

# Impact of a hidradenitis suppurativa patient decision aid on treatment decision making: A randomized controlled trial



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**Background:** Patient decision aids are tools that facilitate shared decision making when clinical evidence and patient values and preferences inform the process. Evidence-based guidelines have been developed for clinicians in hidradenitis suppurativa management. To address treatment decision-making needs of hidradenitis suppurativa patients, we developed a hidradenitis suppurativa patient decision aid.

**Objective:** To assess the efficacy of the hidradenitis suppurativa patient decision aid during treatment decision making.

**Methods:** An online, participant-blinded, parallel-group, randomized controlled trial of the hidradenitis suppurativa patient decision aid versus Mayo Clinic hidradenitis suppurativa website content (Mayo) was conducted with hidradenitis suppurativa patients. Outcomes were knowledge, decisional conflict, and preparation for decision making.

**Results:** Forty participants fulfilled inclusion criteria and were randomized to hidradenitis suppurativa patient decision aid or Mayo. In the hidradenitis suppurativa patient decision aid group, data from 16 and 15 participants were analyzed at phases 1 and 2, respectively. In the Mayo group, data from 15 and 13 participants were analyzed at phases 1 and 2, respectively. Increased knowledge ( $P < .01$ ) and preparation for decision making ( $P < .01$ ), as well as reduced decisional conflict ( $P < .01$ ), were observed in the hidradenitis suppurativa patient decision aid compared with the Mayo group.

**Limitations:** The online methodology and recruitment from online hidradenitis suppurativa support groups limits generalizability of findings.

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**Conclusion:** A hidradenitis suppurativa patient decision aid increased knowledge and preparation for decision making and reduced decisional conflict. (JAAD Int 2020;1:190-9.)

**Key words:** decisional conflict; hidradenitis suppurativa; patient decision aid; patient knowledge; randomized controlled trial; shared decision making.

## INTRODUCTION

Informed shared decision making in medicine combines communication of clinical evidence, health care provider experience, and patient values and preferences. Treatment decisions require deliberation of values-based trade-offs between potential risks and benefits.<sup>1</sup> Clinical practice guidelines recommend engagement of patients in treatment decision making,<sup>2</sup> which can be facilitated by patient decision aids. These aids can present comprehensive, evidence-based treatment options and establish individualized patient values and preferences. Thus, they can reduce time and other resources required of clinicians in education and counseling. Patient decision aids have increased knowledge and reduced decisional conflict in various medical conditions,<sup>3</sup> but are largely unknown in dermatology despite the value-based decisional needs of patients.

Hidradenitis suppurativa is a chronic, debilitating skin condition with considerable adverse effects.<sup>4,5</sup> In a survey of stakeholders including patients on hidradenitis suppurativa priorities, 6 of the top 10 involved treatment uncertainties.<sup>6</sup> Thus, hidradenitis suppurativa patients desired assistance in treatment decisions.<sup>7</sup> We previously described development of a hidradenitis suppurativa patient decision aid to facilitate treatment decision making.<sup>8</sup> The objective of this study was to assess the efficacy of the hidradenitis suppurativa patient decision aid in increasing patient knowledge of hidradenitis suppurativa and its treatments, increasing preparation for treatment decision making and reducing decisional conflict.

## METHODS

### Hidradenitis suppurativa patient decision aid development

Hidradenitis suppurativa patient decision aid development followed the Ottawa Hospital

## CAPSULE SUMMARY

- The hidradenitis suppurativa patient decision aid is a patient-focused tool providing information on hidradenitis suppurativa, its treatments, and a values-based component to facilitate treatment decision making.
- The hidradenitis suppurativa patient decision aid significantly increased knowledge and preparation for treatment decision making and reduced decisional conflict.

Research Institute Decision Aid development framework and International Patient Decision Aid Standards.<sup>8-10</sup> The hidradenitis suppurativa patient decision aid is freely available at <https://www.informed-decisions.org>.<sup>11</sup>

### Study design

This was a participant-blinded, parallel-group-controlled trial of hidradenitis suppurativa patient decision aid versus Mayo Clinic hidradenitis suppurativa website content (Mayo) with 1:1 randomization. The latter

comparator was recommended by our patient collaborators as being an accessible and informative publicly available resource. The University of Windsor Research Ethics Board approved the study protocol. This study was deemed ineligible for registration with [ClinicalTrials.gov](https://www.clinicaltrials.gov) because the anonymous enrollment strategy denotes that the study does not meet the standard for Human Subjects Research under 42 CFR part 11. All participants provided informed consent before participation. On completion (>90% of each phase), a US \$30 e-gift card was provided as compensation.

