

Usability and Improvement Opportunities of a Mobile App-Based Interactive Care Plan for Migraine: A Survey Study of Users

Nathan P Young, Jennifer A Stern, Stephanie J Steel, Jon O Ebbert

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Table of Contents

Original Manuscript	5
Supplementary Files	
Multimedia Appendixes	26
Multimedia Appendix 1	

Usability and Improvement Opportunities of a Mobile App-Based Interactive Care Plan for Migraine: A Survey Study of Users

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Abstract

Background: We implemented a novel mobile app-based Migraine Interactive Care Plan (MICP) integrated with our EHR. The MICP facilitates remote assessment of adult migraine patients, delivery of educational content, and care team communication. Feasibility of the MICP was demonstrated in a pilot implementation study.

Objective: We aimed to assess the preferences and satisfaction of migraine patient users of a mobile app-based care plan integrated with the electronic health record (EHR).

Methods: An electronic survey was administered to a single cohort of MICP users between 12/6/21 and 12/30/21. The survey assessed patient preferences for which data to track, frequency of tracking, and satisfaction with the MICP. Survey responses were compared between subsets determined by patient-reported headache frequency, treatment with and without botulinum toxin and CGRP antagonist therapy. The Wilcoxon rank-sum test was utilized for continuous variables and Chi-square test or Fisher's exact test for categorical variables.

Results: The response rate was 30.4% (n=56/184). No significant differences in age (P = 0.2579) or sex (P = 0.1944) between respondents and non-respondents were observed. Respondent median age was 42 (range, 20-72) years and 94.6% (n=53/56) were female. Headache frequency was: 1) 0 to 8 days (n=26/56, 46.4%); 2) 9 to 14 days (n=12/56, 21.4%); and 3) 15 or more days (n=18/56, 32.1%). No difference was observed in survey responses based on headache frequency or treatment.

Majority of respondents preferred to track headache days weekly (n=30/56, 53.6%) or daily (n=15/56, 26.8%) and preferred to change the frequency of headache tracking reminders (n=42/56, 75%). Respondents were somewhat or very interested in daily tracking personal observations in free text (n=41/52, 78.8%), medication treatment (n=43/52, 82.7%) and treatment response (n=39/56, 69.6%), class of medication treatment (n=36/52, 69.2%), severity of functional impairment (n=39/56, 69.6%), type of functional impairment (n=35/53, 66%), headache day (n=40/54, 74.1%), and headache pain level on a scale of 1 to 10 (n=38/53, 71.7%). Respondents agreed or strongly agreed that the education content was useful (n=31/51, 60.8%) but lacked personalization (n=25/51, 49%). Most respondents agreed or strongly agreed that they were satisfied with the MICP (n=38/50, 76%) and that it helped them communicate with their care team (n=38/53, 71.7%).

Conclusions: Most MICP users were motivated to track headache frequency, medication treatment with response, functional impairment, and pain intensity. Opportunities to improve the MICP include: 1) allowing patients to change the frequency of assessments and notifications; 2) record personal observations/comments via free text which may include headache triggers; 3) assessment of headache severity using a 1 to 10 pain scale; and 4) tailoring headache education based on frequency and severity (episodic vs chronic migraine). These observations may be useful to improve usability of the MICP and similar EHR-integrated migraine care platforms that others may develop.

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Original Manuscript

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Migraine: A Survey Study of Users

ABSTRACT

Background

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our EHR. The MICP facilitates remote assessment of adult migraine patients, delivery of educational

content, and care team communication. Feasibility of the MICP was demonstrated in a pilot

implementation study.

Objective

We aimed to assess the preferences and satisfaction of migraine patient users of a mobile app-based

care plan integrated with the electronic health record (EHR).

Methods

An electronic survey was administered to a single cohort of MICP users between 12/6/21 and

12/30/21. The survey assessed patient preferences for which data to track, frequency of tracking, and

satisfaction with the MICP. Survey responses were compared between subsets determined by patient-

reported headache frequency, treatment with and without botulinum toxin and CGRP antagonist

therapy. The Wilcoxon rank-sum test was utilized for continuous variables and Chi-square test or

Fisher's exact test for categorical variables.

