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Development of a hidradenitis suppurativa patient decision aid

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Abstract

Background: Patient decision aids (PDAs) are tools that facilitate informed shared decision-making between patients and health care providers. To address a previously identified need in treatment decision-making in hidradenitis suppurativa (HS), we developed an HS-PDA.

Methods: Development of the HS-PDA was based on International Patient Decision Aids Standards. Evidence was derived from the North American Clinical Management Guidelines for HS.

Results: Content from guidelines was transformed into patient-friendly language and reviewed by three physicians and two patient representatives. Feedback on HS-PDA content, presentation and practicality was obtained from 7 HS patients and 5 physicians. Revisions were made following thematic analysis. All patients felt the content on treatment options contained the right amount of information and 5 found it helpful to see these options contextualized to their values. Each stated they would use the HS-PDA during treatment decision-making. Three and four physicians respectively indicated the content was accurate and language was patient-friendly.

Limitations: Small sample sizes may limit generalizability.

Conclusion: This HS-PDA was developed in accordance with international standards based on current HS guidelines with input from patients and physicians. It is available online without cost.

Keywords: hidradenitis suppurativa, informed, shared, preparedness, decisional conflict, uncertainty, patient decision aid, decision-making, treatment

Introduction

Hidradenitis suppurativa (HS) is a chronic disorder of hair follicles characterized by painful inflamed and swollen nodules, abscesses, and sinus tracts [1,2]. Its association with reduced quality of life [3-5], a wide array of treatments, and absence of a singular best treatment requires that individual values and preferences be incorporated into treatment decision-making [6].

In a survey of HS patients, all 107 respondents indicated they required further support in HS management, specifically regarding treatment options [7]. Another survey conducted within an online HS support group found that the majority of the 151 respondents experienced decisional conflict (83%, N=125) and moderate or lower levels of preparedness for decision-making (63%, N=95), [8]. These findings indicate an unmet need for tools to facilitate treatment decision-making [8].

Informed shared decision-making is the interaction between patients and health care providers that combines patient values and preferences with

clinical experience and best-available evidence to inform medical decisions. Patient decision aids (PDAs) are tools that have demonstrated efficacy in helping patients and providers engage in shared decision-making [9]. Patients who used PDAs felt more knowledgeable, better informed, and were more likely to have a more active role in their decision-making [10]. This patient-centered approach has been increasingly used in various medical specialties and is also encouraged through policy as a means of ensuring patient-centered care [9,11]. Although well suited to the values-based needs in dermatology practice, few dermatological PDAs exist [6]. Nevertheless, prior studies found that the vast majority of patients desired to actively participate in their treatment decision-making [12].

The objective of this study was to develop a PDA for HS patients (HS-PDA) to facilitate informed shared treatment decision-making with their health care providers.

Methods

Hidradenitis suppurativa-PDA development was based on International Patient Decision Aids Standards [13] and consisted of three stages: 1) content development; 2) patient evaluation; 3) health care provider assessment. Following each stage, data were analyzed and used to revise HS-PDA content and format. The University of Windsor Research Ethics Board approved this study on July 26, 2019 (#19-109). All participants were provided informed consent prior to participation.

Content development

A literature search was conducted for HS clinical practice guidelines published in English. Given its relevance for North American patients and in accordance with the remit of the grant to develop a tool appropriate for this region, the North American Clinical Management Guidelines for HS was selected for information transformation [14,15]. Where the latter provided inadequate data, other sources were consulted including primary articles and general medical resources (UpToDate.com, epocrates.com, and Drugs.com). Extracted data items consisted of general background information on HS and

treatment information including mechanism, indications, contraindications, efficacy, potential adverse effects, safety, and convenience. Some data items (e.g., indications and contraindications) could not be extracted for treatments with insufficient evidence or more novel options (e.g., cryosurgery, combined medical-surgical treatments) not discussed in detail within the guidelines. Using Microsoft Word's readability programs, Flesch Reading Ease [16], and Flesch-Kincaid Grade Level formulas [17], content was adjusted to an 8th grade reading level as suggested by International Patient Decision Aids Standards for low-literacy and low-numeracy populations [13]. Where colloquial medical terms were used, simpler terms and phrases were provided to meet this standard.