### Study participants

Participants were recruited through 2 Facebook support groups (Hidradenitis Suppurativa Warriors for Research, and Hope for HS), with permission of group administrators. Both groups are based in the United States, but members' locations are unknown. Inclusion criteria were prior hidradenitis suppurativa diagnosis, older than 16 years, English proficiency, having an e-mail address, access to a device with internet connectivity, not participating in an interventional clinical trial, being able to provide informed consent, and not a previous participant in hidradenitis suppurativa patient decision aid development. This study was conducted online from September to October 2019.

**Abbreviations used:**

CI: confidence interval  
SD: standard deviation

**Study interventions**

Participants were randomly assigned 1:1 to hidradenitis suppurativa patient decision aid or Mayo. Participants completed 2 phases on SurveyMonkey (SurveyMonkey Inc, San Mateo, CA) and were given 1 week to complete each phase. Phase 1 comprised the following: preintervention survey, evaluating knowledge,<sup>12</sup> and decisional conflict<sup>13</sup>; and then intervention (website viewing), whereby participants viewed the hidradenitis suppurativa patient decision aid<sup>11</sup> or Mayo.<sup>14,15</sup> Although the hidradenitis suppurativa patient decision aid is an interactive resource allowing personalized input of patient values and preferences, Mayo is a solely informational resource discussing hidradenitis suppurativa symptoms, causes, diagnosis, and treatments. According to Microsoft Word's readability programs, Flesch Reading Ease,<sup>16</sup> and Flesch-Kincaid Grade Level formulas,<sup>17</sup> readability of hidradenitis suppurativa patient decision aid and Mayo content was equivalent to an eighth- and ninth-grade level, respectively. Definitions for colloquial medical terms were provided in the hidradenitis suppurativa patient decision aid. Postintervention 1 survey evaluated knowledge, decisional conflict, preparation for decision making, and resource acceptability.<sup>12,13,18,19</sup> Ten days after completing the postintervention 1 survey, participants completed phase 2, called postintervention 2 survey, evaluating knowledge, decisional conflict, and decision regret.<sup>12,13,20</sup> For individuals who started phase 1 but did not fully complete it, phase 2 was administered 10 days after their phase 1 end date.

**Randomization and blinding**

Hidradenitis suppurativa patient decision aid and Mayo groups were randomly labeled as group A or B by one researcher (O.M.) via a coin toss, and allocation was concealed from another researcher (D.M.). D.M. performed simple block randomization using <http://www.randomization.com> with a fixed block size of 2 (group A or B) to generate a random sequence that was concealed from O.M., and informed O.M. of participants' allocation group. O.M. was responsible for enrollment and administration of surveys.

Content sources were deidentified, and both the hidradenitis suppurativa patient decision aid and Mayo were hosted on an independent website to

ensure blinding. Only O.M. was aware of participants' allocated group.

**Study outcomes**

All outcome measurements are scales developed by the Ottawa Hospital Research Institute Patient Decision Aids Research Group.<sup>12,13,18-20</sup> Scales for decisional conflict, preparation for decision making, and decision regret are validated.<sup>21-23</sup> The survey platform was SurveyMonkey (SurveyMonkey Inc).

Primary outcomes included the difference in knowledge and decisional conflict, defined as uncertainty regarding choice of treatment (measured at the preintervention, postintervention 1, and postintervention 2 surveys), as well as preparation for decision making, defined as preparation to make a treatment decision (measured at the postintervention 1 survey).<sup>12,13,18</sup> Secondary outcomes included resource acceptability and decision regret, defined as regret after treatment decision making (measured at the postintervention 1 and 2 surveys, respectively).<sup>19,20</sup> Higher scores indicated more knowledge correctness (possible scores 0%-100%), decisional conflict (possible scores 0-64), preparation for decision making (possible scores 10-50), and decision regret (possible scores 5-25). Resource acceptability was scored descriptively in terms of positive or negative responses.

