

The BOA-register

Better management of patients with osteoarthritis

Annual report 2012

www.boaregistret.se

This annual report summarizes the results from the Swedish National initiative for Better management of patients with osteoarthritis, BOA, for the year 2012.

A full version in Swedish, and more information about BOA (partly in English) can be found at www.boaregistret.se

Figures and tables can be viewed at www.boaregistret.se.

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Introduction

The BOA-register "Better Management of patients with Osteoarthritis", continues to successfully improve the quality of life for an increasing number of patients with osteoarthritis. It is gratifying to note that an increasing number of units report patients as never before so that both the number of included patients and reporting units have basically doubled every year since the inception of the register. This calls for structure and communication within the organization, something that the registry has thus far been able to live up to. Patients with osteoarthritis are one of the largest diagnostic groups consulting primary care. Several counties and regions have realized that the BOA-register is a resource when it comes to measuring adherence to the national guidelines for osteoarthritis. This is the BOA-registry's third annual report covering activities from 2012.

The 2012 report comprises 197 units and a total of 14,705 patients. Each county has reported to the register since 2012. When the annual report was compiled (April 2013) the number of units connected to the register was 296.

There has previously been a lack of structured treatment for patients with osteoarthritis in the period before arthroplasty as an option, and variation in care within the country is great. The BOA-register has captured and shown these variations that now make up the starting point for quality improvement, with the aim of reducing these differences. For the first time we can present results on a regional level in a separate chapter. Consideration should be taken, when making comparisons, to those variations that still exist between regions in the number of patients and size of the population.

BOA converts the scientific evidence for information and training for hip and knee OA to clinical practice in a so-called "supportive osteoarthritis self-management program" lead by a physiotherapist, in many cases in cooperation with an occupational therapist and patient representative. The aim is to provide patients with knowledge to enable decisions on their health, and support a change in life style to promote better patient reported health. The BOA-register contains mainly patient reported outcomes as a basis for quality improvement in healthcare. The physiotherapist reports which treatment the patient previously received as well as adherence to the intervention. Data on a clinical level is presented only for units that have reported at least 10 patients with hip and knee symptoms, respectively. "The country" is represented by the means from all patients reporting to the register. All units can retrieve their results online, independent of the number of patients, and compare it to the country's mean.

The annual report presents an overview of the register's contents. Statistics are descriptive and some mean values are presented without statistical dispersion in consideration to the limited material at a clinical level. Results should therefore be considered preliminary and interpreted with caution. Results are presented separately for hip and knee. The breakdown by most troublesome part is based on the physiotherapist's assessment upon examination. Many patients indicate problems from both hip and knee.

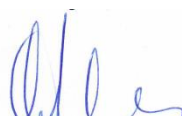
In order to provide the reader with an overview we have chosen to report patient composition at the clinic, the so-called case-mix, as a value compass. We have also selected a number of outcome variables, indicators, which are presented at the clinic level and compared with the national average. All results are paired data, that is, only those patients with complete data from first visits and follow-up are included in the results.

The questions in the patient forms were updated on September 1st, 2012 in order to comply with National Board of Health's proposed wording of questions regarding physical activity. In conjunction with this change, we also took the opportunity to make a few other updates. Thus the questions concerning physical activity before and after the first of September are no longer compatible. The results regarding physical activity in this annual report are based solely on results from the previous wording, that is, data gathered before September 1st. All responses to the new wording, after the first of September, will be included in the annual report for 2013.

We hope that this annual report will continue to inspire in-depth analyses and the work of improvement within the osteoarthritis field.



The BOA register



The BOA register



The BOA register

Summary

BOA stands for Better Management of Patients with Osteoarthritis. The BOA-register evaluates patient-reported outcomes following a physical therapy intervention – a supportive osteoarthritis self-management program. The self-management program converts the scientific evidence for information and training of the arthritic hip and knee to clinical practice. A supportive osteoarthritis self-management program is lead by a physiotherapist, often in collaboration with an occupational therapist and an osteoarthritis communicator. By means of a supportive osteoarthritis self-management program knowledge gained enables patient decisions regarding personal health, as well as support for life style changes, for the promotion of better health. Osteoarthritis of the hip and knee are among the most common diagnoses in primary care, and the need for early interventions to prevent functional deterioration and worsening of symptoms is considerable. Based on data from four regions/counties comprising 40% of the population over 45 in Sweden, we have estimated the total "Osteoarthritis population" seeking open care in Sweden during a five-year period at roughly 500 442 individuals, or approximately 12% of the population. Statistics obtained from the health care data base in Region Västra Götaland indicate that 13% of all primary care consultations in 2012 were related to joint pain or osteoarthritis of the hip and knee.

The BOA-register has existed as a national quality register since December 2010. Both the number of registered patients and affiliated units has in fact doubled each year since its inception. The 2012 annual report encompasses 197 units and 14 705 patients. Since 2012 all municipalities and county councils contain units reporting to the register. At the compilation of the annual report (April 2013) 296 units are affiliated with the register.

By referring patients to a supportive osteoarthritis self-management program and recording results in the BOA-register the Swedish National Board of Health and Welfare's national guidelines for osteoarthritis have thus been adhered to. This enables the reporting of a measurement of the suggested indicator for proper management of osteoarthritis: The proportion of people with osteoarthritis who received training, supervised practice and advice on weight loss.

The primary aim of BOA is to offer all patients with osteoarthritis adequate information and training according to current treatment guidelines, and that surgery is to be considered only when non-surgical treatment fails to provide satisfactory results. The goal is to increase quality of life and activity levels of patients with osteoarthritis chiefly of the hip and knee, and reduce health care consumption and sick leave as a result of osteoarthritis. Patients with osteoarthritis should be received equally at their first contact with the health care system, regardless of

where this takes place. Further, BOA aims towards quality improvement within physical therapy by systematic evaluation, open comparison and feedback of results. Each unit reporting data to the register can, at any time, retrieve their results in real time to compare them with the national average.

BOA's goals:

- Improve the EQ5D by 0.10
- Reduce the mean age of the patients in the register (to 58 years)
- Reduce the proportion of those X-rayed (and where X-rays show osteoarthritis findings)
- 150 minutes of weekly activity after one year for 80% of the patients in the register
 - The goal of every unit is an increase of 10% after one year

An improvement of the EQ5D by 0.10 after one year is a relatively lofty goal, but probably not impossible if every unit strives to improve their results. We presently see that some units have achieved this goal at three months, but that effects are partially lost over time. Measures for osteoarthritis taken before symptoms worsen have the greatest possibility of preventing disability and deteriorated health. We know that many have had problems for years before seeking healthcare. By increasing knowledge of available help in the general population and among care providers we hope to lower the mean age in the register from today's 65 years to 58 years. We can observe in the register that only a handful came to a supportive osteoarthritis self-management program before having previously consulted health care, and that many had problems for a very long time. Our goal to include patients with problems from the hip and knee before the joint is X-rayed is in accordance with the Swedish National Board of Health and Welfare's recommendations for clinical diagnostics, as well as a means of reaching patients at an earlier stage of the illness process. A goal of a supportive osteoarthritis self-management program is an increased physical activity level. Physical inactivity and fear of joint destruction through training is common among patients with osteoarthritis, which in turn increases the risk for inactivity-related diseases. The world health organization WHO has suggested that all adults should be physically active, at least at a moderate intensity, for a minimum of 150 minutes weekly. The BOA-register introduced in 2012 the two questions concerning physical activity that the Swedish National Board of Health and Welfare's guidelines for disease-preventive methods suggested. We see that the proportion of patients attaining 150 minutes of activity prior to a supportive osteoarthritis self-management program is currently 66%.

According to calculations based on the data received by the register's contacts in eight counties and regions 56% of those units conducting a supportive osteoarthritis self-management programme report to the register, and 77% of all patients involved in a

supportive osteoarthritis self-management program have been registered. It is not reasonable to assume that all patients should be registered, since a supportive osteoarthritis self-management program also welcomes patients with osteoarthritis of the hands. Many patients with osteoarthritis of the hip and knee also have osteoarthritis of the hands. Patients with osteoarthritis of the hands alone have not as yet been registered. If we assume that BOA had had, for the last five years, the current yearly capacity of circa 7 500 patients, we would have reached 37 500 patients, corresponding to 7.5% of all those seeking primary care with joint pain, or a diagnosis of osteoarthritis of the hip or knee at least once during the same period. This is an increase of 0.5% from the previous year. The BOA-register has a high response rate. Each question had more than a 97% response rate, 89% of the patients responded to the one-year follow-up, and studies of data quality (sample) at the one-year follow-up show that misreporting was less than 0.01%.

For BOA, patient participation implies strict cooperation with the Swedish Rheumatism Association and representatives of those patients comprising a target group for a supportive osteoarthritis self-management program. One of the theory sessions in a supportive osteoarthritis self-management program is lead by a patient with experience of living with osteoarthritis and managing problems through life style changes. The aim of this cooperation is to provide a good example and give participants an opportunity to identify with the osteoarthritis communicator who can tell them that physical activity works. The osteoarthritis communicator is trained by the Swedish Rheumatism Association in the same way that BOA trains all physical and occupational therapists that are to lead a supportive osteoarthritis self-management program. Training aims toward the osteoarthritis communicator to pedagogically speak about and initiate discussion of how an active life style can affect health and joint problems. A physiotherapist with experience of a supportive osteoarthritis self-management program participates in the training of the osteoarthritis communicator, and the osteoarthritis communicator participates in the training of the physical and occupational therapists.

A supportive osteoarthritis self-management program has become routine in health care. In many areas of the country the orthopaedic surgeon returns referrals for patients that have not met a physiotherapist for basic treatment. A supportive osteoarthritis self-management program is included in several guidelines for patients with osteoarthritis of the hip and knee. Some regions have included a supportive osteoarthritis self-management program and the BOA-register in their procurement process surrounding care choices. An international interest for the BOA-registry's activities has also been noted. Statistics from the website show that 75% of all visitors are from Sweden, while USA represents 10% of all visitors, Japan for 3% and China, 2%. Visitors from more than 50 countries have visited the BOA-register's website.

The findings of this report are presented separately for hips and knees. Patients with complaints from both the hip and knee are classified based on the joint that the physiotherapist assessed as causing the most problems. Two-thirds have most of their difficulties from their knees. Circa 70% of the patients in the register are women. Gender differences are only presented on a national level in this report. Henceforth, when the number of patients per unit increases, the annual report will present results for men and women separately. We would like to emphasize that the patient base can differ significantly 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 sectors. These aspects must be considered when interpreting results. This annual report should be seen primarily as a description of activities and as a starting point for future improvement within the field of physical therapy. In regard to quality improvement we would like to encourage all units to actively utilise their results. Thus, possible incorrect data and the validity of the register can be further improved. It is rewarding to see that regional networks are being formed in order to utilize and further develop local experience and knowledge of osteoarthritis.

The following interesting observations can be highlighted from the results of the BOA-registry's third annual report:

- A supportive osteoarthritis self-management program reduces pain and improves health-related quality of life for patients with osteoarthritis of the hip and knee.
- After three months the EQ5D increases on the average by 0.07. After one year the mean improvement is 0.03 for hips and 0.04 for knees. Variation between units is considerable thus creating fertile ground for local improvement measures and, on the whole, a better health-related quality of life for patients.
- Pain according to a VAS shows a mean reduction of 11 per cent after three months. (Variation between units is 5.5 – 18.4)
- 95% of patients were satisfied or very satisfied with a supportive osteoarthritis self-management program after three months and 85% after one year.
- 92% of patients stated that at three months they used what they had learned in a supportive osteoarthritis self-management program at least once every week. After one year the corresponding figure was 74%.
- The proportion of patients confirming pain daily or constantly was reduced by circa 18 per cent after a supportive osteoarthritis self-management program. The results remain over time with particularly good long term effects for osteoarthritis of the knee.
- Only a fifth of the patients that had seen a physiotherapist for their current difficulties prior to a supportive osteoarthritis self-management program had received adequate treatment (information and customized training).

- Approximately 10% of patients with osteoarthritis of the hip and knee in the register were on sick leave for their difficulties.
- More than 80% of patients were x-rayed prior to joining a supportive osteoarthritis self-management program, despite the Swedish National Board of Health and Welfare's guidelines stating that x-rays are unnecessary for a diagnosis of osteoarthritis. X-rays probably delay treatment initiation. Variation among regions is large.
- Patients in the register with osteoarthritis of the hip receive surgery nearly three times as often as patients with osteoarthritis of the knee. Indications for prosthetic surgery include a supportive osteoarthritis self-management program having been tested without satisfactory results.
- Only every fifth patient coming to a supportive osteoarthritis self-management program is aware of having osteoarthritis or knows what it is. Equally large proportions have been told they have worn out joints, which probably increases the risk for misunderstanding and inactivity.
- Only every fifth patient with osteoarthritis of the hip and knee is adequately physically active to avoid ill health.
- Fear that physical activity will damage joints lessens after a supportive osteoarthritis self-management program in 10% of patients.
- Nearly half the patients state that they have increased their physical activity level following a supportive osteoarthritis self-management program.
- Among patients with osteoarthritis of the hip roughly 60% are overweight or obese. Corresponding figures for patients with osteoarthritis of the knee is 80%.
- It is common to have osteoarthritis in several joints. Every fifth patient with osteoarthritis of the hip and every third with osteoarthritis of the knee have bilateral symptoms. Nearly half with osteoarthritis of the hip or knee also have problems with their hand or finger joints.
- Co morbidity is very common with osteoarthritis. Nearly half the patients indicate reduced walking ability due to reasons other than hip and knee problems. A supportive osteoarthritis self-management program has only limited possibilities to influence these other causes.
- 8 of 10 patients in the register state that they take joint-related medication. Roughly 50% take Paracetamol for their symptoms. Paracetamol is the primary recommendation according to the guidelines of the Swedish National Board of Health and Welfare.
- 7% state taking natural medicines. Knowledge of the consumption of natural medicines can be of importance to the attending physician, whereas some preparations can affect other medications.

