


A Qualitative Examination of the Preferred Language for Patients Discussing Genital Psoriasis With the Physician

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Abstract

Background: Psoriasis is a chronic inflammatory disease that may affect the genitalia in up to 60% of patients. This is a significant concern to patients; however, they may be too embarrassed to report genital involvement or seek help for it spontaneously. Information on preferred language that would put patients more at ease discussing disease in sensitive areas is lacking. **Objective:** To address language as a barrier to care in patients with psoriasis by identifying preferred terminology when discussing genital involvement of the disease with physicians. **Methods:** A qualitative study was performed that consisted of one-on-one interviews with patients with psoriasis; thematic analysis was used to analyze the data. **Results:** Themes included (1) personal experience with genital psoriasis; (2) timespan between genital psoriasis symptom onset and diagnosis; (3) patient–provider communication; (4) patient–provider preference, and (5) patient terminology preference. **Conclusion:** Our study highlights providers’ failure to ask psoriasis patients about genital involvement of the disease and variation in patient response on preferred language when discussing sensitive topics. Dermatologists may need to be cognizant of the patient’s comfort level using verbal and nonverbal communication and tailor their approach to the individual.

Keywords

psoriasis, genital disease, genital psoriasis, language, patient-centered care, patient-physician relationship, terminology

Introduction

Psoriasis is a chronic inflammatory disease that presents as diffuse erythematous scaly papules and plaques on patients’ skin, including their genitalia.^{1,2} Up to 60% of patients with psoriasis have genital psoriasis at some point during the course of their disease. While genital involvement may be a major concern to patients, they may be too embarrassed to spontaneously report genital involvement or seek help for it. Information on preferred language that would put patients more at ease discussing disease in sensitive areas, such as the genitalia, is lacking. In order to create a framework for this topic, we performed a qualitative study on psoriasis patients’ preferred terminology when discussing genital involvement of disease with the physician.

Methods

Following Wake Forest Health Sciences University Institutional Review Board approval, psoriasis patients greater than or equal to 18 years of age were recruited when presenting for a standard-of-care appointment at Atrium

Health Wake Forest Baptist Dermatology. The presence of genital involvement was neither a requirement nor an exclusion for participation.

For those willing to participate, signed consent was obtained, and individuals were asked to participate in a one-time 15–20 min interview consisting of fourteen open-ended questions ([appendix 1](#)). Interviews were conducted one-on-one by authors A–C and were audio recorded and transcribed. Thematic analysis was used to analyze the transcripts. A codebook was created after

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reviewing the first 3 transcripts, this codebook continued to be modified as new themes arose in the subsequent transcripts. Interviews were concluded once no new themes were arising.

Results

We achieved saturation with 28 subjects, 15 females and 13 males ages 26 to 82 years (Table 1). Themes included (1) personal experience with genital psoriasis, where 11 (39%) of 28 psoriasis patients reported having genital psoriasis. (2) Timespan between genital psoriasis symptom onset and diagnosis, where 2 (18%) of 11 patients with genital psoriasis reported a timespan greater than 2 years between symptom onset and diagnosis; both delayed seeking care due to embarrassment. (3) Patient-provider communication, where 21 (75%) of 28 psoriasis patients denied the dermatologist asking about genital involvement of the disease, and

23 (82%) patients said they feel comfortable speaking about genital psoriasis with the provider. (4) Patient-provider preference, where 18 (64%) patients had no preference for the provider's specialty and 10 (36%) patients said the provider of preference is the dermatologist. The majority (93%) of patients did not have a strong preference for providers of similar age or sex. (5) Patient terminology preference, where 14 (50%) and 4 (14%) of 28 said they prefer the use of general terms (eg genitals, down there) and specific terms (eg vagina, penis, anus), respectively. The themes are detailed in (Table 2).

Discussion

Patients with genital psoriasis report severe pruritus, pain, dyspareunia, and a negative impact on self-confidence, sexual relations, and mental health.^{1,2} Despite the profound impact on patients' lives, genital psoriasis is under-treated². This can be due to misdiagnosis, patient underreporting, and physician lack of inquisition.^{1,2} Barriers to care are augmented by language, as vague questions and assumptive talk risk a lack of patient disclosure on sensitive topics.^{3,4,5}

Our study serves as a preliminary investigation and highlights providers' failure to ask psoriasis patients about genital involvement of the disease and variation in patient response to preferred language when discussing sensitive topics. Dermatologists may need to be cognizant of the patient's level of comfort using verbal and nonverbal communication and tailor their approach to the individual. Subjects were recruited at a single-center academic institution which may limit generalizability as individual opinions differ across locations. Further robust research is needed to implement guidelines for providers treating patients with GP.

