Patient Preference and Adherence

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ORIGINAL RESEARCH

Exploring Information Needs and Perspectives on a Patient Decision Aid for Biologic Therapy: A Qualitative Interview Study Among Individuals with Rheumatoid Arthritis

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Purpose: Significant advances in therapeutic and management options have been made for rheumatoid arthritis (RA), including the development of biologics. However, some patients have expressed hesitancy with respect to their use. We aimed to (1) investigate RA patient perspectives on a biologic patient decision aid; and (2) explore how this decision aid addressed their broader information needs in a US healthcare context.

Patients and Methods: We conducted in-depth telephone interviews with RA patients who were considering either initiating a biologic for the first time or switching to another biologic. Participants were recruited from across the US by a research coordinator based at Massachusetts General Hospital. Participants were first invited to access an existing decision aid developed to support individuals with RA who are considering a biologic. We conducted an iterative content analysis guided by the grounded theory approach.

Results: We interviewed 14 patients with RA, among whom five were biologic-naive. We identified four major themes: 1) *treatment-related information seeking behavior* (including connecting with others with a chronic disease); 2) *helpful aspects of the decision aid* (including access to patient stories); 3) *decision aid limitations and potential solutions* (including content preferences and accessibility); and 4) *impacts on the decision to initiate a biologic* (including empowerment to engage in shared decision-making).

Conclusion: These four themes highlight key factors to consider for the design/refinement and implementation of patient decision aids in the US (including key information needs and the utility of patient stories) to appropriately meet the needs of patients who are considering a biologic.

Keywords: rheumatoid arthritis, DMARDs, biologic therapy, qualitative research, patient education, decision aid

Introduction

Rheumatoid arthritis (RA) is a chronic inflammatory rheumatic disease that is characterized by progressive articular damage and extra-articular manifestations.[1] RA is associated with an increased comorbidity burden, high rate of health resource utilization, and corresponding high cost of illness spanning both direct medical costs and indirect costs from lost productivity.[2–4] There have been significant advances in therapeutic and management options for RA, including the development of several classes of biologic medications.[1] Despite these advances, treatment adherence varies widely, with a meta-analysis estimating a 66% adherence rate across all disease-modifying anti-rheumatic drugs (DMARDs),[5]

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although biologic treatment adherence may be slightly higher compared with that for conventional DMARDs.[6,7] Nevertheless, despite the demonstrated clinical benefit of biologic use among those with RA who are indicated for treatment, some patients continue to report feelings of hesitancy with respect to initiating or continuing these medications.[8–10] This may be driven by multiple factors, including fear of needles, cost, confusion about treatment options, perception of illness, and, in marginalized communities, awareness of historical injustices in healthcare and health research.[8–10] To that end, a shared decision-making approach using a patient decision aid may improve disease management by supporting RA patients through the process of making informed treatment decisions. Patients who have used decision aids are more knowledgeable about their treatment, have more realistic expectations, and feel less conflicted with their decisions compared to those in usual care,[11] which may in turn lead to improved medication adherence and outcomes. These findings suggest that a patient decision aid may serve as a useful tool for individuals with RA and their clinicians who are considering the use of a biologic. To assess this further, we recruited patients with RA living in the US who were considering initiating or switching biologics to access an existing web-based decision aid and provide their perspectives on its use as well as discuss their broader information needs through in-depth telephone interviews.

Materials and Methods

Participant Recruitment and Eligibility

Eligible participants were those who met all the following criteria: 1) who received a diagnosis of RA from a rheumatologist; 2) whose rheumatologists have recommended that they consider either starting a biologic or switching to another biologic; 3) who resided in the US; 4) who had Internet (and email) access; and 5) who were comfortable speaking and accessing online content in English. Primary recruitment took place at Massachusetts General Hospital (MGH) and was led by a research coordinator. To supplement our clinic-based recruitment, we employed several web-based strategies. We advertised our study on Research Match, a nonprofit program that is funded by the National Institutes of Health. Web advertisements were deployed in the Arthritis Foundation's RA-focused newsletter, on Craigslist, and through institutional Twitter accounts. Finally, through word of mouth, additional participants were recruited from internet RA-focused support groups. For individuals recruited outside of MGH clinic settings, the research coordinator conducted a phone screen to confirm they met eligibility criteria. We collected baseline demographic data as well as information on participants' present self-rated health status and perceived change in health status compared with one year ago. These data were collected and managed using the Research Electronic Data Capture (REDCap) web-based platform.[12,13] Participant recruitment continued until thematic saturation was reached.

Online Decision Aid

Enrolled participants were asked to access an independently developed online decision aid that was designed specifically for individuals considering initiating or switching to a new biologic. Originally developed for the Canadian context, this decision aid has been described in detail previously[14] and excerpts are provided in Supplementary Figure 1. Prior to study commencement, this existing decision aid was minimally adapted to suit a US healthcare context (namely removing references to Canadian provinces and updating insurance language to reference the combination of public and private payers rather than a single-payer system). The decision aid included information from current systematic reviews and clinical practice guidelines, and spanned all tumor necrosis factor (TNF) inhibitors, an interleukin-6 antagonist, an anti-CD28 drug, an anti-B cell drug, and a JAK inhibitor.[14] Participants were asked to access the decision aid at home (estimated completion time ~30 minutes) following a visit with their rheumatologist where they had been recommended to either initiate or switch to a new biologic. Qualitative interviews took place approximately one month after participants accessed the decision aid. Participants in the current study received a $75 honorarium for their efforts.

