Toward Electronic Health Recording: Evaluation of Electronic Patient-reported Outcome Measures System for Remote Monitoring of Early Rheumatoid Arthritis

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ABSTRACT. ***Objective.*** To assess the use of electronic patient-reported outcome measures (ePROM) in standard clinical practice for early rheumatoid arthritis (RA) management, the ePROM ability to enhance clinical care, and how computing technology can improve the patients' adherence to therapy.

Methods. In a double-blinded randomized-controlled study, 211 patients with early RA diagnosed according to American College of Rheumatology/European League Against Rheumatism criteria completed a PROM in paper format at their first clinic visit. Patients were then randomized to Group 1, which completed an ePROM questionnaire monthly, or Group 2, which continued the standard paper PROM format. Over a 12-month period, Group 1 patients were assessed every 3 months in the clinic, whereas Group 2 patients were assessed in the clinic initially monthly for 6 months, then every 3 months. The primary endpoint was the equivalence of outcomes [Routine Assessment of Patient Index Data 3 (RAPID-3) and 28-joint Disease Activity Score (DAS28)] in both groups. The secondary endpoint was the patients' adherence to their medications.

Results. There was no significant difference between disease activity measures as well as DAS28 and RAPID-3 scores at 3, 6, and 12 months of management, although there was a trend toward lower patient-reported tender joint count and functional disability score in the active group versus the control group. The patients' adherence to antirheumatic therapy was significantly higher ($p < 0.01$) in the ePROM group, whereas stopping disease-modifying antirheumatic drugs for intolerability was significantly higher ($p < 0.01$) in the control group at 12 months of treatment.

Conclusion. We found ePROM equivalent to standard paper PROM format. Further, it enabled the patients to personally monitor how they are doing regarding their disease activity and helped to optimize their adherence to their treatment. (J Rheumatol First Release September 15 2016; doi:10.3899/jrheum.151421)

Key Indexing Terms:
PATIENT-REPORTED OUTCOME MEASURES
EARLY ARTHRITIS
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Patient-reported outcome measures (PROM) are defined as measures of a patient's health status or health-related quality of life at a single point in time[1]. They facilitate an insight into the way patients perceive their illness as well as the effect that treatment has had on their quality of life and ability to carry out their activities of daily living[2]. In standard practice, the patients, being the most knowledgeable persons able to calibrate their pain and global estimate, do most of the work by completing a questionnaire prior to their assessment in the clinic. Completion of the questionnaire, which usually comes in paper format, helps the patients prepare for their visit and reflect on their current disease activity status, and enables the treating rheumatologist to have a good estimate of the patient's current disease activity status[3,4].

In contrast to several chronic diseases, where a single gold standard measure is applicable for the disease diagnosis and management such as glycosylated hemoglobin in diabetes mellitus, blood pressure in hypertension, and lipid profile in hyperlipidemia, there is not a single gold standard measure for chronic inflammatory arthritic conditions (excluding gouty arthritis) to assess outcomes. This is applicable both in short-term trials such as joint and laboratory measures as well as in longterm studies involving radiographic progression, disability, and death. The absence of such a gold standard

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measure highlighted the need for pooled indices as a valid tool[5,6].

As electronic health records started to have their place in standard rheumatology practice, direct provision of patient-reported outcomes through standardized electronic questionnaires was suggested as a tool to improve the efficiency, completeness, and accuracy of data collection. This overall approach is consistent with a broader movement in healthcare delivery toward a patient-centered approach, with a focus on the quality of care provided, as well as the functioning of electronic health records. This was paralleled by the introduction of disease-specific PROM tools, in addition to the available nonspecific instruments[7]. This study was carried out aiming at assessment of (1) the role of ePROM in facilitating management of early rheumatoid arthritis (RA); (2) the ability of ePROM to enhance clinical care by flagging activity flares (predictive of additional structural damage), recording disease activity, and saving clinicians' time; and (3) ability of this tool to improve the patients' compliance and adherence to therapy.

