RESEARCH ARTICLE

Evaluation of Rheumatoid Arthritis Outcome Measures between Users and Non-Users of the Patient Portal

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Abstract

Introduction

Patient engagement has become a growing focus in healthcare, catalyzed with the passage of the HITECH Act in 2009. Stage 2 of Meaningful Use has criteria dependent on a patient portal, however whether electronic patient engagement translates into better clinical outcomes is yet to be determined. To begin an evaluation into this we reviewed outcomes in rheumatoid arthritis patients who had signed up for the patient portal compared to those who did not.

Methods

Data was obtained from a retrospective chart review of rheumatoid patients seen at the Ohio State University Rheumatology Clinics. Outcome measures including the most recent sedimentation rate (ESR), Rapid 3, and swollen joint count were evaluated. Two tailed t tests for these outcomes were done between each the group who had signed up for the patient portal and those that did not.

Results

132 patients were included with 66 having signed up for the patient portal (users) and 66 not signed up for the patient portal (non-users). 103 (78.0%) of patients were female, with a mean age of 55 ±13.79 years. Outcome measures between the patients who signed up for the patient portal compared to those who had not 14.77 ±7.57 compared to 13.48 ±7.73 (p=0.33) for Rapid 3 scores, 1.97 ±2.25 compared to 2.86 ±4.06 (p=0.16) for swollen joint count, and 39.88 ±29.76 mm/hour compared to 30.61 ±22.04 mm/hour (p=0.04) for ESR.

Conclusions

This initial study cohort does not demonstrate any clinically significant difference in several key outcome measures in rheumatoid arthritis, particularly Rapid 3 scores and swollen joint counts. However, there was a statistical difference between the ESR, with more favorable values in patients using the patient portal. This data suggests further study is needed to better understand if electronic patient engagement does have an effect on clinical outcomes in RA.

Keywords: rheumatoid arthritis, electronic health record, patient portal

1. Background: US government fosters growth of electronic health records

The last decade of healthcare in the United States has seen the revolution from paper charts to the electronic health record (EHR) system. This pivotal change was spurred by passage of the American Recovery and Reinvestment Act (ARRA) in February 2009.[1] President Barak Obama's landmark piece of legislation included several conditions which comprised the Health Information Technology Economic and Clinical Health Act, or "HITECH Act".[2]

The HITECH Act included provisions for implementing health information technology (HIT) through use of certified EHRs.[3] EHRs could go beyond the traditional paper charts that sat on filing shelves in back offices, and instead could digitally store records and also facilitate exchange of them.[4] The Meaningful Use Incentive Program incentivized payment for eligible physicians and hospitals to implement HIT in a meaningful construct.[5] The goals of meaningful use were based on several health outcomes policy priorities (Table 1) including improvement in quality, safety and efficiency in healthcare.[6] In July 2010, the Centers for Medicare & Medicaid Services (CMS) designed the incentive program to create a payment structure for eligible physicians and hospitals who utilized HIT---the Meaningful Use program was released in a Final Rule entitled Medicare and Medicaid Programs; Electronic Health Record Incentive Program (42 CFR Parts 412, 413, 422, *et al*) to motivate this higher quality EHR adoption.[7]

Table 1: Health outcomes policy priorities that shaped the concept of meaningful use

1. Improving quality, safety, efficiency, and reducing health disparities
2. Engage patients and families in their health
3. Improve care coordination
4. Improve population and public health
5. Ensure adequate privacy and security protection for personal health information

Adapted from Yu PP. Why Meaningful Use Matters. J Oncol Pract 2011 Jul;7(4):206–209.

EHR systems would have to be integral to achieving the Meaningful Use parameters. In order to ensure the EHR standards, the HITECH Act mandated the Office of the National Coordinator for Health Information Technology (ONC) under the Department of Health and Human Services (HHS) develop criteria for certification of EHRs.[8] The criteria were designed to help support physicians and hospitals to achieve the incentive metrics set by CMS.[8] In July 2010, the ONC released a Final Rule entitled Health Information Technology: Initial Set of Standards, Implementation Specifications, and Certification Criteria for Electronic Health Record Technology (45 CFR Part 170) which outlined this certification criteria for the electronic technologies.[9]

Stage 2 of Meaningful Use was rolled out in 2014 and outlined criteria for increasing patient engagement through patient portal (PP) use.[10] The PP is part of an EHR system which allows for 24 hour access to personal health information via the internet.[11] PPs also allow patients to communicate with their health care providers.[12-14] Stage 2 of Meaningful Use stipulated that at least 50% of patients must be able to view, download, and transmit health information within 4 days of an office visit or 36 hours of a hospital discharge with at least 5% of these patients actually accessing their health information via the portal, and at least 5% of these patients sending a secure electronic message to their provider.[15]

