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Background

- Patient passports have been used in chronic diseases to promote active involvement of patients in their care.
- In RA, patient monitoring of their disease activity could facilitate the treat to target approach by providing early warning signs when disease is not controlled.
- The Arthritis Health Journal (AHJ) is a patient-centered online tool that helps patients track symptoms, monitor disease activity and develop action plans.
- **Objective:** to perform a proof of concept study of the AHJ to assess its use in people with RA.

Methods

Sample: Participants were recruited from arthritis clinics, consumer newsletters and advertisements

Randomization:

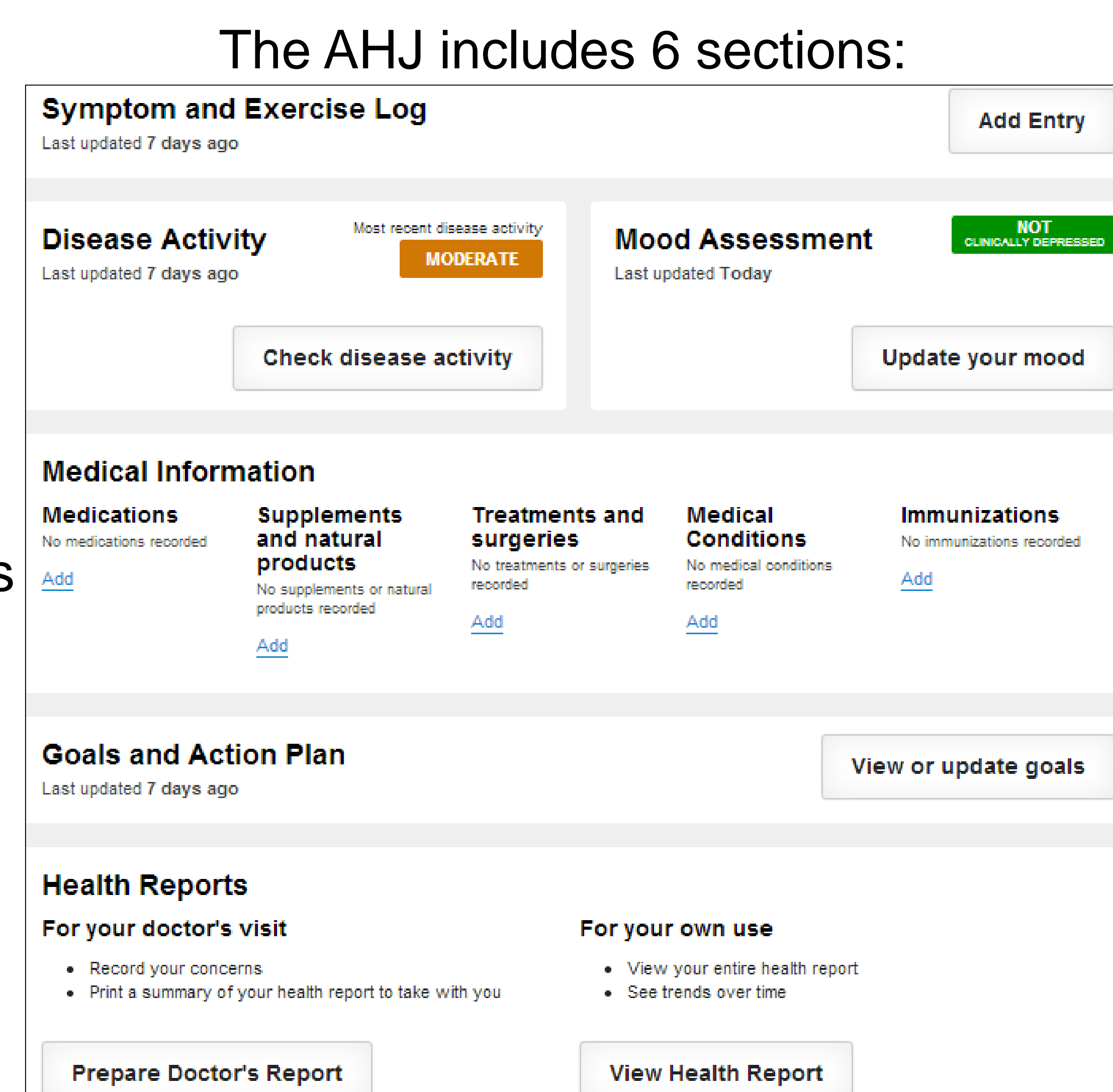
- 1:1 to immediate vs. delayed group (i.e. received intervention after 6 months)
- First 6 months of delayed group served as control

