The BOA-register

Annual report 2008-2010 (brief summary)

Better Management of patients with OsteoArthritis (BOA)
www.boaregistret.se

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Content

Introduction

The BOA-register, for Better management of patients with OsteoArthrtis, was designated in December 2010 as a National Quality Register by the Swedish Association of Local Authorities and Regions, (SALAR). This is a summary of the first annual report encompassing activities from the start of 2008 until December 2010.

Evidence is a catchword within medicine. However, a large part of the treatments used, within health care in general and physiotherapy in particular, are based chiefly on clinical experience due to lack of evidence. There is strong support within osteoarthritis research for physical therapy interventions such as training and information. Reality, however, has shown considerable variation throughout the regions concerning treatment offered to patients with osteoarthritis. Our aim, through BOA, is to offer all patients equivalent treatment regardless of where they live or seek health care. In BOA, the evidence for information and training in hip and knee osteoarthritis is manifested in a so-called osteoarthritis school under the leadership of a physical therapist, often in cooperation with an occupational therapist and patient representative. The BOA-register is the first National Quality register to evaluate a physical therapy intervention. By means of the register we are able to systematically gather clinical results within areas difficult to scientifically evaluate. This affords us possibilities to learn from each other in order to optimise care on an individual basis.

BOA was initiated as a pilot project at ten health care units in four regions in 2008. Activity has, since then, continued to develop in both quality and volume. The first annual report contains data from 39 units in 11 regions that entered 3766 patients to the register before the end of 2010. When this annual report was compiled in August 2011 the register comprised 105 units. Nearly all regions will have physical therapists trained in osteoarthritis schooling and register skills by the end of 2011.

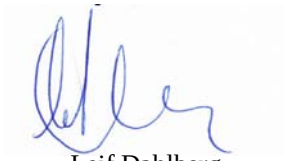
The BOA-register contains predominantly patient-reported outcomes. The physical therapist reports which treatment the patient had previously as well as their compliance to the intervention. Since our intention is to reach patients as early as possible in the course of the disease, the osteoarthritis school is directed mainly toward primary care patients. Health care's diverse organisation results in patients with ostearthritis of the hip and knee, in some regions, to be referred extensively to orthopaedic clinics. In order to reach these patients, a number of orthopaedic clinics have initiated osteoarthritis schools throughout Sweden. We also have a number of private clinics feeding data to the register. In time we will be able to compare the different clinics. The foundation for this type of grouping is, however, too small at the time of this first report.

The annual report is primarily aimed at providing a simple overview of the contents of the register. The statistics are descriptive and most of the means are presented without distribution measurements with regard to the limited material on a clinical level. Results should therefore be considered preliminary and interpreted with caution. Results are presented

separately for hips and knees. Classification according to the most troublesome joint is based on the physical therapist's assessment upon examination. Many patients indicate difficulties from both hips and knees. In 28 cases where it wasn't possible to discern which joint was the most troublesome, patients were grouped as knees, since they comprised the largest group. The influence of these 28 patients on the group's total mean is diminished more in the group with roughly 2000 individuals with knee problems than in the group with 1000 individuals with hip problems.

We hope that this annual report will provide inspiration for in-depth analyses and further the work efforts to improve care within osteoarthritis.

Carina Thorstensson



Leif Dahlberg

Göran Garellick

Summary of the 2010 annual report

The BOA-register (Better management of patients with OsteoArthritis) evaluates patient-reported outcomes following a physical therapy intervention – an osteoarthritis school. BOA was initiated as a pilot project in 2008 in cooperation with 10 units in four regions. The register granted access to other units in the spring of 2010. Interest for participation was great and the register was approved as a National Quality Register in December 2010. The first annual report consists of data from 39 units in 11 regions that registered 3766 patients before the end of 2010. At the annual report's publication (August 2011) 105 units had joined the register.

The osteoarthritis school according to the BOA concept has been developed from current research in the field as well as from patients' thoughts and desires for the treatment of osteoarthritis and is in good agreement with The Swedish National Board of Health and Welfare's preliminary guidelines for musculoskeletal disorders/osteoarthritis. The target group is patients with disorders of the hip and/or knee serious enough to require them to seek medical care. Patients in BOA do not need to have an X-ray verified diagnosis but are assessed according to symptoms, clinical findings and medical history. In order to present and evaluate the osteoarthritis school in an equivalent way the osteoarthritis school is led by a physical therapist with a 2-day training under the auspices of BOA. Up until the end of 2010 roughly 650 physical and occupational therapists throughout the country had been trained. The osteoarthritis school present patients with information and individually adjusted and monitored training for 6 weeks. During this time home training and other alternatives are introduced in order to maintain training continuity over an extended period of time. The importance of being physically active for a long time is accentuated in all aspects of patient education.

Osteoarthritis is ubiquitous causing many visits to the health care system. Statistics from health care databases (Region Västra Götaland and Region Skåne) show that 1600 unique individuals with hip and knee osteoarthritis per 100 000 inhabitants over the age of 45 seek primary health care yearly. Osteoarthritis school for all those seeking would require 160 schools/100 000 inhabitants over 45 years of age. Despite information and adapted physical activity having shown good results in the treatment of osteoarthritis in a number of scientific studies many patients have never been offered this treatment. One of the goals of BOA is to ensure equal and safe care by spreading knowledge and changing routines in health care so that all patients with osteoarthritis of the hip and knee will be able to gain information concerning their illness and what they themselves can do to alleviate their disorders and prevent disability as early as possible in the course of the illness. Another goal is to systematically evaluate and improve the quality of the results of physical therapy measures. Each unit reporting data to the register can at any time retrieve their results in real time and compare them with the national average. Continuous feedback is an important tool in operational development. The data quality in the BOA-register is very high if we judge by the percentage of questions answered and entered. Each and every question has been answered in more than 98% of cases.

The results of this report are presented separately for hips and knees. Patients with disorders from both hip and knee are categorised by the joint which the physical therapist judges as the most problematic. Two-thirds have most difficulties from their knees. Approximately 70% of

the patients in the register are women. We would also like to emphasize that the patient base can differ greatly between clinics whereby we at the BOA- register present data from both orthopaedic clinics and primary care as well as from both the private and public sector. These aspects must be considered when interpreting the results. This first report should be seen primarily as an operational description and as a starting point for coming efforts for the improvement of physical therapy practices.

In Västerbotten the introduction of the osteoarthritis schools and registration of BOA has resulted in reassessment of routines as part of the work and process of improvement. Since health care has been struggling with longer queues to orthopaedic surgeons, ostearthritis schools were introduced to orthopedic clinics in 2008. Patients were offered a place in the osteoarthritis school while on the waiting list. Roughly 2/3 of the patients referred from primary care to Umeå's orthopedic clinic with a diagnosis of hip or knee osteoarthritis considered themselves, after having completed the osteoarthritis school, to be so improved that they no longer needed to consult an orthopedic surgeon to discuss surgery. The majority of the 1/3 of patients that did not improve sufficiently by the osteoarthritis school had surgery within one year. The good results from the osteoarthritis school at the orthopedic clinic in Umeå have led to a decision by the county council to introduce an osteoarthritis school to primary care. At present the possibility of demanding completion of the course in the osteoarthritis school before referring patients to the orthopedic clinic is being discussed.

The following interesting observations from the results of the BOA-register's first three years of operation can be highlighted:

- X-ray is a frequently used diagnostic tool. It is a relatively inexpensive but somewhat blunt instrument for diagnosing osteoarthritis, where it often takes 10-15 years between the first symptoms and visible X-ray findings. The relatively high proportion of patients in the BOA-register reporting X-ray findings as seen in osteoarthritis brings to mind that many patients may have had to await X-ray verification of the diagnosis before treatment initiation.

- Every third man and fifth woman wants surgery.

- Men, to a greater extent than women, fear their joints will be injured by physical activity. Only 15% of those physically active patients are active on a level considered sufficient to maintain health.

- Roughly 40% of the patients state that they hadn't received an explanation for their disorders or that they have degenerative joint disease. The impression that a joint is worn out most likely leads to a fear of greater injury due to physical activity thus increasing the risk for inactivity, and thereby increasing the risk for poor health and premature death.

- A third of the patients have other disorders, besides hip and knee, influencing their walking capacity. Even if measures are taken to reduce disability and symptoms as a consequence of osteoarthritis, there are other problems obstructing an increased activity level.

- Patients with the most complaints from the knee joints gain greater lasting effects on their pain from the osteoarthritis school than patients with mainly hip complaints.

- Health-related quality of life measured by the EQ5D improved by 0.07 for both hip and knee. After 12 months the difference is 0.04 compared to the first visit.

- After three months 63% state that they make use of that which they have learned in osteoarthritis school every day or several times a day and 92% say they make use of it at least every week. After 12 months 32% have daily use of their knowledge from the osteoarthritis school and 63% use it each week.

Osteoarthritis diagnostics

The osteoarthritis diagnosis has been traditionally made with the help of X-rays. The association between symptoms and X-ray findings in osteoarthritis is weak, often taking many years from the first symptoms to the appearance of visible X-ray changes. Approximately half of those with pain have no radiological signs of osteoarthritis and half showing X-ray findings have no pain. There is, as yet, no cure for osteoarthritis so that treatment aims are to relieve symptoms and prevent disability, improve function, and increase quality of life. For best treatment results it is important to initiate measures as early in the course of the disease as possible.

