

Total Hip Replacement in Immigrants and Swedish Patients

Evaluation of preoperative care, socioeconomic background, patient-reported
outcomes and risk of reoperation

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Cover illustration by Javid Khoram "Language barriers"

“Knowing is not enough; we must apply,
Willing is not enough; we must do”

Johann Wolfgang von Goethe

To my parents Šefka and Rasim,
my most devoted teachers.

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ABSTRACT

Total Hip Arthroplasty (THA) aims to reduce pain and improve mobility, function and quality of life in patients with osteoarthritis, when non-surgical treatment has failed. Despite good or excellent results in the majority of patients, some of them are dissatisfied. This variability in outcome is multifactorial. Preoperative information, hospital care and postoperative rehabilitation may be more demanding if the patient is not familiar with the domestic language, belongs to a cultural minority or lives in poor socioeconomic circumstances.

This thesis aimed to investigate the influence of ethnicity and socioeconomic factors on the outcome after primary THA. Demographic information and data relating the surgical procedure, patient reported outcome collected preoperatively and one year after the operation and any subsequent revision/reoperation were retrieved from the Swedish Hip Arthroplasty Register. Cross-matching with data from the Patient Register and Statistics Sweden was performed to retrieve information about comorbidities, cohabiting, education, and country of birth. Interviews and a self-administered questionnaire on given preoperative information, pre- and postoperative pain and patient satisfaction including the DASS 21 score for mental health of patients were also used. The interviews were analyzed using content analysis according to Graneheim and Lundman. The patients were analyzed in four groups (born in Sweden, the Nordic countries, Europe and outside Europe including the Soviet Union) or two groups (born in or outside Sweden).

Patients from both groups in the qualitative study, expressed concern about inadequate pre-operative information on implants used, pain relief, choice of anaesthesia, no or

too short a time to put questions to the surgeon and an overall stressful clinical situation. All the immigrant groups had more negative interference relating to self-care ($p \leq 0.02$), some immigrant groups tended to have more problems with their usual activities ($p \leq 0.05$) and patients from Europe and outside Europe more frequently reported problems with anxiety/depression ($p \leq 0.005$). Patients born abroad showed an overall tendency to report more pain on the VAS than patients born in Sweden. One year after the operation the immigrant groups reported lower values in all EQ-5D dimensions. After adjustment for covariates including the preoperative baseline value most of these differences remained apart from pain/discomfort and regarding immigrants from the Nordic countries, anxiety/depression as well. One year after the operation pain according to the VAS had decreased substantially in all groups. The immigrant groups indicated however more pain than those born in Sweden both before and after adjustment for covariates ($p < 0.001$). Patients born outside Sweden had generally a poorer mental health than those born in Sweden. The risk of revision and reoperation within a period of two years did not differ between immigrants and patients born in Sweden.

The difficulties for the patients born outside Sweden may depend on cultural differences, communication problems and differences in indications. This patient group could benefit from improved pre- and postoperative information and other measures to facilitate and improve their rehabilitation.

Keywords: Swedish Hip Arthroplasty Register, total hip arthroplasty, immigrants, patient-reported outcome measurement, health-related quality of life, EQ-5D, mental health.

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SAMMANFATTNING PÅ SVENSKA

Målet med en total höftprotesoperation är att minska smärta, förbättra rörlighet, funktion och livskvalitet hos patienter med artros, när den icke-kirurgiska behandlingen har misslyckats. Trots goda eller utmärkta resultat för de flesta patienter blir ca.5-10% av patienterna missnöjda. Denna variation i resultatet kan fränsett uppenbara komplikationer bero på flera andra faktorer som t.ex. brister i den preoperativa informationen, sjukhusvårdens kvalitet och den postoperativa rehabiliteringen. Språkförbristningen, religiösa, kulturella och socioekonomiska skillnader kan också vara av betydelse för utfallet.

Avhandling syftar till att undersöka hur ursprungsland (i eller utanför Sverige) och socioekonomiska faktorer påverkar resultatet efter en primär total höftprotes operation. Demografiska data och uppgifter om det kirurgiska ingreppet, patientrapporterade uppgifter om smärta och global livskvalitet insamlades preoperativt och 1 år efter operationen. Faktorer som påverkade risken att drabbas av ett eventuellt ytterligare kirurgiskt ingrepp riktat mot den tidigare operationen analyserades med hjälp av data från Svenska Höftprotesregistret. Dessa data matchades med uppgifter från Patientregistret och Statistiska Centralbyrån för att inhämta information om patientens övriga sjukdomar, civilstånd, utbildningsnivå, inkomst och födelseland. Djupintervjuer och självadministrerade frågeformulär om den givna preoperativa informationen, smärtnivå och patienttillfredsställelse jämte frågeformulär DASS 21 för psykisk hälsa av patienter användes också.

Patienterna analyserades antingen i 4 grupper (födda i Sverige, Norden, Europa och utanför Europa inklusive Sovjet Unionen) eller i 2 grupper (födda i eller utanför Sverige). Samtliga patienter (födda både i och utanför Sverige) uttryckte oro och/eller missnöje relaterat till en bristande preoperativ information angående val av implantat, smärtlindring, val av anestesi, alltför kort tid för frågor till operatören och en genomgående stressad vårdssituation. Alla invandrar-grupper rapporterade mer problem med den dagliga kroppsvården ($p < 0.02$), vissa invandrar-grupper tenderade att ha mer problem med enklare dagliga rörelseaktiviteter ($p < 0.05$) och de flesta patienter angav ofta besvär med ångest och depressiva symptom ($p < 0.005$). Patienter födda utanför Sverige visade dessutom generellt en tendens att rapportera mer smärta på VA-skalan än de som var födda i Sverige. Ett år efter operationen rapporterade invandrargrupperna lägre livskvalitet i alla EQ-5D:s dimensioner. Efter statistisk justering för samvariation mellan de i analysen ingående variablerna inklusive preoperativa ingångsvärden återstod de flesta av dessa skillnader med undantag för dimensionerna smärta samt ångest/depression i gruppen som hade de Nordiska grannländerna som födelseland. Ett år efter operationen hade smärta enligt VA-skalan minskat betydligt i alla grupper. Patienter födda utomlands hade dock mer smärta än de som var födda i Sverige både före och efter den statistiska justeringen ($p < 0.001$). Patienter födda utanför Sverige mätte dessutom psykiskt sämre. Risken för omoperation av höften skiljde sig inte mellan invandrare och patienter födda i Sverige.

Svårigheter för de patienter som är födda utanför Sverige kan bero på kulturella skillnader, kommunikations problem och skillnader i indikationer. Förbättrad patient information

både före och efter operation, bättre utbildning av sjukvårdspersonal om invandrades sociala situation och villkor, bättre tillgång till välutbildade tolkar och även andra riktade åtgärder skulle sannolikt kunna underlätta dessa patientgruppers kontakt med sjukvården, och förbättra deras resultat efter en primär höftprotesoperation.

LIST OF PAPERS

This thesis is based on the following studies:

Study I

Influence of ethnicity and socioeconomic factors on outcome after total hip replacement.

Krupic F, Eisler T, Garellick G, Kärrholm J.

Scandinavian Journal of Caring Sciences. 2013; 27 (1): 139-146.

Study II

Preoperative information provided to Swedish and immigrant patients before total hip replacement.

Krupic F, Määttä S, Garellick G, Dahlborg Lyckhage E, Kärrholm J.

Medical Archives. 2012; 66 (6): 399-404.

Study III

The association between peroperative information and patient-reported outcomes one year after total hip arthroplasty in immigrants and patients born in Sweden.

Krupic F, Rolfson O, Nemes S, Kärrholm J.

Submitted

Study IV

No influence of immigrant background on the outcome of total hip arthroplasty.

140, 299 patients born in Sweden and 11,539 immigrants in the Swedish Hip Arthroplasty Register.

Krupic F, Eisler T, Eliasson T, Garellick G, Gordon M, Kärrholm J.

Acta Orthopaedica. 2013; 84 (1): 18-24.

Study V

Different patient-reported outcomes in immigrants and patients born in Sweden.

18,791 patients with 1 year follow-up in the Swedish Hip Arthroplasty Register.

Krupic F, Garellick G, Gordon M, Kärrholm J.

Acta Orthopaedica. 2014; 85 (3): 221-228.

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ABBREVIATIONS

ASA	American Society of Anesthesiologists physical status classification system
CHD	Childhood hip disease (congenital or acquired)
CI	Confidence interval
DALY	Disability-adjusted life year
DASS 21	Depression, Anxiety, Stress Score with 21 items
EQ-5D	The five dimensions self-assessment tool from the EuroQoL-group
GBD	Global Burden of Disease
HRQoL	Health-related quality of life
IHD	Inflammatory hip disease
ISCED	The International Standard Classification of Education
OA	Osteoarthritis (osteoarthrosis)
OR	Odds ratio
PRO	Patient-reported outcome
PROM	Patient -reported outcome measures
RA	Rheumatoid arthritis
RR	Relative risk
SD	Standard deviation
SEK	Swedish currency croons
SF-36	The 36-item Short-form Health Survey
SHPR	The Swedish Hip Arthroplasty Register
THA	Total hip arthroplasty (synonymous with THR)
The Register	The Swedish Hip Arthroplasty Register
TKA	Total knee arthroplasty (synonymous with TKR)
VAS	Visual analogue scale

WOMAC Western Ontario McMaster Universities Osteoarthritis Index
YLD Years lived with disability

DEFINITIONS IN SHORT

Cross-cultural	This concept originates from anthropological research in which cultural groups are contrasted and compared with one another. In this context cross-cultural means diversities across cultural groups, which is in contrast to the term transcultural, which means similarities across cultural groups.
Culture	The way of life that is shared by a group of people regarding beliefs, values, ideas, language, communication, norms and visibly, expressed forms such as customs, music, art, clothing and manners. Culture is dynamic and changing, it influences people and is influenced by people.
Confidence interval	A measure of the uncertainty relating to the main finding of a statistical analysis. It is usually reported as 95% CI, which is a range of values within which it is possible to be 95% sure that the true value for the whole population lies.
Confounder	A factor that is associated with both an intervention (or exposure) and the outcome of interest.
DALY	One DALY can be thought of as one lost year of "healthy" life. The sum of these DALYs across the population, or the burden of disease, can be thought of as a measurement of the gap between current health status and an ideal health situation, where the entire population lives to an advanced age, free from disease and disability.
Ethnicity	A common culture (language, religion, ancestry, uniqueness and so on) that leads to the feeling of kinship and group solidarity. It could also be defined as collective identity.
Health	According to the World Health Organization (WHO) health is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".
Hip disease	Collective term for any pathological condition of the hip joint.
Immigrant	A person born in another country and settled in Sweden, irrespective of citizenship and reason for immigration.
Linear regression	A form of statistical analysis where one variable can predict the other and the dependent variable is a continuous variable whose relationship to the independent variable is linear.
Regression analysis	Statistical method for assessing the degree of relationship among variables, where a dependent variable is related to one or several independent variables.
Re-operation	Any surgical procedure related to a previous arthroplasty of a specified joint (in this Thesis hip).

Response rate	The proportion of respondents in relation to all the patients who received the questionnaire.
Revision	A re-operation with extraction or exchange of all or parts of the implant.
YLD	Years lived with disability. To estimate YLD for a particular cause in a particular time period, the number of incident cases in that period is multiplied by the average duration of the disease and a weight factor that reflects the severity of the disease on a scale from 0 (perfect health) to 1 (dead).

01 INTRODUCTION

At present, we live in a time in which a large-scale migration of peoples is a fact, and that each one of us regularly meet people from different parts of the world. We are also witnesses of a mass migration of people who, in their search, of new homes inhabit areas that differ greatly from their own, in cultural, economic and other ways. Due to such processes current societies are becoming more and more multicultural and multiethnic in their nature. There are now about 231 million people living outside their country of birth, which means that one in every thirty people in the world is an immigrant^{1,2}. Each change in the society affects its basic elements. One of them is a health-care which is becoming more individually oriented and there is a great challenge imposed on health-care professionals to provide holistic care which would fulfill each individual's needs and treat all patients in the equal and impartial way regardless of their origin, religion or cultural background and in the same manner to provide equal accessibility to each individual³⁻⁶. This form of a health-care which proved to be very successful does not only include individuals but their families as well, and all individuals should be treated fairly, equally, and impartially⁷⁻¹⁰. Accordingly the main goal for Swedish health-care is to provide this kind of health protection⁷.

In order to pursue the holistic health-care it is crucial to establish clear, unquestionable communication in the affected triangle that involves a health-care professional, a patient and patient's family. Communication is crucial and the key to success in all aspects of health-care. People need to communicate in order to function and to live. Successful communication, in that sense, is very important for all social aspects among which are the health-care's as well. If, on the other hand, communication is being reduced or endangered in any way, it may present great problems for the society in general¹¹. For a successful health-care professional it is essential to establish good communication with their patients and if they do not speak the same language the challenge is even greater^{9,10}.

1.1 Background

1.2 Immigration from an international perspective

Migration is a phenomenon that occurs in all nations at all times. According to Oxford English Dictionary, an immigrant is a person who comes to live permanently in a foreign country¹². In this thesis, the term “immigrant” refers to persons residing in Sweden who were born abroad and most probably have a native language other than Swedish.

The increasing number of immigrants in Sweden has imposed a need for a successful communication with the immigrant communities, in every meaning of that word, so that health-care and social service which need to be provided for the immigrants would be of high-quality. The past recent years were marked by the significant migration processes which are either voluntary or forced by various reasons such as war, starvation or political circumstances. When we look back through the history we will see that migration has always existed as a form of human existence. There is a tendency to differentiate between the terms of forced migration which was first introduced on organized scale with the slave trade from Africa to America and voluntary migration. In that context we can speak of two different terms, “refugee” and “immigrant”. The term “refugee” refers to those individuals who were forced by many different elements to flee from their own country and was first used after the First World War¹³, while “immigrant” refers to those who voluntarily, out of their own will and desire decide to move to another country. Both of these groups of people have been treated in the equal way once they become residents of our country.

Despite the fact that refugees and immigrants decide to migrate due to different reasons, they still face the same problems and difficulties in adapting to the new environment in their new country of residence. Migration is not a simple process that contains only a physical aspect within itself. This process is much more since each individual who immigrated faces great changes in cultural, religious and moral environment. They all tend to adhere to the old values and relations and for them to lose these old networks is something they simply cannot allow in order to preserve their identity and integrity. On the other hand the need for the establishment of the new networks presents a necessity which cannot be avoided if the society is to function properly. Therefore to keep the balance between these two opposed issues presents a difficult but inevitable task¹⁴⁻¹⁶. The number of immigrants has increased rapidly in the 21st century due to the political and other circumstances. According to the information offered by the United Nation Refugee Agency (UNHCR) by the end of 2013 a total of 231 million people were forcibly displaced from their own homes worldwide. About 7200 members of the staff in the UNHCR provide humanitarian help for 5.3 milliard dollars in 126 countries².

"REAL WORLD"



©Swedish Hip Arthroplasty Register

1.3 Migration to Sweden

Sweden is a country that is open to immigrants from all over the world and as a result the immigration community grew significantly over the past decades and now it presents a quite significant part of the Swedish society while the process of immigration is still ongoing. If we examine the historical background of the migration processes in Sweden we can conclude that they exist as long as the Swedish nation itself. At certain points in history, as it was the case in 19th century the emigration exceeded immigration, though from the period after the Second World War these processes have changed significantly due to which Sweden became a country desirable for many immigrants who have found their new homeland here. Up to 1970s most immigrants were labor immigrants from the Northern European countries, while recently the structure and the character of immigrants have changed and nowadays they mainly come as refugees and asylum-requesters from countries such as Iran, Iraq and former Yugoslavia^{17,18}. More recently, refugees from the African continent, particularly from Somalia, have increased. According to the Swedish official statistics in 2013, 23.3% of the Swedish population of 9.7 million had a foreign background and 15.4% were born outside the country¹⁹. In the last ten years, labor migration associated with European Union regulations and immigration to join family has increased. In 2013, 115 845 persons immigrated to Sweden which is an increase of 3% compared with 2012. Of them, 64% are men and 36% women. Among the immigrants, 171 nationalities were represented.

Many of these immigrants were Swedish citizens who returned to Sweden after a long stay abroad. The second largest group comprised Iraqi citizens, followed by Polish citizens. The immigration of citizens from Afghanistan and Syria has increased over the last four years. Of those who immigrated to Sweden in 2013, 36% settled in one of the three largest cities; 15 644 went to Stockholm, 7 584 to Gothenburg and 8 210 to Malmö. Sweden has received a substantial number of immigrants. In 2007 the percentage of immigrants in the population was 13.4%, in year 2011 the immigration increased to 14, 1% and in 2013 the corresponding percentage had increased to 15.4 %^{19,20}. Many of these people suffer from hip disease, which may ultimately result in a total hip replacement.

1.4 The migration process and its influence on health

The process of migration in its very essence is very stressful since it brings such dramatic changes to the lives of those who participate in such processes. These newly created, potentially stressful situations might lead to a number of problems in different segments of life which finally might cause health problems for the immigrants²¹⁻²⁴. The connection between the endangered psychological state and poor physical health has been indicated in numerous studies²⁵⁻²⁹. First and even second generations of immigrants, due to the great amount of psychological stress that they are being exposed to during the process of resettlement, are in greater risk of suffering from different physical as well as psychiatric disorders than the native-born inhabitants³⁰⁻³³. As it has been mentioned before the communication between the health-care professional and the patient is crucial for the successful medical treatment and quite often it is not being achieved due to the lack of language skills or distrust that immigrant might feel towards the health-care institution³⁴⁻³⁶.

Very often the life in exile and second homeland, according to Sundquist et al.³⁷, is described as “a beautiful prison in gold” since immigrants feel discriminated, socially disintegrated, they feel that their essential role in life which was established in their native country does no longer exist, while they themselves have a very low level of control over their “new” life. Such people who experience great and numerous difficulties in the social segment of their lives tend to have more contact with the healthcare facilities and system in general³⁷.

1.4.1 Culture

One of the leading factors in the interaction and communication processes between people is their cultural background. In order to develop successful communication between the involved parties in the health-care process it is essential to understand the cultural role in it. After all, our entire cultural heritage is being transferred from one generation to the other through the means of communication³⁸. Since our society is multicultural and multiethnic in its character it considers, as one of its prime duties, to develop a sort of transcultural health-care which would provide an adequate and successful health care for all of its citizens which in return has become an area of an extensive research. The-

refore health-care professionals need to express a great deal of cultural sensitivity and to learn about different cultures if they are to establish a good communication with their patients from different backgrounds³⁹. One of the difficulties that health-care professionals face is how to provide an appropriate linguistic service to all patients since great number of patients is of different linguistic backgrounds⁴⁰⁻⁴². It is essential for the high quality health-care to help foreign-born patients to learn about the healthcare system in their second homeland as well as to provide conditions for the health-care professionals to learn about basic cultural values of the immigrant patients that they encounter in their work⁴³⁻⁴⁵.

Culture can also present one of the elements that to certain extent may hinder the establishment of a successful relationship between the patient and the health-care professional. We are all aware of different attitudes towards the biomedical perspective of treatment that mainly originate in the cultural background of the patient. Therefore the efforts that healthcare professionals put in order to improve the health and quality of life of each patient are not always fertile due to the different factors among which are those related to the socio-economic barriers. Apparently it has become essential to adopt the healthcare system to the referred cultural diversity⁴⁶⁻⁴⁹.

1.4.2 Religion

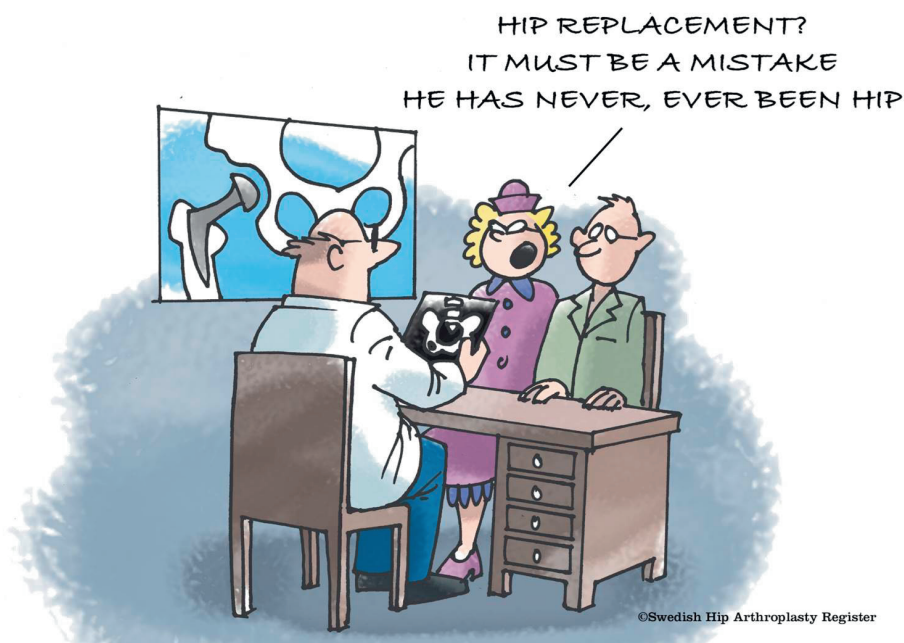
There are different perceptions of religion that we need to differentiate, religion per se and religious behaviour. Sociologists who have specialized in religion focus mainly on the communal aspects of religious life, while psychologists specializing in religion are primarily concerned about individual's beliefs, emotions, behaviour, motivation and also other factors⁵⁰. The psychological aspect of religion was often exemplified by William James's⁵¹ much quoted definitions of religion that refers to "the feelings, acts, and experiences of individual men in their solitude". In the scope of social psychology religion is perceived as a mere attempt of a human being to find a way to deal with the existential issues that derive from the awareness of the existence and its main aspect of life and death that we all must experience at certain point of time.

Religion can influence the health-care treatment in many ways. It can boost the individual's will and strength to conquer the disease but it can also affect the use of a certain form of health-care treatments. There are certain religious groups that are totally against the use of certain treatments or that may discourage the use of others which does affect the use of health-care practices at all levels. On the other hand religion and groups gathered around it encourage certain practices that focus more on preventive care than the health-care level services. Religion can also present an enabling element by, for example educating their followers about the ways how to access the health-care system, or they can offer certain services in the field of care themselves or through financial support. The most important individual characteristic, in the health-care system is "need for care". However this important characteristic can be ignored when the attention in the treatment is directed to the preventive services. The evidence prove that the degree of religious involvement is

higher for women than for men⁵²⁻⁵⁶, which implies that the influence of religion on health is much higher for women than for men⁵⁷. Health-care could serve as possible connection between the religion and the health. It is also important to study the influence of religion and health in an elderly population since age influences the religious involvement and the use of a healthcare. Older individuals are more religious, are more inclined to and more often need to use health-care services. The reports regarding the rate of church attendance show that the highest level of participants is of those who are 65 and older reflecting that the number of participants increases with the age⁵⁸. It has also been reported that the percentage of people using health-care services increases with the increase of age of the beneficiaries⁵⁹⁻⁶¹. In the United States for example the elderly population present hardly 13% of the population but accounts for 35% of total healthcare costs⁶².

1.4.3 Language

A very important mean for the communication and the interpretation of the culture is language. Healthcare professionals, in order to be successful in the communication with their patients, need to be aware of their own culture and to understand it in the best possible way which would enable them to learn about other cultures and as a result understand different cultural behavior⁶³. The lack of language or cultural knowledge can lead to misunderstandings between health-care professionals and patients⁶⁴ due to which the risk of misdiagnosis⁶⁵ is increased and it can lead to an inadequate or even worse, incorrect treatment⁶⁶. The difficulties in communication resulted in lower degree of health-care servi-



ces that were offered to the foreign-born patients⁶⁷. There are other difficulties that might appear due to the lack of language understanding such as inadequate number of medical contacts⁶⁸, patients who are not satisfied with the acquired treatment⁶⁹ as well as the increase of the number of tests that are being conducted due to the fact that individuals are admitted more frequently to the hospital and that they are receiving more treatments.⁷⁰ Very often crucial clues within the treatment are being overlooked, subsequent treatment is not being performed, symptoms that suggest traumatic stress are not being reported and psychological care is not being adequately presented due to the mentioned difficulties in communication⁶⁸. One of the consequences, which are by far the worst, is the increase of the mortality rate since the hospital care is not properly determined and the establishment of clear diagnosis is often hampered⁷¹. Accordingly, good communication is crucial for the proper integration of an individual into the society as well as the proper delivery of healthcare⁷². The conclusion we might come to is that the best way to avoid previously mentioned difficulties and obstacles is to always use the services of a registered interpreter.^{9,10,73,74}



1.5 The epidemiology of hip disease

The prevalence and incidence of the different hip joint diseases are not easily studied, not least because there are different ways of defining and diagnosing the various conditions. The diagnostic criteria may be based on symptoms, radiographic and other imaging technology findings, micro- or macroscopic changes, biochemical markers or a combination of these. For example, symptoms of osteoarthritis (OA) of the hip may be present without radiographic findings, radiographic findings may be present without symptoms

and symptoms mimicking hip disease may be due to other conditions not related to the hip joint. This makes it problematic to study the epidemiology of hip disease in general and osteoarthritis (OA) in particular. The prevalence of osteoarthritis increases with age and with population ageing. The so-called “burden of hip disease” has increased dramatically over the past five decades. In the last report from the WHO the estimates for disability-adjusted life years (DALYs) in 2000-2011 in terms of osteoarthritis show an increase throughout the world (Table 1). Furthermore, the prevalence varies greatly all over the world and is highest in Europe and America and smallest in Africa.