**Sample size and statistical methods**

We aimed for a minimum sample size of 30 (15 participants per group) and targeted to recruit 40 to account for possible dropouts.<sup>24-26</sup> No sample size calculations were performed because there were no prior estimates of variance of outcome measures for the hidradenitis suppurativa population. Descriptive statistics were obtained with IBM SPSS Statistics for Windows, Version 26.0 (IBM Corp, Armonk, NY). To address missing data,<sup>27</sup> the Little missing completely at random test was performed, and a nonsignificant  $\chi^2$  value ( $\chi^2_5 = 4.43$ ;  $P = .49$ ) confirmed that the data were missing completely at random.  $\chi^2$  Tests and  $t$  tests were run for categorical variables and continuous variables, respectively, to investigate the degree to which both groups differed. To explore within-group differences, McNemar test and paired-samples  $t$  tests were used to evaluate differences in knowledge and decisional conflict, respectively, both before and after the intervention. A  $\chi^2$  test was not appropriate because the independence of observation assumption was violated, because these data represent responses from the same patients over time. For between-group differences, 2 repeated-measures analyses of variance were used to evaluate differences in knowledge and decisional conflict before and after the intervention. The within-subject factors

were preintervention, postintervention 1, and postintervention 2 surveys, and the between-subjects factor was group.

### Missing data

Missing data were observed in the postintervention 1 survey (8.80%;  $n = 3$ ; hidradenitis suppurativa patient decision aid group) and postintervention 2 survey (17.60%;  $n = 3$  per group). The extent of the missingness was described for categorical (true and false) variables: both the preintervention and postintervention 1 surveys (5.88%;  $n = 1$  per group) and postintervention 2 survey (20.59%), 4 from hidradenitis suppurativa patient decision aid and 3 from Mayo.

### Group differences

Bonferroni corrections were used for each, with the new  $P$  value against which to assess significance for the categorical variables and continuous variables being .004 and .01, respectively.<sup>28</sup> Four and 13 tests were run comparing continuous and categorical variables, respectively.

### Between-group differences

**Knowledge.** The assumptions of a repeated-measures analysis of variance were satisfied. The main effect of time was significant ( $P < .001$ ; partial  $\eta^2 = .37$ ) but was not for group ( $P = .92$ ; partial  $\eta^2 = .01$ ). The interaction of time by group was significant ( $F_{2,52} = 5.76$ ;  $P = .01$ ; partial  $\eta^2 = .18$ ; observed power = 0.85), suggesting that participants' knowledge varied by group over time.

**Decisional conflict.** The assumptions of a repeated-measures analysis of variance were satisfied. The main effect of time was significant ( $P = .002$ ; partial  $\eta^2 = .22$ ) but was not for group ( $P = .40$ ; partial  $\eta^2 = .03$ ). The interaction of time by group was significant ( $F_{2,50} = 6.08$ ;  $P = .004$ ; partial  $\eta^2 = .20$ ; observed power = 0.88), suggesting that participants' decisional conflict varied by group over time.

Bonferroni corrected pairwise comparisons of the 3 times were conducted. There were significant differences between preintervention and postintervention 1 (mean difference = 9.65; 95% confidence interval [CI] 4.69-14.61; Cohen's  $d$  value [effect size] = .72) and preintervention and postintervention 2 (mean difference = 9.81; 95% CI 2.62-17.00; Cohen's  $d$  value [effect size] = 2.24).

## RESULTS

### Participants

Forty subjects fulfilled inclusion criteria and were randomized to hidradenitis suppurativa patient decision aid ( $n = 21$ ) or Mayo ( $n = 19$ ) (Fig 1). In the hidradenitis suppurativa patient decision aid group,

18 initiated the study; 16 and 15 completed phases 1 and 2, respectively, and their data were analyzed for all outcomes. In the Mayo group, 16 initiated the study; 15 and 13 completed phases 1 and 2, respectively, and their data were analyzed for all outcomes.

Although 34 participants initiated the study, complete responses for phase 1 were available for only 31. Demographics of participants initiating the study are shown in Table 1. The sample ( $n = 34$ ) was largely women ( $n = 32$ ; 94%) and white ( $n = 22$ ; 65%), with mean age approximately 36 years. All participants indicated having either current or previous hidradenitis suppurativa treatment. Participants between groups differed in race, with 89% in the hidradenitis suppurativa patient decision aid group identifying as white and 63% in the Mayo group identifying as black/African American ( $P = .002$ ).