1.1 Previous outcomes from patient portals

Several studies have examined patient satisfaction with patient portals.[16,17] However it is not fully clear what impact PPs have on actual clinical outcomes. There are models to suggest general patient engagement, not specific to a patient portal, in those with chronic medical conditions may lead to improved outcomes.[18] It is not clear what impact, if any, PP technology has on actual clinical outcomes. Of the evidence that is available regarding PPs, there appears to be no clear improvement in clinical outcome measures.[19]

Grant et al, has the one randomized controlled trial evaluating clinical outcomes associated with PPs in patients with diabetes. In this study, diabetic patients randomized to the intervention arm had access to their laboratory results as well as opportunities to answer questions regarding barriers to care and send messages to their provider. At the end of the 1 year study there was no statistical difference in clinical outcome with regard to Hemoglobin A1c (HbA1c), blood pressure, and low density lipoprotein-cholesterol (LDL-C).[20]

In another trial, clinical outcomes in congestive heart failure also did not appear to be significantly affected by use of PPs. Researchers at the University of Colorado Health Sciences Center investigated whether patient engagement through a PP with access to medical records, an educational guide, and a provider messaging system led to a change in clinical outcomes based off the Kansas City Cardiomyopathy Questionnaire (KCCQ), which measures patient perception of health status. The PP intervention arm was not superior to the control arm in overall KCCQ scoring as well as subdomains including symptoms, functional status, and quality of life.[21]

Like diabetes and congestive heart failure, rheumatoid arthritis (RA) is a chronic medical condition that may require lab monitoring, long term medications, and ongoing physician care. In RA management, labs play an important role in both disease monitoring and drug safety. Numerous RA therapeutics require regular lab monitoring to evaluate for drug toxicity.[22] In addition, inflammatory markers are commonly used for various RA disease activity indices including the Disease Activity Score (DAS) -28, DAS-28 CRP, Simplified Disease Activity Index (SDAI).[23-26]

To date there is no study investigating whether patient engagement through the PP results in a change in clinical outcomes in RA patients. As the US healthcare system becomes more entrenched in PPs it is worthwhile to investigate the effect this massive endeavor has on clinical outcomes in chronic diseases such as rheumatoid arthritis. To begin an evaluation into this we reviewed outcome measures in rheumatoid arthritis patients who had signed up for the patient portal compared to those who did not.

2. Study methods

The study was a retrospective chart review. Data from routine clinical practice of eligible patients was collected by completion of manual chart review from charts randomly selected from 2014-2016 from across our multiple clinic sites and providers. Eligible patients were considered those with an ICD-9 or ICD-10 diagnosis consistent with rheumatoid arthritis. Only patients who had been seen in the clinic for at least 18 months were included in the study. Any patients seen for less than 18 months were excluded.

Since the review was conducted retrospectively, no procedures or follow-up of patients was conducted. Data was collected from the most recent visit. Baseline demographic data was obtained as well as identification of whether or not the patient had signed up for the PP. Outcome measures were recorded including the most recent sedimentation rate, total swollen joint count, and Rapid 3 score at most recent visit and at the visit closest to 18 months prior to the most recent visit. The Rapid 3 is a disease activity index for monitoring of RA activity; disease severity may be classified on the basis of RAPID3 scores: >12 = high; 6.1-12 = moderate; 3.1-6 = low; < or =3 = remission.[27]

Data was entered into a Microsoft access database. Descriptive statistics including mean and standard deviations were calculated using Microsoft excel. Two tailed t tests for these outcomes were done between each the group who had signed up for the patient portal and those that did not.

Approval for the study was given by the IRB Ethics Committee at the Ohio State University Wexner Medical Center. Informed consent was waived due to the retrospective nature of the study and patient anonymity has been preserved.

3. Study results

A total of 132 patient charts were reviewed. In total 66 patients had signed up for the PP (users) and 66 had not signed up for the PP (non-users). In total 103 (78%) of patients were female with a mean age of 55 ±13.79 years. This high female prevalence is typical with incidence of RA amongst women (28, 29). Demographic data for users and non-users is summarized in Table 2.

