
Go, go, GoTreatIT!

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information technology

ABSTRACT

Patient monitoring has been emphasised in rheumatology for decades. However, many obstacles must be overcome before successful monitoring is part of routine care. We describe one model: GoTreatIT.

Measuring of outcomes in rheumatology over time

In 1983, over 30 years ago, Verna Wright pointed out that “Clinicians may all too easily spend years writing ‘doing well’ in the notes of a patient who has become progressively crippled before their eyes...” (1). Thirty-three years later, at EULAR 2016 in London, when this was addressed to a full auditorium of rheumatologists who measure psoriatic arthritis outcomes, very few hands rose.

The role of measuring in clinical medicine

Medicine is not an exact science. Diseases manifest differently in different people; the experience of disease differs from one person to another. Disease feels different on a sunny day than on a rainy day, in outdoor temperature of +30°C or -30°C. A man is not a paper mill. Therefore, monitoring and measures can provide only a picture of the truth, a picture that requires interpretation. A rheumatologist is the specialist who must learn how to interpret the picture: his patient, patient’s symptoms, and many measures and the results of monitoring.

It is easiest not to measure at all

Traditionally, the doctor listens to a patient, observes, performs some basic examinations, orders some lab tests, draws a conclusion, writes a prescription; the patient gets along so and so, and the story continues. Or, with the current technology, all imaginable lab tests and imaging modalities are being used instead of listening and observing the patient. In the most unfortunate

scenario, the doctor *believes* that she/he knows and the patient *believes* that the doctor knows. Many patients get better and some are cured, but many become “crippled before the doctor’s eyes”. It appears that until current times, rheumatologists remained prisoners of their traditions: not to measure. Or to replace a patient with technology. A literature review of disease-modifying anti-rheumatic drugs in cohorts of patients with rheumatoid arthritis (RA) around the world suggested that for decades, traditions dictated medications for rheumatoid arthritis (RA) (2).

What to measure?

Over many years, lectures and articles have addressed the issue of measures in rheumatology (3). There are measures of the state and measures of improvement. Measures may be considered as “objective” and some measures can be considered “subjective”. However, sometimes subjective measures are more objective than objective measures. Some measures are surrogates for actual outcomes. In the short term, disease activity matters, but over decades, measures of permanent damage matter. However, the patient’s functional capacity and ability to work matter most, from the point of the patient, health care, society, and the tax payers.

Why to measure?

Outcomes of chronic conditions do not appear to be on the priority list of health authorities. They ask for savings in health care when they should ask for outcomes, whether patients could maintain the ability to work. Furthermore, it appears that “hotel-based rheumatology”(4) remains the trend; randomised, controlled clinical trials (RCTs) that provided the best remission rates ever (5), are ignored by rheumatology opinion leaders (6). Doctors may be paid for performing procedures including patient monitoring although in settings of socialised medicine,

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Date	25.01.2012
ID	xxxxxx-xxxx
	N.N.
Age, Gender	67, Female
Work status	Pensioner
Diagnosis	Rheumatoid Arthritis
Diagnosis criteria	- Symptoms (ACR RA): Polyarticular 1.2011 - Clinical diagnosis (ACR RA): 6.2011
Highest RF (IgM)	Positive (150) 5.2011
Highest (aCCP)	Positive (340) 5.2011
Erosions	Positive 5.2011
Drug (now)	Prednisolone 6.2011 - 2,50 mg Peroral Every day Methotrexate 6.2011 - 20,00 mg Peroral Once a week Hydroxychloroquine 6.2011 - 300,00 mg Peroral Every day
Comorbidity	Arterial hypertension 9.2008
Data confirmed	01.12.2011, miina_I (Miina, Leena)