Qualitative Interviews

Eligible individuals participated in a telephone interview with a facilitator trained in qualitative research to describe their experience with using the decision aid. We developed an interview topic guide, which included open-ended questions

Box 1 Topic Guide for Qualitative Interview Facilitation

1. In this study we asked you to use a web-based decision aid. What do you think about this process to help you decide about using a biologic agent?
2. Have you talked to your rheumatologist, rheumatology nurse, or any other health care providers regarding your decision about biologics after using the decision aid?
3. How did you feel about getting information on biologics from the decision aid?
4. What other independent research did you do (if any) on biologic medications? How did these other information sources compare to the decision aid?
5. When you finished using the decision aid, what did you chose to do? Please tell me what's happened since then.
6. What do you think would make decision aids like this successful in arthritis care? What do you think might prevent people with arthritis from using decisions aids?
7. Would you recommend the decision aid to other people with rheumatoid arthritis? Why or why not?
8. Is there anything else about your experience with the decision aid that you would like to add?

about the participants' feelings about receiving medication information on this digital platform compared with other sources and whether the tool was helpful in making decisions surrounding biologics (Box 1). All interviews were digitally recorded and transcribed verbatim. Transcripts were checked against the recording for accuracy. All participants were assigned a pseudonym.

Qualitative Data Analysis

We imported all transcripts (verbatim) into QDA Miner Lite® for data analysis. We conducted an iterative content analysis that was guided by the grounded theory approach, wherein theories are "grounded" in the data (ie, they emerge from the data collected as the data guides the research [contrasted with the use of a guiding framework for data exploration]).[15] Two authors (SKR and NM) independently read all transcripts and assigned (and revised) categories and subcategories belonging to overarching themes in an iterative coding process. The same two authors subsequently discussed their coding scheme for consensus. In instances where a third opinion was required, a third author (CY) provided input, and discussion continued among all three authors until consensus was achieved.

Engagement of Patient Research Partners

This project was originally refined through discussions with six patient partners living with RA, including representatives from patient groups (ie, the Arthritis Patient Advisory Board and Arthritis Consumer Experts). Patient collaborators participated in discussions with the research team through e-mails, telephone calls, and/or face-to-face meetings, and have offered unique and constructive advice for developing this project. Throughout our work, we employed the "FIRST" model (Facilitate, Identify, Respect, Support, and Train) as a guiding framework for consumer-researcher collaborations.[16]

Ethics Approval

The current study was approved by the Institutional Review Board of Mass General Brigham (protocol identification number 2015P002116) and was conducted in accordance with the guidelines outlined in the Declaration of Helsinki. All participants provided written informed consent to participate as well as have their anonymized responses included in published scientific reporting prior to study participation.

Results

Participant Characteristics

A total of 14 individuals with RA participated in qualitative interviews; their characteristics are provided in Table 1. Nearly all participants were women (85.7%). Five participants were newly considering a first biologic, while the other nine participants were considering switching to a new biologic. Ten participants had completed a bachelor's degree or

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Table 1 Participant Characteristics

Participant Pseudonym	Age Decade	Gender	Highest Level Of Education Attained	First-Time Biologic Initiator	Self-Rated Health Status	Perceived Change In Health Status Compared to 1y ago	Recruitment Source
Hanna	20's	Woman	Bachelor's degree	No	Fair	About the same	Clinic referral
Larry	60's	Man	Bachelor's degree	No	Fair	Somewhat worse now	Word of mouth
Olivia	50's	Woman	Postgraduate degree	Yes	Good	Much worse now	Word of mouth
Emily	30's	Woman	Bachelor's degree	No	Good	Somewhat better now	Research Match
Brooke	60's	Woman	Some college	No	Fair	Somewhat worse now	Research Match
Madeline	60's	Woman	Bachelor's degree	No	Fair	Somewhat worse now	Research Match
Donna	30's	Woman	Postgraduate degree	Yes	Fair	Somewhat worse now	Clinic referral
Lucas	50's	Man	Some college	Yes	Fair	About the same	Web advertisement
Blair	30's	Woman	Postgraduate degree	Yes	Excellent	About the same	Research Match
Zoe	50's	Woman	Bachelor's degree	Yes	Fair	Somewhat worse now	Clinic referral
Monica	60's	Woman	Postgraduate degree	No	Good	Somewhat better now	Web advertisement
Penelope	40's	Woman	Bachelor's degree	No	Good	About the same	Web advertisement
Angela	60's	Woman	Some college	No	Good	Somewhat worse now	Clinic referral
Taylor	30's	Woman	Some college	No	Fair	About the same	Clinic referral

higher. Over half of participants rated their current health status as "fair" with another five rating it "good". Half of the participants rated their current health status as either "somewhat worse" or "much worse" compared with one year ago.