Table 2. Demographics for Patient Portal Users and Non-Users

	Patient Portal Users	Patient Portal Non-Users
Total (N)	66	66
Age (years)	52.01(±11.77)	58.7 (±14.79)
Female (%)	78.70%	77.27%
Race (N)		
White	53	41
Black	7	16
Hispanic	0	5
Other	6	4
Insurance		
Medicare	7	27
Medicaid	17	15
Private	22	18
Not specified	16	4
None	4	2
Job status		
Employed	30	16
Unemployed	19	14
Disability	6	15
Retired	9	19
Not listed	2	2

Outcome measures between users and non-users was 14.77 ±7.57 compared to 13.48 ±7.73 (p=0.33) for Rapid 3 scores. Both groups were similarly classified as high disease activity on the Rapid 3. There was no statistical difference between the Rapid 3 subsections including patient rated function, pain, and overall disease activity. Physician examined swollen joint count between users and non-users was 1.97 ±2.25 compared to 2.86 ±4.06 (p=0.16). Sedimentation rate (ESR) between users and non-users was 39.88 ±29.76 mm/hour compared to 30.61 ±22.04 mm/hour (p=0.04). Other clinical measures evaluated were if there was a history of prescriptions for prednisone at any time in the 18-month study period. PP non-users had a lower percentage of incidence of prednisone scripts (62.12%) compared to PP users (75.76%). Results are listed in Table 3.

Table 3. Rheumatoid Arthritis Outcome Measures between Patient Portal Users and Non-Users

	Patient Portal Users	Patient Portal Non-Users	
ESR	30.61 (±22.04)	39.88 (±29.76)	p=0.04
Swollen Joint Count	2.86 (±4.06)	1.97 (±2.25)	p=0.16
Rapid 3	13.48 (±7.73)	14.77 (±7.57)	p=0.33
Patient rated function score	2.92 (±2.25)	3.43 (±2.37)	p=0.21
Patient rated pain score	5.34 (±3.13)	5.81 (±3.19)	p=0.39
Patient rated disease activity score	5.18 (±3.06)	5.54 (±3.03)	p=0.50
CRP	9.67 (±9.83)	15.32 (±24.5)	p=0.09
Prednisone use	75.76%	62.12%	

4. Discussion: Barriers to patient portal use

To our knowledge this is the first study to examine not only clinical outcomes measures in RA patients using the PP but it also is the first to examine who among the RA population signs up for the patient portal. While the numbers are too low to draw clear statistical significance, the results suggest that at least in our cohort, the typical RA PP user is a white, employed, female, who is on non-Medicare insurance. What is most striking in the demographics is that it is much more likely for a Medicare patient to not be a PP user. This distinction is especially of interest as Medicare patients are generally older patients. In the US older adults are the most frequent utilizers of healthcare services, incurring the highest number of clinic visits and hospitalizations compared to any other age group.[30]

This high likelihood for a Medicare user not to utilize the EHR can exist for many reasons. This generally is an older demographic who may not have access or comfort with readily using an internet based patient portal.[31] Some older patients may be more so economically disadvantaged with limited incomes which may pose a further barrier to access of internet technologies.[32] Health barriers including limited vision in older patients may present a challenge to reading from a computer screen or smartphone.[33]

In contrast, a higher number of patients using the PP were employed. In our cohort not having access to a job (including those who are retired, unemployed, or on disability) had the strongest association with not using a patient portal. The financial disparities amongst non-working patients regardless of age, may pose an additional cost barrier to obtaining internet access.[34-36] A workplace may not only create an income stream, but it also may allow for access and experience with internet technologies that not all patients may have, especially amongst older adults.[36-39]

Previous studies have looked at inpatient PP use on hospital outcomes. Here all patients have access to the internet so this particular barrier is removed. When allowing all patients access to a PP, those that elected to utilize it were still younger (58.8 years versus 62.3 years) suggesting that access to internet alone is not the only barrier to use.[40]

4.1 Clinical outcomes between patient portal users and non-users

The origin of our study took root in the hypothesis that patients who were more engaged over the PP would have better control of their chronic disease. The supposition was that users with online engagement would have less chronic disease activity as they would be more aware and invested in their chronic medical condition. However, we could not demonstrate a strong correlation for this. PP users had no statistically significant difference in measures in clinical outcomes with regard to joint count, rapid 3 scores, and CRP. One speculation for this lack of variance is that patients may only be vested in measures they can directly see on the patient portal. In our hospital system rapid 3 scores and joint counts from the physician exam are not visible on the patient portal. Therefore, it possible that the out of sight out of mind construct explains why some of these outcomes are not effected by PP use. However, the CRP which is visible, was not statistically distinct between the groups. Other studies evaluating visible clinical outcomes over a PP in other chronic disease states also did not result in statistically significant improvements in these viewable parameters.[20]

