

# Integrating primary palliative care into hidradenitis suppurativa management

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## ABSTRACT

Hidradenitis suppurativa (HS) is a chronic, often debilitating skin condition that disproportionately impacts women in the United States and other Western nations. Dermatologists should consider incorporating palliative care principles into HS management to optimize care. Primary palliative care principles include utilizing evidence-based frameworks in serious illness communication, acknowledging and addressing physical and psychosocial suffering, recognizing and validating the burden of disease in partners, families, and caregivers, and engaging in collaborative care coordination. Certain patients may also benefit from outpatient, or sometimes inpatient, palliative care specialist collaboration, such as those with refractory HS and superimposed challenging psychosocial dynamics and symptom burden. Through integration of these palliative care domains into HS care, dermatologists can optimize their ability to provide comprehensive and compassionate care for patients suffering with this disease.

**Keywords:** hidradenitis suppurativa, palliative care, prevention

Hidradenitis suppurativa (HS) is a chronic, debilitating, and painful disease that disproportionately impacts women in many regions of the world and severely diminishes quality of life (QOL).<sup>1</sup> Despite the recognized impact of reduced QOL, the role of integrating palliative care in HS management has not been explored. Palliative care focuses on improving QOL for people with serious illness; while it is often associated with terminal conditions, it can be provided concurrently with medical and procedural therapies. All clinicians caring for patients with serious illness should develop skills in primary palliative care. When providers address symptom management, evaluate psychosocial context and stressors, and utilize evidence-based frameworks for serious illness communication, they are practicing primary palliative care. Although there is a lack of palliative care studies specifically in HS, recommendations can be made for patients with HS based on evidence in other disease states. Herein, we highlight several palliative care domains<sup>2</sup> that dermatologists can integrate into HS care to better meet patients' complex needs.

First, providers can build a skillset for varied communication tasks. Due to a lack of awareness from the public and health-care community, patients with HS often suffer from initial misdiagnoses and may experience significant disability by the time of diagnosis. This delay diminishes confidence in the healthcare system. A patient's first visit with their HS provider is critical to developing an effective, long-term therapeutic relationship. Structured discussions about serious illness improve patient/caregiver satisfaction.<sup>3</sup> Dermatologists can apply evidence-based strategies when facing challenging communication tasks, such as building rapport, addressing prognostic uncertainty, discussing complex treatment decisions, and responding explicitly to emotion; examples of helpful communication phrases are provided in Table 1. Although these frameworks have not been specifically studied in HS, structured discussions in the context

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## What is known about this subject with respect to women and their families?

- Hidradenitis suppurativa (HS) is a chronic, often debilitating skin condition that disproportionately impacts women.
- Despite the recognized negative impact of HS on patient quality of life, specifically integrating palliative care into HS management has not been explored.

## What is new in this article with respect to women and their families?

- In caring for patients with HS, dermatologists should consider utilizing primary palliative care principles, which includes utilizing evidence-based frameworks in serious illness communication, acknowledging and addressing physical and psychosocial suffering, and coordinating care across involved specialties.
- This article includes a table with practical examples of communication phrases that dermatologists can utilize in their everyday clinic encounters with patients with HS.
- Integration of palliative care domains into HS management will allow dermatologists to provide improved empathetic and comprehensive care for women and men with HS and their families.

