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Patient and Clinic Personnel Feedback on Implementation of an Individualized, Computerized, Culturally Tailored, Patient Self-Administered Lupus Decision-Aid (Ptda): A Mixed-Methods Study

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Abstract

Objective: To iteratively modify and finalize patient and clinic personnel materials for an implementation study of a systemic lupus erythematosus (SLE) patient decision-aid.

Methods: We conducted a mixed-methods study. We used a semi-structured interview guide to debrief consecutive patients with SLE at our rheumatology clinic and our clinic personnel, to receive feedback on the lupus decision aid, clinic personnel surveys and interview guides. We also used brief surveys.

Results: We studied several cohorts: (1) *Decision Aid Debriefing Patient Cohort after viewing the lupus PtDA (n=20)*: mean age, 51.1 years (standard deviation, 14.7); 19 females and 1 male; (2) *Whiteboard Debriefing Patient Cohort after viewing a whiteboard animation (n=11; all female:* mean age, 44.7 years (standard deviation, 14.1); (3) *Clinic Personnel Decision Aid interviews (n=4) and Clinic Personnel Survey Cohort (n=7).* Most patients (45%) were pleased with the way the decision-aid was presented; and how these medications helped disease management and compared to each other for benefits and harms (55%). Most patients (70%) found the length of the decision-aid appropriate. Majority of the patients agreed (81%) that the lupus PtDA will be useful for making treatment and medication decisions in the future. Patients requested a decision-aid phone app version. Some patients were concerned about the contents being too focused on treatment of lupus kidney disease. Clinic personnel provided feedback on their surveys being easy to understood with minor exception and provided comments for the modification of their interview guide.

Conclusion: We successfully iteratively modified and finalized patient and clinic personnel materials for our implementation study.

Keywords: patient decision-aid; systemic lupus erythematosus; development; racially diverse; patient; clinic personnel; mixed methods study; qualitative, quantitative

Introduction

Systemic lupus erythematosus (SLE) is a chronic, multisystem, autoimmune disease that disproportionately affects young women and racial and ethnic minorities.[1] SLE has a severe impact on patients' self-esteem and independence, physical, mental and social functioning.[2] Racial and ethnic minorities with lupus have worse outcomes related to gaps in patient knowledge of effective treatment options,[3,4] poor healthcare access, and other social determinants of health (SDOH).[5] Patients are risk-averse and decline organ-saving treatments due to their concerns about side effects.[2,3,6-8]

We have previously described the development and testing[9] of our Shared Decision-Making In Lupus Electronic (SMILE) tool, referred to as the lupus patient decision aid (PtDA) from here onwards. This individualized, computerized, culturally tailored, patient self-administered lupus PtDA was developed based on the International Patient Decision aid Standards (IPDAS) principles[10] in both English and Spanish languages and allows individualization of content review based on patient choice and preference.[11] The lupus PtDA was more effective than a standard pamphlet in reducing decision-conflict and improving informed choice in lupus kidney disease.[9] The development of the lupus PtDA was done in the target population of interest[4,12,13] using the

comparative effectiveness research (CER) data on medication benefits and risks.[14-16]

The objective of this study was to finalize materials for our implementation study with key stakeholders' feedback (patients with SLE and clinic personnel) before launching the full-scale implementation trial of lupus PtDA to be conducted during regular rheumatology clinic visits, i.e., the Implementing Decision-Aid for Lupus in clinics (IDEAL) study.[17] We performed a pilot mixed methods study of patients with lupus and clinic personnel (survey and de-briefing). The survey instrument and interview guides were developed for our main implementation study. We also conducted semi-structured interviews (over the phone), and online surveys with key clinic personnel to finalize key interview procedures and surveys for the main implementation trial.