Clinical diagnosis

The preliminary version of the Swedish National Board of Health and Welfare's national guidelines for musculoskeletal disorders has established that osteoarthritis is to be diagnosed with the help of the history and clinical examination. X-rays should only be used in those cases where there is uncertainty concerning the diagnosis or where a specialist referral is considered. Osteoarthritis generally develops slowly and the time between the first symptoms and visible radiological changes is often more than 10 years. The debut of osteoarthritis is often gradual with increasing stiffness and pain on loading as the first symptoms, especially in the hip. But symptom debuts from both the hip and knee can occur suddenly and, at times, as the result of seemingly insignificant trauma that would not normally cause symptoms. Symptoms often fluctuate so that worse periods are followed by better periods. The length of these periods of worsening and improvement can vary from days to months. Some become worse relatively fast while in others the condition progresses extremely slowly, stands still or disappears. An individual prognosis is not possible to predict at present. The slow course and symptom variation over time make the correlation between symptom and structural changes as seen on X-rays weak. To avoid treatment delay and optimise treatment effect, it is essential to introduce measures to the large population with osteoarthritis as early as possible in the course of the illness.

X-ray

The medical profession traditionally seeks objective and quantifiable methods of measurement. X-ray examination, doubtlessly our oldest means of revealing the skeleton, has become a frequently used diagnostic method for joint problems. Cartilage cannot be seen in X-rays, but what *is* visible is a lessening of the joint space with a reduced distance between joint surfaces. Other typical osteoarthritic changes are osteophytes, which are bony projections around the edges of the joint surfaces and thickened bone under the cartilage, so-called bone sclerosis. A plain X-ray examination reveals only relatively advanced joint changes when the disease has progressed for many years and the cartilage already pretty much gone. Many, however, have joint problems without X-rays being able to show any changes. For the patient with reduced function, with or without radiological visible joint changes, leading to a health care consultation, it is symptoms and not X-ray findings that determine the choice of treatment. X-ray examinations are invaluable in the planning of joint prosthetic surgery but not for the initiation of the treatments recommended by the Swedish National Board of Health and Welfare as a first measure, that is, information and training.

MRI

Examination by magnetic resonance imaging (MRI) is an excellent method of demonstrating changes in the tissues of the joint. The disadvantage of MRI is that some discovered changes are incorrectly assumed related to current problems, with the consequent risk of unnecessary and misdirected treatment. Medial knee pain as experienced in medial knee osteoarthritis can, for example, be easily mistaken for a medial meniscus injury. The meniscus is not visible on plain X-rays. When an injury is suspected an MRI is performed which almost always reveals signal changes in the menisci in those over 35-40 years of age. A study from 2008 (1) showed that many findings are just as extensive in the menisci of symptom-free individuals as in those with symptoms. That a finding is technically possible to influence surgically does not, in other words, imply that it necessarily produces symptoms or even requires measures. The presence of meniscal findings increases with age, and is a routine finding in patients with radiological demonstrable osteoarthritis. The risk that an MRI finding of meniscal anomalies will lead to arthroscopy is imminent, with the consequence that a correct diagnosis is drawn out thus delaying the start of evidenced-based treatments such as are mentioned below. There is reason to suspect that MRIs of the knee for this group of patients are performed much too often, something that has been noted in the listing of National Medical Indications (SALAR).

Arthroscopy

Arthroscopy is performed considerably more often on the knee than the hip joint. Arthroscopy was initially used in the knee mainly to assess the condition of the joint. There is now a broad consensus for the use of arthroscopy chiefly for surgery rather than diagnostics. Arthroscopy in osteoarthritis or meniscus injury has been researched in several well-designed studies where arthroscopy was compared to a placebo as well as training of the thigh muscles (2,3). Results showed that arthroscopy has a placebo effect, but it is doubtful whether it contributes anything to the good results of training. Experience also shows that many patients having undergone arthroscopy have infrequently gained adequate symptom relief of a rinsing and cleansing of the joint via arthroscopy. It is important to recall that these results are on a group level. There is an ongoing debate within the profession concerning which patients with meniscal lesions can be helped via arthroscopy treatment but also a lack of studies to answer this question. Physical activity and training are completely harmless and are prescribed as treatment for osteoarthritis in the preliminary version of the Swedish National Board of Health and Welfare's national guidelines for musculoskeletal disorders. This treatment should be tested by a majority of these patients for about 2-3 months. Thereafter, the possible need for arthroscopy can be assessed. An exception is the occurrence of locking of the knee joint, extension defect, or following trauma with knee pain and hemarthrosis. Arthroscopy as an overexploited measure has been brought out in Open Comparisons 2009 (Swedish Association of Local Authorities and Regions, SALAR, Swedish National Board of Health and Welfare, The Swedish National Institute of Public Health). Of the 12 000 arthroscopies carried out on patients over 40 with osteoarthritis or meniscus injury it has been estimated that 10 000 were carried out with doubtful indications. Approximately 6000 of these had a diagnosis of osteoarthritis. In the national guidelines for musculoskeletal disorders arthroscopy is on the "not-to-do list" for osteoarthritis.

1. *Englund M, Guermazi A, Gale D, Hunter DJ, Aliabadi P, Clancy M, et al. Incidental meniscal findings on knee MRI in middle-aged and elderly persons. N Engl J Med. 2008 Sep 11;359(11):1108-15.*

2. *Moseley JB, O'Malley K, Petersen NJ, Menke TJ, Brody BA, Kuykendall DH, et al. A controlled trial of arthroscopic surgery for osteoarthritis of the knee. N Engl J Med. 2002*

Jul 11; 347(2):81-88.

3. *Herrlin S, Hallander M, Wange P, Weidenhielm L, Werner S. Arthroscopic or conservative treatment of degenerative medial meniscal tears: a prospective randomised trial. Knee Surg Sports Traumatol Arthrosc. 2007 Apr; 15(4):393-401.*

The Swedish National Board of Health and Welfare guidelines

The preliminary version of the Swedish National Board of Health and Welfare's guidelines for musculoskeletal disorders was released in November 2010. The guidelines are intended to contribute to just and equal health care throughout Sweden.

New guidelines for musculoskeletal disorders

The final version of the Swedish National Board of Health and Welfare's national guidelines for musculoskeletal disorders is scheduled to arrive in the spring of 2012. The Swedish National Board of Health and Welfare's national guidelines are to aid in establishing priorities and provide guidance as to which treatments and methods the diverse health care and social welfare operations should invest their resources. The guidelines contain recommendations for the diagnostics, treatment, and rehabilitation of musculoskeletal disorders. They illuminate areas where the need for guidance is great due to differences in practice, controversies, and the need for quality development. The goal is to contribute to the effective use of health care resources, distributing them according to need, steered by systematic and open guidelines. The aim is to promote good patient care. The recommendations provide guidance for decisions at a group level. The recommendations also indirectly guide and support decisions affecting individual people, although there can arise, of course, situations motivating personnel to sidestep the recommendations. The Swedish National Board of Health and Welfare's recommendations are the result of collective assessment of:

- condition severity
- a measure's benefit to the condition (effect)
- evidence for the effect (how strong is the scientific evidence)
- a measure's cost effectiveness (compared to other measures or no measures whatsoever)

Guidelines for osteoarthritis

The guidelines state that health care providers should make a diagnosis with the aid of a collective assessment from the medical history, three typical symptoms and three typical clinical findings. Common symptoms of osteoarthritis are pain, stiffness following inactivity, and reduced physical function. An example of common findings upon examination are crepitation (a crunching sound that can be heard in a joint with osteoarthritis), reduced range of motion and joint swelling. Examination of the hip can show the clinical signs of reduced flexion and internal rotation as well as pain with internal rotation. X-rays are necessary when there is no response to treatment (for example, training under the guidance of a physical therapist, or painkilling medication) within the expected time or when caregivers need to exclude other serious illnesses as the source of pain and reduced function. The Swedish National Board of Health and Welfare recommends health caregivers not to treat with glucosamine or hyaluronan for osteoarthritis of the knee or hip joint. These substances have no effect on pain or joint function. The Swedish National Board of Health and Welfare also consider that health care providers should not perform arthroscopic surgery in the form of

joint cleaning or meniscus resection for osteoarthritis of the knee joint. Arthroscopy as treatment of osteoarthritis has no better effect on pain and function than training and painkilling medication. It is recommended that health care providers should provide recurrent, monitored training for en extended period of time (1).

BOA and the guidelines

Care of patients with osteoarthritis according to the BOA concept follows the Swedish National Board of Health and Welfare's guidelines. Patients under BOA need no X-ray-confirmed diagnosis but are to be assessed according to symptoms, clinical findings and medical history. In BOA patients are offered individually adjusted and monitored training for 6 weeks. During this time home exercise and other alternatives to maintain continuity of training for an extended time is introduced. The significance of being physically active for longer periods of time is emphasized throughout patient education.