Results

The response rate was 30.4% (n=56/184). No significant differences in age (P = 0.2579)

or sex (P = 0.1944) between respondents and non-respondents were observed. Respondent median

age was 42 (range, 20-72) years and 94.6% (n=53/56) were female. Headache frequency was: 1) 0 to

8 days (n=26/56, 46.4%); 2) 9 to 14 days (n=12/56, 21.4%); and 3) 15 or more days (n=18/56,

32.1%). No difference was observed in any survey responses based on headache frequency or

treatment.

Majority of respondents preferred to track headache days weekly (n=30/56, 53.6%) or daily (n=15/56, 26.8%) and preferred to change the frequency of headache tracking reminders (n=42/56, 75%). Respondents were somewhat or very interested in daily tracking personal observations in free text (n=41/52, 78.8%), medication treatment (n=43/52, 82.7%) and treatment response (n=39/56, 69.6%), class of medication treatment (n=36/52, 69.2%), severity of functional impairment (n=39/56, 69.6%), type of functional impairment (n=35/53, 66%), headache day (n=40/54, 74.1%), and headache pain level on a scale of 1 to 10 (n=38/53, 71.7%). Respondents agreed or strongly agreed that the education content was useful (n=31/51, 60.8%) but lacked personalization (n=25/51, 49%). Most respondents agreed or strongly agreed that they were satisfied with the MICP (n=38/50, 76%) and that it helped them communicate with their care team (n=38/53, 71.7%).

Conclusion

Most MICP users were motivated to track headache frequency, medication treatment with response, functional impairment, and pain intensity. Opportunities to improve the MICP include: 1) allowing patients to change the frequency of assessments and notifications; 2) record personal observations/comments via free text which may include headache triggers; 3) assessment of headache severity using a 1 to 10 pain scale; and 4) tailoring headache education based on frequency and severity (episodic vs chronic migraine). These observations may be useful to improve usability of the MICP and similar EHR-integrated migraine care platforms that others may develop.

Key Words: migraine; remote monitoring; mobile app; mHealth; patient-reported outcomes; care plan; digital health

Introduction

Background

Patients with migraine often face significant barriers in access to evidence-based care, with approximately one-quarter of those with episodic migraine and less than 5% of those with chronic migraine receiving appropriate treatment [1-4]. Access to care is especially challenging for women, minorities, and patients living in rural areas[5]. Novel health care delivery models may improve care access when resources are limited and projected to worsen[2, 6]. Studies have demonstrated that telemedicine improves access to migraine care, and that it is associated with favorable outcomes including patient and provider satisfaction[7, 8]. Internet or smartphone app-based remote assessment and monitoring of migraine [9] may increase the efficiency of care delivery and facilitate telemedicine, electronic[10], and face-to-face visits while delivering migraine educational content. Headache clinicians are comfortable treating patients via telemedicine and most have indicated a high level of interest in prescribing migraine apps[11] while citing the importance of integrating remote monitoring data into the electronic health record (EHR)[12]. Smartphone-based apps may also improve diagnosis[13], deliver educational content[14], guide behavioral treatment[15, 16], and advance clinical trials[17].

Prior Work

We implemented a novel smartphone app-based Migraine Interactive Care Plan (MICP) integrated with the EHR (Epic[™]) in our community neurology practice. Development and testing of the MICP has been previously published[14]. Feasibility of the MICP was demonstrated in a pilot implementation study, but usability did not reach a predetermined threshold of 75% of users completing at least one electronically assigned task 127/171 (74.3%)[14].

Access to the MICP was ordered by a provider at the time of a face-to-face neurology consult and integrated into the existing EHR app (i.e., Epic[™] MyChart platform). This integration allowed patient access to their medical record, care team messaging, and appointment management. The MICP was designed to facilitate remote monitoring of adult patients with migraine, deliver educational content, and streamline care delivery. Key features of the MICP included: 1) weekly

assessments of headache days, treatment days, reduced function, and absenteeism; 2) monthly assessments of patient satisfaction (Likert scale) with their migraine treatment plan; 3) migraine disability survey (MIDAS)[18] assessment every three months; 4) scheduled delivery of migraine education content; and 5) weekly assessment of medication compliance and concerns and electronic messaging with the care team if needed.