Methods

Study Sample and Procedures:

We reviewed an electronic list of patients with a diagnosis of systemic lupus erythematosus (SLE; referred to as lupus in this article from here onwards) was obtained from the Electronic Health Record (EHR) database to screen potential participants. We approached a convenience sample of lupus patients from the University of Alabama (UAB) rheumatology clinics during their regular outpatient clinic appointments. Patient participants were recruited during regular outpatient visits. Participants viewed a whiteboard animation created to introduce the lupus PtDA before viewing it completely and completed a patient acceptability and feasibility questionnaire (relevance of information, satisfaction with the decision-aid, usefulness in decision-making). We used a semi-quantitative interview guide to de-brief the patients about each questionnaire, and the lupus PtDA. The goal was to have patients with lupus view the computerized lupus PtDA detailing lupus treatments without disrupting the normal clinic flow. Debriefing lasted about 10-25 minutes each. We continued iterative modification and enrolling participants until we noted saturation for both the lupus PtDA and the whiteboard presentation debrief. No formal sample size calculations were done. We aimed to continue the interviews till saturation of themes was noted. The study was approved by the institutional review board at the University of Alabama at Birmingham (UAB).

We approached four key clinic personnel (a clinic front desk clerk, a nurse practitioner, a clinic nurse manager, and a physician) to participate in semi-structured interviews to ensure the representativeness of a clinic team. We conducted semi-structured in-depth interviews, which lasted between 30-60 minutes each. The key clinic personnel (n=3) were recruited from the UAB Whitaker clinic (n=1) and at the UAB Kirklin clinic (n=1), two adjacent clinics. We sent a link to the lupus PtDA via email to all clinic personnel participants ahead of the interview to give them a chance to get familiar with it and be prepared to answer any questions asked. After a brief introduction, participants were asked a series of questions about their background and individual characteristics, clinic infrastructure (staff structure), culture in the clinic including readiness to implement change, staff awareness of patient needs, and process and strategies to implement new changes in the clinic, their opinions of the decision-aid, and patient needs. The purpose of this baseline assessment was to ensure that the interview questions were clearly worded, ordered in a way that makes sense, to generally assess how prepared the clinic is to implement the lupus PtDA, and identify barriers to using it. Each interview was recorded and was transcribed verbatim for accuracy and analyzed.

We also emailed a short Qualtrics survey questionnaire to seven clinic staff members who represented all key team members of the target clinic (two medical assistants and another front desk clerk in addition to the four members listed above). The clinic personnel were requested to complete an online prototype survey planned for administration in our future implementation trial across multiple sites, the IDEAL study.[17] The purpose of the clinic survey was to capture clinic personnel's thoughts about making the decision-aid work for their patients during a busy clinic without disrupting the clinic flow. A brief introductory email was sent to participants ahead of time explaining the purpose of the study and how their responses will be used to improve the implementation of the survey in the future trial. We the use of validated questionnaires, the Organizational Readiness for Implementing Change Survey (ORIC)[18] and the Team Learning and Psychological Safety Survey (TLPSS).[19] In these questionnaires, participants were asked several questions related to the clinic's readiness to implement change, climate of the clinic (the environmental and social atmosphere within a clinic, the clinic's sustainability and resilience), the clinic's learning environment, and clinic culture, i.e. the shared values, beliefs, and behaviors that shape how staff interact and approach their work, ultimately impacting patient care. No compensation was provided to patients or key clinic staff.

Results

Study Cohort Characteristics:

Decision Aid Debriefing Patient Cohort. The decision-aid debriefing and questionnaires were administered to an overall sample of 20 patients with SLE, after viewing the lupus PtDA. This included 19 females and 1 male; mean age was 51.1 years (standard deviation, 14.7). There were 14 White, 5 African American, and 1 Hispanic participants; none were experiencing a lupus flare currently or needed of a change of medication at the time of the pilot study. The lupus PtDA was provided for patients to view on a printed hard copy in addition to seeing it on the touchpad computer.

Whiteboard Debriefing Patient Cohort. Eleven female patients were approached during the regularly scheduled lupus clinic. Each participant viewed a whiteboard animation created to introduce the lupus PtDA before viewing the lupus PtDA. There were five African American and six White participants with mean age 44.7 year (standard deviation, 14.1).

Clinic Personnel Decision Aid and Clinic Survey Cohort. The seven clinic personnel that completed the survey including the four that were interviewed; it consisted of six females, and one male and the age range was 25-64 years. There were two African Americans and five White participants (one with Hispanic descent). The educational background was comprised of one Doctorate degree, one Professional degree, one four-year degree, and four with some college education. Clinic personnel had been in the current position ranging three months to nine years.