- Men want surgery performed more often than women. Every sixth woman and every third man have so many difficulties that they prefer surgery.
- Men are more afraid that the joint will be damaged by physical activity. Slightly less than every sixth woman and every fourth man believe the joint will be damaged by physical activity.
- Men leave a supportive osteoarthritis self-management program more frequently than women.
- Implant surgery is 12% more common among men compared to women. 6% of patients in the register have received a new hip or knee joint implanted within one year.
- Women more frequently retain symptoms from several joints and other diseases that influence their ability to walk.
- In the regions of Västerbotten, Kronoberg, Kalmar, Örebro and Gävleborg a negative trend can be seen in the number of patients registered from 2011 to 2012. Västerbotten reduced the number of registered patients by 45%.
- The regions of Östergötland and Skåne together accounted for one-third of the patient recorded in 2012. Östergötland increased its volume of patients by 71% compared to the previous year, while Skåne, previously showing a relatively high volume, further increased by 9%. The greatest increase can be seen in the region of Jämtland where the number of registered patients has increased 19-fold, from 25 to 475 patients in one year thanks to an initiative to increase the use of a supportive osteoarthritis self-management program and the BOA-register in the region. Jämtland was awarded the 2012 BOA-award for this achievement.

Our thanks

The BOA-register would never have become what it is today without the help of a number of people. A special thanks to Nader Nazari, Ronny Thörnwall and Krister Arlinger at the Registercentrum VGR for their patient work and intelligent IT solutions and system development. Equally special thanks to all the users of the register!

BOA's three branches

BOA stands for Better Management of Patients with Osteoarthritis.

BOA consists of three branches: patient education (a supportive osteoarthritis self-management program), training of health care personnel to deliver and evaluate a supportive osteoarthritis self-management program in an equivalent manner, and the National Quality Register, the BOA-register. The BOA-register is an intervention register for patients with problems of the hip and knee, and evaluates the results of a physical therapy intervention - a supportive osteoarthritis self-management program.

The aim and goal of BOA

The aim of BOA is to offer every patient with osteoarthritis adequate information and exercise according to evidence-based recommendations, and to increase awareness that surgical interventions should only be considered if non-surgical treatment has been tried and failed. The goal is to reduce the need for health care and sick leave due to osteoarthritis, as well as increase quality of life, independence and physical activity among patients with osteoarthritis of the hip or knee. Patients with osteoarthritis should receive equal and optimal management at their first contact with the health care system, regardless of where it occurs. Previous research has shown that information and individually adjusted training has as good an effect on pain as medication. In BOA we have utilised this knowledge by offering a supportive osteoarthritis self-management program for patients. Osteoarthritis is one of the most common causes of inactivity among the elderly, and many fear that activity will damage their joints. Inactivity is a large risk factor for poor physical and psychological health as well as premature death (1). The aim of a supportive osteoarthritis self-management program is to raise the level of physical activity and patient knowledge of how to manage their disease to avoid illness, and live a good life despite osteoarthritis. Further, BOA aims for physiotherapists to raise their quality levels of treatment by means of systematic assessment, open comparison, and feedback.

Here's how it all began

BOA was initiated in 2008 as 3-year collaboration between the Regions of Västra Götaland and Skåne, and Värmland's and Västerbotten's county councils. The background was the high cost of sick leave due to osteoarthritis, and the knowledge that only a fraction of all patients receiving surgery 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 financing to the regions. 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. Depending on the health care organisation of each region both primary care and inpatient units were included in the project. The BOA-register was introduced as a National Quality Register in 2010.

Patient education - A supportive osteoarthritis self-management program

Target group

A supportive osteoarthritis self-management program 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 are not prerequisites. All patients assessed as benefiting by a supportive osteoarthritis self-management program meet a physiotherapist for an individual consultation prior to possible participation. This approach is fully consistent with the National Board of Health and Welfare guidelines for musculoskeletal diseases including osteoarthritis, published in May 2012. According to these guidelines the diagnosis is made through the patient's medical history, typical symptoms and a clinical examination. X-rays should only be used in unclear cases or when a specialist referral is being considered (2). Even if it should later become apparent that their problems were not caused by osteoarthritis, training as offered in a supportive osteoarthritis self-management program – information and training – is directed toward functional limitation and only implies negligible risks. Patients with inflammatory joint disease, other diseases causing more dominant symptoms (for example malignity, widespread pain or a failed femoral neck fracture) are primarily in need of another care form, and therefore excluded from a supportive osteoarthritis self-management program and the register. Patients lacking an understanding of 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 in the BOA-register.

Information

A supportive osteoarthritis self-management program arose from current research in the field as well as from patient's thoughts and wishes for treatment of osteoarthritis. The supportive osteoarthritis self-management program within BOA comprises a "minimal intervention" carried out in a similar manner at all units (Figure 1). 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 supportive osteoarthritis self-management program includes a session led by an "expert patient", that is a patient with osteoarthritis that has completed a special training course to relate experiences of living 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 a supportive osteoarthritis self-management program to more easily identify with those providing advice and recommendations, and thus jointly find solutions to the 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 a supportive osteoarthritis self-management program 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 representative in schools is cost-free. The osteoarthritis representative participates on an idealistic basis and the Swedish Rheumatism Association pays for travel expenses.

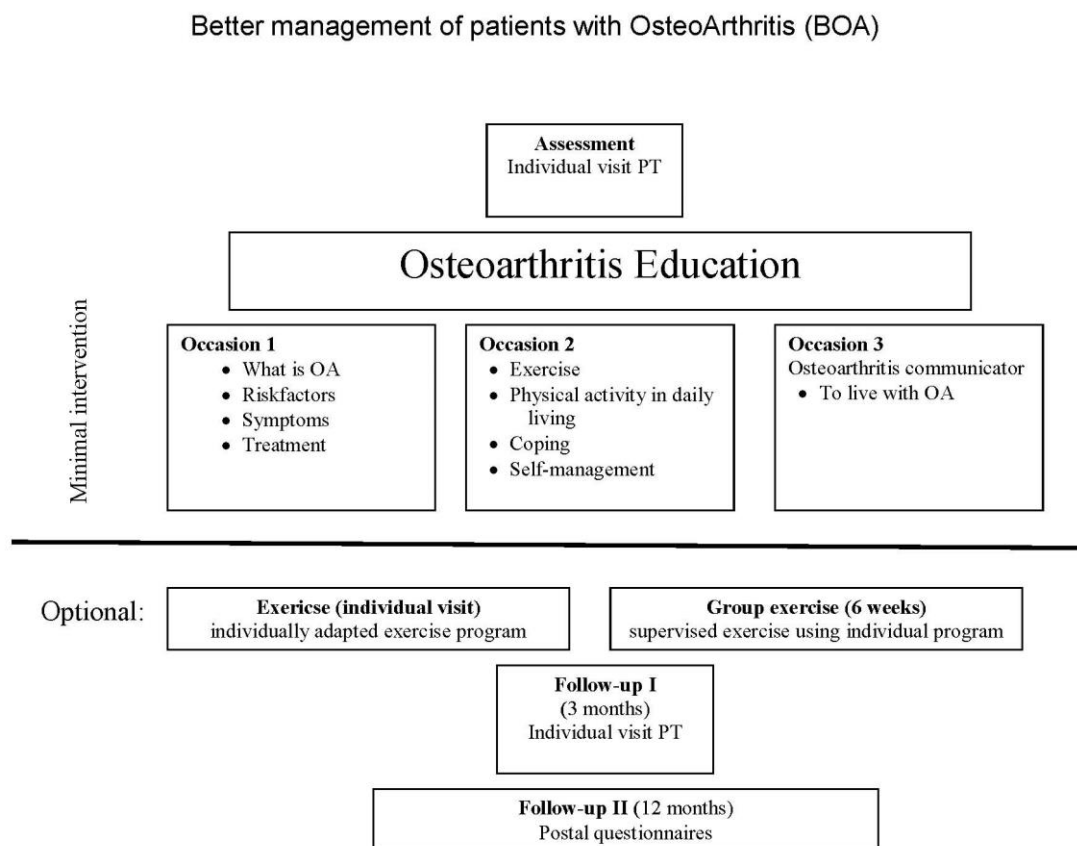


Figure 1. Plan for a supportive osteoarthritis self-management program.

Individually adapted training

Training can include sessions to improve fitness, strength and function. Training is voluntary but aims for as many as possible to feel the desire and need to learn more of how to best deal with their illness and the accompanying difficulties, through correct training and daily physical activity. Discussions concerning suitable home exercise and planning for continued physical

activity/training after a supportive osteoarthritis self-management program is an important part of the intervention. Follow-up of all patients takes place three months after the first visit, or at the program's conclusion. Discussions concerning suitable training for planning and continued physical activity/training after completion of the program comprise an important part of the plan. Training can effectively reduce symptoms of osteoarthritis but the effect is only temporary. A lasting effect of training of treatment demands planning and continual training. Prescribed physical activity can be a suitable tool for health care to stimulate increased activity levels of patients. Long lasting illness demands long lasting treatment. After the theoretical part of a supportive osteoarthritis self-management program 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 of professionals

Physiotherapists and interested occupational therapists are trained through BOA to enable carrying out and evaluating a supportive osteoarthritis self-management program in an equivalent way. A two-day training program includes current evidence in the field and strives to provide deeper knowledge of osteoarthritis and its non-surgical treatment. The training also includes basic knowledge of registers, since quality registers within physical therapy are still relatively new and unfamiliar.

The National Quality Register

A supportive osteoarthritis self-management program aims at influencing health-related quality of life, pain, physical activity levels, kinesiophobia, motivation to surgery, and self-efficacy for influencing symptoms. These variables are registered in the BOA-register, along with among other items, patient satisfaction. The physiotherapist leading a supportive osteoarthritis self-management program usually also reports to the register. Evaluation takes place prior to a supportive osteoarthritis self-management program, after three months (at the end of a supportive osteoarthritis self-management program) and after one year. One hundred patients that responded to the one-year follow-up the previous year are chosen randomly each coming year.

The BOA register today

Interest for BOA and a supportive osteoarthritis self-management program remains extensive among patients and care providers. Up until the end of 2012 roughly 1200 physical and occupational therapists have been trained according to the BOA concept. There are currently 296 units connected to the register. Data from circa 17 500 patients has been fed in to the register up until April 2013, whereof two-thirds have been followed up after 3 months, and a

third after 12 months. All the more units are connecting to the register. In many places in Sweden a supportive osteoarthritis self-management program has become a routine intervention, and orthopedic surgeons return referrals for patients not having met a physiotherapist for basic treatment. A supportive osteoarthritis self-management program is now part of several guidelines for patients with osteoarthritis of the hip and knee. Some regions have included a supportive osteoarthritis self-management program and the BOA-register in the procurement process for free choice of care. Even international attention has been shown for the activities of BOA. Statistics from the website show that 75% of all visitors are from Sweden, while the USA represents 10% of all visitors, Japan for 3% and China 2%. Visitors from more than 50 countries have visited BOA's website.

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.
2. Nationella riktlinjer för rörelseorganens sjukdomar 2012. Socialstyrelsen.
www.socialstyrelsen.se

Development goals and areas for improvement

Based on the goals of BOA and a supportive osteoarthritis self-management program, as well as the Swedish National Board of Health and Welfare's guidelines for osteoarthritis and disease preventive methods, BOA's management team has developed target levels for the register both as a whole and for each unit. These target levels can assist users of the register to identify possible areas for improvement in order to achieve set goals.

Target levels

- Improve the EQ5D by 0.10
- Reduce the mean age of the register (to 58 years)
- Reduce the proportion of those X-rayed (and where X-rays show osteoarthritis findings)
- 150 minutes of weekly activity after one year for 80% of the patients in the register

Motivation for selected levels

The EQ5D is an index for the measurement of health-related quality of life. It is calculated using five questions that can assume values from zero to one, where zero corresponds to a health-related quality of life equal with death and one with full health. A change in patient-reported outcome of 10%, or in this case 0.10, is generally considered a clinically meaningful change. Total hip replacement (THR) increases the EQ5D by 0.36 according to the Hip Arthroplasty Register's annual report. THR is thus a successful but also major procedure for the patient. Patients about to undergo THR have a mean EQ5D of 0.34. Those patients that come to a supportive osteoarthritis self-management program have a mean EQ5D of 0.64 for osteoarthritis of the hip and 0.65 for osteoarthritis of the knee. This implies that we reach patients at an earlier stage of the illness process, before their health-related quality of life deteriorates as much as before THR, but also that the potential for improvement is also narrower. A change must, of course, also be related to the cost of the intervention. A costly measure could well be justified if patients feel better long afterwards, while a cheaper measure may still be cost effective even though it provides less change. An improvement in the EQ5D of 0.10 after a year is a relatively lofty goal, but probably not impossible to achieve if each unit strives to improve its performance.