Goal of this Study

In the current study, we sought to better understand the MICP user satisfaction and preferences and to identify opportunities to improve usability.

Methods

This quality improvement project was granted an exemption from the Mayo Clinic (IRB # 20-000606). A novel electronic survey was developed and formatted (Qualtrics, Provo, UT). Between 12/6/21 and 12/30/21 all MICP users (n = 184) received an electronic mail invitation to a secure web-based survey with a personalized letter from a physician on the migraine care team (NPY) explaining the goals of the survey and encouragement to participate. Weekly electronic mail reminders were sent to non-respondents for a total of 4 weeks. Patients electronically confirmed HIPPA agreement prior to starting the survey. Demographic variables including age and sex, were retrieved from the EHR for respondents and non-respondents and were compared using the t-test. Categorical variables were summarized. Survey responses were compared between subsets determined by patient reported headache frequency, treatment with and without botulinum toxin and calcitonin gene-related peptide (CGRP) antagonist therapy. The Wilcoxon rank-sum test was utilized for continuous variables and Chi-square test or Fisher's exact test for categorical variables using a two-tailed alpha level of 5%. Missing survey response data was excluded from analysis. Analysis was performed using SAS software version 9.4 (SAS Inc. Cary, NC).

Results

The survey response rate was 30.4% (n=56/184). No significant differences in age (P = 0.2579) or sex (P = 0.1944) between respondents and non-respondents were observed. The survey responses of all respondents are summarized in Table 1 and a comprehensive table include the subgroup analysis and P values are summarized in Supplement 1.

Table 1. Survey Responses of Migraine Users of the Migraine Interactive Care Plan

Survey question	Total respondents (N=56)
How often would you prefer to track your headache days on a smartphone application?	
Daily	15 (26.8%)
Weekly	30 (53.6%)
Monthly	8 (14.3%)
Every 3 months	3 (5.4%)
How often would you like to be reminded to record a headache day on a smartphone application?	. 60
Daily	14 (25%)
Weekly	33 (58.9%)
Monthly	7 (12.5%)
Every 3 months	2 (3.6%)
No In addition to headache days, please tell us what else you are interested in tracking with your headache days?	
Migraine/headache triggers	
Yes	41 (73.2%)
Stress Level	
Yes	38 (67.8%)
Sleep Yes	37 (66.1%)
Step Count	
Yes	9 (16.1%)
Heart Rate	
Yes	4 (7.1%)
Diet	
Yes	16 (28.6%)
Exercise	1= (00.00()
Yes	15 (26.8%)

Survey question	Total respondents (N=56)
Diet calories	
Yes	9 (16.1%)
Please rate your level of interest and motivation track, on a daily basis, the following factors in the M Clinic Migraine Care Plan	
Headache days (yes/no)	
Not at all interested	3 (5.6%)
Not very interested	3 (5.6%)
Neutral	8 (14.8%)
Somewhat interested	15 (27.8%)
Very Interested	25 (46.3%)
y	
If yes, then pain level on scale 1- 10	
Not at all interested	3 (5.7%)
Not very interested	1 (1.9%)
Neutral	11 (20.8%)
Somewhat interested	17 (32.1%)
Very Interested	21 (39.6%)
-	
Functional impairment (mild, moderate, severe)	
Not at all interested	3 (5.7%)
Not very interested	2 (3.8%)
Neutral	9 (17%)
Somewhat interested	17 (32.1%)
Very Interested	22 (41.5%)
What type of functions was impaired (work, schofamily, personal)	ool,
Not at all interested	3 (5.7%)
Not very interested	4 (7.5%)
Neutral	11 (20.8%)
Somewhat interested	16 (30.2%)
Very Interested	19 (35.8%)
Did you take medication (yes/no)	2 (5 00/)
Not at all interested	3 (5.8%)
Not very interested	0 (0%)
Neutral	6 (11.5%)
Somewhat interested	14 (26.9%)
Very Interested	29 (55.8%)
If yes, then which class (s) of medication (pick fr multiple in list)	rom
Not at all interested	5 (9.6%)
Not very interested	1 (1.9%)
Neutral	10 (19.2%)
Somewhat interested	19 (36.5%)
Very interested	17 (32.7%)

