A qualitative study of dermatology patients and providers to understand discordant perceptions of symptom burden and disease severity

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Background: Patients often present with symptoms that are disproportionate to the observed disease state, and grade disease severity differently from healthcare providers (HPs). This discordant symptom burden and severity grading (DSG) results in poorer patient care. Current research on DSG is limited, relying on structured models that are theoretically incomplete.

Objective: To fully understand the factors driving DSG.

Methods: Qualitative study of dermatology patients and HPs. Interview data were analyzed using grounded theory to derive a model of the causes of DSG.

Results: Eighteen patients and 12 HPs were interviewed. Results reflect a tendency for patients to grade their conditions more severely than HPs. Factors driving DSG are related to emotional and cognitive disparities in the constructs used to grade severity, varying consequences of disease due to differing resilience and coping methods, socio-psychological factors influencing how patients report their symptoms, and the context of the consult.

Conclusion: A better understanding of DSG is required for achieving mutual understanding and patient-centered collaborative care. It is easy to label a patient with high symptom burden as having a low threshold for discomfort, or for a patient to presume that the doctor is unempathetic. This study suggests the causes of DSG are nuanced and multifactorial.

Introduction

The degree to which patient-centered care improves patient satisfaction and quality of life (QoL) (1–3) depends on the patient’s honest disclosure of information, confidence in fully expressing disease burden, and the physician’s willingness to personalize treatment plans in response (4–6). Collaborative care thus relies on patients’ and physicians’ concurrence of symptom burden and disease severity.

The difference between patient and physician graded severity is known as discordance in patients’ and physicians’ rating (7), patient-physician discordance (8,9), and concordance between caregiver-reported and physician-rated ratings (10). In this paper, we use the term discordant severity grading (DSG) to describe the concept of discordance in symptom severity assessment between patient and healthcare provider. Previous studies have found a significant degree of DSG ranging from 22 to 43% with an overall low agreement in symptom burden and disease severity (7–16). This phenomenon is generally due to a tendency for patients to grade their disease more severely than physicians (8,9,11–14) although some studies show the converse is also true (7,12,16). The reasons are multifactorial and complex. Quantitative studies have found demographic and personality factors associated with patients over-graduating their severity, including female gender (14), education level (11,14), concurrent psychiatric disorders (8,9,11,13), and poorer QoL (12,14).

Critically, discordance was associated with patient dissatisfaction (17) and poorer subsequent QoL. (13,15). However, past studies using quantitative approaches are limited by predetermined theories of discordance and unable to explain complex and interrelated constructs. This limit can result in inappropriately attributing variations in symptom reporting to certain demographic factors. This may result in suboptimal care, for example in the undertreatment of pain in patients of color (18–20). In this study, we employ grounded theory to allow the data to tell us the reasons for and relationships between the factors contributing to the DSG phenomenon.

Materials and methods

Sample and data

Thirty-one participants comprising 19 dermatology patients from the National University Hospital, and 12 dermatology healthcare providers (HPs) across Singapore were approached between January to June 2020 (Table 1). One patient declined participation, and thus 30 participants were recruited. Twenty interviews were conducted in person while 10 were held over video conferencing due to COVID-19 social distancing measures. Two patient interviews were conducted in Mandarin and the rest in English. The mean interview duration was 23.2 min (SD 10.2 min).
Patient inclusion criteria included being aged 18 years or above, ability to communicate in English or Mandarin, and being on follow-up for a chronic dermatological condition. HP inclusion criteria included being a doctor or nurse whose primary service was to dermatological patients. Informed consent was taken for all participants. The study was approved by the hospital institutional review board.

Disease severity was independently reported on a 1–10 scale, with 10 being the most severe. Physician rating was performed by the consulting dermatologist or the study team based upon EMR data using pre-established standardized criteria (Table 1 footnotes). The difference in patient-HP disease severity scores measures the degree of discordance. In-depth interviews were conducted using a semi-structured interview guide. The audio recordings were transcribed verbatim for textual analysis. The interviews explored variations in symptoms experienced, coping strategies, factors influencing perceived severity, and efforts to mitigate DSG. Questions were aimed at exploring the differing perceptions between patients and HPs. Although the literature was consulted, the initial interview guide was less structured (Supplementary File 1), allowing for spontaneity in inquiry. After each round of interviews, refinements and further questions were added to the interview guide to explore themes evolving from the accumulated data (Supplementary File 2). Field observations of the consultations were conducted when possible. All interviewers (E.C., F.Y., and L.T.) were trained in gathering qualitative information.