MATERIALS AND METHODS

Study design. This was a double-blind, randomized, controlled, multicenter study, which included 211 patients with early RA diagnosed according to the American College of Rheumatology/European League Against Rheumatism (ACR/EULAR) criteria and managed in 3 rheumatology centers[8]. Local ethical and methodological protocols for approval of the study were followed and approved by the Ain Shams University ethics committee (approval number: 17585-R13). All patients who participated in the study signed an informed consent agreement according to the Declaration of Helsinki General Assembly (October 2008).

Participants. On confirming the RA diagnosis, disease-modifying antirheumatic drug (DMARD) therapy was commenced following the UK National Institute for Health and Care Excellence (NICE) guidelines[9], adopting a shared-decision approach[10]. According to the NICE, a combination of DMARD (including methotrexate and at least 1 other DMARD, plus short-term glucocorticoids) is offered as first-line treatment, ideally within 3 months of the onset of persistent symptoms. In people for whom combination DMARD therapy is not appropriate, DMARD monotherapy was started, placing greater emphasis on fast escalation to a clinically effective dose rather than on the choice of DMARD. Biologic therapy was started for those patients whose disease remained active [28-joint Disease Activity Score (DAS28) > 5.1] after 6 months of DMARD therapy. Monitoring disease (using a composite score such as DAS28) was to be carried out initially monthly, then every 3 months until treatment controlled the disease activity[9].

Prior to their initial assessment, each patient completed a PROM questionnaire[11]. The questionnaire, whether in paper or electronic format, included 11 domains assessing for functional disability, quality of life, visual analog scale (VAS) for joint pain, global status, fatigue, duration of morning stiffness, review of the systems, falls and cardiovascular risks, patient motivation index, and self-reported joint pain. The patients then were examined clinically for measures of disease activity, and the results assessed and recorded: tender and swollen joint count (28 joints) and inflammatory marker levels [erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP)].

After their clinical assessment, the patients were randomly allocated (simple randomization) to either a study group or a control group. Of the 251 patients, 224 agreed, initially, to participate in the work, a response rate of 89.2% (Figure 1).

Study group. The 106 patients of the study group completed an online ePROM questionnaire on a monthly basis. The ePROM data were incorporated into the electronic medical record[12] and were available to the study personnel. A rheumatology nurse specialist, not involved with the patients' treatment, was informed of the questionnaire results through a secured e-mail address set up for this study. The nurse was able to recommend a rheumatologist assessment in a clinic for acute inflamed joints in view of the patient's ePROM outcomes. The ePROM enabled the automatic calculation of DAS28[13] and Routine Assessment of Patient Index Data 3 (RAPID-3)[14] scores. All the patients were assessed in the outpatient clinic every 3 months by a rheumatologist blinded to the patient treatment followup approach. Prior to each clinic visit each patient completed a PROM paper format questionnaire. At the end of each clinic visit, DAS28 and RAPID-3 scores were calculated and the patient's data were recorded electronically by the treating rheumatologist. Medication intensification or change was considered in view of the patient-reported outcomes data.

Control group. There were 105 patients who continued their monthly assessment and management in the outpatient clinic for 6 months, after which they were assessed every 3 months. Prior to their assessment, every patient completed a paper format of the PROM questionnaire. The treating rheumatologist was blinded to the patients' treatment approach. All the disease activity variables were directly incorporated into the electronic medical record by the clinic staff and discussed with the patient. All the completed paper PROM forms were filed in the patients' notes and shared with the patients during their consequent visits. PROM data were used to guide clinical care and medication changes.

To avoid influencing the outcomes, all subjects were informed that there will be different monitoring protocols and that some of them will be contacted at some stage regarding the electronic format. All the patients included were instructed not to discuss their treatment group assignments with their rheumatologists or other patients. The study group patients attended, individually, an educational session to learn how to assess themselves for swollen joints, how to monitor their disease activity status, and meaning/cutoff points of DAS28/ RAPID-3, target of treatment, and how to complete an online ePROM. Each patient was given a hard copy record of their ESR and CRP results for use when they complete the ePROM. Similarly, the clinicians were asked not to discuss group assignments with the patients. All the patients in both groups were given access to a telephone advice line should they have any query or if they had any flare of their symptoms or a problem with their current medications. If required, the patients were reviewed earlier in a clinic set up for acute joint pain or inflammation. Treatment was adjusted according to their disease activity status.