Survey question	Total respondents (N=56)
Not at all interested	3 (5.8%)
Not very interested	1 (1.9%)
Neutral	9 (17.3%)
Somewhat interested	15 (28.8%)
Very interested	24 (46.2%)
Your own personal observations/comments (free text)	
Not at all interested	3 (5.8%)
Not very interested	1 (1.9%)
Neutral	7 (13.5%)
Somewhat interested	20 (38.5%)
Very interested	21 (40.4%)
Please rate your level of agreement with the following statements about the Mayo Clinic Migraine Care Plan.	3
I felt confident using the Mayo Clinic Care Plan	
Strongly disagree	1 (1.9%)
Disagree	2 (3.8%)
Neither agree nor disagree	8 (15.1%)
Agree	24 (45.3%)
Strongly agree	18 (34%)
The Mayo Clinic Care Plan app was easy to use	
Strongly disagree	2 (3.8%)
Disagree	4 (7.5%)
Neither agree nor disagree	11 (20.8%)
Agree	21 (39.6%)
Strongly agree	15 (28.3%)
The equipment helped in my care at home	
Strongly disagree	1 (1.9%)
Disagree	8 (15.1%)
Neither agree nor disagree	23 (43.4%)
Agree	11 (20.8%)
Strongly agree	10 (18.9%)
<u> </u>	
I felt comfortable interacting with my care team through the Mayo Clinic Care Plan	1
Strongly disagree Disagree	2 (5 90/)
	3 (5.8%)
Neither agree nor disagree	7 (13.5%)
Agree	24 (46.2%)
Strongly agree	18 (34.6%)
It helped me better understand my condition	1 (1 22 ()
Strongly disagree	1 (1.9%)
Disagree	7 (13.2%)
Neither agree nor disagree	23 (43.4%)
Agree	12 (22.6%)
Strongly agree	10 (18.9%)
	T .

Survey question	Total respondents (N=56)
Strongly disagree	1 (1.9%)
Disagree	9 (17%)
Neither agree nor disagree	24 (45.3%)
Agree	9 (17%)
Strongly agree	10 (18.9%)
It helped me understand what I should be trac	cking
throughout my care	1 (1 00/)
Strongly disagree	1 (1.9%)
Disagree	5 (9.4%)
Neither agree nor disagree	24 (45.3%)
Agree	14 (26.4%)
Strongly agree	9 (17%)
It helped me understand what steps I could taking improve my health	ce to
Strongly disagree	1 (1.9%)
Disagree	8 (15.1%)
Neither agree nor disagree	25 (47.2%)
Agree	11 (20.8%)
Strongly agree	8 (15.1%)
ottorigi) ugree	5 (15:17:0)
It helped me communicate with my care team	• 0
Strongly disagree	2 (3.8%)
Disagree	5 (9.4%)
Neither agree nor disagree	8 (15.1%)
Agree	27 (50.9%)
Strongly agree	11 (20.8%)
It helped to inform me when to contact my care about concerning symptoms	team
Strongly disagree	2 (3.8%)
Disagree	9 (17%)
Neither agree nor disagree	15 (28.3%)
Agree	17 (32.1%)
Strongly agree	10 (18.9%)
Please rate your level of agreement with the follo	
statements about the education provided while the Mayo Clinic Care Plan.	
The educational materials were useful to me	
Strongly disagree	2 (3.9%)
Disagree	6 (11.8%)
Neither agree nor disagree	12 (23.5%)
Agree	22 (43.1%)
Strongly agree	9 (17.6%)
The information was easy to understand	
Strongly disagree	1 (2%)
Disagree	- (-/-)
Neither agree nor disagree	11 (21.6%)
Agree	26 (51%)
Strongly agree	13 (25.5%)
onongry agree	10 (20.070)

