasks at home.”

”Mies näk, että mitenkä mää männä renttasin, kun ol kip-pee jalaka, ni se yritti tehdä sitten niitä minunki hommia.”

Giving meaning to a long-term illness

“I am a guinea pig and that’s it.”

”Minä oon koekaniini ja sillä siitä.”

“I have been thinking this is my destiny and this is the way I have to live.”

”Minä ainaki oon aatellu, että se on minun kohtalo ja se on näin mäntävä.”

Family support

“My son bought me a flat which I have been very pleased with and would not swap to anything.”

”Et poikani hommas asunnon ja sitten ollu oikein tyytyväinen, enkä haluaisi enää vaihtaa.”

“My children have tried to get me all sorts of things to make life easier for me.”

”Lapset on kyllä yrittäny mulle kaikkee hommata semmos- ta helepotusta.”

“All the men in my family will drive me anywhere I want to.”

”Mul on perheessä noita miehiä, jotka mua kuskaa

autolla.”

“My family is helping me very much.”

”Kyllä mejän porukka niinkun jelppii hyvin.”

Autonomy

“The very good thing is that old people can live their own lives by themselves. At least I would not want to live with my children.”

”Hyvä se puoli, että vanahat saa asua erillään ja on oma asunto. En minä ainakaan osais olla mun lasten perheissä.”

“At least I would not want any helping hands at this stage. About the future one does not know.”

”En minä ainakaan haluais kettää avustajaa tällä kertaa vielä. Tulevaisuuttaha ei tiijä.”

“So they took me here (when admitted to hospital) even if I didn’t want to.”

”Et nehän ottaa tänne ihan, vaikka ei ite haluaiskaan (sairaalaan tarkkailuun).”

Help seeking behaviour

“In general I do not make the appointment for a minor problem. It has to be something worth going and then I really need the help of the doctor.”

”Yleensä en turvaudu heti paikalla pieniin kipuihin, enkä näihin, että se täytyy olla sitten todella jo sen arvosen a se lääkäriin meno, että minä tarvitsen lääkäriä ja apua.”

“I always try to postpone the visit to the doctor as long as I can cope somehow.”

”Minäkää en ihan ensimmäisessä häässä oo lääkäriin mänössä aena, että minä koetan kahtoo sitten niin kaavan, kun pärjeen.”

“Now I was thinking why should I jump to make an appointment to the private doctor when we have a perfectly nice health centre next to where I live.”

”Nyt mä aattelin niin, että miks mä hyppään yksityislää- kärille, kun meil on ihan hvyin miellyttävä terveyskeskus siinä ihan lähellä missä mä asun.”

“I am too shy to make an appointment for every symp- tom so I prefer to tolerate the pain for some time.”

”En minä nyt kehtoo sinne lähtee iha joka vaivaa ainakaa, että, et tuota mieluummin vähän niitä kipuja kärsii kö.”

“I myself have never visited the doctor until the situa- tion has really been serious.”

”Itekkii on menny vasta sitte, ku on pää kainalossa.”

Patient explanatory models

“I have never been in such a poor condition as I was now maybe caused by the fact I have stayed indoors all winter.”

”Mä en oo eläissäni ollu niin huonos kunnossa, kun mä olin nyt, ehkä johtuen siitä, että mä en viime syksystä asti voinu ulkoilla.”

“My mother had very bad knees and varicotic veins. And I have tried to avoid varicotic veins by lifting up my legs and so on. I have not inherited them but I suppose the knee problem comes from my mother.”

”Mun äidilläni oli nimittäin pahat polvet ja suonikohjut. Ja

mä oon suonikohjuja yritin varoa, et mä oon niit hoitau ja pitäny jalvoja ylhäällä, et mä en oo niitä niiku periny, mutta mä luulen, et nää polvet on kyllä perua sieltä.”

“I kept thinking could it be that something got into the joint but I don’t really believe this. The skin was erupted, maybe some bacteria entered.”

”Minä vielä mietin, että lähtikö siitä jottai tähä, mut en minä usko, että, kun tuota se sitten rikkoutu vähän tuo polovi. Siihen pääs joku bakteeri.”

Alternative care

“I was mixing and preparing myself some ointment from herbs and flowers (laughing) and all kinds of compresses. I have studied these things since I am interested in alternative care.”

”Keitin itsekin salvaa vesiangervosta ja kuismasta ja kehäkukasta (naurahtaen) ja kaikenlaisia kääreitä. Mä oon tutkinu ja, ja kaikkee tälläst, et kun mua kasvit kiinnostaa kaikki tämmöset.”

“I have been taking the fish oil capsules, I am not sure whether they will lubricate my joints.” (laughing).

”Minnoon syönä noita kalanmaksatablettia, nuiita kapselia, että en minä tiijä, voitelooko ne (naurahtaen) sitten vae ei.”

“Now I have started having this zone therapy for this knee. All parts of our body can be found in the soles of our feet.”

”Nyt minä alottelin semmosen, kun vyöhyketerapiahoidon tälle (polvelle). Ihmisen elimistöhän löytyy jalkapohjista kaikista....“

“I started taking regularly these ginger and mussel products and I believe that made it possible to postpone the worsening of the joint problem for ten years.”

”Rupesin jatkuvasti syömään niitä simpukka ja inkivääri ja mitä näitä oli tabletteja ja sillä tavalla minä todennäköisesti sain jatkettua tätä kymmenen vuotta eteenpäin.”

Accepting psychological reasons behind symptoms

“I almost know when it sometimes gets going and one senses when it does, one has to press the brakes.”

”Minä melkeen tiijän, että ku se joskus lähtee mänemää vähän sillo ku tietää, millon se männöö, pittää lyyväh vähä jarruja.”

“I asked one of the doctors are you going to diagnose me as crazy, bloody hell.”

”Minä jo sanoin tuolle yhelle lääkärielle, minä sanoin, että meinaatteko työ tehdä minusta hullun, saakeli.”

Between the ears problem

“Obviously my negative feedback has reached her ears... after this she even started to write the referral and took me seriously since not everybody has the problem between their ears.”

”Nähtävästi tää mun negatiivinen arvostelu on nyt menny hänelle tietoon... sen jälkeen hän rupes siitä lähetettäkin, että hän niinku otti tosissaan, että eihän nyt kaikilla oo korviin välissä se vika.”

“Since I was having so severe pain in my stomach during the night I told the doctor I already thought I was having problems between my ears.”(laughing).

”Kun ne ol nyt niin kovat kivut yöllä sitä alamahassa, ni minä sanoin (lääkärielle), että minä jo luulin, että se on korviin välissä.”(nauraen).

“Maybe that’s why I always postponed the visits to the doctor so that he wouldn’t think there is something wrong in my head since I am such a frequent visitor.”(laughing).

”Ehkä mä sen takia niinku pitkitinki niitä aina (lääkäriissä käyntejä), että nyt en viitsis juosta tuonne koko ajan, et lääkärikin aattelee, että mitä tuo nyt täällä myötäänsä, että onks sillä pollassa vikaa.”(nauraen).

“Maybe the doctors did think the problem was between the ears since they could not find anything wrong with my big toe even if I was always complaining terrible pain.”

”Jos ne lääkärit sillon arvel aena, kun minä sitä valitin, ku se on nii kippee, ja tuota, että se on korviin välissä viikko, että kun tota ee viikko löyvy varpaasta.”

Coping with a chronic illness

“Somehow I have managed with my knees through life so far.”

”Jollain tavalla sit vaan taiteillu sit sen elämäni näitten polvien kanssa.”

“One should not let life get to the depressive mood.”

”Ei se parane ruveta tuota antaa elämän mennä masennuksen puolelle.”

“There has to be humour, this is merely life.” (laughing).

”Pittää sitä huumoria olla, eehä tämä oo ku elänee vaa (naurahtaa).”

“I have kept this thing going, I haven’t locked myself in here totally.”

”Mulla on ollu se homma, että minä en oo sulukeutuna tänne iha kokonaa.”

“One did not ever think about oneself so much.”

”Sitä vaan ei ihteeä kait aatellu niin paljo aina.

“So you always managed somehow? Yes, somehow I did manage.”

”Et aina jotenki pärjäs? Jotenni pärjäs aina.”

Self care

“Well obviously I was hanging on the ladder outside and did all sorts of things” (to ease the pain).

”No minä tiesti roikun tikapuilla ulukona tuolla ja palotikkaalla ja vaikka mitä yritin sitte.”

“I will do every day some physical exercise. It should be beneficial preoperatively.”

”Joka päivä niitä on vähän niinku voimisteluna. Se on muka niinku sitä leikkausta varten tehhään tuota.”

“I was recording every thing I was eating five times a day into a note book. It was very helpful.”

”Nii, täsmällisesti ja viis kertaa päiväsä ja sitten minä, pantava, että mitä syöpi. Ja siit oli kova apu”

“When I wake up I always do the dry brushing for my

skin standing on one leg.” (for the balance training).

