# **Towards Evidence-Based Self-Management for Spondyloarthritis Patients**

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*Abstract*—We developed a concept including a set of tools for self-management for patients suffering from axial spondyloarthritis (SpA). This concept involves patient-recorded outcome measures, both subjective assessment and clinical measurements, that are used to present recommendations. We report from experiences made while implementing a proof of this concept. Besides giving the patient a self-management tool, our work also improved the methodology for clinical measurements.

Keywords—axial spondyloarthritis; self-mangement; healthcare; self-assessment; evidence-based; mobile applications.

### I. INTRODUCTION

For a variety of chronic diseases, patients managing the condition themselves (self-management) can result in reduced costs in the health care sector and an improved clinical outcome [1]. Self-management encompasses methods where the patient participates in managing their disease through education and changes of behaviour and lifestyle [2] [3]. In evidence-based self-management, elements such as clinical assessment, collaborative priority and goal-setting, patient selfefficacy, and active follow-up are essential [4]. We look closer at self-management settings [5] where patients assess the status of their disease using sensors and questionnaires on their smartphones and report the results (i.e., patient-reported outcome measures) [6] [7]. Based on the results patients receive non-pharmacological recommendations from the selfmanagement system to increase their coping skills, help with pain management, adhere to their medication regime, improve self-care behaviours, and enact lifestyle changes.

Spondyloarthritis (SpA) describes a group of several related, but phenotypically distinct rheumatic diseases, such as ankylosing spondylitis (AS). The condition axial SpA is characterised by inflammatory back pain and mainly affects the axial skeleton, which is distinct from peripheral SpA with other symptoms. In axial SpA, the first appearance is mainly in young adulthood and can lead to structural and functional impairments and a decrease in health related quality of life. Although axial



Fig. 1: Concept for controlling the disease with the three parts: selfmanagement, clinical assessment, and patient-health personnel communication.

SpA is a chronic condition, the symptoms and disease activity vary over time [8]. The primary goals for managing axial SpA are to maximise long term health-related quality of life by controlling symptoms and inflammation, preventing progressive structural damage in the spine, and normalising function and social participation. Relevant medication and physical training are recommended as the foundation of the management of axial SpA [9].

Currently, there are few self-management tools for axial SpA that are evidence-based. Some tools for subjective assessment exist, but sensor-based tools for objective assessment are not yet available to the wider public. Also, there are obstacles to let patient-assessed data be of use in a clinical setting [10].

This paper presents a concept for evidence-based, selfmanagement of axial SpA, supported by an implementation of a smartphone and sensor-based system that can give recommendations to the patients. We report from experiences from this implementation.

The remainder of this paper is organised as follows: After a brief presentation of related work (Section II) and presenting

our concept of self-management for axial SpA patients (Section III), we show details from the proof of concept implementation involving subjective and sensor-based clinical assessment and recommendations to the patient (Section IV). Further, we present the results from a usability test (Section V). We discuss our findings (Section VI) and conclude in Section VII.

### II. RELATED WORK

Considerable work has been done on self-management programs for chronic diseases with good results in terms of quality of life, and reducing the need for care and cost efficiency [11]. Programs such as *The Chronic Disease Self-Management Program* have shown significant improvement in health distress and increased perceived self-efficacy [12]. The motivation for these programs is to provide people with chronic diseases the tool to efficiently mange their own condition.

We can find management support for some chronic conditions using information and communication technology (ICT). These include: a self-management application called SoberDiary for alcoholism [13], a mobile application for diabetes that integrates with personal smartwatches [14], a virtual coach for chronically ill elderly [15], a smartphone app for rheumatic diseases management [16]. There are also generic apps for integration vital signs into personal health devices or electronic medical record systems [17].

Within axial SpA there are ICT apps like SpA Helper [18] that helps monitor the disease. But the results from the monitoring are not part of a feedback cycle; i.e., they do not use the treat-to-target principle (Section III-A).

#### III. SELF-MANAGEMENT

We find multiple definitions of *self-management* in the literature. But we prefer the definition by Barlow et al. [19] "... the individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and life style changes inherent in living with a chronic condition." Barlow et al. stress that monitoring one's condition and the effect of responses to daily life can lead to a dynamic and continuous process of self-regulation.