The intervention. Patients could access ePROM on computers/smartphones and tablets. A link was provided so that patients could access it on whatever device they had. The ePROM questionnaire has to be completed in one sitting. There were no age restrictions among the patients included in this work. To bridge a possible gap of familiarity with digital technology, older adults with limited experience/access to computers were allowed to seek help from relatives. Reminders appeared on the screen if a question or more was missed. To make it easier, touch rather than tick/circle was used to choose a response on the gadget.

End of the study. At the end of 12 months of management, every patient participating in the study was asked to complete a 5-item post-treatment questionnaire[15] to assess the patient's perspective of how their disease was monitored and discussed, and expectations for improvement and the credibility of the intervention, whether visual feedback (in the study group) or the paper format (for the control group). These scales were administered using numerical VAS (scale 0–10, where "0" equals not at all and "10" corresponds to the maximum of that measure). The 5 items asked the patient "Did the questionnaire…?": 1. help you understand the effect of treatment on your disease activity; 2. motivate you to take medication; 3. increase trust in the treating doctor; 4. alleviate concerns about the future; 5. help you in coping with daily life and the disease.

Comprehensibility of both the ePROM and the paper format question-

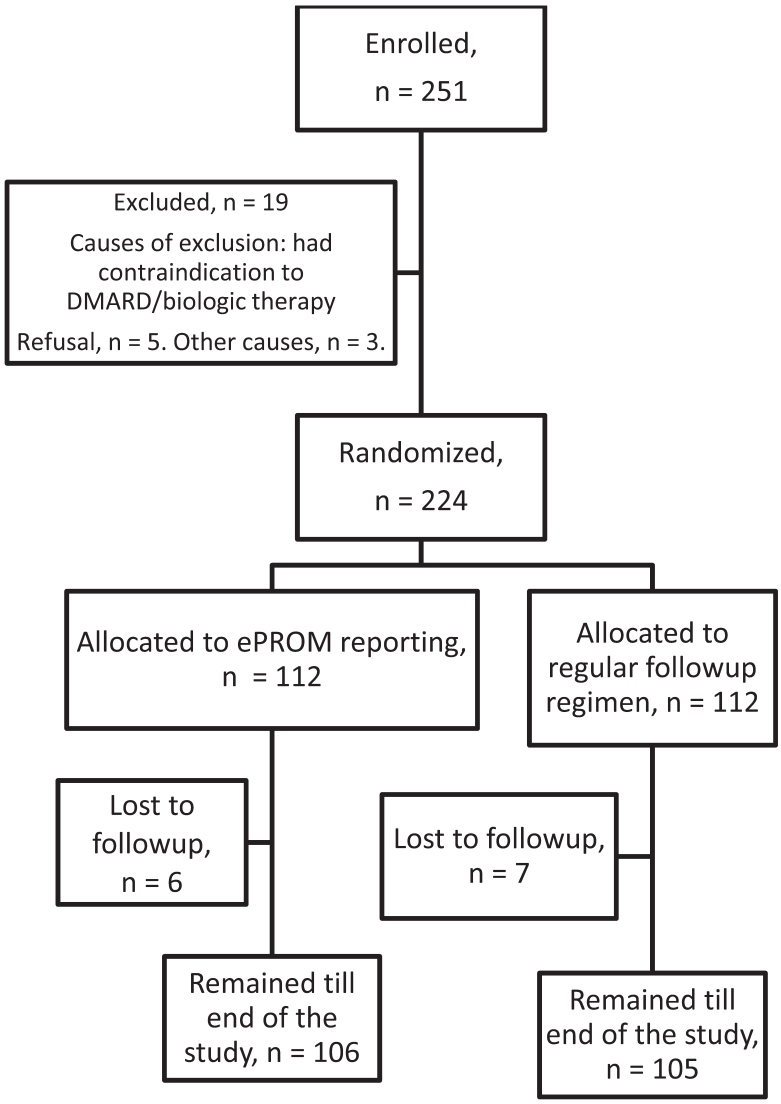

Figure 1. Enrollment chart of the patients with early rheumatoid arthritis who were included in the study. DMARD: disease-modifying antirheumatic drugs; ePROM: electronic patient-reported outcome measures.