The lone measure that showed a disparity was the ESR however this was an unadjusted ESR in the study. A consideration for the discordant ESR level between users and non-users is that an unadjusted ESR, not corrected for age and gender, may not be a truly valid measure. ESR is generally higher amongst women and rises with age.[41-43] In our cohort, the genders were essentially equal between users and non-users, however there was a difference in age with the non-users being older than users. This variance in age may account potentially for the higher ESR in this group. We also do not have data on other measures that can affect ESR including obesity, cardiovascular disease, interstitial lung disease, infection and other comorbid conditions.[44-47]

Previous studies have looked at larger more generalized clinical outcomes of health with regard to PP use. However here too, despite higher patient engagement with use of a PP, there was no statistically significant difference in key clinical outcomes amongst hospitalized patients. These specific outcomes included 30-day readmission, inpatient mortality and 30-day mortality.[40]

4.2 One factor clinical outcomes

Monitoring disease activity and communicating this to patients is complex with regard to RA. Rheumatologists are integrating data regarding patient history, physical exam, laboratory and imaging to determine how active the disease is. For patients to fully understand these multiple measures of disease activity require substantial levels of health numeracy and health literacy. Health numeracy refers to the ability to interpret and communicate mathematical information and health literacy refers to the ability to interpret and utilize written text.[48]

The degree of data assimilation done for RA may be complex for some patients. If a patient cannot truly understand the health data viewable on a patient portal, actual usage of the PP would be unlikely to have a real impact on clinical outcomes. It perhaps is likened to showing someone instructions in a different language, while the person is able to see the text, they do not have the capacity understand it or carry out any action related to it.

Some studies have looked at health outcomes that may be more easily recognized by the general population, where only one factor is related to measuring outcomes, such as blood pressure. Many patients may be able to better understand at least the concept that a higher blood pressure number is a non-optimal result. With regard to blood pressure studies and patient engagement, results have been mixed. Some have shown improvement in BP control with adoption of a PP,[49-50] while others have shown no improvement.[51-53]

This concept of a one factor clinical outcome can also be applied to glycemic control with regard to hemoglobin A1c. Again, the paradigm that a higher number equates to a bad result may be easier to grasp concept for some patients. However, studies again show mixed results. Patient engagement through a PP did not yield sustained long-term improvements in hemoglobin A1c when comparing PP users and non-users.[52,53]

In further dissecting our study with regard to RA, one could extrapolate the ESR or CRP as this one factor clinical outcome that patients could follow for level of disease activity. Again in our EHR system, these are both values patients with access to the PP are able to view. Like the studies above, our results are again mixed. While there was a difference in unadjusted ESR levels between users and non-users of PP, there was no similar difference with regard to CRP. Both the previous studies and ours suggest there is more to improving clinical outcomes than merely granting patient access to a portal to view lab results.

4.3 Improved access to disease management with the patient portal

Our study also compared history of prednisone prescriptions between the PP users and non-users. It is important to note that prednisone usage is not necessarily an agreed upon measure of disease activity; some rheumatologists often use prednisone as a possible long term disease modifying agent.[54-56] However, many rheumatologists may resort to prednisone when RA becomes poorly controlled to try to improve pain and function more rapidly. Some patients may be able to better equate worsening disease with need for additional steroid control.

Interestingly our study found a higher incidence of prednisone prescriptions amongst the PP users. One hypothesis has less to do with patient engagement with regarding to understanding disease activity, and more to do with the ease of requesting scripts with PP use. It is possible that PP users may have a higher incidence of medications to treat acute worsening of chronic disease states compared to non-users simply due to the ease of requesting medications. Previous studies reviewing PP use in regard to requesting medication refills found patients touted the ease for requesting meds over the portal.[57] It would be interesting to look further into whether PPs leads to less office visits and more in between office management.

5. Study conclusions

The HITECH Act has spawned the widespread use of EHRs that include PPs with goals of improving quality of care. However, few have actually examined what impact these measures actually have on clinical outcomes, which ultimately are the real measure of quality of care. This is the first study to look at use of the PP on rheumatoid arthritis clinical outcomes. It also is the first study to review the demographics of PP users in the rheumatoid arthritis patient population. Our cohort identified a disparity between Medicare users being less likely to use a PP. Additionally, the data found unemployment for any reason including retirement and disability, were more strongly associated with being a non-user of the PP.

Quality of care is one of the pillars of Meaningful Use. One would contend that improvement in clinical outcomes is the definitive measure of quality of care. With regard to clinical outcomes in rheumatoid arthritis and other chronic disease states, more studies should be done to investigate whether the widespread adoption truly is leading to a meaningful clinical change.

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