Qualitative Themes

Theme 1: Treatment-Related Information Seeking Behavior

The first theme, treatment-related information seeking behavior, which encompassed how and where participants seek information about treatments for RA, comprised conceptual categories of: 1) gathering information from internet sources; 2) discussions with physicians or allied health providers; 3) talking with friends or close contacts with a chronic disease; 4) evaluating the credibility of information; and 5) other miscellaneous sources (Table 2). *Gathering information from internet sources* describes the various web-based sources that participants typically reviewed, including general searching, evidence-based or technical sources, and the pharmaceutical company's website. Some participants described changes to their information needs as time passed after their initial diagnosis:

> Most of it was just, you know, searching around, but my searches weren't very focused, I mean in July when I was first diagnosed, I was in so much pain I didn't care what he gave me. So it's only since, you know, August, beginning to middle of August after I had, you know, steroid shots and everything else. So I started feeling better to where I actually could look at things to say 'okay, what do I want to do.' (Olivia, 50's, first-time initiator)

Other participants described utilizing specific scientific resources, which included websites maintained by established medical institutions, foundations, and government agencies, as well as technical sources such as peer-reviewed research

Table 2 Conceptual Categories and Illustrative Quotations from Participants for Theme 1

Theme 1: Treatment-Related Information Seeking Behaviors	
Conceptual Category	**Illustrative Quotation**
Gathering information from internet sources	**General searching** "Oh, I think I just, like, typed 'Drug A' into Google and just saw whatever came up, so, it was just pretty much whatever was there". (Donna, 30's, first-time initiator) **Evidence-based or technical sources** "I mostly use internet-based research. Mayo Clinic, and Cleveland Clinic, and Johns Hopkins". (Monica, 60's, switching to a new biologic) "I have trusted websites, as I call them, and places like Mayo Clinic, the Arthritis Foundation, National Institutes of Health, places that I just feel like the information's reliable". (Brooke, 60's, switching to a new biologic) "If I am looking for specific stuff about a drug I will actually go into, like, published research papers, and that kind of thing. I am kind of curious about everything so I tend to get into the more technical aspects of how stuff works you know, like how drugs actually work against a specific disease and so I will look for that kind of stuff". (Larry, 60's, switching to a new biologic) **Pharmaceutical company website** "I like to see what the drug company is saying, because there's always that part that lists all the possible side effects and the percents that occurred during a clinical trial". (Madeline, 60's, switching to a new biologic) "I try and stay away from drug sites and pharmaceutical sites, because it's written in such technical language that it's hard for me to understand". (Monica, 60's, switching to a new biologic)
Discussions with physicians or allied health providers	"I am fortunate enough to have a rheumatologist who, you know, not only presents her information and her advice, but, you know, she, she listens and she, you know, she understands what I am talking about and she listens and I am sure she does that for all patients, so I am fortunate in that sense, yeah". (Lucas, 50's, first-time initiator) "I think that nurses could give me a lot of anecdotal information, and patients as well. But nurses in particular can say, well you know, we've seen a lot of people respond well to this". (Brooke, 60's, switching to a new biologic)
Talking with friends or close contacts with a chronic disease	"I guess so, I mean, it's beneficial to talk to someone who's actually going through something similar even though we are not exactly dealing with the same thing, you know, we all have different symptoms and all that, are at different places in care, but to have someone who actually has some personal knowledge rather than a caretaker who might not have the personal experience, just the professional background, if that makes any sense". (Blair, 30's, first-time initiator) "Another thing that I take into consideration when researching is actual patients that have used it, and whether or not it has worked for them. And, I actually have a couple of friends who have taken some of the medications that I have taken, and it's worked for them in other anti- or excuse me, in other autoimmune diseases. So it's, I think I tend to do a little bit of here and there and try to make my own, you know, make my own conclusion from it". (Hanna, 20's, switching to a new biologic)
Evaluating the credibility of information	"I try to consider what the resource is that I am looking at and how credible it is. You know, is it something being put up by a drug company, where it's more of an advertisement, obviously they want me to buy their product, is it a third party that's just providing neutral information, but it's almost impossible to get someone like that". (Blair, 30's, first-time initiator) "A reputable source, so that's where I usually like to start, is making sure it's a reputable source". (Penelope, 40's, switching to a new biologic)
Other miscellaneous sources	"RA Connect is one, like I said the Arthritis Foundation, and Arthritis Power, you kind of load in your symptoms, so they can kind of do work with the data, it's an online collection of information from a lot of people". (Penelope, 40's, switching to a new biologic)

literature. Finally, some individuals reviewed the information provided by pharmaceutical companies, which they felt presented a comprehensive list of side effects and corresponding statistics. Others did not share this perspective, instead feeling that this information was either too technical or contained some bias.