naire was assessed using VAS (scale 0-10). Lastly, every patient in the study group was asked which gadget he/she used and what was the best time to complete the online PROM questionnaire.

Adherence to therapy. All patients received their RA medications from the hospital pharmacy and adherence measurement was based on the pharmacy data. Adherence, as defined by Cramer, *et al*[16], was evaluated using the variables of compliance and persistence. Compliance was estimated by the medication possession ratio (MPR) and persistence by the time from treatment initiation to discontinuation with no medication refill gap for a period of 30 days or more during the period of interest. MPR was defined as the ratio of actually available doses against the expected doses that the patient should possess over a fixed period of time. Study patients were rated as having good compliance if the annual MPR was ≥ 80%.

Cost effectiveness was assessed based on the number of visits to the clinic whether in the primary or secondary care, adherence to therapy, and the number of interventional procedures carried out during the study periods.

Outcome measures. The primary endpoint was the equivalence of gold standard outcomes and management of the patients (RAPID-3 and DAS28 scores) in both groups. Secondary endpoints were the patients' adherence to their medications by the end of the 1-year assessment period, and the equivalence of data collection using electronic versus paper format regarding disease activity variables assessment.

Statistical analysis. Data collected were introduced to a database for data management and statistical analysis using the 16th version of SPSS. Categorical variables are expressed as number and percentage, i.e., frequency tables, while quantitative scaled variables are presented as mean and SD. Percentage changes in different disease variables over time were calculated by dividing changes in the measured disease variable over time by its corresponding initial figure as a percentage. Chi-squared test was used to test association between 2 categorical variables and Student t test for 2 groups' means comparison. Skewed data were tested using the nonparametric Mann-Whitney test. The α error was always set at 0.05. To assess for equivalence between the 2 approaches, 95% CI were calculated and the significance level was set at $\alpha = 2.5\%$.

RESULTS

Demographic measures. At baseline, there were no significant differences between the treatment groups regarding age, sex, race, disease duration, socioeconomic status, or other comorbidities. Mean age in the study group was 52.7 ± 11.3 years, whereas it was 51.9 ± 10.7 years in the control group. Females were 79/106 (74.5%) in Group 1, whereas they were 78/105 (74.3%) in Group 2. There was no significant difference in education level between the 2 patient groups studied (low 20.5% vs 19.7%; medium 60.4% vs 60.2%, and high 19.1% vs 20.1% in the study and control groups, respectively). Mean disease duration in the study group was 6.7 ± 2.5 months, whereas it was 6.5 ± 2.7 months in the control group. Table 1 depicts a comparison of the baseline data in both groups assessed. Of the study group, 14/106 (13.2%) required help from a relative to complete the ePROM questionnaire (mean age was 76.4 ± 5.2 yrs), whereas 15/105 (14.3%) from the control group needed help to read the questionnaire because they had forgotten their reading glasses or needed other help in reading the questionnaire. Comprehensibility of ePROM was 9.4 ± 0.3, whereas it was 9.3 ± 0.4 for the paper format.