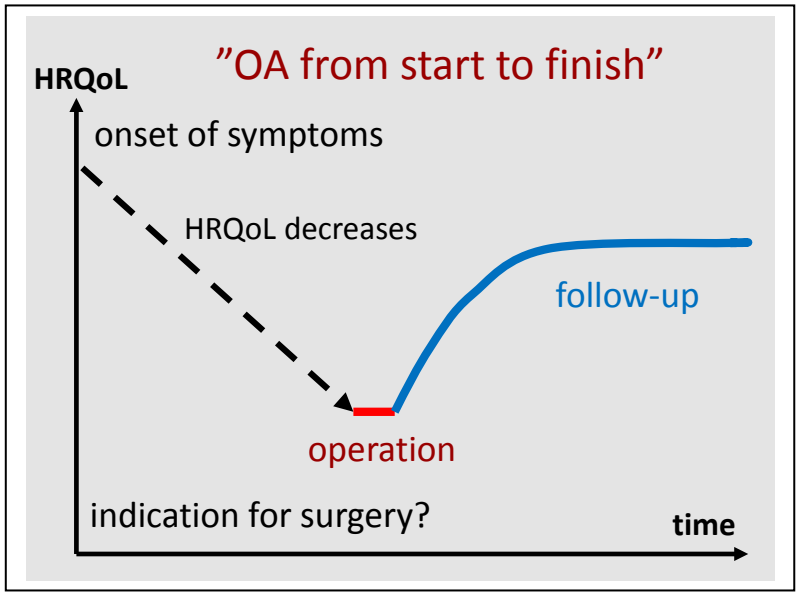
1. *Nationella riktlinjer för rörelseorganens sjukdomar 2010 – stöd för styrning och ledning – Preliminär version.*
   http://www.socialstyrelsen.se/publikationer2010/2010-11-15

Osteoarthritis – goal and vision

Have we any benefit of a physical therapist-based National Quality Register?

Osteoarthritis is one of our most widespread illnesses. The World Health Organization (WHO) has estimated that every second woman and every fourth man over the age of 60 suffer some form of osteoarthritis. Osteoarthritis of the knee and hip is the greatest cause of patients seeking health care services. We have in Sweden, since the 1970s, a unique means of monitoring outcomes for those patients who, in the final stages of knee and hip osteoarthritis, have been subjected to knee and hip prosthetic surgery. This individual-based monitoring is by means of Sweden's oldest National Quality Registers: The Swedish Knee Arthroplasty Register and the Swedish Hip Arthroplasty Register. We know, with great exactitude, how these patients fare after the decision to operate. On the other hand, we have little knowledge of the course of the illness from the first time patients show symptoms from their arthritic joints to surgery. (figure 1) .

Figure 1. The course of osteoarthritis



There is a great need for mapping the osteoarthritis patient's journey through the health care system. Osteoarthritis in one of the larger joints costs the Swedish insurance system as much as 1 billion SEK yearly. The dashed line in the above diagram comprises the time line for the development of osteoarthritis, poorly mapped at the present time. One of the most important goals for the future BOA is to contribute knowledge of how patients are cared for prior to eventual surgery by interconnecting a nationwide BOA-register and the established National Implant Register to achieve a comprehensive system for operative analyses, improvement, and clinical research concerning OA of the larger joints. If interconnecting also includes Statistics Sweden (a government agency producing statistics), The National Board of Health and Welfare's public health data registers (for example: the National Patient Register, The National Pharmaceutical Register, etc.), The Swedish Social Insurance Agency, and the Cost

per Patient database, we can then gain access to universally unique and individual-based databases with the potential to completely map this large patient group's care within the Swedish health care system. Such an analysis can then encompass process and outcome measurements as well as predictors for both good and bad outcomes after BOA's intervention. A number of outcome variables are obtained by means of the registers' results, both objective and patient-reported (PROM). By means of the official statistical databases socioeconomical variables and levels of comorbidity can be included in the analysis that can also be utilised for health economic studies. We can, for the first time, follow a standardised physiotherapeutic intervention via a national, prospective, observational study. Both the BOA's database and future interconnecting databases will open a new research field with the potential of a considerable number of masters and doctoral projects.

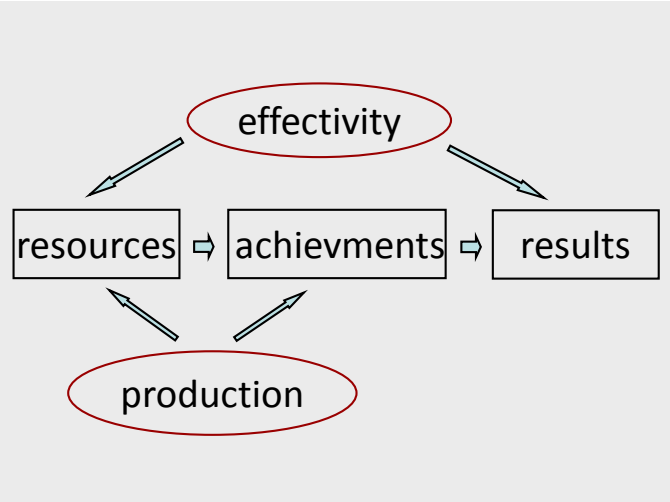
The Swedish system of National Quality Registries

Sweden's first national quality register the Swedish Knee Arthroplasty Register, was started in 1975 by the orthopaedic clinic of Lund, Sweden. A few years later, in 1979, the Swedish Hip Arthroplasty Register in Gothenburg, Sweden was started.

The technique for replacing osteoarthritic joints with prostheses was relatively new in Sweden at the start of the 1970s, and complications were initially frequent. By means of creating national registers where all operations were registered, extensive data with strong statistical power was gathered for poorly functioning prostheses and techniques. Discussions were held and conclusions drawn throughout the country's orthopaedic clinics and the registers have, with great probability, contributed to Sweden's place in the international forefront of prosthetic surgery.
During the following years, still more national quality registers gradually appeared. Representatives for that time's Swedish Association of Local Authorities and Regions (SALAR) and The National Board of Health and Welfare (Socialstyrelsen) formed in 1993, along with two registries and The Swedish Society of Medicine, that which was later named The Decision Group for National Quality Registers. The group discussed how more registers were to be created and financed, and the principles for today's decentralised register system were formed. Since 2007 SALAR manages all central administration of the quality registers. The decision group now has representatives for SALAR, The National Board of Health and Welfare, The Swedish Society of Medicine, The Swedish Society of Nursing, and three county councils via three county council directors.

An expert group, with knowledge of health care, epidemiology and statistics, register management, and clinical quality improvement work, goes through applications from the National Quality Registers yearly.

The county councils, regions, and local authorities have traditionally followed up its activities using productivity and cost outcomes, but there has been no previous systematic association to the actual outcome and utility of its activities. The National Quality Registers have been developed to fill this gap. Sweden is the country that has come the farthest in developing quality registers. 89 National Quality registers cover over 30% of health care's total costs and approximately 45% of somatic inpatient health care.



Sweden, despite being a small country, has maintained from an international perspective very high quality in both health care and medical research. An effective system of following up the results of health care and clinical research of the highest international standard is a necessity for maintaining the quality of Swedish health care and Sweden's competitiveness. Health care should focus more on its value to patients.

The quality registers are and can be an even more effective tool for health care personnel. When it is possible to make international comparisons those areas of operations in Sweden that have made extensive long term use of quality registers have practically without exception shown greater survival, better treatment results and less complications than other countries.

The last years, via diverse government investigations and a report from the Boston Consulting Group, have brought a powerfully increased focus on the National Quality Registers and their potential for operative analyses, clinical auditing, and clinical research. The interest of politicians and other decision makers on different levels such as from the universities has increased dramatically.

The investigation of clinical research and the delegation of cooperation within clinical research has shown that we have lost some ground to other countries in regard to clinical research and that we have, at the same time, realised the importance of a strong investment in registers. There has also been agreement that, in effect, there is only one area where Swedish health care and medical research have unique competitive advantages over the rest of the world. Personal identification numbers, all-encompassing population and health care data registers and the National Quality Register of high quality provide us with the conditions to follow up patients and thereby develop health care and carry out research that most countries outside Scandinavia lack.

General comments on register studies in clinical research

Observational clinical studies have long been considered having a low evidence level compared to randomised trials (RCTs). Within surgical disciplines it is however very difficult, and in many instances impossible, to carry out an RCT of "statistical power". Since randomisation seldom involves the surgeon/physical therapist it is impossible to avoid "performance bias", and the innovator and/or "centre of excellence" publish a large proportion of the articles within the area.

Register studies have some apparent advantages compared with an RCT; statistical power to analyse unusual occurrences and complications, description of subgroup results, finding predictors for outcomes and avoidance of ”performance bias” according to the above. Register studies can report generalizable results shedding light on the entire orthopaedic/physical therapy world (”the real world”) – clinical research results from registers can then go hand in hand with local quality improvement work in all clinics, not only specialty clinics.

It is now gratifying that Cochrane (musculoskeletal group) is considering including register results in its overviews, which will then raise the evidence value of this type of study. The same discussion is ongoing at several institutions of learning in Sweden.

BOA

BOA stands for Better management of patients with OsteoArthrtis. The BOA-register can be said to be a combination of diagnosis and intervention register for patients with hip and knee problems.