Survey question	Total respondents (N=56)
I was comfortable with how often I received educational	
materials	2 (2 22/)
Strongly disagree	2 (3.9%)
Disagree	3 (5.9%)
Neither agree nor disagree	11 (21.6%)
Agree	26 (51%)
Strongly agree	9 (17.6%)
I was able to find the educational materials when I needed them	
Strongly disagree	3 (5.9%)
Disagree	2 (3.9%)
Neither agree nor disagree	13 (25.5%)
Agree	25 (49%)
Strongly agree	8 (15.7%)
The educational materials matched my personal needs	
Strongly disagree	1 (2%)
Disagree	5 (9.8%)
Neither agree nor disagree	20 (39.2%)
Agree	19 (37.3%)
Strongly agree	6 (11.8%)
Care Plan matched the information received from my Mayo Clinic Care Team Strongly disagree	1 (2%)
Disagree	
Neither agree nor disagree	18 (35.3%)
Agree	21 (41.2%)
Strongly agree	11 (21.6%)
Please rate your level of agreement with the following statements.	
I would recommend the Mayo Clinic Care Plan to others with similar health condition(s)	
Strongly disagree	1 (2%)
Disagree	2 (4%)
Neither agree nor disagree	8 (16%)
Agree	24 (48%)
Strongly agree	15 (30%)
Overall, I am satisfied with the Mayo Clinic Care Plan	
Strongly disagree	1 (2%)
Disagree	4 (8%)
Neither agree nor disagree	7 (14%)
Agree	25 (50%)
Strongly agree	13 (26%)

The median age of respondents was 42 (range, 20-72) years and 94.6% (n=53/56) were female.

Respondents reported treatment with an injectable CGRP antagonist (n=17/56, 30.4%) or botulinum toxin (n=22/56, 39.3%). Patient reported headache frequency at the time of the survey was 1) 0 to 8 days (n=26/56, 46.4%); 2) 9 to 14 days (n=12/56, 21.4%); and 3) 15 or more days (n=18/56, 32.1%). No differences in survey responses were observed comparing patients reporting CRGP antagonist treatment vs no CGRP treatment, botulinum toxin treatment vs no botulinum toxin treatment, or between headache frequency groups at the time of the survey.

In terms of frequency, respondents had highest preference for tracking headache days weekly (n=30/56, 53.6%) followed by daily (n=15/56, 26.8%) and monthly (n=8/56, 14.3%), with a tracking frequency of every three months being the least preferred (n=3/56, 5.4%). Respondents indicated a similar preference for how frequently they would like to be reminded to record a headache day. Most respondents preferred to have control over the frequency of headache tracking reminders (n=42/56, 75%). In addition to tracking headache days, most respondents indicated a preference for tracking migraine/headache triggers (n=42/56, 73.2%), stress level (n=38/56, 67.8%), and sleep (n=37/56, 66.1%). Fewer preferred tracking diet (n=16/56, 28.6%), exercise (n=15/56, 26.8%), caloric intake (n=9/56, 16.1%), step count (n=9/56, 16.1%), and heart rate (n=4/56, 7.1%).

When asked about the level of interest and motivation to track on a daily basis, respondents were somewhat or very interested in tracking personal observations/comments in free text (n=41/52, 78.8%), medication treatment (n=43/52, 82.7%), response to medication (n=39/56, 69.6%), class of medication treatment chosen from a list (n=36/52, 69.2%), functional impairment graded mild, moderate, or severe (n=39/56, 69.6%), type of function impaired including work, school, family, personal (n=35/53, 66%), headache day (n=40/54, 74.1%), and headache pain level on scale 1- 10 (n=38/53, 71.7%).

The majority of respondents agreed or strongly agreed with statements about the Migraine Care Plan that they "felt confident using" (n=42/53, 79.2%), "was easy to use" (n=36/53, 68%), "felt

comfortable interacting with my care team" (n=42/52, 80.8%), "helped to the inform me when to contact my care team about concerning symptoms" (n=27/53, 50.9%), and "helped me communicate with my care team" (n=38/53, 71.7%). A minority of respondents agreed or strongly agreed with statements that "the equipment helped in my care at home" (n=21/53, 40%), "helped me better understand my condition" (n=22/53, 41.5%), "understand how to care for myself" (n=19/53, 35.8%), "understand what I should be tracking throughout my care" (n=23/53, 43.4%), and "understand steps I can take to improve my health" (n=19/53, 35.8%).

Respondents agreed or strongly agreed that the education materials were useful (n=31/51, 60.8%) and easy to understand (n=39/51, 76.5%), but fewer agreed that the education content "matched my personal needs" (n=25/51, 49%). Most respondents agreed or strongly agreed that they were satisfied with the Migraine Care Plan (n=38/50, 76%).