Early interventions for osteoarthritis, before symptoms become too severe, have the greatest potential to prevent disability and impaired health. We know that many have symptoms for many years before seeking medical care. By increasing awareness among the public and health care providers that help is available, we hope to lower the average age in the register from 65

to 58 years.

According to the Swedish National Board of Health and Welfare's guidelines for osteoarthritis the diagnosis should be made clinically, by means of the medical history and typical clinical findings. X-rays should be used only in cases of uncertainty, or when considering a referral to an orthopedic specialist. It can take 10-15 years from first symptoms until osteoarthritic changes become visible on X-rays. During this time, many patients are referred to health care without receiving a concise answer, and many are worried about what their symptoms may be due to. Confirming the diagnosis clinically, according to the Swedish National Board of Health and Welfare's recommendation, allows people with discomfort from the hip and knee to gain reassurance and appropriate treatment much earlier in the course of the disease. Today we see that 80% of those with hip osteoarthritis and 84% of those with knee osteoarthritis are x-rayed before entering the supportive osteoarthritis self-management program, and the majority have radiographic changes. They have probably had their symptoms for many years. Our goal to include patients with disorders from the hip and knee before the joint is x-rayed is part of efforts to monitor the Swedish National Board of Health and Welfare's recommendation for clinical diagnostics, as well as a way to reach patients at an earlier stage of the disease process.

A goal of a supportive osteoarthritis self-management program is increased physical activity levels. Physical inactivity and fear of destroying the joint through training is very common among patients with osteoarthritis, which in turn increases the risk of inactivity-related diseases. The World Health Organization has suggested that all adults should engage in physical activity of moderate or higher intensity at least 150 minutes per week. This is a slightly different calculation than the previous recommendation of 30 minutes a day for most days of the week. In the Swedish National Board of Health and Welfare's guidelines for disease prevention methods two questions were adopted to calculate activity minutes. Since September 1, 2012, the BOA-register included these questions in a patient questionnaire. We see that the proportion of patients who reach 150 activity minutes before starting a supportive osteoarthritis self-management program is currently 66%. The goal of each unit is that the proportion will increase by 10% between new visits and the one-year follow-up. The register's goal is that 80% of all patients will achieve 150 minutes of activity weekly after one year.

Participation and reporting

To determine whether results from the register are representative and generalizable it is important that the register covers the intended population. Data to the register shall be reported thoroughly and accurately. Depending on whether the BOA-register is seen as an intervention register or a diagnosis register coverage in the register can be described in several ways: 1) by how many entities carrying out a supportive osteoarthritis self-management program also report (coverage) 2) by the proportion of patients who attend a supportive osteoarthritis self-management program and are reported (completeness), and 3) how many of those with the diagnosis of hip and knee osteoarthritis are reported. The goal of BOA is for all patients undergoing a supportive osteoarthritis self-management program to be reported, but we also strive to offer all patients with osteoarthritis of the hip and knee a supportive osteoarthritis self-management program as early as possible.

Geographical coverage

During 2012 all regions had at least one unit reporting to the register. Both the number of patients participating in a supportive osteoarthritis self-management program and the number of units that report to the register have basically doubled every year since its inception in 2008 (Figure Cumulative). In 2012, 197 units reported patients to the BOA-register. Several units were affiliated but had not, at the end of 2012, registered any patients (Table "Unregistered units "). When the annual report was compiled (April 2013), the number of units connected to the register was 296 (see Table "Participating units"). At the end of 2013 the BOA-register will have trained about 1 500 physical and occupational therapists in a supportive osteoarthritis self-management program and register skills.

Cumulative development of the BOA-register

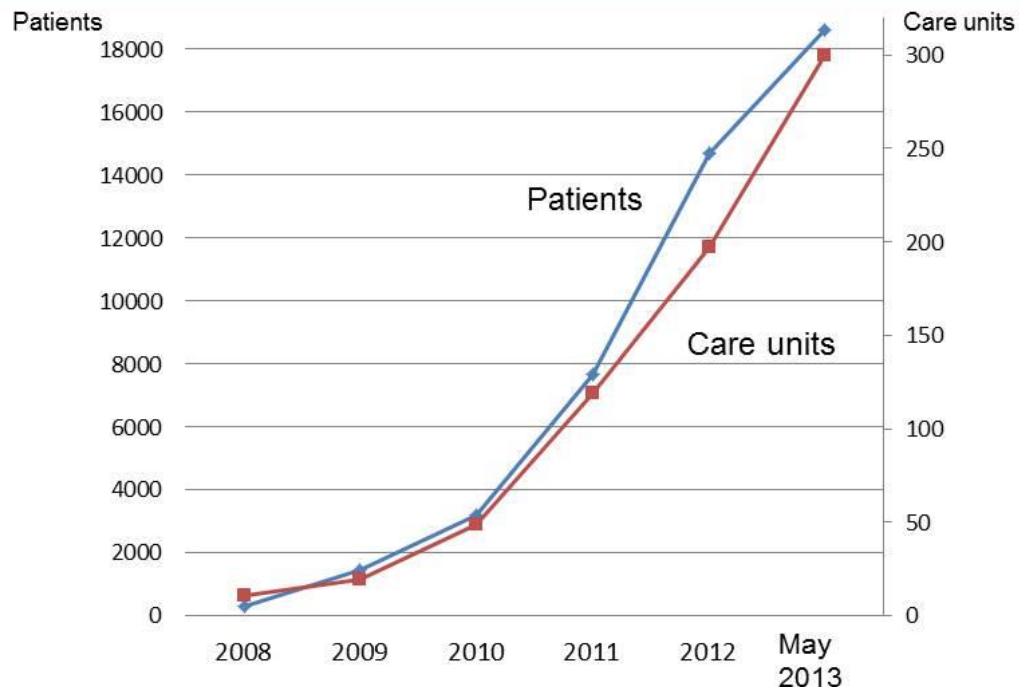


FIGURE Cumulative development of the BOA register

Number of supportive osteoarthritis self-management programs (coverage) and number of patients (completeness) reporting

BOA registers those patients that have participated in a supportive osteoarthritis self-management program. Good coverage requires involved units running a supportive osteoarthritis self-management program to report all patients having participated in the program to the register. However, there is no system for checking how a supportive osteoarthritis self-management program is run, and it is difficult to estimate how many operate without registering results. A survey was conducted via the contact persons that work for BOA on a county council level. There are contact persons in 12 county councils/regions (Table contact persons, pages XX). Eight responded by detecting the number of units running a supportive osteoarthritis self-management program in the region in question. In Jämtland and on Gotland all active supportive osteoarthritis self-management programs are registered (100%). In the Västra Götaland region a supportive osteoarthritis self-management program is conducted at 51 units, whereof 42 (82%) reported. In Värmland a supportive osteoarthritis self-management program is offered at 18 units and 10 (56%) of reported to the register. There are approximately 76 units providing supportive osteoarthritis self-management

programs in Region Skåne, whereof 31 (41%) reported. Västerbotten has 27 units that ran a supportive osteoarthritis self-management program in 2012 where 9 (33%) reported. In Kronoberg 14 units ran supportive osteoarthritis self-management programs and 4 (29%) reported. Örebro ran a supportive osteoarthritis self-management program at 28 units and 2 (7%) reported. The average, based on the counties and regions that have submitted data, shows that 56% of the units engaged in a supportive osteoarthritis self-management program reported to the register.

It is also difficult to estimate the proportion of all patients participating in a supportive osteoarthritis self-management program reported (completeness). Physiotherapist (PT) visits in primary care are not regularly reported to health care databases, and many medical record systems do not have "a supportive osteoarthritis self-management program" as a search term, which makes it difficult to match the number of patients participating. The proportion of registered patients of those participating will never be 100%. Patients with other diseases or diagnoses more symptomatic than osteoarthritis can be assessed as benefiting from a supportive osteoarthritis self-management program, but do not meet the inclusion criteria for registration in BOA. The cause for this is that questions concerning health-related quality of life and pain in the patient's questionnaire are probably answered in relation to the influence of other diseases rather than problems related to osteoarthritis. Patients with only hand osteoarthritis, without symptoms from the hip or knee, are not registered, but may participate in a supportive osteoarthritis self-management program. It is difficult to estimate the proportion of patients that have other symptoms or diseases that exclude them from registering. A reasonable estimate can be that an average of 5-10% of the participants should not be registered. We have requested informants to gather data on the number of patients that have participated in a supportive osteoarthritis self-management program from as many units as possible. There is data from six units in Kronoberg where 81% of the patients have been registered. Data from the region of Västra Götaland has been collected from 14 units with a mean registration of 65%. Data from six units registering in Västerbotten shows that 38% participating in a supportive osteoarthritis self-management program were registered. In Kungsbacka 44% were registered, Falun reported that 86% were registered, while Mönsterås, Abels Rehab, Gotland and Jämtland reported that more than 95% of the patients were registered. An average based on this data shows that 77% of the patients who had participated in a supportive osteoarthritis self-management program during 2012 had also been registered.

In order to trust results the register demands high quality data. The response rate of the BOA-register is high. Each question has more than a 97% response rate, 89% of the patients participated in the one-year follow-up, and studies of data quality (sample) at the one-year follow-up show that misreporting was less than 0.01% (see chapter "Validation of data").

Prevalence of Osteoarthritis in the population

It is difficult to estimate the prevalence of osteoarthritis. Approximately 15% of the population under 60 is estimated as having knee problems such as those associated with osteoarthritis, and the majority develops radiographic changes in time. Osteoarthritis of the hip joint is not as common, while hand and finger joint osteoarthritis, or of the spinal joints is much more common. About 40% of the population is over 55 and more than half over 70 are estimated to have osteoarthritis in some joint. The diagnosis is made in several ways, depending on symptoms, radiological findings, or both. Radiological classification varies as well, such as limit value selection or osteoarthritis criteria. Symptoms arise often long before it is possible to radiologically verify the diagnosis. We know, moreover, that only a minority of all those with an osteoarthritis diagnosis seek health care, and consultations in primary health care are not routinely reported. According to the National Board of Health and Welfare's national guidelines for osteoarthritis the diagnosis should be made with the aid of the medical history, usual symptoms, and typical clinical findings. Radiological examination should be used only when considering a specialist referral. Many have inaccurately received the information that osteoarthritis is a matter of aging or worn out joints, with nothing to be done but undergo surgery when symptoms become too severe. However, we know that it is only a minority of those with osteoarthritis that become candidates for implant surgery. Based on studies we can assume that about 10–15% of all those with the diagnosis of osteoarthritis ever develop difficulties requiring surgery. According to the Swedish hip Arthroplasty register and the knee Arthroplasty register, approximately 30 000 implant operations are performed on the hip and knee yearly in Sweden. The Swedish National Board of Health and Welfare suggests that an indicator of good care should be that as many patients as possible with a joint implant due to osteoarthritis shall have completed a supportive osteoarthritis self-management program prior to surgery. The yearly base for a supportive osteoarthritis self-management program is thus at least 30 000 patients. The program should be introduced as soon as symptoms appear. Approximately 7 000 patients in 2012 that underwent a supportive osteoarthritis self-management program were registered, representing approximately 23% of the number who undergo surgery in a year.

Number of patients seeking healthcare for osteoarthritis of the knee and hip

Due to the lack of reliable data for the number of individuals with hip and knee osteoarthritis (Diagnosis code M16 and M17) within primary care on a national level, we have chosen to ask a selection of county councils/regions to present data for a number of patients with the Diagnosis codes M16 and M17 from regional health care databases. Some osteoarthritis patients seek care several times per year, while others do so sporadically or not at all. In order to collect data for many individuals with hip and knee osteoarthritis as possible we have requested data on the number of unique individuals that have at some time consulted open

care during a five-year period (2008-2012). Since the diagnosis of osteoarthritis is often made before findings appear on X-rays we chose to also include joint pain (Diagnosis code M25.5).

Statistics from health care database in Stockholm show that 90,701 unique individuals with joint pain or a diagnosis of osteoarthritis of the hip or knee generated 229,091 visits 2008-2012. This corresponds to 10.8% of the population over 45 years. In Västra Götaland 49 018 individuals, or 7.0% of the population over 45 sought primary care at least once during the same period with a diagnosis of joint pain or osteoarthritis of the hip or knee as the primary diagnosis. The corresponding figure for Östergötland was 60,458 individuals, or 31.1% of the population over 45 years. Of all the consultations for these diagnoses in primary care in Östergötland 89% of patients had met with a physician, 28% had seen a physiotherapist, and 7% an occupational therapist.