Aim and goals of BOA

The aim of BOA is to present all patients with osteoarthritis adequate information and training according to current treatment guidelines, and that surgical measures are to be considered only in those cases where non-invasive treatment has been unsatisfactory. The goal is to improve quality of life and increase activity levels in patients with osteoarthritis, chiefly of the hip and knee, and to reduce consumption of health care and sick leave due to osteoarthritis. Patients with osteoarthritis shall have equivalent care at their first contact with the health care system regardless of where this takes place. Previous research has shown that information and individually adjusted training has as good an effect on pain as medication. We have utilised this knowledge by offering an evidence-based osteoarthritis school to patients. Osteoarthritis is one of the most common causes of inactivity among the elderly and many fear that activity will damage the joints. Inactivity is a large risk factor for poor physical and psychological health as well as premature death (1). The aim of osteoarthritis school is to raise the level of physical activity and patient knowledge of how they themselves can manage their disease to avoid illness and live a good life despite osteoarthritis. Further, BOA aims for physiotherapists to raise their quality level of treatment by means of systematic assessment, open comparison, and feedback from results.

Here's how it all began

BOA was initiated 2008 as a 3-year collaboration between the Regions of Västra Götaland and Skåne, and Värmland's and Västerbotten's county councils. The background was the high costs of sick leave due to osteoarthritis and the knowledge that only a fraction of all patients operated on due to osteoarthritis had met a physiotherapist at some point prior to surgery. This despite the fact that information, training and weight control form the basis of osteoarthritis treatment according to both national and international treatment guidelines. The project was financed by The Swedish Social Insurance Agency and government grants to the regional authorities. Ten health care units in these four regions (Mölndal, Kungälv, Munkedal, Trollhättan, Vänersborg, Malmö, Trelleborg, Lund, Karlstad, and Umeå) formed the pilot units of the register. Based on how health care was organized in each region/county council, out- and inpatient care units were included in the project. Physiotherapists and interested occupational therapists were trained in BOA to present and evaluate osteoarthritis schools in an equivalent manner. Two-day courses encompassed current evidence within the area aiming to provide a deeper knowledge of osteoarthritis and its non-invasive treatment. Training also included basic register skills because quality registers are a somewhat new and unknown area within physiotherapy. Whereby the osteoarthritis school aims to influence self-rated physical activity levels, fear of movement, motivation for surgery and faith in self-ability to influence symptoms, these were included as outcome measures in the BOA register, along with patient satisfaction and patient-reported variables as used in The Swedish Hip Arthroplasty Register for several years, such as pain and health-related quality of life (EQ5D). The physiotherapist presenting the osteoarthritis school to patients was also responsible for entering data to the register. During the consolidation phase the questionnaire and database of the ten pilot units were tested at the same time as physiotherapists at several units were trained in order to be

able to start osteoarthritis schools and join the register. The register was made available to more units in the beginning of 2010.

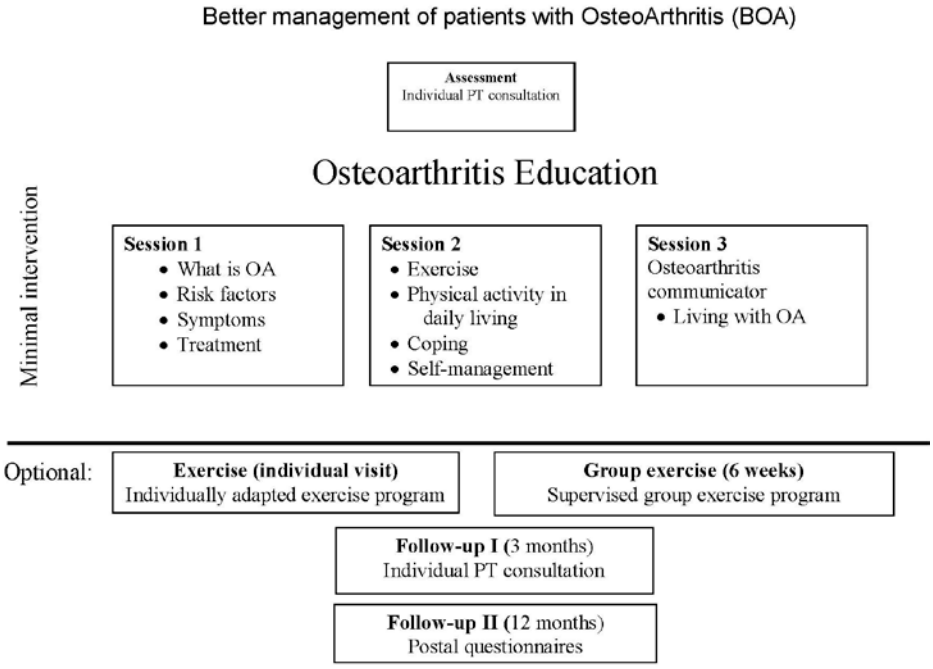
Osteoarthritis school

Osteoarthritis school is directed toward patients with problems from the hip or knee of such dignity that they must seek health care. X-rays or a previous diagnosis is not a prerequisite. All patients assessed as benefiting of osteoarthritis school meet the physiotherapist for an individual consultation prior to osteoarthritis school. The patient's medical history and the physiotherapist's examination provides the possibility of making a clinical diagnosis, or alternatively, to exclude other reasons for their difficulties. Even if it should later become apparent that their problems were not caused by osteoarthritis, treatment as offered in osteoarthritis school – information and training – is directed toward functional limitation with only negligible risks. Patients with inflammatory joint diseases, other diseases causing more dominant symptoms (for example malignity or widespread pain or a failed femoral neck fracture) are primarily in need of another care form and therefore excluded from osteoarthritis school and the register. Patients that do not understand Swedish should be provided with individual care, possibly with the aid of an interpreter, to ensure that information is used correctly. They need not answer the questionnaire registered in the BOA register.

Information

The osteoarthritis school arose from current research in the area as well as from patient's thoughts and wishes for treatment of osteoarthritis. The osteoarthritis school within BOA comprises a "minimal intervention" carried out in a similar way at all units (Figure1). The contents encompass information of what osteoarthritis is, risk factors, available treatments, and self-care tips. The school is led by a physiotherapist and, in some areas, an occupational therapist with special training and a thorough knowledge of osteoarthritis. Moreover, the osteoarthritis school includes a session led by an "osteoarthritis communicator", a patient with osteoarthritis that has completed a special training course to be able to speak of how it is to live with osteoarthritis and of their experience of basic treatment. The Swedish Rheumatism Association trains these expert patients. The aim of their participation is for participants of an osteoarthritis school to more easily identify with those providing advice and recommendations, and thus jointly find solutions to those difficulties encountered in everyday physical activities. In those places where the local rheumatism association has the resources and activities for patients with osteoarthritis, participants of the osteoarthritis school can deepen their knowledge of osteoarthritis through study circles or lectures through the local association and be offered further training through the auspices of the association. Participation of an osteoarthritis communicator in schools is cost-free for health care. The osteoarthritis communicator participates on an idealistic basis and the Swedish Rheumatism Association pays for travel expenses.

Figure 2. Layout for osteoarthritis school.



Individually customized training

After the theoretical part of the osteoarthritis school patients are offered an individually tested training program as well as the opportunity to train with this program along with others under the guidance of a physiotherapist. Training is voluntary but the goal is for as many as possible to feel the desire and need to learn more of how to best deal with their illness and the difficulties it entails, through correct training and physical activity in their daily lives. Discussions concerning suitable home exercise and planning for continued physical activity/training after osteoarthritis school comprises an important part of the arrangement. Osteoarthritis cannot yet be cured and in order to gain a long lasting effect of training as demanded by the treatment it is also important to plan training far in advance and carry it out continuously. Prolonged illness demands prolonged treatment.

Today's BOA register

The interest for BOA and osteoarthritis schools is considerable among both patients and care providers. Up until the end of 2010 approximately 650 physiotherapists have been trained according to the BOA concept, and another 29 units have joined the 10 pilot units. Data from more than 3 500 patients has been fed into the register, whereof about two-thirds have been followed up after 3 months and one-third after 12 months. All the more units are continuously joining the register. The osteoarthritis school has become a routine part of health care in many parts of the country and orthopaedic surgeons return referrals for patients that have not met a physiotherapist. In Västerbotten the osteoarthritis school has been assessed at the orthopaedic clinic and the results are presented in the next chapter: *BOA and continuous improvement of care.*

1. *Nuesch E, Dieppe P, Reichenbach S, Williams S, Iff S, and Juni P. All cause and disease specific mortality in patients with knee or hip osteoarthritis: population based cohort study. BMJ. 342: p. d1165.*

BOA and continuous improvement of care

The operational results of any osteoarthritis school can be monitored by means of the BOA register. Each unit can retrieve their own data in an Excel format in real time for analysis. The register also offers overview reports with the possibility, in real time, evaluating the results in comparison with the national average, as well as the percentage of questions that have not been answered. By means of continuously using their data each unit can monitor its own reports to the register, and in addition use the data to actively participate in discussions of the content of their own activities. The orthopaedic clinic in Umeå has done so.