Latest score

Date	03.06.2011	15.06.2011	01.09.2011	01.12.2011
HEALTH STATUS				
Pain	81	7	4	4
Fatigue	81	3	11	9
Morning stiffness	1,00	0,25	0,00	0,00
Rheumatic activity	80	8	5	10
Physical exercise	1-2/week	1-2/week	>=3/week	>=3/week
M-HAQ (0-3)	0,75	0,13	0	0
MDHAQ (FN) (0-3)	1,2	0	0	0
MDHAQ (PS) (0-3)	0,25	0	0	0
HAQ (0-3)	1	0,5	0,5	0,5
Raw HAQ (0-24)	8	2	0	0
DISEASE ACT.				
Inv. global	50		5	11
ESR	86		26	14
CRP	55		2	6
TJC 28/32	7/7		0/0	0/0
SJC 28/32	10/10		0/0	1/1
Patient global	58	11	6	18
DAS28 (4)	6,3		2,4	2,4
DAS28 (3)	6,1		2,6	2,5

Fig. 1. Example of automatic extract of real-life patient data using GoTreatIT

monitoring is not translated to greater earnings of health care providers.

Very few colleagues have the courage to ask an important question (7): which of many clinics scores the best in terms of treatment results? Seeking an answer to this question would help to identify the best practices and to reveal the most effective treatment strategies. These results could be disseminated to all other clinics in order to improve disease outcomes. Routine patient monitoring in actual clinical care reveals inequality in patients' disease activity and health status between countries (8), and provides insight into clinical cost-effectiveness of treatment strategies (9).

Patient monitoring stems from the basics of medicine: the primary goal of measuring is to optimise clinical decisions that maintain the patient in as

good health as possible with minimal side effects from the therapies.

How to measure?

Patient monitoring as an order from an outsider – with financial or other benefits – will die as soon as the benefit loses its value. Patient monitoring for a specified project will continue as long as the project requires – after that, measuring becomes forgotten. Possibly the only approach to perform long term patient monitoring consistently is to build it into the infra structure of the clinic, as an automatic procedure that is not affected by mood, doubts, trends or projects. Monitoring as part of infrastructure provides data for decision-making in clinical care for anyone who wishes to use it, and also accumulates big data that can be mined for many purposes over time.

Information technology (IT) in patient monitoring

In a Finnish story, in the beginning, there was swamp, a hoe, and Jussi. In patient monitoring in rheumatology, in the beginning, there was paper, a pencil and Pincus (10). Very few highly dedicated rheumatologists were able to arrange for the required machinery for patient monitoring before large scale use of IT. In fact, prior to IT, patient monitoring was beyond capacity of regular clinical rheumatologists. User-friendly IT solutions are a major advance for successful patient monitoring.

Go: GoTreatIT!

We describe below how patient monitoring is organised in a single clinic as part of a practical clinic model [text adapted from Vare *et al.* (11)].

Vision

The vision of the clinical model is based on “a Finnish treat-to-target” manifest from the 1970's “We are treating not only the actual inflammation of the joints but also the quality of the patient's life for many decades in the future” (12). In this model, treatment target is early and aims for early and permanent remission. The model aims at an informed patient and an informed health professional so that treatment decisions would not be based on the beliefs of the patient or the doctor.

Setting

Jyväskylä Central Hospital is Finland's biggest non-university hospital, covering the secondary level health care for 250,000 inhabitants. The rheumatology clinic model has its roots in the development of rheumatology care and its scientific reporting, which started many decades ago (13). The goal was to enhance the patient 'journey' through rheumatology services by providing all necessary education, treatment and care, avoiding unnecessary visits and optimising the overall quality of care provided.