”Mä kun herään, ni mä aina kuivaharjaan siis, lähden siis, et mä seison yhdellä jalalla .”

“I wake up during the night and do the massage for the other leg since I notice it helps to take the pain away.”

”Mä jopa yölläki, ni toisella jalalla mä hieron tiettyjä kohtia, kun mä huomaan, et se helpottaa ja se kipu niinku häviää .”

“There was one peculiar common feature for all those centenarians; they had a positive approach to life and they were curious.”

”Yks merkittävä yhteinen piirre oli niille satavuotiaille, että ne olivat positiivisia elämänsenteeltään ja uteliaita.”

Patient responsibility of own health

“I was secretly taking aspirin even if I didn't know that may help.” (in angina pain).

”Otin vähän niinku salloo aspiriinia ja tuommosia jottain, kun minä en tiennykkään, että se aattas sekkii .”

“I am doing physical exercise so I am getting on very well.”

”Pittää ite jumpalla huolta, ni sen kans pärjää erittäin hyvin .”

“They will not nowadays even take you to the hospital for an operation if you are physically in a poor condition.”

”Ne ei ota kuulemma nykysin, jos on oikeen huonokunto- nen ihminen, ni leikkaukseenkaan .”

“At least I cannot blame the doctor, many people already had told me I need to go and get it sorted out.”

”Ei se oo ainakaan lääkärin vika, että kyllä minulle jo monetii sano, että tuo on mentävä hoijattaa.”

Pain killer use

“Last winter I was basically just sitting, reading and watching tv while taking the pain killers”.

”Koko viime talven minä melkeen istun vaan ja luin, katoin telkkua ja söin särkylääkkeitä”

“I had to take lots of pain killers and my liver function has not been normal since.”

”Minä jouvuin niitä särkylääkettä hirveen paljon syömään. Ja maksa-arvot on ollut sitten koholla ihan siitä lähtiin vähän aena.”

“For a very long time I was having so much pain even at rest so I had to take pain killers and I made all kinds of analgesic gels myself too.”

”Mulla oli kamalan pitkän aikaa oli niin, että mulla oli ihan leposärkyäki, et mä jouduin ottamaan särkylääkkeitä ja kaikkia, kaikki kielit ja kaikki minä voitelin ja tein.”

“I have tried to be careful not to take too much medication so I will listen to the pain before taking anything.”

”Kun mä oon koittanu vähän varoa etten söis niin noita läkkeitä, et mä en, et mä vähän kuuntelenkin tuota kipua.”

“I brought from Estonia some ampules of pain killers and my wife gave me the injections but they did not help either. They are not real drugs.”

”Minä toin tuota Virosta toin nuita ambullia, kun siellä kirjotti joku, ni emäntä tupsii niitä perskannikkaan mulle vaan. Ee nekkään aattanna, ee ne oo huumeita.”

“These coxids which influence through the central nervous system, I decided to stop taking them. I will rather yell from pain but I will not take them. I don't have that much of brain function left that I would chemically destroy it even more.”

”Näist koksisteista, jotka vaikuttaa keskushermoston kautta, nin minä lopetin niihin syömisen, minä ennen vaikka huudan, mutta minä en syö niitä. Mulla ei oo tätä älyä niin paljon ja muistia, että minä enää sitä kemiallisesti sillä tavalla tuhoisin lisää ”

“But I will not take pain killers for nothing if it only removes the symptom. So what causes the pain?”

”Mutta turhaan minä syön kipulääkkeitä, jos se vaan oireen poistaa, että mistä johtuu se kipu ”

“I don't like taking the pain killer, the pain has to be very bad so as to make one sweat.”

”En mielläni, en missään, siis ihan helpossa tapauksessa ota kipulääkettä, pitää kipu olla tosi, jotta hiki tippuu päästä.”

SYSTEM ENCOUNTERS

UNFAIR SUFFERING

Treatment failure

“It was just bad luck when they did the lumbar puncture, the anaesthetic rose into my head...”

”Huono tuuri kato kävi, että kun sehän tehään sillä selekäränkaan punktio, no se nous latvaan asti se puudutus sitte.”

“So it is your back again giving you trouble. I said I don’t know. He did not check anything, just gave me the prescription for an anti-inflammatory drug.”

”Että selekähkö sulla tuas. Minä sanoin, en minä tiijä, ei kahtona mittää, anto vaan Buranoita anto mulle.”

“It was just these heart problems emerging when I decided to go and see the doctor and ask about the tightness in my throat. I was only given cough medicine.”

”Just nämä syvänhommat tulj, jotta niistä P:lle mäniin sittä valittammaan sitä jo, että mikähän se on, ku se kurkkua ahistaa, ni se anto vaan yskänliäkettä.”

“The joint was not inflamed since the tendons were torn. That’s what it was all about.”

”Ei se ollu tulehtunu, kun siitä ol ne jänteet poikki oli näistä. Siitähän se ol kysymys eikä mistään.”

“When I had my neck massage on Thursday I was not able to stand on Saturday. And was the blood pressure high? Well, it was almost 300.”

”Kun minä kävin torstaina niskat hierottamassa, ni minen laavaintaina kestäni seisallan ollenkaa.

Ja olikse korpkee se verenpaine? No melekeen kolome-sattaa.”

Feeling anger

“I think if you are employed by the municipality, you should stay at your own work place.”

”Kyllä pitäs olla, jos kerta palakattaan, ku kunta palakkaa, ni kyllä pitäs pysyä siellä omalla työmaalla.”

“He asked me to lay on the examination table, lift my leg and said this is osteoarthritis, we will do nothing for this. If something is done, it will be an artificial joint but since you are not old enough we’ll do nothing. Goodbye (annoyed).”

”Pani siuhe pöytälle, heilaatti jalkoo ja sano nivelrikko, näil ei tehä mittää. Sit jos tehää, pannaan nivel, mutta ku ikä on tuommonen ei tehä mittää, näkemiin” (äkäisesti).

“So you are already using the walking stick. The only equipments left are the walking aid and the wheel chair. These are your choices. I was shocked to hear the doctor talking to the patient like this.”

”Että joo, teillähän, mut keppihän teillä on, eihän tässä oo, kun rolaattori ja pyörätuoli. Nää on teidän vaihtoehdot. Minusta se oli aika järkyttävä, että lääkäri sano potilaalle tällä tavalla.”

“He said he will not start dealing with this since there is only a fifteen minutes appointment time allocated for

me. So I stood up and left.”

”Hän sano, että hän ei ota tähän kantaa, et teille on varattu vaan viistoista minuuttia aikaa, ni mää sitte nousin siitä ja läksin.”

Doctor indifference towards the patient

“The doctor, if he is not experiencing some pain himself, does not know how miserable this can be.”

”Näihin ei niinkun lääkäri, jos ei itse koe kipuja, ni ei tiedä, miten se voi olla viheliästä.”

“He took me as if I only was of secondary importance, made me feel like “poor you, why did you come to bother him, you should have gone somewhere else.”

”Ottaa vähän niinku toisarvoisesti, ei oikeen, tai se antas semmonsien kuvan, että voi ukko, kun tulit hänen luokseen, oisit mennä muuvalle.”

“The bad doctor is somebody whom the patient tells his worries to and the doctor only gives him a prescription and says, “next”.”

”Huono lääkäri on sellanen, et potilas tulee ja kertoo, mikä sillä on ja lääkäri iskee jonkun reseptin kouraan ja sanoo, et seuraava.”

“Somebody who couldn’t care less...he did not pay any attention to the patient.”

”Semmonen hällä välii, nii. Että se ei potilaaseen kiinnittännä ollenkaan huomiota.”

“Then I was told this belongs to aging, this problem of mine, nothing else.”

”Sitte vaan sanottiin, että joo se kuuluu ikääntymiseen tuokin vaiva, että se ei mitään muuta.”

“They say people get tired of things, when the doctor is getting old and at some level begins to feel tired of his work at the health centre.”

”Jottii sano, että taitaa työlääntyvät, ku sanotaan, että lääkäri tulloo ikkään ja vähän niinku, että varmaan on niinku työlääntynä V:n kuntaan.”

Patient talking to doctor’s back

“But sometimes it happens that the doctor is facing his computer and the patient is left looking at his back.”

”Mutta joskus sattuu, että lääkäri istuu sinne koneeseensa päin ja jää sinne selän taa.”

“The papers seem to be more important to him than talking with me. I am not able to get any contact with him just now.”

”Sillä on nyt tärkeemmät noi paperit, että ei se jaksa mun kanssa keskustella, esimerkiks. Etten mä saa siihen kontaktia nyt millää.”

“During the visit to the doctor, the PC seems to be too important to them.”

”Lääkärille kun mennee, ni minusta se on liian tärkeä niille se tietokone.”