#### A. Integrating Treat-To-Target

The *treat-to-target method* [20] has been developed for treating axial SpA. This evidence-based method is used after diagnosis and early treatment, when the disease has reached a stable state (Fig. 1). At this stage, an individual treatment plan has been created for the patient. This method uses a treatment goal (*target*) for a *treatment plan*. Following the treatment plan and regularly assessing the patient's status provides evidence about how the disease develops. When the patient's status moves away from the treatment target to a worse condition, health personnel, in discussion with the patient, might adjust the treatment plan or target.

As part of an evidence-based, self-management setting, the treat-to-target method is extended so the patient can perform self-assessment to gather evidence about the current disease condition by performing assessments, answering questionnaires,



Fig. 2: Treat-to-target in a self-management setting, showing tasks to be performed by patient and health personnel, respectively.

and following the progress from the patient diary. The patient diary data can be used for patient-health personnel communication by making it available to the clinical personnel, either regularly or when needed (e.g., a patient visit).

Fig. 2 shows how treat-to-target can be aligned with selfmanagement. The upper unshaded part of the drawing is the health personnel domain. This is where health personnel perform clinical assessments and decide the treatment target and treatment plan. The lower shaded part is the patient's domain. This is where the patient can perform assessments, compare with the target, and adjust some elements of the treatment, e.g., physiotherapy or exercise.

#### B. An Architecture for axial SpA Treatment

Our concept (Fig. 3) builds on a) a solution for selfmanagement, b) better quality and effectiveness of *clinical assessment*, and c) enhanced *patient-health personnel communication*.

The solution for self-management lets the patients use tools at home to control the disease. It includes patient-reported outcome measures [7], the assessment of ample parameters, the use of a patient diary [21], patient guidance with respect to the treat-to-target principles, and alerts in case of changes of the patient's condition or physical function.

The concept also enhances the quality and effectiveness of clinical assessment; assessment methods developed for selfmanagement are made available for clinical assessment.

The concept includes a foundation for patient-health personnel communication. Self-reported assessments can be used for patient-health personnel communication to explain or visualise the development of the disease and data transfer to the hospital.

# IV. PROOF OF CONCEPT FOR AXIAL SPA Self-Management

The parts of this architecture that include data exchange between a health cloud or a patient's devices and the electronic health record (EHR) system are beyond the scope of our work. These are parts that rely on policies defined by public healthcare providers. So, we focused on implementing tools for clinical assessment and self-management.



Fig. 3: Architecture of a self-management system including three parts: selfmanagement, clinical assessment, and data exchange.



Fig. 4: Drawing of the APERTUS sensor used for axial movements.

#### A. Medical Assessment Methods for axial SpA

Medical self-assessment is essential for evidence-based selfmanagement. So, these self-assessment methods should be based on medical assessment methods since evidence for their effectiveness is documented.

The AS Disease Activity Score (ASDAS) is used for measuring and monitoring disease activity in axial SpA. It is based on a composite score of domains relevant to patients and clinicians, including both self-reported items and objective measures [22].

The Bath indices [23] present outcome measures for use with SpA patients, and consist of four indices: the Bath AS Metrology Index (BASMI), the Bath AS Functional Index (BASFI), the Bath AS Disease Activity Index (BASDAI), and the Bath AS Patient Global Score (BAS-G). These indices are designed to give a good clinical assessment using a minimum number of measurements or questions to be answered. The BASMI is five simple clinical measurements; the other indices consist of a number of questions that are answered on a rating scale from zero to ten.

Østerås et al. [24] described a set of assessment tests that are candidates for axial SpA self-assessment. These exercises include: lateral spinal flexion, modified Schober's, cervical rotation, occiput to wall distance, tragus to wall distance, intermalleolar rotation around the vertical axis, lumbal/thorcal rotation, six-minutes walking test, stair climb test, sit-to-stand test, fingertip-to-floor test, and maximum grip strength test.

### B. Sensor-based clinical measurements

APERTUS developed a sensor that can measure rotation around the vertical axis such as cervical rotation, thoracic rotation and hip abduction (measured in the supine position). Furthermore, the result can be transmitted via a wireless connection to a receiver, such as PC, tablet, or smartphone. This inertial sensor is packaged in a small box (Fig. 4) that can be attached to the body. The size of the device is  $55\text{mm} \times 35\text{mm} \times 3\text{mm}$ . The sensor contains radio technology that follows Bluetooth standards that might influence electronic devices in 2.4 GHz ISM, but to a significantly lower degree than mobile phones.