Drafted HS-PDA content was reviewed by three dermatologists (authors JT, CS, and BR) for accuracy and comprehensiveness. Additionally, two HS patient representatives (authors SG and CY) provided input on content. Hidradenitis suppurativa photos of pertinent anatomical regions were obtained from two dermatologists (authors CS and BR) to facilitate visual representation of Hurley staging (I-III). Images were sorted for quality and de-identified prior to inclusion in the HS-PDA.

Final HS-PDA content was transformed into an online HS-PDA with 6 sections (**Figure 1**): 1) introduction; 2) my options; 3) my skin; 4) my values; 5) my trade-offs; 6) my decision [18]. The PDA concludes with a "Patient Summary Page" (**Figure 2**), the contents of which can be brought to a health care provider to summarize a patient's decisional process, values, and preferences.

Patient evaluation

The membership of Hope for HS, an online support group of HS patients, was invited to 1) evaluate the format, accessibility, and content of the HS-PDA website, as well as to 2) evaluate patient values considered during the treatment decision-making process. Inclusion criteria were the following: diagnosed HS patients (either medical or self-diagnosis), over 16 years of age, proficient in English, able to provide informed consent, and have an email address and access to a device with internet connectivity. Participants viewed the entire online



Figure 1. Online format of the hidradenitis suppurativa patient decision aid.

HS-PDA and completed a 58-item online survey using SurveyMonkey™ (SurveyMonkey Inc., San Mateo, California, USA) prior to attending an online group discussion on the web conference platform FreeConference.com™, v2.6.74.1 (FreeConference.com, Virginia, USA). Depending on completion percentage, full (US\$50) or partial compensation (US\$10, US\$25, or US\$35) was provided in the form of an e-gift card. Thematic data analysis was utilized to analyze all survey data and major themes were identified to revise the HS-PDA.

Health care provider assessment

Physicians who were authors of the North American Clinical Management Guidelines for HS [14,15], and board members of the Hidradenitis Suppurativa Foundation, Inc. were invited to assess HS-PDA content, accessibility, ease-of-use, and applicability. Invitations were also extended to one physician who was an author of the guidelines but not a board member, as well as to one physician who was only a

board member but not an author. Participants completed a 29-item survey using SurveyMonkey™ (SurveyMonkey Inc., San Mateo, California, USA) addressing the above items and the Patient Summary Page. Thematic data analysis was performed, and major themes were identified to revise the HS-PDA.

Results

Patient evaluation

Seven HS patients completed the online survey (see **Table 1** for demographics, **Table 2** for responses). Although there are 8 participants in **Table 1**, one skipped the majority of the survey. Thus, responses reflect the remaining 7 participants. Inductive thematic analysis was used as a framework to analyze the data (see **Table 3** for a summary of the themes), [19,20]. This data, as opposed to a pre-determined coding scheme, was used to develop the analysis structure.

Within the survey, all patients indicated that the *My Options* section was *helpful* and that it contained the *right amount of information*, though one patient stated they wished more information was available about treatment options. Almost all (86%, N=6/7) believed that the choice of treatment was up to them. However, one patient indicated that having the alternative treatment as the last choice made them less likely to select it. In the *Learn More* section, almost all (86%, N=6/7) indicated that each of the tabs was *helpful*. All indicated that they liked the *My Skin* section. Most (86%, N=6/7) appreciated the drag-and-drop list of values and indicated that all definitions in the *My Values* section were either *very clear* or *extremely clear* (71%, N=5/7), though one found some definitions *somewhat clear* or *extremely clear*. Another indicated that all definitions were *somewhat clear*, stated the drag-and-drop list was “not [their] favorite” because of the layout and wording, and wished to see more alternative options (e.g., acupuncture) but were glad to have the option of adding their own values. All indicated the *My Values* section helped them think about what was important to them. Most (71%, N=5/7) indicated that

Table 1. Demographic characteristics of patient evaluation respondents (N=8).