Data collection was performed through recursive induction. After each round of six interviews, the research team reviewed, reconciled, and coded the raw data into themes. Disagreements were resolved by consensus. The interview guide was further developed to reflect team learning. A new set of participants was then recruited through purposive sampling by focusing on demographics, disease characteristics, and symptom burden so the sample included a spectrum of patients with and without DSG. This iterative process of data collection, analysis, and

Table 1. Demographics and characteristics of patients and healthcare professionals (HP).

| Patient demographics (n = 18)                      | Mean = 44.8 (SD 18.4) |
|---------------------------------------------------|------------------------|
| Age (years)                                       |                        |
| Gender                                            |                        |
| Male                                              | 14                     |
| Female                                            | 4                      |
| Race                                              |                        |
| Chinese                                           | 13                     |
| Indian                                            | 2                      |
| Caucasian                                         | 2                      |
| Other                                             | 1                      |
| Education level                                   |                        |
| Primary                                           | 1                      |
| Secondary                                         | 5                      |
| High school/Junior college                       | 5                      |
| University undergraduate                          | 6                      |
| Post-graduate                                     | 1                      |
| Disease condition                                 |                        |
| Eczema                                            | 6                      |
| Psoriasis                                         | 6                      |
| Vitiligo                                          | 2                      |
| Others (acne vulgaris, chronic urticaria, pityriasis lichenoides, drug hypersensitivity syndrome) | 4                      |
| Duration of disease (years)                       | Median = 8.5 (range 0.5–60) |
| Duration of interview (min)                       | Mean 22.6 (SD 9.62)    |
| Language interview conducted in                   |                        |
| English                                           | 16                     |
| Chinese                                           | 2                      |
| Patient graded severity (from 0 to 10, 10 being most severe) | Mean 6.4 (SD 1.69) |
| Physician graded severity (from 0 to 10, 10 being most severe) | Mean 5.6 (SD 2.28) |
| Number with exact concordance of graded severity  | 3                      |
| Number with patient graded severity higher than physician | 10                    |
| Number with patient graded severity lower than physician | 5                      |
| Healthcare professional demographics (n = 12)      |                        |
| Age                                               | Mean = 35.1 (SD 8.16)  |
| Gender                                            |                        |
| Male                                              | 7                      |
| Female                                            | 5                      |
| Professional role                                 |                        |
| Nurse                                             | 3                      |
| Resident/fellow                                   | 5                      |
| Consultant                                        | 3                      |
| Years of professional service                     | Mean = 9.46 (SD 6.07)  |
| Duration of interview (min)                       | Mean = 24.1 (SD 11.3)  |
| Language interview conducted in                   |                        |
| English                                           | 12                     |

*Footnotes: For consistency of grading across disease types, physician graded severity was arbitrarily defined as follows:

0–2: minimal/well-controlled disease on no treatment/topical treatment.

3–5: moderate disease on topical treatment or minimal/well-controlled disease on phototherapy.

6–8: moderate/poorly controlled disease on phototherapy or minimal/well-controlled disease on systemic/biologic therapy.

9–10: poorly controlled disease on systemics, generalized erythroderma or recent life/organ threatening complications from skin disease.
further data collection was repeated until theoretical saturation was reached, defined as the stage when no new themes were identified.

**Data analysis**

Data analysis followed the grounded theory techniques described by Charmaz (21). Descriptive open coding was first performed using line-by-line and incident coding independently by two coder pairs (E.C. and F.Y., and E.C. and L.T.). This was followed by axial coding where the codes were compared and related to each other through analytic induction as more data were collected and analyzed. First level themes from patient’s reported experiences and HP’s observations were triangulated. First-level themes were subsequently categorized into higher-ordered themes, performed independently by E.C and F.Y yielding similar findings. Representative quotations supporting these themes are reported briefly in Table 2 and comprehensively in Supplementary Files 3, 4. These were then used to construct the DSG framework (Figure 1), which was initially performed independently by E.C and L.T., and thereafter endorsed by the research team after extensive discussions and refinement. The framework was presented to a random selection of interviewees to assess the face validity of the model and to streamline for theoretical parsimony. This step ensured that the conclusions were faithful to the data. Further refinement of the model was made, and the final themes and relationships were reviewed and agreed upon by all authors with no major disagreement. Analysis was performed in ATLAS.ti 8.0 (22). The study was designed and reported following the COREQ reporting guideline for qualitative studies.