The osteoarthritis school of the orthopaedic clinic in Umeå

Osteoarthritis schools according to the BOA concept of Västerbotten's County Council (VCC) started in the fall term of 2008 at the orthopaedic clinic at Norrland's University Hospital (NUH). The schools have been in full time operation by two physiotherapists, and a total of 44 schools have been held through the end of April 2011. As a consequence of the county council's decision to start the osteoarthritis schools within primary care in VCC with full entry into force from mid-year 2011, the osteoarthritis schools at NUH will be terminated in June 2011.

Approximately 900 referrals are sent to the orthopaedic clinic at NUH yearly with the diagnosis/assessment request of hip or knee osteoarthritis, in a proportional distribution of 60:40 between knee and hip osteoarthritis, respectively. Up until 2008 it was relatively unusual for patients in outpatient care with an osteoarthritis diagnosis to receive any systematic physiotherapy treatment, and those few that had contact with a physiotherapist (PT) usually had only been given sparse training instructions. Waiting time for a physician consultation at the time of the osteoarthritis schools' start was slightly more than 3 months. With the kick-off of the schools in the fall semester 2008 it was decided that patients, referred to the orthopaedic clinic at NUS with the diagnosis/assessment request of hip or knee osteoarthritis and living within the district of the Umeå health care district, would be randomly invited to the osteoarthritis school while awaiting a physician consultation. It was made clear to the participating patients that they had, following completion of the osteoarthritis school, the right to utilise their consultation according to the referral if they so desired. If, however, they felt that the result of the osteoarthritis school was satisfactory, the consultation was cancelled and the osteoarthritis school physiotherapist wrote a referral response. All patients were also guaranteed time for a physician consultation within 1 year after the osteoarthritis school, without a new referral if the initially good results were to later become worse. A total of 253 patients were enrolled in this way directly to the physiotherapist.
Another 115 patients completed the osteoarthritis school. These patients were sent to the osteoarthritis school after consulting an orthopaedic specialist at the orthopaedic clinic. These were patients where either the physician decided that there was no indication for surgery, or that the patient for some reason didn't feel an operation was indicated. Some patients in this group also wanted to test osteoarthritis school before making their final decision for surgery.

In the middle of February 2011 a total of 368 patients had been invited to begin the osteoarthritis school. Circa 10 per cent chose to leave osteoarthritis school early. The reasons could have been; lack of time, poor motivation, dissatisfaction with the results, or

transportation problems. Approximately 65 % had osteoarthritis of the knee and 35 % of the hip. Women comprised 61 %, and 64 % were above the age of 60.

Results

Results are shown in Table 1. Of all patients (368), 66 (18 %) have to date had surgery or are on a waiting list.
The majority of these were operated on within 1 year of attending osteoarthritis school. Thirty-seven (10 %) patients terminated osteoarthritis school prematurely, and several (< 1 %) were dissatisfied with the results but didn't feel they needed surgery (then). Remaining were 253 patients (69 %) that passed the 3-month follow-up without expressing the desire for a physician consultation. About half of them have still not undergone the 12-month follow-up, and it is probable that several more will request surgery. Of the patients coming directly from primary care, 22% have had surgery while 64 % can be characterised as "satisfied", that is to say, they see no reason as yet to consider surgery. The frequency of surgery and the proportion of those "satisfied" with osteoarthritis school differ between sexes. On the other hand, one can point out that in general more patients with knee osteoarthritis seem to have benefited from osteoarthritis school as did those patients under 60.

Conclusions

Approximately 2/3 of the patients referred from primary care to NUH with the diagnosis hip or knee osteoarthritis considered themselves, after completing osteoarthritis school, to be so improved that they had no desire to consult an orthopaedic surgeon to discuss surgery. The majority of patients that did not improve sufficiently with osteoarthritis school were operated on within a year. Osteoarthritis school appeared to provide better results for arthritis of the knee than the hip, and it appeared that younger patients responded better than those over 60. The results show that many patients in primary care with osteoarthritis can be adequately treated so that the time for referral to surgery can be moved ahead. The good results from osteoarthritis school at the orthopaedic clinic in Umeå have led VCC to decide to introduce osteoarthritis school to primary care. We are now discussing the possibility of introducing the demand to complete osteoarthritis school as a prerequisite to referral to the orthopaedic clinic.

	Withdrawn	**Dissatisfied but not operated**	**Operated**	**"Satisfied"**
The entire sample (n=368)	10 %	3,6 %	17,9 %	68,5 %
Referral from primary care (n=253)	9,9 %	4,7 %	21,8 %	63,6 %
From the orthopaedic surgeon (n=115)	10,4 %	0 %	8,7 %	80,9 %
Knee osteoarthritis (n=245)	10,6 %	3,3 %	10,2 %	75,9 %
Hip osteoarthritis (n=123)	8,9 %	4,1 %	32,5 %	54,5 %
Women (n=223)	9,0 %	1,8 %	18,8 %	70,4 %
Men (n=145)	11,7 %	5,5 %	16,6 %	66,2 %
≤ 60 years (n=135)	8,9 %	2,9 %	10,4 %	77,8 %
> 60 years (n= 233)	10,7 %	3,5 %	21,9 %	63,9 %

Tabel 1. Summary of the results of osteoarthritis school in Umeå.

Participation and reporting

To determine whether results from the register are representative and generalizable it is important that the register encompass the intended population. Decisive, as well, is the quality of the data, that is, how exact and accurately data is entered to the register. The Bosteoarthritis register is primarily an intervention register, where our intention is to register all patients with osteoarthritis of the hip and knee offered participation in osteoarthritis school. Our goal is, however, that *all* those with osteoarthritis of the hip or knee will be offered osteoarthritis school as early as possible in the course of the disease. We are thereby attempting to present a diagnosis register that strives to register all persons with the diagnosis of hip and knee osteoarthritis.

Prevalence of osteoarthritis in the population

Osteoarthritis is very common, more common than diabetes and high blood pressure. It is difficult to estimate how large a proportion of the population has osteoarthritis. The numbers vary depending on whether one means that someone with osteoarthritis must show radiological osteoarthritis, symptomatic osteoarthritis, or a combination thereof. In the first place, to make the diagnosis the patient must seek health care, which is not always so in osteoarthritis. Many still believe, incorrectly, that osteoarthritis means worn out joints, that it is a factor of age, that nothing can be done and thus do not seek health care. The prevalence of osteoarthritis increases with age, but this does not mean that osteoarthritis is an illness of aging. Not all elderly people have osteoarthritis and osteoarthritis appears in people as early as in their thirties. Since osteoarthritis still cannot be cured the number of people with the diagnosis accumulates in older age groups. It is estimated that roughly 5% of the population between 35 and 55 have radiological osteoarthritis. Many of these have no symptoms and thus need no treatment, other than preventive. Swedish studies show that approximately 15%, or every sixth adult under 60, has osteoarthritis-like knee problems and these problems in most cases lead to radiological findings in time. Osteoarthritis of the knee is more common than osteoarthritis of the hip, but not as common as osteoarthritis of the small joints of the spine and finger joints. The most common location for osteoarthritis of the hand is the proximal joint of the thumb and the distal joints of the fingers. Above the age of 65 it is more common to have osteoarthritis in a finger joint than not. It is also very common to have osteoarthritis in finger joints along with some other joint. Roughly 40% of the population over 55 and more than half of all over 70 are estimated to have osteoarthritis in some joint. An English study by Peat et al estimate that 25% of all those over 55 have constant knee problems for one year and that 10% have considerable problems due to osteoarthritis of the knee (1). According to Statistics Sweden there were 2.9 million people over 55 in Sweden by December 31, 2010.This means that approximately 1.2 million people over 55 have osteoarthritis in some joint. Half a million of these are of working age. In Region Västra Götaland 58 115 unique individuals of all ages visited primary care with the diagnosis of osteoarthritis of the hip or knee as a first diagnosis during the period of 2006-2010. This represents 8% of the population aged 45 or older. The number of individuals visiting inpatient care during the same period was 14 703. In Region Skåne corresponding estimates show that 10% of all those over 18, and 27% of those over 65 with the diagnosis of osteoarthritis in some extremity joint seek a physician. (A Turkiewicz, IF Petersson, M Englund. Consultation prevalence of osteoarthritis in upper and lower limbs in southern Sweden. Abstract OARSI 2011).

Geographical coverage and need for osteoarthritis schools

Up until the end of 2010, 11 of 21 county councils/regions had osteoarthritis schools reporting to the register. Geographical coverage can be seen in Figure 3. The population of the different counties vary and, consequently, the actual need for osteoarthritis schools. It is difficult to estimate how many osteoarthritis schools are needed to meet the demand. At present there is a large number of patients that have not received adequate information and care despite having difficulties and a diagnosis for many years. In the long run supply and demand can even out. Based on the figures from the Västra Götaland region, that 8% of the population 45 or older have the diagnosis of osteoarthritis of the hip or knee as a first diagnosis and seek health care some time in a 5-year period, we have estimated the yearly need. If we assume that visits are spread evenly over the five years, the yearly patient base for osteoarthritis schools in primary care is 1 600/100 000 inhabitants over 45. An osteoarthritis school has an average of 7-10 participants and a middle-sized primary care unit holds 6-8 osteoarthritis schools yearly. To meet the yearly need in a region equivalent to Region Västra Götaland would, according to these calculations, require 20 care units, or 160 completed osteoarthritis schools /100 000 inhabitant 45 or older. For a current picture of the availability in the 11 counties see Table 2. (There are osteoarthritis schools not reporting to the register. These have not been included). One goal is that all those operated on with hip or knee replacement due to osteoarthritis shall have completed osteoarthritis school at some time prior to surgery. During 2010 approximately 16 000 hip replacements and approximately 14 000 knee replacements were performed, the majority performed on patients with osteoarthritis. In a future merging of the BOA-register, The Swedish Knee Arthroplasty Register, and the Swedish Hip Arthroplasty Register we can determine the proportion of patients having received adequate information and individualised training prior to surgery, as well as the factors affecting the health care process. The study by Peat et al (1) estimates that roughly 10% of all those with osteoarthritis of the knee are so troubled by their joint that they could be considered candidates for surgery. This means that the 14 000 operated on in Sweden are only a small fraction of all patients with osteoarthritis of the knee that, in one year, are in need of health care.

