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Patient Experience and Attitudes Toward Electronic Intake and Patient-Reported Outcomes Within an Outpatient Whole Health Center

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Abstract

Background: The use of electronic intake forms within the electronic health record (EHR) is an emerging method for routinely collecting patient-reported outcomes (PRO). However, few studies have evaluated experiences/perspectives toward electronic forms among outpatients receiving care within Integrative Health and Medicine (IHM) clinics. The study purpose was to understand patients' perspectives of electronic intake and PRO forms in the outpatient IHM setting.

Methods: Electronic intake (e.g., treatment expectations, medical history, chief complaints, prior experience with integrative modalities) and PRO forms (i.e., Patient Reported Outcome Measurement Information System [PROMIS]-29, Perceived Stress Scale 4, Oswestry Disability Index) were designed in collaboration with clinic leadership and the Information Technology team. Semi-structured interviews were used to gather perspectives of the functionality and acceptability of the forms among outpatients receiving care at the IHM center. Interviews were coded to describe themes regarding perceptions and suggestions for improvement.

Results: Qualitative interviews were completed with 10 participants (median age 51 years, 70% female, 30% Black/African American). Participants considered electronic intake and PRO forms as relevant to their health concerns, valuable for conveying important health information to providers, and easy to navigate. Suggested changes to the intake form included adding relevant open-ended questions, save and print functions, and examples and definitions to prompt responses.

Conclusion: Participants felt the electronic format was a feasible and acceptable method of collecting patient information and PROs. Future goals are to implement the revised forms in a common EHR to patients receiving care at multiple IHM clinics across the United States.

Keywords

electronic delivery, intake forms, patient reported outcomes, complementary and integrative health, outpatient

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Introduction

Patient-reported outcomes (PRO) are subjective measures that quantify perceptions of therapeutic impact, ranging from pain and psychological symptoms to aspects of health-related quality of life (HRQoL).^{1,2} Unlike results of objective or laboratory measurements obtained by an investigator or clinician, these data are provided directly by patients.³ Increasingly, institutions are using PRO data to evaluate patient care models and innovate quality improvement.⁴ PROs are especially important for evaluating the effectiveness of health care interventions among patients with chronic conditions, where primary treatment goals include improved function and symptom management.⁴⁻⁶ Such measures help to inform clinicians' understanding of the impact of an illness, treatment, or intervention and to complement conventional, biomedical outcomes.⁷

Integrative Health and Medicine (IHM) addresses the needs of the whole person incorporating allopathic medicine with evidence-based modalities such as acupuncture, massage and chiropractic care.^{8,9} Recently published systematic reviews of PROs in outpatient IHM settings suggested that IHM modalities demonstrate potential to improve HRQoL¹⁰ and pain management.¹¹

An observational review of a trauma registry suggests traditional paper PRO capture is less efficient than electronic data capture, and patients are less likely to fully answer paper PRO questionnaires at follow-up visits.¹² Additionally, paper questionnaires are often completed in the office or clinic, limiting portability and convenience.¹³ In contrast, a metaanalysis of 32 studies collecting electronic PRO found improved patient-provider communication.¹⁴ A cross-sectional study comparing paper vs electronic PRO collection demonstrated better visualization of treatment progress and increased treatment adherence with electronic data capture.¹⁵

A meta-analysis of 21 studies including 7977 pain patients supports the validity of electronic data capture.¹⁶ A randomized control trial of 24 cancer and non-cancer pain patients suggests that patients are less likely to fabricate answers on electronic forms as compared to paper-based data capture.¹⁷ In addition, reports on quality improvement at large health care institutions recommend integrating PRO capture within clinic workflow for optimal implementation.^{18,19} A retrospective review and a quality improvement study found best practices include standardizing processes – which may play a role in addressing symptom management disparities while exploring the nuances of implementation at a given site.^{20,21} Aesthetics and user interface within electronic platforms affect patients' perceptions of PROs. According to a quality improvement evaluation of electronic PRO implementation at cancer centers, adaptability of the user interface to a variety of devices (e.g., tablets, smartphones, and laptops) may improve accessibility for various populations.²² However, few studies have evaluated the experience of completing electronic intake forms and PROs among IHM

outpatients. Accordingly, the purpose of this study was to understand perspectives of electronic intake and PRO forms among outpatients receiving IHM modalities.