Pre-clinic investigations

Patients are usually first seen by their primary care physician, who initiates the referral to rheumatology. All incoming referrals are screened by a senior rheu-

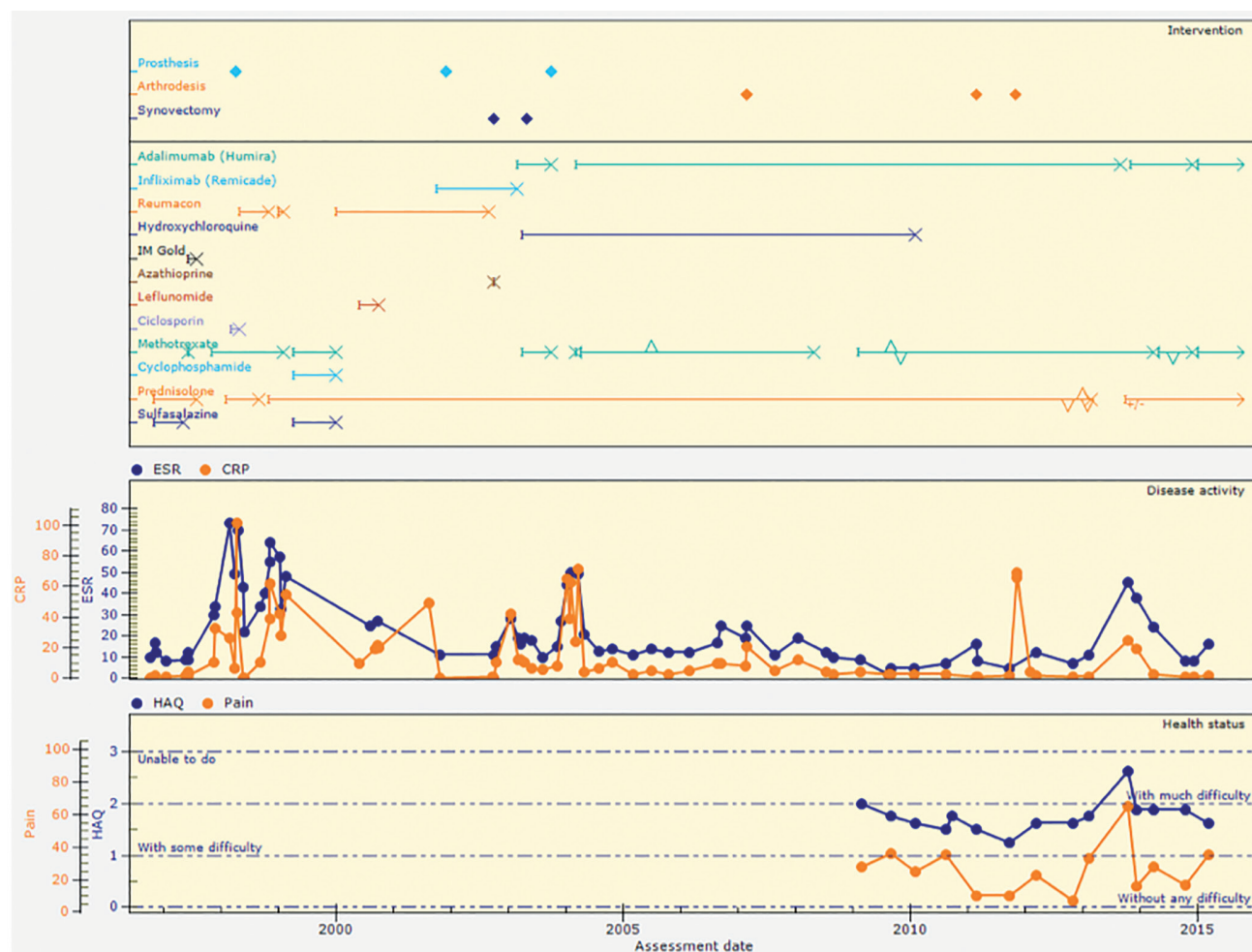


Fig. 2. Graphic presentation of patient data in GoTreatIT.

matologist. The majority are usually accepted for review with additional laboratory investigations and radiographs, including MRIs organised prior to the review. The screening of referrals aims to reduce unnecessary visits to rheumatology and to enable a pre-clinic work-up that would enhance the patient's first appointment with the rheumatologist, leading to a confirmed diagnosis and initiation of treatment without delay.