Table 1. DALYs (thousands) by cause and by WHO region

Year 2000							
	World	Africa	America	Asia	Europe	Eastern Mediterranean	Western Pacific Region
Population(thousands)	6089957	656445	829324	1572713	868328	480820	1682327
GHE* 2012	DALY#s	DALYs	DALYs	DALYs	DALYs	DALYs	DALYs
Osteoarthritis n, %	13375 <i>0.5</i>	1001 <i>0.1</i>	2106 <i>0.8</i>	2309 <i>0.3</i>	2780 <i>0.8</i>	898 <i>0.4</i>	4281 <i>0.9</i>
Year 2011							
Population(thousands)	6938255	857380	938646	1830361	899442	604475	1807951
GHE* 2012	DALY#s	DALYs	DALYs	DALYs	DALYs	DALYs	DALYs
Osteoarthritis n, %	18146 <i>0.7</i>	1350 <i>0.2</i>	2811 <i>1.1</i>	3194 <i>0.4</i>	3145 <i>1.0</i>	1308 <i>0.5</i>	5679 <i>1.2</i>

*Global Health estimates, #Disability-adjusted life year

According to the same report the estimated number of years due to disability (YLDs) caused by OA globally has moved from place 13 in year 2000 (13.3 millions) to place 10 (17.4 millions) in 2011⁷⁵.

1.5.1 Musculoskeletal disease among immigrants

There are studies of musculoskeletal pain conditions in immigrants in general and in immigrants from Turkey in Sweden in particular. Sandquist et al.⁷⁶ found that being born outside Sweden was associated with an increased prevalence of musculoskeletal disease, compared with people born in Sweden. Looking at differences between immigrants and Swedish patients with musculoskeletal pain, Saores and Grossi⁷⁷ found that the immigrant patients lived under more strained psychosocial conditions and experienced a deeper impact of pain compared with those born in Sweden.

1.5.2 Common causes of hip pain

The most common cause of chronic hip pain and disability is arthritis. Osteoarthritis, rheumatoid arthritis, and traumatic arthritis are the most common forms of this disease.

Osteoarthritis. This is an age-related type of arthritis. It usually occurs in people aged 50 years of age and older and often in individuals with a family history of arthritis. The cartilage cushioning the bones of the hip wears away. The bones then rub against each other, causing hip pain and stiffness (Figure 1). In the Nordic countries THR due to primary osteoarthritis is more common in Sweden (78.8%) than in other Nordic countries, Denmark (77.6%) and Norway (73.7%)⁷⁸. Worldwide, the highest prevalence of osteoarthritis is in Europe and America (1.0%) (Table 1).

Rheumatoid arthritis. This is an autoimmune disease in which the synovial membrane becomes inflamed and thickened. This chronic inflammation can damage the cartilage, leading to pain and stiffness. Rheumatoid arthritis is the most common type of a group of disorders termed “inflammatory arthritis.” In the Nordic countries surgery with THR due to RA is more common (years 1995-2011: 4.5%) in Finland than in Denmark, Norway and Sweden (1.7-2.6%, personal communication). Worldwide, the highest prevalence of rheumatoid arthritis is highest in Europe (1.0%), followed by America (0.8%) and the Western Pacific Region (0.6%)⁷⁵.

Post-traumatic arthritis. This condition can follow a serious hip injury or fracture. Degenerative changes may occur due to permanent cartilage damage and/or joint incongruence. In countries with a high incidence of high-energy trauma caused by traffic accidents, hip dislocations, pelvic and hip fractures can be expected to be more common as the incidence of their sequelae in terms of post-traumatic hip disease is high. A high incidence of THA due to hip fracture can also be expected in countries with a large proportion of osteoporotic elderly people.

Avascular necrosis. An injury to the hip, such as a dislocation or fracture, may limit the blood supply to the femoral head. The blood supply could be obstructed without any known reason (idiopathic necrosis). This is called avascular necrosis (AVN). Subchondral fractures may occur leading eventually to more or less of a collapse of the femoral head. Some diseases and medications have been associated with an increased incidence of avascular necrosis. In the Nordic countries the relative percentage of patients undergoing THR due to AVN is lower (about 2.2%)⁷⁹.

Childhood hip disease. Osteoarthritis may be caused or accelerated by conditions of instability or primary and secondary disturbances of growth in the neonatal period or during childhood. Examples include neonatal hip instability, congenital dislocation, Perthes disease and slipped capital epiphyseolysis. They all have the potential to cause osteoarthritis in adult life. The incidence of THR

due to this type of osteoarthritis varies throughout the world. In the Nordic countries, Norway has the highest prevalence (8.6%), followed by Denmark (3.1%) and Sweden (1.8%)⁷⁸.

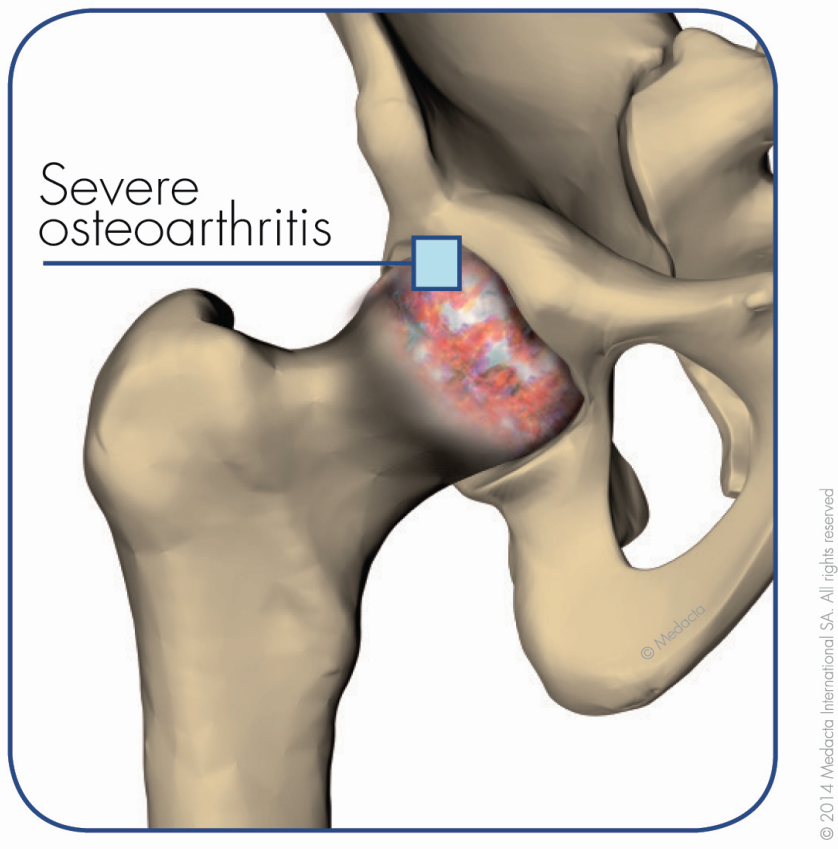


Figure 1. Schematic drawing of a hip with osteoarthritis.

1.6 Management of hip diseases

1.6.1 Total hip arthroplasty (THA)

In the majority of patients with symptomatic degenerative hip disease THA, performed on correct indications can be expected to reduce or eliminate pain, improve function and the quality of life. Since the introduction of modern THA in Sweden its incidence has

continuously increased. What seems to present certain problems in this area is the determination of indications for the procedure and assessment of the intervention itself. The EUROHIP project, initiated in 1997, resulted in a comprehensive publication entitled "Health Technology Assessment of Hip Arthroplasty in Europe"⁸⁰. The authors of this article have tried to stress the fact that there is a certain number of patients, smaller one though, who do not perceive this kind of surgery as successful one. This issue has been stressed and emphasized in the Swedish Arthroplasty Register⁸¹. On the other hand the results of the completed European project indicate that there is no standard opinion or attitude towards indications for THA. It has been noticed that significant variations do exist in different countries in Europe and even within the actual countries themselves when it comes to different aspects that include the care that is being provided, implants and fixation that are being used, costs of the procedures and clinical and patient-reported outcomes. All that has been mentioned up to now clearly indicates an urgent need for the multidimensional assessment of the outcome of hip disease and THA surgery.

1.6.2 Registers, personal integrity and response rate

Since there are many quality registers in Sweden that undertake significant activities in the quality measurement the risk of the possible compromising of personal integrity has become evident. However, a recent amendment to the Patient Data Act⁸² provides better grounds for the protection of integrity and ensures greater support of the quality registers. For example, the act requires a higher degree of authentication than before. The matter of authentication has not been fully developed, it could be, however, improved with the use of ID or smartcards when health professionals enter data into registers. In this way the better grounds for the future methods of collecting PROMs will be provided. In addition there is a very sensitive balance between the integrity and the benefit to patients and society. The difficulties in presenting the PROM questionnaire to all THA patients prior to the operations as well as in the response rate of the PROM^{83,99-103} instruments have been indicated. Possible reason lies in the PROMs taken from the patients who come with acute conditions and who require surgery within the first 24 hours where, due to such circumstances, it is very difficult if not impossible to collect the required data. Therefore mentioned facts define different problems that are more of logistic nature, and that emerge in the presentation of questionnaires to all patients eligible for THA. However the rate of responses in the post-operational period is much higher when it is compared with the one taken from the most questionnaire studies. The number of patients who do not respond to the questionnaire is approximately 10% and the possible reason might be invalid addresses, the cases of patients who are moving abroad, possible human errors in sending out questionnaires, language problems and other factors. Accordingly the actual response rate has not been determined in full scope. The exact number of patients who have been offered pre-operative questionnaires is still unknown and it is still not possible to determine it accurately as well as it is still impossible to determine the number of patients who actually receive the follow up procedure in the period of one year after the operation.

1.6.3 The operation and follow-up

In most parts of Sweden the patient visits the outpatient clinic about two weeks before the operation to meet an anaesthesiologist, an orthopaedic surgeon, a physiotherapist and a contact nurse. During this visit patients are examined and given further information about the type of anaesthesia, surgical procedure and rehabilitation following surgery. The surgeon provides oral and written information about the operation and implant. The patients are frequently also able to view an educational film describing the surgical procedure as well as see and touch the hip implant. They are admitted to hospital the day before or the same day as the operation is planned.

This process was developed for patients born in Sweden, but little is known about the extent to which it should be modified in immigrants. Probably any such modifications must be adapted in different ways depending on the background of the individual patient.

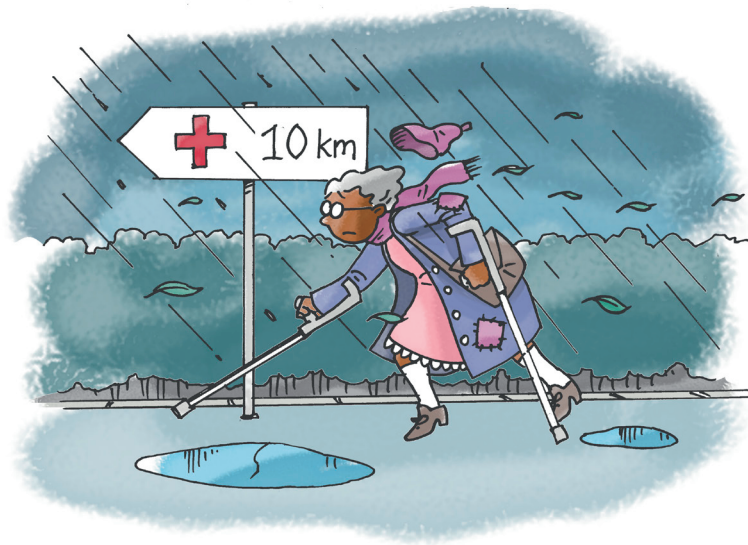
1.6.4 Equal health care in immigrants

The goal of public health in Sweden, as stipulated by the Swedish National Board of Health and Welfare, is to provide equal and high quality care for the complete population⁸⁴. The healthcare must:

- a) Be of good quality and take account of the patients need for safe care and treatment,
- b) Be readily available,
- c) Be based on respect for the self-determination and privacy of the patient and
- d) Promote good relationships between patients and healthcare.

Accordingly, all residents of Sweden, including all immigrants, have economically “equal access” to the health care system and pay a maximum annual charge for prescription medications for acute and/or chronic diseases. Care and treatment must, in as far as possible, be designed and conducted in agreement with the patient⁸⁴.

However, communication between health-care providers and patients may be more difficult if the patient does not speak or understand the language. All of the immigrant patients who do not speak Swedish language, have right to engage interpreters, if so needed. It is important to know whether the goal of providing equal and high quality care for all patients in Sweden has essentially been achieved, not least regarding those undergoing Total Hip Replacement. Despite that the group is increasing, the immigrant group is still a minority group and still more so if their different origins are considered. The individuals born outside Sweden are often excluded from research studies due to communication and



©Swedish Hip Arthroplasty Register

language difficulties.

There is however several previous studies indicating that immigrant groups may require specific consideration in their contact with health-care systems. In one study of patients with chronic heart failure, coming from different ethnic minorities, it was found that problems coping with the disease could sometimes be related to communication barriers and cultural differences in illness beliefs and treatment preferences⁸⁵. Another similar study of patients with the same disease describes factors that influence their adherence to treatment such as the level of knowledge of the condition and beliefs about the regimens provided and its possible long-term benefits. Other factors such as age, gender, educational level, marital status, severity of the condition and depressive symptoms, also emerged to have some influence⁸⁶.

A review of the Scandinavian literature on transcultural issues in primary care also reveals that relatively few studies are sufficiently comprehensive to assure the generalizability of the findings⁸⁷. The main focus in other disciplines and in research on chronic heart failure is often on pathophysiology, clinical or risk factors, epidemiology, and economical costs. Comparatively, little is currently known about immigrants' beliefs, perspectives and experiences of care and treatment.

One aspect of a multicultural society is also that immigrants may have different patterns to utilize health-care, such as e.g. in breast cancer care. In one study based on a nationwide

Family-Cancer Database (11.8 million patterns) some 15% were born abroad, and the author's analysed age at diagnosis of breast cancer in female immigrants by their region of origin and compared the results with the age at diagnosis in native Swedish women matched for birth year and other relevant factors. The authors showed that the SIRs (standardised incidence ratios) were lower in many immigrant groups compared with Swedish natives; women from Turkey had the lowest SIR of 0.45, followed by those from Chile with 0.54 and South Asia with 0.57. Women from nine regions showed an earlier mean age at diagnosis than their matched Swedish controls, the largest differences being 5.5 years for women from Turkey, 5.1 years for those from Asian Arab countries, 4.3 for women from Iran, and 4.0 years for those from Iraq⁸⁸.

Several previous studies have shown that socioeconomic status (SES) and ethnicity influence not only the risk of type 2 diabetes but also degree of metabolic control. In one study from Sweden, comparing men and women (aged 35-56 years) measured socioeconomic status in childhood, adolescence, and adulthood and found that a low socioeconomic status in adulthood was associated with an increased risk of type 2 diabetes in men (relative risk 2.9) and women (relative risk 2.7)⁸⁹.

In another study, the authors described how disease severity and duration was associated with gender, age, ethnicity and socioeconomic status in patients undergoing hip or knee replacement⁹⁰.

One study investigated factors predicting the level of HRQoL (EQ-5D) one year after Total Hip Arthroplasty in patients undergoing surgery in Sweden and Denmark. The authors examined the extent to which age, gender, comorbidity and country of surgery were associated with quality of life and (EQ-VAS) after surgery. They found that patients from Denmark had an overall higher EQ-5D index and EQ-VAS than patients born in Sweden⁹¹.

Moreover, one factor that influences mental health is immigrant status to^{92,93}. The mental health of migrants is different from that of native born. It seems that the mental health of immigrants may be influenced by experiences in their home country; the process of migration itself and by the living conditions in the new country. Immigrant status is associated with lower degrees of use of mental health services, even with universal health insurance. This lower rate of utilization of care likely reflects cultural and linguistic barriers to care. These studies indicate that language barriers are associated with longer visit time per clinic visit, less frequent clinic visits, less understanding of physician's explanation, more lab tests, more emergency room visits, less follow-up, and less satisfaction with health services. Especially female immigrants from low-income countries are found among these patients^{92,93}.

Also, the preparation of a patient before total hip arthroplasty is a multidisciplinary process, which involves patient education and information about surgery. The goals of

the process are to reduce anxiety, manage postoperative pain, preventing postoperative complications and eliciting the patient's participation in the rehabilitation process after surgery. Numerous previous studies have shown that provision of adequate preoperative information can alleviate preoperative anxiety, and may improve short-term surgical outcomes, shorten hospital stays and minimise lifestyle disruption.^{94,95,137,154}

However, the question is whether immigrant patients awaiting total hip arthroplasty surgery in Sweden are given the pertinent attention in relation to language barriers, cultural and/or religious differences, educational differences, gender and psychosocial background.

The overall goal of this thesis is to investigate effects of ethnicity and socioeconomic factors on the outcomes of total hip arthroplasty.

The specific aims of the studies were as follows:

- I. To investigate whether patients living in the Gothenburg area but are born outside Sweden report equal effects of a total hip replacement in terms of EQ-5D subscores, pain and overall satisfaction compared with those born in Sweden.
- II. To explore how immigrants and Swedish patients described information provided before elective total hip replacement.
- III. To explore to what extent information about pain and pain relief before and after insertion of a Total Hip Replacement and information about the surgical procedure itself varied between patients born inside and outside Sweden. Further, the aim was to investigate if the perceived quality of this information was associated with different patient-reported outcomes one year postoperatively.
- IV. To investigate whether certain immigrant groups in Sweden with a primary total hip replacement more frequently undergo repeat surgery within 2 years and/or revision surgery within 14 years compared to those born in Sweden.
- V. To investigate whether patients who live in Sweden, but are born outside this country report equal effects of a total hip replacement in terms of EQ-5D subscores, pain and overall satisfaction compared with those born in Sweden.

03 PATIENTS AND METHODS

This thesis comprises of three types of studies:

- Qualitative (interview) study (Study II).
- Questionnaire (Study III)
- Register studies (Study I, III, IV, and V).

Table 2. *Patients included in the studies*

	Total number of patients <i>Born in Sweden/born abroad</i>	Data collection	Period
Study I	1216 (1075/141)	SHPR, Statistics Sweden, the patient register	2002-2006
Study II	20 (10/10)	Interview, DASS 21	March-November 2010
Study III	189 (139/50)	SHPR, Questionnaire, DASS 21	March 2010-December 2012
Study IV	151 838 (140 299/11 539)	SHPR, Statistics Sweden Sweden, the patient register	1992-2007
Study V	18 791 (17 340/1451)	SHPR, Statistics Sweden, the patient register	1992-2007
Total	172 054 (158 863/13 191)		1992 - 2012

3.1 Design

3.1.1 Study II

A qualitative descriptive design was selected due to the exploratory nature of the study. This design was judged to be appropriate, as the knowledge of patients' experiences of preoperative information before elective total hip replacement, pain relief, implant, anaesthesia type and postoperative rehabilitation were included. Open-ended interviews were regarded as a suitable data collection method in relation to the aim, since they offered an opportunity to explore the subjective experiences of hip arthroplasty surgery from the patients' perspective⁹⁶.

3.1.2 Studies I, III, IV and V

Based on the study aims, information about health-related quality of life (HRQoL), pain and pain relief (VAS scale), patient demographics and socioeconomic data, comorbidity and patients mental health (DASS 21) was collected using forms or touch screens (via SHAR) and cross-matching with the patient register and Statistics Sweden. Information about revisions, re-operation, mortality and time to any of these events was obtained from the Swedish Hip Arthroplasty Register (SHAR) database. A questionnaire comprising 31 questions in four dimensions was constructed, used and evaluated (Appendix 2). An overview of designs and methods are displayed in table 2.

3.2 Settings

3.2.1 Study II

Participants were recruited during the standard routine for THR surgery at the hospital. In Sweden, patients seeking help for hip problems in primary care receive a referral to specialist care. About two weeks before the operation the patients visit the orthopaedic clinic, where they meet an anaesthesiologist, an orthopaedic surgeon, a physiotherapist and a contact nurse. During the visit patients are examined and given further information about the type of anaesthesia, surgical procedure and rehabilitation following surgery. The surgeon provides oral and written information about the operation and implant. Patients can also view an educational film describing the surgical procedure and see and touch the hip implant. They are admitted to hospital the day before the intervention or early in the morning the same day as the intervention. At the visit two weeks before the operation, the contact nurse invited eligible patients to participate in the study. Those willing to participate signed a consent form attached to the electronic patient records. The contact nurse informed the first researcher about patients interested in participating.

3.2.2 Studies I, III, IV and V

The Swedish Hip Arthroplasty Register records all primary hip replacement surgeries performed in Sweden. The degree of completeness is almost 98%⁹⁷. Demographic factors, surgical technique, choice of implant and prosthetic complications resulting in any type of reoperation related to the hip surgery are recorded. In 2002, the register started to record patient-reported outcome measurements (PROM) in terms of EQ-5D and pain recorded on a VAS before and one year after surgery. In addition, Charnleys functional categories (A, B and C)¹¹² and patient satisfaction reported on a VAS one year after the operation are registered. Patient-reported outcome measurements have gradually been introduced at present to cover almost all hospitals in Sweden performing THA.

3.3 Data collection

3.3.1 Study II

Patients were recruited two weeks prior to THR surgery at the Sahlgrenska University Hospital, Mölndal, Sweden. The inclusion criteria were patients with primary or secondary osteoarthritis, admitted for surgery from their own homes in the surrounding area. An exclusion criterion was patients who were unable to participate in an interview. Twenty patients were invited to participate and they all agreed. They were recruited consecutively until 10 immigrants and 10 Swedish patients had been enrolled.

An interview was conducted on the day before the planned surgery. Data were collected by the first author through face-to-face interviews using open-ended questions. The interviews began with small talk. The opening question was “Can you please describe the information you received before surgery?” The participants were urged to speak freely using their own words. During the interviews, the interviewer encouraged the participants to respond to questions as comprehensively as possible. The interviewer only interrupted to pose further questions or follow up the information. The interviews were performed on the ward, lasted between 60 and 90 minutes and were audio-taped and transcribed verbatim.

In order to obtain background data, all participants completed the Depression and Anxiety Stress Scale-21 items (DASS 21)⁹⁸ a few minutes after the interview finished. The DASS 21 scores have been validated and translated into Swedish. They were used to measure the participants’ depression levels. The participants who were unable to read and understand Swedish were helped by a professional interpreter. The categories were: no depression 0-9, mild 10-13, moderate 14-20, severe 21-27 and extreme depression >28 (see Appendix 3).

3.3.2 Studies I, III, IV and V

3.3.3 Prospective observational data since 1979

In the Swedish Hip Arthroplasty Register prospective observational studies data on all hip arthroplasty surgery in Sweden are continuously collected. The overall aim of the register is to improve the outcome following THA^{97,99-103}. The feedback of analyzed data stimulates the participating units to reflect and improve. Since the register was initiated in 1979, its purpose has been to monitor technical issues related to surgery (e.g. surgical technique, the performance of different implants, prophylactic measures, environment in operating theatre) to minimize complications and adverse events related to THA. The introduction of the PROM programme has added a new dimension to the recordings and enabled a more complete evaluation of outcome.

3.3.4 The Swedish Hip Arthroplasty Register (SHAR)

The Swedish Hip Arthroplasty Register (SHAR) was initiated in 1979¹⁰⁴⁻¹¹⁰. The Swedish Hip Arthroplasty Register records all primary hip replacement surgeries performed in Sweden. The degree of completeness is almost 98%^{97,110}. Demographic factors, surgical technique, choice of implant and prosthetic complications resulting in any type of re-operation related to the hip surgery are recorded. In 2002, the register started to record patient-reported outcome measurements (PROM) in terms of EQ-5D and pain recorded on a VAS before and one year after surgery. In addition, Charnley category and patient satisfaction reported on a VAS one year after the operation are registered. Patient-reported outcome measurements have gradually been introduced at present to cover almost all hospitals in Sweden performing THA. More recently, information about the American Society of Anaesthesiologists' (ASA) classification of physical status¹¹¹, height and weight has been added to the variables collected (Figure 2).

Svenska Höftprotesregistret

Årsrapport 2011

FÖR VERKSAMHETSÅRET 2011



Figure 2. Annual report of the SHAR (available at: [Annual reports SHAR](#)).

3.3.5 Databases

In the Swedish Hip Arthroplasty Register, there are six databases:

- *Primary THA databases*
- Re-operation THA databases (revision and re-operation)
- Environmental / technical profile (aggregated data per unit)
- *Patient-reported outcome measurement databases*
- Primary hemi-arthroplasty databases
- Re-operation hemi-arthroplasty databases (revision and re-operation)

For the analyses in this thesis (Studies I, III, IV and V and the additional results) the primary THA database and the PROM database were used.