Methods

Qualitative Interview – Recruitment

Adult patients with (1) the ability to read, write, and speak English; (2) a history of attending at least one IHM outpatient appointment, including the current appointment for new patients, and (3) no requirement for a proxy were approached in waiting rooms to ascertain initial interest in participating.

This study was approved by the University Hospitals of Cleveland Institutional Review Board within the health system. All participants provided written informed consent for participation and audio recording. Consent was collected electronically in a private location or virtually over Zoom.

Setting

The present study was conducted at two outpatient IHM clinics embedded within a large academic health system in the Midwestern United States. The IHM center partners with physicians, providers, and institutes to meet the growing demand for the comprehensive treatment of chronic health conditions and overall well-being, with the objective of weaving IHM modalities throughout the fabric of the entire health system. IHM modalities include chiropractic, massage therapy, acupuncture, integrative medicine consultations, music therapy, and art therapy.

This IHM clinic completes 29 000 patient visits with approximately 6000 patients each year. The majority of the patient population are female, white, non-Hispanic, presenting with musculoskeletal pain. Referrals are not required and IHM is personalized to the patients' goals. Patients are not expected to discontinue other services used throughout the health system.

PROs are used within the IHM clinics to evaluate the severity of patients' presenting symptoms and functional challenges upon presenting to the clinic and track progress on achieving patients' goals over time.

Instrument Development

An initial version of the intake form was developed within Research Electronic Data Capture (REDCap)²³ following a review of existing paper intake forms at the IHM clinic and forms developed for use at the Osher Center for Integrative Health at Vanderbilt.²⁴ This initial intake form (see Supplemental Material 1) contained a series of items assessing (1) expectations for treatment experience at the IHM outpatient clinic; (2) chief health concerns and their respective start date, frequency, and severity; (3) prior experience seeing IHM practitioners and practicing IHM modalities; (4) social history (i.e., who lives in household and children's ages); (5) food insecurity (i.e., Hunger Vital Sign²⁵); (6) exercise history in the past 6 months; (7) use of alcohol, tobacco, and recreational drugs; (8) nutrition (e.g., water intake, dietary restrictions, and daily fruit and vegetable intake); (9) medications, supplements, and opiate use; (10) a review of systems with follow up questions for each domain (e.g., appetite, digestion, mental health, sleep); and (11) pain (e.g., frequency, duration, location, intensity, description).

In addition to the intake questions, the intake form contained consents for patients to sign to receive care. Based on Dusek et al. (2022),²⁶ a separate PRO form including the Patient-Reported Outcomes Measurement Information System (PROMIS)-29,²⁷ Perceived Stress Scale (PSS)-4,²⁸ and the Oswestry Disability Index²⁹ was developed to accompany the intake form. The initial REDCap draft of the combined forms underwent multiple review iterations by the leadership team at the IHM clinic, which included the Director of Operations, chiropractors, researchers, acupuncturists, and integrative medicine physicians. Through this review process, branching logic was optimized to reduce response burden, wording was modified, and questions were reordered to improve user experience.

E-Forms

E-Forms is an electronic survey platform developed by the Information Technology (IT) team within the health system where the study occurred. In addition to allowing multiple response types (e.g., radio button, checklist, matrix, and free text) for questionnaires, E-Forms provides additional functionality including (1) automatically sending questionnaires via text message using information from the scheduling platform; (2) generating a color-coded dashboard summarizing trends in PROs; and (3) uploading PDF versions of completed forms to the electronic health record (EHR).