There were 4 254 234 people in Sweden older than 45 by the 31st of December 2012, according to Statistics Sweden. Stockholm, Östergötland and Västra Götaland together stood for 41% of the citizens in this age group. If we assume that the number of individuals with joint pain or a diagnosis of osteoarthritis of the hip or knee are distributed thusly in the population we can assume that the number of individuals seeking primary care in these four regions (200 177) represent about 40% of the osteoarthritis population in Sweden. Our simple example should then estimate the total "osteoarthritis population" seeking primary care in Sweden at least once in a five year period to about 500 442 people, or approximately 12% of the population. This appears reasonable when looking at the statistics from the various regions. According to www.vantetider.se Västra Götaland 100 635 physician consultations took place in primary care during 2012. The statistics we have obtained from the medical care database indicates that 12 903 visits in 2012 were related to joint pain or a diagnosis of osteoarthritis of the hip or knee. This implies that 13% of all visits to primary care in 2012 were related to joint pain or to osteoarthritis of the hip or knee.

The Boa-register is not a diagnostic register, but the Swedish National Board of Health and Welfare's treatment guidelines advise that all patients with osteoarthritis of the hip or knee should be offered information and supervised training as first action, and that a supportive osteoarthritis self-management program should successively strive to reach all patients. There is a considerable need of individuals in the population that have lived for a long time with their illness without receiving adequate treatment. BOA has included 14 705 patients in five years (2008-2012) that have participated in a supportive osteoarthritis self-management program corresponding to 3% of the "osteoarthritis population". The first 2 years of BOA's activities was on a pilot basis, and capacity has successively increased since then, which is visible in the cumulative trend of the number of patients. If we assume that we, in a five year period, had

had the current annual capacity of approximately 7 500 patients, we would have reached a total of 37 500 patients in five years, representing 7.5% of anyone seeking primary care with joint pain or a diagnosis of hip or knee osteoarthritis. That is an increase of 0.5% from the previous year.

The proportion of the population over 45 consulting for osteoarthritis and reporting to BOA

Based on estimates from the Annual Report 2011, we estimated that 1.5% of the population over 45 seek primary care yearly with osteoarthritis of the hip or knee as the primary diagnosis. The figure is likely underestimated, whereby joint pain without radiographic changes in many cases is not diagnosed as osteoarthritis. The goal is for all who seek primary care with hip and knee osteoarthritis are to be offered a supportive osteoarthritis self-management program if they have not previously done so. From Statistics Sweden we have obtained population statistics for the age group over 45 by the day of December 31, 2012, according to county councils, and based on this, calculated how many individuals correspond to 1.5%. Coverage per county council has therefore been calculated by dividing the number reported the BOA-register per county council with the estimated number in each county council seeking primary care yearly. (Figure "coverage")

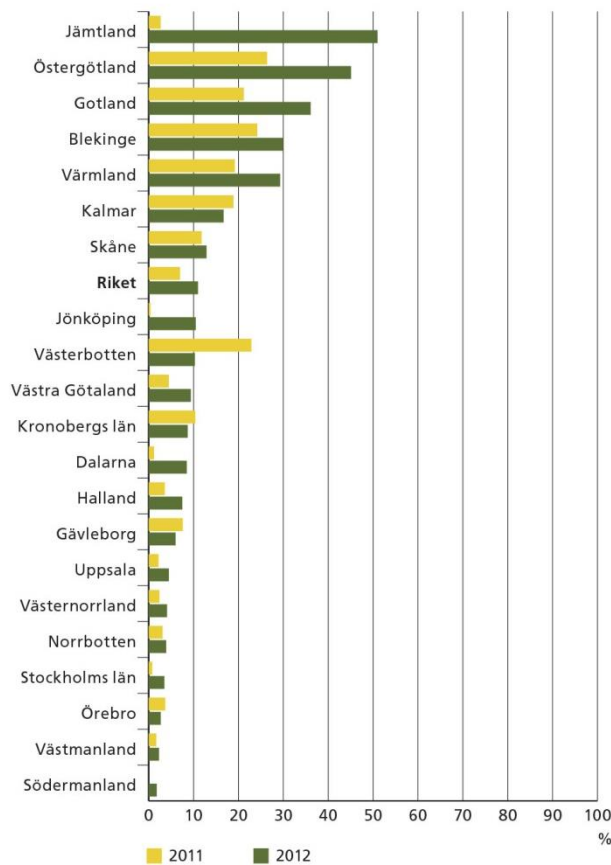


FIGURE Coverage

Results 2012

This chapter presents the results based on cumulative data from the first entries of the pilot units from 2008 to December 31, 2012. The "Realm" indicated in this report describes mean values from all registered patients. This represents only clinics that have registered at least one patient before the end of 2012, and cannot be considered representative of the entire country any more than that presented in the chapter "Participation and reporting".

Figures and tables can be viewed at www.boaregistret.se.

The number of individuals in the register are continually updated and validated. Questionnaires can be registered retrospectively and incorrect or missing data can be corrected or entered later. Patients may discontinue participation at any time. These factors influence both the number of unit-based individuals as well as all those registered, resulting in yearly variations.

This annual report is based on data from 14 705 patients with at least one visit to a physiotherapist before December 31, 2012. 7034 (48%) of these had registered consultations during 2012 (Table 2). Thirty per cent were assessed by the physiotherapist as having most symptoms from their hips, and 70% from the knees. We refer to them in the annual report as patients with osteoarthritis of the hip or knee. Many patients have problems from both hips and knees. In this report we do not distinguish patients with symptoms from several joints from those with single joint problems. One hundred and twenty two patients reported symptoms from a joint other than that reported from the physiotherapist examination and assessment. Seventy-nine patients reported as symptom-free at three months.

Some descriptive data (explanations the patient had previously received for symptoms, medication use, etc.) and changes over time (EQ5D, VAS and ASES) are reported on a county council level. When interpreting data the fact that some county councils have relatively few patients reported should be taken into account.

Number of patients and clinical characteristics

Age

The first symptoms of osteoarthritis can often be seen as early as at forty years of age, but it is not unusual for both patient and health care providers to seek other explanations for symptoms than osteoarthritis. Symptoms may come and go and do not often lead to medical consultations before a number of years when problems lead to functional difficulties in daily life. The prevalence of osteoarthritis increases with age because sufferers of osteoarthritis retain the illness throughout their lives, although symptoms vary over time. The average age

of patients at the first visit in the BOA registry was 65.2 years, ranging from 22 to 93 year. Age distribution for the entire registry can be seen in Figure 4. Two thirds of the patients are between 56 and 74 years (Table 3). The average age for men was 65.4 (SD 9.8) years and for women 65.1 (SD 9.6) years (Table 4)

Gender

Studies of osteoarthritis prevalence in the population show somewhat more men than women with osteoarthritis in the under 45 age group. This can depend on the fact that roughly half of all those suffering meniscus or cruciate ligament injury develops osteoarthritis within 10-15 years. A meniscus injury in 20-year-olds can also lead to osteoarthritis in 35-year-olds. At more advanced ages it is, however, more common with osteoarthritis in women. In the BOA-register 70% were women. This corresponds well with how gender distribution has been described in other studies. Still, the number of patients per unit is too small to be able to make correct comparisons between men and women at the clinical level. In the BOA-register 71% were women. In the previous annual report we noted a difference between men and women on the whole in the register. Some variables are reported again by gender, but to study gender differences in more detail, specific research projects should be based on register data. Table 4 shows similarities and differences between men and women at the first visit to a supportive osteoarthritis self-management program.

Figure 17a and 17b on page 76 shows fear of movement for men and women in the register.

Table 5a and 5b presents the number of patients, age, BMI and proportion of women per unit for osteoarthritis of the hip and knee.

BMI

Overweight is a known risk factor in the development of osteoarthritis, primarily in knee joints, but also for osteoarthritis of the finger joints. Concerning correlations between overweight and osteoarthritis of the hip the evidence is not quite clear, even if overweight has a strong correlation with a greater amount of hip problems and risk for replacement surgery. The body mass index (BMI) is often used for classification of body weight in relation to body mass. BMI is calculated by dividing body weight expressed in kg with height squared, expressed in meters. The limit for normal weight is, according to WHO, 25 kg/m², overweight implying a BMI between 25.0 and 29.99, and people with a BMI of 30 or more are classified as obese. In the BOA-register we study mean values for groups of individuals. In this way single values become less important. In order to gain reliable values height and weight should be measured by length gauges and scales. In the BOA-register BMI is based mostly on the patient's self-reported data, and should therefore be interpreted with some caution. At the clinical level one

should take into account that in some cases only relatively few patients are involved causing a few values to make a greater impact. Only units with more than 10 patients with BMI data reported in Table xxx.

Patients with osteoarthritis of the hip had a BMI of 27.0 (SD 4.4) kg/m² compared to 28.6 (SD 5.0) kg/m² for those with osteoarthritis of the knee, as seen in Tables 5a and 5b. Every third patient with osteoarthritis of the hip and every fourth with osteoarthritis of the knee were of normal weight. A third of the patients with osteoarthritis of the knee were obese as compared to a fifth of the patients with osteoarthritis of the hip (Figure 5a-b). The patient reveals weight only at the program's start. Weight reduction is an integral part of the basic treatment of osteoarthritis. Both weight reduction and increased physical activity involves lifestyle changes for most patients with osteoarthritis. Physiotherapists' expertise lies primarily in the area of physical activity and customized training, which is why a supportive osteoarthritis self-management program focuses on the increase of physical activity levels rather than in weight reduction.

Symptoms from hand and finger joints

Osteoarthritis of the hand is very common. After 65 years of age it is more common to have osteoarthritis in some finger joint than not to have it at all. Many patients with osteoarthritis of the hip and knee also have symptoms from their hands, which influences their daily activities. There is not nearly the amount of research for the treatment of hand osteoarthritis as there is for the hip, or above all, for osteoarthritis of the knee. On the other hand there is nothing indicating that information and adjusted physical activity as presented in a supportive osteoarthritis self-management program would be injurious to people with osteoarthritis of the hand. Osteoarthritis of the hip and knee in combination with osteoarthritis of the finger joint can be an indication of a more generalised condition, affecting more of the body's joints (three or four joint systems). In the BOA-register we see that despite limiting registration of patients with hip or knee symptoms, four of ten patients also report symptoms from their hand or finger joints. Table 6a-b shows the numbers and percentages of patients with disorders of the hand and finger joints at the clinical level.

Charnley categories

Osteoarthritis can appear in one or several joints at the same time. Co morbidity is also very common in osteoarthritis. It is impossible to point out the cause, but inactivity-related illnesses such as diabetes, high blood pressure and cardiovascular disease are highly prevalent in patients with osteoarthritis. The Charnley category is basically calculated by means of two questions: "Problems from the other hip/knee?" and "Have you for some other reason difficulties walking?" Charnley category A stands for unilateral problems, category B for

bilateral, and category C for any other illnesses affecting walking ability. This is, of course, a rough measurement of co morbidity whereby there can be several diagnoses or problems that do not affect walking ability. However, one can say that category C patients assess themselves as less mobile than the two others. Figures 6a-b show the distribution of Charnley categories in the BOA-register for the patients included during 2012. A third of the patients have symptoms from one joint alone, while 45% state other causes of gait problems than osteoarthritis in the joint in question. A supportive osteoarthritis self-management program is probably most effective for those with Charnley category A.

Marital status and sick leave

People who have difficulty reading and understanding Swedish may have difficulties responding to questionnaires, which are not yet available in other languages. Language difficulties are no obstacle to obtaining information in a supportive osteoarthritis self-management program, but participation is then preferably individual. Patients registered in the BOA-register should have a good understanding of the Swedish language.

Osteoarthritis afflicts a large portion of the working population. Half of those in the BOA-register are under 65. Medical leave, sickness compensation, and production loss make up large proportions of societal costs as a consequence of osteoarthritis. Patients with osteoarthritis of the knee are more often on sick leave than the general population (1). It is unclear if this is due to osteoarthritis, or as a consequence of co morbidity. Table 7a-b shows that 12% of those with osteoarthritis of the knee and 7% of those with osteoarthritis of the hip are on sick leave. One of the objectives of BOA is that knowledge and individually adjusted training will reduce medical leave as a result of osteoarthritis of the hip and knee. Sick leave alone with no other intervention has no or little effect on osteoarthritis of the hip or knee. People with osteoarthritis that have physically heavy work should probably consider the possibilities of other activities. Prolonged sitting also affects the development of osteoarthritis negatively. A job with varied tasks or opportunities for movement and motion can often help reduce symptoms caused by osteoarthritis, just as much as physical training.

Previous measures

Health care providers have informed many osteoarthritis patients that nothing can be done and have therefore consequently received either no treatment whatsoever or only pain relief through 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” and that osteoarthritis is disease that only affects cartilage. Many also have an erroneous understanding of the nature and function of cartilage. Research in the last decades has taught us how osteoarthritis can affect tissues throughout the joint, that cartilage requires loading, and has the ability to regenerate. There is much to be done mostly by patients themselves, with the help and support of correct advice and guidance.