Discussion

Principle Results

We observed that most respondents prefer to track headache outcomes that are of interest to clinicians engaged in migraine management including headache days, treatment days and response, and functional impairment [19]. Most respondents in this study preferred weekly tracking as well as the option to change the frequency of tracking reminders along with the ability to enter free text data and observations and rate the severity of pain on 1 to 10 pain scale, all of which were not included in the MICP. Most respondents were not interested in monitoring non-headache data such as diet, exercise, caloric intake, or heart rate. Most respondents agreed that the educational content delivered was useful but that the content lacked personalization. Most respondents were satisfied with the MICP and felt that it helped them communicate with their care team, supporting ongoing use in our practice.

Strengths

We present survey findings from a unique group of patients that utilized a novel digital tool directly interfacing with the EHR within a community neurology practice. We assessed preferences for a broad range of features that may both inform migraine care and promote patient engagement. We compared respondents to non-respondents and between subsets of patients. The overall survey response rate was similar to other survey studies of the same population [6] [26, 27].

Limitations

Limitations included the small sample size. In addition, the study was underpowered to detect differences in user preferences based on headache frequency or treatment type. Most patients in the survey likely had chronic migraine or frequent episodic migraine as is typical of our specialty practice. Majority of patients were treated with botulinum toxin injections or CGRP antagonist therapy at the time of the study and majority of patients reported less than 15 headache days per month, likely reflecting the effectiveness of their current treatment plan. We did not retrospectively review records to confirm the migraine diagnosis documented in the medication record. In addition, the majority of the population we assessed were white and female, with high migraine frequency and access to a Neurology specialty clinic and for these reasons our observations are not generalizable to other patient populations or health care systems.

Key MICP improvement opportunities and Compatison to Prior Work

Free Text Capability

We observed that 78.8% of patients were somewhat or very interested in recording their own free text observations (n=41/52). This capability was not included in the MICP because of concern that free text data might be difficult for clinicians to interpret or might not be clinically actionable or easy to summarize in the EHR. Minen *et al.* also reported a similar migraine patient preference for recording free text data [20]. Although such data may be difficult for clinicians to efficiently review

within the EHR and contain clinical irrelevant observations[19], it may be important for patient engagement and improve usability. As we enter the era of artificial intelligence, such free text data may be a powerful data set for artificial intelligence tools that may be able to quickly summary such data or use in algorithm development to facilitate patient assessment and management [21-24].

Frequency of monitoring

Only 15/56 (26.8%) of respondents in our study indicated a preference for daily monitoring and only 5/171 (2.9%) of users in the pilot study of the ICP responded to 90% or more of assigned assessment tasks [14]. Raffaeli *et al.* described a cohort of highly engaged users of a commercial app that engaged with the app daily for more than 7-13 months. This cohort consisted of only 1.8% of 85,000 active app users that used the app daily for 7 months [25]. These observations suggest that sustained engagement on a daily or weekly basis may not be a realistic goal for most patients. Whether giving patients the option to change the frequency of assessments would improve overall engagement is not known.

Our MICP allowed weekly tracking of the number of headache days, treatment days, and days with functional impairment. However, most of our patients indicated an interest in changing this tracking frequency (n=42/56, 75%). The range of different preferences in tracking frequency supports allowing patients to choose the frequency of monitoring even though the accuracy of the data may be less precise the longer a patient may be asked to recall. It is also possible that the preference for tracking frequency might depend on migraine frequency, for example patients with less frequent episodic migraine may be prefer less frequent monitoring than a patient with uncontrolled chronic migraine. We suspect that as patients are effectively treated with appropriate acute and preventative migraine therapies, headache frequency and disability decrease such that daily and even weekly monitoring would no longer be necessary. Study in a larger population of patients is needed to

determine if flexibility would increase overall engagement.

Patient preferences for tracking frequency may not always align with clinician preference or insurance requirements. In addition, different tracking frequencies serve different purposes. For example, the diagnosis of episodic vs. chronic migraine depends on three months of data, whereas a shorter period may be ideal for making changes in medications or other aspects of care.