Compared with other technology such as lasers or optical sensors, this sensor's advantages include its high precision and being cheaper, smaller, and lighter than the other solutions. Compared to the traditional way of measuring rotation with a goniometer or myrinometer (e.g., compass) the sensor provides more precise measurements. The sensor is a simple way to achieve satisfactory measurements in acceptable use of time and without health personnel assisting.

In a laboratory setting, the sensor has excellent criterion validity and reliability for rotation around the vertical axis in the range of motion from 10 to 120 degrees. The angle can be measured with a precision of  $\pm 1.3^{\circ}$ . These findings justify proceeding with further evaluations of the sensor for this kind of measurements [25] [26]. A clinical trial of the rotation measurements with 60 patients suffering from axial SpA is currently under evaluation.

We developed a suitable user interface for the assessment process with the sensor. The assessed data are stored locally in the patient diary and forwarded to the health cloud for permanent storage.

#### C. Self-Assessment of Subjective Conditions

For the assessment of the subjective conditions for BASDAI and BASFI we implemented suitable user interfaces in our prototype (Fig. 5). We also implemented a questionnaire for ASDAS, a composite score including subjective evaluation and the inflammatory markers C-reactive protein (CRP) and Erythrocyte sedimentation rate (ESR). Patients answer The questions on a scale from zero to ten by tapping on the appropriate number. We did not choose sliders because we assumed that tapping on the appropriate field would be easier for the target group with their possible movement restrictions.

After the form is finished, the data are stored locally. An estimate of the current health condition is shown to give the patient feedback along with the possibility to report these data to the health cloud for permanent storage.

Questionnaires can be scheduled using the mobile device's calendar by creating calender entries with a specific syntax. The calendar then reminds patients to perform assessments at a given time.

# D. Self-Management and Recommendation

A self-management system needs to support the patient in the following ways: a) deciding the type and degree of adjustments for non-pharmacological changes in a treatment plan, such as diet, training, lifestyle, or other minor adjustments; b) identifying significant deviations from the expected progress and present these deviations to the patient and health personnel; c) advising changes of treatment plan to the health personnel; and d) suggest changes of patient's target to the health personnel. Qi et al. [27] present an approach for how to make decisions that are presented to the patient. We use a diary in our solution.

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(a) The	(b) The BASFI menu.	(c) The result page.

ASDAS/BASDAI menu.

Fig. 5: Screenshots for the data collection module.



(a) The diary login (b) The diary patient (c) The diary history view screen. view. for BASDAI.

Fig. 6: Screenshots from the patient diary app.

The diary shows the disease's development visually, deviations from the treatment plan, and gives recommendations using *trend labels*. The patient view (Fig. 6b) shows the patient's birth year, the current left and right cervical rotation, and the current scores for ASDAS, BASDAI, and BASFI, including their targets. Each of these scores can have historical data; this is shown in the patient history view (Fig. 6c) and summarized in the trend labels (Fig. 7) to the right of the value. There are five trend labels: (*a*) disease activity is increasing, but below target; (*b*) disease activity is increasing, either below or heading towards target; and (*e*) disease activity is decreasing, but still very high and needs more treatment.



### E. Heuristic Decision Support Based on Medical Expertise

We created simple rules to guide patients and health personnel. These rules are based on the values from ASDAS, BASDAI, and BASFI.

The values derived in ASDAS and BASDAI indicate the amount of disease activity. Machado et al. [28] define cutoff values for disease activity measured using ASDAS: *a*) under 1.3 the disease is inactive; *b*) between 1.3 and 2.1 disease activity is moderate; *c*) 2.1 to 3.5 disease activity is high; and *d*) Over 3.5 disease activity is very high. A change on the ASDAS scale of 1.1 or more is considered a clinically important change while 2.0 or more is considered a major change. Based on this work, we indicate the trend of the scores (up, down, or steady), as well as the severity (colour). The thresholds can be personalised for patients where health personnel defines alternative values.

Braun et al. [29] propose a similar approach for BASDAI by calculating a trend line that uses BASDAI targets for cutoffs. Situations where the BASDAI is above 4.0 - indication of high disease activity - or changes of the BASDAI over 50% or a factor of two also generate a warning to contact health personnel.

BASFI indicates the disability level. Wariaghli et al. [30] ran a large survey with Moroccan patients and defined the target values depending on the patient's age in three age ranges. We use similar rules as above for determining the trend based on the patient's target or age information, depending on what is available.