3.3.6 Quality of register data

The data in register analysis depends generally on the quality of data in the existing registers database. There are different dimensions of data quality such as:

- Validity and reliability of metrics
- Coverage and completeness of registration
- Patients response rate to questionnaires

3.3.7 Validity

Validity indicates the extent to which data and findings are true for the population studied. In order for data to be valid requires high quality data (data quality). High quality data is relevant, complete, accurate and consistent. Data validation (data validation) involves checking that the data is correctly registered. This can occur, for example, by checking that only allowed values are registered (according to value lists and thresholds), to determine if there is consistency in the data (e.g. the deceased patients did not have surgery after his death date), compared with source data (such as medical records and operation reports) or to implement adjustment of data¹⁰².

3.3.8 Reliability

Specifies how precise a measurement method is, that is, the degree to which the measurement method gives the same measurement value when the same object is measured repeatedly (provided that the item not changed). Reliability is crucial to reliably measure changes over time, such as the weight or quality of life. An instrument with high reliability-

ty gives virtually the same readings on repeated measurements. High degree of reliability does not necessarily mean that the measured values are true. Data with poor reliability leads to misleading analysis results. Errors might be caused by misclassification, which may lead to under- or overestimated results¹⁰².

3.3.9 Coverage and completeness

The term coverage is commonly used synonymously with the English term completeness. In SHPR coverage is used to describe the number of participating hospitals that perform THR and report data about the operations to the Register.

Completeness refers to the proportion of individuals operated with a THR in Sweden, who also are reported to the register. The Swedish Hip Arthroplasty register has been cooperating for years with the National Board of Health and Welfare which operates the National Patient Register based on the personal identity numbers.

According to Swedish law, all departments are required to report all medical interventions to the patient register. A link between Swedish Hip Arthroplasty register and the National Patient Register is completed every year. The total numbers of THR performed in Sweden is set to the number of operations recorded either in the National Patient Register or the SHPR or both these registers¹⁰².

3.3.10 Response rate

The quality of data also depends on response rate in the PROM programme. Response rate is defined as the proportion of responders in relation to the number of patients who during optimum circumstances could answer, which most commonly corresponds to those who receive a questionnaire or the responders in the studies. However, it is often difficult to give a correct picture of participant's true willingness to answer the questionnaire and participate in the studies because of non-medical logistical reason related to language problems or simply that a questionnaire may not reach all participants¹⁰².

3.4 The PROM programme

The PROM programme includes all patients eligible for THA. They are asked to complete a questionnaire prior to their operation. The questionnaire contains ten items including Charley's functional categories (A, B, and C)¹¹², a VAS for pain (no pain (0) to unbearable pain (100)), and the generic EQ-5D instrument and are answered one, six and ten years after the operation. On the postoperative forms there is also a VAS for satisfaction (satisfied (0) to dissatisfied (100), disease-specific question). The satisfaction level we are mentioning here refers to the outcome of surgery. The PROM protocol is presented in Appendix 1. In order to collect targeted data the questionnaire is mailed to patients, with a cover

letter and a stamped addressed envelope. The cover letter contains the general information about the PROM programme, the survey and it also instructs the patient to contact his or her orthopaedic surgeon if he or she has hip problems. Those who do not respond receive only one reminder. For each operating unit a database including the answers is delivered to the SHPR. The individual hospital-based database is also available for internal use (e.g. continuous monitoring and local improvement).

3.4.1 The definition of outcome quality

The parameters that are traditionally used, such as implant survival, usually do not provide a complete and sometimes misleading picture of the subjective results after hip replacement and other implant procedures^{113,114}. Patient-reported outcomes (PRO) provide another important dimension to the result of the operation corresponding to the subjective opinion of the patient and the influence of the procedure on pain and the quality of life.

The demands for the measurements of PROs in Sweden, as in many other countries are increasing. The Swedish Association of Local Authorities and Regions and the National Board of Health and Welfare share the same stand that the health-care quality registers should include PROs and that collected information should be presented publicly. The rationale for measuring PROs was eloquently phrased by Berwick in a British Medical Journal editorial in 1997; “Sociologically, professions tend to reserve the right to judge the “quality” of their own work. The best route to the future is for the medical profession to externalise the definition “quality”. In other words the most adequate measurement of the quality of the medical intervention is to determine, on the grounds of patients’ personal opinion, the extent to which it helps them and their families. On the other hand everything that is done in the field of health-care that does not really help a patient or family is of no use, regardless of the fact whether or not the professions and relevant associations support it¹¹⁵. Regretfully there have been very few examples of PROMs requested and as such collected in the entire health system.

3.4.2 Patient-reported outcome measurements (PROM)

There are many PROM instruments that differ in their quality and purposes. In the decision making process as to which PROM to choose for a specific disease or condition there are different issues that need to be taken in consideration. To begin with, the PROM instruments that are used must comply with the basic requirements of validity and reliability from the methodological point of view. Secondly, the applied set of instruments should include both generic and disease-specific PROMs in order to provide information about the effect of the procedure on a person’s health state as well as overall life and how the condition affects the functioning of a targeted body part or other particular limitations/problems that patients can experience. It is of vital importance to apply generic instrument in order to provide comparison of the gathered information within different patient and population groups. Further on, the survey should contain sufficient number of ques-

tions in order to provide an adequate response rate. And finally, the selected instruments need to have the ability to respond to possible changes as well as to detect changes that might occur in a due process. PROMs should not be confused with patient-reported experiences measurements (PREMs). PREMs on the other hand provide information on how the patients value and perceive the received care, which in other words tells us more about their opinion and experience of the care and not the actual outcome of the care. These measurements of experience should not be neglected since they prove to be extremely useful in the process of improvement of the work within this branch, but regrettably they cannot be used as relevant ones for the quality register.

3.4.3 Disease-specific and generic instruments used in the PROM programme

3.4.4 Visual Analogue Scales (VAS)

In the PROM programme, the disease specific instrument for pain and satisfaction are VA scale. The patients were asked to rate the severity of pain in the operated hip on the VA scale for pain which are divided from 0 (no pain) to 100 (worst imaginable pain). The question estimates the pain-experience from the hip preoperatively and at repeated occasions after the operation. (In this Thesis only after 1 year). The vertical line has subscale indicators and ordered response levels (no or slight pain, mild pain, moderate pain, severe pain and unbearable pain). The VAS for satisfaction with the outcome of the hip arthroplasty is divided from 0 (satisfied) to 100 (dissatisfied). This vertical line also has subscale indicators and ordered response levels (very satisfied, satisfied, moderately satisfied, not satisfied and dissatisfied).

3.4.5 Charnley's functional categories

In the PROM programme, the Charnley category is apportioned as two self-administered questions a) "Do you have any symptoms from the other hip?" and b) "Do you have problems walking because of other reasons?" (e.g. angina, back pain, pain from other joints, or any other medical condition prejudicing patients walking capacity)". This simple clinical classification system was developed in 1972 by Sir John Charnley¹¹². The system is divided into three categories; A, B or C. Category A includes patients with unilateral hip disease, category B patients with bilateral hip disease and category C those with multiple joint disease or other major medical conditions impairing walking capacity.

3.4.6 The EQ-5D self-completion instrument

The EQ-5D¹¹⁶ is a generic HRQoL instrument that evaluates patients in five dimensions, mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Each dimension is divided into three levels of severity (no = 1, moderate = 2 and extreme problems =

3). In total, these questions will result in one of 243 possible combinations represent different health status. The EQ-5D is presented as a health profile or as a global health index with a weighted total value. To adjust to cultural differences in response pattern, different national/regional tariffs are used when computing the index. The form is standardised for use as a measurement of health outcome and has been translated into more than 120 languages. Because there was no Swedish EQ-5D tariff, we used the UK117 time-trade –off value set to calculate the EQ-5D index. The patients completed the Swedish-translated questionnaire. This value set gives indices ranging from -0.594 to 1 where health states 0 and below represents health states worse than death and 1 the best possible health states. The EQ-5D questionnaire also includes a VAS for general health from 0 (worst imaginable health state) to 100 (best imaginable health state).

Use of the EQ-5D-5L instead of the EQ-5D-3L offers a possibility to obtain more fine-tuned answers and perhaps also to catch differences caused by cultural background. In the five level version of the EuroQoL questionnaire each level corresponds to: no problems, slight problems, moderate problems, severe problems, and extreme problems. The numerals 1-5 have no arithmetic properties and should not be used as a cardinal score¹¹⁶.

3.4.7 DASS 21

The DASS 21 score⁹⁸ is a quantitative measurement of distress along the axes of depression, anxiety (symptom of psychological arousal) and stress (the more cognitive, subjective symptoms of anxiety) It is not a categorical measurement of clinical diagnosis but a set of three self-report scales designed to measure the negative emotional states of depression, anxiety and stress. Each of the three DASS 21 scales contains seven items, divided into subscales with similar content. The DASS 21 score is based on a dimensional rather than a categorical conception of psychological disorder. The DASS 21 score therefore has no direct implications for the allocation of patients to discrete diagnostic categories postulated in classification systems (Appendix 3). The DASS 21 score have been validated and translated into Swedish. The categories were: No depression 0-9, mild depression 10-13, moderate depression 14-20, severe depression 21-27 and extreme depression 28 and above.

3.5 Data analysis

3.5.1 Study II

3.5.2 Qualitative content analysis

Content analysis is a method that can be used with either qualitative or quantitative data; furthermore, it can be used in an inductive or deductive way. The one that is used is determined by the purpose of the study. If there is not enough former knowledge about the phenomenon or if this knowledge is fragmented, the inductive approach is recommended¹¹⁸. The categories are derived from the data in inductive content analysis. Deductive content

analysis, on the other hand, is used when the structure of analysis is operationalized on the basis of previous knowledge and the purpose of the study is theory testing¹¹⁹. An approach based on inductive data moves from the specific to the general, so that particular instances are observed and subsequently combined into a larger whole or general statement¹²⁰. A deductive approach is based on an earlier theory or model and therefore it moves from the general to the specific¹²¹. These approaches have similar preparation phases.

Depending on the research question, the unit of analysis can be a letter, word, sentence, portion of pages or words, the number of participants in a discussion or the time used for a discussion^{122,123}. Graneheim and Lundman (2004)⁹⁶ pointed out that the most suitable unit of analysis is whole interviews or observational protocols that are large enough to be considered as a whole and small enough to be kept in mind as a context for meaning unit during the analysis process. When starting the analysis, the researcher must also decide whether to analyse only the manifest content or the latent content as well.

One issue in the analysis is to be aware of the various modes, manifest or latent content. Analysis of what the text says deals with the content aspect and describes the visible elements (manifest content). Analysis of what the text is about involves an interpretation of the underlying meaning of the text (latent content). Both manifest and latent content deal with interpretation but the interpretations vary in depth and level of abstraction.

A qualitative content analysis was carried out in accordance with Graneheim & Lundman⁹⁶. The analysis was performed in several steps, beginning with careful repeated readings to gain an overall picture of the text. In accordance with this method⁹⁶ the transcripts were read carefully by several authors in order to identify the informants' experiences and conceptions of communication. The analysis then proceeded by extracting meaning units consisting of one or several words, sentences, or paragraphs from the interview text. The words, sentences or paragraphs containing aspects related to each other through their content and context, i.e. related to the same central meaning and addressing a specific topic, were grouped together into meaning units. The researchers compared the meaning units to find similarities and differences⁹⁶.

In the third step, each meaning unit was condensed, which meant shortening the text while still preserving the core meaning⁹⁶. The condensed meaning units were abstracted and inductively labelled with a code. In the following step, the codes were compared in a comprehensive process that generated six subcategories and two categories. Finally, the categories were compared with the original text to ensure that they were rooted in the material.

When the interviews in the present study were completed, the text was read for an overview of the material. Meaning units were identified as a few words of some sentences or even paragraphs, i.e. a constellation of words and statements that relate to the same central meaning. In this way, the units of meaning had aspects related to each other through

their content and context. A number units of meaning transformed between the authors were interpreted and condensed to concepts and notions – subcategories – and later grouped into categories and a theme. Finally, the categories were compared with the original text to ensure that they were rooted in the material.

3.5.3 Illustration of the analysis process in various stages (Study II)

I. **Meaning unit.**

The first step is to identify the words, sentences and paragraphs that have the same essential meaning and contain aspects related to each other through their content and context.

II. **Condensed meaning unit description close to the text.**

Meaning units related to each other through their content and context were then abstracted and grouped together into a condensed meaning unit, with a description close to the original text.

III. **More condensed meaning unit interpretation.**

The condensed text in the meaning unit was further abstracted and and labelled with a code.

IV. **Subcategories.**

Codes were grouped together based on their relationship and codes that addressed similar issues were grouped together in subcategories.

V. **Categories.**

Subcategories that focused on the same problem were brought together in order to create more extensive conceptions.

3.6 Statistical methods

3.6.1 Regression models (Studies I, III, IV and V)

Study I. Differences between patients born abroad and in Sweden in terms of the five separate EQ-5D dimensions and EQ-5D, Charnley categories, gender, age, pain and satisfaction (measured on a VAS) were first studied as independent variables using non-parametric tests (Fisher's exact test, chi-square, Mann-Whitney and Kruskal-Wallis tests). To evaluate whether any of the five subcategories in the EQ-5D form (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) was able to discriminate between patients born in Sweden and immigrants we performed logistic regression analyses first based on preoperative data and then using data recorded at one year. In this analysis the answers were dichotomised into no or moderate/severe problems for each of the five subcategories. VAS pain and satisfaction were analysed using ANOVA and ANCOVA to adjust for confounders. As the EQ-5D has a bimodal, non-normal distribution (Lilliefors Significance Correction: $p < 0.001$), we refrained from any advanced statistical analysis of this parameter. Possible confounders entered in these analyses were age, gender, Charnley category (1-2/3), diagnosis (primary/secondary OA), living alone/married or cohabiting and income ($\leq 200\,000$ / $> 200\,000$ SKR). In the analysis of one year data the preoperative value for each of the five subcategories were entered into the regression analysis.

Study III. At the statistical analysis the answers about the perceived quality of the information was dichotomized. Answers to the question "information about the surgical procedure" were separated into yes and no or I can't remember. Answers to the two questions "information about pre- and postoperative pain treatment" were split into acceptable to very good and a second group who had answered that they had received poor or no information at all on both questions. To become included into the group "poor information" they should also have answered, that they had received no information about the surgical procedure itself or that they could not remember having received any information ($n = 52$). The remaining patients had reported that they received acceptable or good information on at least one of the questions. These patients were classified into the "some information" information group ($n = 137$). Factors with possible influence on the risk to become classified into the "poor information" group were studied using binary logistic regression. Variables entered were age, gender, country of birth (born in or outside Sweden), diagnosis (primary/secondary osteoarthritis), level of education, cohabiting (yes or no), Charnley class (A/ B or C) and perioperative anxiety (yes/no). After calculation of odds ratio we computed ROC (receiver operating characteristics) curves for some of the variables predicting that the patient will belong to the "poor information" group and computed the area under these curves (C-statistics). In the next step we evaluated if the outcome according to the PROM protocol one year after the operation differed between four subgroups based on how patients perceived the information and based on place of birth (inside or outside Sweden). Patients born in Sweden belonging to the "some information" group was used as reference.

Results were evaluated using logistic and linear regression models. In these analyses our primary outcomes were answers according to the five dimensions in the EQ-5D index. The answers were dichotomized into no or moderate/severe problems. In further analyses using multiple linear regression models secondary outcomes in terms of results according to the three visual analogue scales (EQVAS, pain satisfaction) were studied.

A reliability test was performed among 20 patients, who were sent the same questionnaire 3-4 weeks after they had returned the first one.

Cohen's kappa was used to study the repeatability of the answers. A kappa value of 1 indicates exact agreement and above 0.7 is regarded as satisfactory agreement.

Study IV. In the survival analyses the endpoint was defined as either re-operation within two years or revision within 14 years, death or December 31, 2007, whichever came first. In the analyses of revisions a time limit of 14 years was used to secure a sufficient number of observations in each patient group at the end of the study period. At this time point there were 77 observations left in the smallest group (born outside Europe including the former Soviet Union). The hazard ratios (HR) for the three immigrant groups were computed without and with adjustment for possible confounders and with using patients born in Sweden as a reference using Cox's proportional hazard regression model. In this analysis age was classified into five groups (<50, 50-59, 60-69, 70-79, 80 years and above) using the group with most observations as a reference (70-79 years). Diagnosis was also classified into six groups (primary osteoarthritis, inflammatory arthritis, hip fracture or sequelae after hip fracture, sequelae after paediatric hip disease, idiopathic femoral head necrosis and other) using the first diagnosis as a reference. Data from Statistics Sweden and the National Patient Register on ethnicity, educational level, cohabitation or not and comorbidity were also entered. The relative hazard assumption was tested by plotting the hazard ratios, log minus log plots and the computation of Schoenfeld residuals for the chosen co-variables.

Study V. To evaluate if any of the 5 subcategories in the EQ-5D form (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) could discriminate between patients born in Sweden and immigrants, the answers were dichotomized into either no or moderate/severe problems for each of the 5 subcategories. Any differences between the patients born in Sweden and the immigrant groups were tested using a non-parametric test (chi-square). To evaluate any influence of covariates we performed binary logistic regression analyses with use of the outcomes no problems/moderate or severe problems for each of 5 EQ-dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression).

In the logistic regression the odds ratio is calculated, which not is equal to relative risk. The odds, that a patient born in a certain region will report some problems, correspond to the probability of this event occurring divided by the opposite outcome (that they will report no problems). The odds ratios we present correspond to the odds for reporting some problems in a region outside Sweden divided by the odds for the same outcome among those born in Sweden. Values statistically significantly above 1 indicate that patients born abroad had increased probability to report problems and values significantly below 1, that

the probability of reporting problems in this group was less.

The covariates included in the model were age (<60, ≥60 years of age), sex, diagnosis (primary and secondary OA), Charnley class (A and B or C), education (low, middle or high), cohabitation (yes or no), comorbidity, type of incision (lateral, posterior incision), and choice of implant fixation (cemented, uncemented, hybrid or reversed hybrid). The item preoperative pain was not studied with use of regression analysis because at that time point almost all patients reported moderate/severe problems for pain/discomfort. At the 1-year follow-up and for each of the dimensions studied (mobility, self-care, usual activities, pain/discomfort, anxiety/depression) the preoperative value for this dimension was also entered.

A directed acyclic graph (DAG) was used to select covariates needed for an unbiased parametric estimate of the exposure. This gave us 2 alternative models, where some of the covariates could be excluded (type of incision, choice of fixation, diagnosis and comorbidity). These models resulted in no or minor (<10%) changes of the odds ratios (data not shown). VAS pain, VAS satisfaction and EQ-VAS were analysed using ANOVA and Student's t-test. These parameters were also analyzed in a multiple linear regression model with using the covariates presented above. In this analysis age, education and preoperative VAS (evaluation EQ-VAS and VAS pain at 1 year) were entered as linear variables. To reduce the number of statistical tests the 3 immigrant groups were condensed into 1, meaning that only differences between patients born in Sweden and all those defined as immigrants were studied. The appropriateness of the linear regression models was tested by examination of residual plots. The deviation from normal distribution was judged to be within acceptable limits. EQ-5D data are presented for the 4 patient groups, for completeness. The level of significance was set at $p < 0.05$. Statistical analysis was performed using SPSS version 19.0 and 20.0.

3.7 Ethical considerations

The studies presented in this thesis conform to the Declaration of Helsinki. The Swedish Hip Arthroplasty Register constantly collects nationwide prospective nationwide observational data regarding all hip arthroplasty surgery in Sweden. This collection is regulated by the Patients Data Act⁸² and the Personal Data Act⁸⁴. The data from the Swedish Hip Arthroplasty register are presented in gathered form so that no information can be drawn to any individual. According to the Patient Data Act all patients must be satisfactorily informed, in written or orally form, before registration. This information is routinely given in written form pre-operatively in connection with all other information then provided. Patients even get the information that they may at any time, and without giving reasons, request that their data in the register should be erased.

The following approvals from the Local Ethical Review Board in Gothenburg apply to the studies in this thesis: S 328-08 (**Studies I, IV and V**), decision 275-10 (**Study II**) and decision 339-13 (**study III**).

4.1 Summary of results of the studies

4.1.1 Study I

The average age, gender, relative frequency of primary osteoarthritis, and distribution of Charnley categories did not differ between patients born in Sweden or abroad. Nor was there a difference in the relative number of patients who lived alone or together with a partner nor between the relative frequency of married and unmarried persons.

Ethnicity and socioeconomic data

Sixty-two of the 141 immigrants were born in a Nordic country (Norway 24, Finland 28 and Denmark 10 patients) and 79 in a non-Nordic country (Germany 16, Poland 12, 41 from 23 other countries of which 17 were located outside Europe). Seven hundred and forty-four patients had an income up to 200 000 SEK (about 22 000 Euro) and 458 had a income above this level (14 with missing data). Six hundred and twenty-three were reported to live alone and 593 were married or lived with a partner. Most patients in both of groups had an income up to 10 000 - 22 000 Euro (62%). A few (2.7%) had no income at all (born in Sweden/born abroad:3.5/2.6%). In the group of patients with an income of $\leq 200\ 000$ SEK (about 22 000 Euro) there were 643 patients born in Sweden (61 %) and 101 patients were born abroad (72 %, $p=0.01$, Fisher's exact test).

Before surgery patients born abroad stated that they experienced more negative interference concerning self-care ($p=0.006$, item 2 on the EQ-5D form) and experienced more anxiety ($p=0.01$, item 5, Table 3). The EQ-5D and the amount of pain according to the VAS did not differ. After adjustment for confounders these differences remained without any substantial change in the odds ratios and their confidence limits (Table 3).

Table 3. Distribution of answers (%) and statistics (Logistic Regression) within each domain of EQ-5D0 (preoperatively) for patients born in Sweden and immigrants

EQ-5D%	Mobility		Self-care		Usual activities		Pain/discomfort		Anxiety/depression	
	Sweden	Immigrants	Sweden	Immigrants	Sweden	Immigrants	Sweden	Immigrants	Sweden	Immigrants
No problem	3.7	2.8	72.2	61.0	31.3	29.8	1.1	2.8	52.2	41.1
Moderate or severe problems	96.3	97.2	27.8	39.0	68.7	70.2	98.9	97.2	47.8	58.9
*OR, CI (95%), p-value	1.32 (0.46-3.75)		1.66 (1.15-2.39)		1.07 (0.73-1.57)		0.39 (0.12-1.22)		1.56 (1.09-2.23)	
**OR, CI (95%), p-value	1.23 (0.43-3.51)		1.60 (1.10-2.32)		1.02 (0.69-1.51)		0.33 (0.10-1.08)		1.55 (1.07-2.24)	
	P=0.59		P=0.006		P=0.72		P=0.10		P=0.01	
	P=0.70		P=0.01		P=0.92		P=0.07		P=0.02	

* Unadjusted

** Adjusted for age, gender, Charnley category, income (\leq / $>$ 200 000,Sk) and cohabiting (yes/no)

At the one-year follow-up the patients born abroad reported more problems (moderate or severe) with self-care ($p < 0.0005$), usual activities ($p = 0.001$) and anxiety/depression ($p = 0.005$). After adjusting for confounders including baseline, immigrants still reported more moderate or severe problems with self-care ($p = 0.008$) and usual activities ($p = 0.001$), whereas the observation of more anxiety/depression turned out to be more strongly influenced by the confounders that were studied including the baseline value (Table 4).

Preoperatively the EQ-5D and VAS pain did not differ ($p > 0.05$, Mann-Whitney). Univariate ANOVA analysis of preoperative VAS pain suggested a slightly higher value for immigrants ($p = 0.05$), even after adjustment for confounders ($p = 0.04$, ANCOVA)

At one year EQ-5D and VAS pain obtained higher scores in the patients born in Sweden ($p \leq 0.01$, Mann-Whitney test), whereas the patient satisfaction (VAS) and the pre-operative to one-year change on the EQ-5D did not differ without any adjustment for confounders ($p \geq 0.09$). Univariate ANOVA confirmed the presence of less VAS pain in patients born in Sweden ($p = 0.01$), even after adjustment for confounders ($p = 0.01$) including the baseline ($p = 0.02$, ANCOVA). These analyses were not able to reveal any definitive difference between the groups in terms of patient satisfaction (p-value before and after adjustment: 0.24, 0.31).