Proportion radiological-confirmed osteoarthritis

The Swedish Board of Health and Welfare has established in its new guidelines that osteoarthritis is to be diagnosed with the aid of the medical history and clinical examination, and that radiological examination should be used only in unclear cases, or if a specialist referral under consideration. For many years the diagnosis of osteoarthritis has been based on radiographic changes, with or without symptoms. The diagnosis is often a prerequisite for treatment initiation. In BOA the diagnosis is based on the medical history and examination, and by excluding other possible causes of hip and knee problems. X-ray is not necessary for participation in a supportive osteoarthritis self-management program. We strive to reach patients with problems from the hip and knee as early as possible in the course of the disease to reach the best effect through life style changes and increased activity levels.

Previous physical therapy

Patients in the BOA-register reply to questions from the physiotherapist concerning earlier treatments. Patients can apply for a supportive osteoarthritis self-management program directly without necessarily having been in contact with health care prior to a supportive osteoarthritis self-management program. About half the patients indicated having met a physiotherapist for their hip or knee problems before a supportive osteoarthritis self-management program. This does not, however, always imply that patients have received adequate basic treatment. According to both national and international guidelines all patients with osteoarthritis of the hip and knee should be offered information, individually adjusted training and advice on weight reduction when needed. This also comprises the evidence forming the basis for the Swedish Board of Health and Welfare’s guidelines. About 50% of the patients in the BOA-register had met a physiotherapist prior to osteoarthritis school, but only roughly 14% of the patients with osteoarthritis of the hip and 22% of the patients with osteoarthritis of the knee were offered adequate basic treatment.

Grundbehandling (Tables 8a-b).

Information

Sometimes you hear that osteoarthritis is described for patients as 'wear and tear'. This choice of words is ill advised since they lead thoughts to worn out joints not to be used for fear of

wearing them out through further activity. In actuality research shows that inactivity is a greater risk factor for osteoarthritis and poor health in connection with osteoarthritis and that cartilage fares better of dynamic loading such as in walking, cycling, and calisthenics. It is important for the sufferer to know what osteoarthritis is and that there is much one can do oneself to influence symptoms and function. The result of a survey conducted by BOA in autumn 2012 showed that 6 out of 10 adults over 40 were not aware of what osteoarthritis was and that 36% thought that osteoarthritis was due to worn out joints.

In the BOA records, we see that one-fifth of the patients told that they wear before they get to a supportive osteoarthritis self-management program. Many have been told that they have osteoarthritis, but do not know what osteoarthritis means or what to do about it (Figures 9a-10b). From 2012 a new response option was introduced to the BOA form: "The patient did not seek medical care for current trouble before". In time it is hoped that a large proportion of patients will go directly to a physiotherapist and a supportive osteoarthritis self-management program without prior medical consultation. This is still only a small percentage even when taking into consideration that only patients from 2012 could respond.

Pharmaceuticals

Pain reducing medication is recommended as a complementary treatment when information and physical activity are insufficient. Pharmaceuticals that stop the most intense pain can be needed in order to remain active, and should only be used as an exception and for short periods as the only treatment. Paracetamol is recommended as the drug of choice. If insufficient, or when there are contraindications for paracetamol, non-steroid anti-inflammatory and pain reducing medication is recommended (NSAID). Glucosamin is mentioned on the "not-recommended" list in the The Swedish Board of Health and Welfare's guidelines since there are not high quality or impartial studies that have been able to show adequate effect. The same is true for hyaluronic acid. Cortisone injections can have a good but short lasting effect. A number of natural medicines claim in ads to have a good effect but there is currently only very limited evidence for these results.

Patients themselves state in the BOA-register which medications they take for their hip and knee problems. Three fourths of the patients stated in 2012 that they took some joint-related medication (TABLE 9a-b). Paracetamol and NSAID preparations were used regularly and were used by about half the patients. Compared with previous years, the use of drugs largely unchanged. A trend towards increased use of paracetamol and decreased by NSAIDs for hip problems may be seen for men. Among women, consumption of paracetamol decreased somewhat for knee pain. The proportion of patients reporting taking glucosamine continues to decline slightly compared with the previous year (Figure 11a-b). Cortisone injections are most

common in the knee, since injection in the hip joint requires fluoroscopy of the joint to ascertain correct injection placement. Seven percent say they are taking some herbal preparations. This can valuable information since some preparations can have a negative influence on the effect of other medications. "Other" means for example Tramadol and Lederspan. Each patient can take more than one preparation. Distribution of medication indicates the distribution of the total amount of medication taken by the patients in the register and says nothing of how many preparations are taken by each individual.

Previous surgery

In the BOA-register the physiotherapist asks the patient about previous joint-related surgery (not muscle or other soft tissue surgery) for the most difficult as well as for the opposite side. For osteoarthritis of the knee every fifth patient has been operated on for the most bothersome joint and every sixth on the opposite side (Table 10b). Many arthroscopies are performed on doubtful grounds and unnecessarily according to open comparisons 2009-2012 and The Swedish Board of Health and Welfare advises against arthroscopic surgery for osteoarthritis in its national guidelines for musculoskeletal diseases/osteoarthritis (2). Comparison with the results from the annual report 2011 shows a proportionate increase of 10-14 per cent in the contra lateral joint. The proportions who were operated on the most problematic hip are less than 10% (Table 10a).

Changes in the EQ5D, pain VAS, and self-efficacy

Below are the changes after 3 and 12 months for a number of patient-reported variables. Distribution measurements are not reported and the results should be interpreted with caution as the number of patients in some cases is still relatively low. The tables display comparisons at county council level, while changes at the clinical level can be seen in Figures 13a-14b. All results are paired data, which implies that only individuals who have completed a one-year follow-up before December 31, 2012 with data from all three follow-ups, are reported. The results are reported separately for patients with the most symptoms from the hip and knee, respectively. For the interpretation of clinic-based results subject demographics (case-mix) should be taken into account. Regions/units with fewer than 50 complete registrations on the EQ5D for hip and knee, respectively, are not reported separately, but as part of the national data. For VAS-pain, ASES-pain and ASES-symptom at least 20 complete registrations are needed for separate presentation.

EQ5D

The EQ5D measures health-related quality of life. The patient answers five questions on mobility, hygiene, activity, pain and anxiety/depression. There are three choices for each

question (no symptoms, moderate symptoms, extreme symptoms) and based on the responses, an index can be calculated ranging from 0 to 1, where 0 equals "death" and 1 equals "full health". The EQ5D-index can assume values less than zero, which means that they rate their health as worse than death. The EQ5D has been used in numerous studies of various diseases and diagnoses, and can also be used for health economic calculations. Our goal in BOA is to reach patients before their health-related quality of life has been affected excessively, and that through a supportive osteoarthritis self-management program make a difference in the EQ5D of 0.1 after a year. The goal is plotted as a line in Figures 13a-b, respectively. At present, we can show a mean change in the EQ5D after three months of 0.07 for osteoarthritis of both the hip and knee. After one year, the change is on average 0.03 for osteoarthritis of the hip and 0.04 for osteoarthritis of the knee compared with the supportive osteoarthritis self-management program. The major challenge is to improve or maintain a change over time.

Pain (VAS)

The Visual Analogue Scale (VAS) is an instrument for estimating 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 pain is experienced in so many different ways it is difficult to compare VAS between individuals. The VAS should be used only to measure changes in pain over time. One of the great advantages of the VAS is its simplicity for use in the clinic. For a change to be clinically meaningful it should be at least 10. A decrease of VAS over time means improvement. The results at the clinical level are sorted by one-year results. It is common to see an improvement in pain after three months, but the results in many cases are lost at the one year follow-up.

Self-efficacy concerning pain and other symptoms

A supportive osteoarthritis self-management program aims, among other things, to increase physical activity levels for patients with osteoarthritis of the hip and knee. This entails a change in life style for many participants. Life style changes are difficult and demanding. A possibly decisive factor for the success of the intervention is self-efficacy. Low self-efficacy concerning symptoms will probably negatively affect motivation to life-style changes. Studies have shown that high self-efficacy concerning symptoms can be of great value in the initiation and successful implementation of life style changes such as becoming physically active. The Arthritis Self-Efficacy Scale (ASES) is used by BOA for measuring changes in self-efficacy for affecting pain and other symptoms. The ASES starts from 10 (low self-efficacy) to 100 (high self-efficacy) and a meaningful change should be greater than 10.

"Case-mix" profile

Patient composition, or case-mix, can vary both geographically and between clinics. This is an important factor to consider when studying results. Variations in age, gender distribution and co morbidity can influence outcomes of one and the same treatment.

The case-mix profile consists of six variables:

- **Percentage with most symptoms from the hip.** It appears as if a supportive osteoarthritis self-management program has slightly less effect on osteoarthritis of the hip.
- **Proportion with hand problems.** Symptoms from the hands may indicate a more generalized form of osteoarthritis affecting multiple joints.
- **Proportion Charnley category C.** Charnley C means that the patient has problems other than osteoarthritis affecting walking ability. For these patients, a supportive osteoarthritis self-management program has a limited effect on health-related quality of life and physical activity, as there is another illness present.
- **Percentage age 65 or older.** We do not yet know whether a supportive osteoarthritis self-management program has the best effect on younger or older patients. The hypothesis is that intervention early in the course of the disease has the greatest potential for improvement.
- **Percentage on the waiting list for surgery.** Patients with more severe osteoarthritis awaiting surgery have worse outcomes. The very fact that you are waiting for surgery can also affect expectations.
- **Proportion of women.** For many medical conditions, women have a worse prognosis. It is unclear whether the female sex means a better or worse starting point for a supportive osteoarthritis self-management program. Further analyses will show which gender constitutes the most difficult case mix.

The left hand column below shows graphically how subject demographics (case-mix) are in throughout the country (yellow) and at the different units (blue). A large blue area corresponds to a "difficult" case-mix and a small area means in this case "best" conditions for successful results. The limit value is set to the respective variables largest and smallest value, respectively ± 1 standard deviation (SD). Only units with at least 50 patients and data on all variables at the 3-month follow-up are presented. When interpreting the clinic's value compass and results the case-mix must be taken into account.

Indicators/value compass

The value compasses show the national results after three months (red) related to five

variables (indicators) and results per clinic (blue). The best value is in the periphery and the worst value is at the origin. A large blue area therefore means a good result. The limit values are set to the respective variable's largest and smallest value, respectively ± 1 SD. Clinics with better values than the national average covers the colour compass. Only units with data from at least 50 patients on all variables after three months are presented. The cumulative results for hip and knee, respectively, are combined to obtain a larger patient base.

The value compass contains the following variables:

- EQ5D gains after 3 months
- Change in pain after three months. A value in the periphery means a reduction in pain.
- Change in fear of movement after three months. A value in the periphery represents a greater proportion of reduced fear of movement.
- Application of knowledge represents the proportion who says they use what they have learned in a supportive osteoarthritis self-management program school every week, every day or several times a day. Satisfaction with a supportive osteoarthritis self-management program corresponds to the proportion of those who felt that a supportive osteoarthritis self-management program was good or very good.

For details of the values for each variable, see Tables 15, page 75.

Change in fear of movement, desire for surgery and physical activity

Fear of joint damage

It is a common misunderstanding among patients that joints “wear out” and that continued use or activity will cause further damage. Many also believe that pain or other symptoms means that one should avoid the activity that triggers symptoms. This type of misunderstanding can be an obstacle to physical activity, and information from the osteoarthritis school aims toward attitude changes. Such a misunderstanding can be an obstacle to physical activity and activities of daily living. The information provided in a supportive osteoarthritis self-management program aims inter alia at changing perception among patients (see Chapter patient participation). The figure below shows the proportion of men and women who fear that the joint will be damaged by physical activity or exercise before a supportive osteoarthritis self-management program, and after three and twelve months for the entire register (cumulative number). For values at the clinical level, see Table 15.

Proportion with daily pain

Osteoarthritic pain frequently relapses. Periods of more intense pain are followed by periods of

lesser or no pain. These periods may vary in duration from a few days up to several months or years and are difficult to predict. Figures 18a-b shows the percentage of patients at the first consultation, at three and twelve months, stating that they have pain every day or constantly in the hip or knee, respectively. Only units with at least 10 patients who have completed the one-year follow-up before December 31st, 2011 and data from all three cases are reported in the figure. The results are sorted by the proportion with pain at the one-year follow-up. In the entire register 84% of patients with osteoarthritis of the hip indicate pain every day at the first visit. The percentage drops to 66% after three months, still 14% below the initial value of 70% after one year. The corresponding figures for osteoarthritis of the knee are 81% at the first consultation, 64% after three months and 62% after one year. A reduction of nearly 20%.

Desire for surgery

Many patients erroneously believe that surgery is the only treatment for osteoarthritis and that osteoarthritic hips and knees must be replaced sooner or later. They then desire surgery as soon as possible to gain as much benefit as possible from their new joint. This attitude can convey false expectations, and the figure below shows the proportion of patients desiring surgery before osteoarthritis school and after three and twelve months for the hip and knee, respectively. Figures 19 a-b represents the entire register (cumulative data) and is presented according to gender. The proportion seeking a surgical solution is higher among men than women.