### Within-group differences

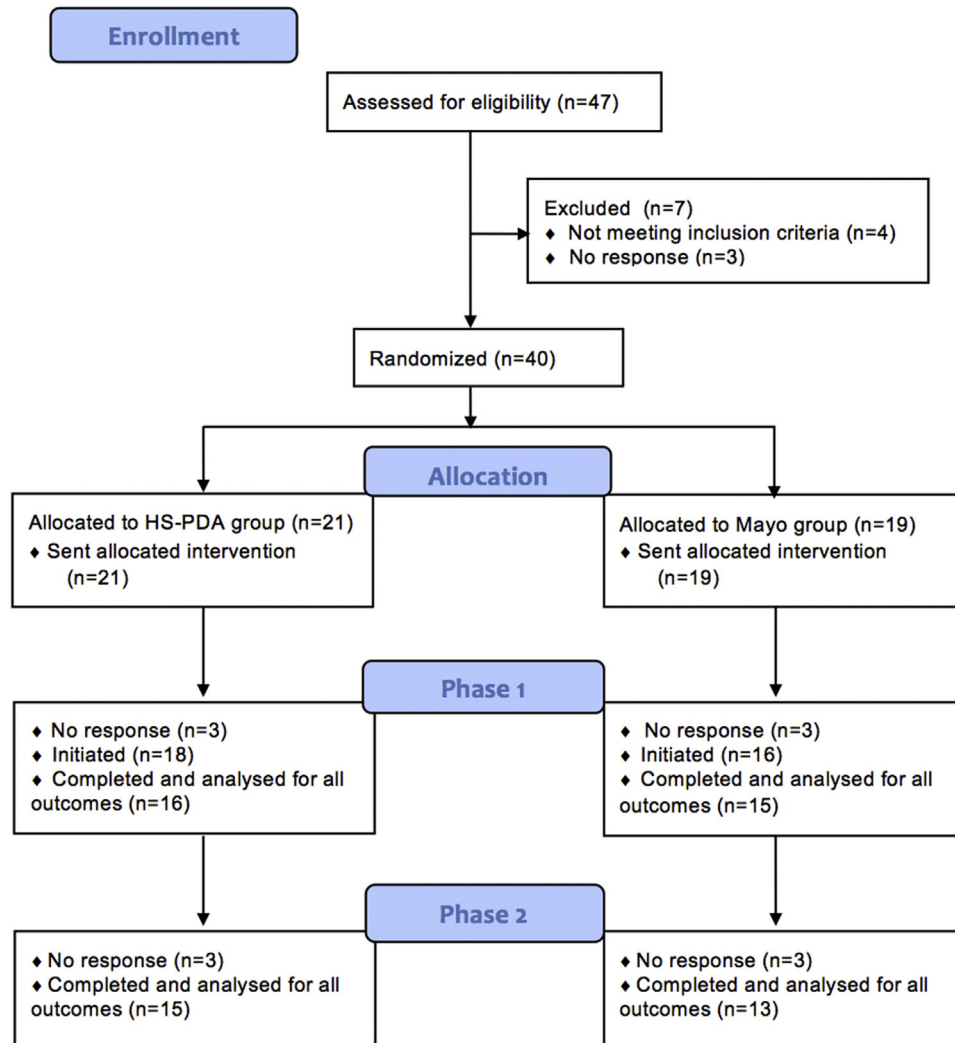
**Knowledge.** Change in knowledge from preintervention to postintervention 1 with hidradenitis suppurativa patient decision aid was significant (odds ratio = 2.85;  $P = .01$ ; 95% CI 1.19-2.85), but was not with Mayo (odds ratio = 1.61;  $P = .06$ ; 95% CI 1.00-2.58).

**Decisional conflict.** Significant reduction in decisional conflict was observed before (mean = 30.36; standard deviation [SD] = 15.67) and after (mean = 13.93; SD = 11.35) the hidradenitis suppurativa patient decision aid ( $t_{15} = 4.24$ ; 95% CI 8.16-24.69;  $P = .001$ ; Cohen's  $d$  value [effect size] = 1.06) but not with Mayo ( $t_{14} = 1.84$ ; 95% CI -0.39 to 5.23;  $P = .09$ ; Cohen's  $d$  value [effect size] = .49).