> And I, I did, last week, look at the Drug A website, and the tools that they have, but I didn't look at them extensively, because again, I have in my mind that the drug company wants you to take their drug, and your body to become acclimated to it, so that you can no longer live without this drug, and I have a hard time with that. (Zoe, 50's, first-time initiator)

Discussions with physicians or allied health providers describes the conversations that participants have had with different healthcare providers. Many participants described gathering information from their rheumatologist, and they felt that it was important to have a rheumatologist who listened in addition to providing advice. Nurses were also suggested as a valuable resource for providing information about biologic use, particularly with respect to recounting anecdotal experiences of previous patients who initiated a biologic. *Talking with friends or close contacts with a chronic disease* describes how participants connected with other individuals based on shared lived experiences. Participants detailed how they spoke with others living with chronic disease (including conditions other than RA) to learn about their symptoms and whether certain medications worked for them. They described feeling that this personal knowledge gained from lived experience was valuable. One participant countered this perspective by caveating that "everybody's experience is different" and noted that

> …. people with chronic illnesses, we carry a lot of other baggage (…) I don't like the online support groups and that sort of thing, the negative that comes with it. (Brooke, 60's, switching to a new biologic)

Evaluating the credibility of information encompasses how participants assessed the information they found. Participants described how they evaluated the trustworthiness of various sources, including considering its reputation (eg, Mayo Clinic) and whether the source had a financial incentive to provide specific information. *Other miscellaneous sources* encompassed additional resources that participants consulted, including programs run by pharmaceutical companies, books, and meetings held by professional organizations:

> I had also ordered a bunch of books, I have followed a lot of stuff from the American College of Rheumatology, like … when they have their yearly conventions and stuff. (Taylor, 30's, switching to a new biologic)

Theme 2: Helpful Aspects of the Decision Aid

The second theme, helpful aspects of the decision aid, which encompassed the positive and beneficial aspects that participants experienced while utilizing the decision aid, comprised conceptual categories of: 1) overall positive impressions of decision aid usability; 2) useful content presented in the decision aid; 3) feeling a sense of connection by hearing patient stories; and 4) perceived trustworthiness of information (Table 3). While describing their *overall positive impressions of decision aid usability*, participants indicated a high level of overall satisfaction with the decision aid:

> I think that it is something that will be helpful for them to make their decision. I mean choosing something like a biologic is really a big decision, and it's a scary decision. So I just feel that, yeah it would help a lot. (Madeline, 60's, switching to a new biologic)

Participants felt that the decision aid was user friendly, delivered at an appropriate level, and required a reasonable amount of time. Moreover, participants felt that it was presented in an interactive and engaging format, and most individuals enjoyed the incorporation of videos as these added a "human" dimension to the decision aid:

> I actually liked to look at the videos, because I like to hear more about it, there's just something about having a human voice tell you rather than reading it. (Madeline, 60's, switching to a new biologic)

Participants described reviewing *useful content presented in the decision aid*. In addition to learning new information, one participant described how the material prompted her to think about her decision in a new way:

Table 3 Conceptual Categories and Illustrative Quotations from Participants for Theme 2

Theme 2: Helpful aspects of the decision aid	
Conceptual Category	**Illustrative Quotation**
Overall positive impressions of decision aid usability	**High overall satisfaction** "About the videos and the focus of the tool, it was very straightforward. It wasn't condescending, it wasn't silly, but it was very straightforward to get you to think about these options". (Olivia, 50's, first-time initiator) "Overall, the tool was wonderful. It's a great tool to use, it certainly something that, well, great to be aware of, because it can help you, it could help anyone who's unsure, and it probably would assist in making a better decision". (Lucas, 50's, first-time initiator) **User friendliness** "Very user friendly. And I've done different kinds of studies before and then different kinds of tools before, but this one was really user friendly". (Penelope, 40's, switching to a new biologic) **Interactive and engaging format** "I think it walked me through the process to make the decision and gave me the pros and cons in a way that, as I said, you know, it was visual to me, more than just hearing my doctor explain it to me". (Brooke, 60's, switching to a new biologic) "I think if I see too much text on a paper, I may be discouraged … I think for me it might just be that I'm a visual learner, and looking at it was easier for me than, you know, maybe reading a paragraph about it". (Hanna, 20's, switching to a new biologic) **Appropriate literacy level** "I think it would be good for anybody to use. None of the talk is over or under people's knowledge level, but, you know, you can have very little knowledge of the medical based stuff behind the medication, and so I think the tool is—still would be very useful". (Penelope, 40's, switching to a new biologic) **Suitable time requirement** "I felt like the amount of time it took was definitely reasonable for the information I got out of it. I really didn't have a gripe with it". (Olivia, 50's, first-time initiator)
Useful content presented in the decision aid	**Providing new information and perspectives** "With these medications in particular, a lot of people will maybe be expecting some kind of results, and they may not happen quickly … so I really got a grasp of how important it is to take those medications as prescribed and … over a duration of time before you can expect to see results". (Lucas, 50's, first-time initiator) "I thought it was very helpful, it actually gave me some insight on things that I didn't know, so it was very helpful". (Emily, 30's, switching to a new biologic) **Listing all medications and providing a comparison of these options** "I think the way it was presented is very helpful. Like I said, it's much easier than looking up each individual drug on the internet, and then also, how do you know what to look up? Because you do not know what's out there unless you saw it on TV or something". (Angela, 60's, switching to a new biologic) "When my doctor discussed things, they don't go in as much detail, you know. And they don't do the comparison either, so, it's helpful whenever you're deciding on a medication". (Emily, 30's, switching to a new biologic)
Feeling a sense of connection by hearing patient stories	**Hearing candid accounts of how other patients have navigated their rheumatoid arthritis** "It was very frightening when I was first diagnosed, thinking I'm always going to hurt. So to hear people talk about going through this and maybe took time to get it settled, but if they're able to get it under control, that makes me feel better". (Olivia, 50's, first-time initiator) "Yeah, like a lot of things they were saying were like dang, you know, I feel the same way! You know, so it really helps a lot, you know, for them to personalize their situation, and, you know, like I said there's a lot of things that I dealt with too, you know". (Emily, 30's, switching to a new biologic) **Learning how others weighed the benefits and risks of trying a biologic** "I think there's more value to all that information beyond just deciding medication. You know, to hear more people sharing their stories, I know it takes time, you know, I did this, I chose to use Drug A or Drug B or whatever it is, here are the pros and cons, maybe to hear people who tried one and went to another". (Olivia, 50's, first-time initiator) "It was suggested two years ago … and if I had the decision aid where I could see some of the videotapes of some of the people that, especially the lady that really did not want to go on it initially, and then, you know, after, I guess six months … the woman did decide to do it. If I had probably seen that, I would've felt more comfortable going on a biologic, it's really scary to go on such a potent medication, or such a medication that leaves one open to having a greater chance of an infection that could kill you". (Zoe, 50's, first-time initiator) **Receiving reassurance about injectable medications by hearing first-hand experiences** "I think my biggest hang up about biologics itself was the actual injection. Like so many other people I just have this thing about any kind of needles or pricks in the skin, I just, you know, I just cannot … one of the patients on the tool, you know you got to actually hear their experience, and I got to understand that over the course of time it actually does get better". (Lucas, 50's, first-time initiator)
Perceived trustworthiness of information	"I felt the women who presented their videos had credibility. I like that they told me their story, I like that they told me the background. I did not feel like they pulled punches and their backgrounds were so diverse, that helped. It may be an easy mark but I felt very comfortable with, you know, believing the information given". (Olivia, 50's, first-time initiator)