Increased physical activity

One of the goals of a supportive osteoarthritis self-management programs is to motivate patients to physical activity at a level sufficient to maintain good health. There are no validated and reliable questionnaires for patients with osteoarthritis. We have, until the 31st of December, used three questions from the Public Health Institute's studies in BOA. When The Swedish National Board of Health and Welfare published the proposed new disease prevention methods 2011, there were questions about tobacco use, alcohol consumption, physical activity and diet. We decided to replace questions from the Public Health Institute with the The Swedish National Board of Health and Welfare's two proposed questions about physical activity. The new questions were introduced on September 1, 2012. We also included a question concerning smoking habits. Agreement with the Public Health Institute's questions is relatively good, but to avoid uncertainty in the results the annual report for 2012 includes only data on physical activity until August 31, using exclusively the Public Health Institute's wordings. Results after September 1, 2012 will instead be reported in the Annual Report 2013.

Figures 20a-b shows the percentage of patients that have increased somewhat or greatly increased their physical activity levels over the past three months. The results are presented at

the clinical level for units that have had at least 10 patients at the 3-month follow-up. Note that the number of units that have reached sufficient numbers of patients is less than last year due to the fact that the number of patients for 2012 has only been calculated up until including August 31st, 2012.

Percentage exercising weekly

Physical activity is defined as any form of physical exercise that increases your heart rate. Exercise is physical activity that is done with a specific purpose, such as to improve strength or fitness. For physical activity to promote health it should be performed at least at a moderate intensity, i.e., so that one becomes slightly out of breath or sweaty. The figures below show changes in the proportion of patients who say they exercise enough to become short of breath or sweaty, at least once a week at three and twelve months compared to the first consultation. Figures represent the entire register (cumulative number). Results are presented at the clinical level for units having had at least 10 patients at the one-year follow-up in 2012 with complete data for all three occasions. The results are sorted by the magnitude of change after one year. (Figures 21a-b)

Proportion exercising at a recommended level for health

The World Health Organization recommends that all people, regardless of age or illness, must be active at least 30 minutes per day, several days a week, with such an intensity that they become short of breath or work up a sweat. BOA's goal is that 80% of patients will achieve this level after one year. The goal of each unit is that 10% of patients will achieve 30 minutes per day most days per week at one year compared to the first consultation. The figures below show the proportion of patients who say they exercise at least 30 minutes at least four days per week and how this proportion changed over time. Figures represent the entire register (cumulative number). The results are presented at the clinical level for units that have had at least 10 patients at the one-year follow-up with complete data for all three occasions (Figures 22a-b).

Patient views of a supportive osteoarthritis self-management program

Percentage considering a supportive osteoarthritis self-management program good or very good

After three months 92% of patients reported that they thought that a supportive osteoarthritis self-management program was good or very good, 5% said it was neither good nor bad, and 0.7% (65 patients) indicated that they found a supportive osteoarthritis self-management

program to be poor or very poor. Two percent could not make an assessment or had not responded (data not shown).

In connection with the one-year follow-up the register received a letter along with a questionnaire in December:

"To whom it may concern"!

A supportive osteoarthritis self-management program truly lifted me up by providing me with a much higher quality of life. It helped me overcome my fear of physical activity and has gradually left me practically symptom free, I can now do just about anything I feel like doing. Kind regards, Rolf"

Percentage daily using the knowledge from a supportive osteoarthritis self-management program

One way to measure the benefit of a supportive osteoarthritis self-management programs is to ask patients how often they use what they have learned in supportive osteoarthritis self-management programs in their everyday lives. After three months 62% indicate that they use what they have learned in a supportive osteoarthritis self-management program once or several times a day, and 92% say they use what they have learned at least once weekly. Six percent could not decide or had not responded. One percent said they never use any of what they have learned in supportive osteoarthritis self-management programs. After a year 75% still use what they learned at least weekly, an increase of 4 percent from last year. Thirty-six percent use knowledge from a supportive osteoarthritis self-management programs daily.

Participation in a supportive osteoarthritis self-management program

The minimal intervention in a supportive osteoarthritis self-management program (see Figure 1) consists of information on osteoarthritis and the available treatments. The information is provided by physiotherapists, and in some cases, occupational therapists, who have gone through a two-day training in osteoarthritis and a supportive osteoarthritis self-management program. Information about lifestyle changes such as weight loss or exercise may seem insurmountable and difficult to absorb for those with joint pain and difficulty moving without pain. The same message from someone in a similar situation, which one can identify with, can be experienced easier to receive. In a supportive osteoarthritis self-management program we work with osteoarthritis communicators, i.e. patients with osteoarthritis who have tried to follow recommendations and has experienced the difference a change in lifestyle and activity level can bring. Osteoarthritis informants are trained by the Swedish Rheumatism Association

to share, in an educational way, their experiences of non-surgical treatment and how to live a good life in spite of osteoarthritis (Patient Interaction).

The National Board of Health and Welfare recommend in their national guidelines for musculoskeletal disorders that patients with hip and osteoarthritis of the knee should be offered supervised exercise for a long time (2). Those who accept to participate in a supportive osteoarthritis self-management programs are offered in most cases an individually adapted and tested training program, and the opportunity to practice this program under the guidance and supervision of a physiotherapist in six weeks. Group training is carried out together with others with osteoarthritis who had their own programs. The patient can choose which elements in a supportive osteoarthritis self-management programs that he/she wants to participate in. If the patient actively chooses to have their exercise program and participate in group training, he/she has also moved away from a being passive recipient to being an active and motivated participant.

Figures 25a-27b show how percentage of patients with hip and osteoarthritis of the knee who chose to participate in the different parts of a supportive osteoarthritis self-management programs. There are large variations between the units in terms of participation. There may be several explanations. Neither the causes nor consequences of these differences can be seen directly in the results, but are subject to local analyses.

Dropouts/operated

A total of 887 patients (6%) had been operated before the 12-month follow-up. Operation implies total joint replacement of the hip or knee. Descriptive data for these patients compared with the rest appear in Table 16. The number of individuals with complete data varies slightly between the different variables. In Table 17 averages for those who have answered the questions are presented.

One thousand two hundred forty nine patients (8.4%) dropped out from a supportive osteoarthritis self-management before the 12-month follow-up for reasons other than surgery. Table 17 shows descriptive data for these in comparison with others.

Two-year Follow-up

Each year, the two-year follow-up is sent to 100 randomly selected patients among those that responded to the one-year follow-up the previous year. They are then monitored annually for as long as they live. The number of patients in 2012 participating in a multi-year follow-up is still relatively small. The number of patients participating in the two-year follow-up

accumulates yearly. For the 143 patients who completed the two-year follow-up of 2012 the EQ5D was 0.67 and pain VAS 39.

Practice

BOAs policy is that all those running a supportive osteoarthritis self-management program are to have been trained in managing a supportive osteoarthritis self-management program, and the registrant should have completed training in register skills at least equivalent to what BOA offers. Furthermore, the primary target is the patient's best, which requires evaluation and analyses. Each unit offers structured information corresponding to a supportive osteoarthritis self-management program to patients, and evaluate and register their results in the BOA-register to meet minimal requirements. How a supportive osteoarthritis self-management program conducted at each clinic we call practice. Variations in practice for the different clinics may affect results. Practice is therefore a factor to be considered, along with patient composition (case-mix), when interpreting the results of a supportive osteoarthritis self-management program. Advice about exercise and activity can be organized in a way that best suits the unit. Training is implemented in a way that each department considers appropriate, provided that the structure is similar for all patients in the clinic involved in a supportive osteoarthritis self-management program. The structure is reported to the register once yearly, or when a change occurs, or when changes occur, through the practice document on the website. Training is optional. The patient's choice of exercise (supervised/home training) is registered.

Training of muscle function is not based on a specific number of 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 considered acceptable to the patient. An eventual increase of pain after training should also be gone within 24 hours, otherwise duration and/or intensity should be adjusted. Interviews with patients have shown that feedback is experienced as a particularly important aspect of training. The physiotherapist is present and available for continuous feedback of both movement quality and execution and choice of exercise and dosage on each training occasion. Parallel to supervised training home exercise and continued activity after osteoarthritis school's completion is planned to stimulate continuity and a health-inducing activity level over time.

Not all clinics have access to training equipment and thus cannot offer training. Others have chosen to focus on information alone and can then have a greater flow of patients. Not all clinics have established cooperation with a local osteoarthritis patient organisation and can thus have difficulties offering the services of an osteoarthritis informant. Some clinics work with other professionals such as occupational therapists or dieticians within the sphere of the

osteoarthritis school. Examples of other factors that can vary between clinics are patient flows, number of involved lecturers, length and number of sessions per program.

Each clinic is asked to annually, or when changes in the structure occur, report back as to how their supportive osteoarthritis self-management programs are conducted.

1. Hubertsson J, Petersson IF, Thorstensson CA, Englund M. Risk of sick leave and disability pension in working-age women and men with knee osteoarthritis. *Ann Rheum Dis*. 2013 Mar;72(3):401-5. PubMed PMID: 22679305.

2. Nationella riktlinjer för rörelseorganens sjukdomar 2012. Socialstyrelsen.
www.socialstyrelsen.se

Validating data

The results can never be better than the quality of the data collected. The risk for incorrect data entries increases due to the several stages involved in data collection. The BOA-register strives toward minimizing the sources of error and has created routines for providing users the opportunity to check and correct their data. Thanks to the fact that participating units themselves use the data fed into the register the probability of eventual incorrect entries being revealed, corrected and thereby improved also increases as does the quality of the register's data.

The majority of the data in the BOA-register is based on patient-reported outcomes. The physiotherapist answers questions concerning previous examinations and treatment, as well as adherence to the intervention. The patient completes a questionnaire at the physiotherapy reception on the first visit and at a follow-up visit after 3 months. Responses are fed into the register by the physiotherapist or in some cases by the administrative personnel. At the one-year follow-up the questionnaire is sent to the patient by mail along with a self-addressed stamped envelope. The physiotherapist answers questions concerning previous examinations and treatment, as well as adherence to the intervention.

Response frequency and "missing values"

The BOA-register has a very high response rate. The question with the highest proportion of missing values, having been left unanswered by 3.5% of the first consultation patients, is the question "Have you been on sick leave during the last year due to your hip/knee problems?". There can be several reasons for this but the most probable is that they are uncertain whether sick leave was due to joint symptoms or some other cause. The question to the physiotherapists most often left unanswered has to do with symptom duration (1.7%). A probable cause can be that the patient, at the time of the history, does not remember when the symptoms began. The question concerning the most symptomatic joint was unanswered in 1.7% of cases, and thus the question with the most missing values. For the physiotherapist the report on adherence to the intervention is the major source of missing values, even if it is only missing in 2.9% of cases.

At the one-year follow-up the questionnaire is sent to the patient. Of the 4014 one-year follow-ups sent during 2012, 88.5% were returned first after a reminder. The question most often left unanswered at the one-year follow-up was "Do you have problems with your other hip/knee?" with 8% unanswered.

Data quality

There are certain limit values for input to the register. The values beyond these limits cannot be entered. In other cases quality controls can be made by means of descriptive reports. A minimal number of responses to questions is presently necessary in order to be able to save the questionnaire, such as the consultation date, or the joint and side which is most symptomatic. It is possible for each unit to fetch their own reports online in real time. By processing data the possibility for identifying incorrect data increases. Checks for data quality are now routine procedure for the BOA-register twice yearly. Eventual incorrect entries, extreme values or questions without responses are mailed to each respective unit before the summer and Christmas breaks when activities at the physical therapy reception are slow and there is time to check and correct the data. During 2013 a number of visits to units were carried out with the aim of providing support and to facilitate data entry and the use of the unit's data for operative analyses and the work of improvement. On these occasions, the correlation between input data and responses to the paper copies are to be checked on a random sample of forms in order to gain an idea as to the proportion of incorrect entries. A check of the one-year form against input data showed that 4 of 100 forms had some kind of error. Input data was otherwise correct for 3196 of 3200 (99.9%) responses.

Prior to the production of the 2012 annual report a number of further checks of the input data was carried out in order to confirm data quality. "Impossible" dates (for example a consultation date prior to the start of the register in 2008), duplicates and missing values were identified and examined in more detail. Some data could not, for various reasons, be corrected, leaving 133 individuals who had extreme or missing data and 2 with no information whatsoever concerning the most symptomatic joint. These patients could thus not be classified. Forms for 482 individuals from the first visit were lacking and 52 registrations were duplicates. These were removed from the dataset prior to the compilation of the annual report. One patient had written to the register and told of how he/she had received another explanation for his/her joint problem than osteoarthritis and this patient was consequently removed from the register.

BOA and improvement efforts

The effect of a physical therapy intervention, a supportive osteoarthritis self-management program, can be monitored in the BOA-register. Physiotherapists report activities that can be quality improved by means of feedback. Results from the BOA-register can be used to improve the entire continuum of care for patients with osteoarthritis of the hip and knee.