**Table 1****Applying serious illness communication frameworks to hidradenitis suppurativa care**

Communication Task	Communication Framework	Example Phrases for Patient Encounters
Building rapport	<ul style="list-style-type: none"> <li>Negotiate a shared agenda for visits.</li> <li>Listen to the patient's story.</li> <li>Acknowledge and validate suffering.</li> <li>Ask permission before sharing medical information or providing recommendations.</li> <li>Inquire patient's preferred role in decision-making.</li> <li>Track emotions and respond.</li> </ul>	<ul style="list-style-type: none"> <li>What are the big items you want to cover today? Great. Here's what I propose...</li> <li>Would you be willing to share your experience in receiving your HS diagnosis?</li> <li>I can see how much you are suffering.</li> <li>Would it be okay if we spoke about something that's concerning me?</li> <li>When making medical decisions, some people like to decide on their own, some like to decide with me, and some like to know my recommendations. What is best for you?</li> <li>I'm hearing how hard this has been for you.</li> </ul>
Prognostic uncertainty	<p>ADAPT</p> <ul style="list-style-type: none"> <li>Ask</li> <li>Discover</li> <li>Anticipate ambivalence</li> <li>Provide information</li> <li>Track emotion</li> </ul> <p>Wish/Hope and Worry statements</p> <ul style="list-style-type: none"> <li>"I wish..."—convey empathy</li> <li>"I hope..."—align with optimism</li> <li>"I worry..."—share concern</li> </ul>	<ul style="list-style-type: none"> <li>I'm wondering what you already know about what to expect with HS?</li> <li>Can you share what questions or concerns you have about HS?</li> <li>Some patients tell me that talking about the future can be scary. Do you feel the same?</li> <li>Let's talk about what you might expect in the future.</li> <li>What are you taking away from this talk? I know it's been a tough one to have.</li> <li>I wish things were different. I wish we had something that could instantly fix this.</li> <li>I really hope we can achieve good control of your symptoms quickly.</li> <li>I worry this may be a longer journey than you were expecting.</li> </ul>
Complex treatment decisions	<p>REMAP</p> <ul style="list-style-type: none"> <li>Reframe</li> <li>Expect emotion</li> <li>Map the future</li> <li>Align with patient's values</li> <li>Plan treatments that match patient values</li> </ul>	<ul style="list-style-type: none"> <li>If it is okay, I would like to talk about what may come next if the current approach is not as effective as we hope.</li> <li>When you look to the future, what are you most hopeful for? ... Worried about?</li> <li>It would help me care for you better if you share what is most important to you. What are the things you hope to get back to? What would you be willing to do to get there?</li> <li>Based on what I'm hearing is important to you, I think we should consider combining both medical and surgical treatments.</li> </ul>
Responding explicitly to emotion	<p>NURSE</p> <ul style="list-style-type: none"> <li>Naming</li> <li>Understanding</li> <li>Respecting</li> <li>Supporting</li> <li>Exploring</li> </ul>	<ul style="list-style-type: none"> <li>You seem surprised. I can see that hearing this information was upsetting/frustrating.</li> <li>It sounds like you are concerned about this. Could we talk more about that?</li> <li>What you just said really helps me understand your perspective better.</li> <li>I want to acknowledge the strength you have shown living with this.</li> <li>We will take this one step at a time.</li> <li>Tell me more about how you're feeling after hearing that.</li> </ul>

See the following websites for additional information: <https://www.vitaltalk.org/guides/discussing-prognosis/>; <https://www.vitaltalk.org/guides/transitionsgoals-of-care/>; <https://www.vitaltalk.org/guides/responding-to-emotion-respecting/>.

of serious illness have been shown to improve patient/caregiver satisfaction,<sup>2</sup> and incorporating specific communication strategies such as setting an agenda and listening actively does not actually require more time.<sup>3</sup> Clinicians may further enhance their primary palliative care communication skillsets through available educational resources ([www.vitaltalk.org](http://www.vitaltalk.org)).

Eliciting and addressing burdensome physical symptoms is paramount to improving QOL and functional status. Routine use of validated instruments can improve identification of distressing symptoms. In time-constrained clinic visits, the HS patient global assessment is a useful one-question tool to assess the impact of HS on QOL over time.<sup>5</sup> Pain and itch can be assessed every visit using a numeric rating scale.<sup>1</sup> Other symptoms to assess include drainage, odor, and fatigue.<sup>1</sup> Pain should be managed using nonpharmacologic, pharmacologic, and complementary modalities.<sup>6</sup> Pharmacologic management of pain in HS should target nociceptive and/or neuropathic pain, and prioritize opioid-sparing strategies.<sup>6</sup> Consider early collaboration with primary care and other relevant specialties (pain management, wound care, and integrative medicine care).

Patients with HS should be screened for psychological distress and connected to specialist mental health care when appropriate. Given the loss of control, dignity, and identity that often stems from HS disease burden, it is understandable why this population has increased rates of depression, anxiety, and suicide.<sup>7</sup> Unrecognized psychological suffering may contribute to and exacerbate physical pain and affect response to disease-directed treatment.<sup>8</sup> Patients can either be screened with tools such as the patient health questionnaire (PHQ)-2, PHQ-9

for depression and the General Anxiety Disorder (GAD)-7 for anxiety, or referred to primary care for screening.<sup>9</sup> Empathic acknowledgment of distress may help patients feel supported. Equally important to the clinician's identification of psychological distress is the timely referral to specialist mental health services.

It is critical to recognize the impact of social factors in the care of patients with HS, as well as on their intimate partners or caregivers. Stigmatization may foster isolation, and psychological and physical distress contribute to sexual health dysfunction and higher rates of disability and absenteeism.<sup>1</sup> HS is associated with low socioeconomic status, which may impact patients' resources and access to recommended care. Patients, partners, and caregivers may benefit from connection to HS support groups and organizations, social workers and care coordinators, and other community, spiritual, and cultural organizations to help address psychosocial burdens and barriers to care.<sup>10</sup>

Dermatologists should facilitate comprehensive interdisciplinary care coordination.<sup>9</sup> HS-associated symptoms and comorbidities contribute to complexity of care.<sup>1</sup> As the principal HS providers,<sup>11</sup> dermatologists play a vital role in assessing patient needs and proactively coordinating care across disciplines, including nonphysician colleagues such as social workers, wound care specialists, dietitians, and therapists. Regular meetings discussing patient care from the perspective of each discipline can foster more holistic and coordinated care.