Table 4. Distribution of answers (%) and statistics (Logistic Regression) within each domain of EQ-5D0 (1 year postoperatively) for patients born in Sweden and immigrants

EQ-5D(%)	Mobility		Self-care		Usual activities		Pain/discomfort		Anxiety/depression	
	Sweden	Immigrants	Sweden	Immigrants	Sweden	Immigrants	Sweden	Immigrants	Sweden	Immigrants
No problem	51.7	44.0	88.2	77.3	68.6	54.6	38.2	32.6	71.9	60.3
Moderate or severe problems	48.3	56.0	11.8	22.7	45.4	31.4	61.8	67.4	28.1	39.7
*OR, CI (95%)	1.36 (0.95-1.94)		2.19 (1.41-3.38)		1.81 (1.27-2.58)		1.27 (0.88-1.85)		1.69 (1.17-2.42)	
p value	P= 0.08		P<0.0005		P=0.001		P= 0.20		P= 0.005	
**OR, CI (95%)	1.53 (0.98-2.39)		1.94 (1.19-3.18)		1.98 (1.31-3.01)		1.35 (0.87-2.10)		1.69 (1.13-2.53)	
p value	P= 0.06		P=0.001		P= 0.001		P= 0.23		P= 0.01	
***OR, CI (95%)	1.53 (0.98-2.40)		2.21 (1.39-3.53)		1.96 (1.30-2.93)		1.30 (0.84-2.03)		1.51 (0.99-2.31)	
p value	P= 0.06		P= 0.008		P= 0.001		P= 0.18		P= 0.06	

* Unadjusted

** Adjusted for age, gender, Charnley category (A, B or C), income (\leq / $>$ 200 000 Skr) and cohabiting (yes/no)

*** Adjusted for age, gender, Charnley category (A, B or C), income (\leq / $>$ 200 000 Skr), cohabiting (yes/no) including preoperatively values for each domain, respectively.

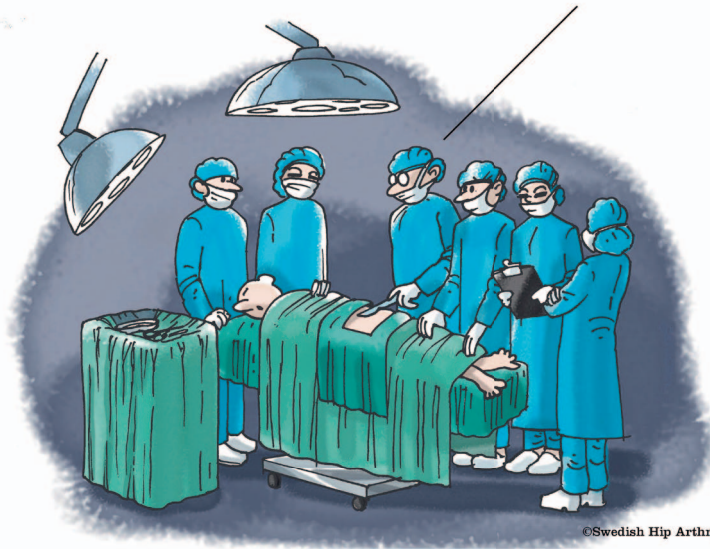
4.1.2 Study II (qualitative study)

Two main categories and six subcategories of the participants' descriptions of the preoperative information could be identified. These categories were; "Getting information about surgery" and "Getting a new hip".

4.1.3 Getting information about surgery

Some patients stated that it was important to be informed before surgery. They wanted information about pain management, the surgical procedure, anaesthetics and individual implant selection. Most of the patients described the preoperative information as limited; the doctor had no time to explain the operation, there was no time for questions and it was very stressful. One participant was not interested in information and wanted to have the surgery as soon as possible.

LET'S START CUTTING AND SEE WHAT HAPPENS



4.1.3.1 Managing hip pain

Information on pain relief was considered important. Most participants described their pain as being caused by their osteoarthritis, but they revealed that information on how to relieve it was not part of the pre-operative information. Pain-relieving medication was often used, but most participants said it did not help. Some had contacted their doctor

for stronger medication, whereas others did not want additional medication because they disliked taking drugs.

Some participants discovered their own methods for easing pain such as aquatic exercise and massage. One had discovered a way to manage pain by sitting in a certain position. All participants regarded surgery the only way to become permanently pain free.

4.1.3.2 Limited information from hospital staff

Most participants wanted both oral and written information from the hospital staff before surgery, but many felt that the information was inadequate and lacked details about the operation. Much of the written information was sent by mail from the hospital several days before surgery. However, it was considered insufficient by most participants. They had no knowledge of what would happen before or during surgery. The participants who did not speak Swedish were assured that an interpreter would be provided to help them. Sometimes, however, the interpreter didn't show up. Some immigrant participants said that they had received information about the surgical process by mail. The letter informing them about the surgery was in Swedish and could sometimes be difficult to understand, especially for those who did not speak or understand Swedish.

4.1.3.3 Finding information themselves

Participants lacking information on their forthcoming operation found different ways of searching for it. Some searched on their own. Those that could understand Swedish searched the internet, read books about hip replacement surgery or asked friends or relatives who had undergone THR. Sometimes the time allotted to informing patients was too short. In these cases the participants were told to search for information themselves. Some immigrants only received meagre information about their operation. For those that could not speak Swedish, had no friends or relatives to ask and had never visited a hospital before, the situation was complicated.

4.1.3.4 Choosing anaesthesia

Many participants were informed about the different types of anaesthesia. They described that during the preoperative visit they had been given the impression that they would be asked which type of anaesthesia they would prefer during surgery. However, when they spoke to the anaesthesiologist the day before surgery, they felt that she/he had already made a decision. Details relating to the surgery and the surgical procedure were also decided quickly. Participants described being asked about the operation, but they described that they felt unable to make decisions without preparation. The rapid pace caused them considerable stress. Being asked many questions during a short period of time confused and prevented them from deciding on the details of their surgery. However, most participants were clear on one point, namely that they did not want to hear the noise of power tools or hammering during surgery. The participants also stated that they themselves had

to argue for their wishes to be met.

4.1.4 Getting a new hip

The participants also received inadequate information about the process after surgery. However, they had many thoughts and ideas on what would happen. A new hip implant meant new opportunities and they thought that life would be better after the operation. Some thought they might become active again, while others hoped they would be able to return to work. Some only wanted to spend more time with their grandchildren and enjoy life. Being able to meet friends once again was an example of a positive approach to everyday life. However, all the participants focused on their pain and looked forward to pain relief immediately after surgery.

4.1.4.1 Being pain free

The participants were informed about pain after surgery from different sources. Some were informed by health care professionals, others by relatives and friends who had previously undergone surgery. They expressed many different thoughts about life after surgery. Some thought about their families, while others thought about their work and job, business or employers. They had hopes and expectations that surgery would help them to lead a normal life again. All the participants expected that the pain would decrease or disappear. All the participants had great expectations of a pain-free life after surgery.

4.1.4.2 Being independent

The participants had little information about life after surgery. They expressed hopes of being more mobile and less dependent on others. They wanted to fend for themselves at all costs. The participants expressed hopes of becoming active again and enriching their lives by walking, housework, hobbies and other activities. One participant described his hobby as the most important aspect of his life. He only thought about football and everything else was insignificant. Some participants expected that their health would improve after surgery. They declared that they wanted to look after themselves at all costs. However, the expectations of life after surgery were not only positive, as some participants had concerns about dislocation of the prosthesis or falling after the operation, which could damage the implant.

The immigrant group of patients in the present study tended to have more depression than those born in Sweden. (Table 5).

Table 5 Patient Demographics

Background data	Born in Sweden	Born outside Sweden
<i>Education</i>		
<i>Elementary or below</i>	6	2
<i>Junior secondary school</i>		5
<i>Secondary school</i>	4	
<i>Academic degree</i>		3
<i>Marital status</i>		
<i>Never married</i>	1	1
<i>Married</i>	2	7
<i>Divorced</i>	2	1
<i>Cohabiting</i>	3	1
<i>Widowed</i>	2	
<i>Number of children</i>		
<i>No children</i>	4	2
<i>1-2 children</i>	1	4
<i>3-4 children</i>	5	4
<i>DASS 21</i>		
<i>No depression</i>	3	2
<i>Mild</i>	1	2
<i>Moderate</i>	1	
<i>Severe</i>	2	
<i>Extreme depression</i>	3	6

4.1.5 Study III

4.1.5.1 Risk factors to become poorly informed

Patients born outside Sweden showed similar demographics, educational level and social status as those patients born in Sweden (Table 6). Outside born patients did however, more frequently report anxiety during the hospital stay and had lower DASS 21 score both before and one year after the operation. Patients born abroad also more frequently belonged to the group, who reported that they had been poorly informed as reflected by a relative dominance in the group with “poor information”. In the logistic regression analysis two of the variables, country of birth (adjusted OR 3.6, 95% confidence interval: 1.7-7.8, $p=0.001$; C-statistics: 0.62 95% CI: 0.52-0.72) and anxiety after the operation (adjusted OR 4.5, 95% CI: 1.9-10.9, $p=0.001$; C-statistics: 0.64, 95% CI: 0.56-0.73) were associated with increased risk of perceiving poor information. Individual analysis (unadjusted odds ratios) of each of these variables showed similar odds ratios (born abroad/ born in Sweden: OR 3.6, 95% CI: 1.6-6.4, $p=0.001$; anxiety/no anxiety: 4.4, 95% CI: 1.9-10.1, $p<0.0005$).

Addition of variables from the preoperative PROM protocol (answers on the separate EQ-5D questions, pain VAS, EQ-VAS and EQ-5D) had no or minor influence this outcome (Data not shown).

Table 6. Demographics, social data, groups according to level of perioperative anxiety and information and DASS21 scores.

Variables	Born in Sweden n, (% or range)	Born outside Sweden n, (% or range)	p-value
Sex			
Male	52 (37)	23 (46)	0.31 ¹
Female	87 (63)	27 (54)	
Age median, range	71 (28-96)	69 (36-90)	0.36 ²
Diagnosis			
Primary OA	128 (92)	45 (90.7)	0.77 ¹
Secondary OA	11 (8)	5 (9.3)	
Charnley Category			
A or B	80 (58)	27 (527)	0.51 ¹
C	57 (42)	25 (483)	
Cohabiting			
Yes	71 (51)	26 (52)	1.0 ¹
No	68 (49)	24 (48)	
Education (ISCED 97)			
Low	34 (24)	15 (30)	0.59 ¹
Middle	61 (44)	18 (36)	
High	44 (32)	17 (34)	
Postoperative anxiety³			
No	52 (37)	17 (34)	0.73 ¹
Some or pronounced	87 (63)	33 (66)	
Information³			
Acceptable or good	110 (79)	27 (54)	0.001 ¹
Poor or absent	29 (21)	23 (46)	
DASS21 score median range			
Preoperatively	2 1-4	3 1-5	<0.0005 ²
One year after the operation	2 1-5	4 1-5	<0.0005 ²

¹Chi-square, ²Mann-Whitney test, ³Condensed from questionnaire (see text).

4.1.5.2 Influence on outcome at 1 year

Patients born abroad in the poor information group showed an inferior outcome one year after the operation according to several of the variables in the PROM protocol. Evaluation of the five dimensions in the EQ-5D index revealed more problems with self-care and anxiety/depression also after adjustment for covariates (Tables 7 - 9).

Patients in the poor information group not born in Sweden also reported more problems with usual activities, but this difference became insignificant after adjustment for covariates. They also reported lower EQ-5D index, EQVAS and pain VAS. Before any adjustment for covariation, patients born in Sweden in the poor information group reported similar results as those in the some information group born in Sweden. After adjustment for covariation there was one exception. In the “poor information” group born in Sweden, fewer of the patients thought they had problems with pain/discomfort according to the individual questions in the EQ-5D protocol. Thus, several of the outcomes after one year was inferior in patients classified into the “poor information” group, but only if the patient was born outside Sweden.

Table 7. EQ-5D index, EQVAS, pain VAS before and one year after the operation. Satisfaction VAS one year after the operation.

	preoperatively	1 year
	Mean, 95%CI	Mean, 95%CI
Pain VAS		
<i>Some information</i>		
Born abroad	63.0 54.1-72.0	22.5 14.9-30.0
Born in Sweden	64.6 61.4-67.8	17.9 14.5-21.4
<i>Poor information</i>		
Born abroad	60.1 50.6-69.6	28.8 18.6-39.0
Born in Sweden	66.7 60.9-72.6	17.3 10.1-24.4
Satisfaction VAS		
<i>Some information</i>		
Born abroad		36.1 25.8-46.4
Born in Sweden		26.5 21.6-31.4
<i>Poor information</i>		
Born abroad		29.1 21.1-37.2
Born in Sweden		25.7 15.3-36.0
EQVAS		
<i>Some information</i>		
Born abroad	49.6 41.2-58.1	63.2 53.2-73.2
Born in Sweden	54.8 50.4-59.1	71.9 68.0-75.8
<i>Poor information</i>		
Born abroad	57.8 50.2-65.5	55.8 45.5-66.2
Born in Sweden	57.1 50.4-63.8	77.4 70.3-84.6
EQ-5D index		
<i>Some information</i>		
Born abroad	0.67 0.48-0.86	0.70 0.60-0.80
Born in Sweden	0.42 0.32-0.51	0.68 0.63-0.73
<i>Poor information</i>		
Born abroad	0.48 0.26-0.70	0.55 0.43-0.68
Born in Sweden	0.55 0.36-0.74	0.75 0.65-0.84

Table 8. Association between outcome at 1 year according to the 5 EQ-dimensions, country of birth and perceived information according to the logistic regression analysis.

	Unadjusted		Adjusted*		
	Odds ratio 95% CI	<i>p</i> -value	Odds ratio	95% CI	<i>p</i> -value
Mobility					
<i>Some information</i>					
Born abroad	1.6 0.6-4.0	0.32	1.5 0.6-4.0		0.39
Born in Sweden	1		1		
<i>Poor information</i>					
Born abroad	1.6 0.6-4.3	0.33	1.7 0.6-4.8		0.31
Born in Sweden	0.5 0.2-1.1	0.10	0.4 0.2-1.0		0.06
Self-care					
<i>Some information</i>					
Born abroad	2.0 0.7-5.6	0.17	1.8 0.6-5.2		0.28
Born in Sweden	1		1		
<i>Poor information</i>					
Born abroad	6.0 2.3-15.9	<0.001	5.5 1.9-15.3		0.001
Born in Sweden	0.6 0.2-2.3	0.50	0.6 0.2-2.4		0.48
Usual activities					
<i>Some information</i>					
Born abroad	0.9 0.4-2.2	0.83	0.7 0.3-1.8		0.46
Born in Sweden	1		1		
<i>Poor information</i>					
Born abroad	2.7 1.1-6.7	0.04	2.6 0.98-6.9		0.06
Born in Sweden	0.8 0.3-1.8	0.77	0.7 0.3-1.7		0.40
Pain-discomfort					
<i>Some information</i>					
Born abroad	1.2 0.5-3.4	0.68	1.1 0.4-3.1		0.92
Born in Sweden	1		1		
<i>Poor information</i>					
Born abroad	1.3 0.5-3.9	0.6	1.1 0.4-3.5		0.84
Born in Sweden	0.5 0.2-1.1	0.07	0.4 0.1-0.9		0.02
Anxiety-depression					
<i>Some information</i>					
Born abroad	2.6 1.1-6.3	0.03	2.2 0.8-5.6		0.12
Born in Sweden	1		1		
<i>Poor information</i>					
Born abroad	5.4 1.9-14.9	0.001	5.7 1.9-17.3		0.002
Born in Sweden	1.4 0.6-3.1	0.50	1.1 0.4-2.7		0.90

*adjusted for age, sex, diagnosis, Charnley class, civil status (cohabitation), education and preoperative value for each of the five EQ-5D dimensions

Table 9. Association between outcome for each of the variables pain VAS, satisfaction VAS, EQVAS and EQ-5D index according to the EQ-5D dimensions, country of birth and perceived information according to the linear regression analysis.

	Unadjusted		Adjusted*	
	B-coefficient, 95% CI	p-value	B-coefficient, 95% CI	p-value
Pain VAS				
<i>Some information</i>				
Born abroad	5.2 -2.9-13.3	0.20	5.6 -2.5-13.8	0.18
Born in Sweden	1		1	
<i>Poor information</i>				
Born abroad	10.9 2.4-19.5	0.01	12.0 3.4-20.6	0.006
Born in Sweden	-0.6 -8.3-7.2	0.88	-1.4 -9.1-6.3	0.72
Satisfaction VAS				
<i>Some information</i>				
Born abroad	10.4 -0.3-21.2	0.06	9.0 -1.8-19.8	0.10
Born in Sweden	1		1	
<i>Poor information</i>				
Born abroad	2.7 -8.6-14.0	0.64	2.3 -9.1-13.6	0.70
Born in Sweden	-0.8 -11.0-9.4	0.89	-1.2 -11.4-9.0	0.82
EQ VAS				
<i>Some information</i>				
Born abroad	-5.7 -14.8-3.3	0.22	-5.6 -14.8-3.6	0.23
Born in Sweden	1		1	
<i>Poor information</i>				
Born abroad	-15.5 -25.0 - -5.9	0.001	-15.7 -25.3 - -6.0	0.001
Born in Sweden	6.1 -2.5-14.9	0.16	6.2 -2.5-14.8	0.16
EQ-5D				
<i>Some information</i>				
Born abroad	0.00 -0.11-0.12	0.96	0.04 -0.07-0.15	0.49
Born in Sweden	1		1	
<i>Poor information</i>				
Born abroad	-0.13 -0.25 - -0.01	0.03	-0.13 -0.24 - -0.01	0.03
Born in Sweden	0.06 -0.05-0.17	0.26	0.08 -0.03-0.18	0.15

*adjusted for age, sex, diagnosis, Charnley class, civil status, education and preoperative value for

each of the five EQ-5D dimensions.

4.1.6 Study IV

4.1.6.1 Demographics

The mean age was lowest in the group of patient coming from outside Europe and the former Soviet Union (61 years) and highest in the Swedish population (70 years). There were more female (64 %) than male (36 %) patients. This was a consistent pattern in the four ethnic groups, and it was most pronounced in the Nordic countries outside Sweden (68% females) and least pronounced in Sweden (60 % females).

Primary osteoarthritis was the most common preoperative diagnosis in all ethnic groups. In the population from Europe outside the Nordic countries it was 80%, followed by Sweden and the Nordic countries outside Sweden (78 % and 77 %). In patients born outside Europe and the former Soviet Union this diagnosis accounted for only 65 %. This group also had a high share of paediatric hip diseases (11 % vs. 1.6-3.6% in the three other groups). Cemented designs were the most frequently used in all 4 groups (relative share: 69 - 89%). There was, however a trend toward choosing uncemented components more frequently- either as an all uncemented, hybrid or reversed hybrid arthroplasty- the further away from Sweden the patient was born. As a result, all-uncemented components were used in 4.4% in the Swedish population, 6% in patients born in the other Nordic countries, 7.3% in patients born in the remaining part of Europe and 16,2% in patients born outside Europe. A similar trend was observed for hybrids and inverse hybrids.

Most of the patients were classified as having a low educational level (53 – 67%). The highest proportions of intermediate educational level were observed in the groups born in the Nordic countries (26 %) and Europe outside the Nordic countries (32 %), whereas the last mentioned region and patients born outside Europe had the highest proportions of high educational level (16 % and 17 %). Between 42 and 46% were living alone and in the four groups 69 - 73% had no comorbidity registered.

4.1.6.2 Survival and revisions

Reoperation up to two years

Re-operation had been performed on 2,654 hips (1.7%) within two years, most frequently due to dislocation (38 %) followed by infection (24 %). The unadjusted frequency of reoperation varied between 1.3% (Europe outside the Nordic countries) and 2.0% (outside Europe and the former Soviet Union). The unadjusted two-year survival based on re-operation within two-years varied between 97.9% (95% CI: -4 to 4) (outside Europe and the former Soviet Union) and 98.7% (95% CI: -2 to 2) (Europe outside the Nordic countries). Before adjustment, patients born in Europe excluding the Nordic countries ran a lower risk of undergoing early re-operation (HR=0.73, CI: 0.56-0.97, p=0.03), which increased after adjustment to HR=0.76 (CI: 0.58-1.01, p=0.05). Patients born in the Nordic countries and outside Europe had a risk ratio closer to that of the population born in Sweden ($p \geq 0.6$), which showed minor changes after adjustment ($p \geq 0.4$). In the regression analysis male gender and all five groups of secondary OA ran a higher risk than their corresponding reference groups. All-uncemented, inverse hybrids and resurfacing replacements were associated with an increased risk of early re-operation compared with all cemented components. Patients living alone and those with any comorbidity according to Elixhauser entered an increased risk of early reoperation (HR=1.15, CI: 1.06-1.25; and HR=1.41, CI: 1.30-1.52, respectively) (Table 10).

Table 10. Reoperation within 2 years. Hazard ratios according to regression analysis			
Variables	HR	95% CI	P- value
Countries of birth (unadjusted)			
Born in Sweden ^a	1		
Born in the Nordic countries ^b	1.07	0.89-1.29	0.5
Born in Europe ^c	0.73	0.56-0.97	0.03
Born outside Europe ^d	1.16	0.77-1.75	0.5
Countries of birth (adjusted)			
Born in Sweden ^a	1		
Born in the Nordic countries ^b	1.09	0.91-1.31	0.4
Born in Europe ^c	0.76	0.58-1.01	0.05
Born outside Europe ^d	1.00	0.66-1.53	1.0
Sex			
M	1.42	1.31-1.54	<0.001
F ^a	1		
Age (years)			
<50	0.84	0.67-1.05	0.1
50-59	1.04	0.90-1.19	0.6
60-69	0.95	0.85-1.06	0.4
70-79 ^a	1		
≥80	1.02	0.91-1.13	0.8
Diagnosis			
Primary OA ^a	1		
Inflammatory disease	1.30	1.05-1.57	0.01
Fracture	2.72	2.47-2.99	<0.001
Pediatric hip disease	1.56	1.19-2.06	<0.001
Idiopathic femoral head necrosis	2.03	1.69-2.43	<0.001
Others without tumor	2.12	1.58-2.84	<0.001
Marital status			
Cohabiting	1.15	1.06-1.25	0.001
Living alone ^a	1		
Educational level (ISCED 97)			
Low ^a	1		
Middle	1.07	0.92-1.24	0.4
High	1.03	0.88-1.20	0.7
Comorbidities			
Elixhauser 0 ^a	1		
Elixhauser 1	1.41	1.30-1.52	<0.001
Type of fixation			
Cemented ^a	1		
Uncemented	1.56	1.29-1.87	<0.001
Hybrids	1.19	0.97-1.46	0.09
Inversely hybrids	2.06	1.67-2.53	<0.001
Hip resurfacing	2.82	1.92-4.14	<0.001

^a=reference group. ^bexcluding Sweden ^cexcluding the Nordic countries and former Soviet Union ^dincluding former Soviet Union

4.1.6.3 Revision up to 14 years

There were 7,358 revisions up to 14 years (4.8%), most often due to aseptic loosening (56%) followed by infection (24 %). The unadjusted frequency of revision varied between 4.9% (Europe outside the Nordic countries) and 6.5% (outside Europe and the former Soviet Union). The unadjusted 14 year survival varied between 82.5% (CI: -3 to 3) outside Europe and the former Soviet Union) and 87.5 % (CI: -3 to 3) for Europe excluding the Nordic countries. Before adjustment, patients born in the Nordic countries and outside Europe including the former Soviet Union ran a higher risk of undergoing revision than patients born in Sweden (HR=1.14, CI: 1.02-1.3; p=0.03 as opposed to HR= 1.5, CI: 1.2-1.9 p=0.001), but this difference disappeared after adjustment (HR=1.1, CI: 1.0-1.2; p=1.0 as opposed to HR=1.04, CI: 0.82-1.3; p=0.77). Patients born in Europe outside the Nordic countries had an unadjusted risk ratio close to that of the reference group (HR=1.08, CI: 0.9-1.2), which approached 1 after adjustment for confounders HR=1.01, CI: 0.88-1.16). After excluding the type of prosthetic fixation from the analysis, the risk ratios for the groups with different geographical origin remained almost unchanged. In the complete regression analysis decreasing age, male gender, all groups of secondary OA apart from inflammatory arthritis, and the use of uncemented components on the acetabular, femoral or both sides were associated with a statistically significantly increased risk of revision. Patients without any type of comorbidity according to Elixhauser had a reduced risk of revision, regardless of whether or not they were cohabiting and educational level had no certain influence (Table 11).

Table 11. Revision within 14 years. Hazard ratios according to regression analysis			
Variables	HR	95 % CI	P- value
Countries of birth (unadjusted)			
Born in Sweden ^a	1		
Born in the Nordic countries ^b	1.14	1.02-1.27	0.03
Born in Europe ^c	1.08	0.94-1.24	0.3
Born outside Europe ^d	1.49	1.18-1.88	0.001
Countries of birth (unadjusted)			
Born in Sweden ^a	1		
Born in the Nordic countries ^b	1.09	0.98-1.23	1.0
Born in Europe ^c	1.01	0.88-1.16	0.9
Born outside Europe ^d	1.04	0.82-1.31	0.8
Sex			
M	1.42	1.35-1.49	<0.001
F ^a	1		
Age (years)			
<50	2.20	1.99-2.44	<0.001
50-59	1.72	1.59-1.86	<0.001
60-69	1.32	1.24-1.41	<0.001
70-79 ^a	1		
≥80	0.83	0.75-0.91	<0.001
Diagnosis			
Primary OA ^a	1		
Inflammatory disease	1.11	0.99-1.24	0.6
Fracture	1.80	1.67-1.94	<0.001
Pediatric hip disease	1.49	1.31-1.70	<0.001
Idiopathic femoral head necrosis	1.47	1.30-1.67	<0.001
Others without tumor	1.38	1.15-1.65	<0.001
Marital status			
Cohabiting ^a	1		
Living alone	0.98	0.93-1.03	0.5
Educational level (ISCED 97)			
Low ^a	1		
Middle	0.94	0.87-1.01	0.1
High	0.96	0.89-1.04	0.4
Comorbidities			
Elixhauser 0 ^a	1		
Elixhauser 1	1.11	1.06-1.20	<0.001
Type of fixation			
Cemented ^a	1		
Uncemented	1.42	1.29-1.56	<0.001
Hybrids	1.40	1.29-1.53	<0.001
Inversely hybrids	1.29	1.08-1.54	0.004
Hip resurfacing	1.66	1.20-2.30	0.002

^a=reference group. ^bexcluding Sweden

^cexcluding the Nordic countries and former Soviet Union

^dincluding former Soviet Union

4.1.7 Study V

4.1.7.1 Preoperative evaluation

Pre-operatively almost all the patients reported problems in the domains pain and mobility. A substantial proportion also reported problems with usual activities and with anxiety/depression. In contrast, a minority reported problems with self-care (Table 2 supplementary data in Appendix 4). In the logistic regression model and before adjustment patients born outside Sweden turned out to have more problems with self-care, usual activities and anxiety/depression than patients born in Sweden. Patients born in Europe outside the Nordic countries also reported a more negative interference concerning mobility than did patients born in Sweden (Figure 3).