Figure 3. Map of county councils with units operating osteoarthritis schools connected to the BOA register by the end of 2010

□ = Having at least one unit reporting to the BOA register

□ = No units reporting to the BOA register

County council	Number of reporting units per county council	Number of osteoarthritis school units per 100 000 inhabitants 45 years or older	Number of inhabitants older than 45 years
Stockholm	2	0,25	809 535
Östergötland	1	0,53	189 919
Kalmar	4	3,30	116 313
Gotland	1	3,30	28 556
Blekinge	1	1,40	73 266
Region Skåne	13	2,40	537 587
Västra Götaland	11	1,60	686 687
Värmland	1	0,80	133 481
Gävleborg	1	0,70	135 630
Västerbotten	4	3,30	115 549
Norrbotten	2	1,70	122 358

Table 2. Coverage based on inhabitants 45 years and older and number of units that have joined the BOA register per participating county council. 20 units per 100 000 inhabitants over 45 years of age would be needed to meet the estimated yearly need.

The register's data quality

Another means of measuring coverage is to estimate the proportion of missing values, that is to say how many questions have been left unanswered or not entered to the register. In general the proportion of unanswered questions per questionnaire is very low for the BOA register. The question in the patient questionnaire most often left unanswered lacks values in 2% of all forms. The questions patients tend to skip are ”Indicate your weight”, ”Do you have so much difficulty that you wish to undergo surgery?” and ”Have you been on sick leave during the last year due to your hip or knee problems?”. It is possible they did not wish to say what they weighed, but another probable reason is that they had not been weighed for a long time and simply didn't know their weight. One solution could be to have a scale in the waiting room or in the room where patients sit and fill in their questionnaires. Physiotherapists running osteoarthritis schools at an orthopaedic clinic have reported that patients are sometimes uneasy about the consequences of answering “no” to the question of whether they have so much difficulty that they want surgery. They fear the orthopaedic surgeon will see their responses and thus lose the option of future surgery. Distinct information that the physician will not see their responses and that their responses will in no way influence the care they require now or in the future is essential. We can only speculate as to why the question concerning sick leave has not been filled in. It can be difficult to recall one year back. It can also be difficult to remember if it was the hip, knee joint or some other reason for the latest sick leave.

1. Peat, G., R. McCarney, and P. Croft, *Knee pain and osteoarthritis in older adults: a review of community burden and current use of primary health care.* Ann Rheum Dis, 2001. 60(2): p. 91-7.

Results 2008-2010

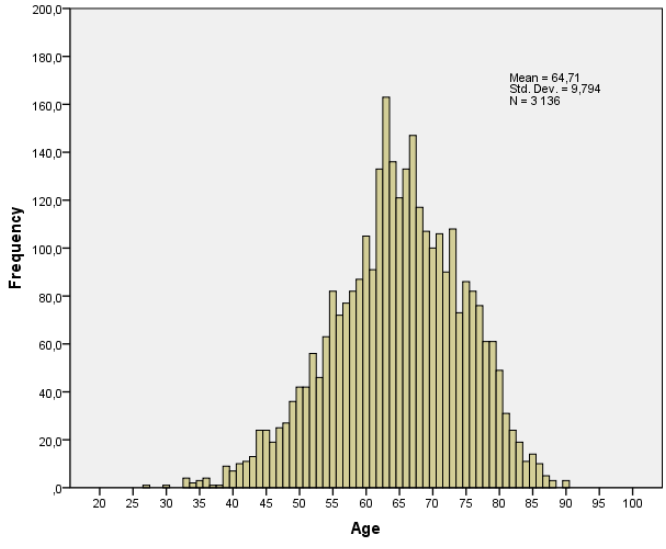
This chapter presents results based on data from the first entries of the pilot units from 2008 until December 31, 2010. ”The nation” in the annual report indicates the means of all registered patients.

Number of patients and clinical characteristics

A total of 3 766 patients have been reported to the register; 32% were assessed by the physiotherapist as having most problems from the hip and 68% from the knee. We will continually refer to them as osteoarthritis of the hip and knee. Many patients have problems with both the hip and knee. We, in this report, do not distinguish patients with problems from several joints from those with isolated joint problems. In 73 cases the patient indicated a joint other than that which came forth at the physiotherapists examination and assessment.

Osteoarthritis is relatively unusual before the age of 30, but by no means an illness affecting only the elderly. People that develop hip osteoarthritis as a consequence of congenital deformity and early hip disease can have had symptoms from their joint for more or less their entire lives, but problems worsen in their 30s. About half of all those suffering anterior cruciate ligament or meniscus injuries when young develop knee osteoarthritis after 10-15 years. The first symptoms of osteoarthritis without previous injury or disease can often be noticed at about 40 years of age, but it is common that both the sufferer and health care providers seek explanations other than osteoarthritis. Research has, however, shown that constant knee pain with no other explanation is in most cases the first sign of knee osteoarthritis. Symptoms can come and go and give seldom rise to a medical consultation until after a number of years when symptoms have lead to functional problems in daily life. Since osteoarthritis is incurable the prevalence increases with age. The mean age in the BOA register was 64.7 years. Age distribution for the entire register can be seen in Figure 4. The mean age for men was 64.8 (SD 10.1) and 64.7 (SD 9.7) for women. Seventy % of patients in the register were women.

Figure 4. Age distribution in the BOA register.



BMI

Overweight is a known risk factor for the development of osteoarthritis, mainly of the knee joints, but even for the finger joints. However, the evidence of a correlation between overweight and hip osteoarthritis is not as clear. A usual means of estimating overweight is to calculate body mass index (BMI). BMI is calculated by dividing body weight in kilograms with the square of body height, expressed in meters. The cut-off for normal weight is, according to the World Health organisation WHO, 25 kg/m^2; overweight entails a BMI between 25.0 and 29.99; and people with a BMI of 30 or more are classified as obese. BMI is a rough measure and can, for very muscular individuals, give a misleading result. In the BOA register we study the means for groups of individuals. In this way isolated values have less importance. In order to obtain reliable values length and weight should be measured with a ruler and scale. In the BOA register BMI is, in most cases, based on patients' self-reported data and should therefore be interpreted with some caution. Patients with knee osteoarthritis had a BMI of 28.6 kg/m^2 as compared to 26.8 kg/m^2 for those with hip osteoarthritis.

Previous measures

Health care providers have informed many osteoarthritis patients that nothing can be done and have therefore consequently received no treatment whatsoever other than pain relief and medication. Many have tried different medicines with varying results and only a few have been referred to a physiotherapist or other adequate non-surgical or non-pharmacological treatment. A contributing reason for this erroneous point of view among both patients and health care personnel is most likely the myths about osteoarthritis that live on, such as ”natural aging” and ”wear and tear”. The latest decades' research now enables us to know better. There is much to be done mostly by patients themselves, with the help and support of correct advice and guidance.

Adequate non-surgical treatment

According to both national and international guidelines all patients with hip and knee osteoarthritis are to be provided information, individually adjusted training, and advice on weight reduction, if necessary. This also makes up the scientific evidence that forms the basis for The National Board of Health and Welfare's guidelines. In the BOA register approximately 10% of patients with knee osteoarthritis and 6% of the patients with hip osteoarthritis state they have been offered these treatments.

How osteoarthritis has been described to patients

The earlier term for osteoarthritis ”wear and tear” was an unfortunate choice since it led to thoughts of “worn out” joints that shouldn't be “worn out” even more through further activity. In actuality, research shows that inactivity is a greater risk factor for ill health associated with osteoarthritis and that cartilage fares better through dynamic loading, such as in walking, cycling, and exercise activities in general (1). It is important that the term osteoarthritis becomes accepted rather than the concept of “worn out” joints. It is also important for sufferers to know what osteoarthritis is and that there is a great deal they themselves can do to influence symptoms and function.

In the BOA register we have seen that roughly a fifth of the patients learned that they have suffered from “wear and tear”. Many have also gotten to know they have osteoarthritis, but do not know what it is or what can be done about it.

1. Van Ginckel, A., et al., *Functional adaptation of knee cartilage in asymptomatic female novice runners compared to sedentary controls. A longitudinal analysis using*

delayed Gadolinium Enhanced Magnetic Resonance Imaging of Cartilage (dGEMRIC). Osteoarthritis and Cartilage. 18(12): p. 1564-9.)