### Between-group differences

**Knowledge.** Significant increase in knowledge was observed in the hidradenitis suppurativa patient decision aid group from preintervention (mean = 64.67; SD = 18.27) to postintervention 1 (mean = 82.33; SD = 11.93;  $P < .001$ ) but not in the Mayo group: preintervention (mean = 70.38; SD = 13.61) to postintervention 1 (mean = 72.69; SD = 14.09;  $P = .18$ ) (Fig 2). There was a significant increase in the hidradenitis suppurativa patient decision aid group from preintervention (mean = 64.67; SD = 18.27) to postintervention 2 (mean = 78.67; SD = 14.07;  $P < .01$ ), and in the Mayo group from preintervention (mean = 70.38; SD = 13.61) to postintervention 2 (mean = 83.85; SD = 9.39;  $P = .01$ ).

**Decisional conflict.** Significant reduction in decisional conflict was observed in the hidradenitis suppurativa patient decision aid group from preintervention (mean = 31.45; SD = 15.58) to postintervention 1 (mean = 14.53; SD = 11.48;  $P < .01$ )



**Fig 1.** A hidradenitis suppurativa patient decision aid versus Mayo Clinic hidradenitis suppurativa website. *HS-PDA*, Hidradenitis suppurativa patient decision aid.

compared with no significant change in the Mayo group: preintervention (mean = 17.41; SD = 12.83) to postintervention 1 (mean = 15.22; SD = 11.82;  $P = .09$ ) (Fig 2). Improvement in the hidradenitis suppurativa patient decision aid group endured from preintervention (mean = 31.45; SD = 15.58) to postintervention 2 (mean = 13.53; SD = 10.88;  $P < .01$ ) but there was no change for the Mayo group: preintervention (mean = 17.41; SD = 12.83) to postintervention 2 (mean = 17.74; SD = 11.77;  $P = .92$ ).

**Preparation for decision making.** The hidradenitis suppurativa patient decision aid group was significantly more prepared for treatment decision making compared with the Mayo group ( $P < .01$ ). Prominent differences between groups in items selected were the following: prepared you to make a better decision (88% vs 27% for Mayo), helped you think about the pros and cons of each option (88% vs

27% for Mayo), and helped you think about which pros and cons are most important (81% vs 40% for Mayo) (Table II).

**Resource acceptability.** The hidradenitis suppurativa patient decision aid group more often rated the information they viewed as good or excellent compared with the Mayo group ( $P = .04$ ). All participants in the hidradenitis suppurativa patient decision aid group indicated that they would find this informational resource useful when making a treatment decision compared with 73% in the Mayo group ( $P = .05$ ) (Table III).

**Decision regret.** Sixty percent ( $n = 9$ ) and 38% ( $n = 5$ ) of participants in the hidradenitis suppurativa patient decision aid and Mayo groups, respectively, made a treatment decision during postintervention 2. No participants who made a treatment decision indicated regret or harm as a result of their choice. Although decision regret was