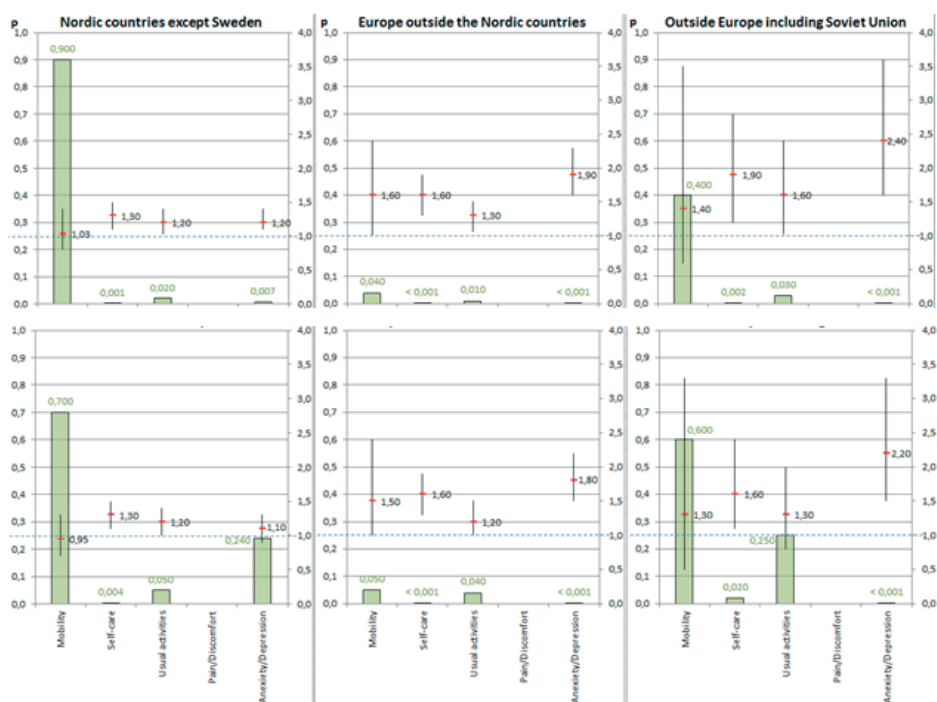


Figure 3. Odds ratio to report moderate or severe preoperative problems in 4 of the 5 EQ5D domains. Unadjusted (top) and adjusted data (bottom) are presented. Pain/discomfort was not analyzed because of poor variability. The risk ratios and their 95% confidence intervals are shown. Bars indicate p-values.

After inclusion of covariates in the regression model all immigrant groups had about 30 to 60 % increased odds ratio for having problems related to self-care. Immigrants from the Nordic countries outside Sweden and Europe tended to have more problems with their

usual activities and patients from Europe and outside Europe had about doubled odds ratio for having problems related to anxiety / depression (Figure 3).

Before operation patients born in Sweden reported less pain on the VAS scale, than did those born in the Nordic Countries and outside Europe (Figure 3, supplementary data in Appendix 4). In the linear regression model and after adjustment for covariates, patients born outside Sweden still turned out to report more pain on the VAS (regression coefficient: 1.3, 95% CI: 0.4-2.2, p=0.005).

Preoperatively patients born in the Nordic countries reported lower EQ-VAS than those born in Sweden. After adjustment for covariates the preoperative EQ-VAS in the compiled group of patients born outside Sweden did not statistically significantly differ from those reported in the group born in Sweden (regression coefficient: -1.1, 95% CI: -2.2 - 0.0, p=0.06).

Preoperatively the baseline EQ-5D score index was lower in all immigrant groups. The lowest value was observed in patients born outside Europe, followed by immigrants from Europe outside the Nordic countries (Table 12).

Table 12. VAS for pain and EQ-5D values preoperatively and after 1 year and VAS for patient satisfaction after 1 year for patients born in and outside Sweden

	preoperatively		1 year	
	Mean, 95%CI	p-value	Mean, 95%CI	p-value
Pain VAS				
Sweden	61 60-61	<0.001 ^a	14 13-14	<0.001 ^a
Nordic Countries	63 62-64	0.003 ^b	17 16-18	<0.001 ^b
Europe	63 61-64	0.05 ^b	19 18-21	<0.001 ^b
Outside Europe	66 63-69	0.001 ^b	23 19-26	<0.001 ^b
Satisfaction VAS				
Sweden	-	-	16 (16-17)	<0.001 ^a
Nordic Countries	-	-	19 (17-20)	0.008 ^b
Europe	-	-	20 (18-22)	<0.001 ^b
Outside Europe	-	-	24 (20-28)	<0.001 ^b
EQ-VAS				
Sweden	53 52-53	0.002 ^a	75 (75-76)	<0.001 ^a
Nordic Countries	50 48-52	<0.001 ^b	73 (71-74)	0.002 ^b
Europe	52 49-54	0.19 ^b	69 (67-71)	<0.001 ^b
Outside Europe	53 48-58	0.87 ^b	69 (64-73)	0.002 ^b
EQ-5D				
Sweden	0.40 0.39-0.41	<0.001 ^a	0.78 (0.77-0.78)	<0.001 ^a
Nordic Countries	0.36 0.34-0.38	<0.001 ^b	0.74 (0.72-0.76)	<0.001 ^b
Europe	0.33 0.30-0.36	<0.001 ^b	0.70 (0.67-0.72)	<0.001 ^b
Outside Europe	0.29 0.23-0.36	<0.001 ^b	0.64 (0.58-0.70)	<0.001 ^b

^aall groups (ANOVA)

^bborn in Sweden vs. immigrant groups (Student's t-test)

4.1.7.2 Postoperative evaluation and pain values

The post-operative evaluation showed that almost half of the patients or slightly more reported problems in the domains pain and mobility. A substantial proportion also reported problems with anxiety/depression and with usual activities. Problems with self-care were least commonly reported (Table 3 supplementary data in Appendix 4). Before adjusting for covariates all 3 immigrant groups had an increased odds ratio for doing worse in all dimensions according to the regression analysis (Figure 4).

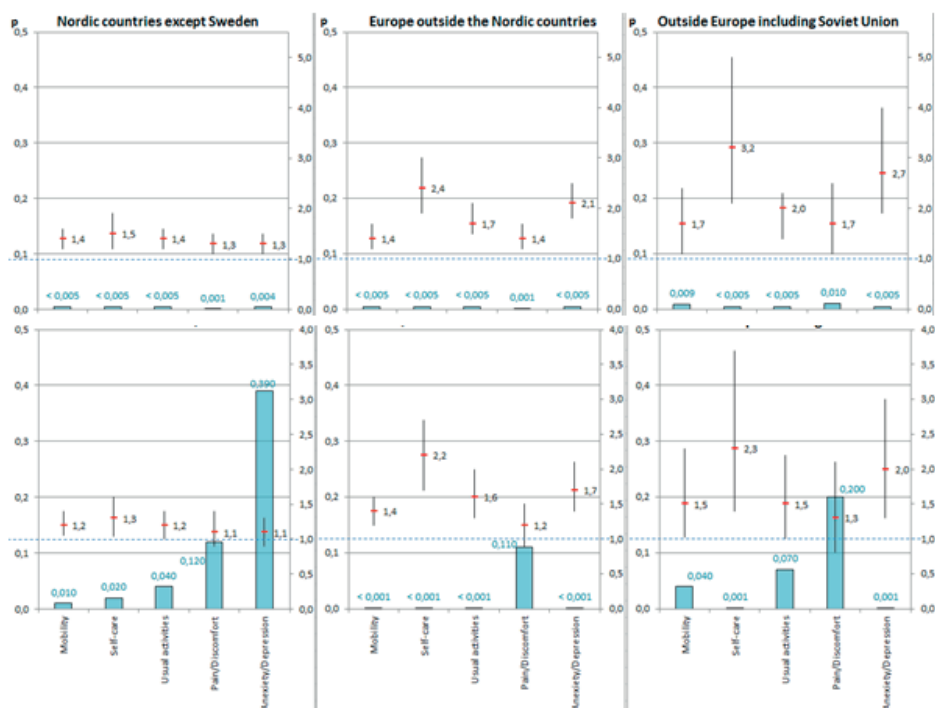


Figure 4. Odds ratio to report moderate or severe postoperative problems in 5 of the 5 EQ5D domains. Unadjusted (top) and adjusted data (bottom) are presented. The risk ratios and their 95% confidence intervals are shown. Bars indicate p-values.

After adjustment the odds ratios showed an overall tendency of slight decrease. In 2 of the comparisons between patients born in Sweden and abroad (usual activities in the group born outside Europe and pain in addition to anxiety/depression in patients from the Nordic countries) the difference was not statistically significant. Thus, after adjustment for covariates the immigrant groups and especially those from non-Nordic part of Europe and outside Europe reported more problems in most of the EQ-5D dimension except for pain/discomfort as reflected by an elevation in the odds ratios in those 2 groups, of 50 % up to 130 %.

The pain according to VAS decreased substantially in all groups (Table 12, Figure 3 supplementary data in Appendix 4). All immigrant groups indicated more pain than those born in Sweden (Table 12 and Figure 4). The multiple linear regression analysis confirmed more pain according to VAS after adjustment for covariates in patients born abroad (regression coefficient: 3.5, 95% CI: 2.5-4.4, $p < 0.001$).

Patients born outside Sweden were less satisfied after 1 year (Table 12). After adjustment for covariates in the regression analysis the merged immigrant group turned out to be less satisfied (with higher VAS scores) than patients born in Sweden (regression coefficient: 2.4, 95% CI: 1.3-3.5, $p < 0.001$).

At 1 year postoperatively patient born in Sweden had higher EQ-VAS than those patients born abroad. After adjustment for covariates patients born outside Sweden reported lower quality of life in the EQ-VAS than those born in Sweden (regression coefficient: -2.8, 95% CI: -3.9 to -1.8, $p < 0.001$).

At 1 year patients born in Sweden reported higher EQ-5D than the immigrant groups. The improvement (preoperatively to 1 year) was about the same for patients born in Sweden and those born outside Sweden.

5.1. Summary of the discussions of the studies

Study I Our hypothesis that patients born abroad benefited from the operation as much as those born in Sweden was not wholly verified. In addition, they reported more pronounced disability before surgery. One year after the insertion of the THR, the problems reported with self-care remained and more immigrants reported moderate or severe problems related to usual activities. The degree of anxiety/depression showed only a minor improvement and the immigrants reported more VAS pain.

The pre-operative EQ-5D dimensions, self-care and anxiety/depression, differed between the study groups. As expected, patients born outside Sweden also reported a lower income. Even if they were well-educated, some of these people may have difficulty gaining employment because of language problems, because their education is not completely adapted to Swedish requirements or other circumstances. This situation may cause anxiety, nervousness and lower self-confidence. More anxiety/depression may explain why these patients reported more pain. Some of them (n=12) came from countries or areas with more or less pronounced conflicts. Other reasons for increased anxiety may include problems adapting to a new society and separation from relatives.

Burström et al.¹²⁴ showed that health-related quality of life varies greatly between socio-economic groups and different disease groups. The QoL was lower for women than for men and varied with socio-economic group in the expected manner. The QoL was 0.88 in the highest socio-economic group and 0.78 in the lowest socio-economic groups. Considerable differences between different disease groups were found¹²⁴.

In a study predicting outcome after knee replacement surgery, the SF-36 mental health scale was positively related to the disease-specific WOMAC outcome scores at one year and two years after surgery. This study showed that patients who have marked functional limitation, severe pain, low mental health scores and other co-morbid conditions before total knee arthroplasty are more likely to have a poorer outcome at one and two years post-operatively. The authors claim that studies which examine psychometric variables more specifically are needed for interventions aimed at improving HRQoL in patients with diseases that include chronic pain^{117, 125, 126}. If an evaluation of this kind cannot be made available to all patients, our study suggests that it is particularly important to address immigrants.

All patients and especially those with an anxious/depressive disposition are more likely to experience pronounced pain in stressful circumstances. If so, more detailed information and in some cases different measures to improve their mental health status in terms of

anxiety reduction before the operation could be of value.

Rolfson et al.¹²⁹ found that pre-operative anxiety/depression is a predictor of pain and patient satisfaction one year after operation. Pain is the main indication for THR and all the mechanisms behind pain in osteoarthritis are still not known. The feeling of pain can be expected to be unaffected by ethnicity, but different ethnic groups do not express and communicate pain in the same way^{127,128}. We observed that patients born abroad reported significantly more pain on the VAS and more anxiety, but did not report less overall satisfaction as could be expected. We speculated that this could be due to the fact that experience of pain in different countries is not the same. In some countries, it is culturally prescribed that, if you have pain and anxiety, these problems should not or should only vaguely be passed on to relatives. In other countries, it is normal to “dress” pain and anxiety in words and show emotions, not only the negative ones but also positive ones such as post-operative satisfaction with the surgical procedure.

Patients born abroad reported significantly more pain on the VAS after adjustment in the regression analysis one year after the operation. A corresponding difference was not observed for pain/discomfort as reported as a subscore on the EQ5D. The reason for this discrepancy is not known. It could be that, as a result of its construction, the VAS is more sensitive to small differences even if other factors such as the way of communicating pain in patients with different cultural backgrounds might have had an influence¹²⁹⁻¹³³.

Zola et al.¹³⁴ reported that in Irish and Italian Americans in Boston, cultural and psychosocial factors influence the way patients communicate and express health concerns such as pain. Italian Americans were reported to be more “emotional” and “dramatic”, whereas Irish Americans were found to be more likely to playdown their distress.

In a study of 251 patients the way to describe back pain was analyzed. African Americans and Caucasians differed significantly in the words they selected to describe their pain. Garron et al.¹³⁵ also reported significant inter-ethnic differences in the description of the quality of pain between African-American, Irish, Italian, Jewish and Puerto Rican patients. The extent to which these differences influence the way the patients report pain or discomfort on a standardised questionnaire is not known.

Study II In this study, descriptions of the information provided before elective total hip replacement surgery was analysed. It is important to note that most participants described the preoperative information given by the healthcare professionals, as very limited. There was too little time for questions and the situation prior to surgery was stressful. Some participants reflected that much of the responsibility for making choices was placed on patients. Interestingly, there were only small variations in the descriptions of preoperative information between patients born in Sweden and immigrants. Both groups felt that the information was of poor quality. However, this was especially true for participants who were unable to speak Swedish. As a result, standardised information about surgery to patients who were unable to speak Swedish could be experienced as offensive. The study

showed that participants without experience of hospitalisation constitute an important group that must be taken into account. It is important that health-care professionals are aware of this group and their considerable need for information about what is going to happen during and after surgery. Being in a foreign environment as well as lacking knowledge about and having no control over the situation, often leads to feelings of powerlessness and insecurity¹³⁶. This group of patients might have a greater need for modified pre-operative information.

In the present study, the findings also revealed that nearly all the participants emphasised the importance of adequate information before surgery. They wanted to know more about the surgical procedure, types of anaesthesia, implant selection and life after surgery. These findings can be seen in the light of Sjöling et al.¹³⁷, who showed that information given prior to total knee arthroplasty helped patients to obtain better pain relief after surgery. Post-operative pain declined more rapidly, the level of pre-operative anxiety was lower and patients were more satisfied with post-operative pain management. The importance of pre-operative information was also illustrated by Kiyohara et al.¹³⁸, who found that participants who received no information about surgery had higher state-anxiety levels. The study suggested that pre-operative information may reduce anxiety regardless of diagnosis. Kagan and Bar-Tal¹³⁹ also demonstrated that pre-operative anxiety negatively affected post-operative recovery, while pre-operative uncertainty negatively affected mental and physical recovery after surgery.

The present study indicated how the time allotted for information was important and the number of health-care professionals involved in providing it played a critical role. On the day of enrolment, the participants met many staff members, all of whom provided information about the surgical process. The question is which information should be provided and how much the patient remembers on the day of the operation, two weeks after receiving the information. The timing and amount of information are thus important for patients undergoing elective total hip replacement^{140,141}.

So what can patients do if they receive too little or contradictory information from health-care professionals? Our study revealed that many of them asked relatives and friends or searched for information on the internet. However, some participants who had only lived in Sweden for a short period had few people they could ask. It is important to be aware of patient expectations of surgery and how they may be affected by information from friends and relatives. Information from the latter and from health-care professionals may be incompatible. Health-care professionals should pay greater attention to patients with language barriers. Our study revealed that, although knowledge of the information needs of patients with language barriers has existed for a long time, the use of interpreters still appears to be limited. It is vital to be responsive and adjust information to the patient's needs¹⁴².

The present study also demonstrated that the opportunity to influence the choice of anaesthesia was important. We also found that participants preferred general anaesthesia,

mainly to avoid the sounds of surgery. Being involved in the process of choosing anaesthesia therefore appears to be important in patient care. The feeling of controlling the sounds of surgery might also be a topic for further research. Some participants in our study, especially those who had only lived in Sweden for a short time, described a lack of information about pre-operative pain relief. Some were not informed about the availability of stronger pain relief or the right to contact their doctor if necessary. On the other hand, Lam et al.¹⁴³ studied patients on a neurosurgical ward and found that they were well informed about pain management and that the majority reported receiving adequate pain relief.

In this study, the participants' hopes for the future were sometimes mixed with fear about post-operative complications. Above all, they wanted their pain to disappear and hoped that their desire to engage in different activities would return and that their lives would revert to normal after surgery. They believed that an operation was the only option in order permanently to rid them of their pain. The importance of being pain-free has been demonstrated by Gustafsson et al.¹⁴⁴, who reported that freedom from pain and life without analgesics resulted in a feeling of gratitude, freedom and satisfaction and the opportunity to enjoy life. The analysis also revealed fears of dislocation of the joint replacement. This is in line with the report by Fujita et al.¹⁴⁵, who also found that participants undergoing THR and knee replacement were afraid, especially due to the risk of dislocation and that this fear was more pronounced after the operation. All the participants in our study should have received information about how to use and move with the implant. However, the information might have been difficult to understand for those with language barriers.

Study III This study showed that patients born in Sweden had retained more information than those born abroad. We do not know if this difference is caused by the personnel at the hospital providing more sparse information to this patient group. Most probably other factors such as a poorer mental status as indicated by the DASS score and insufficient experience of the Swedish language could have had an influence. Persons in a state of distress can due to several reasons be expected to have difficulties to retain information¹⁴⁶. Patients, who on the postoperative form, reported some or more pronounced anxiety were significantly overrepresented in the poorly informed group. The distribution of patients with anxiety born abroad and in Sweden was however rather equal contradicting the theory that preoperative anxiety should be of decisive influence.

Slightly less than half of patients in both groups lived with a partner or with child and the level of education was rather equally distributed. Patients living together with someone else and those with higher education could be expected to more easily obtain information and those with higher education might have more realistic expectations and more knowledge about how to optimize the rehabilitation period, but none of these factors had a significant influence on any of the outcome parameters studied at the one year follow up. Despite the high educational level, some of these patients may have difficulties to become employed and especially if born abroad because of language problems and other factors. Thus, it might be that educational level and socio-economic belonging not always are

correlated and especially not in patients born outside their country of living^{147,149}.

For patients undergoing hip replacement surgery, there is insufficient evidence to support the use of preoperative information above standard care to improve postoperative outcomes, especially with respect to pain, and functioning¹³⁷. There may be beneficial effects when preoperative information is tailored according to anxiety, or targeted to those most in need of support (e.g. those who are particularly disabled, or have limited social support structures). There is however, evidence that preoperative information has a modest beneficial effect on preoperative anxiety¹³⁷.

In a previous study an education programme was used to prepare the patients before performing a total hip replacement¹⁴⁸. In this study, the authors showed that a collective multidisciplinary information session 2 to 6 weeks before the operation may decrease pain before surgery and prevent an increase in anxiety. The patients included in this programme had a better idea of what to expect and had an interactive discussion with the team members. The same patients also felt less pain, perhaps because they were less stressed and better prepared to cope with pain. The patients were mobilized earlier, probably because of better motivation^{149,148}. Anxiety has been reported to increase sensitivity to pain and reduction of anxiety decreases complaints of pain^{137,150}. Improved preoperative information is also an important part of so called "fast track" treatment, which has a proven effect on the quality total hip and knee arthroplasty¹⁵¹⁻¹⁵³. It might; however be that some patient groups require especially tailored information.

In an interview study with use of qualitative content analysis we found that the information to our patients could be substantially improved both to patients born in Sweden and immigrants¹⁵⁴. The study design of this previous investigation did not allow a detailed quantitative analysis. The present study shows a difference in how patients born in Sweden and those born abroad perceive the quality of pre- and postoperative information. In the previously quoted interview study patients from both of groups expressed concern about inadequate preoperative information pertaining to the surgery, implant selection, pain relief, choice of anaesthesia and complained about no or too short a time to put questions to the surgeon and an all overall stressful situation. Insufficient preoperative information may be especially harmful to immigrants because this group tends to have more depression than those born in Sweden¹⁵⁴. After the present and the previous study performed by us, new routines have been implemented to improve not only the preoperative information, but the entire process associated with total hip and knee operations at our hospital.

In a randomized study, Jjala et al.¹⁵⁵ found that viewing a short information film before operation reduced the anxiety of patients undergoing elective surgery under regional anaesthesia. The prevalence of "high" anxiety two weeks before surgery was 17% in the assessment clinic. Immediately before surgery, this increased to 27% among those who watched the film and 36% among those who did not. After operation, only 2% reported high anxiety in the film group compared with 5% among controls.

Stanley et al.¹⁵⁶ analysed if detailed information improved patients understanding and if it could influence the level of anxiety. All patients were given routine information and were then randomized to receive standard verbal, standard written information or both or no other information at all. The patients filled in questionnaires on the day of admission to

the hospital and after discharge including rating of anxiety and depression levels. The authors found that written information increased patient satisfaction, but it did not enhance understanding of the risks and complications of the procedure¹⁵⁶.

Study IV This is the largest and first nationwide study of the influence of ethnicity on the outcome of hip arthroplasty. We used two outcome parameters. Revision is the standard outcome reported from national registers. Re-operation within two years is exclusively reported by the Swedish register. This is dominated by surgical procedures caused by dislocation and infections—reasons for repeated surgery that can be related to the quality of the surgical process. So this outcome is therefore reported by the Swedish Hip Arthroplasty Register as an indicator of surgical quality.

Previous studies have indicated that the variable use of osteoarthritis treatment may be related to differences in perception of the usefulness of treatment with arthroplasty¹⁵⁷. Ibrahim et al¹⁵⁸. studied the willingness of African-American and white patients to undergo arthroplasty or non-surgical arthritis care. African-Americans were less likely to undergo arthroplasty, but after adjustment for patient expectations this difference became insignificant.

Choice of treatment may vary regionally. Havelin et al⁷⁸. compared three national hip arthroplasty registers (Norway, Sweden and Denmark) in the Nordic Arthroplasty Database (NARA). They found differences in treatment relating to the choice of fixation technique and incision. In Sweden and Norway most of the total hip replacements were all cemented (89% and 79 % respectively), whereas the all cemented hip replacements in Denmark only accounted for 46%. The posterior approach was chosen more frequently in Denmark than in Sweden, and even more so than in Norway. Our immigrant patients from countries outside Europe more frequently received uncemented implants. We believe that this was mainly the decision of the surgeon based on the patient's lower age and high prevalence of secondary osteoarthritis often associated with anatomical variations, which were judged to be more adequately addressed with uncemented fixation.