**Trustworthiness**

The diligent writing of memos and reflexive documentation were emphasized to guard against preconceived notions and biases. Although a comprehensive literature review was conducted to understand the state of knowledge, subsequent coding of the data did not refer to the literature for theme development. The researchers maintained a high level of sensitivity to their role as co-constructors of meaning and coding was performed independently by multiple coders to mitigate observational and analytical bias. Finally, the resulting framework was shown to four participants to ensure hermeneutic reliability (23).

**Results**

Patient and HP characteristics are described in Table 1. Of 18 patient-dermatologist severity gradings, three were concordant, 10 had patient graded severity higher, and five had patient graded severity lower than their dermatologists. Eleven of 12 HPs reported that when a discordance existed, patients were more likely to grade their conditions more severely.

![Figure 1](image-url)

**Figure 1.** Framework for understanding discordant symptom burden and severity grading (DSG).
The data structure suggested that DSG is related to the consequences of the disease, patient resilience and coping, symptom reporting, factors used to grade disease severity, the context of the consult, and selection bias of patients who present to dermatology (Table 2).

Consequences of disease
This refers to the physical, emotional, and functional impact of the skin disease. The itch was repeatedly mentioned and described as ‘uncontrollable,’ while some patients expressed fear of stigmatization from the outward appearance of their skin. Others experienced functional limitations that were related to activity level or occupation: 63-year-old male with psoriasis, ‘I went to see the doctor and the doctor said, “you try to drop this job.”’ DSG results when the symptoms, such as itch, depression, or functional impairment are not immediately visible or valued by the HP. What may seem like a simple solution, of switching jobs, to the doctor, may actually be a disruptive change to the patient’s lifestyle or economic security.

Resilience and coping
This construct refers to how patients identify with their disease and manage the symptoms. It consists of the categories: mindset, self-efficacy, personality, knowledge of the disease, reserves of capital, coping strategies, and expectations of treatment outcomes.

For example, patients with a lower symptom burden were observed to have a mindset reflecting greater acceptance of the disease and its chronic nature: a 42-year-old male with psoriasis who graded his severity 6/10 while the physician graded 9/10, ‘I can’t control the skin much…. So, whatever happens to the skin, it happens.’ Self-efficacy was reflected through active problem-solving behavior including reading up on their condition, searching for and improvising alternate solutions.

Participants overwhelmingly suggested personality traits, such as anxiety and self-consciousness contributed to the over-grading of severity, while stoicism was associated with under-grading: 30-year-old doctor, ‘[Those] who have anxiety tend to experience a lot more symptoms from the disease.’ Poor knowledge and understanding of the cause and chronicity of disease were also cited as associated with increased helplessness and greater symptom burden.

The concept of reserves of capital refers to the patient’s financial, physical, and emotional reserves that enable them to cope with a chronic skin disease. The presence of competing stressors in life, such as medical comorbidities and financial difficulties can deplete these reserves and increase symptom burden: 29-year-old doctor, ‘When the patient has multiple comorbidities, they seem to cope more poorly.’

Patients had few answers when asked about their coping strategies. Most cited compliance with treatment as a coping mechanism even though 64% (9/14) commented that treatment was not always helpful. Patients with lower symptom burden also demonstrated coping techniques, such as emotional reappraisal: 61-year-old female with psoriasis, ‘Everybody has something…don’t let this be the one that’s going to define you.’ Many patients expressed optimism for ‘complete remission.’ Relatedly, unrealistic expectations for a cure were mentioned by HPs as a source of frustration: 26-year-old nurse, ‘They want a cure…to see instant results that may not be possible.’

Symptom reporting
Underlying motives may influence the degree of symptoms expressed. Subconscious motives for over-reporting include the desire to be taken more seriously, to receive sympathy, or to vent their emotions: 21-year-old nurse, ‘I think they just want to vent…. We might be the best outlet for them to vent all their frustrations.’ Conscious motives were cited as being less common but included forms of malingering to obtain medical exemptions.

The ability to communicate, self-consciousness, and motives for reporting affected the way patients reported their symptoms. For example, self-consciousness and embarrassment may drive patients to trivialize their condition: 23-year-old male with chronic spontaneous urticaria, ‘Some people tend to minimize their symptoms …because they are embarrassed about it.’

Conversely, patients may under-report to ‘avoid a certain treatment’ or ‘avoid burdening their family’: 34-year-old doctor, ‘There’s…an emotional burden, not to cast their burden onto loved ones, so much so that they escape from their symptomatology.’

Factors used to grade the severity
The data suggest that disparities in the grading of severity are driven by differences in diagnostic criteria, social comparison, and disease cyclicity.