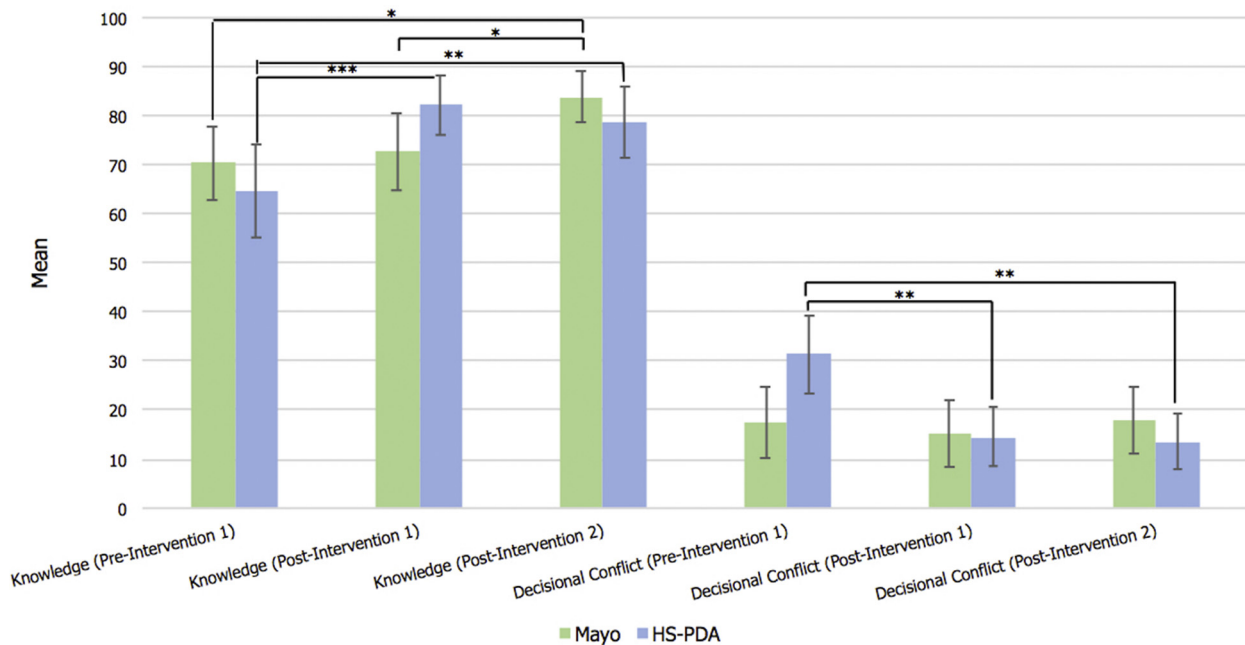
**Table I.** Demographic characteristics and hidradenitis suppurativa–related information by group

	HS-PDA group (N = 18), mean (SD)	Mayo group (N = 16), mean (SD)	P value
Age, y	35.61 (8.87)	36.63 (13.12)	.79
Average age of HS diagnosis, y	29.47 (9.89)	26.13 (15.26)	.46
Average no. of years with HS	17.81 (8.04)	18.14 (12.40)	.87
Average no. of physicians consulted for HS	4.44 (2.58)	9.63 (14.70)	.18
	No. (%)	No. (%)	
Sex			.12
Men	—	2 (12.50)	
Women	18 (100.00)	14 (87.50)	
Race			.002
White	16 (88.90)	6 (37.50)	
Black or African American	1 (5.56)	10 (62.50)	
American Indian or Alaskan Native	—	—	
Asian (Asian Indian, Chinese, Filipino, Japanese, Korean, Vietnamese, or other Asian)	—	—	
Native Hawaiian or other Pacific Islander (Native Guamanian, Chamorro, Samoan, or other Pacific Islander)	—	—	
Other	—	—	
Prefer not to answer	1 (5.56)	—	
Education			.34
Current high school student	—	—	
Some high school	1 (5.56)	—	
High school diploma	4 (22.22)	—	
Current college/university student	2 (11.11)	3 (18.75)	
Some college or university	3 (16.67)	3 (18.75)	
College certificate/diploma	2 (11.11)	1 (6.25)	
Associate's degree	1 (5.56)	3 (18.75)	
Bachelor's degree	3 (16.67)	5 (31.25)	
Graduate degree (master's or doctorate)	2 (11.11)	1 (6.25)	
Frequency consulting a physician			.18
Never	3 (16.67)	—	
Monthly	1 (5.56)	4 (25.00)	
Bimonthly	—	1 (6.30)	
Every 3 mo	4 (22.22)	1 (6.30)	
Three times/y	2 (11.11)	1 (6.30)	
Biyearly	2 (11.11)	4 (25.00)	
Yearly	1 (5.56)	1 (6.30)	
Every few years or as needed	5 (27.77)	3 (18.77)	
Prefer not to answer	—	1 (6.30)	
Stage of HS			.21
1	2 (14.30)	—	
1-2	—	2 (13.30)	
2	4 (28.60)	3 (20.00)	
2-3	2 (14.30)	—	
3	6 (42.90)	8 (53.30)	
4	—	1 (6.70)	
Prefer not to answer	—	1 (6.70)	
	No. (%) yes	No. (%) yes	
Area(s) where HS presents*			
Groin	11 (61.10)	11 (68.80)	.64
Buttocks	1 (5.56)	4 (25.00)	.11
Underarms	8 (44.40)	8 (50.00)	.75
Breasts	3 (16.67)	3 (18.80)	.87
Stomach	—	3 (18.80)	.05
Legs	—	1 (6.30)	.28
Thighs	1 (5.56)	2 (12.50)	.34
Neck	1 (5.56)	—	.48

HS, Hidradenitis suppurativa; PDA, patient decision aid; SD, standard deviation.