Following the refinement of the form in REDCap, the IT team built the combined forms within E-Forms using the REDCap instrument as a guide. This E-Forms version then underwent multiple revisions to (1) ensure an accessible user interface on mobile devices (e.g., appropriate text wrapping, orientation of response choices, and elimination of extra text entry for patients); (2) verify branching logic; and (3) ensure appropriate grammar and punctuation. Participants completed the combined forms using the E-Forms test environment portal on an iPad or computer.

Data Collection

An interview guide was developed based on obtaining participants' perspectives on the electronic intake and PRO forms. Semi-structured qualitative interviews were conducted in-person or virtually (via Zoom for Health care). All interviews occurred in private locations either immediately after participants' appointment or scheduled for a later time based on participants' availability. Audio recordings of each session were professionally transcribed. Data was collected in March 2023. Interviews were conducted by the authors TS, SRM, and JS.

Data Analysis

Transcripts were uploaded into NVivo (v1.0, QSR International, Melbourne, Australia) to facilitate coding. Thematic template analysis was used to identify and address the electronic form and PRO strengths and opportunities. TS designed a preliminary coding scheme based on the forms' subject headings and the objectives of the study. TS coded the full set of data and revised the coding scheme as new themes emerged. TS and SRM reconciled the coding decisions and data interpretations. Participants' comments were evaluated for relevance and significance to the research objective.

Results

Sample

The current study recruited 10 participants over a one month period; 115 patients were screened, 6 were excluded due to language barriers, needing a proxy or age, 47 declined for lack of interest or time, and 52 patients were missed while investigators were speaking to other patients or conducting interviews. Suggested sample size is 8-15 participants with data saturation often met with a sample less than 20.^{30,31}

Demographics

Participants had a median age of 51 years (interquartile range: 36-57), with a range from 20 to 78 years. Participants were generally female (70%), White (60%) or Black/African American (30%), non-Hispanic (90%), and married (50%).

Acceptability

Open-Ended Questions. Several participants emphasized the importance of incorporating open-ended questions within the intake form (e.g., "What are you hoping to achieve during your upcoming appointment?"). They felt allowing patients to describe their concerns beyond the prescribed questions would be valuable, help them feel heard, and offer their provider a better understanding of their concerns.

I would say it's nice that there were open-ended boxes to let people delve into more detail about their specific pain and any other concerns they have, 'cause it helps a patient feel more heard to have that space.

I like the section of 'Is there anything else you want to tell us?' That's very helpful, too, 'cause I think sometimes we get into all the questions and then there's something else more or just as pressing and we almost forget about it. So that's helpful....

Overall Forms. Most participants reported a positive experience with navigating through the E-Forms platform. The forms were easy to read, looked aesthetically pleasing, and featured clear instructions.

[The E-Form is] easy to understand. It kind of opens your own eyes, as you're filling it out, what's going on with you, so it helps and it's very easy to function through that.

Electronic Presentation. The electronic format was wellreceived by most. The participants appreciated the portability and ease of using an electronic format.

This is easy to read. So like patient name will probably be up here [participant points to form header] and then I see my [name] - easy, verifiable, that it's me. I wouldn't know my MRN number, so to speak, but at least my birth date could be validated. Going through, I like that there's this marker [participant points to completion status bar]. I like that there is kind of like that gauge. And then I like that it's easy...So even if you had a mouse, or on your phone, it would be easy to scroll through. This is relevant for today's world. It was user-friendly. Absolutely.... This is something that can be done on a phone.

One participant expressed concerns regarding accessibility for populations lacking access to technology or having less familiarity with electronic platforms.

Who's the audience? And I'm thinking about that because I'm older, but I'm fairly fast with the computer. I mean I know how to do these electronic forms, and I don't know that everybody you'd want to reach could even use a computer like this, so that would mean that your audience would already be determined, because you're gonna do this electronically, right?

One participant suggested distributing the link to multiple devices could mitigate accessibility issues and increase portability.

...I would probably prefer it to come to me and do it on my phone because I could do it anywhere. If I had to do it on a laptop, I've got to wait until I get a laptop. If I'm at home, I've got to wait... If it's on my phone... and I get a text message, it's a link, you just hit the link and go right to it, get it done.