Intervention:

- Online access to the AHJ for 6 months
- Frequency of use not specified

Data Collection:

- On-line questionnaires every 3 months evaluated frequency of use, satisfaction, self-management, consumer effectiveness, and health status
- Semi-structured interviews were conducted on a purposive sample selected to represent a variety of experiences with the AHJ



Results

Sample: 94 participants (45 immediate/49 delayed)

Sample Characteristics	
Gender, females	88%
Ethnicity, caucasian	78%
Education	
Less than high school	3%
High school	9%
Post-secondary	88%
Mean (SD) age, years	52.9 (11.0)
Mean (SD) RA duration, years	12.5 (10.6)

Results

Frequency of Use:

- The AHJ was used less frequently than expected, likely because participants were not instructed about how often to use it
- Disease activity was the most frequently used section [median (25Q;75Q) use over 3 months: 1.0 (0;3)].

# of times used over 3 months	Symptom & Exercise Log	Disease Activity	Mood Assessment
0	45%	44%	48%
1	15%	12%	14%
2	15%	17%	12%
3	6%	9%	4%
4	9%	4%	8%
5-10	5%	6%	8%
11+	5%	8%	6%

User Satisfaction:

- Participants were asked to rate their satisfaction with each section on a 1-10 scale
- User satisfaction was moderate to high across sections, with highest satisfaction with the disease activity section

Arthritis Health Journal Section	Median (25 th ; 75 th percentile)
Symptom and Exercise Log	7.3 (5.0; 9.4)
Disease Activity Section	7.8 (5.0; 9.9)
Mood Assessment Section	7.0 (5.0; 9.9)
Medical Information Section	7.0 (5.0; 9.8)
Goals and Action Plans Section	6.3 (5.0; 8.1)
Health Reports Section	7.0 (5.0; 10.0)

Scale: 1=completely dissatisfied, 10=completely satisfied

Outcome Assessment:

- No significant differences were observed in consumer effectiveness attributes (Effective Consumer Scale, Partners in Health Scale), self-efficacy (managing disease, symptoms and communication with rheumatologist), satisfaction with care, or in health status [overall health, depression (Patient Health Questionnaire 9), Patient Global Assessment of disease, pain and fatigue, physical function (Health Assessment Questionnaire), and disease activity (RADAI)] after 6 months of use

Synopsis of Qualitative Analysis

Benefits:

Enhanced self-awareness, ability to see relationships between symptoms, ability to see patterns over time in symptoms and disease activity, which were felt to facilitate shared decision making about medications during medical visits

Barriers:

Lack of perceived need when disease was stable, well-controlled or longstanding arthritis (stating they would have used it at disease onset), internal factors (e.g. fatigue, unwillingness to focus on disease, denial), external factors (lack of time due to life events)

Participant Quotes:

"I thought, 'Oh, well, how much more can I know about me? About living with this illness every single day'. And it just...it's an organized way to keep track of your illness and then it makes you see how you can improve or not daily, right, or with the little changes. So I was happily surprised. I was not expecting help from it". Participant living with RA for 20 years.

"So I think, initially, I saw... I wasn't aware of how to use it well. I wasn't using it frequently enough for it to be able to inform me. Once I was informed that more frequent would be helpful, I gave that a whirl, and sure enough it was significantly more helpful that way." Participant living with RA for 3 years.

Conclusion

- Our proof of concept study shows that people were satisfied with the AHJ, but many did not use it frequently for a variety of reasons.
- No difference between groups were detected in consumer attributes or health status in preliminary analyses; however, the 6-month timeline might be too short to expect such a difference.
- A number of benefits were identified, especially in people who used it frequently.

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