Decision Aid and Whiteboard Debriefing by the Patient Cohorts

We asked patient participants several questions about the lupus PtDA including the presentation of the lupus PtDA, feasibility of the patient survey, satisfaction with the decision-aid, and preparation for lupus decision making. Twenty patients participated. Most patients (45%) were pleased with the way the decision-aid was presented since they gained knowledge about how to and which medication to use for treating lupus, and how these medications

helped disease management and compared to each other for benefits and harms (55%). The length of the decision-aid was appropriate for 70% of the patient participants, who reported that it had the right amount of information in a balanced format. Majority participants agreed (81%) that the lupus PtDA will be useful for making treatment and medication decisions about lupus in the future. Participants found the simple graphs and numbers and associated explanations for these in the lupus PtDA very informative1. Patients preferred to additionally see the lupus PtDA in the form of an "app" or available through the patient portal.

Some patients were concerned about the contents of the decision-aid being directed towards lupus kidney disease (none of the patients had current diagnosis of lupus kidney disease, i.e., only had the diagnosis of lupus) making this information challenging to relate to. Less than half of the patients with lupus (45%) knew what medication options are available to them and thought that they would be able to make these decisions without pressure from others. The participant opinion was divided on whether they clearly understood the benefits of each lupus treatment option. Many expressed that it was still difficult for them to make decisions about the risks and benefits of lupus medication, what matters most to them, the side effects, and clarity on what is the best choice, should they develop lupus kidney disease in the future. Participants reported that the decision-aid would help lupus patients recognize and prepare for decisions that need to be made; and what questions to ask the doctor. Participants perceived that the lupus PtDA would have a significant impact on patients organizing their thoughts and thinking about how involved they want to be in the decision-making process. The educational material in the lupus PtDA helped patients a great deal to prepare for the next follow-up visit with their doctor.

Most participants liked the whiteboard presentation and there were very few additional comments related to it. Participants found the whiteboard helpful in orienting them to what decision aids are and why they would help them in thinking of the treatment of lupus. Many participants liked the narrative nature of the whiteboard presentation. Participants considered the length of the whiteboard narrative presentation appropriate.

Clinic Personnel Semi-Structured Interviews

Four clinic personnel were evaluated during a 30 to 60 minutes interview regarding their knowledge of the decision-aid (received prior to interview) and the clinic's current conditions that may support or hinder the implementation of the lupus PtDA. The responses from these interviews were used to improve the interview protocol and eliminate any vague, unclear, or repetitive questions.

The common observations from the semi-structured interviews were that the interview guide is too long and contains some redundancy across questions. Questions related to the lupus PtDA were difficult for clinic personnel to respond to without a fair degree of familiarity of the decision-aid. Participants responded more comfortably to questions about the content of the lupus PtDA rather than its potential ongoing and future use in the clinic. Certain questions were challenging for the front-line staff members (front desk staff, medical assistants) to answer and this presented an opportunity to design potentially multiple versions of the protocol to suit different roles for clinic personnel within the clinic. There was confusion around what the "lupus shared decision-aid" is; a suggestion was to include a description of the lupus PtDA in the introduction section and a concise way to refer to it throughout the interview. Several questions were ambiguous, that included terms that were not clearly defined (e.g. clinic culture). Two clinic personnel felt it would be beneficial to send the interview questions out in advance for the clinic personnel to gain a clear understanding of the protocol and the interview.

The final semi-structured interview was conducted with a physician, who was also the Rheumatology Chief at the VA hospital. His perspective of the decision-aid was that it was very informative, would stimulate conversations, and would be easy for patients to understand. The physician indicated that Veterans are more likely to adhere to the doctor's recommendations for reviewing about the lupus PtDA for reviewing treatment options. The provider also indicated that due the length of time it takes to complete this study, it may be difficult for a veteran to retain information due to cognitive function issues due to chronic pain. The physician also suggested that younger veterans will likely be more open to participate in a future implementation study.