There have only been a few studies that have compared the outcome of joint arthroplasty between groups of different ethnicity. Nwachukwu et al.¹⁵⁹ performed a review of nine studies: four examined total knee replacement, three examined total hip replacement and two studies examined both. Two of four studies found an increased mortality rate for blacks after either total hip or knee replacement. Three of four found an increased risk of infectious complications after total knee replacement in blacks and Hispanics and four of four found an increased risk of aseptic complications in blacks after the same procedure. SooHoo et al.¹⁶⁰ examined the rate of complications during the first 90 days postoperatively for patients undergoing total hip replacement. They found that a variety of patient-related factors were associated with an increased risk of complications such as diabetes, rheumatoid arthritis, age, male gender and black race. Hispanics and Asian patients had lower risks of complications in this study. On the other hand, Ibrahim et al.¹⁶¹ found more complications in Hispanics and in black patients, but after total knee replacement. Specifically, after total knee replacement, it appears that racial and ethnic minorities tend

to have more postoperative complications.^{159,160,162,163}

The present study showed that male gender and all five groups of secondary OA showed a higher risk of reoperation and revision of total hip replacement than their corresponding reference groups. All uncemented, inverse hybrids and resurfacing replacements were associated with an increased risk of early re-operation and revision compared with all cemented implants. Our findings are only similar to a certain extent similar to those reported by Katz et al.¹⁶⁴ and SooHoo et al.¹⁶⁰ who reported that age, gender, comorbidity, race and income had an effect on the risk of complications in the Medicare population.

Immigrant patients were too few in number to be selected from a specific country of emigration, and no details were known about their cultural background, which makes comparison with previous studies uncertain. These studies examined the increased risk of both ethnicity and race exerted on total hip/knee replacement^{159,160,162,163}, whereas we were only partially able to evaluate the specific influence of ethnicity for 2 patient groups from Europe, both with a comparatively wide definition- corresponding to the Nordic countries excluding Sweden and the remaining part of Europe excluding the former Soviet Union. Patients coming from countries outside Europe represented a number of different cultures. Most of our immigrant patients probably also had a different background from those groups evaluated in previous studies. Most of them- and especially those born outside Europe- tended to be younger and to have a higher level of educational than the reference group.

They also more frequently suffered from secondary osteoarthritis and more frequently received uncemented implants, which have a different profile of complications than cemented prostheses. Before adjustment for these and other confounders, the risk of reoperation within two years was slightly reduced in Europeans born outside the Nordic countries, whereas the risk of revision was elevated in patients born in the Nordic countries and still more so in those born outside Europe. These differences in outcome became insignificant after adjustment for confounders.

As a result, our study cannot be compared with previous studies of the influence of ethnicity without taking these factors into consideration. The influence of ethnicity will also most probably vary depending on factors unique to the culture in the specific country to which a person emigrates. The influence of ethnicity can also be expected to vary over time and between different generations of immigrants.

Provided that the indications for re-operation and revision were the same in the four groups studied by us, it emerged that the failure rate was turned to be about the same and independent on the origin of the patient. The outcomes studied by us are, however, only one aspect of the quality of THR. In a previous study we compared the patient reported outcome in terms of EQ-5D, VAS pain and VAS satisfaction in patients born in Sweden and immigrants, all of whom received a THR. One year after the operation and after adjustment for confounders, patients born outside Sweden reported lower scores

for self-care and usual activities on the EQ-5D form and more pain on a visual analogue scale¹⁴⁹. Most of the patients in the present study had a low educational level. The immigrant groups tended to contain a higher percentage of patients with a medium or high educational level. This is in accordance with our previously study, in which we studied patient-reported outcomes before and one year after THR in the Gothenburg region¹⁴⁹. Patients born outside Sweden generally had a higher educational level, but in spite of this they generally declared a lower income than those born in Sweden. Even though they were well educated, some of these patients may have had difficulty gaining employment because of language problems, suggesting that educational level and socio-economic status are not always correlated especially not in immigrants.

Whether or not the patients were living alone could probably be regarded as a fairly poor surrogate variable for social network. In most countries this information is not generally available, which probably explains why its influence on the outcome of medical interventions is rarely reported. Edit et al.¹⁶⁵ studied the effect of psychosocial factors and co-morbidities on the health status of patients with chronic nonspecific low back pain and patients undergoing surgical interventions because of disk herniation. The authors measured quality of life and the presence and degree of depression using validated instruments. They failed to show any correlation between the depression and variables such as marital status, education and co-morbidities and suggested that depression runs parallel with the number of surgical procedures.

In the present study, patients living alone ran an increased risk of early re-operation but not of revision during the entire period, whereas the presence of any comorbidity according to Elixhauser emerged as a risk factor for both these outcomes.

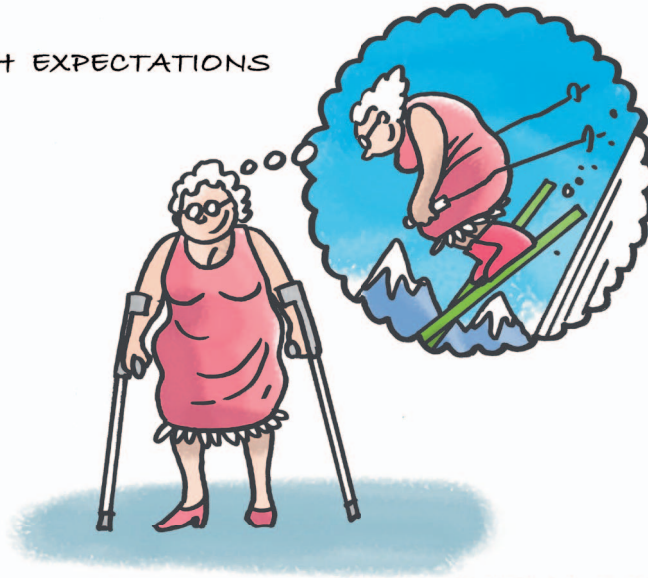
Study V Even though the completeness of data was poor during the early phase of this study, it is probably the first nationwide study of the HRQoL after THA reported from patients born in different parts of the world. We found that before operation patients born outside Sweden reported more problems especially concerning self-care and anxiety/depression than did those born in Sweden. These differences tended to remain or become slightly more pronounced 1 year after the operation. The same phenomenon was reflected by the EQ-5D and EQ-VAS before and 1 year after operation, and the gain-values. The low baseline values in the immigrant groups and especially among those coming from outside the Nordic countries might reflect a general unease as immigrant in a new country. In a previous study from the Stockholm area, Burström et al.¹²⁴ showed that HRQoL not only depended on age and sex, but also on socio-economic status which varied between different groups of disease. The choice between the alternatives in the EQ-5D-form is subjective and this choice may also be subject to variations related to cultural background. The use of a different tariff between countries to calculate the final EQ-5D value is one way to account for this problem. According to the statistical database Numbeo, Quality of life for Countries 2013¹⁶⁶, the highest Quality of life Index was observed for Switzerland (194) and lowest for Iran (33). Quality of life for the Swedish population according to the same report was 172. This weighted index is however, multidimensional

and is based on external factors such as pollution, purchasing power, safety and a rating of the quality of health care systems. These factors will certainly also influence the patient-reported opinion about their HRQoL. Thus, our study will include a certain amount of bias because definition of what is “normal” will vary, which certainly not is the same in Sweden as in many of the countries of emigration. Most of the patients in our study had a low educational level with a tendency of a higher proportion of middle or high educational level individuals in the immigrant groups. This is in accordance with our previous study, where we studied patient reported outcomes before and 1 year after THA in the Gothenburg region¹⁴⁹. Patients born outside Sweden had higher educational level, but despite this they declared lower income than those born in Sweden. Patient with more education may be better informed and therefore have more realistic expectations, as well as better knowledge about what is needed for their recovery. In a study of 16000 individuals in the South-East of Sweden, Eriksson and Nordlund¹⁶⁷ observed that those with the lowest educational level also reported the lowest HRQoL according to EQ-5D and SF-36. They also noted the highest level of education in persons born outside Sweden, and found that this population had a high degree of unemployment. This situation may cause anxiety, depression, nervousness and low self-confidence, factors that will influence the experience of pain. The literature is however, not consistent concerning the influence of educational level. Mancuso et al.¹⁶⁸ reported that patients with lower educational level had higher expectations about the effectiveness of a total hip replacement concerning its ability to alleviate pain and improve walking and everyday activities.

Rolfson et al.¹²⁹ found that that preoperative anxiety/depression is a predictor of pain and patient satisfaction with the outcome 1 year after operation. Depression and anxiety are more disabling in the elderly, particularly when they coexist with physical illness. These patients have more severe pain and more associated symptoms than non-depressed patients.¹⁶⁹⁻¹⁷¹ Pain is the main indication for THA and we found that patients born outside Sweden have more pain on the VAS both preoperatively and at 1 year postoperatively. This might be related to variable ways to express feelings depending on cultural background. In some countries it might be expected that pain and anxiety should not become exposed to your relatives. In other countries it is normal to “dress” pain and anxiety in words and show emotions¹⁷².

Most of the EQ-5D dimension both preoperatively and at 1 year postoperatively differed between patients born in Sweden and immigrants in our study. Sun et al.¹⁷³ compared HRQoL in homeless people who had been born outside Sweden with general population in the Stockholm area. After adjusting for covariates the authors found a lower EQ-5D index for those originally from outside Europe than for those originally from Sweden. Preoperatively, we observed more anxiety/depression in all immigrant groups and also lower EQ-5D. The lowest EQ-5D was found in patients born outside Europe, which is consistent with the findings of the author¹⁷³.

HIGH EXPECTATIONS



©Swedish Hip Arthroplasty Register

5.2 General discussion

Generally, immigration is a process which causes an enormous amount of stress for the individuals who are participating in it since they leave their native countries and search for new homes in other countries throughout the world. Once they arrive to these other countries of refuge, the immigrants need to adjust to completely new conditions of living which include cultural, language and social aspect. These new circumstance are usually quite different from the ones they were adapted to in their own countries. Apart from these difficulties there are many other that might be more or less obvious. During the immigration process many changes occur that might affect greatly the mental and physical condition of involved individuals. Among many problematic issues is the health-care system in the new country which is expectedly quite different from the one they were used to in their own countries and in addition includes quite different framework of reference and the values of health-care professionals.

Patients born abroad and eligible for THR report more problems and especially related to self-care and in terms of anxiety, depression and pain before the operation. One year after the operation, they still report more problems in several of the EQ-dimensions. It might be that the surgical process for total hip replacement for immigrant patients occurs at a later date than for patients born in Sweden. It might be that patients born abroad do not seek health care when they need to according to Swedish references and may not receive the same treatment as patients born in Sweden. If so, cultural and language problems and misunderstandings might be responsible. It should, however, be stressed that these issues

have not been specifically addressed in this thesis.

The different outcome for patients born outside Sweden and those born in Sweden could perhaps be related to a certain degree is related to the health-care system and educational level of the hospital staff. In a previous study comprising hospitals with 33,659 nurses in 12 European countries, there was wide variation across countries concerning the educational level in this occupational group. In Norway and Spain, all the hospital nurses surveyed held a bachelor's degree. None of the nurses in Germany had a corresponding education. In the other countries there was a wide variation from 10% with bachelor's degree in Switzerland to close to 60% in Ireland and Sweden. The same study showed that hospitals with a higher proportion of nurses with a bachelor's education had significantly better patient outcomes and lower risk-adjusted mortality¹⁷⁴. In the same way, a lack of knowledge of the needs of patients from different cultures within one country could, in analogy also play a role.

In the same study, the authors explored about the nurses work environment and how much the nurses were satisfied with their work. They found that more than half the nurses in nine of the 12 countries reported that the work environment in their hospital was poor or only fair as opposed to good or excellent in three of countries. Nurses' job dissatisfaction varied dramatically across the 12 European countries. In Sweden, one of five nurses (20%) was dissatisfied. Depending on country between two up to five in 10 were planning to leave their current job during the next year and of those that expressed this intention, between two to four in 10 intended to seek employment other than nursing. This high percentage of dissatisfied personnel can be expected to influence the quality of the care and might be more deleterious for those requiring special attention¹⁷⁴.

One problem might be that patients born outside Sweden do not trust health-care professionals. The Statistics Central Boards¹⁹ study showed that 21% of immigrant women reported needing of health care, but not seeking it compared with 12% of women born in Sweden. The same study showed that the rate of preventable mortality (death due to illnesses that the health care sector is equipped to address through the application of preventative or targeted medical treatment) is higher among immigrants. Immigrants are treated unequally within several areas of the Swedish health-care sector including the use of well-documented medical treatments for heart attack, heart failure, stroke and chronic obstructive pulmonary disease compared with patients born in Sweden.

These findings underline the fact that the health care in the immigrant population needs to improve regardless of whether poor trust in the health-care professionals is the reason for or the effect of these circumstances. Our findings of poorer health-related quality of life and more pain in the immigrant group both before and one year after total hip replacement supports this conclusion. Our finding that poorly informed immigrants have a poorer outcome after one year also speaks in the same direction.

The need for re-operation within two years and revision in the longer perspective was

found to be about equal in patients born in Sweden and abroad. This finding is encouraging and suggests that these groups at least from a strict technical perspective are treated equally. In our study we were not, however, able to evaluate whether the indications for re-operation or revision differed between the groups. There is no reason to believe that this is the case. Further and more detailed studies including radiographic evaluation and PROM are needed to evaluate this question in more detail.

06 LIMITATIONS

The immigrant groups were heterogeneous and came from different countries and regions, in order to maintain sufficient statistical power. In future studies, it might be valuable to study larger patient populations to enable more differentiated analyses. This was a general problem applicable to all the studies in this thesis.

Problems understanding the Swedish language are another important issue and especially in studies **I**, **III** and **V**. This means that a certain percentage of the patients born abroad most probably, have received help from relatives or friends to fill in the questionnaire. Even if this is sometimes also the case for elderly patients born in Sweden, more immigrants can be expected to have required assistance. Further, a lack of knowledge of the Swedish language might also explain why the number of drop-outs in the immigrant group was slightly higher than in the control group. In future studies, it would be valuable to study larger patient populations and specifically address the language problem to enable more differentiated analyses.

Another potential problem might be for the EQ-5D form is adapted to Northern Europe and there might be a risk bias so that Swedish patients choose the responses in the middle, while some immigrants respond more to one side or the other.

We used the British EQ-5D tariff translated into the Swedish language, which might be better adapted to the Swedish population than to immigrants coming from some other parts of Europe and from outside Europe. The differences between some of the parameters studied were small (e.g. pre- and postoperative EQ-VAS) and their clinical relevance could be questioned. This problem also applies to studies **III** and **V**.

The current literature usually distinguishes between races, whereas our studies focussed on geographical origin based on region of birth. This type of separation was partly used because no information about race was available. We also think that the grouping performed by us is more relevant for the immigrant groups in the Scandinavian countries and Northern Europe.

In study **II** we interviewed the participants the day before surgery. They may therefore have been more nervous due to the scheduled operation than would have been the case if the interview had been conducted a few days earlier. Some participants were visiting a hospital ward for the first time, whereas others had positive or negative previous experiences of hospitalisation. All the participants experienced similar circumstances, but different levels of stress among the participants might nonetheless have had different effects on their ability to communicate with the interviewer.

In study **III** we divided the patients into two groups, one in which the patients had answered that the information was poor or absent with respect to all three questions and the second group who had answered that the information was at least satisfactory on at least one of three questions. By doing this we were able to define one group of patients who had definitely received insufficient information or who for various reasons, did not remember the information provided. Further separation of the answers into different grades of perceived quality of the information is possible, but this would require a larger set of patient material.

In the same study (**III**) there might be several reasons why the group of patients defined as poorly informed was so large. It might be that no information was provided, that its quality was too poor, that the patients did not understand or did not care because they were anxious, depressed or had received narcotics for pain relief. We do not know the extent to which poorly informed patients gathered the information they wanted in other ways. If this was the case, we do not know the extent to which this was done depending on country of birth.

In study **IV**, there were only 77 revisions in the smallest group, suggesting that some analyses are underpowered. However, combined register data (e.g. from the Scandinavian countries) would provide more power for future studies of particular issues.

07 CONCLUSIONS

Study I.

After adjustment for confounders, immigrants reported more problems with self-care, more anxiety/depression before THR and more VAS pain. At one year, their preoperatively observed problems with self-care and to a certain extent with anxiety/depression remained, as did the tendency to report more VAS pain. In addition, there were more cases with moderate or severe problems related to usual activities. Future studies including larger groups enabling studies of immigrants with different ethnic backgrounds and in-depth interviews to obtain a more solid background would be of value.

Study II.

The patients stated that the peri-operative information before elective total hip replacement was limited and insufficient. Patients from both groups wanted more information pertaining to the surgery, implant selection, pain relief and choice of anaesthesia and reported no or little time to put questions to the surgeon and an overall stressful situation. Mental distress and the two-week interval between the time at which the patients received the information and the operation might have contributed to the low degree of retention.

Study III.

Twenty eight percent of the patients were not satisfied with the information provided before and immediately after surgery involving total hip replacement. These patients more commonly reported the presence of peri-operative anxiety and were more frequently born abroad. Poorly informed patients coming from abroad were prone to report an inferior outcome one year after the operation. Further studies of an interventional character and including larger groups enabling studies of immigrants with different ethnic backgrounds to obtain a more solid background would be of value.

Study IV.

After adjustment for confounders, we found no clear-cut differences in re-operation within two years or revision within 14 years between patients born in Sweden and immigrants. Our study does not account for the beliefs of the patient and the attitude of the health-care providers relating to barriers and the benefits of total hip arthroplasty. Based on the results of this study we have no reason to believe that there are any substantial differences relating to these factors in the treatment of a failed THR between patients born

in Sweden and immigrants. Further studies are, however, needed to evaluate whether our observations are biased by the reluctance of immigrants to seek medical attention should any complications occur.

Study V.

The frequency of patients who reported moderate to severe problems differed for most of the dimensions in the EQ-5D between patients born in Sweden and those born outside this country. This difference was observed both before and one year after the operation.

08 FUTURE PERSPECTIVES

Immigrants in Sweden are a heterogeneous population with regard to national origin, socioeconomic status, language, religion and culture. Patients born outside Sweden, as well as other patients with immigrant background are influenced in different ways by their background history and different experiences of life in exile. Insight into and knowledge of these circumstances is often limited. More studies are needed to evaluate how these factors can be addressed in orthopaedic care.

Further qualitative (interview) and quantitative (questionnaire and intervention) research is needed among immigrants, and patients born in Sweden scheduled for total hip replacement surgery. Intervention studies with the emphasis on various ways of providing pre- and peri-operative information should be conducted. The timing of the information provided, its content and presentation should be specifically studied.

In this thesis patients were grouped on the basis of country of birth. Due to the limited number of observations, this division resulted in groups from large areas with many cultural backgrounds. Future studies with a more specific emphasis on cultural background would be of value. These studies would make it possible to more specifically address various needs of different immigrant populations. In addition, information about needs related to health-care should preferably be delivered by dedicated groups of people with a background in the culture or religion of interest.

The findings in this thesis suggest that more research about the opportunities for and benefits of education among health-care professionals. An education of this kind could focus on the provision of more transcultural health care and attitudes toward a subgroup-specific health-care service. This might be a starting point when in developing strategies for reducing ethnic inequalities in the Swedish health-care system.

8.1 Sažetak na Bosanskom jeziku

Totalna endoproteza kuka, kao zahvat u modernoj ortopedskoj hirurgiji ima za cilj smanjenje bola, poboljšanje pokretljivosti, funkcije i kvaliteta života kod pacijenata oboljelih od artroze, kad konzervativni (ne hirurški) tretman ne pokaže vidne rezultate. Uprkos dobrim ili odličnim rezultatima operativnog zahvata kod većine pacijenata, neki od operisanih pacijenata ipak budu nezadovoljni poslije operacije. Varijacija u rezultatu poslije operativnog zahvata može zavisiti od nekoliko faktora: izostanak informacije ili slabo informisani pacijenti prije operativnog zahvata, kvalitet u davanju njege operisanim od strane bolničkog osoblja i od rehabilitacije poslije završenog operativnog zahvata. Faktori koji su usko vezani za samog pacijenta, kao nepoznavanje domaćeg jezika, kulturološki faktori i socioekonomska pozadina pacijenata mogu takođe imati značaja i uticati na ishod operativnog zahvata. Cilj ove doktorske teze je da ispita kako mjesto rođenja pacijenata (u ili izvan Švedske) i socioekonomski faktori utječu na ishod rezultata poslije primarne totalne endoproteze kuka. Demografski podaci i podaci o hirurškom zahvatu, podaci priloženi od samih pacijenata prije operativnog zahvata i 1 godinu poslije operacije uključujući prisustvo eventualno dodatnog hirurškog zahvata usmjerenog prema ranijoj operaciji kod pacijenta (reoperacija ili revizija) uzeti su iz Švedskog Registra za protezu kuka. Podaci uzeti na taj način su se uporedili sa podacima iz Registra pacijenata i Centralnog Zavoda sa statistiku da bi se dobili dodatni podaci kao što su: ostale bolesti pacijenata, bračno stanje, nivo obrazovanja, visina prihoda domaćinstva i mjesto i država rođenja. Intervju i popunjeni formular od strane pacijenata o informaciji prije operativnog zahvata, podnošenju bola i koliko je pacijent zadovoljan poslije operacije kao i DASS 21 formular (Depresija, anksioznost i stres od 21 pitanja) za ispitivanje mentalnog zdravlja kod pacijenata bili su takođe upotrebljeni.

Pacijenti su bili podijeljeni i analizirani u 4 grupe (rođen u Švedskoj, Skandinaviji, Evropi ili izvan Evrope uključujući Sovjetski Savez) ili u 2 grupe (rođen u ili izvan Švedske). Pacijenti rođeni u i izvan Švedske izražavali su zabrinutost i/ili nezadovoljstvo po pitanju lošeg informisanja prije operativnog zahvata, izbora implantata za operaciju, terapiji bola, izboru tipa anestezije, nedostatak ili potpuno kratko vrijeme za diskusiju ili postavljanje pitanja operatoru kao i jedno stanje ispunjeno velikom dozom stresa kod personala. Doseljenički pacijenti u svim grupama pokazali su veliki problem u obavljanju svakodnevnih higijenskih obreda ($p \leq 0.02$), neke od grupa sa doseljeničkim pacijentima su pokazali tendenciju povećanja problema u izvršenju dnevnih aktivnosti ($p \leq 0.05$) dok su pacijenti rođeni u Evropi i izvan Evrope iskazali povećan problem sa anksioznosti/depresijom ($p \leq 0.005$). Pacijenti rođeni izvan Švedske pokazali su jednu nadprosječnu tendenciju sa više bola mjereno VAS ljestvicom u poređenju sa pacijentima rođenim u Švedskoj. Poslije operativnog zahvata (1 godina), pacijenti rođeni izvan Švedske su pokazali da imaju više problema od

pacijenata rođenih u Švedskoj u svim EQ-5D dimenzijama (higijena, mobilnost, dnevne aktivnosti, bol i anksioznost/depresija). Poslije podešavanja sa faktorima koji "smetaju" statističkom procesu i vrijednostima prije operativnog zahvata razlike/rezultat je bio isti osim za pacijente rođene u Skandinavskim državama i za dimenzije bol i anksioznost/depresija. Poslije operacije (1 godina) se bol prema VAS skali smanjio za pacijente u svim grupama. Pacijenti rođeni izvan Švedske pokazivali su indikaciju viška bola u poredjenju sa pacijentima rođenim u Švedskoj, prije i poslije podešavanja podataka sa tkz.faktorima koji "smetaju" statistički proces ($p < 0.001$). Pacijenti rođeni izvan Švedske su se osjećali psihički/mentalno lošije nego pacijenti rođeni u Švedskoj. Rizik za reoperaciju ili reviziju totalne endoproteze kuka nije se razlikovao između pacijenata rođenih u ili izvan Švedske.

Poteškoće i povećani problemi kod pacijenata rođenih izvan Švedske mogu zavisiti od kulturoloških razlika, problemima u komuniciranju sa medicinskim osobljem i od razlika u indikacijama bolesti. Ova grupa pacijenata bi mogla imati koristi od poboljšanja pre/postoperativnog informisanja pacijenata i drugih mjera u olakšanju i poboljšavanju rehabilitacije.

Rizik za podvrgavanje jos jednom operativnom zahvatu (Totalne endoproteze kuka) poslije prvog operativnog procesa nije bio povecan u grupi pacijenata rođenih izvan Švedske. Generalno rečeno, pacijenti rođeni izvan Švedske su pokazali povećan problem u većini dimenzija mjerenih sa EQ-5D i prije i poslije operativnog zahvata. Izostanak ili slaba informisanost pacijenata prije operacije može biti važan faktor na uticaj ishoda operativnog procesa kod pacijenata rođenih izvan Švedske i to bi trebalo biti više ispitano u raznim i budućim interventnim studijama.