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> It was a question about how frequently would you want to take the biologic. And I think it was the woman who said 'you have to do it everyday, because then if you need to change it, you can change it a lot faster instead of waiting every other week,' which I thought was very interesting. I had never thought that way before. (Olivia, 50's, first-time initiator)

Participants appreciated how the decision aid presented information about each biologic, including by providing a comprehensive list of different medications as well as providing information that allowed for direct comparisons between the different options. Participants described *feeling a sense of connection by hearing patient stories*, which included hearing candid accounts of how others have navigated their RA and learning how others weighed the benefits and risks of trying a biologic:

> I think the new part to me was just the way it was presented, coming from an RA sufferer instead of from a doctor, or a drug company. And also to share the thought process of what choices they made. (Olivia, 50's, first-time initiator)

Participants also described receiving reassurance about injectable medications by hearing these first-hand patient experiences in the videos:

> I was most interested in the one that they had to inject themselves, because I thought that's what I was going to end up doing … I remember that one woman talked about it, and how you just don't have to jab it in your whole body, you just put it under your skin, or something like that … watching that video of the woman with the injection that had a drug she was injecting, that made me feel like, you know, it's not that big of a deal after all, you know. It's nothing to be afraid of, really. (Angela, 60's, switching to a new biologic)

Finally, participants perceived the information contained in the decision as trustworthy; this was due, in part, to the patient stories which participants felt lent credibility to the content. Another participant remarked that the decision aid did not feel like an advertisement, which also created a feeling of trustworthiness:

> Yeah, the fact that it was presented by – it didn't reek of a commercial, so therefore it seemed reliable, so that kind of information is good because it sounds, it didn't sound like someone was being paid to advertise. (Brooke, 60's, switching to a new biologic)

Theme 3: Decision Aid Limitations and Potential Solutions

The third theme, decision aid limitations and potential solutions, included conceptual categories of: 1) perspectives on decision aid presentation; 2) identifying content preferences and gaps; and 3) concerns about accessibility and implementation (Table 4). Participants' *perspectives on decision aid presentation* included feedback on the tool's length and format. Some felt that the decision aid was long and included some redundant information, and others expressed a preference for reading written materials rather than watching the videos as this was felt to be quicker:

> I don't really enjoy the videos honestly. I just like to get, you know, into the written stuff. You know, in a lot of cases I find the videos are more of a time waster than informative. So, for me if it's, you know, printed it's just a lot easier and faster for me to get through. (Larry, 60's, switching to a new biologic)

Participants identified several *content preferences and gaps*. Specifically, participants wanted to receive more information about the long-term use of biologics, potential side effects, specific populations who may be at a greater risk for complications, when biologics may be particularly beneficial, and the general risks versus benefits of these medications. Moreover, given the cost of biologics, participants suggested that adding information about insurance would be helpful. Some expressed an interest in more videos featuring physicians rather than patients. Finally, a few individuals who were switching to a new biologic indicated that they would have preferred if the decision aid could eliminate biologic recommendations that they had already tried previously:

> Incorporate that rule that if you'd tried two TNF inhibitors previously, and they're not working, then don't offer it [as a recommendation] anymore. (Monica, 60's, switching to a new biologic)

Lastly, participants expressed *concerns about accessibility and implementation* of the decision aid in a real-world rheumatology practice setting. Although nearly all participants described having positive relationships with their current

Table 4 Conceptual Categories and Illustrative Quotations from Participants for Theme 3