“He turned his back, he did not have a face to face

contact with the patient.”

”Hän niinku selekäsä käänti, ei hän puhuna niinku silmäkkäin niinku potilaan kansa.”

PATIENT PERCEPTION OF HEALTH CARE SYSTEM RELATED INTERACTIONS

Continuity of care

“Of course it is nice to have the same doctor if you need to visit frequently, it feels more safe to go.”

”On se tietenki mukava, ku on sama lääkäri, jos joutuu palajon käymään, ni on niiku turvallisemman tuntunen mennä sinne.”

“You have known him for years? Yes, many years, all the time he has been my doctor.”

”Sä oot vuosia hänet tuntenu? Joo vuosia, minä oon koko ajan hänen hoijossaan ollu.”

“Well I do prefer to visit the permanent doctor since he already has the kind of touch, that is why I visit him.”

”Kyllähän mä niinku, joka vakituiseen on, ni mielellään, koska hänellä on niinku heti semmonen tuntuma, sen takia.”

“I have had the occupational health care doctor, almost thirty years, he has taken care of everything...”

”Työterveyslääkäri, joka on hoitanu sitten lähes kolmekymmentä vuotta, kaikki...”

“Well it is exactly why the communication functions. If you have a new person once again, you need to start explaining everything from the beginning.”

”No just se, että tämä kommunikaatio pella. Taas uus henkilö, kun siinä on, ni se tavallaan se pitäis lähte taas alusta veivaamaan kaikki vaivat.”

“There should be one doctor who is responsible for looking after the major medical problem but at the same time s/he should reflect on the other illnesses as to what extent they have influence too.”

”Että se yks, jolla ois niinku sen suurimman lääketieteellisen ongelman hoitamiset ja vastuu, niin samallahan se niinku tavallaan peilais myös sitten niitä, et mikä merkitys niillä muilla sairauksilla on.”

Access to care

“The thing is that the appointment system is functioning on its’ own way and the doctors are coming and going at their own time so it makes one wonder whether the compatibility is just right.”

”Se ajanvaraus toimii tavallansa ja lääkäri tullee ajallansa ja tekee ajallansa ja että niitten yhteensovittaminen, onko se sitten oikeenlaista.”

“It is difficult to get appointment times.”

”Kyllä vaikee on saaha aikoja.”

“Yes, in my opinion, the guarantee for the treatment has been working alright here in K.”

”Nii, hoitotakuu, ni ainaki minusta se on toiminu hyvin K:ssa.”

“It would be so much better with these osteoarthritis cases to get the right treatment in time.”

”Kyllä se ois niinku aina ois näissä nivelrikoissa varmasti parempi, mitä ajoissa tehtäs se toimenpie.”

“There is no point starting to argue on the phone, when there are no appointments available, that’s how it is.”

”Mittee tuossa ruppee kiistelemään tuossa puhelimessa, kun tuota ei sua (aikaa), kun ei oo, ei oo yksinkertaisesti.”

“They have long queues but I manage to get (an appointment) since I know the girls there.”(laughing).

”On siellä kuulemma pitkät jonot, mut kyllä minä, kun ne tytöt siellä on tuttuja.” (nauraa).

Assertiveness shown by the patient

“Perhaps I was a bit demanding, I made the demand they should take him in to check the situation.” (with her husband’s foot injury).

”Minä ehkä olin vähän sitte semmonen...vaativa? Vaadin, että ottakee nyt katottavaks .”

“Everybody should be allotted enough time at the consultation to be able to tell all their worries connected to the topic.”

”Pittäähän tuota sen verran aakoo olla lääkäriässä kertoo kaakki asiasta, mikä kuuluu siihen juttuun.”

“My daughter is working as a psychologist at the health centre, so she has taught me to be tough, assertive whenever I need to deal with them.”

”On tyttö tuossa terveyskeskuksessa sykologian maisterina, ni se opettannu, että mihinkä hyvänsä se ole kovana .”

“I would like to get a referral to the orthopaedic surgeon now, I want to be referred to the outpatient clinic.”

”Minä nyt haluaisin, että minut lähetettäs ortopedian polille, että minä haluan, että minä saisin lähetteen.”

“The patient needs to take care of her own business and tell the doctor her own opinion.”

”Potilaan pitää itesä ja hoitoo asioitaan ja kertoo lääkäriille, että mitä mieltä on.”

“The patient has to be tough and persistent and to go on complaining.”

”Potilaan pitää olla niin sitkee, että sitä pitää vaan valittaa.”

“I will not ring or sing. I just go to the health centre reception and tell the receptionist I definitely need an appointment right now.”

”Minä en soittale enkä laalele. Sinne (terveysasemalle) mennee kaheksaan ja sannoo, että nyt on asiat niin, että nyt pitäis jottain tehdä.”

Being one’s own advocate

“Maybe I should have been more active myself and explain this is not good like this and this is very painful.”

”Ehkä minun ois vielä pitänä olla enemmän aktiivinen ja sannoo, että tää ee asia nään oo, että tää on tosi kippee.”

“Well it wasn’t easy even after that. A tough struggle was needed.”

”Ei sittenkään kyllä ollunna (helppoa). Tiukan taistelun kansa piti olla.”

“It does help when you go straight to the point...”

”Se vähän aattaa kyllä sekkii, että..[?] niinku sannoo asian

niinku se on, että (asiat hoituvat).

“It depends a lot on the patient’s own activity.”

”Kyl se aika paljon on potilaan aktiivisuudesta kiinni” .

“There is lots of benefit if you can explain things yourself to the doctor who has time to listen to.”

”Kyllä siitä paljon etua on, että ossoo ite sen selevittö, jos on kerta lääkärillä aikoo kuunnella .”

“Of course the patient herself is the best co-ordinator who knows all the things.”

”Tietyst se paras koordinaattori on se potilas itse, joka niinkun tietää ne kaikki.”

“Does one have to be firm and strict? Yes, one does. To be able to get things sorted out? Yes.”

”Pitääkö sitä olla niinku jämpä ja tiukka? Pittää. Että saa asiat hoidettua? Kyllä.”

Patient perception of economic issues for delaying the treatment

“It must be the decline at the health centres that we ordinary people keep noticing, that’s what we feel, the decline of services.”

”Nyt on varmaan se alasajo nuistakin terveyskeskuksista, mitä nyt myö tavalliset ihmiset huomataan, ni meistä tuntuu, että se on alasajoo niistä.”

“I don’t know whether times are so bad since they don’t seem to like giving you a referral to any tests, blood tests or any other.”

”Ei tiijä onko nyt sitten nii huonot ajat, ku ne ei oikeen mielellään pane tuonne kokkeisiin, verikokkeisiin eikä mihinkää.”

“So can it be a lack of resources when they don’t tackle the causes.”

”Että onko resurssien puutetta, että ei niinky siihen syihin pureuduta.”

“One does think that they run out of resources, there are so many sick people queueing.”

”Sitä jotenki aina miettii, että loppuu resurssit kesken, että meitä niin paljo sairaita jonossa.”

“I suppose they did not want to refer me to K hospital. I don’t know whether they were saving money or what.”

”Minua ei vaan haluttu varmaan laittaa K: hon. En tiijä olko se säästettiinkö siinä olevinnaan.”

“He even told me my knee joint is going to cost 12 000 euros to the municipality. The doctor should not be saying things like this.”

”Ku sennii sano, että se minun polvi maksaa kakstoistatuhatta euroa L:n kunnalle, sitäkään ei saa lääkäri sanoa.”

“It is certainly a question of economic cost for the doctors here at our health centre when they consider whether to refer somebody to the hospital.”

”Se on tiällä meijännii terveyskeskuksessa näillä lääkärillä on tuota se on tuo, tuo varmasti, että rahakysymys, että kannattaako sitä laittaa niinku etteenpäin.”

Power struggle between patient and doctor

“I have been examined thoroughly for this (foot prob-

lem) but nobody will...I am saying that a dog will not step on another dog’s tail.”

”On tutkittu vaikka millä lailla sen suhteen, mutta kukkaa ei, minä sanon, että koira ee koiran hännälle astu .”

“It is a bit like walking over the doctor in this matter, it is a little bit awkward of course.”

”Vähän tämmönen, että mennee niinku lääkärin ohi tästä asiasta, että se on vähän kiusallista tietysti .”

“If one argues anything they will be so terribly hurt.”

”Jotaki sanna, ni nehän loukkaantuu niin kauheen verisesti .”

“He did not speak to me for many years, he was all mute to me (laughing).”

”Ei sanona monneen vuoteen mulle mittää. Se ol ihan mykkä mulle (naurahtaa) .”

“When I was telling me off and suggesting there is something wrong in my head, I said to the nurses there is nothing wrong with my head but could there be something wrong with L’s head.”