The survey suggests that patients would prefer to control their tracking and tracking reminder frequency. Individualization of tracking and reminder frequency may enhance patient engagement and understanding, especially for those with a new diagnosis of migraine. Requiring monthly assessments of headache days, treatment days, function, and satisfaction will allow the clinician access to data that will inform best migraine care. For example, monthly tracking may quickly uncover medication overuse behavior. It may also allow the clinician early detection of the transition between episodic and chronic migraine, which in turn may allow new treatment options such as onabotulinumtoxinA. The MIDAS assessment every three months may not be needed except for research purposes to allow comparison with other studies or migraine care model intervention. Monthly data trends would be simple to summarize and easy to interpret for busy clinicians.

Educational materials

Respondents agreed or strongly agreed that the education materials were useful (n=31/51, 60.8%) but the education did not always match personal needs (n=25/51, 49%). The migraine educational content was generally applicable and may be useful to a patient with a new migraine diagnosis. Most MICP users in this study had frequent migraine that led to neurology consultation and, as most were treated with Botox or CGRP, it can be assumed majority failed to respond to multiple first-line preventive options. Education specific to chronic migraine was minimal. The MICP may be improved by delivering educational content that is tailored to the migraine diagnosis or current treatment. Delivering content that is already known or simply not of interest may disengage patients.

Conclusions

Most MICP users were motivated to track headache frequency, medication treatment with response, functional impairment, and pain intensity. Opportunities to improve the MICP include allowing patients to: 1) change the frequency of assessments and notifications; 2) record personal observations/comments via free text which may include headache triggers, accompanying symptoms, prodrome and postdrome symptoms; 3) report headache severity using a 1 to 10 pain scale; and 4) tailor headache education based on frequency and severity (episodic vs chronic migraine). To balance the needs for patient engagement with the changes above, the MICP may be simplified by requiring a monthly assessment of headache days, treatment days, function, and satisfaction with treatment plan without MIDAS every three months. These observations may be useful to improve usability of the MICP and similar EHR integrated migraine care platforms that others that may develop. Continued work to refine remote monitoring tools and reassessment of user preference within diverse populations including both episodic and chronic migraine patients is needed.

Acknowledgements:

We acknowledge Jay Mandrekar, PhD for his assistance with summarizing the survey data and statistical support.

Conflicts of interest:

Mayo Clinic and Epic are partners in the development and commercialization of Care Plans. No individuals involved in this study have a direct financial interest in the Migraine Interactive Care Plan. JOE has consulting agreements with K Health, Exact Sciences, Alnylam Pharmaceuticals and MedinCell and serves on the Scientific Advisory Board for Applied Aerosol Technologies. The remaining authors have nothing to disclose.

Sources of Financial Support:

This study was funded by a grant from the Noaber Foundation and the Mayo Clinic Center for Digital Health.

Abbreviations:

MICP = Migraine interactive care plan

EHR = Electronic health record

CGRP = Calcitonin gene related peptide

References

- 1. Ashina, M., et al., Migraine: epidemiology and systems of care. Lancet, 2021. **397**(10283): p. 1485-1495.
- 2. Raffaelli, B., et al., Health equity, care access and quality in headache part 2. J Headache Pain, 2023. **24**(1): p. 167.
- 3. Lipton, R.B. and S.D. Silberstein, *Episodic and chronic migraine headache: breaking down barriers to optimal treatment and prevention*. Headache, 2015. **55 Suppl 2**: p. 103-22; quiz 123-6.
- 4. Dodick, D.W., et al., Assessing Barriers to Chronic Migraine Consultation, Diagnosis, and Treatment: Results From the Chronic Migraine Epidemiology and Outcomes (CaMEO) Study. Headache, 2016. **56**(5): p. 821-834.
- 5. Buse, D.C., et al., Barriers to care in episodic and chronic migraine: Results from the Chronic Migraine Epidemiology and Outcomes Study. Headache, 2021. **61**(4): p. 628-641.
- 6. Young, N.P., et al., *Episodic and Chronic Migraine in Primary Care*. Headache, 2019. **59**(7): p. 1042-1051.
- 7. Robblee, J., Telemedicine in Headache Medicine: A Narrative Review. Curr Pain Headache