Theme 3: Decision Aid Limitations and Potential Solutions	
Conceptual Category	**Illustrative Quotation**
Perspectives on decision aid presentation	**Length and redundancy** "It was kind of long, and some of that may be that I thought that some of the questions were repetitive. Maybe they're not, but they seemed to me to be repetitive". (Monica, 60's, switching to a new biologic) "I was already, like, pretty aware of how biologics work, so like there was some general information on here, and I was like 'oh that's okay my doctor already told me that' but I guess you have to include that, I just sort of kind of breezed through that part". (Donna, 30's, first-time initiator) **Preference for written materials** "Probably less helpful for me, just because I like … to pour over it and read it, some people are more visual though, so that might be definitely helpful to them". (Penelope, 40's, switching to a new biologic) "I chose to read instead". (Taylor, 30's, switching to a new biologic)
Identifying content preferences and gaps	**Greater depth of information on biologic risks, benefits, and other factors** "Maybe if there was any kind of information about … long-term usage of it. Like, how does it help you, like, over three months, or six months, or a year, you know, so you can kind of see, like okay it's helped, you know, a certain amount of people, a certain percentage like a year down the line, this would be a good thing to try. So like sort of longer-term information". (Donna, 30's, first-time initiator) "Explaining more about side effects, and risk factors, and risk versus benefit, and exactly what populations are at greater risk for various issues, and under what circumstances they—that biologics might be more effective". (Blair, 30's, first-time initiator) "Everybody has different insurance … I would imagine that … a footnote or something that says that, you know, a lot of these medications, drugs, can be extremely expensive, and that, you know, obviously after you make a decision, you have to weigh in that factor that what's your out of pocket going to be?" (Angela, 60's, switching to a new biologic) **Preference for videos featuring physicians rather than individuals with rheumatoid arthritis** "Probably, because I mean the doctor video was probably more from their perspective, so I think … that was probably better than the one from the patient perspective". (Penelope, 40's, switching to a new biologic) **Desire for more opportunities to personalize the user experience** "Well, I had been on Drug A and Drug B before. I do remember that now, and I questioned, why did this come back—this shouldn't have even been an option". (Brooke, 60's, switching to a new biologic) "Perhaps you could offer different levels, maybe a shorter summary video and a longer, more in-depth video … depending on what your patients' need or comfort level is … perhaps having different levels would benefit a larger number of patients". (Blair, 30's, first-time initiator) **Seeking additional information behind the recommendation** "I thought it was interesting that the decision aid came up with Drug A as a first choice and Drug B as a second choice, and I could not quite figure out why that was … I think at one point it said something about injections, you know, if you are, you know, pro or con injections, or like if you are afraid of needles, and I know that Drug B is every other week, versus the Drug A which is every week, so I was surprised even when I put in 'I'm afraid of needles' … that it still came up with Drug A as the first choice. So, I thought, 'I wonder what the difference is and why it says that' and of course I could not readily find an answer to that". (Zoe, 50's, first-time initiator)
Concerns about accessibility and implementation	**Doubts about integration into rheumatology practice** "Yeah, and I do think resistance is, they just don't want anyone bucking their opinion, or bucking their authority, or anyone to think that they – somebody else has a better opinion or better way of doing things, I think. That's my opinion". (Penelope, 40's, switching to a new biologic) **Concerns about internet access and familiarity with digital tools** "I'm not sure what you're considering your target patient. Are you considering, like, someone in their 80's or 90's who may not be that familiar with the internet, or are you considering a range of patients, middle aged, or younger people?" (Blair, 30's, first-time initiator) **Potential mechanisms for expanding availability** "It's a matter of really having it available, you know, in a widespread area, out there. Like if you could get it out on like the Arthritis Foundation, or whatever they are called, you know, or one of the other major arthritis websites, or at least a link to it you know. And just publicity really, is really all it would take I think, you know. Because I think a lot of people have really no great idea about, you know, comparisons between all the ways that they can be treated and how many there actually are out there". (Larry, 60's, switching to a new biologic)

care team, they felt that some rheumatologists may be resistant to incorporating a decision aid for several reasons, including a perceived threat to their expertise or authority, unwillingness to individualize treatment, resistance to trying something new, and lack of appointment time:

> A rheumatologist that has very set opinions of how things work, and doesn't see patients as being different from each other, they may just not want one more thing, or one more thing to take up any more time of their appointment. But I think this would be a time saver, because it actually kind of does some of their work for them. But I do feel like some doctors are resistant to anything new. (Penelope, 40's, switching to a new biologic)

Participants also expressed concerns about internet access and familiarity with digital tools, particularly among older individuals living with RA: "Of course, the other piece is older folks don't necessarily have access or have the capabilities to use these kinds of electronic tools" (Zoe, 50's, first-time initiator). Nevertheless, the web-based format of the tool was also seen as a strength, and several ideas were suggested to increase its availability, including leveraging trusted organization websites such as the Arthritis Foundation as well as other major arthritis websites.