Table 1. Demographics of Patients Interviewed With Psoriasis.

Demographics of Patients Interviewed	
Age mean (range)	54 (26–82)
Sex	N. (%)
Female	15. (53.57)
Male	13. (46.43)
Race/ Ethnicity	N. (%)
White	20. (71.42)
Black	6. (21.43)
Asian	1. (3.57)
Hispanic/ Latino	1. (3.57)

Table 2. Common Themes Among Patients With Psoriasis That Arose From Interviews Regarding Preferred Terminology When Discussing Genital Psoriasis.

Code		Responses	Number of Responses	Examples
Themes	Subthemes			
Personal experience with GP (I)	Patient never had GP (Ia)	3, 5, 7–15, 17, 19, 20, 22, 24, 25, 28	17	"I don't think so" P3
	Patient has/had GP (Ib)	1,2,4,6,13, 16, 18, 21, 23, 26,27	11	"I've had it a couple of times in the genital area" P1
	GP is persistent (Ic)	4, 13, 26	3	"It used to come and go. Now it's persistent" P4
	GP is intermittent (Id)	1, 2, 6, 17, 22, 23, 27	7	"It would come and go, come and go" P6
	Patient suffered from psoriasis for >10 years (Ie)	1,4,5–7,9,13, 16–18, 21, 23, 35–27	15	"I'm 75 and I think I got it when I was about 27 to 30, about 30 years old" P5
	Patient suffered from psoriasis for <10 years (If)	2, 3, 8, 10–12,14, 15, 19, 20, 22, 24, 18	13	"It's probably like the summer of 2018" P2

(continued)

Table 2. (continued)

Code		Responses	Number of Responses	Examples
Themes	Subthemes			
Time of diagnosis of GP (2)	Patient was diagnosed with GP soon after symptoms started(2a)	1, 4, 13, 16, 18, 21, 23, 26, 27	9	“When I was diagnosed (with psoriasis) by a dermatologist a couple of years ago, I asked about those areas. He said that’s what it was.” P4
	Patient was diagnosed with GP >2 years after symptoms started (2b)	2, 6	2	“It really was 15 to 20 years of personal area psoriasis pop-ups before I decided to even start talking.” P6
Patient-provider communication (3)	Physicians fail to regularly ask about GP (3a)	1–9, 11–18, 20, 23, 24, 28	21	“They don’t ask that. They asked. Where else do I have it, you know? But, not specifically.” P5
	Physicians regularly ask about GP (3b)	10, 19, 21, 22, 25, 26, 27	7	“Yes, except for this time.” P10
	Patient feels comfortable initiating GP conversation with their physician (3c)	1, 4, 8, 9–28	26	“There was no embarrassment when I came in here the first time.” P8
	Patient feels uncomfortable initiating GP conversation with their physician (3d)	1, 6	2	“Yes, It was fear and being uncomfortable and embarrassed. All those things are.” P6
	Patient feels comfortable when asked about GP by their physician (3e)	3–5, 10–28	22	“No, I wouldn’t feel uncomfortable. But a lot of people would” P5
	Patient feels uncomfortable when asked about GP by their physician (3f)	1, 2, 6, 7	4	“This is a touchy subject. You know, gosh. You gotta show it and stuff like that. it’s still uncomfortable.” P1
	Patient does not feel rushed during the exam (3g)	15–28	13	“No, no, never” P27
	Patient feels rushed during the exam (3h)		0	
Patient Provider Preference (4)	Patient has no preference for doctor’s specialty (4a)	2, 4, 6, 14, 16–18, 20, 21, 23, 25–28	18	“Any physician, any of them.” P4
	Patient prefers discussing GP with a dermatologist (4b)	1, 3, 5, 10–13, 19, 22, 23	10	“The ones that have helped me the most are dermatologists. So, I would feel better with dermatologists.” P5
	Patient prefers discussing GP with an OBGYN (4c)	7,9	2	“I would probably say, my gynecologist. Because I’ve been with them for so long.” P7
	Patient prefers discussing GP with a primary care physician (4d)	8, 15	2	“In my case it’s probably my family physician that I’m the most comfortable with.” P8
	Patient prefers a provider of a certain age (4e)	22	1	“I like providers who are a bit older. Seems like they’ve seen more” P22
	Patient has no preference for a provider of a certain age (4f)	15–21, 23–28	13	“No it doesn’t bother me. If they’re a doctor, they’re a doctor” P27
	Patient prefers a provider of the same sex (4g)	22	1	“Same sex” P22
	Patient has no preference for a provider of the same sex (4h)	15–21, 23–28	13	“Doesn’t matter, as long as they’re a good doctor” P16
	Patient prefers the provider to be a physician (4i)	15, 16, 27, 28	4	“I prefer a doctor” P16
Patient terminology preference (5)	Patient does not have a preference for the provider’s type of training background (4j)	17–26	10	“Doesn’t matter I’d be comfortable with any” P17
	Patient has no preference for terminology (5a)	3, 11, 19–21, 23–27	10	“It doesn’t matter to me” P3
	Patient prefers specific terms (5b)	1, 9, 16, 22	4	“You have to like ohh, just say what it is” P1
	Patient prefers general terms (5c)	2, 4–8, 10, 12–15, 17, 18, 28	14	“I prefer the genital area” P4 “I think I would prefer intimate area” P7