Outcome measures. Analysis of the measures of disease activity did not reveal any significant difference between the groups at 3 and 6 months of treatment. The frequency of disease activity in both the study and control groups at 3, 6, and 12 months of treatment is shown in Table 2 (low DAS28 < 3.2; moderate DAS28 3.2–5.1; high DAS28 > 5.1). Table 3 shows a comparison of the disease activity measures at 12 months of treatment. Flare of the disease activity was shown by ePROM in 23/106 (21.7%) patients who were seen in the clinic for acute inflamed joints: 16/106 (15.1%) in the first 6 months, and 7/106 (6.6%) in the second 6 months of the study. Outcomes of the management in the clinic for acute inflamed joints in the study group included 11% change in the DMARD dose or medication, 47% local joint injection, 26% 1-time intramuscular steroid injection, and 16% commence/change in nonsteroidal antiinflammatory drug (NSAID) medication. On the other hand, 39/105 (37.1%) of the control group were seen in the inflamed joints clinic — 17/105 (16.2%) in the first 6 months, and 23/105 (21.9%) in the second 6 months of the study ($p < 0.01$). Outcomes of management in the inflamed joints clinic in the control group were 12% change of the DMARD dose or medication, 42% local joint injection, 23% 1-time intramuscular steroid injection, and 23% commence/change NSAID medication.

Table 1. Comparison of age and baseline clinical and laboratory data in studied patients groups.

Characteristics	Study Group	Control Group
No. patients	106	105
Age, yrs, mean ± SD*	52.7 ± 11.3	51.9 ± 10.7
Tender joint count, 28 joints, mean ± SD*	12.8 ± 3.1	13.1 ± 2.9
Swollen joint count, 28 joints, mean ± SD*	3.5 ± 1.7	3.4 ± 1.9
Functional disability, mean ± SD*	1.81 ± 0.3	1.79 ± 0.4
DAS28 score, mean ± SD*	4.7 ± 0.7	4.6 ± 0.9
RAPID-3 score, mean ± SD*	7.8 ± 0.5	7.7 ± 0.8
RF-positive**	51.8%	52.3%
Anti-CCP–positive**	70.7%	71.4%
Patients taking DMARD**	75/106 (70.8%)	74/105 (70.4%)
Patients taking bDMARD**	31/106 (29.2%)	31/105 (25.6%)

*Student t test. **Chi-squared test. DAS28: 28-joint Disease Activity Score; RAPID-3: Routine Assessment of Patient Index Data 3; RF: rheumatoid factor; anti-CCP: anticyclic citrullinated peptide antibodies; DMARD: disease-modifying antirheumatic drug; bDMARD: biological DMARD.

Adherence to therapy. Results of patient reaction toward their illness and its management by 12 months of therapy in the study versus the control group are shown in Table 4. There was a significant main effect in the study group on subjects' mean displays of adherence to medications and coping with activities of daily living. Results of the study revealed that 89.6% of the study group patients were adherent to their medications in comparison to 70.5% in the control group ($p < 0.01$). In addition, the study group was also less likely to stop the medication because of intolerance, more able to cope with their activities of daily living, and had less concern about their future ($p < 0.01$). In both groups, adherence to therapy was significantly correlated ($p < 0.01$) to knowledge about current medications and the patient's involvement in the decision making.

Smart gadget use. There was significant difference in the patients' preferences regarding which smart gadget they used or the time of the day/night they completed the questionnaire. Patients younger than 50 years used mobile phones significantly more than did adults aged > 50 years (who preferred using tablets). Table 5 shows demographics of the smart gadget use stratified according to the patients' age and time of use.

DISCUSSION

For several years, a key barrier to the use of ePROM in standard clinical care was the difficulty of transforming the paper-based questionnaires into an instantly accessible application[16a]. With the rapid expansion of Internet-connected gadgets and mobile devices, it became possible to develop online systems with a broad range of implementations both at home and in the clinical setting. This study was carried out to assess the use of ePROM in patients with RA. Results revealed that ePROM could be administered through tablets, computers, and smart phones. It was feasible to sum the patient's disease activity measures, and based on the scores calculated, clinically relevant actions tailored to the patient's status could be taken that would reflect on the disease control and target achieved. Although there are no earlier data, to our knowledge, published about ePROM in rheumatic diseases, studies done in oncology[16,17,18,19] revealed that these smart electronic systems supported multiple clinical activities, including assessment of symptoms and toxicities related to

Table 2. DAS28 and RAPID-3 results at 3, 6, and 12 months of treatment.