Theme 4: Impacts on the Decision to Initiate a Biologic

The fourth and final theme, the impacts on the decision to initiate a biologic, included conceptual categories of: 1) feeling open to more treatment options; 2) generating questions for the rheumatologist; 3) feeling empowered to engage in shared decision-making; and 4) reinforced confidence in the decision (Table 5). After using the decision aid, participants described *feeling open to more treatment options* that they may have felt more reluctant to try previously:

> Well, before I was just against it, really against it, now … I'll say I'm on the fence, but I'm certainly leaning more towards, towards using the biologic because I understand the importance of it and how some, you know, some forms of the medication are not effective, or not as effective and the biologics could certainly be more effective, so, and if I take into consideration the minor discomfort that I may feel versus the relief that I could possibly gain, I don't think it's too big of a sacrifice. So I'm really leaning more towards just taking, you know, biologics. (Lucas, 50's, first-time initiator)

Participants also reported how the decision aid prompted them to consider a biologic that they had not previously thought of. Moreover, participants found that the content presented in the decision aid was useful for *generating questions for their rheumatologist*, leading to new questions to discuss at their next appointment. Participants reported *feeling empowered to engage in shared decision-making* after working through the decision aid. Specifically, individuals described how they had previously deferred to their physician's recommendations, but now felt that they wanted to ask more questions and partner with their physician moving forward. One participant further noted how the decision aid-generated summary may help initiate these conversations with their physician. Finally, participants felt that the decision aid *reinforced confidence in their decision* of whether to initiate a given biologic. Individuals described the tool as helping to solidify or reinforce their choice:

> It kind of reinforced my decision on my end. And I think, I think it was extremely helpful in feeling confident that I made the correct decision. (Hanna, 20's, switching to a new biologic)

Table 5 Conceptual Categories and Illustrative Quotations from Participants for Theme 4

Theme 4: Impacts on the Decision to Initiate a Biologic	
Conceptual Category	**Illustrative Quotation**
Feeling open to more treatment options	"I never would have thought of really changing if I hadn't tried the tool, I can tell you that right now. Because I hadn't seen anything that really appealed to me, and I really didn't have a reason to, you know. But yeah, the tool made a huge difference". (Larry, 60's, switching to a new biologic) "Well, I actually, so originally I would have gone with Drug A, because that's what my rheumatologist has been going with, but when I see him on Saturday, because the study had said, what was it, Drug B… I actually am going to ask him about that. Because I, just, it stuck in my head about having this daily option". (Olivia, 50's, first-time initiator)
Generating questions for the rheumatologist	"Yeah, I had seen information on it and it was just, I wanted to discuss that one too. I mean I see, when I see the different ones, I think 'well, I haven't tried that one, or I have not tried that one', so it's just one of the ones I am going to bring up to her as we discuss what I should start, to see what we want to go with". (Madeline, 60's, switching to a new biologic) "So, having something that actually gave me some other, you know, ideas to think about and talk to my rheumatologist about was quite helpful in the end". (Larry, 60's, switching to a new biologic)
Feeling empowered to engage in shared decision-making	"The thing that came through the most was the right for me to make decisions and ask questions, so I think that was really the most helpful… Up until now I pretty much deferred decisions to my physician, and I guess I should be asking more questions". (Monica, 60's, switching to a new biologic) "It seemed to me that was repeated that yes, this is a decision you make with your doctor, it's not something your doctor says… The repetition, like I said before, to go be a partner with your doctor I thought was very important, for me, personally, it was very important". (Angela, 60's, switching to a new biologic)
Reinforced confidence in the decision	"I definitely found it to be a helpful resource, it more, like we discussed, solidified my choice, or our choices, you know. And it allowed, still allowed me to entertain the option of another drug, which was good". (Zoe, 50's, first-time initiator) "It's just an extra thing that will help me make my decision. Kind of like, you want to have your mom there to help you make a decision, but your mom's not there, so, anything that can help you make that decision is a plus. So having that to take with me is a plus". (Madeline, 60's, switching to a new biologic)

Discussion

We conducted a qualitative interview study to understand RA patients' perspectives on the use of a decision aid regarding biologic initiation or switching. Findings include one theme describing treatment-related information seeking behaviors, specifically where individuals sought information about treatments for RA as well as how this information was evaluated for credibility, two themes related to the helpful aspects (eg, hearing patient stories) and limitations of the tool, and a fourth theme describing how the decision aid impacted the decision to initiate a biologic, including promoting feelings of empowerment to engage in shared decision-making.

Our findings build on prior literature describing medication-related information needs of RA patients. A 2018 qualitative synthesis of RA and spondyloarthritis (SpA) patient attitudes reported that participants felt that information from their physician was credible when it matched that received from other sources (eg, internet sources, pamphlets).[17] Individuals also noted different types of information that they wanted to inform their decision, including information about alternative treatments as well as how DMARDs may impact their daily life (eg, whether to limit alcohol intake, how to time medications to minimize side effects during certain periods), although this study was not limited to those specifically considering biologic DMARDs.[17] Another 2019 systematic review among individuals with inflammatory arthritis reported that participants desired information about their pharmacological management, including the rationale for medications, side effects, and alternative therapies.[18] In addition to these well-characterized information needs and sources (eg, internet-based searching, discussions with a rheumatologist), our study further identified a key benefit to building relationships with other individuals living with a chronic disease, as they may provide a rich perspective on medication use that is informed by a shared lived experience. This is consistent with prior work showing that individuals with RA will utilize online support groups to discuss their disease experiences (including medication use).[19] Conversely, a recent study in Belgium evaluated the need and potential format of a peer mentoring program for individuals newly diagnosed with RA; while participants did seek more information about medication use, this was perceived to be primarily the responsibility of the healthcare team rather than a peer mentor.[20] While the participants in our study largely described benefiting from talking with peers, one noted that the views shared in online support groups may be more negative than encouraging. It would be valuable for future research to examine how best to integrate peer connections to support medication decision-making.