”Ku se L haakku minua, että taitaa olla piässä vika mulla. Minä niille hoitajille sanoin, että minun piässä ei oo kyllä vikkoo, jos ei L:n piässä oo.”

Power struggle between doctors

“Maybe the permanent doctors disapprove this younger doctor stepping on their toes when he is splashing out money when making the referral.”

”Jos ne (virikalääkärit) kahtoo, että kun tää (sijaislääkäri) männöö heijän ylite se nuorempi sitten, että se toinen laittaa menemään rahhoo.”

“I suppose it is mostly the case that senior doctors don’t allow the younger ones to do things,” (laughing).

”Se kai taitaa olla etupäässä se, että vanhemmat tulloo, ni eivät anna niille (nuorille lääkäreille) oikeuksia oikeen” (naurahtaa).

Partnership with the doctor

“Then also we patients have changed, we are not so much afraid of anymore.”

”Sit on myö potilaatkin muututtu, että ei aristella sillä tavalla.”

“Do you think the doctor and the patient should decide together what to do or is it that the patient should just listen to what the doctor will tell? At least they should plan how to do...”

”No kuulusko teijän mielestä sitte sen lääkärin ja potilaan niinku yhdessä miettiä sitä, miten hoidetaan vai onko se vaan, että potilas kuuntelee, mitä lääkäri sanoo? Siinä suunnitella ainaki, että minkälainen...”

“Do you mean like a friend or someone who supports and is there to help you? My GP is like that, she gives me advice.”

”Niinkun ystävä tai semmonen tukija, joka niinku siinä mukana voi vähän olla auttamassa? Kyllä se ainakkii nyt, mikä mul on tää lääkäri. Hän on, että hän neuvoo.”

“Yes, she encourages me.”

”Nii kannustaa.”

Dealing with uncertainty connected to own treatment

“I don’t know about these things (how to take medication) and what to do. I dare not to decide myself all the time.”

“Ei tiijä noista aina, että mitä pitäis tehdä. Ei oikeen uskalla aina keksiäkkään itte.”

“I suppose I don’t get in during the summer. I called them in the winter and I was told there has only been very few doctors to perform operations during the winter time.”

”Musta tuntuu, ettei taita kesällä päästä. Mie tässä talavella soitin, nin se kirurkia, se mikä siellä ottaa ylös niinko, ni sano, ettei ole lääkäreitä ko muutama koko talavena ollu.”

“It is just that the doctor inspects your joint and gives you a prescription and then you make a revisit if you happen to feel like that since there is not any follow-up arranged, I was reading in the internet.”

”Lääkäri kahtoo vaan tuota ja antaa reseptin ja tuut sitten jos, kun luin netissä, että siinä ei ole jälkiseurantaa.” (nivelrikossa).

“It was very stressful for years not to know what was the matter with the knee. The uncertainty was gnawing.”

”Ni se niinku rassas ihan oikeen, että eikö vois ja se tieto, että mikä siinä loppujen lopuksi on polovessa. Useita vuosia se kalvo, että mikä on vikana.”

“I am a little bit afraid of the operation since I have never had one. I suppose you don’t die during the operation but if you do, so be it.”

”Vähä se niinku pelottaa, (leikkaus), ku en oo koskaa. Ei kai siihen nyt, tai jos kuoloo, ni kuoloo.”

Patient experience of operations

“All my operations have been succesful... I have made a good recovery and the doctor has said that my bones are very good to heal.”

”Leikkaustilanteet on männy ihan oikein hyvin...oon toipunu ja lääkäri on sanonu, että mulla on erittäin hyvin luusto luutunu.”

“The rest of the time I was lying on a plaster and I was not allowed to get up, the nurses just came to cream my back twice a day and I was there for six weeks.”

”Mä sen loppuajan olin sen kipsin piällä. Siitä en saanu nousta enkä laskeutua muuta, kun mitä hoitajat käv kaks kertoo vuorokaavessa riillä voitelemassa minun selän ja minä olin sen kuus viikkoa.”

“I fell from the top of the hay load on my shoulder and broke it. The operation was performed two years later and I think it succeeded.”

”Mä putosin sieltä (heinäkuorman päältä) olkapäälleni ja siinä särky sitte tämä olkapää ja se kyllä leikattiin ehkä parin vuoden viiveellä, että ja siitä minun mielestä hyvä.”

Patient perception of private care

“I am telling as a joke that the letter about the hospital bed for the operation arrived before the wife came back home from the consultation...the leg was operated and it cost a lot of money.”

”Vähän karrikoin aina, että kirje tuli kotia ennen, kun emäntä vastaanotolta, että nyt siellä on paikka, ja se jalka leikattiin ja se makso muistaakseni aika paljo.”

“One knows that you can get help from the private sector faster.”

”Sen tietää, että sitä sieltä (yksityissektorilta) saa apua nopeemmi.”

“At the private clinic they make home visits and the doctor takes care of you very well and shows concern, even calls you later to find out whether your condition has improved.”

Yksityinen lääkäriasema, ni sieltä tulee kottiin lääkäri ja huolehtii ja kyllä varmaan on tosi hyvä ja on huolissaan sitte ja soittaa jälkikäteenki kysyy, että onko mitään apua ollu.”

“I did feel they paid more attention, got in to details here at the private clinic.”

”Kyllä minä kojnin sen, että otettiin niinku enemmän sitte siitä kantaa, että tällä yksityisellä.”

“At least the staff is competent there (at the private clinic) when you visit a certain doctor whom you know to be an expert on that topic.”

”Ainaki on pätevä henkilökunta sitten siellä, että ku ois määrätyn lääkärin luo mennee, että tietää, joka just siitä asiasta tietää..”

“Nothing else except hello and goodbye they will say and take a lot of money.”(private doctors).

”Ee mittään muuta kun sen päävän ja hyvästit sanoo ja paljo rahhoo” (yksityislääkärit).

“It is not good either, the American way...(of arranging health care services).

”Ei se ole sekhään Amerikan malli hyvä.”

Patient perception of public care

“The health centre services have been excellent. No waiting times, the treatment was given without delay and it was very humane.”

”Kyl ne oli loistavia (tk-palvelut). Ei ollu odotusaikoja, hoito tuli heti ja hyvin inhimillistä.”

“The hospitals are not given the resources they require. A few doctors try to look after all the patients coming from skiing centres with broken arms and legs.”

”Meil ei sairaaloihin, eikä meille annetta noille ihmisille resursseja. Pari lääkäriä yrittää tehdä työtä siellä, kun tulee tuota nuista keskuksista niitä katkenneita käsiä ja jalkoja.”

“When I have visited some old people there, I have noticed there are some nurses who are so unfriendly to the residents.”

”Ku on käänä vanhuksia kahtomassa ni siellä on kansa muutamia hoetajia semmosia, että niin ylseesti ottaavat huomioon hoiettavat.”

“I don’t have anything negative to say (about the health centre) and so I decided that for goodness sake, they are all physicians.”

”Et ei mulla mitään negatiivista, ni mä tulin siihen tulokseen, että hyvänen aika kaikkihan ne on lääkäreitä..”

“No need for you to pay 7000 euros, you can have the operation through this system.”

”Ei kannata sinun maksoo sitä seitemmää tonnia, että

käävään tiältä kaatta.”

“I did visit the health centre sometimes and all I can remember from there is the waiting.”

”Joskus terkkarissa käytiin, mut tuota niin ainut, mikä sieltä jäi mieleen oli tietysti se jonottaminen.”

“Well, even I myself call the health centre a guessing centre.”

”No se lähinnä, että arvauskeskukseksiha itekki sanon terveystakeskusta.”

Waiting lists

“Even if they are employed to work at the hospital they will leave to operate at the private clinic during the day.”

”Jos kerta on palakattu tuohon töihin tuohon sairaalaan, ni sitten mennään vaan työaikaanaki menevät leikkaamaan tuohon yksityisele.”

“These waiting lists are far too long even now.”

”Nämä on vaan nämä leikkausjonot on vaan liian pitkät vieläki.”

“I was informed there will be an arthroscopy but it would have taken almost another year to wait.”

”Tuli, että tähytetään ja sitte ois menny taas vuosi melkein.”

“I find it so terrible just to wait, I don’t know.”

”Minusta ihan hirveetä oottoo, en minä tiijä.”

Patient need to please the interviewer

“I was just feeling happy and grateful that everything is so wonderful. If everybody is treated like this I will say this is really great.”

”Minä vaan olin ja kiitin ja olin onnellinen, että näin on ihanasti, että jos kaikkia palvellaan näin, ni minä sanon, että tämä on todella ihana.”

“I have only met good doctors and I just feel grateful.”

”Kyllä minun kohalla on sattunu kaikki hyviä lääkäreitä ja mullon suuri kiitos vaan.”

“I cannot recall any of those (unsuccessful medical consultation).”

”Ei mulla nyt oikeestaan oo mielessä semmosta.” (epäonistunutta lääkäriissä käyntiä).