DAS28 Score	3 Mos		6 Mos		12 Mos	
	Active	Control	Active	Control	Active	Control
DAS28 < 3.2	29/106 (27.4%)	27/105 (25.7%)	59/106 (55.7%)	60/105 (57.1%)	84/106 (79.2%)	81/105 (77.1%)
DAS28 3.2–5.1	56/106 (52.8%)	55/105 (52.4%)	24/106 (22.6%)	23/105 (21.9%)	14/106 (13.2%)	14/105 (13.3%)
DAS28 > 5.1	21/106 (19.8%)	23/105 (21.9%)	23/106 (21.7%)	22/105 (20.9%)	8/106 (7.5%)	10/105 (9.5%)
RAPID-3, mean ± SD	4.9 ± 0.3	5.1 ± 0.2	3.56 ± 0.2	3.58 ± 0.3	1.91 ± 0.3	1.89 ± 0.2

For the DAS28 score, chi-squared test was used. For the RAPID-3 score, Student t test was used. DAS28: 28-joint Disease Activity Score; RAPID-3: Routine Assessment of Patient Index Data 3.

Table 3. Comparison of the disease activity measures at 12 months of treatment. All were measured using Student t test, except prevalence of biologics, which was measured with chi-squared test ($p > 0.05$). All data are mean ± SD unless otherwise indicated.

Characteristics	Study Group	Control Group
Tender joint count, 28 joints	2.8 ± 3.1	3.1 ± 2.9
Swollen joint count, 28 joints	1.6 ± 1.9	1.8 ± 2.3
Functional disability	0.6 ± 0.4	0.8 ± 0.4
DAS28	2.7 ± 0.7	2.9 ± 0.9
RAPID-3	3.2 ± 1.8	3.7 ± 1.3
Prevalence of patients taking biologics	22%	24%

DAS28: 28-joint Disease Activity Score; RAPID-3: Routine Assessment of Patient Index Data 3.

Table 4. Patients' reaction toward their illness, by 12 months of therapy, in the study versus the control group. Values for control group were measured by chi-squared test ($p < 0.01$).

Variables	Active Group	Control Group
Adherence to medication	95/106 (89.6%)	74/105 (70.5%)
Patient stops medications because of intolerance	6/106 (5.7%)	20/105 (19%)
No. procedures done in the clinic (over the study period)	46/106 (43.4%)	77/105 (73.3%)
No. visits for flare of the disease that required early assessment (over the study period)	23/106 (21.7%)	39/105 (37.1%)

chemotherapy and radiation, postoperative surveillance, and symptom management during palliative care.

For patients with early RA, these results revealed that the ePROM system provided a unique opportunity for disease management in standard practice, because it facilitated closer monitoring of the disease activity and real-time disease activity score measurement during this primary phase of inflammation. Further, because the ePROM was based on the original patient-driven PROM questionnaire, the collected data were reliable and meaningful to both the patients and the clinicians. Therefore, the ePROM supported the treating rheumatologists in providing patient-centered care: to identify and track disease progression and to integrate the prompt use of other therapeutic interventions into routine clinical care. The outcome of such an approach was reflected on achieving the treatment target. This comes in agreement with the RA treatment recommendations set by organizing bodies such as EULAR, ACR, or the British Society for Rheumatology[20,21,22].

Our study depicted good agreement between both tools, indicating equality of ePROM to standard paper PROM format. This finding was consistent whether the disease activity was assessed using DAS28 or RAPID-3. Earlier reports raised concerns that paper-based questionnaires might need to be altered to be presented electronically. Because this could change the way patients respond to the questions, PROM methodologists have outlined the reasons and approaches for evaluating the equivalence of the questionnaire data across each mode of administration[23]. In comparison to the paper format, there were insignificant differences between the paper and online formats in disease activity measures assessed in this work. On the other hand, the electronic format helped to handle the complex skip patterns, provided accurate time and date of recording, achieved higher patient compliance with better data quality recorded, and facilitated the availability of the outbound calling option. The equality between the electronic and paper-based PROM in our study is in agreement with the results of earlier studies

Table 5. Demographics of the smart gadget use stratified according to the patients' age and time of use.