Appendix I

Data Collection Forms:

1. When were you diagnosed with psoriasis?
2. Do you have psoriasis in the genital or perianal area, or have you ever had psoriasis in the genital or other sensitive areas?
3. How comfortable are you discussing psoriasis in sensitive areas like the genitals or around the anus with your physician?
4. If you had psoriasis in the genital area, how long did you have it before learning it was psoriasis?
5. Is the psoriasis in the genital area persistent or does it come and go?
6. Has your doctor ever failed to ask about whether you have psoriasis in the genital area?
7. How do you feel when asked about psoriasis in the genital area? Have you had any discomfort?
8. Have you ever not brought up the issue of psoriasis in a sensitive area because of embarrassment or other feelings?
9. What words do you prefer to be used when asking about psoriasis in sensitive areas (for example, genital, private part, down there, covered place, intimate area)?
10. Do you feel more comfortable discussing psoriasis in the genital area with the dermatologist, the gynecologist, or the family physician?
11. Do you prefer to talk to a Health Care Provider of the same sex?
12. Do you prefer to talk to a Health Care Provider of similar age?
13. Do you prefer to talk to a physician vs NP or PA about your genital psoriasis?
14. Did the patient feel rushed during their exam?

Authors' Note

Pichardo worked at the advisory board for Novartis.

Declaration Conflicts of Interest

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Consent

Participants provided written informed consent.

IRB Approval Status

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Supplemental Material

Supplemental material for this article is available online.

References

1. Kelly A, Ryan C. Genital psoriasis: Impact on quality of life and treatment options. *Am J Clin Dermatol*. 2019 Oct;20(5):639-646. PMID 31313079. doi:10.1007/s40257-019-00447-5
2. Meeuwis KAP, Potts Bleakman A, van de Kerkhof PCM, et al. Prevalence of genital psoriasis in patients with psoriasis. *J Dermatolog Treat*. 2018 Dec;29(8):754-760. PMID: 29565190. doi:10.1080/09546634.2018.1453125. Epub 2018 Mar 28
3. Kelder I, Sneijder P, Klarenbeek A, Laan E. Communication practices in conversations about sexual health in medical healthcare settings: A systematic review. *Patient Educ Couns*. 2022 Apr;105(4):858-868. Epub 2021 Jul 29. PMID: 34366226. doi:10.1016/j.pec.2021.07.049
4. Binder P, Borné Y, Johnsdotter S, Essén B. Shared language is essential: Communication in a multiethnic obstetric care setting. *J Health Commun*. 2012;17(10):1171-1186. doi:10.1080/10810730.2012.665421
5. Cather JC, Ryan C, Meeuwis K, et al. Patients' perspectives on the impact of genital psoriasis: A qualitative study. *Dermatol Ther*. 26 Oct. 2017;7(4):447-461. www.ncbi.nlm.nih.gov/pmc/articles/PMC5698203/10.1007/s13555-017-0204-3. Accessed July 26, 2022.