In the current study, participants described their experiences using a decision aid, encompassing both aspects they found helpful and its perceived limitations. Several participants highlighted the visual components of the decision aid as being particularly beneficial, which is consistent with prior research on the use of audiovisual aids and improved health literacy.[21] Accordingly, similar approaches have been applied in the development of decision aids for other conditions, including a biologic decision aid for individuals with inflammatory bowel disease (IBD) that incorporated video content and other visual aids to overcome varying levels of numeracy among end users,[22] as well as fully video-based decision aid for pediatric IBD patients to improve risk communication.[23] At the same time, selected participants in the current study instead expressed a preference for more written content as well as greater depth of certain information (eg, medication risks), suggesting that it may be beneficial to offer individuals the opportunity to select from different media formats and lengths (eg, full length vs. abbreviated summary) where feasible. Next, participants in the current study overwhelmingly responded positively to hearing patient stories as part of the decision aid. Interestingly, although research suggests that hearing another patient's experience helps with understanding one's own chronic illness and the adjustment to treatment, findings are mixed with respect to the potentially beneficial role of patient stories in medication decision-making.[24] Further research in this area is warranted. Participants also wondered whether a decision aid could be implemented in community rheumatology practices, citing time constraints and anticipated reluctance of rheumatologists. Indeed, while rheumatologists agree that patient decision aids could enhance patient care, they have also outlined practical challenges with their implementation, thereby highlighting the need to develop strategies to support their integration into clinical practice.[25] Such strategies may be multipronged, including the use of different formats (eg, print, basic digital, or electronic health record-integrated), availability of training, and the use of clinical champions. As rheumatologists and other healthcare providers are key stakeholders of patient decision aids such as this one, it is imperative that future studies continue to survey and interview these providers to ensure feasible implementation of digital tools.

Finally, participants in our study reported feeling empowered to engage in shared decision-making. This is particularly important in light of a qualitative synthesis of RA and SpA patient attitudes toward DMARD use, which reported that patients wished to maintain a sense of control and feel ownership over the decision to take both conventional and biologic DMARDs.[17] Moreover, participants in the current study described feeling confident in their decision. This is consistent with a recent interview study among psoriatic arthritis patients which identified "gaining confidence" as a key theme toward medication decision-making, which included feeling empowered from gaining knowledge about treatment options as well as experiencing first-hand various physical function benefits after initiating treatment.[26] Future longitudinal studies should examine whether the use of such decision aids translates to lower rates of discontinuation.

The strengths of our study deserve comment. The application of a qualitative interview approach allowed for the identification of detailed perspectives on the decision aid, including among five individuals who were newly initiating a biologic, which is a practically challenging treatment window to capture in research. Indeed, it would be valuable for future work among more patients to examine whether these perspectives surrounding decision-making differed between those who are newly starting a biologic versus those who are switching to a different biologic. Our topic guide was developed and refined using an iterative process, and our iterative analysis ceased upon agreement among the research team that no new codes or themes had emerged.[27,28] Finally, we leveraged several web-based resources to expand our study beyond the Boston area and successfully enrolled individuals across the United States. Our study is also not without limitations. Our sample was restricted to English-speaking individuals living in the US, and >70% of participants had obtained a bachelor's degree or higher. Moreover, our study population was comprised largely of women, and we did not collect data on race/ethnicity, occupation, or other demographic factors. As there are potential demographic differences in the health information needs among those with inflammatory arthritis,[18] it is imperative that future work intentionally recruit individuals from many types of diverse backgrounds, particularly given the critical role that education and health literacy can play in the successful uptake of education tools. Moreover, although RA disproportionately affects women, it would be valuable for future studies to explore potential gender differences in treatment decision-making; indeed, a study among individuals considering hemodialysis found that men and women approach treatment decisions differently and prioritize different expectations for a given treatment.[29] Nevertheless, the current findings do continue to extend our understanding of RA patient decision-making surrounding biologic therapy.

In conclusion, we conducted a qualitative interview study to understand the information needs of individuals with RA who are living in the US, as well as their experiences with a web-based decision aid in the context of considering biologic therapy. We identified key information needs, including participants' desire for more detailed information on potential long-term side effects, as well as an important role for connecting with peers living with chronic disease who can provide information to RA patients considering a biologic that is informed by a shared lived experience. Moreover, we identified unique perspectives on the use of different media, broader decision aid format, and the inclusion of patient voices. Finally, our findings suggest that the current decision aid facilitated feelings of empowerment to engage in shared decision-making. Future work ought to ensure that healthcare provider (particularly rheumatologist) perspectives are evaluated to ensure feasible strategies for implementation, examine perspectives among key subpopulations, and evaluate real-world effectiveness. Taken together, our findings highlight key factors to consider for the design/refinement and implementation of patient decision aids in the US to appropriately meet the needs of patients who are considering a biologic.

Data Sharing Statement

Due to the sensitive nature of the research, these data are not openly available in a central repository. Data sharing requests may be made to the corresponding authors and will be subject to an institutional data use agreement and relevant institutional review board approvals.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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