	Patient Evaluation
Age M (SD)	43.88 (8.46)
	N (%)
Gender	
Male	1 (12.5)
Female	7 (87.5)
Ethnic Background	
White	6 (75)
Black or African American	1 (12.5)
American Indian or Alaskan Native	1 (12.5)
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	–
Education	
Current high school student	–
Some high school	–
High school diploma	1 (12.5)
Some college or university	2 (25)
College certificate/diploma	1 (12.5)
Associate's degree	1 (12.5)
Bachelor's degree	1 (12.5)
Graduate degree (Master's or Doctorate)	2 (25)
Length of Time with Hidradenitis Suppurativa	
< 10 years	–
10 to < 20 years	3 (37.5)
20 to < 30 years	2 (25)
30+ years	3 (37.5)
Severity of Hidradenitis Suppurativa	
Stage 1	–
Stage 2	4 (50)
Stage 3	4 (50)
Number of Healthcare Professionals Seen for Hidradenitis Suppurativa	
< 5	2 (25)
5 to < 10	2 (25)
10+	4 (50)
Current Treatment for Hidradenitis Suppurativa	
Yes	5 (62.5)
No	3 (37.5)
Previous Patient Decision Aid Use	
Yes	–
No	4 (50)
Unsure	4 (50)

the *My Trade Offs* section was helpful in allowing them to see treatment options compared to their values. One indicated that the colored circles were confusing and another indicated not liking the colors or the chart. For the *My Decision* section, all but one indicated that they were either *ready* or *very ready* to

make a treatment decision (the remaining patient indicated they were *somewhat ready*, stating they wish to seek more information and speak with their doctor before deciding). All indicated that when they are ready to choose a treatment, they would use the HS-PDA for assistance.

Suggestions for changes were related to aesthetic elements (e.g., color and font sizes) and ability to view the actual names of treatments. When asked how they would utilize the HS-PDA, patients stated they would *make a list of questions to ask during an appointment* (86%, N=6/7), *print it out to bring to an appointment* (86%, N=6/7), *show it to their health care provider during an appointment on an electronic device* (86%, N=6/7), and use it to educate other doctors (14%, N=1/7). All stated that they would be *likely* or *very likely* to recommend the HS-PDA to friends or family with HS.

Despite attempts to recruit patients for the second part of this stage, the group discussion, only two patients participated. Of these, only one had completed the online survey, thereby rendering them the only eligible patient. Their feedback in the group discussion reflected their survey responses and was therefore not used to inform major changes to the HS-PDA, as the two objectives for this stage were met through the survey.

Health care provider assessment

All physicians reported no prior PDA use. [Table 4](#) summarizes their demographics and responses regarding usage of the Patient Summary Page and HS-PDA in their respective practice. All (100%, N=5/5) understood that the information on the Patient Summary Page was based on patient responses. Most (80%, N=4/5) indicated that they *would* or *possibly would* use a patient's preferred treatment information during a consultation, as outlined on the Patient Summary Page, with one stating they *would not use* the Patient Summary Page because they "would need to understand how the summaries are generated". Regarding the HS-PDA, most (60%, N=3/5) *agreed* that the content was accurate and that the amount of detail was appropriate (compared to the remaining physicians, who answered with *neutral*). All *agreed* that the steps were presented in a logical order. Most (80%, N=4/5) *agreed* that the HS-PDA's language was patient-friendly, with one physician in disagreement (no clarifying information to expand this point was provided). The majority (80%, N=4/5) also indicated that they would recommend patients use the PDA and bring their Patient Summary Page to their next appointment. The physician who indicated they

would not use the HS-PDA stated that they required more information about how the recommendations would be used. Physicians had a range of preferences with regard to the preferred timing of patients' use of the HS-PDA: *before patients visit a dermatologist* (40%, N=2/5), *in a waiting room before an appointment with a general practitioner or dermatologist* (20%, N=1/5), *after patients' initial appointment with a general practitioner or dermatologist* (20%, N=1/5), and *after receiving a diagnosis of HS* (20%; N=1/5).