While dermatologists should feel empowered to integrate elements of these palliative care domains into routine HS care, there may be certain clinical scenarios that would prompt referral to

specialist-level palliative care. Although no formal guidelines exist, patients who may benefit from outpatient, or rarely inpatient, palliative care specialist collaboration include those with refractory HS and superimposed challenging psychosocial dynamics and symptom burden limiting effective communication, decision-making, and delivery of care. Referral to palliative care may be introduced to patients and families as an additional layer of support.

Through integration of several palliative care domains, including the use of frameworks in serious illness communication, acknowledging and addressing physical and psychosocial suffering, and engaging in collaborative care coordination, dermatologists can practice primary palliative care to potentially improve QOL for both women and men with HS and their families. Further research exploring the integration and impact of primary palliative care in HS is greatly needed, including assessing the impact of incorporating palliative care principles on patient QOL and satisfaction with care.

### Conflicts of interest

JLH is on the Board of Directors for the Hidradenitis Suppurativa Foundation (HSF), has served as a consultant for Boehringer Ingelheim, Novartis, and UCB, and has served as a consultant and speaker for AbbVie. VYS is on the board of directors for the HSF, is a stock shareholder of Learn Health and has served as an advisory board member, investigator, speaker, and/or received research funding from Sanofi Genzyme, Regeneron, AbbVie, Eli Lilly, Novartis, SUN Pharma, LEO Pharma, Pfizer, Incyte, Boehringer Ingelheim, Aristeia Therapeutics, Menlo Therapeutics, Dermira, Burt's Bees, Galderma, Kiniksa, UCB, TARGET-Pharmasolutions, Altus Lab, MYOR, Polyfin, GpSkin, Skin Actives Scientific, WebMD, and Alumis. There was no financial transaction for the preparation of this manuscript. All other authors report no conflicts of interest.

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TS and MZ: Participated in writing, review, and editing of manuscript. DK, DRD, JS, and VYS: Participated in review and

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### Study approval

N/A

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### References

1. Sabat R, Jemec GBE, Matusiak L, Kimball AB, Prens E, Wolk K. Hidradenitis suppurativa. *Nat Rev Dis Primers* 2020;6:1–20.
2. Kelley AS, Morrison RS. Palliative care for the seriously ill. *N Engl J Med* 2015;373:747–755.
3. Dugdale DC, Epstein R, Pantilat SZ. Time and the patient-physician relationship. *J Gen Intern Med* 1999;14(Suppl 1):S34–S40.
4. Back A, Arnold RM, Tulsy J. Mastering Communication With Seriously Ill Patients: Balancing Honesty With Empathy and Hope. Cambridge: Cambridge University Press; 2010.
5. Kirby JS, Hereford B, Thorlacius L, et al. Validation of global item for assessing impact on quality of life of patients with hidradenitis suppurativa. *Br J Dermatol* 2021;184:681–687.
6. Savage KT, Singh V, Patel ZS, et al. Pain management in hidradenitis suppurativa and a proposed treatment algorithm. *J Am Acad Dermatol* 2021;85:187–199.
7. Wright S, Strunk A, Garg A. New-onset depression among children, adolescents, and adults with hidradenitis suppurativa. *J Am Acad Dermatol* 2020;83:1360–1366.
8. Riordan P, Briscoe J, Kamal AH, Jones CA, Webb JA. Top ten tips palliative care clinicians should know about mental health and serious illness. *J Palliat Med* 2018;21:1171–1176.
9. Garg A, Malviya N, Strunk A, et al. Comorbidity screening in hidradenitis suppurativa: evidence-based recommendations from the US and Canadian Hidradenitis Suppurativa Foundations. *J Am Acad Dermatol* 2022;86:1092–1101.
10. Butt M, Cotton C, Kirby JS. Support group utilization and impact for patients with hidradenitis suppurativa. *J Am Acad Dermatol* 2020;83:216–219.
11. Garg A, Neuren E, Cha D, et al. Evaluating patients' unmet needs in hidradenitis suppurativa: results from the Global Survey Of Impact and Healthcare Needs (VOICE) Project. *J Am Acad Dermatol* 2020;82:366–376.