Clinic Personnel Survey

Seven clinic personnel participated in an online survey to assess individual opinions and perspectives on issues related to implementing the decision-aid in the usual clinic setting. These responses were used to determine whether future respondents are interpreting the questions correctly. Participants were asked debriefing questions ranging from understanding the introductory email, understanding the purpose of the survey and how to complete it, clarity of the language used, and what it meant to them. There was an introductory email sent to all participants explaining the purpose of the survey and the manner to complete it; participants found this information easy to understand and no additional clarifying language was necessary. The clinic personnel understood the words 'readiness to implement change'; though their individual definitions of the terms differed it did not stop them from answering the first section of questions on the topic. Climate of the clinic was unclear to some participants in the second section and their definitions of the term was scattered. There was a clear comprehension of the third section on the learning environment of the clinic. The final section presented four definitions of culture in the clinic (team culture, hierarchical culture, entrepreneurial culture, and rationale culture of the clinic). Clinic personnel were disconnected with the meaning of culture in this section which made it difficult for participants to label which percentage their clinic attributed to each definition of culture.

The response categories (included agree, somewhat agree, strongly agree, neither agree nor disagree, disagree, somewhat disagree, strongly disagree) were easily understood by clinic personnel. There were multiple items answered neither agree nor disagree. Participants chose this response if they were unsure about the question or did not want to choose to agree or disagree. If we did not include "neither agree nor disagree" response category participants would have skipped the questions they were unsure about; and spent more time to indicate a true response on items they were indifferent on.

We found that some clinic personnel lacked buy-in, and the survey was completed without genuine interest. The clinic personnel that were invested in the survey provided the best responses and detailed feedback about concerns of clarity. As a result of this study, we will provide a more detailed opening paragraph to clearly define the terms used throughout the survey and how to apply these to the perspective clinic when answering the questions.

Discussion

Shared decision-making is a vital to start the conversation

between patients and the physician about medication options. One interesting study finding was that patients perceived the lupus decision-aid to be helpful in making treatment and medication decisions about lupus. This finding is similar to an observation in a previous study, where people diagnosed with rheumatoid arthritis, psoriatic arthritis or ankylosing spondylitis, who were deciding whether to start or switch disease modifying anti-rheumatic drugs (DMARDs), viewed a DMARD decision-aid.[20] After using a DMARD decision-aid, people perceived a more active role in medical decision-making and medication decisions were more in line with patients' personal preference. Our study extends this finding to people with lupus. Patients also liked how the information was presented in lupus decision-aid, and they found this easy to follow and understand. These two observations indicate that we were successful in building a patient decision aid for people with lupus, and that the information provided in this decision aid would assist decision-making in lupus. This is important because patients with lupus frequently make difficult decisions related to use of effective immunosuppressive medications that also have significant toxicity, including gastrointestinal side effects, serious infections, and cancer with long-term use. Many patients decline effective therapies for lupus due to these concerns.[8] Studies demonstrate that risk averseness towards medications is higher in racial and ethnic minorities,[3,8] in general. Thus, it is not surprising that medication adherence in lupus is lower in racial and ethnic minorities compared to Caucasians.[21,22] Therefore, potential solutions include (1) removing knowledge barriers, (2) improving provider-patient communications and (3) providing access to healthcare and mediations for treating lupus. The lupus decision-aid can potentially overcome the first two barriers to potentially reduce treatment disparities in lupus.

Patients also suggested that we should try to develop a phone app version in addition to the existing website version of the computerized lupus decision aid. This was not a study objective for our implementation trial of the lupus decision-aid in regular outpatient rheumatology clinics.[17] However, based on this feedback, we developed phone app versions of our computerized lupus PtDA for both iOS and android systems during the COVID-19 pandemic.[11] Several patients preferred downloading the phone app over viewing the decision-aid on the iPad. iPad-administered lupus decision-aid is provided on a larger screen, which makes it easier for people with poor vision, and older patients, to use the decision aid. The phone app has the advantage of being available to the patient at any time and any location, which allows the patient to re-review the information anytime, and to complete viewing of the decision-aid, if they were not able to complete it during the clinic visit. An interactive smoking cessation decision-aid phone app significantly increased smoking cessation and informed choice.[23] A mobile app version of patient decision aid for providing treatment options to women with overactive bladder led to reduced decisional conflict.[24] In summary, phone app versions of patient decision-aids have been found to be effective in improving shared decision-making and patient outcomes. The availability of the lupus decision-aid as a phone app should support its widespread dissemination.