Target levels as stimulus and guides

By developing target levels (see Development Objectives and Areas for Improvement), the BOA-register identified possible areas of improvement for a supportive osteoarthritis self-management program. In this annual report, for example, we demonstrated how unit performance is relative to the target level of EQ5D (objective improvement of 0.1) and the proportion of those physically active at a level sufficient to maintain health (target 80%). Through careful analyses and intelligent innovation units can reflect on how to best reach the target. By downloading results online and observing them in real time, each unit is able to monitor changes over time. In BOA's report sections it is possible to define a period to obtain specific results. It is essential to evaluate whether a change actually leads to improvement. Focusing solely on results can be misleading. It is essential to spend time and resources on effective measures, i.e. measures that provide optimal results in relation to cost. Simply put, a costly or more resource-intensive treatment should yield better results than a less costly one to justify using greater resources. Results need not, on the other hand, be felt immediately, but may require extended evaluation, for example by reducing the need for care or reduced sick leave over time.

The focus of care and rehabilitation has traditionally been production, "points for money." Results have not been systematically evaluated, and there has been no systematic means to see the long term effects of rehabilitation. The health care system in Sweden should be fair based solely on science and proven experience. Many treatments used in physical therapy are not scientifically documented. That does not mean they have no effect, only that they have not been systematically evaluated. Physical therapy treatment is largely based on practical experience, leading to considerable variations within the country. By measuring variations and comparing them openly as in a national quality register they can be used as a stimulus for improvement. By learning from each other, we can reduce variation and thus provide better care. The stimulus for change is greatest for those units with the poorest outcome. In this way, variation can be utilized. It is, of course, also about measuring and evaluating the right things. It is not primarily about the process but about what really matters to the patient. In the case of osteoarthritis of the hip and knee, there is considerable scientific evidence that

information/knowledge and adapted physical activity (that which is offered in a supportive osteoarthritis self-management program) is effective.

Cost benefit

A health economic calculation performed at Gottsunda Medical center in Uppsala County as part of a project to implement flow of patients showed that a supportive osteoarthritis self-management program costs 1500 dollars per patient (1). The report estimated costs based on 40 patients, taking into account factors such as time consumption, local costs and the cost of educating two physiotherapists in a supportive osteoarthritis self-management program.

A supportive osteoarthritis self-management program is a relatively inexpensive intervention which can therefore be justified even though the effect is not so great on a group level. With the approach commonly implemented in BOA, with six weeks of supervised exercise, we see an improvement in the EQ5D in the register of 0.07 for both hip and knee osteoarthritis. After a year, the effect decreased slightly to 0.03 for hip osteoarthritis and 0.04 for knee osteoarthritis. The calculation from Gottsunda had included supervised training for 12 weeks, and evaluation was carried out after 6 months. A change was then seen in the EQ5D of 0.14 for knees and 0.06 for hips. The study at Gottsunda was conducted on a relatively small number of patients, but can be nonetheless considered representative of BOA: 31 women and 9 men between 49 and 85. Twenty-five had symptoms from the knee, and 12 from the hip. Three had symptoms from both the hip and knee. In light of these comparisons, one must consider whether 12 weeks of supervised practice may possibly have a better effect on knee osteoarthritis than just six weeks. On the other hand it is unclear whether a longer training period results in better outcomes for hip osteoarthritis. This type of continuous evaluation, where resources and costs are related to effects and results are examples of improvement that can be initiated at the individual units by using data from the BOA-register.

The use of a National Quality Register is new for physiotherapists. There is a need for increased knowledge of the potential of quality registers and on improvement skills, both at the undergraduate level and for clinically active physiotherapists. For a register to be of benefit to patients at the individual clinic requires 1) that physiotherapists have time set aside to report, and 2) that there is time to collect and study their results and consider possible areas for improvement. Through BOA, we now have the opportunity to disseminate the practical skills of improvement. We organize one-day internal and external courses in order to both increase the number of units that report to the BOA-register and increase the use of their results. By units using their results units can easily uncover inaccuracies in input and improve the quality of the data.

1. Hälsoekonomisk utvärdering av Artrosskola på Gottsunda vårdcentral. September 2012. Karolina Eldelind, FFoU-enheten, Primärvården; Inna Feldman, Hälso-och sjukvårdsavdelningen, Landstingets ledningskontor
2. Boström G. Hälsa på lika villkor. Resultat från nationella folkhälsoenkäten 2005. Statens Folkhälsoinstitut, 2006 Rapport No.: A 2006:02.

Patient involvement

The patient's understanding of the treatment of osteoarthritis has influenced the design and content of a supportive osteoarthritis self-management program. The BOA-register involves patients in both the intervention and the steering committee. Professionals and the patient organization cooperate as well (The Swedish Rheumatism Association).

How and why

Osteoarthritis is classified as a rheumatic disease and osteoarthritis patient's interests are safeguarded by a strong patient organization, the Swedish Rheumatism Association. The Swedish Rheumatism Association has worked for rheumatic patient's rights to a good life and sought the solution to the mystery of rheumatism since 1945. The Association's work follows four basic paths: local association activities, education of both patients and healthcare professionals, influencing decision makers and supporting research in the area. The Swedish Rheumatism Association is organized into 200 associations divided into 24 districts with about 50 000 members.

The Swedish Rheumatism Association's collaboration with BOA is now conducted on several levels. On a national level in BOA's steering committee (representing both the Swedish Rheumatism Association and the patient perspective), at the county level where BOA's liaison interacts with the Swedish Rheumatism Association's District's representative for patient educational activities, and at the local level, where the physiotherapist is in contact with the informant from the Swedish Rheumatism Association. Cooperation also takes place in the education of both physiotherapists and informants.

The objective of collaboration is to increase adherence over time among participants with the help of role models such as informants. Another aim of the local Rheumatism Association is to offer participants, who do not feel at home in the gym and cannot or will not train at home, an opportunity to continue training when the program has ended. The partnership benefits all those involved.

Coverage and education

At each training session for physical and occupational therapists the Swedish Rheumatism Association recruits a patient with special skills to speak of the importance of collaboration as well as of practical details. Informants involved in a supportive osteoarthritis self-management program do so at no cost to healthcare. As more and more physical and occupational therapists are being trained, all the more supportive osteoarthritis self-management programs

are starting up with an increased demand for osteoarthritis informants. Over 900 patient programs were held with this cooperation throughout Sweden in 2012.

Informants are trained for two days by the Swedish Rheumatism Association to pedagogically inform of their experiences of living with osteoarthritis and how lifestyle changes and active coping strategies can lead to a better quality of life and less symptoms. A physiotherapist from a supportive osteoarthritis self-management program participates in the training of osteoarthritis informants to provide the program involves.

“Nyttan”

One of our informants speaks:

“I was in hospital when a skilful orthopaedic surgeon that had performed surgery on me approached me for a chat. He praised the supportive osteoarthritis self-management programs and told of patients that had benefited from them. Patients don't listen to physiotherapists and even less to physicians, he said, but they do listen to "expert patients". It turned out that he had personal experience because his wife had participated (although I had no idea at the time!) in the group we concluded yesterday. She had benefited greatly and embraced much that he had tried to convey earlier but had apparently not succeeded. We continued to discuss the benefit of training before surgery, of which its importance he had more and more understanding. That was also discussed in the training group yesterday. So be as glad as I am – the Swedish Rheumatism Association represented by patient informants is needed and beneficial to the supportive osteoarthritis self-management programs!”

By involving a patient experienced in living with osteoarthritis in a supportive osteoarthritis self-management program we add another perspective to the message that it is not dangerous to be active when in pain and that training is an effective treatment. When the physiotherapist speaks of the importance of physical activity and training some patients feel that this does not apply to them whereby their experience speaks for the opposite that it hurts to load the joints. If a patient with personal experience of osteoarthritis says the same thing, the message becomes easier to accept since they can identify with the patient's description.

This is probably best illustrated by a patient, now an informant that had participated in a supportive osteoarthritis self-management program:

I went to the doctor with my bad knee in 2010. After being x-rayed and meeting with the orthopaedist, I was advised to participate in a supportive osteoarthritis self-management program. My family doctor had never heard of a supportive osteoarthritis self-management program, so I searched the internet for information. A supportive osteoarthritis self-

management program didn't feel like a reasonable alternative. I had formerly been very active and trained extensively, wanting to get back to it. Surgery felt like the only alternative. Time passed and my quality of life plummeted. I couldn't be nearly as active as before and felt that life was over. Does it have to be like this? I gradually got in touch with a physiotherapist that informed me that they were starting a supportive osteoarthritis self-management program in the spring of 2011. When he called and told me it was time to begin I went there mostly for the sake of my orthopaedist. He had said that I had to try a supportive osteoarthritis self-management program before he would perform surgery. I went twice and was still very doubtful. The third session was held by a so-called "expert patient", an osteoarthritis informer. I went, sat in a corner and brooded. But when the informant began her story I was completely captivated. I could see myself in her. I particularly remember when she said it was okay if it hurt during training. You don't make it worse. She repeated this several times and I became more and more interested in what she had to say. She also said I should use the joint and not spare it as if injured, but should use the bad leg just as I do my good one. It felt like she knew what she was talking about. She had arthritis herself and lived with it. I had used my bad leg only as a support to keep from falling down. When climbing stairs I put all my weight on my good leg. The informant succeeded in getting me ready to give training a try. I began training and felt improvement just after 3 times. After twelve sessions I was like a new person.

I was asked if I would like to be an osteoarthritis informant. At first I didn't feel suited but now I'm out there informing groups with participants on the sides who think "this is not for me". I then tell them that I had been in their shoes. I know exactly how they feel since I had felt that way myself.

I have regained the will to live. Sometimes I have more pain and sometimes less, but I train hard twice a week and, not unusually, walk for an hour. Walking sticks are the best for maintaining balance. I have several painful joints but have decided to avoid surgery for as long as possible. /Göran

Discussion

Osteoarthritis is a common diagnosis in primary care and few patients directly consult a physiotherapist

Statistics BOA has presented and data at www.vantetider.se from Västra Götaland show that 13% of all visits to primary care are related to joint pain or osteoarthritis of the hip or knee. Our estimates also show that 12% of people over 45 consult primary care at some time during a five-year period (equivalent to 2.5% annually) because of joint pain or osteoarthritis of the hip or knee. Most consultations are to physicians, and visits to a physiotherapist are not routinely reregistered. Data from Östergötland shows that 28% of all patients with joint pain or osteoarthritis of the hip or knee have met a physiotherapist, while 89% have consulted doctors. Our figures from the register show that only a small percentage of patients go directly to a supportive osteoarthritis self-management program without having previously sought medical care for symptoms. The information that one can seek a physiotherapist directly, without referral, needs to be disseminated to the general public and patients with joint symptoms.

Results over time

Results in the BOA-register's annual report shows that a supportive osteoarthritis self-management program, in most cases, leads to a distinct reduction of pain and improvement in health-related quality of life (EQ5D) on a unit level after three months. The EQ5D evaluates health-related quality of life with an index from 0 (death) to 1 (full health). This index was calculated from responses in five areas: mobility, hygiene, activities of daily living, pain, and anxiety/depression. Questions are

answered with one of three alternatives: no symptoms, moderate symptoms or major symptoms or difficulties. We see that the patients coming to a supportive osteoarthritis self-management program rate their health-related quality of life to 0.64 for osteoarthritis of the hip and 0.65 for osteoarthritis of the knee. This compares with, for example, patients coming for hip arthroplasty, who estimate their EQ5D to 0.41. A year after arthroplasty the mean value of EQ5D has improved to 0.77, according to the Swedish Hip Arthroplasty Register's annual report 2011. To present the average EQ5D index provides no information for which

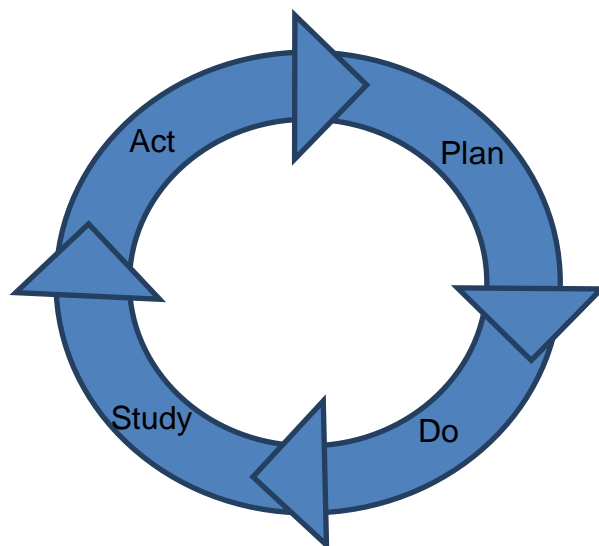


Figure PDSA cycle. The improvement cycle illustrates the different steps in the improvement process (1). It is ideally a continuous process where new learning leads to new ideas that are tested and

subcategory of the EQ5D most affected by osteoarthritis and a supportive osteoarthritis self-management program. It would be of interest to highlight the subcategories individually in future studies.