Patient monitoring

An electronic monitoring tool for continuing treatment-data collection via software, GoTreatIT has been integrated into the every-day clinical work since 2007. The programme was developed by rheumatologists in collaboration with a Norwegian company DiaGraphIT and is used to support the systematic collection of data at every visit and during the entire course of the patient's illness (14).

Upon arrival at the clinic at every visit, the patient signs in to GoTreatIT with his/her unique identification number, to complete a questionnaire, before seeing the nurse or the doctor. The questionnaire consists of questions aimed at identifying the patient's current performance status, quality of life, level of pain, fatigue, disease activity, and any other relevant issues. Several touch screen stations and tablets are reserved for patient self-report, to ensure availability of devices at the arrival of the patient. Questions appear on the screen one by one, with large font, to aid the elderly patient population. The number of questions varies between 20 and 120. The set of questions is pre-defined, depending on the diagnosis and patient's capacities. For example, a young person with axial and peripheral symptoms completes a maximal number of questions and an elderly person with memory problems, completes a short one.

At every visit, the doctor undertakes a complete joint assessment, denoting on GoTreatIT all tender and swollen joints and any intra-articular injections completed using a visual map of joints. In the same way, the doctor can easily compare current joint status to that of previous visits. Entering the data to the system is simple and takes less than half a minute.

In addition to the patient's self-assessment and doctor's observation, socio-demographic data, diagnostic tests, comorbidities, joint surgeries and permanent joint damage are incorporated into GoTreatIT. Any changes in the type and dose of medications during the course of the disease and reasons for that including any adverse events are indicated in GoTreatIT, allowing the doctor to see the complete history of medications used at a glance.

Using the questionnaire completed by patient, current laboratory values and

HEALTH STATUS (QUEST-RA)

01.01.1950 TESTINEN, TAISTO

Quest-RA part 1

Quest-RA part 2

Quest-RA part 3

Quest-RA part 4

Patient self assessment

History

08.11.2010

29.09.2010

Over the last week, were you able to...	Without any difficulty (0)	With some difficulty (1)	With much difficulty (2)	Unable to do (3)
get a good night's sleep?				3
deal with the usual stresses of daily life?			2	
deal with feelings of anxiety or being nervous?			2	
deal with feelings of depression or feeling blue?		1		

SELF REPORTED JOINT PAIN

Self reported joint pain

The diagram shows a human figure with the following pain locations marked by red squares: Neck, Right Shoulder, Left Shoulder, Right Elbow, Left Elbow, Right Wrist, Left Wrist, Right Hip, Left Hip, Right Knee, Left Knee, and both Ankles. White squares are placed at the following locations: Right Shoulder, Left Shoulder, Right Elbow, Left Elbow, Right Wrist, Left Wrist, Right Hip, Left Hip, Right Knee, Left Knee, and both Ankles. The figure is labeled 'R' for right and 'L' for left.

Score

Comments

Fig. 3. Example of a patient self-report.

remission and scheduled patient education, which limits “random” visits to the clinic. Patients with stable systemic rheumatic diseases are seen by rheumatologists once a year. The pre-specified structure of the clinic and a strong input from the rheumatology nurse allows the rheumatologist to devote up to 60 minutes for a patient, which, in the long term may be more meaningful than 5 x 12 minutes over years.

Nurse review

The nurse provides detailed education on any new diagnoses given to the patient and treatments started. The goal of patient education is an informed patient, which is achieved through a motivational interview. The patient should understand the natural course of disease, and remission as the treatment target. Patient education facilitates patient's adherence to the therapy.

Review of data

The electronic monitoring system enables a quick review of the individual patient's history of presentation, medication used, examination findings, comorbidities, values of patient self-report, disease activity measures and any other patient or disease-related details in a table or a graph for individual patients (Fig. 1-2). Responses for patient self-report can also be reviewed one by one and compared to the previous responses. Patient self-report is simultaneously made available to the doctor or the nurse or other health professional while the patient is working on it, and can be reviewed and compared to values of previous visits before patient enters to

joint status completed by doctor, the programme then generates commonly used comparable values such as Health Assessment Questionnaire (HAQ), 28-joint count Disease Activity Score (DAS28) and Bath Ankylosing Spondylitis Functional Index (BASFI) for every visit.