- Rep, 2023. 27(9): p. 371-377.
- 8. Berk, T., S. Silberstein, and P. McAllister, A Novel Virtual-Based Comprehensive Clinical Approach to Headache Care. J Clin Med, 2023. **12**(16).
- 9. Mosadeghi-Nik, M., M.S. Askari, and F. Fatehi, *Mobile health (mHealth) for headache disorders:* A review of the evidence base. J Telemed Telecare, 2016. **22**(8): p. 472-477.
- 10. Robblee, J. and A.J. Starling, *E-Consultation in Headache Medicine*: A *Quality Improvement Pilot Study*. Headache, 2020. **60**(10): p. 2192-2201.
- 11. Minen, M.T., et al., *Telehealth as a new care delivery model: The headache provider experience.* Headache, 2021. **61**(7): p. 1123-1131.
- 12. Minen, M.T., et al., Headache clinicians' perspectives on the remote monitoring of patients' electronic diary data: A qualitative study. Headache, 2023. **63**(7): p. 917-925.
- 13. Roesch, A., et al., Validation of an algorithm for automated classification of migraine and tension-type headache attacks in an electronic headache diary. J Headache Pain, 2020. **21**(1): p. 75.
- 14. Young, N.P., et al., Feasibility and Usability of a Mobile App-Based Interactive Care Plan for Migraine in a Community Neurology Practice: Development and Pilot Implementation Study.

 JMIR Form Res, 2023. 7: p. e48372.
- 15. Minen, M.T., et al., Smartphone-Delivered Progressive Muscle Relaxation for the Treatment of Migraine in Primary Care: A Randomized Controlled Trial. Headache, 2020. **60**(10): p. 2232-2246.
- 16. Minen, M.T., et al., Introduction of a smartphone based behavioral intervention for migraine in the emergency department. Gen Hosp Psychiatry, 2021. **69**: p. 12-19.
- 17. Santoro, A., et al., Effects of Botulinum Toxin on Migraine Attack Features in Chronic Migraine: A Six-Month Open-Label Observation Study through Electronic Diary Smartphone

- Application. Toxins (Basel), 2019. 11(11).
- 18. Lipton, R.B., et al., Clinical utility of an instrument assessing migraine disability: the Migraine Disability Assessment (MIDAS) questionnaire. Headache, 2001. **41**(9): p. 854-61.
- 19. Dodick, D.W., et al., Improving Medical Communication in Migraine Management: A Modified Delphi Study to Develop a Digital Migraine Tracker. Headache, 2018. **58**(9): p. 1358-1372.
- 20. Minen, M.T., et al., Understanding What People With Migraine Consider to be Important Features of Migraine Tracking: An Analysis of the Utilization of Smartphone-Based Migraine Tracking With a Free-Text Feature. Headache, 2020. **60**(7): p. 1402-1414.
- 21. Chiang, C.C., et al., A Large Language Model-Based Generative Natural Language Processing

 Framework Finetuned on Clinical Notes Accurately Extracts Headache Frequency from

 Electronic Health Records. medRxiv, 2023.
- 22. Kreimeyer, K., et al., Natural language processing systems for capturing and standardizing unstructured clinical information: A systematic review. J Biomed Inform, 2017. **73**: p. 14-29.
- 23. Jensen, K., et al., Analysis of free text in electronic health records for identification of cancer patient trajectories. Sci Rep, 2017. **7**: p. 46226.
- 24. Messinger, A.I., G. Luo, and R.R. Deterding, The doctor will see you now: How machine learning and artificial intelligence can extend our understanding and treatment of asthma. J Allergy Clin Immunol, 2020. **145**(2): p. 476-478.
- 25. Raffaelli, B., et al., Determining the Evolution of Headache Among Regular Users of a Daily Electronic Diary via a Smartphone App: Observational Study. JMIR Mhealth Uhealth, 2021. **9**(7): p. e26401.
- 26. Stern, J.I., et al., Migraine Patient Care Model Preferences in a Community Practice. Neurol Clin Pract, 2023. **13**(2): p. e200131.

27. Jonker, L., et al., Digital diary App use for migraine in primary care: Prospective cohort study.

Clin Neurol Neurosurg, 2022. **216**: p. 107225.

Supplementary Files

Multimedia Appendixes

Survey responses and analysis in subsets based on headache frequency and treatment. URL: http://asset.jmir.pub/assets/54a0038b1723b88fb99af4652bef8050.docx