Dashes denote a value of zero.

\*Hidradenitis suppurativa presentation is not mutually exclusive and can present in multiple areas at once.



**Fig 2.** Changes in hidradenitis suppurativa–related knowledge and decisional conflict by group over time. Brackets denote significant changes between same measures.  $*P \leq .05$ .  $**P \leq .01$ .  $***P \leq .001$ . *HS-PDA*, Hidradenitis suppurativa patient decision aid.

not statistically significant between the groups, most believed that their treatment decision was the right or wise choice and would choose the same option again (Table II).

## DISCUSSION

In this study, hidradenitis suppurativa patient decision aid use enhanced knowledge of disease and treatment options, reduced decisional conflict, and increased preparation for decision making. Patients also rated the decision aid content highly and indicated that it would be useful when making treatment decisions.

Patient decision aids are tools that engage patients with information and encourage deliberation of patient values and preferences during treatment decision making. This is especially important for dermatologic conditions with an array of treatment options whereby selection is based on patient values. In a 2014 Cochrane review, patients believed they were more knowledgeable, better informed, and more likely to be active participants in their decision making after using patient decision aids.<sup>29</sup> Correspondingly, we showed that the hidradenitis suppurativa patient decision aid can increase knowledge, reduce decisional conflict, and enhance preparation for treatment decision making. Solely informational resources such as Mayo were less able to address needs inherent to individual hidradenitis suppurativa management because they were

not so designed. The hidradenitis suppurativa patient decision aid can encourage more efficient communication with health care providers by ensuring the provision of information, evidence-based treatment options, and consideration of individual values.<sup>30</sup>

Hidradenitis suppurativa patients have a strong desire for more education on medical and alternative treatments.<sup>31</sup> Various hidradenitis suppurativa clinical guidelines have been published since 2014.<sup>6,31–34</sup> This hidradenitis suppurativa patient decision aid was developed in accordance with the North American Clinical Management Guidelines for hidradenitis suppurativa because of the intended North American target audience.<sup>35,36</sup> As new and evolving treatments become accessible, updates will be incorporated accordingly.

## LIMITATIONS

Because the evidence for the hidradenitis suppurativa patient decision aid was developed from North American guidelines<sup>35,36</sup> and our cohort consisted of those with internet access belonging to hidradenitis suppurativa support groups, our results may not be generalizable to other regions or those without internet or support group affiliations. However, most treatments discussed in the hidradenitis suppurativa patient decision aid are available outside North America. Our cohort was already familiar with the disease and treatments because they were currently