“I would say this study you are doing, must be a valuable study since you are listening to people in it.”

”Sanosin, että kyllä, kyllä tää tutkimuksena mitä teette, niin varmaan on hieno tutkimus, kun siinä kuunnellaan ihmisiä”

“I haven’t got anything negative to say, I have received good care, I cannot say anything else.”

”Ei ole negatiivista sanot-, ei oo semmosta, tuu mieleen, että kyllä mä oon hyvän hoidon saanu, en mä vois muuta sanoa.”

“The modern doctors, they all are so friendly and helpful in my opinion.”

”Kyllä ne nykyajan lääkärit, ni ne kaikki on hyvin ystävällisiä ja auttavaisia minun mielestä ainakkii.”

“I have been given a very good treatment (at the doctor’s consultation) and all my experience is very

positive.”

”Hyvin asiallisesti otetaan (lääkäriissä käydessä) ja nii, että on semmosta ihan myönteistä ollu.”

“How could I tell you now to get it right ?” (when talking about his own experiences with the doctors).

”No mitenkä sen nyt ossoisi kertoo sen, että tulis oikein?”(omista lääkärikokemuksistaan).

Unnecessary visit perceived by the patient

“You get the feeling that you are not being taken seriously.”

”Tulloo se tunne, että ee sillä laella tosissaan ota sitä potilaan kertomoo ja sitä asijoo.”

“If I notice the doctor is thinking whether this woman is now exaggerating this pain...”

”Jos mä huomaan, että lääkäri aattelee, että liioitteleekohan tuo nyt näitä kipuja tuo ihminen.”

“It is nowadays openly brought up that there may be unnecessary visiting in the health care system.”

”Paljohan siitä nyt puhutaan ja onkii se pöyväälle nostettu, että kai siellä (terveydenhuolossa) on sitä turhakäyntiäkii.”

“ I must have had two or three unnecessary visits during my illness but they have been ordered by the doctor, follow up visits.”

”Kyllä mulla tään sairauven aikana varmasti on pariki, kolme kertaa turhaa käyntiä ollu, mut ne on lääkärin määräämiä semmosia, että tarkastuskäynnille tullu.”

“It was an unnecessary visit, why did I make the appointment. Just as well, I could have asked a man in the street what I shall do with my knee and been told I just have to learn to live with it.”

”Olipahan taas turha käynti tuossakii, että miks minä ylleensä menin sinne. Ihan sama, minä olisin voinu kysyä vaikka joltakin kadunmieheltä toulta, että hei mitä minä tälle teen, ni se, hän ois sanonu, että sen kans pitää vaan oppia elämään.”

“On the private sector it has become more business like, I just mean these unnecessary patients.”

”On yksityissairaalapuoella enemmän tullu niinku bisnes sillä puolella, että näitä juuri näitä turhia potilaita.”

“This was a sort of unnecessary visit since I did not get any help.”

”Tää ol vähän niiku turhaan käynti, kun ee sua apua siitä.”

Leadership in health care

“The mistakes were always somebody else’s fault, other than the doctor’s.”

”Pantiin johonkin muuhun tai jonkun muun (kuin lääkärin) syyksi tai miten tahansa (virheet).”

“There is no management here at the A&E department, somebody was saying, and I can state exactly the same.”

”Tääl ei oo ollenkaan työnojohto täällä päivystyksessä, ja minä kyllä totean aivan saman.”

“They should examine the system very carefully since they make same things simultaneously in different

places.”

”Kyllä varmasti olis järjestelmäs niinku pelkästään jo sillä kohdalla niinkun tarkastelemisen varaa, että tehdään hirveesti samoja asioita päällekkäin aivan suotta.”

“It would decrease these congestions and costs and also bring savings if the doctors were allowed to do right things to right patients.”

”Miks sillä näitä ruuhkia ja kustannuksia ja miksei myös säästetä sitä, että tehdään oikeeta tai lääkärit saavat tehdä oikeita asioita.”

Dealing with complaining patients

“There could be someone in the waiting room, a cleaning lady perhaps, who would talk to the unsatisfied patient. It could make the situation much easier.”

”Voishan se olla siellä odotustilassa joku...olkoon se vaikka siivooja, ni sehän vois pelastaa paljo tilannetta sillä, että se jututtas sitä” (tyytymätöntä potilasta).

“The patient who complains should be held by the doctor and kept there for 30 minutes instead of the five minutes and that could end the whining.”

”Seki pitäs ottaa haltuun niinku taas pitäs lääkärin ottaa tämmönen valittaja haltuun, pittää hoijossa sitä puol tuntia eikä sitä viittä minuuttia ja se vois loppua siihe.”

Physical environment of the consultation room

“It was a very clean and comfortable place (the private clinic).”

”Hirveen siisti ja mukava paikka” (yksityinen lääkäriase- ma)

“So why should it be a room which is cold and echoing...”

”Nii että miks ja sit semmonen huone, joka kaikuu ja kylmä...”

“Yes, and certainly no flowers on the table.”

”Just joo, ei oo kukkia pöydällä varmaa.”

“When you are feeling depressed and ill with temperature and you enter an unpleasant cold room (laughing) and if the doctor too, feels cold and distant...you feel even more depressed.”

”Kun hirveesti masentaa ja on kippee olo ja kuumetta ja sinä tuut ovesta sisälle, ni masentaa vielä enemmän, kun (nauraen) tullee semmoseen kalseeseen ja sitten vielä, jos lääkäri on yhtä kalsee, ni.”

Patient perception of fragmented care

“I think this has led to the situation where we have doctors who have specialized to take care of the nail of the left little toe.”

”Minust se on niinku johtanu siihen, että noin kuvainnolli- sesti meillä on lääkäreitä, jotka on erikoistunu vasemman jalan pikkuvarpaan kynnen hoitamiseen.”

“Everyone of them is looking after one ailment or some problem but not anybody is looking after me.”

”Jokainen niistä hoitaa niinku jotain sairautta tai jotain ongelmaa, mut kukaan niistä ei hoida A. K:a, ei kukaan.”

“If they could, I am sure they would separate this rheumatoid arthritis to some laboratory and once a month they would send me a card telling I am fine and enjoying life here with every other rheumatoid arthritis and joint psoriasis.”

”Jos ne pystys, ni ne varmaan niinku eristäs tän reumanki ja pistäisivät jonnekkii labraan ja sieltä tulis kerran kuussa siltä kortti mulle ja hei täällä mä oon ja mä voin ihan hyvin ja meil on kaikkein muitten reumojen, nivelpsorien kans täällä hirmu hauskaa.”

“If you visit the doctor for a headache and then you decide you will also complain about your leg pain they will not treat the leg since you only have made the ap- pointment for the headache.”

”Meet lääkärille ja valitat, että sul on päänsärky ja sitte ruppeet valitaan, että mul on jalaka kippee, ni ei sitä jalakaa hoijetakaan enmää, koska sulle on varattu vaa aika sille päälle.”

Equality in health care

“I am just criticizing this system since when you are old you are not getting anywhere.”

”Sitä minä justtiisa tätä järjestelmöä, että ku vanha on, ni ei pääse millää.”

“There should be some kind of allowance that would be guaranteed when you have lots of costs which make your life hard. It would be much safer then.”

”Et pitäs olla joku semmonen joku hoitotuki, joka tulis ilman muuta sitten, kun tulloo paljon menoja ...ja rasittaa sitä elämätä ja sitte se ois turvallisempaa, jos.”

“As long as we have this public health care system it will guarantee these services also to such people which the private health care will cold bloodedly leave outside.”

”Niin kauan, kun meillä on tämmönen kunnallinen jär- tai tämmönen julkine terveydenhuolto, nii se turvaa nää terveyspalvelut myös semmosille ihmisille, jotka se kaupallinen terveyspalvelu, ni jättää kylmästi kaiken ulkopuolelle.”

“Everybody knows that those who have the money and can visit the private doctors get better quality treatment than those who cannot afford this.”

”Kyllähän se nyt selevä juttu, että jolla on rahhoo ja joka pääsee yksityislääkäriin, ni kyllähän se saa sitte sen paremman avun, ku sellanen, jolla ei oo rahhaa.”

Societal values connected to health care resources

“What about our politicians, don't they (understand), when you look at all those stories about hospitals. Money is splashed to all sorts of happenings given by the president and the politicians to the supporters of the parties.”

”Eikö meidän politikot, kun nyt katsotaan näitä sairaalajut- tuja ja kaikkia noita. Rahaa pistetään tuolla joka puolelle aina presidentin nuita, niitä puolue-, niitä tukijoitten juhlia kaikkia niitä.”

“Certainly this is not improving, the care of old people is completely neglected.”

”Ei tämä ainakaan parempaan päin oo menossa. Vanhus- huolto on ihan retuperällä.”

“Has the morale of the human kind stooped to killing old people when they no longer are useful?”