Relevance

Most participants felt the intake form and PRO questionnaires were relevant to their appointment.

Participant: Most [questions]...seems like it's good information that the doctors would know and [Healthcare Provider] would

know... Interviewer: What did you find the most valuable about these questionnaires or forms? Participant: The biggest thing is getting a breakdown of the issues you have. That's huge for a Healthcare Provider to know exactly to a point what's happening to you.

Several participants felt the topics of some questions (e.g., anxiety, depression, and sleep habits), while relevant to their appointment, were repetitive when completing both the intake form and the PRO questionnaires in the same session.

There just seemed to be some repetitive... Like it asked it in one place, but then you're asking it again in another place, but probably for a different reason, because it's later and you're trying to track the client.... So maybe it's just because I'm getting them all at once that I'm just seeing it like that.

Only one participant felt the forms were not relevant to their appointment and completing them would be a waste of time as they perceived their provider would not have the opportunity to review the responses in time to use results in that visit.

And they're not going to do anything for me here, because I know <Doctor> is on such a time crunch. She barely sees me for 20 [minutes], so I know she's not gonna do anything with this information, so what's the point of asking me... I don't need to waste time answering these questions because they don't have anything to do with the treatment I'm getting done.

Suggested Changes

Individual Questions. Commonly suggested changes to individual questions were (1) making a question more colloquial, (2) making text more prominent in the instructions, and (3) adding definitions lists of disorders and therapies.

If there are these terms, then maybe there could be some sort of description that would explain what that is, 'cause maybe then it would've confirmed, 'Oh yeah. In fact I have done that.'

On the body diagram used for specifying pain location, several participants suggested using separate numbers for the major areas of the lower extremities (e.g., hips, knees, ankles, foot). Additionally, in the pain section, several participants suggested listing examples of pain descriptors to help initiate patients' responses.

...it might be helpful to have a list: 'Is your pain sharp, dull, surging, radiating?' that sort of thing, because the average person doesn't think, 'Well it's radiating.' They just think, 'Oh it hurts across here.'

Interviewers asked participants specifically about the wording of open-ended questions in the General Information

section of the intake form. Most participants did not like or understand the relevance of the questions as they were written and offered suggestions for changes or liked alternative questions provided by interviewers.

Interviewer: What do you think of the phrasing of the questions we've seen so far? Do you think they're necessary? Participant: When it says, 'What's the most important thing in your life right now?' Maybe making that question's wording a little bit more specific, 'cause then you get to the next one, 'What's the most important thing we could do to help you get there?' It's like, 'Oh, okay. That's specific to [IHM clinic].'

Frequency. A few participants suggested that E-Forms links should be sent 1-2 weeks prior to an appointment, with reminders sent a few days before their appointment, if not completed. The suggested time it takes to complete the forms ranged from 2 to 45 minutes. One participant pointed out that this will vary depending on the patient's issues and response detail. Suggestions for how often E-Forms should be completed ranged from one time only, to every 3-6 months, to once a year. Most participants who offered interval suggestions believed that patients should have the opportunity to update their intake information as changes to their health occur.

Patient-Reported Outcomes. The PROMIS-29, PSS-4, and Oswestry Disability Index questionnaires were all deemed appropriate. Participants recommended alternative ways to present the order of the questionnaires, suggesting easing into the topics with less invasive questionnaires (i.e., fatigue and sleep disturbances) first before presenting potentially triggering topics (i.e., depression and anxiety). PRO instructions were said to be easily understood, though some participants suggested time frames (e.g., within the last 7 days in the PROMIS-29) be made more prominent.

Overall Form. One participant expressed concern about the ability (1) to save their progress and return to complete the forms later and (2) to print the form for their own records.

I've done forms like this, it took a long time to fill out, but in this one particular case, I couldn't save my spot, and that is so aggravating. I'm here only on Page 9 of 18, where can I save this? There's nowhere for me to save.... My other [suggestion] is being able to print this out, as a patient, so that I have record of it, not just ever electronically, but I would like to print a PDF of it at the end.