One of the goals of BOA is to achieve a change in the mean of the EQ5D at 0.1 after 12 months. We see that several units reach this result after 3 months, but that the effect of a supportive osteoarthritis self-management program is later reduced over time. Extensive variation can be seen between units. In all comparisons between units and counties caution is called for, and factors such as the number of patients and case mix should be taken into account. Variation should be seen as a prerequisite for improvement. Not everyone can be best, but the units whose performance is below the national average could, by careful analysis and sensible operational changes, implement the work of improvement as do those closer to the goal and higher up in the table comparing units. Physiotherapists are zealous when it comes to reporting data, but data collection is also necessary in order to identify areas for improvement. The value compasses show results after three months for a number of variables, but the units should also monitor other variables and trends in the results after one year. We see a clear tendency amidst results for several variables deteriorate between 3 and 12 months. Without having studied paired data mean values for pain VAS and EQ5D appear unchanged after two years, compared with one-year data. The decline observed probably occurs some time between 3 and 12 months. Each unit should therefore consider what can specifically be done to maintain good performance over time, examine that change and re-evaluate to see if the change also resulted in an improvement. This is the basis for improvement (Figure PDSA-cycle) (1).

The most evident trend of deterioration between 3 and 12 months can be seen in self-efficacy. Self-efficacy for pain and other symptoms decreases after one year to levels lower than for patients consulting for osteoarthritis of the hip for the first time. We also see the percentage of patients preferring surgery is reduced after three months, but increases again at one year, most significantly for men with osteoarthritis of the hip. The proportion is still lower than prior to a supportive osteoarthritis self-management program. What is happening? Does this symbolize the frustration and powerlessness that patients feel when symptoms reappear? Is it when self-efficacy for influencing symptoms falters that patients consider surgery? This is probably not the only explanation. If we look instead at the change in pain between 3 and 12 months, we definitely see a slight increase in pain, but still lower than at first consultation. Similarly, the proportion of patient who report daily pain or after three months is reduced and continues to decrease after one year. The results we see for self-efficacy can partly depend on how questionnaires are designed. Many patients feel that the questions are difficult to answer, and results may vary for reasons other than actual changes in self-efficacy. The chapter

"Ongoing Studies" describes two studies that provide us with more information on whether questions of self-efficacy in BOA are sensitive enough to measure change after a supportive osteoarthritis self-management program, what factors influence the difference in self-efficacy, and if self-efficacy influences the outcome after a supportive osteoarthritis self-management program. It is also very possible that three months is too short for lasting changes in lifestyle and that coping strategies learned during a supportive osteoarthritis self-management program are lost over time. Should we not consider an additional follow-up visit after a supportive osteoarthritis self-management program to maintain the effect? If long-term outcomes are improved by one or two additional visits this may be cost-effective.

Movement fear, or fear that the joint will be damaged by physical activity, is very common among patients with osteoarthritis. It is likely one of the most important factors for increased inactivity and thus increased ill health. Among the men who come to a supportive osteoarthritis self-management program one in five is afraid that the joint will be damaged by activity, while one in eight women share these concerns. A supportive osteoarthritis self-management program aims to inform patients that activity or pain during activity is not dangerous. Activity on the contrary has a proven effect on the symptoms of osteoarthritis. The proportion of men afraid that the joint will be damaged by physical activity decreases by 43 per cent from the first visit to the one-year follow-up. For women, the corresponding figure is 38 per cent. We do not know what this implies in terms of reduced illness and health economic benefits, but it probably lowers the need for care and increases the welfare of individuals.

Another of the register's goals is that 80% of patients after one year are to be physically active at a level that prevents ill health. This particular variable was affected by replacement of previous questions regarding physical activity with The Swedish National Board of Health and Welfare's proposals as of September 1, 2012. In this annual report, we have chosen to report only results up until and including the 31st of August in order to retain comparable values between the first visit and follow-up. This, however, implies that some units had a relatively low number of patients according to results for 2012. The "missing" patients will be reported in the annual report for 2013.

The proportion of patients reaching the recommended 30 minutes of physical activity of at least moderate intensity most days of the week was only about 20% after a year, which is roughly the same figure as before a supportive osteoarthritis self-management program. Improvement is also required here in order to increase adherence to exercise and adapted physical activity over time. It is likely that deterioration seen in pain and the EQ5D after a year is related to decreased physical activity.

Completeness

It is difficult to measure completeness for a physical therapy intervention in primary care, whereby this data is often missing in patient registers. It is also difficult to track down visits in a number of regional medical databases for a particular category of caregiver. In order to later evaluate, for example, how care processes change over time as well as the effect of a supportive osteoarthritis self-management program on patients it is desirable to develop a common information system containing these statistics. Search words can be created in some medical record systems, such as "a supportive osteoarthritis self-management program". It is then simple to search for those patients that have participated in a supportive osteoarthritis self-management program and compare them with the number of patients reported to the BOA-register at a unit (completeness). Most record systems, however, do not have this function.

The proportion of patients reported of those that participate in a supportive osteoarthritis self-management program will never be 100%. Patients with osteoarthritis along with another disease or diagnosis more symptomatic than osteoarthritis can be considered to benefit by a supportive osteoarthritis self-management program, but are not registered with BOA. The reason is that an estimate of health-related quality of life and pain in the patient questionnaire is probably more affected by symptoms caused by diseases other than those related to osteoarthritis. Patients with only hand osteoarthritis, without symptoms from the hip or knee, are not currently registered by BOA, but can participate and benefit from a supportive osteoarthritis self-management program. Patients can also refuse registration. It is difficult to estimate the percentage of patients in a supportive osteoarthritis self-management program that have other symptoms or illnesses that exclude them from registration.

A reasonable assumption can be that an average of 5-10% of the participants should not be registered. We have, for the first time, requested the contact persons of the regions to gather data from as many units as possible concerning the number of people having participated in a supportive osteoarthritis self-management program in the respective regions. This data showed that an average of 77% of all patients participating in a supportive osteoarthritis self-management program is registered. Regional variation is considerable, and we need to study the reasons for low percentages in certain regions in greater detail. Some resistance remains among department heads caught between annual budget demands as opposed to taking time from patient care for registration. Reimbursement schemes generally prioritize productivity alone. Registration of results can, however, save time and money by enabling units to determine whether time is being spent on the right things. The Swedish National Board of Health and Welfare estimates that adherence to guidelines for osteoarthritis can save health care between 20 and 25 million SEK yearly. To systematically evaluate operations with the aid

of quality registers is still something new within rehabilitation. Patients that learn to deal with their illness and feel better will consult health care less frequently, which will win time in the long run.

In BOA's case completeness implies describing the number of supportive osteoarthritis self-management programs that report to the register. According to information we have received from eight regions 56% running a supportive osteoarthritis self-management program report to the register. This number can be representative for the country since it is based on statistics from regions with low registration levels (7% in Örebro region) to those with high levels such as from the regions of Jämtland and Gotland, where all units running a supportive osteoarthritis self-management program report to the register. We see good prospects for bettering completeness within a year whereby Örebro has now, after having evaluated results from those units that have reported, have decided to train more colleagues in a supportive osteoarthritis self-management program, and that all units will report to the register to monitor their results. Eight units that had previously reported patients to the register failed to do so in 2012. This was because two of the units, SU Mölndal and NUS Umeå, ran supportive osteoarthritis self-management programs at the orthopaedic clinics. In pace with greater renown the supportive osteoarthritis self-management programs have moved out from these clinics to primary care. This move was planned. However, it was unclear why the other six units chose not to register. The visible effect of a reduction in completeness was seen in Västerbotten, Kronoberg and Gävleborg. Fewer patients of the estimated number seeking care for osteoarthritis were reported, and the total number of registered patients in the region for 2012 was lower than for 2011. The reasons for this decrease need following up. Primarily the register, through regional contact persons, will contact units to seek out and, wherever possible, address any difficulties or obstacles to registration. There should also be interest, on a county council level, in following up and remedying declining reporting to the quality register.

In an attempt to make their own estimates of the proportion of the number of people over 45 seeking primary care because of osteoarthritis of the hip or knee that are taken care of in a supportive osteoarthritis self-management program, we examined the statistics from a number of health databases. We contacted seven county councils/regions and received replies from six. In three cases the basic material sent was not comparable due to changes in the medical record system leaving, thereby, a lack of complete data, or because it was not possible to gain data on the number of unique individuals.

Changes in the care process

Osteoarthritis is not a disease affecting only the elderly. The register shows that 14% of patients are under 54 and 45% under 65. At user meetings views that we still reach patients

all too late in the disease process emerged. Efforts with information and individualized activity earlier in the disease process probably have more potential for change and the ability to prevent functional impairment. BOA-register users sought efforts to lower the average age to 58 years. To achieve these necessary changes in the chain of care of osteoarthritis patients are needed, so that patients meet first with a physiotherapist. Caregivers and information pages about osteoarthritis on the web need to urge patients to appropriate advice and assistance early in the course of the disease. We should also ensure that waiting periods for patients seeking treatment for osteoarthritis are minimized. This applies both to waiting time due to insufficient numbers of patients to start a supportive osteoarthritis self-management program, and that are due to too few places in relation to the capacity of a supportive osteoarthritis self-management program. Through early intervention, we can probably reduce inactivity and fear of movement, which can result in better conditions for good health and a successful outcome in a supportive osteoarthritis self-management program.

The diagnosis of osteoarthritis should be based on clinical findings and the medical history, as recommended by The Swedish National Board of Health and Welfare's guidelines (2012). The proportion x-rayed in their joints before a supportive osteoarthritis self-management program remains at the same level for osteoarthritis of the hip, but has decreased slightly for osteoarthritis of the knee compared with last year. The decrease is gratifying, whereby it may mean that the guidelines are beginning to show an impact, and that, in turn, implies that patients can receive adequate non-surgical treatment at an earlier stage of the disease. In 2012 the Swedish Hip Arthroplasty Register (SHPR) introduced a question in its register as to whether patients had been in a supportive osteoarthritis self-management program preoperatively. Statistics from March 2013 showed that 17% of patients in the SHPR answered that they had participated in a supportive osteoarthritis self-management program since the question's introduction in 2012, while 57% had met a physiotherapist prior to implant surgery. Data from the BOA-register shows that only 14.5% of those consulting a physiotherapist for osteoarthritis of the hip and 22% of those who applied for osteoarthritis of the knee had previously received adequate treatment.

In trying to estimate the cost-benefit effect of a supportive osteoarthritis self-management program, we ask units reporting in the "practice document" what they receive for treatment reimbursement from the County Council. Many of the units running a supportive osteoarthritis self-management program have no idea. For others, we can see that compensation varies between clinics and between counties. This is interesting because the intervention is standardized and conducted similarly throughout the country. The price list is not public, making it difficult to estimate the economic effects of a supportive osteoarthritis self-management program.

Risk factors

Compared with 2011, the proportion of overweight and obese patients in the register increased. We see that only a third of patients with osteoarthritis of the hip and a fourth of the patients with osteoarthritis of the knee are within the limit for normal weight. Being overweight is a risk factor for the incidence of osteoarthritis but can also increase both the level of symptoms and worsens the prognosis for those already suffering from osteoarthritis. We have, in BOA, focused chiefly on physical activity in life style change. The intervention of a supportive osteoarthritis self-management program is also relatively short, leading us to the decision that it is irrelevant to study changes in BMI over time. Weight is, in many cases, self-assessed, resulting in greater uncertainty. A limited amount of information on weight's importance is provided in a supportive osteoarthritis self-management program. Influenced by the Swedish National Board of Health and Welfare's guidelines for illness preventive methods we are considering adding something about health and diet. Three units in the BOA-register have no obese patients, one in Stockholm, one in Helsingborg, and one in Gothenburg. It may be due to socio-demographic factors, but could also be due to a consciously or unconsciously selected sample of patients at the clinics.

Symptoms from other joints and co morbidity are common for patients with osteoarthritis. We see in the register that 40% of all those with osteoarthritis of the hip and nearly half with osteoarthritis of the knee state also having symptoms from the hand or fingers. The proportion of women with hand symptoms is twice the proportion of men (25% vs. 49%). The men that partake in a supportive osteoarthritis self-management program more frequently have osteoarthritis of the hip, and it is more common that they only have symptoms from one joint. We see that a supportive osteoarthritis self-management program has a slightly better effect on osteoarthritis of the knee than for osteoarthritis of the hip. The fact that a greater proportion of men have osteoarthritis of the hip and that a supportive osteoarthritis self-management program has not been as effective on hips could be one reason why men often request surgery. Four of ten patients have other reasons for difficulty walking than osteoarthritis of the hip or knee. A supportive osteoarthritis self-management program probably has a lesser potential for influencing health-related quality of life in patients who have other illnesses that limit their ability to walk than in patients with only osteoarthritis.

Approximately 7% of those with osteoarthritis of the hip and 12% of those with osteoarthritis of the knee in the register report having been on sick leave because of their hip or knee symptoms, and 3% have been on sick leave for more than three months. Even if these figures are based on self-reported data, it is a high percentage. Sick leave without further measures is ineffective in the treatment of osteoarthritis. On the contrary, it may be a relief to go to work and focus on something other than joint symptoms for a while, provided that the work is not

too heavy.

1. Deming WE. Out of crisis. Cambridge, Massachusetts: Cambridge University Press; 1986.