”Onhan se moraalii sillon vajonnu aika alas ihmiskunnan moraalii, jos ruvetaan vanhuksia tappamaan suoranaisesti, kun niistä ei oo hyötyä..”

“A person is a human being to the very end.”

”Niin se on ihmine loppuu asti kuitenkin.”

“Everybody should get help just during the right moment so that the future life would be better.”

”Jokkaiseha pitäs suaha apua, että oikeessa aikana, että sitte ois se elämä etteenpäin parempi.”

Medical students learning from patients

“I think one should listen to the patient, what s/he has to tell and one should not be in such a hurry.”

”Kyllä minusta sillai, että kuunnellaa ainakin niinkun potilasta, että mitä sil on sanottavvoo, eikä ois niin hirveen kiire.”

“Do you think it comes naturally how to communicate with the patient or should it be taught? Well it may be natural to some doctors but not to everybody. You should not start teaching this.”

”Luuletteko, et se tulee sit ihan luonnostaan vai pitääkö sitä niinku opettaa, että miten (potilaan kanssa keskustellaan)? No kyllä kai se jollekkii tulloo ihan ehkä luonnostaan tullee, mutta toiselle ei tietysti voi tulla ihan. Ei sitä nyt opettamaan passoo männä..”

“You can ask if it is your throat that’s bothering you or some other reason but I would expand the context and ask how things are in general.”

”Voihan sitä kysyä, että onko se kurkku kippee vai minkä takia sinä oot tullu, mutta niinkun kasvattasin sitä niin sanottua oloympäristöö, että onkos muuten kaikki hyvin.

“When you are working, it is easy to forget the customer and just think, bloody hell, I am again sitting here at the health centre this late in the evening.”

”Sitte, ku sitä ollaan työelämässä, ni sitä helposti unoheetaan se (asiakas) ja sitten, että hitto, että minä oon taas täällä teekoossa, näin myöhään.”

Asking for a second opinion

“If it happens that there is no trust between the doctor and the patient then one needs to move on to another doctor.”

”Jos on sillai lääkäri, jonka kans tuntuu, että ei niinku oikeen synny semmost luottamusta, nin tietysti siirrytään toisen luokse.”

“Would you make another appointment (if you are not completely satisfied with the outcome)? Not necessarily if I have been treated well.”

”I went to V in the morning since I thought I will not go back to L anymore as I was sent to have massage and they did not give medication for my blood pressure. I will die if I go there.”

”Mänin sinne V:hen sitte uamusella, kun minä uutelin, minä en L:lle ennee mäne, kun ne käski minut hierojalle, eivätkä antana verenpainelääkettä. Minähän kuolen.”

Patient decision making

“The joints were so painful in christmas time that I went to see dr S and said we need to do something about them now.”

”Ne olj nii hirveen kippeet jo tuossa joul-, tammikuussa, että minä sitte S:n luo mänin ja minä sanoin, että nyt pitäs jottain mejän vissiin tehdä.”

“The artificial joint is the only sensible solution and I said it will be fine right now.”

”Tekonivel on ainoa järkevä ja sanoin, että vaikka heti.”

“I did not take the antibiotics the doctor prescribed and nothing happened.”

”Minä jätin kyllä ottamatta (lääkärin määräämän antibiootin) ihan eikä sen kummemmaks elämä muuttunu.”

“I did say to the doctor I will prefer not to have the operation since I am so old.”

”Minä sillo jo lääkäriille sanoin, että minä en mielellään anna leikata, kun minä oon niin vanha jo.”

“When making the appointment to the doctor one does know why one needs to see the doctor.”

”Kyllä siinä, jos lääkäriin männään, ni kyllä siinä itellään niinku selevä tieto on, että minkä takia minä mään sinne.”

Patient as a customer attitude

“The service has been all right at the health centre.”

”Kyllä sieltä (tk:sta) palvelu on tullu ihan.”

“Well, I did give some feedback, I am not one who keeps quiet.”

”No mä annoin palautetta, minä en, minä en jää kovin hiljaseks.”

“That’s what the doctors are for... the patients. The doctor would be out of work without patients.”

”Sitä vartehan ne lääkärit on, että potilasta varten. Ei kai sillä lääkäriillä mittää töitä ois, jos ei ois potilaita.”

“People know so much more nowadays and they also know which strings to pull.”

”Ihmiset on tulleet semmosiks, että ne ite tietää paljo enemmän...ja ne tietää, että mistä köyvestä veetään.”

Patient responsibility for telling relevant facts

“The patient has to be able to express his illnesses and other issues to the knowledge of the doctor.”

Kyllä se potilaanki on osattava tuua ne sairauvet ja asiat esille ja olosuhteet lääkärin tietoon.”

“You need to open your mouth and tell what has happened so that they can be prepared if there is any risk. They cannot know everything about the patient, all that can be caused by some drug.” (he had had a very severe complication caused by a spinal anaesthetic).
”Pittää suusa aakasta ja sanno, että tämmönen on käänä, että ossoovat varraatuu, jos siinä jottain on, et eehän hyökää voi kaakkee tietee potilaasta, mitä se voe aeheettoo” (spinaalipuudutuksen vaikea komplikaatio).

“When I mentioned this accident to the doctor, he immediately ordered some x rays and everything was very clear even if they don’t normally believe some-

body can have a hip problem at the age of forty five.”

”Kun minä mainihän tämän tapaturman lääkäriille silloin, että kun monasti ei uskota, että lonkkavika on vielä neljäkymmentävuotiaana, että se on enempi vanhempien tauti, hän määräsi röntgenkuviin ja ol hirveen selevä tapaus.”

UNDERSTANDING

Taking blame on oneself

“This obesity is my problem, I have tried everything. It must be between the ears, cannot be anything else since I am not able to loose weight.”

”Tää on mulla ongelma tämä lihavuus, minähän oon yrittänny vaikka mistä, mutta se on kyllä korviin välissä mulla nyt kyllä, ei pysty muualla olemaan, en minä saa poikkeen.”

“I was thinking I should have gone and visited the doctor twenty years ago.”

”Mä ajattelin, että mun olis pitäny mennä jo kaksikymmentä vuotta sitten lääkäriin.”

“At least I cannot blame the doctor, many people already had told me I need to go and get it sorted out.”

”Ei se oo ainakaan lääkärin vika, että kyllä minulle jo monet sano, että tuo on mentävä hoijattaa.”

“Maybe I should have been more active myself and explain this is not good like this and this is very painful.”

”Ehkä minun ois vielä pitäny olla enemmän aktiivinen ja sanna, että tää ee asia nään oo, että tää on tosi kippee.”

Patient understanding the doctor

“Not everybody can be equally competent even if they would study the same subjects. One doctor knows how to perform and the other one doesn’t.”

”Ei kaikki voi olla samantasosia, vaikka ne lukis kuinka paljon samaa ainetta, ni toinen osaa, toinen ei.”

“She was friendly but not able to perform her task.”

”Hän oli ystävällinen, mut hän ei sit osannu...tehä sitä asiaasa.”

“There are difficult days in patients’ lives as well, so there can be bad days in doctors’ lives too, they are only humans after all.”

”Niin niitä on raskaita päiviä potilaillaki ja huonoja päiviä, että eihän se lääkärikkään oo, ku ihminen.”

“I was thinking that this doctor cannot do anything more here...surely he must have done his best.”

”Mää aattelin näin, et eihän se lääkäri voi tässä nyt tämän enemppää tämä lääkäri... et parhaansahan hän on varmasti yrittänny.”

“There must be these unnecessary patients between the real ones whom the doctor would like to shout, out, there is nothing wrong with you.”

”Näitä turhia potilaita on varmaan siellä välissä, joille tekisi mieli huutaa, että out, sulla ei oo mitään vikaa.”

“So just now the doctor is unable to listen to me much, this is the moment to keep to the point.” (if the doctor is having a bad day).

”Niin, että nyt se lääkäri ei varmaan jaksa kuunnella, että nyt ei paljo puhuta asian sivu.” (jos on huono päivä).

Appendix 3

TIEDOTE TUTKITTAVALLE

”Polvi ja lonkka – arthroosipotilaiden kokemuksia konservatiivisesta hoidosta ennen artroplastiaa”

Olette saanut lääkäriiltänne lähetteen KYS:n ortopedian poliklinikalle ja nyt Teille on lähetetty kirje, jossa kerrotaan tuleva vastaanottoaikaan ortopedian poliklinikalla. Jokaisen potilaskirjeen mukaan liitetään ”Polvi- ja lonkka-arthroosipotilaiden kokemuksia konservatiivisesta hoidosta ennen artroplastiaa” kartoitettavasta tutkimuksesta kertova tiedote ja yhteystietolomake Teidän osoitetietojanne ja puhelinnumeroa varten sekä palautuskirjekuori.