#### V. USABILITY TEST OF THE PROTOTYPES

Usability, how easy something is to use, is an important factor for adoption and continuous use of a system or application. Motivated by this, we performed a usability test of the two developed prototypes. We wanted to see how appropriate the apps are for their purpose, and to get feedback on the usability. We employed the System Usability Scale (SUS) developed by Brooke [31]. The SUS consists of ten questions that are rated by the participants on a five point or a seven point Likert scale [32]. The ratings are used to calculate a score on a scale from 0 to 100 where 70 is the average score. Additionally, we added six questions on related matters that are not part of the SUS scale, e.g., the need for the apps, satisfaction, and whether participants would recommend the apps to others.

For the usability test, we recruited eighteen individuals with Android smartphones among members of the Norwegian Rheumatology Association (Norsk Revmatikerforbund). We asked the eighteen to download the two apps and sign up for the usability test. Of the invited participants, fourteen followed the procedure, downloaded the app, and registered at the health cloud site. The individuals received the link to the surveys after they had downloaded the apps and a text message with instructions. Of the eighteen individuals, nine used the apps and completed the test.

With only nine respondents, the usability test is more a pilot study. If an application has major usability weaknesses, these will likely be revealed with small sample sizes also. Our

TABLE I: SUS scores for the collection module app and patient diary app with highest and lowest scores removed.

	Average	Median
Collection module	73.73	80.20
Patient diary	74.05	74.35

test did not indicate major weaknesses. We did not perform statistical analysis of the data beyond calculating SUS scores.

We performed separate tests for each app. The average and median from the SUS are presented in Table I with the highest and lowest scores eliminated. The SUS scores of the apps are 73 and 74, respectively.

## VI. DISCUSSION

The proposed concept for self-management is based on a feedback loop with the patient is involved. Axial SpA does not require immediate attention when the condition worsens, but an appointment with a clinic needs to be scheduled. Also, not adhering to the self-management regime does not have other side-effects beyond not adhering to the treatment, and these patients need to keep the conventional frequency of clinical follow-ups. Note that other chronic diseases might require immediate attention in some situations or not adhering to the self-management regime might worsen the patient's condition. Thus, an evaluation is needed for other conditions than axial SpA to see if our self-management architecture can be applied.

Data assessed in self-management are usually not complete or might be of a different nature in terms of the clinical indices. For example, the values extracted from blood samples might not be available, only selected values from the BASMI examinations might be available, or the patient assesses alternative measurements that are not part of the established indices. To support recommendations in these cases, it is necessary to predict an individuals axial SpA disease condition based on a combination of physiological, behavioural and subjective (self-reported) features. To achieve this, Schiboni et al. [33] have proposed a fuzzy rule-based evidential reasoning (FURBER) approach for multiple assessment fusion. But this approach requires enough real patient data as training data to be considered for real treatment.

The medical indices for axial SpA and the data retrieved from the FURBER method are only suited to give an indication of the disease conditions at one moment. For predicting the probable development of the patient's health condition and whether actions need to be taken requires temporal reasoning. Modelling the disease development as a stochastic process to optimise the treatment recommendations could be done by a Markov Decision Process (MDP) [34]. Yet a large sample size could make this approach less viable [35]. Alternatively, the *patient profiling* method described by Lutz et al. [36], could be feasible.

The new assessment methodology for rotation exercises using sensor technology will also impact clinical use as it will save time and provide better results. Today, health personnel use goniometer or compass-based measurements that are time consuming but have acceptable accuracy. The trials in clinics have shown this new methodology simplifies clinical measurements, greatly improves accuracy, and saves time for the health personnel and the patient. The time saved and higher-quality data quickly make up for the cost of the sensors. Specifically, the much higher accuracy and easier handling of the sensor technology compared to the traditionally used methods is attractive to health professionals. Furthermore, the sensor will enable patients to perform the measurements themselves without the involvement of health personnel.

### VII. CONCLUSION

We presented an architecture for self-management of axial SpA patients that is based on self-assessment by these patients. We have performed a proof of concept by implementing vital parts of a self-management system including clinical measurements, patient-reported outcome measurements, feedback module, patient diary, and decision making software.

Further user evaluations will be necessary before a system based on our architecture can be brought into clinical practise. In addition, communication modules to the EHR system of the clinics need to be implemented. Further, the development of suitable measurements for exercises beyond rotation exercises need to be developed in a way that allows patients to perform these at home.

Finally, since patient-reported data might not be of the best quality (e.g., they have not undergone quality assurance or might be incomplete) estimation methods both for the current disease status and for temporal prediction need to be developed. While we could show the viability of the methods, further implementation work needs to be done.

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