Type of Gadget	Patients < 50 Yrs Old, n = 52	Best Time to Complete	Patient > 50 Yrs Old, n = 54	Best Time to Complete
Smart phone	27/52 (52%)	8 AM–9 AM, 8 AM–10 PM	14/54 (26%)*	7 PM–10 PM
Tablet	16/52 (31%)	7 AM–10 AM	29/54 (54%)*	8 AM–12 PM, 4 PM–10 PM
Desktop/ laptop computer	9/52 (17%)	7 PM–10 PM	11/54 (20%)	10 AM–5 PM

*Chi-squared test: $p < 0.01$.

that showed that paper- and Web-based surveys provide data that are essentially equivalent[24]. Another recent study[25] assessed the patients' preferred mode of administration, whether Web-based or a standard paper questionnaire. Results revealed that more respondents were willing to fill out a questionnaire online than a paper one, which will lead to faster data availability.

In addition to its value in monitoring disease activity, ePROM helped to optimize the patients' adherence to their treatment. This agrees with the outcome of earlier studies that reported that by using an iterative design process that focuses on patient outcomes and disease activity variables, the patients' perception of their therapy was augmented with sensor technology[11,26]. In addition to the reported finding, implementing a PROM system in standard practice did improve patient-rheumatologist communication during clinic visits[27,28,29]. Results of this work showed that ePROM was able to alert clinicians to acute needs for symptom management between visits. This is in agreement with outcomes of earlier studies revealing values of electronic systems in the management of patients' chronic conditions between their clinic appointments[18,19,30,31,32,33]. Further, some systems have been designed to provide educational material to patients, tailored to their reported symptoms and needs, right after they complete a survey[18,31]. The electronic format enabled the treating rheumatologist(s) to have systematically collected symptom data that can support clinical decision making. These features have been found to improve patient satisfaction with their care and have the potential to improve symptom management[12,34]. On another front, the significant correlation between adherence to therapy and the information the patients get about their medication, as well as the patient's contribution in the decision making, highlight the importance of shared decision making in the management process.

The ePROM system does not replace the patient-clinician clinical assessment and discussion, but it helps to focus the dialogue on symptoms that need consideration and allows the clinician to quickly determine whether the patient's symptoms are worsening or improving over time. Therefore it has a time-saving effect on clinic visits. Results of this work revealed that ePROM performance achieved the same outcomes as monthly visits to the clinics. Further, the study group patients' contact was significantly less than that of the control group, further endorsing the time-saving effect of the electronic approach. Earlier studies carried out on PROM investigated the differences between patient- and clinician-reported outcomes. There was no significant difference between patient- and physician-reported tender joints[35,36]; further, patients were able to detect symptoms earlier and with a higher sensitivity than clinician reports[37,38,39].

The integration of the ePROM system into standard care requires a significant investment of planning and resources. Developing a new ePROM system requires a significant amount of programming time as well as dedicated project management and leadership[39,40]. Results of the work revealed that the added value of an ePROM system is very dependent on the type of outcomes it is designed to assess and on how well the system was designed for its purpose and context of use. In addition, getting doctors/nurses on board remains a challenge. This can be handled with proper training and education regarding interpretation of scores, integration of the system into clinic workflow, and management[16a].

Although it might be early in the process of integrating ePROM assessment into standard rheumatology care, results of this work demonstrated the feasibility and usefulness of bringing the patient perspective into practice. The ePROM approach provided a patient-focused, clinically relevant, and reliable perspective on the patient's disease management. The growing interest in PROM in general and ePROM in particular across the healthcare field suggests that this is just the start. In addition to its role in clinical practice, ePROM can also be used as a performance index. However, the most compelling argument in favor of implementing patient reporting into rheumatology practice is that it enables patients to actively share in their own care by providing the information they know best.

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