Pyydämme Teitä perehtymään tähän tutkimustiedotteeseen, jossa kerrotaan Kuopion yliopiston kansanterveystieteen laitoksen ja Kuopion yliopistollisen sairaalan ortopedian klinikan yhteistyönä tehtävästä tutkimuksesta. Siinä tapauksessa, että perehdyttyänne tähän tiedotteeseen päätätte osallistua tutkimukseen ja ilmoitatte sen postittamalla yhteystietolomakkeen mukana olevassa palautuskirjekuoressa tutkijalääkäri Pirkko Heasmanille, hän ottaa Teihin yhteyttä puhelimitse. Siinä yhteydessä voitte esittää lisää kysymyksiä tutkimuksesta. Saatuanne haluamanne selvitykset Teiltä pyydetään vielä kirjallinen suostumus tutkimukseen osallistumisesta ennen haastattelun tekemistä.

Tutkimuksen tarkoitus

Tämän tutkimuksen tarkoituksena on saada uutta tietoa potilaiden omista kokemuksista liittyen avoterveydenhuollon vastaanottokäynteihin ja lääkärin antamasta hoidosta koettuun hyötyyn. Tutkimustuloksia voidaan käyttää hyväksi lääketieteen opetusta kehitettäessä ja pyrittäessä lisäämään potilaiden oman äänen kuulumista terveydenhuollon palvelujen tuottamisessa. Tavoitteena on, että nivelrikkopotilaiden palveluketjua ja leikkausta edeltävän hoidon laatua voidaan tulevaisuudessa kehittää ottaen huomioon potilaiden kokemukset ja mielipiteet saamastaan hoidosta. Teitä on pyydetty osallistumaan tähän tutkimukseen sen perusteella, että hoitava lääkäriinne on kirjoittanut Teistä lähetteen KYS:in ortopedian poliklinikalle ortopedian konsultaatiota varten. Jokaiselle henkilölle, joka saa tiedon tulevasta vastaanottoajastaan KYS:in ortopedian poliklinikalla, postitetaan tämä sama tiedote. Pohjois-Savon sairaanhoitopiirin tutkimuseettinen toimikunta on arvioinut tutkimussuunnitelman ja antanut siitä puoltavan lausunnon.

Tutkimuksen kulku

Mikäli päätätte osallistua tähän tutkimukseen ja postitatte yhteystietolomakkeen tutkijalääkäri Pirkko Heasmanille, Teihin otetaan puhelimitse yhteyttä ja sovitaan haastatteluaika. Haastattelu voidaan tehdä joko Teidän kotonaan tai Kuopion yliopiston Kansanterveystieteen ja kliinisen ravitsemustieteen laitoksella Pirkko Heasmanin toimesta. Haastattelun kesto on 1–2 tuntia. Tarkoituksena on, että Te saatte aluksi omin sanoin kertoa sairastamiseenne liittyviä kokemuksia erilaisista vastaanottokäynneistä ja annetuista hoidoista sekä niiden vaikutuksista terveydentilaanne. Tämän jälkeen tutkija pyytää Teitä kuvailemaan jonkin omasta mielestänne erityisen hyvin onnistuneen lääkärin vastaanottokäynnin ja myös kertomaan jostakin vähemmän onnistuneesta käynnistä, jos haluatte. Teitä pyydetään myös kertomaan, miten Te olette kokeneet hyötynne saamastanne hoidosta. Toivomuksena on, että tutkija saisi tutustua myös Teidän sairauskertomustietoihinne terveyskeskuksessa. Haastattelukertoja on vain yksi ja haastattelu nauhoitetaan Teidän luvallanne. Jos päädytte siihen, että Te tulette mieluummin haastatteluun Kuopion yliopiston Kansanterveystieteen laitokselle, jossa tutkija Pirkko Heasman Teidät haastattelee aivan saman kaavan mukaan kuin edellä kuvattiin, Teidän matkakustannuksenne korvataan. Tutkimukseen osallistumisesta ei makseta palkkiota.

Tutkimukseen liittyvät hyödyt ja riskit

Tutkimukseen osallistumisesta ei ole teille välitöntä hyötyä, mutta tulevaisuudessa tutkimuksen tuloksia voidaan toivottavasti hyödyntää nivelrikkopotilaiden hoidossa. Potilaiden mielipiteiden ja kokemusten huomioon ottaminen entistä paremmin terveydenhuollon palvelujen suunnittelussa ja kehittämisessä on myös tärkeää toiminnan laadun kehittämisen kannalta.

Luottamuksellisuus, tietojen käsittely ja säilyttäminen

Teistä kerättyä tietoa ja tutkimustuloksia käsitellään luottamuksellisesti henkilötietolain edellyttämällä tavalla. Yksittäisille tutkimushenkilöille annetaan tunnuskoodi ja tieto säilytetään koodattuna tutkimustiedostossa. Tulokset analysoidaan ryhmätasolla koodattuina, jolloin yksittäinen henkilö ei ole tunnistettavissa ilman koodiavainta. Koodiavainta, jonka avulla yksittäisen tutkittavan tiedot ja tulokset voidaan tunnistaa, säilyttävät tutkijalääkäri Pirkko Heasman ja yleislääketieteen professori Esko Kumpusalo Kuopion yliopiston Kansanterveystieteen ja kliinisen ravitsemustieteen laitokselta eikä tietoja anneta tutkimuksen ulkopuolisille henkilöille. Tutkimuksessa kerättävistä tiedoista ja tutkimustuloksista ei tehdä merkintöjä sairauskertomukseenne. Lopulliset tutkimustulokset raportoidaan ryhmätasolla eikä yksittäisten tutkittavien tunnistaminen ole mahdollista. Tutkimustiedoston muodostavaa haastatteluaineistoa säilytetään Kuopion yliopiston Kansanterveystieteen ja kliinisen ravitsemustieteen laitoksella 5 vuotta, jonka jälkeen se hävitetään.

Vapaaehtoisuus

Tutkimukseen osallistuminen on täysin vapaaehtoista ja voitte keskeyttää tutkimuksen koska tahansa. Tutkimuksesta kieltäytyminen tai sen keskeyttäminen ei vaikuta millään tavalla hoitoon. Mikäli keskeytätte tutkimuksen, teistä kerätyt tiedot hävitetään, jos niin haluatte.

Tutkimustuloksista tiedottaminen

Tämä Kuopion yliopiston Kansanterveystieteen ja kliinisen ravitsemustieteen laitoksen sekä KYS:n ortopedian ja traumatologian klinikan yhteistutkimus on yleislääketieteen erikoislääkäri Pirkko Heasmanin väitöskirjatyö, joka toteutetaan Kuopion yliopiston yleislääketieteen professorin Esko Kumpusalon ja Helsingin yliopiston kasvatuspsykologian professorin Kirsti Longan ohjauksessa. Tutkimus on tarkoitus saada valmiiksi vuoden 2007 loppuun mennessä. Tuloksista tiedotetaan niiden valmistuttua maakunnallisissa ja valtakunnallisissa tiedotusvälineissä.

Lisätiedot

Pyydämme teitä esittämään mahdollisia kysymyksiänne tutkimuksesta tutkijalääkäri Pirkko Heasmanille, jonka yhteystiedot ovat lomakkeen lopussa.

Tutkijoiden yhteystiedot

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Arvoisa herra / rouva XX

Olen yleislääketieteen erikoislääkäri ja toimin tutkijana Kuopion yliopiston Kansanterveystieteen ja yleislääketieteen yksikön ja Kuopion yliopistollisen sairaalan kirurgian klinikan yhteistutkimuksessa **”Lonkka- ja polviartroosipotilaan kokemuksia konservatiivisesta hoidosta avoterveydenhuollossa ennen artroplastiaa”**.

Yleislääketieteen professori Esko Kumpusalo toimii opinnäytetyöni ohjaajana täällä Kuopiossa. Tutkimukseni keskeinen teema on potilaiden kokemana hyötyä lääkärin vastaanottokäynteihin liittyen. Tavoitteena on saada esiin potilaiden omakohtaisia kuvauksia hyvistä ja huonoista kokemuksista terveydenhuollon palvelujen käyttäjinä. Tämän tutkimuksen tekemistä varten haluaisin haastatella henkilöitä, joilla on todettu lonkka- tai polvinivelen nivelrikko. Te olette saaneet lähetteen lääkäriltänne KYS:n kirurgian poliklinikalle. Minä olen saanut kirurgian klinikan ylilääkärin, professori Heikki Krögerin suostumuksen siihen, että sain liittää Kirurgian poliklinikalta Teille lähetettyyn kirjeeseen selvityksen tutkimuksestani ja pyynnön mahdollisesta osallistumisestanne. Tutkimussuunnitelmani on hyväksytty Kuopion yliopistollisen sairaalan tutkimuseettisessä toimikunnassa. (päättös, pvmäärä)

Jos päätätte osallistua tähän tutkimukseen, haluaisin sopia kanssanne haastatteluajan. Haastattelu voidaan tehdä kotonanne Teille sopivana ajankohtana. Minä toivon voivani haastatella Teitä noin yhden tunnin ajan.