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10 REFERENCES

1. **IOM** (International Organization for Migration) 2013. Retrieved on 30 September 2013. hq@iom.int.
2. **UNHCR** (United Nation High Commissioner for Refugees). Global Refugees trends. Statistics/Statistical Yearbook, September 2013. Available from <http://www.unhcr.org/cgi-bin/texis/vtx/home>.
3. **Taylor G**. Migration and refugees. In: Papadopoulos I (ed). Transcultural health and social care: development of culturally competent practitioners. Churchill Livingstone Elsevier Publishing. London. 2006. Page 45-63.
4. **Purnell L D, Paulanka B J**. Transcultural health care: a culturally competent approach. 2nd ed. FA Davis Publishing. Philadelphia . 2003.
5. **Fishman J**. Ethnicity as being, doing and knowing. In: Hutchinson J, Smith A D (eds). Ethnicity. Oxford University Press. New York. 1996. Page 62-68.
6. **Taylor G, Papadopoulos I, Dudau V, Maerten M, Peltegora A, Ziegler M**. Intercultural education of nurses and health professionals in Europa (IENE). *Int. Nurs Rev.* 2011; 58(2): 188-95.
7. **Wilow K**. Författningshandbok. Liber. Stockholm. 2003. (In Swedish).
8. **WHO**. Basic documents, 43rd ed. World Health Organization. Geneva. 2001.
9. **Leininger M M, Mc Faraland M R**. Culture Care Diversity and Universality: A Worldwide Nursing Theory. 2nd edition. New York. NY: Jones and Barlett. 2006.
10. **Ginger N J, Davidhizar E R**. Transcultural Nursing Assessment and Intervention. 5th edition. Elsevier. Mosby. 2008.
11. **Gandhi R, Razak F, Davey J, Mahomed N**. Ethnicity and patients perception of risk in joint replacement surgery. *The Journal of Rheumatology.* 2008; 35; 1664-1667.
12. **Oxford Reference Online**. Retrieved 2007-10-27 from <http://www.ub.gu.se>.

13. **Kraut A.** Historical aspects of refugees and immigration movements. In: **Marcella A J, Bornemann T, Ekblad S, Orley J.** (eds): *Amidsk peril and pain. The mental health and well-being of the world's refugees.* American Psychological Association . Washington DC. 1994. Page 33-53.
14. **Ekman S L.** Monolingual and bilingual communication between patients with dementia diseases and their caregivers. Academic Thesis. Department of Advanced Nursing. Umeå University. Umeå. 1993.
15. **Schierup C U.** Danser de for traditionens skyld? Invandrare, kultur og samfund. (Do they dance to keep up the tradition? Immigrants, culture and society). Academic Thesis. Department of Sociology. Umeå University. Umeå. 1987.
16. **Heikkilä K, Sarvimäki A, Ekman S-L.** Culturally congruent care for older people: Finnish care in Sweden. *Scandinavian Journal of Caring Sciences.* 2007; 21; 354-361.
17. **Svanberg I, Tyden M.** Tusen år av invandring: en svensk kulturhistoria (A thousand years of immigration: a Swedish cultural history), 3:rd ed. Dialogos Publishing. Stockholm. 2005.
18. **Lundh C, Ohlsson R.** Från arbetskraftsimport till flyktinginvandring (From import of labour migrants to immigration of refugees), 2nd ed. SNS Publishing. Stockholm. 1999.
19. **SCB (Statistiska Centralbyrån).** Statistiskadatabasen, Sveriges befolkning 31 december 2012 (Population statistics 31 December 2012). Available from <http://www.scb.se>
20. **SIV (Statens Invandrarverket) (Swedish Migrations Board).** På tal om invandrare (Talking about immigrants). SIV, Norrköping. 1993.
21. **Wiking E, Johansson S E, Sundquist J.** Ethnicity, acculturation, and self-reported health. A population based study among immigrants from Poland, Turkey, and Iran in Sweden. *J Epidemiol Community Health.* 2004 Jul;58(7):574-82.
22. **Bhugra D, Becker M A.** Migration, cultural bereavement and cultural identity. *World Psychiatry.* 2005;4;18-24.
23. **Taloyan M, Sundquist J, Al-Windi A.** The impact of ethnicity and self-reported health on psychological well-being: a comparative study of Kurish-born and Swedish born people. *Nordic Journal of Psychiatry* 2008;62;392-8.

24. **Mohseni M, Lindström M.** Ethnic differences in anticipated discrimination, generalised trust in other people and self-rated health: a population-based study in Sweden. *Ethn. Health.* 2008 Nov 1;13(5):417-34.
25. **Teodorescu DS, Heir T, Hauff E, Wentzel-Larsen T, Lien L.** Mental health problems and post-migration stress among multi-traumatized refugees attending outpatient clinics upon resettlement to Norway. *Scand J Psychol.* 2012 Aug;53(4):316-32.
26. **Ellis B H, MacDonald H Z, Lincoln A K, Cabral H J.** Mental health of Somali adolescent refugees: the role of trauma, stress, and perceived discrimination. *J Consult Clin Psychol.* 2008 Apr;76(2):184-93.
27. **Thomas J L, Wilk J E, Riviere L A, McGurk D, Castro C A, Hoge C W.** Prevalence of mental health problems and functional impairment among active component and National Guard soldiers 3 and 12 months following combat in Iraq. *Arch Gen Psychiatry.* 2010 Jun;67(6):614-23.
28. **Hermansson A C.** The well-being of war-wounded asylum applicants and quota refugees following arrival in Sweden. *Journal of Refugee Studies.* 1996;9:166-81.
29. **Marshall G N, Schell T L, Elliott M N, Berthold S M, Chun C A.** Mental health of Cambodian refugees 2 decades after resettlement in the United States. *Journal of the American Medical Association.* 2005; 294: 571-9.
30. **Kosidou K, Dalman C, Lundberg M, Hallqvist J, Isacson G, Magnusson C.** Socioeconomic status and risk of psychological distress and depression in the Stockholm Public Health Cohort: a population-based study. *J Affect Disord.* 2011 Nov;134(1-3):160-7.
31. **Aichberger MC, Bromand Z, Heredia Montesinos A, Temur-Erman S, Mundt A, Heinz A, Rapp MA, Schouler-Ocak M.** Socio-economic status and emotional distress of female Turkish immigrants and native German women living in Berlin. *Eur Psychiatry.* 2012 Jun;27 Suppl 2:S10-6.
32. **Levecque K, Lodewyckx I, Bracke P.** Psychological distress, depression and generalized anxiety in Turkish and Moroccan immigrants in Belgium: A general population study. *Social Psychiatry and Psychiatric Epidemiology.* 2009; 44: 188-97.

33. **Leao S T, Sudquist J, Johansson L M, Johansson S E, Sudquist K.** Incidence of mental disorders in second-generation immigrants in Sweden. A four-year cohort study. *Ethnicity and Health*. 2005; 10; 243-56.
34. **Suurmond J, Rupp I, Seeleman C, Goosen S, Stronks K.** The first contacts between healthcare providers and newly-arrived asylum seekers: a qualitative study about which issues need to be addressed. *Public Health*. 2013 Jul;127(7):668-73.
35. **Spike E A, Smith M M, Harris M F.** Access to primary health care services by community-based asylum seekers. *Med J Aust*. 2011 Aug 15;195(4):188-91.
36. **O'Donnell C A, Higgins M, Chauhan R, Mullen K.** Asylum seekers expectations of and trust in general practice: a qualitative study. *British Journal of General Practice*. 2008; 58; 1-11.
37. **Sundquist J, Iglesias E, Isacson Å.** Migration and Health. A study of Latin American refugees, their exile in Sweden and repatriation. *Scandinavian Journal of Primary Health Care*. 1995; 13; 135-40.
38. **Devito J A.** *Interpersonal communication book, 9th edition. The nature of culture.* Longman Publishing. New York. 2001. Page 40-56.
39. **Papadopoulos I.** *Transcultural health and social care: development of culturally competent practitioners.* Churchill Livingstone Elsevier Publishing. London. 2006. Page 7-24.
40. **Hermansen J A, Bernsen R M, Bruijnzeels M A, Meeuwesen L.** Patients evaluation of quality of care in general practice: what are the cultural and linguistic barriers? *Patient Educ. Couns*. 2008; 72 (1): 155-62.
41. **Whitman M V, Davis J A.** Cultural and linguistic competence in healthcare: the case of Alabama general hospitals. *Journal of Healthcare Management*. 2008; 53: 26-39.
42. **Höye S, Severinsson E.** Intensive care nurses encounters with multicultural families in Norway: an exploratory study. *Intensive Crit.Care Nursing*. 2008; 24(6): 338-48.
43. **Wiking E, Saleh-Stattin N, Johansson S E, Sundquist J.** Immigrant patients experiences and reflections pertaining to the consultation: a study on patients from Chile, Iran and Turkey in primary health care in Stockholm, Sweden. *Scandinavian Journal of Caring Sciences*. 2009; 23(2): 290-7.

44. **Kleinman A, Kunstadter P, Alexander E R, Gale J L.** Culture and healing in Asian societies. *Anthropological psychiatric and public health studies*. Schenkman Publishing. Cambridge. 1978.
45. **Wachtler C, Brorson A, Troein M.** Meeting and treating cultural differences in primary care: a qualitative interview study. *Family practice*. 2006; 23: 111-5.
46. **Pesquera M, Yoder L, Lynk M.** Improving cross-cultural awareness and skills to reduce health disparities in cancer. *Med Surg. Nursing*. 2008; 17(2): 114-20.
47. **Brusin J H.** How cultural competency can help reduce health disparities. *Radiol. Technol*. 2012; 84(2): 129-47.
48. **Brach C, Fraser I.** Can cultural competency reduce racial and ethnic health disparities? A review and conceptual model. *Medical Care Research and Review*. 2000; 57: 181-217.
49. **Kawaga-Singer M, Kassim-Lakha S.** A strategy to reduce cross cultural miscommunication and increase the likelihood of improving health outcomes. *Academic Medicine*. 2003; 78: 577-87.
50. **Spilka B, Hood R W Jr, Hunsberger B, Gorsuch R.** *The Psychology of religion. An empirical approach*. 3rd edition. London, New York: Guilford Press. 2003.
51. **James, W.** *The varieties of religious experience*. Cambridge, MA: Harvard University Press. 1985.
52. **Blazer D G, Palmore E.** Religion and aging in a longitudinal panel. *The Gerontologist*. 1976; 16: 82-85.
53. **Ferraro K H, Koch J R.** Religion and health among black and white adults: Examining social support and consolation. *Journal for the Scientific Study of Religion*. 1994; 33(4): 362-375.
54. **Koenig H G.** Religious beliefs and practices of hospitalized medically ill older adults. *International Journal of Geriatric Psychiatry*. 1998; 13: 213-224.
55. **Koenig H G, Larsson D B.** Use of hospital services, religious attendance, and religious affiliation. *Southern Medical Journal*. 1998; 91(10): 925-932.

56. **Sherkat D E, Eliason C G.** Recent developments and current controversies in the sociology of religion. *Annual Review of Sociology.* 1999; 25: 363-394.
57. **Strawbridge WJ, Cohen R D, Shema S J, Kaplan G A.** Frequent attendance at religious services and mortality over 28 years. *American Journal of Public Health.* 1997; 87: 957-961.
58. **Princeton Religion Research Center.** Importance of religion climbing again. *Emerging Trends.* 1994; 16: 1-4.
59. **Lubitz J, Prihoda R.** Use of medicare services in the last years of life. In *Health, United States, DHHS publication.* Washington. DC: Government Printing Office. 1983. Page 84-1232.
60. **Soldo B J, Manton K G.** Changes in the health status and service needs of the oldest old: Current patterns and future trends. *Milbank Memorial Fund Quarterly.* 1985; 63: 286-323.
61. **US Senate Special Committee on Aging.** *Aging America: Trends and projections.* Washington DC: Department of Health and Human Service. 1988. Page 1987-1988.
62. **US Department of Health and Human Services.** *United States. Health United States.* Washington DC: US Department of Health and Human Services. Publication 1990. page 90-1232.
63. **Sandbacka C.** Understanding other Cultures. *Studies in the Philosophical Problems of Cross-Cultural interpretation. Acta Philosophica Fennica.* 1987. *Helsinki.*
64. **Hultsjö S, Hjelm K.** Immigrants in emergency care: Swedish health care staff's experiences. *International Nursing Review.* 2005; 52: 276-285.
65. **Hampers L C, Cha S, Gutglad D J, Binns H J, Krug S E.** Language barriers and resource utilization in a pediatric emergency department. *Pediatrics.* 1999; 103: 1253-1256.
66. **Rhodes P, Nocon A.** A problem of communication? Diabetes care among Bangladeshi people in Bradford. *Health and Social Care in the Community.* 2003; 11: 45-54.
67. **Bischoff A, Bovier P A, Isah R, Francoise G, Ariel E, Louis L.** Language barriers between nurses and asylum seekers: their impact on symptom reporting and referral. *Social Science & Medicine* 2003; 57: 503-512.

68. **Bernstein J, Bernstein E, Dave A, Hardt E, James T, Linden J, Mitchell P, Oishi T, Safi C.** Trained medical interpreters in the emergency department: Effects on services, subsequent charges, and follow-up. *Journal of Immigrant Health*. 2002; 4 (4): 71–176.
69. **Baker D W, Parker R M, Williams M V, Coates W C and Pitkin K.** Use and effectiveness of interpreters in an emergency department. *Journal of the American Medical Association* 1996; 275: 783–787.
70. **Hampers L C, McNulty J E.** Professional interpreters and bilingual physicians in a pediatric emergency department. *Archives of Pediatrics Adolescent Medicine* 2002; 156:1108–1111.
71. **Albin B.** Morbidity and mortality among foreign-born Swedes. Doctoral Thesis. Lund University. Lund. 2006.
72. **Berry D.** *Health Communication: Theory and Practice*. 2006; Buckingham, GBR: Open University Press.
73. **Bischoff A.** Caring for migrant and minority patients in European hospitals. A review of effective interventions. Vienna, Institute for the Sociology of Health and Medicine. 2003. Retrieved from: www.mfh-eu.net/public/files/mfh (accessed 20 November 2006).
74. **Förvaltningslagen** (Management Act) (1986:223).
75. **WHO** (World Health Statistics Annual. Geneva, Switzerland). World Health Organization; 2013.
http://www.who.int/healthinfo/global_burden_disease/eng/
76. **Sundquist J, Rosen U, Johansson S E.** Ethnicity as a risk for musculoskeletal disease, long consultation times and care utilization: A prospective visitor study of 438 consecutive adult consultations of a primary health care centre. *International Journal of Social Welfare*. 1994; 3(4): 212-217.
77. **Soares J J F, Grossi G.** Experience of musculoskeletal pain: Comparison of immigrant and Swedish patients. *Scandinavian Journal of Caring Sciences*. 1999; 13(4): 254-266.

78. **Havelin L I, Fenstad A M, Salomonsson R, Mehnert F, Furnes O, Overgaard S, Pedersen A B, Herberts P, Kärrholm J, Garellick G.** The Nordic Arthroplasty Register Association: a unique collaboration between 3 national hip arthroplasty registries with 280,201 THRs. *Acta Orthop.* 2009 Aug;80(4):393-401.
79. **Bergh C, Fenstad A M, Furnes O, Garellick G, Havelin H I, Overgaard S, Pedersen A, Mäkelä K, Pulkkinen P, Mohaddes M, Kärrholm J.** Increased risk of revision in patients with non-traumatic femoral head necrosis. *Acta Orthopaedica.* 2014; 85(1): 11-17.
80. **Dreinhöfer K, Dieppe P, Gunther K, Puhl W.** Eurohip-Health Technology Assessment of Hip Arthroplasty in Europe. Springer, 2009.
81. **Rolfson O.** Patient-reported Outcome measures and Health-economic aspects of Total Hip Arthroplasty. A study of the Swedish Hip Arthroplasty Register. Doctoral Thesis. University of Gothenburg. 2010.
82. **Patient Data Act.** SFS 1998:204: Ministry of Health and Social Affairs, 2008.
83. **Garellick G, Kärrholm J, Rogmark C, Rolfson O, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2012. Department of Orthopaedics, Sahlgrenska University Hospital, 2013.
84. **National Board of Health and Welfare.** Svensk Författningssamling (SFS). 2006, Vol. 1982:763.
85. **Pattenden J, Roberts H, Lewin R.** Living with hearth failure; patient and carer perspectives. *European Journal of Cardiovascular Nursing.* 2007; 6(4): 273-9.
86. **van der Wal M, Jaarsma T, van Veldhuisen D.** Non-compliance in patients with heart failure; how can we manage it? *Eur.Journal Heart Failure.* 2005; 7(1): 5-17.
87. **Löfvander M, Dyhr L.** Transcultural general practice in Scandinavia. *Scandinavian Journal of Primary Health Care.* 2002; 20: 6-9.
88. **Hemminki K, Mousavi S M, Sundquist J, Brandt A.** Does the breast cancer age at diagnosis differ by ethnicity? A study on Immigrants to Sweden. *The Oncologist.* 2011; 16: 146-154.

89. **Sundquist K, Chaikiat Å, Ramirez V, Johansson S E, Sundquist J.** Country of birth, socioeconomic factors, and risk factor control in patients with type 2 diabetes: a Swedish study from 25 primary health-care centres. *Diabetes Metab. Res.Rev.* 2011; 27: 244-254.
90. **Neuburger J, Hutchings A, Allwood D, Black N, van der Meulen J H.** Sociodemographic differences in the severity and duration of disease amongst patients undergoing hip or knee replacement surgery. *Journal of Public Health.* 2012; 34: 421-429.
91. **Gordon M, Paulsen A, Overgaard S, Garellick G, Pedersen A, Rolfson O.** Factors influencing health-related quality of life after total hip replacement – a comparison of data from the Swedish and Danish hip arthroplasty registers. *Musculoskeletal Disorders.* 2013; 14:316.
92. **Kirmayer L J, Weinfeld M, Burgos G, du Fort G G, Lasry J C Young A.** Use of health care services for psychological distress by immigrants in an urban multicultural milieu. *Can J Psychiatry* 2007; 52: 295-304.
93. **Hollander A C, Bruce D, Burström B, Ekblad S.** Gender-related mental health differences between refugees and non-refugee immigrants- a cross-sectional register-based study. *BMC Public Health* 2011; 11:180. doi: 10.1186/1471-2458-11-180.
94. **Hughes S.** The effects of giving patients pre-operative information. *Nurs. Stand.* 2002; 16: 33-7.
95. **Klopfenstein C E, Forster A, Van Gessel E.** Anesthetic assessment in an out patient consultation clinic reduces preoperative anxiety. *Can J Anaesth.* 2000; 47: 511-5.
96. **Graneheim U H, Lundman B.** Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Education Today.* 2004; 24: 105-12.
97. **Garellick G, Kärrholm J, Rogmark C, Rolfson O, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2011. Department of Orthopaedics, Sahlgrenska University Hospital, 2011.

98. **Lovibond S H, Lovibond P F.** Manual for the Depression Anxiety Stress Scales. (2nd ed.) Psychology Foundation, Sydney, 1995.
99. **Kärrholm J, Garellick G, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2005. Department of Orthopaedics, Sahlgrenska University Hospital, 2006.
100. **Kärrholm J, Garellick G, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2006. Department of Orthopaedics, Sahlgrenska University Hospital, 2007.
101. **Kärrholm J, Garellick G, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2007. Department of Orthopaedics, Sahlgrenska University Hospital, 2008.
102. **Quality Registries in Sweden.**
<http://www.kvalitetsregister.se/sekundarnavigering/>
 Valideringshandbok. 2014 (In Swedish).
103. **Garellick G, Kärrholm J, Rogmark C, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2009. Department of Orthopaedics, Sahlgrenska University Hospital, 2010.
104. **Malchau H.** On the importance of stepwise introduction of new hip implant technology: assessment of total hip replacement using clinical evaluation, radiostereometry, digitized radiography and national hip registry. Doctoral Thesis. University of Gothenburg. 1995.
105. **Malchau H, Garellick G, Eisler T, Kärrholm J, Herberts P.** Presidential guest adress: the Swedish Hip Registry: increasing the sensitivity by patient outcome data. Clin. Orthop. Relat. Res. 2005; 441: 19-29.
106. **Herberts H, Ahnfelt L, Malchau H, Strömberg C, Andersson G B.** Multicenter clinical trials and their value in assessing total joint arthroplasty. Clin. Orthop. Relat. Res. 1989; 249: 48-55.
107. **Herberts P, Malchau H.** How outcome studies have changes total hip arthroplasty practices in Sweden. Clin. Orthop. Relat. Res. 1997; 344: 44-60.
108. **Herberts P, Malchau H.** Long-term registration has improved the quality of hip replacement: a review of the Swedish THR Register comparing 160,000 cases. Acta Orthop.Scand. 2000; 71-2: 111-21.

109. **Malchau H, Herberts P, Eisler T, Garellick G, Söderman P.** The Swedish Total Hip Replacement Register. *J Bone Joint Surg Am.* 2002; 84-A Suppl2: 2-20.
110. **Garellick G, Kärrholm J, Rogmark C, Rolfson O, Herberts P.** The Swedish Hip Arthroplasty Register, Annual Report 2011. Department of Orthopaedics, Sahlgrenska University Hospital, 2012.
111. **Saklad M.** Grading of Patients for Surgical Procedures. *Anesthesiology.* 1941; 2-3: 281-4.
112. **Charnley J.** Low friction arthroplasty of the hip: theory and practice. Berlin; Springer-Verlag, 1979:376 s.
113. **Britton A R, Murray D W, Bulstrode C J, McPherson K, Denham R A.** Pain levels after total hip replacement: their use as endpoints for survival analysis. *J Bone Joint Surg Br.* 1997; 79-1: 93-8.
114. **Garellick G, Malchau H, Herberts P.** Survival of hip replacements. A comparison of a randomized trial and a registry. *Clin Orthop Relat Res* 2000; 375: 157-67.
115. **Berwick D M.** Medical associations: guilds or leaders? *BMJ.* 1997; 314-7094: 1564-5.
116. **EuroQol Group.** EuroQol – a new facility for the measurement of health related quality of life. *Health Policy.* 1990; 16-3: 10.
117. **Dolan P, Roberts J.** Modelling valuations for EQ-5D health states: an alternative model using differences in valuations. *Med Care.* 2002; 40-5: 442-6.
118. **Lauti S, Kyngäs H.** Developing nursing theories (Finish: Hoitotieteen Teorian Kehittäminen). 2005. Werner Söderström, Dark Oy, Vantaa.
119. **Kyngäs H, Vanhanen L.** Content analysis (Finish). *Hoitotiede.* 1999; 11: 3-12.
120. **Chinn P L, Kramer M K.** Theory and nursing a Systematic Approach. 1999. Mosby Year Book, St. Louis.
121. **Burns N, Grove S K.** The Practice of Nursing Research: Conduct, Critique and Utilization. 2005. Elsevier Saunders, St. Louis.
122. **Robson C.** Real World Research. A Resource for Social Scientists and Practitioner-Researchers. 1993. Blackwell Publishers, Oxford.

123. **Polit D F, Beck C T.** Nursing Research. Principles and Methods. 2004. Williams and Wilkins, Philadelphia, PA.
124. **Burstrom K, Johannesson M, Diderichsen F.** Health-related quality of life by disease and socio-economic group in the general population in Sweden. Health Policy. 2001; 55: 51-69.
125. **Jansson K-Å, Granath F.** Health-related quality of life(EQ-5D) before and after orthopedic surgery. Acta Orthoprdica 2011; 82 (1): 82-89.
126. **Ballamy N Buchanan WW, Goldsmith CH, Campbell J, Stitt LW.** Validation of WOMAC; a health status instrument for measuring clinically important patient relevant outcomes to anti-rheumatic drug therapy in patients with osteoarthritis of the hip or knee. J Rheumatol. 1988;15:1833-40.
127. **Garratt A M, Ruta D, Abdalla M I, Buckingham J K, Rusell I T.** The SF-36 health survey questionnaire: an outcome measure suitable for routine use within the NHS? BMJ. 1993; 306:1440-4.
128. **Lindgard E A, Katz J, Wright E A, Sledge C B.** Predicting the outcome of total knee arthroplasty. J Bone Joint Surgery. 2004; 86-A: 2179-86.
129. **Rolfson O, Dahlberg L E, Nilsson J A, Malchau H, Garellick G.** Variables determining outcome in total hip replacement surgery. J Bone Joint Surg Br. 2009; 91: 157-61.
130. **Said A. Ibrahim C J B, Mercer M B, Laura A. Siminoff, C. Kwoh K.** Older patients` Perceptions of Quality of Chronic Knee or Hip Pain: Differences by Ethnicity and Relationship to Clinical Variables. Journal of Gerontology:Medical Sciences. 2003; 58A No.5: 472-7.
131. **Thomas V J, Rose F D.** Ethnic differences in the experience of pain. Soc Sci Med. 1991; 32, No.9: 1063-6.
132. **Greenwald H P.** Interethnic differences in pain perception. Pain. 1991; 44: 157-63.
133. **Zborowski M.** Cultural components in responses to pain. J Soc Issues. 1952; 8: 16-30.
134. **Zola I K.** Culture and symptoms: an analysis of patients` presenting complaints. Am Socio Rev. 1966; 3: 615-30.
135. **Garron D, Leavit F.** Demographic and affective covariates of pain. Psychosom Med. 1979; 41: 525-34.