Constructive feedback from the participants was that the lupus decision-aid was focused on kidney disease. Patients wondered whether and to what extend the decision-aid would be useful to all patients with lupus, regardless of the presence or absence of kidney disease. Based on this feedback, we performed a significant update to the initial version of the decision-aid and released the version 2.0 prior to the initiation of our implementation trial. In addition to all the date from version 1.0 on treatment choices of immunosuppressive drugs for lupus kidney disease, the version 2.0 also included detailed information on treatment options for treatment of lupus other than kidney disease. This included information on drugs for treating lupus skin disease, lupus joint disease and most importantly all the available biologics for the treatment of lupus, including but not limited to, new approved therapies. We followed an iterative process for the update using the same three steps as in the original lupus PtDA development:[25] (1) an updated systematic review of the new evidence and evidence on treatment of non-kidney lupus disease; (2) provision of this information at the 5th grade reading level with additional information pages; and (3) iterative testing of the new content with the target population till no new corrections or improvements were noted. The original development of the lupus PtDA was very patient-centered and evidence-based.[4,12-16] We used version 2.0 of the lupus PtDA for the implementation study that followed this study. The results of the implementation study that include the shared decision-making outcomes will be published separately (manuscript submitted).

Another important finding was that after viewing the lupus PtDA, less than half of these patients knew of the available treatment options for lupus. While it is possible that some patients had mild lupus or a recent onset of lupus, it is more likely that there are gaps in patient knowledge, and patient physician communication, cognitive deficits leading to poor recollection of benefits/risks of these medications due to poor memory, and limited time to devote to patient education in a busy clinic practice. Few educational materials for lupus are written at the fifth-grade level that don't require advanced health literacy. Our lupus PtDA is at the fifth-grade level, includes graphics that don't need advanced skills to understand them that potentially overcomes several challenges.

Decision-making in lupus is difficult, and many participants recognized that this challenge exists despite the availability of knowledge with regards to the side effects and benefits of each medication. We recognize that while lupus decision-aid can get the conversation started regarding the treatment of difficult lupus, significant challenges in the lupus management still remain.

There are some interesting findings from the clinic personnel interviews. Few clinic personnel still had questions about what a shared decision It is, while others understood that very well, confirming a lack of engagement. Clinic personnel recommended that we include an explanatory email while sending this to clinic personal. We noted a wide range of interest by the clinic personnel on this project and some lacked buy in. We recognize that every clinic flow is different, and adaptations are required to implement this decision-aid in each clinic's structure. Buy-in from key clinic personnel is necessary to ensure implementation is initiated and sustained in a busy clinic. We made changes to the materials for clinic personnel for the main implementation trial based on this feedback. Additional strategies for the engagement of clinic personnel includes leadership support that prioritizes and rewards the clinic personnel for a patient-centered care focus on patient education and empowerment, and tailored training of the clinic personnel so they have better buy-in into the implementation and continued use of the lupus PtDA.

Our study findings must be interpreted with caution. We enrolled a convenience sample at one clinic and therefore these results cannot be generalized to all clinics and all settings. We did not calculate sample size for this study. However, we continued iterative feedback with patients until saturation of the themes was documented. Therefore, the qualitative work with the clinic personnel should be interpreted with caution due to a small sample size. We continued qualitative work with patients until we noted saturation of concepts.

Our future plans include widespread implementation of the lupus PtDA across diverse private practice settings, a study of its long-term effectiveness in improving patient outcomes and shared decision-making, to potentially reduce the disparities in patient knowledge and outcomes in lupus.

In conclusion, we performed a mixed-methods study with patients with lupus and clinic personnel, the key stakeholder groups. This helped us to successfully iteratively modify and finalize the materials for our implementation study. The lupus PtDA will be offered to patients attending regular rheumatology clinic visits at the participating sites. Our goal is to inform at least 500 lupus patients using our lupus PtDA.

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Ethical Approval

This study was approved by the institutional review board at the University of Alabama at Birmingham in Birmingham, AL.

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