Haastattelun haluaisin luvallanne nauhoittaa ja myöhemmin nauhoitusta voivat minun lisäksi kuunnella ainoastaan opinnäytetyöni ohjaaja professori Esko Kumpusalo sekä toinen ohjaajani, kasvatuspsykologian professori Kirsti Lonka Helsingin yliopistosta. Tämän tutkimuksen päätyttyä kasetit tuhoataan asianmukaisesti eikä valmiista tutkimuksesta ole kukaan yksittäinen henkilö tunnistettavissa.

Haastattelun lisäksi haluaisin päästä tutustumaan Teidän sairauskertomustietoihinne X:n terveyskeskuksessa. Tarkoitukseni on selvittää niistä teille tehdyt tutkimukset, annetut hoidot, lääkitykset ja sairauslomat. Tietoja ei missään vaiheessa tulla luovuttamaan millekään muulle taholle ja tiedot ovat täysin luottamuksellisia. Tutkimuslomakkeet ja haastattelunauhoitukset säilytetään lukollisessa kaapissa tutkijan työhuoneessa tutkimuksen ajan, jonka jälkeen ne asianmukaisesti tuhoataan.

Tutkimuksen tavoitteena on saada uutta tietoa potilaiden omista kokemuksista liittyen avoterveydenhuollon vastaanottokäynteihin ja lääkärin antamasta hoidosta koettuun hyötyyn. Jatkossa toivon tämän tiedon hyödyttävän myös lääketieteen opetusta ja omalta osaltaan lisäävän potilaiden äänen kuulumista lääkärikoulutuksessa. Tarkoituksena on myös voida vaikuttaa nivelrikkopotilaan palveluketjun ja leikkausta edeltävän hoidon laadun kehittämiseen ottaen huomioon potilaiden omat näkemykset ja mielipiteet.

Haluan korostaa, että jos päätätte kieltäytyä osallistumasta tähän tutkimukseen, se ei millään tavoin vaikuta teidän sairausasianteen jatkosäilytykseen KYS:ssä.

Myös mahdollinen myönteinen päätöksenne, siis suostumus osallistua tutkimukseen, ei muuta Teille varattua vastaanottoaikaa kirurgian poliklinikalla. Tähän tutkimukseen osallistuminen ei vaikuta millään tavoin teidän sairautenne hoitoon tällä hetkellä, mutta toivottavasti tutkimuksen tuloksia voidaan tulevaisuudessa hyödyntää nivelrikkopotilaiden hoidossa. Siinä tapauksessa, että päätätte osallistua tutkimukseen, voitte ottaa yhteyttä minuun postittamalla vastauskirjeuoren ja voimme sopia haastatteluajankohdasta.

Vastaan mielelläni kaikkiin kysymyksiinne. Jos luetuanne tämän kirjeen päätätte, että Te ette halua osallistua tähän tutkimukseen, Teidän ei tarvitse ilmoittaa sitä minnekään.

Kunnioitavasti

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15.03.2006

Arvoisa potilas

Olette saanut lähetteen Kuopion yliopistollisen sairaalan ortopedian klinikkaan operatiivisen hoidon arviointia varten. Ohessa on Teille varattu aika ortopedille.

Ennen ortopedin vastaanottoa yleislääketieteen erikoislääkäri Pirkko Heasman tulisi mielellään haastattelemaan Teitä kotonanne tai haastattelu voidaan järjestää Teidän niin halutessanne Kuopion yliopiston kansanterveystieteen laitoksen tiloissa. Hän tekee tutkimusta polven ja lonkan nivelrikkopotilaiden kokemuksista saamastaan lääkärihoidosta ennen kirurgista hoitoa. Tutkimuksen tarkoituksena on saada esiin potilaiden omakohtaisia kuvauksia kokemuksistaan terveydenhuollon palvelujen käyttäjinä.

LL Pirkko Heasmanin tutkimussuunnitelma "Polvi- ja lonkka-arthroosipotilaiden kokemuksia konservatiivisesta hoidosta ennen artroplastiaa" on saanut puoltavan lausunnon Pohjois-Savon sairaanhoitopiirin tutkimuseettiseltä toimikunnalta 14.03.2006.

Voitte osallistua tutkimukseen palauttamalla liitteenä olevan yhteystietopaperin täytettynä oheisessa kirje-kuoressa. Postimaksu on maksettu puolestanne.

Tutkija Pirkko Heasman (puh. 017 162963, matkapuh. 040 5275335, s-posti pirkko.heasman@uku.fi) ottaa Teihin yhteyttä puhelimitse kirjeen saatuaan. Häneltä saatte myös tarvittaessa lisätietoja tutkimuksesta.

Heikki Kröger, ylilääkäri
ortopedian ja traumatologian professori
Kuopion yliopistollinen sairaala

Esko Kumpusalo, ylilääkäri
yleislääketieteen professori
Kuopion yliopistollinen sairaala

SUOSTUMUS TUTKIMUKSEEN

Tutkimuksen nimi: Polvi- ja lonkka-arthroosipotilaan kokemuksia konservatiivisesta hoidosta ennen artroplastiaa.

Tutkija: LL Pirkko Heasman, Kuopion yliopisto, Kansanterveystieteen ja yleislääketieteen laitos

Tutkittavalle suullisen ja kirjallisen selvityksen on antanut LL Pirkko Heasman

Olen saanut suullisen ja kirjallisen selvityksen tutkimuksesta "Polvi- ja lonkka-arthroosipotilaan kokemuksia konservatiivisesta hoidosta ennen artroplastiaa" LL Pirkko Heasmanilta. Minulla on ollut mahdollisuus suullisten ja kirjallisten kysymysten esittämiseen ja vastausten saamiseen tästä tutkimuksesta.

Suostun täysin vapaaehtoisesti siihen, että tutkija, LL Pirkko Heasman, saa haastatella minua kotonani minulle parhaiten sopivana ajankohtana tutkimustaan varten vuoden 2006 aikana ja saa nauhoittaa haastattelun. Nauhoitusta saavat kuunnella tutkijan lisäksi hänen opinnäytetyönsä ohjaajat, professori Esko Kumpusalo Kuopion yliopistosta ja professori Kirsti Lonka Helsingin yliopistosta sekä tutkimusryhmään kuuluva tutkimusavustaja, joka kirjoittaa haastattelun.

Olen tietoinen, että ääninauhat tuhoataan tutkimuksen päätyttyä asianmukaisesti. Samoin minulle on selvitetty, että yksittäisen henkilön tunnistaminen tutkimuksen raportointivaiheessa on mahdotonta. Annan myös suostumukseni minua koskevien sairauskertomustietojen käyttöön tutkimusaineistoksi. Minulle on selvitetty, että tietoja ei luovuteta kenellekään muulle ja kaikki kerättävä tieto on ehdottoman luottamuksellista.

Minulla on oikeus peruuttaa suostumukseni tähän tutkimukseen osallistumisesta syytä ilmoittamatta milloin tahansa.

Ymmärrän, että tähän tutkimukseen osallistuminen tai siitä kieltäytyminen ei millään lailla vaikuta minun saamaani hoitoon tai asemaani terveydenhuollon palvelujen käyttäjänä nyt eikä tulevaisuudessa.

_____/_____/2006_____
Paikka Pvm Tutkittavan allekirjoitus

Nimen selvennös

Vastaanottaja: Pirkko Heasman

Kopio lomakkeesta tutkittavalle

TUTKITTAVAN ILMOITUS HALUKKUUDESTA OSALLISTUA TUTKIMUKSEEN

"POLVI- JA LONKKA-ARTROOSIPOTILAIDEN KOKEMUKSIA KONSERVATIIVISESTA HOIDOSTA ENNEN ARTROPLASTIAA "

Suostun siihen, että tutkijalääkäri Pirkko Heasman Kuopion yliopistosta saa ottaa minuun yhteyttä puhelimitse tai postitse sopiaukseen kanssani haastatteluajan.

Tutkittavan nimi _____

Lähiosoite _____

Puh. no : 017/ _____ käsipuh: _____

Palautetaan oheisessa kirjekuoressa tutkijalle, kiitos.

PIRKKO SALOKEKKILÄ
*Encounters in
the Health Care*

The Voice of the Patient



This is a study of the experiences of people consulting their doctors and narratives they have told based on these experiences during the interviews with one researcher who has then interpreted their stories.

The main result of the study is that the competent doctor gives face to the system and influences the patient perception towards the whole health care system and makes it more trustworthy and acceptable.

If the patient does not perceive she has gained any benefit during the consultation, there is no added value connected to the visit and the patient may assess the visit unnecessary.



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