Discussion

Patient decision aids are informational resources with personalized input on patient values to facilitate shared decision-making with health care providers. Both patients and health care providers are integral pieces to informed decision-making [21]. Similar to prior initiatives [22], the goal of this HS-PDA is to inform patients of their treatment options, compare those treatments with their individual values and preferences, and engage in an informed dialogue with their health care provider.

Hidradenitis suppurativa patients indicated high overall satisfaction with this HS-PDA and valued the features allowing for individualized treatment decision-making. Previous research has shown that the most important aspects in patient treatment decision-making are treatment convenience, efficacy, and risk of side effects, which have all been included in the HS-PDA with the option for users to input additional personal values [22,23]. All patients reported they would use the HS-PDA when making a treatment decision. These findings reflect the ability of the HS-PDA to satisfy patients' need for HS information, treatment options and engagement with health care providers.

One patient stated that they would like to see more complementary and alternative treatment options, such as acupuncture. This is consistent with prior research showing that HS patients' use of complementary and alternative methods is increasing [24]. Some patients also wished to be presented with as many treatment options as possible, as there is no singularly effective treatment

[25]. However, as our HS-PDA was constructed to be in accordance with current best-evidence and the North American Clinical Management Guidelines for HS [14,15], evidence was limited to those presented in the latter. As treatment evidence, practices, and policies evolve the PDA will be updated accordingly.

Most physicians responded positively regarding HS-PDA content, accuracy, and amount of detail. The majority indicated they would use the HS-PDA with patients at their next appointment. However, we recognize that there are potential barriers to uptake including lack of awareness of the HS-PDA, time constraints, and provider-perceived applicability to the patient or clinical setting [26,27].

One barrier for health care provider HS-PDA use may be time. Physicians preferred patients use the HS-PDA independently and bring the Patient Summary Page to their appointment. Similarly, patients indicated they would complete the HS-PDA prior to showing the Patient Summary Page to their health care provider at their next appointment. Patients appreciated the ability to complete the HS-PDA at their convenience and its interactive design permitting input regarding disease severity and values. Further, patients appreciated playing an active role in considering a treatment plan prior to a consultation with their health care provider. The availability of a Patient Summary Page can inform the health care provider of patients' values and treatment preferences in a time-efficient manner.

Limitations

Although various groups have developed treatment guidelines for HS, this HS-PDA was based on the North American Clinical Management Guidelines for HS since both have an intended North American audience [14,15]. This focus may limit generalizability to other geographical regions.

For the patient and health care provider assessment stages, a limitation was small sample sizes. Nevertheless, small sample sizes are typical for qualitative research and thematic analysis and have been used in prior PDA development [23]. We conducted these exclusively online owing to perceived ease of access for a population that may have mobility restraints, our desire to involve online

HS patient support groups and health care providers across North America, and the online format of the HS-PDA. For the second part of the patient evaluation stage (the group discussion), accessing the online conference platform and/or scheduling issues may have hindered participation.

Participation of self-diagnosed HS patients was allowed because of the nature of the online recruitment method. As we wanted to involve physicians with an interest and expertise in HS management, only a selected cohort of physicians were invited to provide feedback during development. This group may not be representative of all physicians involved in the care of HS patients.

Practice implications

The HS-PDA was deemed of value in HS management by both patients and physicians. It is a comprehensive resource for HS patients that presents information on HS and its treatments and summarizes patient values and preferences to increase efficiency of clinical encounters with health care providers. It is freely available online and we anticipate this will promote accessibility for patients and may reduce time barriers in counseling for health care providers.

Conclusion

As HS patients require tools to facilitate informed decision-making, this HS-PDA provides evidence-based support aligned with the recent North American Clinical Management Guidelines for HS [14,15]. Patient and physician feedback on HS-PDA content, format, accessibility, and use was positive. Further evaluation of the HS-PDA in increasing patient knowledge of disease and treatment options, reducing decisional conflict, and improving preparedness for decision-making will be conducted. The HS-PDA is now available without cost at www.informed-decisions.org.