Changes Implemented from Patient Feedback. Changes were made to the initial electronic intake (See Supplemental Material 1) in response to the suggestions made by participants (See Supplemental Material 2). Definitions were added to the lesser known IHM modalities and therapies as reported by the participants. Examples were added to questions to help clarify anticipated responses. In response to feedback on the E-Forms body diagram of pain locations, additional numeric labels were added for a more comprehensive list of body areas. Open-ended questions on the General Information page were revised to be more relevant to health goals, (e.g., "What are you hoping to achieve during your upcoming appointment?" and "What is the most important thing that we could do to help address your health concerns at your upcoming visit?"). Save and return and print functions were added to the E-Forms instruments.

Discussion

The purpose of this study was to understand patients' perspectives of electronic intake and PRO forms in the outpatient IHM setting. Overall, participants perceived the intake and PRO questionnaires to be acceptable and easy to use. Throughout the intake form, participants offered minor suggestions for ways to better present or phrase questions. These suggestions did not significantly change the intent of the questions or sections as a whole. Additionally, participants deemed the use, wording, placement, and scales used throughout the forms (e.g., food insecurity, Likert scales, and medication-use questions) as being appropriate for these screenings and relevant to their appointments. Offering options for patients to complete the forms on a variety of devices (i.e., phones, tablets, or laptops) could ameliorate accessibility issues for those with vision or dexterity limitations. Additionally, offering tablets in the clinics may bypass barriers to form completion, such as Internet accessibility, or instances when patients forget to complete forms prior to their appointments.

One participant was frustrated by the possibility of their PROs not being reviewed by the provider, which reduced that patient's desire to complete the PRO forms. When discussed during a clinical encounter, PROs demonstrate to the patient that health care providers are concerned for their overall health and wellbeing and interested in what they have to say; further, routine PRO collection allows providers to monitor patient progress longitudinally.³² Participants expressed interest in viewing changes in their own PROs over time, noting that providing these data would open the opportunity for communication with their health care provider. Accordingly, training providers to locate documents within the EHR to review patients' responses and creating a PROs dashboard will be essential for demonstrating to the patient the importance of completing the intake and PROs. Previously, we have successfully incorporated PROs within discussions between medical providers and patients in the immediate clinical encounter.33

This study had several limitations. Lack of participant diversity limits generalizability. Further study with patients whose primary language is not English is prudent. Additional collaborators in the development of coding schemes and interview analysis is warranted. The intake and PRO questionnaires were lengthy, and the estimated time to complete the interview was about an hour. Consequently, many of the patients approached perceived this time commitment as burdensome. Offering to complete interviews inperson or virtually and remaining flexible to accommodate patient schedules helped relieve the time burden for those who did participate. Response bias may have been present as participants may have felt the need to provide positive feedback about a workflow related to a practice for which they have had a positive experience. Conversely, two patients did not feel comfortable offering their opinion on this type of electronic workflow. However, considering these limitations, we were able to meet our recruitment goals.

Conclusions

Our results suggest that electronic data capture is acceptable and feasible for collecting intake (e.g., treatment expectations, medical history, chief complaints, and prior experience with integrative modalities) and PRO measures within IHM outpatient clinics. To advance implementation, the study team subsequently worked with the EHR and IT teams to revise the E-Forms in accordance with participants' suggestions. The revised forms will be incrementally distributed to wider audiences within the outpatient IHM clinics in real-time, while the study team documents implementation and troubleshoots issues and resolutions reported by stakeholders. Demonstrations and training guides will be made available to providers for accessing and interpreting the intake and PRO forms, stressing the importance of reviewing data prior to appointments in order to address patients' concerns expressed in their forms. As the larger health system implements a new EHR system (Epic), we expect to embed these intake and PRO collection procedures within routine clinical practice at outpatient IHM clinics across the US. We also plan to make available the electronic intake and PRO questionnaires in REDCap and the EHR system to facilitate use across the BraveNet Practice Based Research Network of 21 IHM clinics.34

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Supplemental Material

Supplemental material for this article is available online.

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