Doctor review

The doctor review is conducted over 30 to 60 minutes. At every visit, whether a first or a follow-up visit, the patient is assessed for important comorbidities.

ties including cardiovascular disease and related risk factors. Osteoporosis-screening using bone densitometry can be arranged if needed. Blood pressure, lipid profile, and vitamin D-levels are screened and recorded on a routine basis with follow-up instructions as necessary. Every doctor's visit should be meaningful with long-haul treatment decisions; "see you back in three months" without an appropriate assessment and management plan is practically forbidden. Structured treatment paths have been built for early diseases with the goal of

the doctor's room. Review of patient self-report directs the doctor's attention to current problems: *e.g.* an extract from a patient self-report shown in Figure 3, can be reviewed before the patient's visit and in the specific example suggests a diagnosis of fibromyalgia.

Data extraction for groups of patients is quick and easy to complete on the press of a button, and can be limited to certain periods of time, certain diseases or diagnoses.

Treatment path for new chronic patients

Since 1997, the clinic has employed a standard management protocol for patients with RA to ensure early, intensive and uniform care as per existing recommendations (15). All patients have their auto-antibodies (rheumatoid factor and anti-cyclic citrullinated peptide), inflammatory markers and other baseline laboratory tests along with radiographs of the hands and feet and patient questionnaires arranged at baseline. Patients have follow-up visits arranged at 3, 6, 12 and 24 months after the initial (baseline) appointment, with phone access to the rheumatology nurse any time needed between the scheduled visits. Each time the patient is reviewed by both the rheumatologist and the nurse. Physiotherapy and occupational therapy are organised within one month of the initial appointment, physiotherapy continuing at every visit throughout the 24-month treatment path. At 24 months radiographs of the hands and feet are repeated.

The goal of treatment is achievement of disease-remission by the three-month, latest by the six-month visit. If this is not achieved, treatment is intensified. At each visit, swollen joints are treated with local (intra-articular) long-lasting glucocorticoid injections. To ensure adherence to treatment, automated mobile phone monitoring is employed for the first 6 months (16). At five and ten years after diagnosis, patients are invited back for follow-up visits with the above procedures including patient questionnaires, laboratory tests and radiographs repeated. A similar clinical model has been used for patients with other chronic arthritides such as psoriatic arthritis and chronic reactive arthritis.

Remote patient monitoring with GoTreatIT

In patients who are in stable remission, remote monitoring is a potential option. At certain intervals such as every half a year, reminder via text message or an e-mail to complete the GoTreatIT self-report and laboratory tests is sent to the patient. Results will be reviewed by the rheumatology nurse or the rheumatologist, comparing the patient's previous values with remarks made in the electronic medical record, which the patient can review online. If disease activity is increased or other problems are identified, remote monitoring will lead to a telephone contact and/or patient visit to the clinic as judged appropriate.

Discussion

We have practiced the specific clinical model for 20 years with electronic patient monitoring using GoTreatIT already for a decade. The success of the clinical model may lie in the fact that it has been built with the 'KISS' principle: Keep It Simple Stupid (17). The patients have a key role in their monitoring since they do most of the monitoring work themselves, while waiting to see the nurse or the rheumatologist. The work load for the rheumatologist is thus kept to a minimum.

A principle for medications used in RA, "Strategy more important than the agent" (18), may also apply here. Indeed, the clinical model and strategy may be more important than patient monitoring itself. Patient monitoring *per se* is of limited value while patient monitoring as part of the infrastructure of the clinic, to maintain the patient's quality of life for decades in the future (12), is beneficial in many ways.

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