Potential conflicts of interest

Olivia McBride, Donna McLean, and Mia Sisic received salaries from Windsor Clinical Research Inc. Sandra

Guilbault is the director of Hope for HS and a board member for the Hidradenitis Suppurativa Foundation, Inc. Christopher Sayed has been an advisory board member and speaker for, and/or received honoraria and grants from Abbvie, Chemocentryx, InflaRx, Novartis, and UCB. Barry Resnik has been an advisory board member for Abbvie. Robert Dellavalle is a member of Cochrane Council, received other independent peer reviewed grants from Pfizer, and received honoraria from Brown University and Altus Labs. Jerry Tan is the president of Windsor Clinical Research Inc. He has been a speaker and consultant for, and/or received honoraria, grants, and research support from Almirall, Bausch, Boots/Walgreens, Botanix, Cipher, Galderma, Incyte, Novartis, Pfizer, Promius, Sun, UCB and Vichy. All other authors report no conflicts of interest.

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Table 2. Summary of patient evaluation responses (N=7).

Select Responses	N (%)
My Options Page	
This information was helpful	7 (100)
Was there enough information presented?	
1 - Not enough	–
2	–
3	–
4 - The right amount	7 (100)
5	–
6	–
7 - Too much	–
What is it and how does it work' tab was helpful	7 (100)
Who is this for' tab was helpful	7 (100)
Who is this NOT for' tab was helpful	6 (86)
How well does it work' tab was helpful	7 (100)
What are the possible side effects' tab was helpful	7 (100)
Will it inconvenience me' tab was helpful	7 (100)
Did it seem like we wanted you to choose one treatment over the other?	
Yes	1 (14)
No	6 (86)
My Values Page	
The definition of 'risk of serious side effects' was extremely clear or very clear	6 (86)
The definition of 'speed of results' was extremely clear or very clear	5 (71)
The definition of 'convenience' was extremely clear or very clear	5 (71)
The definition of 'cost' was extremely clear or very clear	6 (86)
The definition of 'how well treatment works' was extremely clear or very clear	6 (86)
The definition of 'length of treatment' was extremely clear or very clear	4 (57)
My Decision Page	
How ready did you feel to make this choice?	
1 - Not ready at all	–
2 - A little ready	–
3 - Somewhat ready	1 (14)
4 - Ready	3 (43)
5 - Very ready	3 (43)
Patient Decision Aid Use	
How might you use this with your doctor or healthcare professional? (Select all that apply)	
Make a list of questions to ask during an appointment	6 (86)
Ask to show my doctor or healthcare professional during an appointment from my mobile phone or tablet	6 (86)
Print it out to bring to an appointment	6 (86)
You would use it to help you when you go to choose a treatment	7 (100)
You would be likely to recommend its use to a family member or friend with hidradenitis suppurativa	7 (100)

Table 3. Thematic analysis summary of patient evaluation responses.