Participation in osteoarthritis school

Minimum intervention in osteoarthritis school (see Figure 1) consists of information about osteoarthritis and available treatments. Information is provided by physiotherapists, and in some cases occupational therapists, that have received training in osteoarthritis and osteoarthritis schooling. Information about lifestyle changes, such as weight control or starting exercise, can be experienced as insurmountable and difficult to adapt to for someone with joint pain and difficulties in moving painlessly. The same message from someone in a similar situation, someone patients can identify with, can be experienced as easier to accept. In the osteoarthritis schools we cooperated with osteoarthritis communicators, that is, patients with osteoarthritis who have themselves tried following recommendations and experienced the difference a change in life style and activity level can make. The osteoarthritis communicator is trained by the Swedish Rheumatism Association in how to share, in a pedagogical way, his/her experiences of non-surgical treatment and how one can live a good life despite osteoarthritis.

Those that accept participation in osteoarthritis school are offered, in most cases, an individually adjusted and tested training program, as well as the possibility to carry out this program under the supervision of a physiotherapist for six weeks. Group training is carried out along with others with osteoarthritis having an individual program. All parts of the osteoarthritis school are voluntary for the patients. By actively deciding on a training program and participation in group training he/she has also taken the step from being a passive recipient to being an active and motivated participant.

Practice

All units offering osteoarthritis school in some form and reporting to BOA meet the criteria for minimal intervention, and in those cases where training is offered it is to be carried out according to the principals as applied in BOA. Additionally, there are possibilities for each clinic to adjust content and extent to local resources.

Training of muscle function is not based on a certain number of specific exercises, sets or repetitions, but on neuromuscular control and movement quality. Pain during training is no obstacle but should not exceed the limit for what is experienced as acceptable pain by the patient. An eventual increase in pain after training should also be gone after 24 hours; otherwise the duration or intensity should be adjusted. Interviews with patients have shown that feedback is experienced as a particularly important element of the training. The physiotherapist is present and available for continuous feedback of both movement quality and performance and choice of exercise and dosage at every training session. Parallel to supervised training is also a discussion of the arrangement of home exercise and continued activity after the osteoarthritis school's termination in order to stimulate continuity and health-giving activity level over time.

Not all clinics have access to training equipment, and thus cannot provide training. Others have chosen to focus solely on information thus gaining a greater flow of patients. Some clinics have not initiated a functioning collaboration with a nearby arthritis association and can therefore find it difficult to offer participation of an osteoarthritis representative. Some clinics cooperate with other professionals such as occupational therapists or dieticians in the periphery of the osteoarthritis school. Further factors that may vary between clinics are for example patient flow, the number of involved lecturers, length and number of sessions, and number of patients per school.

Changes over time

Changes in a number of patient-reported variables after 3 and 12 months are presented below. Only individuals with data from all three measurement sessions are presented in the tables below, and all results are based on paired data.

EQ5D

The EQ5D is a measure of health-related quality of life. An index, ranging from 0 to 1, where 0 is equal to death and 1 is equal to "perfect health", can be calculated by the patient answering five questions concerning mobility, hygiene, activity, pain, and anxiety/depression. The EQ5D index can assume values lower than zero, which means that the subject rates health as worse than death. The EQ5D has been used in a large number of studies of different diseases and diagnoses and can also be used for health economic calculations. EQ5D gain is the difference between follow-up and first consultation. Our goal in BOA is to reach patients before their health-related quality of life has been affected too extensively and, by means of the osteoarthritis school, achieve a change in the EQ5D of 0.1. For the moment we can show a mean change in the EQ5D of 0.07 after three months. After one year the change is 0.04 compared with the time before osteoarthritis school.

Pain VAS

A Visual Analogue Scale (VAS) is an instrument used for the assessment of pain from 0 (no pain) to 100 (worst imaginable pain). The reliability of the VAS has been discussed in scientific studies. Pain is a subjective experience and, since people experience pain in so many different ways, it is difficult to compare VAS between individuals. One of the great advantages of VAS is that it is easy to use clinically. At least a change of 10 in VAS is needed in order for it to be considered clinically significant.

Fear of movement

It is a common misunderstanding amongst patients with osteoarthritis that the joint is "worn out" and that further use or activity can cause further damage to the joint. Such a misunderstanding can form an obstacle to physical activity, and information from the osteoarthritis school aims to correct this misunderstanding among patients. The figure below shows the proportion of patients that fear the joint will be damaged by physical activity or training prior to participation in osteoarthritis school, after three and twelve months for the entire register, and on a clinical level. Only clinics with 10 or more participants with complete data for all sessions are shown.

What do patients think of the osteoarthritis school?

After three months 88% stated that they thought the osteoarthritis school was good or very good; 7 % thought it was neither good nor bad; 4% couldn't decide or had not answered (data not shown). One per cent stated that they thought the osteoarthritis school was bad.

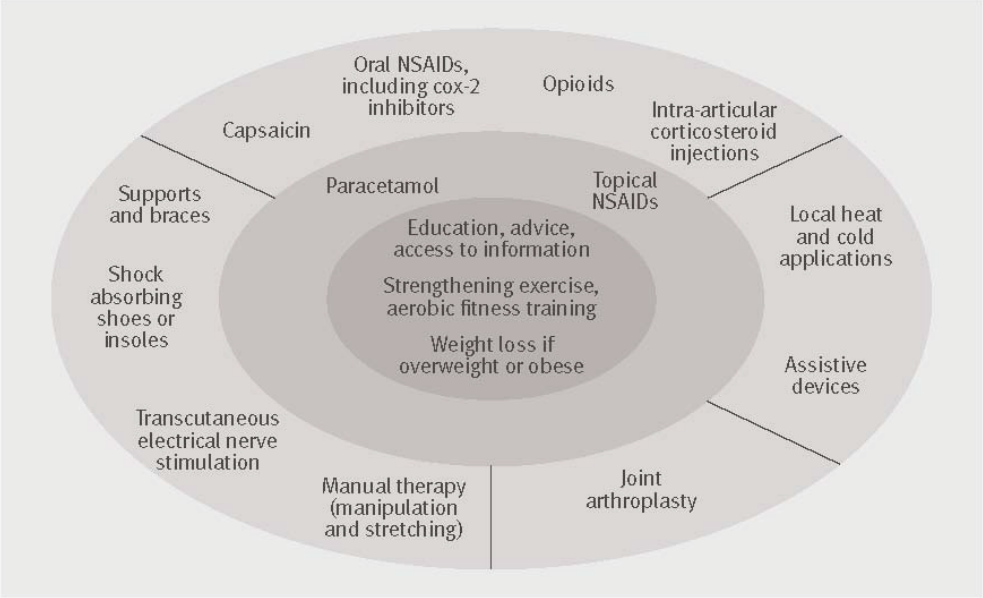
Proportion using what they learned

One way of measuring the utility of the osteoarthritis school is to ask patients how often they use what they have learned in daily life. After three months 63% stated that they utilised what they had learned daily or several times a day, and 92% said they use it every week. After one year the corresponding numbers were; 32% for daily use, and 63% every week (data not shown). Two per cent stated they used what they learned once a month of never.

Discussion

Guidelines for osteoarthritis treatment

Osteoarthritis has long been considered an illness that nothing could be done about. It is not, that is true, possible to cure osteoarthritis. However, the last decades' research has shown there is much that can be done to relieve symptoms and prevent disability. The best treatment of light to moderate osteoarthritis is information, adjusted physical activity, and weight loss if overweight. This implies lifestyle changes that people with osteoarthritis themselves can achieve with proper support from health care and their immediate surroundings. Both Swedish and international guidelines underline the importance of information and training as a first measure in the treatment of osteoarthritis (Figure). The Medical Products Agency – Sweden's recommendations with a similar content was published in 2001. It takes time before guidelines and recommendations make a clinical impact. In this report we can see how things look for a sample of patients with insufficient information and lowered quality of life in patients with osteoarthritis. In the BOA register less than half the patients can recall having visited a physiotherapist for their symptoms. Less than 10% have been offered what can be called adequate treatment, that is, information about osteoarthritis, the importance of weight, and adjusted physical activity in osteoarthritis. It could be argued that this is because we reach patients early in the course of the disease, but considering the mean age in the register, that so many have undergone radiological examination where radiological findings typical for osteoarthritis could be shown, it is not probable that such is the case.



Treatments for osteoarthritis in adults. Starting at the centre and working outwards, the treatments are arranged in the order in which they should be considered, taking into account individuals' different needs, risk factors, and preferences. The core treatments (centre) should be considered first for every person with osteoarthritis. If further treatment is required, consider the drugs in the second circle before the drugs in the outer circle. The outer circle also shows adjunctive treatments (both non-pharmacological and surgical), which have less well proved efficacy, provide less symptom relief, or increased risk to the patient compared with those in the second circle

Figure. Guidelines for osteoarthritis treatment according to NICE, UK.
Conaghan, P.G., J. Dickson, and R.L. Grant, Care and management of osteoarthritis in adults: summary of NICE guidance. BMJ., 2008. 336(7642): p. 502-3.