136. **Lithner M, Zilling T.** Pre- and postoperative information needs. *Patient Education and Counseling.* 2000; 40: 29-37.
137. **Sjöling M, Nordahl G, Olofsson N, Asplund K.** The impact of preoperative information on state anxiety, postoperative pain and satisfaction with pain management. *Patient Education and Counseling.* 2003; 51: 169-76.
138. **Kiyohara L Y, Kayano L K, Oliveira L M, Yamamoto M U, Inagaki M M, Ogawa N Y, Gonzales P E, Mandelbaum R, Okubo S T, Watanuki T, Vieira J E.** Surgery information reduces anxiety in the pre-operative period. *Rev Hosp Clin Fac Med.* 2004; 59: 51-6.
139. **Kagan I, Bar-Tal Y.** The effect of preoperative uncertainty and anxiety on short-term recovery after elective arthroplasty. *Journal of Clinical Nursing.* 2008; 17: 576-583.
140. **Ley P.** Memory for medical information. *British Journal of Social and Clinical Psychology.* 1979; 18: 245-55.
141. **Jansen J, Butow P N, van Weert J C, van Dulmen S, Devine R J, Heeren T J, Bensing J M, Tattersall M H.** Does age really matter? Recall of information presented to newly referred patients with cancer. *Journal of Clinical Oncology.* 2008; 26: 5450-7.
142. **Leininger M.** *Culture Care and Diversity: A Theory of Nursing.* National League for Nursing Press, New York, 1991.
143. **Lam P, White C L, Runions S, Miller C A.** Continuity of care for short-stay neurosurgery patients: a quality improvement initiative. *Axone.* 2001; 23: 14-21.
144. **Gustafsson B A, Ponzer S, Heikkila K, Ekman S L.** The lived body and the perioperative period in replacement surgery: older people's experiences. *Journal of Advanced Nursing.* 2007; 60: 20-8.
145. **Fujita K, Makimoto K, Hotokebuchi T.** Qualitative study of osteoarthritis patients' experience before and after total hip arthroplasty in Japan. *Nursing Health Sciences* 2006; 8: 81-7.
146. **Robinson OJ, Vytal K, Cornwell BR, Grillon CH.** The impact of anxiety upon cognition: perspectives from human threat of shock studies. *Frontiers in Human Neurosciences.* 2013; 7: 182-203.

147. **Gilholly M.** Ethical issues in researching later life. In *Research in Ageing and Later Life. The Practice of Social Gerontology.* 2002. p. 211-225.
148. **Quintres J S G, Coste J, Vastel L, Pacault V, Jeanne L, Lamas J-P, Kerboull L, Fougeray M, Conseiller C, Kahan A, Courpied J-P.** Positive effect of patient education for hip surgery. *Clin. Orth.and Rel. Research.* 2002; 414: 112-120.
149. **Krupic F, Eisler T, Garellick G, Kärrholm J.** Influence of ethnicity and socioeconomic factors on outcome after total hip replacement. *Scandinavian journal of caring sciences.* 2013; 27 (1): 139-146.
150. **Reading A E.** The short-term effects of psychological preparation for surgery. *Soc.Sci.Medica.* 1979; 13: 641-654.
151. **Howell S M, Rogers S L.** Method for quantifying patient expectations and early recovery after total knee arthroplasty. *Orthopaedics.* 2009; 32: 884-890.
152. **Nilsdotter A K, Toksvig-Larsen S, Roos E M.** Knee arthroplasty: are patients expectations fulfilled? A prospective study of pain and function in 102 patients with 5-year followup. *Acta Orthopaedica.* 2009; 80: 55-61.
153. **Husted H.** Fast-track hip and knee arthroplasty: clinical and organizational aspects. *Acta Orthop.Suppl.* 2012; 83: 1-39.
154. **Krupic F, Määttä S, Garellick G, et al.** Preoperative information provided to Swedish and immigrants before total hip replacement. *Medical Archives.* 2012; 66(6): 399-404.
155. **Jjala H A, French J L, Foxall G L, Hardman J G, Bedforth N M.** Effect of preoperative multimedia information on perioperative anxiety in patients undergoing procedure under regional anaesthesia. *Brit. Journal of Anaesthesia.* 2010; 104 (3): 369-74.
156. **Stanley B M, Walters D J, Maddern G J.** Informed Consent: How much information is enough ? *Aust.N.Z.J.Surgery.* 1998; 68:788-791.
157. **Ang D C, Ibrahim S A, Burant C J, Siminoff L A, Kwoh C K.** Ethnic differences in the perception of prayer and consideration of joint arthroplasty. *Med Care.* 2002; 40: 471-6.
158. **Ibrahim S A, Siminoff L A, Burant C J, Kwoh C K.** Understanding ethnic differences in the utilization of joint replacement for osteoarthritis: the role of patient-level factors. *Med Care.* 2002;40:144-51.

159. **Nwachukwu B U, Kenny A D, Losina E, Chibnik L B, Katz J N.** Complications for racial and ethnic minority groups after total hip and knee replacement: a review of the literature. *J Bone Joint Surgery (Am)*. 2010;92:338-45.
160. **SooHoo N F, Farnig E, Lieberman J R, Chambers L, Zingmond D S.** Factors that predict short-term complication rates after total hip arthroplasty. *Clin Orthop Relat Res*. 2010;468:2363-2371.
161. **Ibrahim S A, Stone R A, Han X, Cohen P, Fine M J, Henderson W G, Khuri S F, Kwoh C K.** Racial/ethnic differences in surgical outcomes in veterans following knee or hip arthroplasty. *Arthritis Rheum*. 2005;52:3143-51.
162. **Collins T C, Daley J, Henderson W H, Khuri S F.** Risk factors for prolonged length of stay after major elective surgery. *Ann Surg*. 1999;230:251-9.
163. **Weaver F, Hynes D, Hopkinson W, Wixson R, Khuri S, Daley J, Henderson W G.** Preoperative risks and outcomes of hip and knee arthroplasty in the Veterans Health Administration. *J Arthroplasty* 2003;18:693-708.
164. **Katz J, Losina E, Barrett J, Phillips C B, Mahomed N N, Lew R A, Guadagnoli E.** Association between hospital and surgeon procedure volume and outcomes of total hip replacement in the United States medicare population. *J Bone Joint Surgery (Am)*. 2001;11:1622-9.
165. **Edit V, Eva S, Maria K, Istvan R, Agnes C, Zsolt N.** Psychosocial, educational, and somatic factors in chronic nonspecific low back pain. *Rheumatol.Int*. 2012; 33(3): 587-592.
166. **Quality of life for cities and countries worldwide**, report February 2013. <http://numbeo.com>
167. **Eriksson E, Nordlund A.** Health and Health Related Quality of Life as measured by the EQ-5D and the SF-36 in South East Sweden: Results from Two Population Surveys. 2002, Folkvetenskaplig Centrum, Linköping (In swedish)1-42. www.lio.se/fhvc
168. **Mancuso C A, Sculco T P, Salvati E A.** Patients with poor preoperative functional status have high expectations of total hip arthroplasty. *J Arthroplasty*. 2003; 18: 872-8.

169. **Flor H, Fydrich T, Turk D.** Efficacy of multidisciplinary pain treatment centers: a meta-analytic review. *Pain.* 1992; 49: 221-30.
170. **Casten R J, Parmelee P A, Kleban M H, Lawton M P, Katz I P.** The relationship among anxiety, Depression and pain in a geriatric institutionalized sample. *Pain.* 1995; 61: 271-6.
171. **Linton S, Hallden K.** We can screen for problematic back pain: a screening questionnaire for predicting outcome in acute and subacute back pain. *Clin J Pain.* 1998; 3: 209-15.
172. **Breivik H, Collett B, Ventafridda V, Cohen R, Gallasher D.** Survey of chronic pain in Europe; Prevalence, impact on daily life, and treatments. *Eur J Pain.* 2006; 10: 287-333.
173. **Sun S, Irestig R, Burström B, Beijer U, Burström K.** Health-related quality of life (EQ-5D) among homeless persons compared to a general population sample in Stockholm County, 2006. *Scandinavian Journal of Public Health.* 2012; 40: 115-125.
174. **Aiken L H, Sloane D M, Bruyneel L, Heede van den K, Sermeus W.** Nurses reports of working conditions and hospital quality of care in 12 countries in Europe. *International Journal of Nursing Studies.* 2012; 50: 143-153.

- 1. The PROM protocol**
- 2. Questionnaire form (31 items)**
- 3. DASS 21 score**
- 4. Supplementary article data (Study 5)**

1. The PROM protocol

Uppföljningsformulär efter höftprotesoperation i Västra Götaland

Bäste patient!

Det är viktigt att Du fyller i samtliga frågor enligt instruktionen och därefter returnerar formuläret i bifogat svarskuvert (portot är betalt).

All information Du lämnar kommer att behandlas med största sekretess och Du som person kommer att skyddas på så sätt att inga resultat som kommer ifrån forskningen kommer att kunna spåras till Dig som individ.

Tack för Din medverkan!

Ortopedklinikerna i Västra Götaland

Svenska Höftprotesregistret



Operation (år):

Sjukhus: _____

Sida:

 Höger Vänster

Personnr:

Markera Ditt svar på nedanstående frågor genom att kryssa i en ruta (så här):

Har Du besvär från andra höften?

 Ja Nej

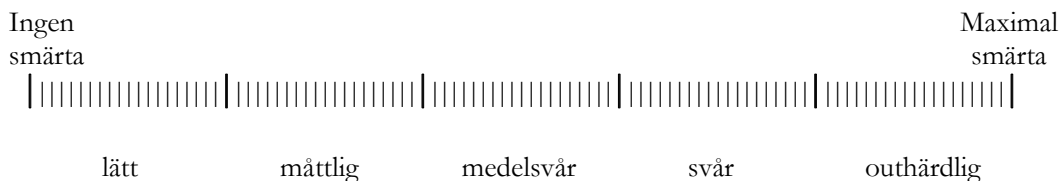
Har Du av någon annan anledning svårt att gå?
(T ex smärtor från andra leder, ryggvärk, kärlkramp eller
andra sjukdomar som påverkar Din gångförmåga.)

 Ja Nej

Skala 1

Smärta

Sätt ett *kryss* på det *streck* som Du tycker motsvarar Din genomsnittliga smärtupplevelse från den aktuella höften under senaste månaden:



Skala 2

Tillfredsställelse

Sätt ett *kryss* på det *streck* som Du tycker motsvarar hur nöjd Du är med operationsresultatet:



Markera, genom att kryssa i en ruta i varje nedanstående grupp (så här ☒), vilket påstående som bäst beskriver Ditt **allmänna hälsotillstånd** i dag (ej enbart beroende på den aktuella höften).

Rörlighet

- Jag går utan svårigheter
- Jag kan gå men med viss svårighet
- Jag är sängliggande

Hygien

- Jag behöver ingen hjälp med min dagliga hygien, mat eller påklädning
- Jag har vissa problem att tvätta eller klä mig själv
- Jag kan inte tvätta eller klä mig själv

Huvudsakliga aktiviteter (*t ex arbete, studier, hushållsyror, familje- och fritidsaktiviteter*)

- Jag klarar av mina huvudsakliga aktiviteter
- Jag har vissa problem med att klara av mina huvudsakliga aktiviteter
- Jag klarar inte av mina huvudsakliga aktiviteter

Smärtor/besvär

- Jag har varken smärtor eller besvär
- Jag har måttliga smärtor eller besvär
- Jag har svåra smärtor eller besvär

Oro/nedstämdhet

- Jag är inte orolig eller nedstämd
- Jag är orolig eller nedstämd i viss utsträckning
- Jag är i högsta grad orolig eller nedstämd

Jämfört med mitt allmänna hälsotillstånd de senaste tolv månaderna är mitt hälsotillstånd idag:

- Bättre (kryssa endast i en ruta)
- Oförändrat
- Sämre

Till hjälp för att avgöra hur bra eller dåligt ett hälsotillstånd är, finns den termometerliknande skalan till höger. På denna har Ditt bästa tänkbara hälsotillstånd markerats med 100 och Ditt sämsta tänkbara hälsotillstånd med 0.

Vi vill att Du på denna skala markerar hur bra eller dåligt Ditt hälsotillstånd är, som Du själv bedömer det. Gör detta genom att dra en linje från nedanstående ruta till den punkt på skalan som markerar hur bra eller dåligt Ditt nuvarande hälsotillstånd är.

**Ditt
nuvarande
hälsotillstånd**

OBS!

Dra en linje från den svarta rutan till den punkt som Du tycker motsvarar Ditt nuvarande allmänna hälsotillstånd.

Bästa
tänkbara
tillstånd

100

90

80

70

60

50

40

30

20

10

0

Sämsta
tänkbara
tillstånd

2. Questionnaire form (31 items)

Questions about your background

Please respond by placing an X in a box in each of the sections below

1. Age

I am.....years old

2. I am

Female

Male

3. Civil status

Cohabiting

Living alone

4. Number of biological children

one child

two children

three children

four children

more than four children(please specify the number)

5a. Nationality

.....(please state nationality)

5b. Country of birth

.....

6. Education (please state highest level achieved)

Primary school (or equivalent)
Vocational school/Upper secondary school (or equivalent)
College/University

7. Current work situation

In employment (employee, self-employed or equivalent)
In employment (currently sick-listed)
Unemployed
Retired
Other

Questions about the information you received after the operation

8. What type of anaesthesia/sedation did you receive in connection with the operation? (You can tick more than one alternative if applicable).

General anaesthesia (sedation)
Spinal anaesthesia (anaesthesia of the spinal cord)
Local anaesthesia of the wound

9. Have you experienced worry or fear after the operation?

Yes, a little worry/fear
Yes, a great deal of worry/fear
No, not at all

10. Did you receive any information about the operation itself after surgery?

Yes
No
Don't know (can't remember)

11. If you answered YES to the previous question, where did you receive the information? (You can tick more than one alternative if applicable)

- In the operating room immediately after surgery
- In the post-operative department
- In my ward
- At discharge
- Other..... (please indicate where)

12. In what form was the information provided? (You can tick more than one alternative if applicable)

- Verbal Video, Film
- Written Searched for the information myself
- Other.....(please specify)

Comment.....
.....
.....

13. Who provided you with information about your operation? (You can tick more than one alternative if applicable).

- Surgeon (doctor who operated on me)
- Operating room nurse
- Both the operating room nurse and the surgeon
- No one
- Obtained information in another way
.....(please specify)

14. How important is it to you to receive the information about the surgery from the person who performed it?

- Not at all important
- Somewhat important
- Fairly important
- Very important

15. If you received information – was it adequate?

- Yes
- No
- Don't know

16. Was the information easy to understand?

- Yes
- No
- Don't know
-

17. Did you receive similar information from someone other than the surgeon?

- Yes
- No

18. If yes, who gave you the information?

- Other doctor
- Nurse
- Other staff member

19. In light of your own experiences, how do you consider that the information could be improved?

.....

.....

.....

.....

.....

- I am satisfied with the information provided

22. Did you ask for extra pain relief at any time during your time in hospital?

- Yes
- No

23. If you answered NO to question 22, why did you not request help?

- I didn't think it was necessary
- I can't speak Swedish
- I waited for the staff member(s) who speak my own language
- I didn't want to disturb staff members
- I was shy
- I felt ashamed of being in pain
- Other.....(please specify)

24. If you received extra pain relief, are you satisfied with the pain treatment provided?

- I am very satisfied
- I am fairly satisfied
- I am fairly dissatisfied
- I am very dissatisfied

Comment.....
.....

25. Was the staff attentive to how much pain you experienced?

- Definitely
- Partly
- To a limited extent
- Not at all

Comment.....
.....
.....

26. What is your opinion of the information you received *before* the operation (for example when you were admitted) regarding different types of pain treatment?

- Good
- Fairly good
- Very good
- Neither good or bad
- Bad
- I did not receive any information

27. What is your opinion of the information you received *after* the operation (for example on the ward) regarding different types of pain treatment?

- Good
- Fairly good
- Very good
- Neither good or bad
- Bad
- I did not receive any information

28. How would you describe your present physical health status?

- Very poor
- Fairly poor
- Neither good nor bad
- Fairly good
- Very good

29. How would you describe your present mental well-being?

- Very poor
- Fairly poor
- Neither good nor bad
- Fairly good
- Very good

Your overall impression after surgery

30. I'm particularly satisfied

with.....
.....
.....
.....

31. The following aspect(s) could be improved.....

.....
.....
.....

Thank you for your time

3. DASS 21 score



BLACK DOG INSTITUTE

DASS 21 NAME _____ DATE _____

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale is as follows:

- 0 Did not apply to me at all - NEVER
- 1 Applied to me to some degree, or some of the time - SOMETIMES
- 2 Applied to me to a considerable degree, or a good part of time - OFTEN
- 3 Applied to me very much, or most of the time - ALMOST ALWAYS

FOR OFFICE USE

		N	S	O	AA	D	A	S
1	I found it hard to wind down	0	1	2	3			
2	I was aware of dryness of my mouth	0	1	2	3			
3	I couldn't seem to experience any positive feeling at all	0	1	2	3			
4	I experienced breathing difficulty (eg, excessively rapid breathing, breathlessness in the absence of physical exertion)	0	1	2	3			
5	I found it difficult to work up the initiative to do things	0	1	2	3			
6	I tended to over-react to situations	0	1	2	3			
7	I experienced trembling (eg, in the hands)	0	1	2	3			
8	I felt that I was using a lot of nervous energy	0	1	2	3			
9	I was worried about situations in which I might panic and make a fool of myself	0	1	2	3			
10	I felt that I had nothing to look forward to	0	1	2	3			
11	I found myself getting agitated	0	1	2	3			
12	I found it difficult to relax	0	1	2	3			
13	I felt down-hearted and blue	0	1	2	3			
14	I was intolerant of anything that kept me from getting on with what I was doing	0	1	2	3			
15	I felt I was close to panic	0	1	2	3			
16	I was unable to become enthusiastic about anything	0	1	2	3			
17	I felt I wasn't worth much as a person	0	1	2	3			
18	I felt that I was rather touchy	0	1	2	3			
19	I was aware of the action of my heart in the absence of physical exertion (eg, sense of heart rate increase, heart missing a beat)	0	1	2	3			
20	I felt scared without any good reason	0	1	2	3			
21	I felt that life was meaningless	0	1	2	3			
TOTALS								

DASS Severity Ratings

The DASS is a **quantitative** measure of distress along the 3 axes of depression, anxiety¹ and stress². It is not a categorical measure of clinical diagnoses.

Emotional syndromes like depression and anxiety are intrinsically dimensional - they vary along a continuum of severity (independent of the specific diagnosis). Hence the selection of a single cut-off score to represent clinical severity is necessarily arbitrary. A scale such as the DASS can lead to a useful assessment of **disturbance**, for example individuals who may fall short of a clinical cut-off for a specific diagnosis can be correctly recognised as experiencing considerable symptoms and as being at high risk of further problems.

However for clinical purposes it can be helpful to have 'labels' to characterise degree of severity relative to the population. Thus the following cut-off scores have been developed for defining mild/moderate/severe/extremely severe scores for each DASS scale.

Note: the severity labels are used to describe the full range of scores in the population, so 'mild' for example means that the person is above the population mean but probably still way below the typical severity of someone seeking help (ie it does not mean a mild level of disorder).

The individual DASS scores do not define appropriate interventions. They should be used in conjunction with all clinical information available to you in determining appropriate treatment for any individual.

¹Symptoms of psychological arousal

²The more cognitive, subjective symptoms of anxiety

DASS 21 SCORE

DEPRESSION SCORE	ANXIETY SCORE	STRESS SCORE

	Depression	Anxiety	Stress
Normal	0 - 4	0 - 3	0 - 7
Mild	5 - 6	4 - 5	8 - 9
Moderate	7 - 10	6 - 7	10 - 12
Severe	11 - 13	8 - 9	13 - 16
Extremely Severe	14 +	10 +	17 +

4. Supplementary article data (Study 5)

Supplementary article data

Different patient-reported outcomes in immigrants and patients born in Sweden

18,791 patients with 1 year of follow-up in the Swedish Hip Arthroplasty Register

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Table 2. Preoperative distribution of patients with no or moderate-to-severe severe problems in the 5 EQ-5D dimensions

Preoperatively, n (%)	Sweden	Nordic Countries ^a	Europe ^b	Outside Europe ^c	Chi-square
Mobility					
No problems	1,108 (6)	51 (6)	22 (4)	5 (5)	0.2
Moderate-severe problems	16,232 (94)	678 (94)	501 (96)	104 (95)	
Self-care					
No problems	12,987 (75)	571 (69)	341 (65)	67 (62)	<0.001
Moderate-severe problems	4,353 (25)	248 (31)	182 (35)	42 (38)	
Usual activities					
No problems	6,328 (36)	265 (32)	162 (31)	29 (27)	0.001
Moderate-severe problems	11,012 (64)	554 (68)	381 (69)	80 (73)	
Pain/Discomfort					
No problems	173 (1)	8 (1)	6 (1)	7 (6)	<0.001
Moderate-severe problems	17,167 (99)	811 (99)	517 (99)	102 (94)	
Anxiety/Depression					
No problems	9,960 (57)	431 (53)	217 (42)	39 (36)	<0.001
Moderate-severe problems	7,380 (43)	388 (47)	306 (58)	70 (64)	

^a Excluding Sweden.
^b Excluding previous Soviet Union.
^c Including previous Soviet Union.

Table 3. Postoperative distribution of patients with no or moderate-to-severe problems in the 5 EQ-5D dimensions

1 year postoperatively, n (%)	Sweden	Nordic Countries ^a	Europe ^b	Outside Europe ^c	Chi-square
Mobility					
No problems	10,285 (59)	422 (52)	263 (50)	51 (47)	<0.001
Moderate/severe problems	7,055 (41)	397 (48)	260 (50)	58 (53)	
Self-care					
No problems	15,790 (91)	714 (87)	423 (81)	83 (76)	<0.001
Moderate/severe problems	1,550 (9)	105 (13)	100 (19)	26 (24)	
Usual activities					
No problems	12,965 (75)	564 (69)	330 (63)	65 (60)	<0.001
Moderate/severe problems	4,375 (25)	255 (31)	193 (37)	44 (40)	
Pain/Discomfort					
No problems	7,311 (42)	299 (37)	181 (35)	33 (30)	<0.001
Moderate/severe problems	10,029 (58)	520 (63)	342 (65)	76 (70)	
Anxiety/Depression					
No problems	13,471 (78)	601 (73)	326 (62)	61 (56)	<0.001
Moderate/severe problems	3,869 (22)	218 (27)	197 (38)	48 (44)	

^a Excluding Sweden.
^b Excluding previous Soviet Union.
^c Including previous Soviet Union. Excluding Sweden.

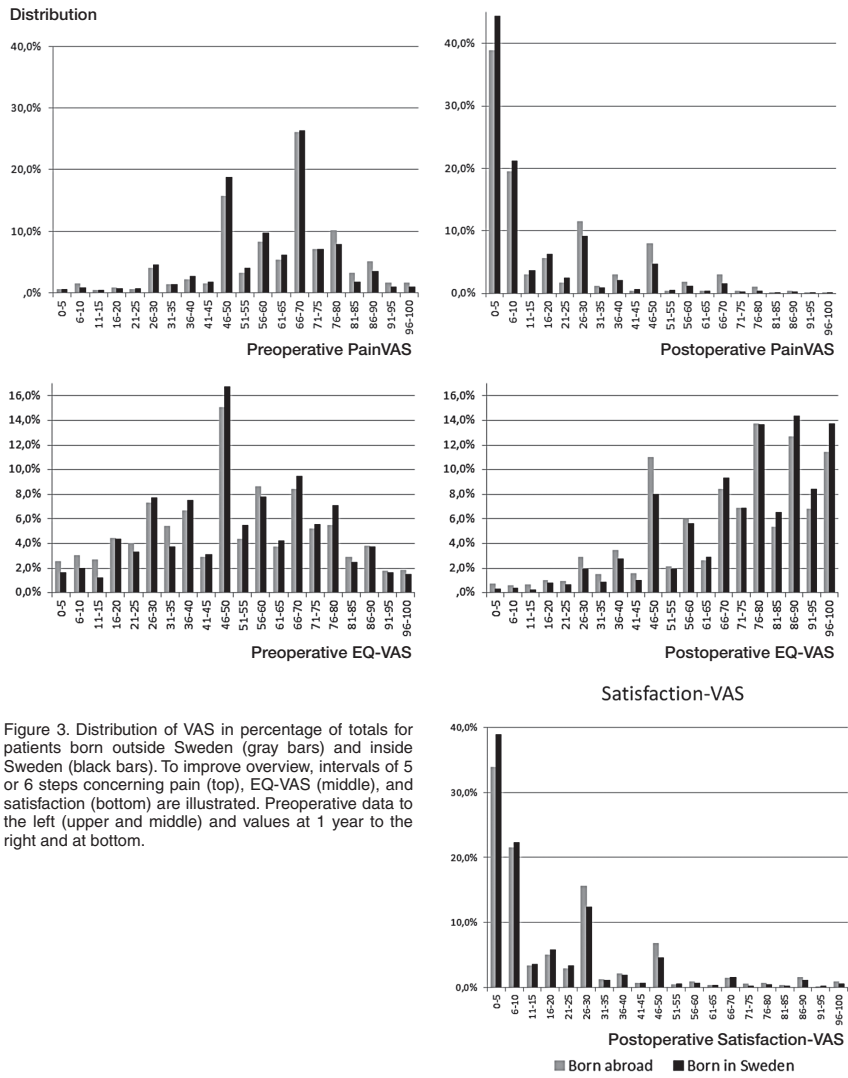


Figure 3. Distribution of VAS in percentage of totals for patients born outside Sweden (gray bars) and inside Sweden (black bars). To improve overview, intervals of 5 or 6 steps concerning pain (top), EQ-VAS (middle), and satisfaction (bottom) are illustrated. Preoperative data to the left (upper and middle) and values at 1 year to the right and at bottom.