A patient’s assessment of severity grading encompassed physical, psychological, and functional aspects of the disease. In contrast, HPs almost exclusively graded severity based on objective criteria, such as body surface area: 38-year-old doctor, ‘So it would be better….if you have a flare….you just take a picture because dermatology is more of a visual diagnosis rather than just listening to the symptoms.’ A 42-year-old doctor, ‘When we score patients, all these things are supposed to be objective …we don’t put the subjective thing in there.’ This difference in criterion used to grade severity is a crucial factor contributing to DSG.

In addition, there is often a difference due to social comparison, wherein patients compare their conditions to people they know, or their previously healthy skin, while HPs compare to groups of other patients that may present with more severe disease, contributing to DSG.

The fluctuating and cyclical nature of many skin diseases may cause the HP to underestimate severity when the disease is quiescent during the consultation: 23-year-old male with chronic spontaneous urticaria, ‘How do I tell the doctor that it’s been quite bad when in the daytime it is actually okay but….at night….it’s very bad?’

Context of the consult
This construct refers to the contextual factors driving the patient-HP consult, including interpersonal rapport, past experiences, HP empathy, mutual strategies to reduce discordance, and practical considerations, such as consult time.

The rapport between patient and HP influences the openness of patients toward reporting symptoms: 42-year-old doctor, ‘Some patients might not dare to say something, but…if you
Table 2. Themes and representative quotations explaining reasons for discordant symptom burden and severity grading (DSG).