Our estimates show that roughly 16 of 1000 inhabitants over 45 years of age consult primary care yearly with hip or knee osteoarthritis as a first diagnosis. It is possible that many are sent home again, eventually with some pain-relieving medication. Despite little correlation between radiological changes and symptoms, and the fact that radiological findings play no part in treatment selection, many are sent to radiological examination that will, in many cases, fail to reveal anything, since it takes many years from the first symptoms before radiological changes become visible on X-ray. There is a risk that those who have already undergone a radiological examination showing normal findings are dissatisfied since they received no explanation for their symptoms. They will perhaps be sent for an MRI that will later lead to an arthroscopic examination. Those that have tried medication without effect will perhaps be sent to an orthopaedic specialist for assessment and a decision on surgery, sometimes despite not wanting surgery or having no need for it at the moment. The patient with considerable symptoms will perhaps be sent on sick leave while awaiting an orthopaedic consultation. Unfortunately, in this way patients with osteoarthritis are often sent around in circles in health care. It costs society enormous sums and patient gets no better for wandering around the medical system without being offered evidence-based improving treatment. Unhappily, the results of the BOA register show that it is common for osteoarthritis patients to be treated in this way. Many have osteoarthritis and many are of working age; and the indirect costs in Sweden for osteoarthritis in the form of production loss, sick leave, and early retirement are greater than five times the cost of medical treatment. The mean age of patients in the BOA register is 65, that is to say roughly half are of working age. The proportion of those on sick leave among all those with knee problems is 15%. The corresponding figure for those with hip problems is 10%, and 5% have been on sick leave for more than three months. Percentages have been calculated for all patients, even for those over 65 years of age. The actual proportion of working age persons is thus considerably greater. By means of BOA and a successive introduction of osteoarthritis schools throughout the country we hope to provide information and adjusted physical training to all those with hip and knee osteoarthritis as early as possible in the course of the illness for the improvement of health-related quality of life and to prevent sick leave and illness. It is our intention that the physiotherapist be the first choice for patients with osteoarthritis of the hip and knee.

Radiological examination

Statistics in the register show that X-ray is a common examination in both hip and knee osteoarthritis. X-ray findings for osteoarthritis often calm patients since they can then assume that symptoms are due to osteoarthritis, and can subsequently exclude other causes. Paradoxically, there is also a risk that a patient with difficult symptoms without visible radiological findings will be made uneasy by the results. Whereby radiological findings in no way change the early treatment of osteoarthritis the motive for a radiological examination should be well defined. Radiological examination should take place only in the case of an uncertain diagnosis or if a specialist referral is being considered. The relatively high proportion of patients in the BOA register that state their X-rays show typical osteoarthritis findings may indicate that many patients have been made to wait for a radiological-confirmed diagnosis before treatment initiation.

Comorbidity

Roughly a third of patients in the BOA register state having a lowered walking ability for reasons other than osteoarthritis of the hip and knee. What this comorbidity consists of can be illuminated through future interconnections with the Swedish National Board of Health and Welfare's patient register. Comorbidity can of course influence the expected results of those treatments provided for osteoarthritis. Even if osteoarthritis school can have the potential to

reduce pain and improve function related to osteoarthritis there are other problems presenting obstacles for an increased activity level. Approximately a third of the patients registered in BOA have unilateral symptoms. Having osteoarthritis in more than one joint is thus common. Forty per cent have symptoms even from hand and finger joints. The prevalence of osteoarthritis in several joints simultaneously and, in many cases, comorbidity and symptoms affecting functional ability have important clinical implications for treatment planning and assessment of the results. Pain in a knee or hip can be one part of more wide spread problems.

Previous surgery
A third of all men and a fifth of the women in the BOA register have stated having undergone some form of joint surgery (not soft tissue surgery) in the most symptomatic knee and every tenth had been operated on the opposite knee. Removal of an altered meniscus, often the first sign of osteoarthritis, or "cleaning up" the joint by removing unevenness does not eradicate osteoarthritis and seldom reduces symptoms. Arthroscopy in osteoarthritis, in well designed studies, has been no better than sham surgery (1). All forms of surgery imply, moreover, a risk for infection and should therefore be avoided if indications are unclear. The proportion of those having had hip surgery is less than 10%.

Osteoarthritis as described for patients
Fifty to sixty percent of the patients in the BOA register know they have osteoarthritis, but most do not know its implications. About 40% have not received any information whatsoever concerning the cause of their symptoms; or worse, have been told they have "worn out" joints. The image of worn out cartilage most likely contributes to many osteoarthritis patients not daring to be active for fear they will cause more damage. This is catastrophic and forms an obstacle for recommendations of physical activity and training provided by osteoarthritis school. Some patients get over their fear of movement after receiving greater knowledge and have felt the benefit of adjusted physical exercise; but even after completing osteoarthritis school less than 10% state fearing the joint will be injured by physical activity. The proportion of persons at the 12-month follow-up that believe the joint will be damaged by physical activity increased further. More men than women fear the joint will be damaged, this is more frequent in hip osteoarthritis than in knee osteoarthritis. More men than women state wanting surgery. These factors can be related in that if one holds the belief that the joint is worn out and is afraid that further damage will be caused by activity, surgery can be seen as the only option.

Practice
Varying form of osteoarthritis school can influence the outcome and cost of the intervention. When calculating the cost of osteoarthritis school it is important to include an eventual improvement in patient-reported outcomes. Investing relatively small sums to improve health can save society large sums over time. By following accepted practice and stimulating health economic analyses we can optimise the balance between intervention and outcome.

Changes over time in health-related quality of life
The EQ5D is a patient self-reporting questionnaire that has been used for a number of diagnoses and conditions for measuring health-related quality of life. An index is calculated where 0 is equivalent to "death" and 1 the highest possible health-related quality of life. In the Swedish Hip Arthroplasty Register's 2009 annual report patients had a preoperative EQ5D index of 0.41 and 0.78 one year postoperatively; that is to say a gain of 0.37 in the EQ5D index with a hip replacement. Prosthetic surgery is a big and complicated operation with considerable costs. In all probability the placebo effect of surgery is also considerable greater

than that of information and training. All effects must be considered and placebo should not be underestimated. In a study comparing mobilization, taping, and training for knee osteoarthritis with a placebo in the form of ultrasound with a ”dummy apparatus”, patients in both groups improved and the effect remained over time (2). Another study comparing traditional Chinese acupuncture with sham (placebo) acupuncture was unable to show any differences between groups. On the other hand even the physiotherapists in this study were randomised to differing behaviours toward patients: half the physiotherapists were asked to act convincingly saying that they had had many patients with good results of the treatments; while the other half were asked to be neutral and inform patients that the reason for the study was that it was uncertain whether the treatment had any effect. Patients treated by the convincing physiotherapists experienced greater pain relief (3). By behaving in an involved manner and with conviction we can achieve results not always explainable by the evaluation methods we presently use in health care. In the BOA register we see a gain in the EQ5D after 3 months of 0.07 and a residual effect of 0.04 after 12 months. The variation between units is large. We strive to gradually reach an EQ5D gain of 0.10 through feedback and activities of quality improvement for the routines and content of the osteoarthritis school.

Development potential

From December 2010 and up to the printing of the annual report (August 2011) the number of units that have joined the register has nearly tripled, from 39 to 105. This speaks for an encouragingly large interest and perhaps a pent-up need among physiotherapists to be able to evaluate, display and quality improve their activities. Osteoarthritis school is mostly considered a treatment alternative for primary care. There is here a considerable potential for development, not least when it concerns developing the teamwork around patients with osteoarthritis. The primary care physician and district nurse have an important role in making an early diagnosis of knee and hip osteoarthritis. In the future detailed knowledge of osteoarthritis and the contents of the osteoarthritis school should be a part of the basic training of both physiotherapists, occupational therapists, as well as physicians and nurses.

Through teamwork in osteoarthritis the patient can, in a natural way, get their knowledge from osteoarthritis school followed up at all check ups at the primary care unit. The follow-up of physical activity and function will, in the future, be carried out for all our common illnesses where the ordination of physical activity by prescription according to www.fyss.se (physical activity in the prevention and treatment of disease) comprises all basic treatment. Physical activity shall presently be prescribed according to the FaR model (Physical activity on prescription) by all licensed health care personnel, both within primary and hospital care. The need for a care chain around the prescription of physical activity (FaR) has been identified within health care’s national network for Physical Activity on Prescription. This is particularly suitable for middle-aged and elderly patients at hospital and where it is apparent there is a great need for improved physical conditioning, strength, and daily physical activity. Considering the prevalence of comorbidity with osteoarthritis in the BOA register and an increasing presence of inactivity-related illnesses in the population, development of teamwork and an increase in the use of Physical Activity on Prescription can be expected to generate substantial health gains for patients and save society money.

1. *Moseley, J.B., et al., A controlled trial of arthroscopic surgery for osteoarthritis of the knee. N Engl J Med, 2002. 347(2): p. 81-8.*
2. *Bennell, K.L., et al., Efficacy of physiotherapy management of knee joint osteoarthritis: a randomised, double blind, placebo controlled trial. Ann Rheum Dis., 2005. 64(6): p. 906-12.*

3. *Suarez-Almazor, M.E., et al., A randomized controlled trial of acupuncture for osteoarthritis of the knee: effects of patient-provider communication. Arthritis Care Res (Hoboken). 62(9): p. 1229-36.*