**Table II.** Treatment-related information, including preparation for decision making and decision regret, by group

	HS-PDA group (N = 18), no. (%)	Mayo group (N = 16), no. (%)	P value
Current treatment?			.31
Yes	7 (38.89)	8 (53.33)	
Not right now, but in the past	11 (61.11)	7 (46.67)	
No	—	—	
Preparation for decision making: the informational resource...			.01
Helped you recognize that a decision needs to be made	11 (68.75)	6 (40.00)	
Prepared you to make a better decision	14 (87.50)	4 (26.67)	
Helped you think about the pros and cons of each option	14 (87.50)	4 (26.67)	
Helped you think about which pros and cons are most important	13 (81.25)	6 (40.00)	
Helped you know that the decision depends on what matters most to you	13 (81.25)	8 (53.33)	
Helped you organize your own thoughts about the decision	9 (56.25)	6 (40.00)	
Helped you think about how involved you want to be in this decision	11 (68.75)	10 (66.67)	
Helped you identify questions you want to ask your physician	11 (68.75)	9 (60.00)	
Prepared you to talk to your physician about what matters most to you	14 (87.50)	10 (66.67)	
Prepared you for a follow-up visit with your physician	13 (81.25)	8 (53.33)	
Pre: preference of treatment options			.15
None			
Topical	2 (11.11)	5 (31.25)	
Systemic	1 (5.56)	—	
Biological	1 (5.56)	2 (12.50)	
Light devices and lasers	1 (5.56)	—	
Surgery	—	4 (25.00)	
Complementary and alternative	6 (33.34)	1 (6.25)	
Unsure	7 (38.89)	3 (18.75)	
Other: combination	—	1 (6.25)	
Post 1: preference of treatment options			.23
None	—	—	
Topical	3 (18.75)	4 (26.67)	
Systemic	2 (12.50)	—	
Biological	3 (18.75)	3 (20.00)	
Light devices and lasers	1 (6.25)	1 (6.67)	
Surgery	—	4 (26.67)	
Complementary and alternative	6 (37.50)	2 (13.33)	
Unsure	1 (6.25)	1 (6.67)	
Other	—	—	
	(N = 15)	(N = 13)	
Post 2: preference of treatment options			.48
None	1 (6.67)	—	
Topical	3 (20.00)	3 (23.08)	
Systemic	2 (13.33)	—	
Biological	2 (13.33)	2 (15.38)	
Light devices and lasers	2 (13.33)	2 (15.38)	
Surgery	—	3 (23.08)	
Complementary and alternative	4 (26.67)	1 (7.69)	
Unsure	1 (6.67)	1 (7.69)	
Other: combination	—	1 (7.69)	
Post 2: treatment decision since first survey			.23
Yes	9 (60.00)	5 (38.46)	
No	6 (40.00)	8 (61.54)	
Decision regret*			.48
It was the right decision	6 (66.67)	5 (100.00)	
I regret the choice that was made	—	—	
I would make the same choice if I had to do it over again	7 (77.78)	4 (80.00)	
The choice did me a lot of harm	—	—	
The decision was a wise one	7 (77.78)	3 (60.00)	

HS, Hidradenitis suppurativa; PDA, patient decision aid.

Dashes denote a value of zero.

\*Only participants who indicated “agreement” or “strong agreement” with questions 1, 3, and 5 are depicted. Also, only participants who indicated “disagreement” or “strong disagreement” with questions 2 and 4 are depicted.



**Table III.** Resource-related information by treatment group

	HS-PDA group (N = 18), no. (%)	Mayo group (N = 16), no. (%)	P value
Used a previous information resource for HS			.21
Yes	6 (33.33)	6 (37.50)	
No	7 (38.89)	3 (18.75)	
Unsure	5 (27.78)	7 (43.75)	
Information good or excellent			.04
Effect of HS	14 (87.50)	9 (60.00)	
Risk factors	15 (93.75)	9 (60.00)	
Treatment options	16 (100.00)	10 (66.67)	
Evidence of effects on symptoms	15 (93.75)	8 (53.33)	
Length of the informational resource			.74
Too long	3 (18.75)	1 (6.67)	
Too short	—	3 (20.00)	
Just right	13 (81.25)	11 (73.33)	
Amount of information			.45
Too much	2 (12.50)	—	
Too little	1 (6.25)	4 (26.67)	
Just right	13 (81.25)	11 (73.33)	
Informational resource			.87
Slanted toward lifestyle options	—	—	
Balanced	13 (81.25)	12 (80.00)	
Slanted toward taking medical treatments	3 (18.75)	3 (20.00)	
Informational resource useful when making a treatment decision			.05
Yes	16 (100.00)	11 (73.33)	
No	—	4 (26.67)	
Informational resource's effect on decision making			.04
Made it easy	16 (100.00)	10 (66.67)	
Made it more difficult	—	4 (26.67)	

HS, Hidradenitis suppurativa; PDA, patient decision aid.  
Dashes denote a value of zero.

being or had previously been treated. Nevertheless, the hidradenitis suppurativa patient decision aid was useful to this cohort, implying that currently available information on hidradenitis suppurativa is inadequate for treatment decision making, and those without such resources may benefit even more from being provided the hidradenitis suppurativa patient decision aid during in-office visits.

Although English proficiency was required for study inclusion, this was not formally measured because of the online recruitment method, nor was socioeconomic status. Because of sample size limitations, stratification by race could not be undertaken. These factors may limit generalizability.

## CONCLUSION

The hidradenitis suppurativa patient decision aid is an informational and decisional resource designed to be used with health care provider clinical expertise to facilitate informed shared decision making. This randomized controlled trial demonstrates that the hidradenitis suppurativa patient

decision aid significantly improved knowledge and preparation for decision making, and reduced decisional conflict.

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