Theme	Subtheme	Explanation	Quotes
Presentation of the PDA ¹	Ease of use	Participants found that the PDA ¹ was user-friendly	"It was very easy to use" "I liked the simplicity of it, and the information was very clear"
	Effective use of visuals	Participants found the visuals to be a helpful addition to the PDA ¹	"Great visual" "Nice to see them [the red, yellow, and green circles] and differentiate between the others"
Use of the PDA ¹	Autonomy in decision-making	Participants felt that they were able to assess the options and make the right treatment decision for themselves	"Like having the ability to make decisions" "I like how it was very informative about the different options. I also liked how it didn't push certain options over others"
	Use for dialogue with medical professionals	Participants could bring the PDA ¹ with them to medical appointments and start a conversation around treatment options	"Print it out to bring to an appointment" "Ask to show my doctor or health care professional during an appointment from my mobile phone or tablet"
Tool for decision-making	Customizable for different parts of the body	The PDA ¹ allows for targeted information pertaining to the area(s) that participants experience HS ²	"I liked being able to select what parts of my body has HS ² " "I loved how I could click to put where I get my HS ² . It gives me a visual of actual how much of my body has HS ² "
	Narrowing down treatment options	The PDA ¹ allows participants to compare treatment options	"It made me consider each option. The ranking made me think more" "Good to narrow down points of reflection"
User-based alteration recommendations	Visual changes	Changes pertaining to the visual appearance of the PDA ¹ website	"The font size could be a little bigger" "The 'color' chart indicating the treatments and how well they do/do not work. Confusing to me and not quite so helpful in making a decision"
	Content changes	Changes pertaining to the information found on the PDA ¹ website	"Who is this not for is an unnecessary tab" "When it comes to calculating percentage [on the <i>My Skin</i> page], most of us are not mathematicians"
	Breadth in treatment options	More options to be added so that participants can feel confident knowing they are familiar with all options before making treatment decisions	"More alternatives what about photo treatment or alternative smoothies and acupuncture? I want every possible help resolution" "I want as many options to help with this HS ² and I understand that it's hard to offer everything but each person is different and

		all information to healthy results should be offered,"
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¹Patient Decision Aid.

²Hidradenitis Suppurativa.

Table 4. Summary of health care provider assessment responses (n=5).

	N (%)
Age M (SD)	51.75 (6.26)
Gender	
Male	1 (20)
Female	3 (60)
Ethnic Background	
White	3 (60)
Black or African American	–
American Indian or Alaskan Native	1 (20)
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 (20)
Specialty	
General practice	–
Dermatology	4 (80)
Obstetrics and Gynecology	–
Anesthesiology	–
Pathology	–
Pain Medicine	–
Other: Plastic Surgery	1 (20)
Years Practicing	
Less than 5 years	–
5-9 years	1 (20)
10-14 years	1 (20)
15-19 years	1 (20)
20+ years	2 (40)
Practice Location	
United States	4 (80)
Canada	1 (20)
Other	–
Previous Patient Decision Aid Use	
Yes	–
No	5 (100)
(a) Patient Summary Page	
How might you respond if a patient brought you a Patient Summary Page like the one you just reviewed? I would . . .	
Review this Patient Summary Page with my patient to help them make a decision	2 (40)
Want to research where the information came from before using the Patient Summary Page	2 (40)
Ask the patient to summarize their thoughts for me, rather than reading the Patient Summary Page	–
Have a nurse or other staff member discuss the Patient Summary Page with the patient	1 (20)
Not have time to read a Patient Summary Page in consultation	–
Not use the Patient Summary Page because of concerns about information from the Internet	–
Other (please specify)	–
Did you understand that the information on the Patient Summary Page was based on a patient's responses?	
Yes	5 (100)

Was there enough information presented on the Patient Summary Page to help you make a shared treatment decision with your patient?	
There was not enough information	–
There was the right amount of information	4 (80)
There was too much information	–
I would not use this Patient Summary Page with a patient	1 (20)
(b) Patient Decision Aid	
How might you use or recommend the use of this Patient Decision Aid? Select all that apply. I would . . .	
Not use this Patient Decision Aid	1 (20)
Use this Patient Decision Aid with my patients in a consultation	–
Recommend my patients complete this Patient Decision Aid on their own and bring their Patient Summary Page to our next appointment	4 (80)
Recommend my patients use this Patient Decision Aid on their own	–
Have a nurse or staff member use this Patient Decision Aid with my patients	–
Promote this Patient Decision Aid indirectly in my waiting room	–
Promote this Patient Decision Aid directly to colleagues or other staff	–
Other (please specify)	–
When do you think patients should use this Patient Decision Aid?	
Before they visit a general practitioner	–
Before they visit a dermatologist	2 (40)
In a waiting room before an appointment with a general practitioner or dermatologist	1 (20)
After their initial appointment with a general practitioner or dermatologist	1 (20)
If treatment is not effective or adhered to	–
Other: Once diagnosed with Hidradenitis Suppurativa	1 (20)