| Theme                                      | Patient                                                                                       | Healthcare provider (HP)                                                                 |
|--------------------------------------------|------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| Consequences of disease                   | 'When it [the itch] comes it's hard to control. Sometimes I don't touch it, then it's itchy, then it is very hard not to touch, then I need to scratch.' | 'A lot of skin disease causes itch and it can be very difficult to treat.'                 |
| Physical consequence                       | 'It is kind of difficult to be happy or to be normal especially when it [psoriasis] starts to flare up.' | 'For example patients with predominant genital psoriasis; so objectively on the last visit they graded him quite mildly but he might be very bothered by it for various psychosocial reasons.' |
| Emotional consequences                     | 'I went to see the doctor and the doctor said, try to drop this job.'                         | 'So taking the skin condition in the context of function and work is very important. So what may seem not very important to us may be very very important to patients.' |
| Functional consequence                     | 'I keep wondering to myself, why doesn't this condition care, no matter what I do, what medications I take.' | 'I have come across patients who seem not bothered by their skin at all. They would say, oh I lived with it for so long, and it's just a part of their life. I think they just move on.' |
| Resilience and coping                       | 'You need people who support you, to encourage you, to tell you that it can eventually recover.' | 'When you teach them how to self-monitor and take photographs and monitor, I think that's an example of healthy coping.' |
| Mindset                                     | 'I'm a very positive person, I try to be. I'm pretty upbeat, I don't let things knock me down.' | 'Because the patient is very anxious, sometimes even a single nail onychodystrophy, they can come to the clinic for like many many years.' |
| Self-efficacy                               | 'I wish I can have complete remission.'                                                      | 'I find that when patients can understand the disease, the nature of the disease, the chronicity of the disease and how the aim of treatment is at control and not at cure, they seem to do better because they have more realistic expectations of their condition.' |
| Personality                                 | 'I'm supposed to put [creams] on my back, and I don't have anybody. So I'm going to have to improvise somehow, make a long stick or something.' | 'When the patient has multiple comorbidities, they seem to cope more poorly when there's an additional dermatosis on top.' |
| Knowledge of disease                        | 'I think if I took care of it properly, it would be much easier to stop … but I did not really try my best to stop it.' | 'When patients who are able to understand what we have educated them about, internalize it and then learn to weigh the severity, the waxing and waning of their disease, I think that's also healthy coping.' |
| Reserves of capital                         | 'You need people who support you, to encourage you, to tell you that it can eventually recover.' | 'Some patients who have multiple comorbidities, they seem to cope more poorly when there's an additional dermatosis on top.' |
| Coping strategies                           | 'I just listen to the doctor's instruction and I apply moisturizer and apply steroid.'       | 'When patients who are able to understand what we have educated them about, internalize it and then learn to weigh the severity, the waxing and waning of their disease, I think that's also healthy coping.' |
| Expectation of treatment outcomes          | 'I wish I can have complete remission.'                                                      | 'When the patient has multiple comorbidities, they seem to cope more poorly when there's an additional dermatosis on top.' |
| Symptom reporting                           | 'A caregiver brings them and they're not very involved in their care, then they may feel like it's an unnecessary issue.' | 'But it's just that sometimes they don't know how to describe.' |
| Ability to communicate                      | 'Some people tend to minimize their symptoms, especially like my grandparents … because they are embarrassed about it they may not say that it is as bad as it is.' | 'Sometimes there is a cultural or social conditioning, like man are more stoic.' |
| Self-consciousness                         | 'I tell the doctor everything as I feel everybody needs to know.'                         | 'Sometimes they feel if they over-report they will be taken more seriously and maybe get better, stronger medications.' |
| Underlying motives                          | 'This is one of those conditions where it almost like psychiatry where it's a lot more about the impact on daily function and activities rather than the disease itself' | 'When we score patients, all these things are supposed to be objective … the BSA is our assessment and we don't put the subjective thing in there.' |
| Factors used to grade severity             | 'Among the people that I know, I think, they mention that my are way worse than theirs.'       | 'Our clinical grading is meant to be objective and we have compared it to every other patient that we've seen. The patient can only compare it to themselves.' |
| Diagnostic criteria                         | 'How do I tell the doctor that it's been quite bad when in the daytime it is actually okay but it's at night that it's very bad?' | 'Quite often patients do report significant symptom burden at night at times where the urticaria flares but we don't see any.' |
| Social comparison                          | 'Some really go [the] extra mile to understand the patient.'                               | 'It [symptoms experienced vs. reported] correlates better when the physicians have better rapport with the patients.' |
| Disease cyclicity                           | 'It [symptoms experienced vs. reported] correlates better when the physicians have better rapport with the patients.' | 'It also boils down to their past experiences, their own personal emotions and own demons and struggles that they have.' |
| Context of the consult                      | 'This is one of those conditions where it almost like psychiatry where it's a lot more about the impact on daily function and activities rather than the disease itself' | 'So because we have all experienced pain, itch and whatsoever, we perceive it as just that, we think that their itch is just the itch that we have when we have a mosquito bite.' |
| Interpersonal rapport                       | 'Some really go [the] extra mile to understand the patient.'                               | 'I would probe further about their coping mechanism and also the social support.' |
| Past experiences                            | 'This is one of those conditions where it almost like psychiatry where it's a lot more about the impact on daily function and activities rather than the disease itself' | 'We are often limited by the time, so unfortunately this investigating and managing social aspects of treatment is not practical.' |
| Empathy                                     | 'It is kind of difficult to be happy or to be normal especially when it [psoriasis] starts to flare up.' | 'It is kind of difficult to be happy or to be normal especially when it [psoriasis] starts to flare up.' |
| Strategies to reduce discordance            | 'It would be great if doctors can … put themselves in their patient's shoes … instead of throwing like generic textbook treatment options.' | 'We are often limited by the time, so unfortunately this investigating and managing social aspects of treatment is not practical.' |
| Practical considerations                    | 'Occasionally when the doctors are very busy, they tend to prescribe a lot of things which I have to judge myself whether I need it or not.' | 'We are often limited by the time, so unfortunately this investigating and managing social aspects of treatment is not practical.' |
| Selection bias from patients who present to dermatological clinics | 'They may not even go to a doctor, saying: it's just a rash.' | 'Definitely in dermatology I think most patients tend to be of the anxious subtype, and it's also a bit self-selecting.' |
appear approachable ... they do open up.’ Past interactions or prior treatments also influence the patient’s current behaviors. The degree of empathy among HPs is also variable: 54-year-old doctor, ’To the patients, their diseases are 100% ... it’s very easy to forget that if we have a patch of something on our face we are going to be really bothered.’ Interestingly, some patients also expressed empathy toward their HPs: 42-year-old male with psoriasis, ’[HPs] are limited to what they can do actually. I understand. So, it’s okay.’

Strategies to reduce DSG include exploring non-medical solutions, reducing the knowledge gap, and referring patients to allied health professionals (Supplementary Table 2). Many HPs also mentioned moderating treatment expectations to reduce DSG but were quick to note that such approaches require caution: 29-year-old doctor, ’The brutality of ... something being incurable, maybe a tough pill to swallow .... Some patients may equate incurable as ... the doctor [saying] there is nothing we can do.’ Reframing the patient’s mindset by comparing themselves with others suffering from more severe disease also requires tact: A 42-year-old doctor, ’There’s no use comparing when a patient is in distress ... But when they see it [other patients with worse severity] themselves, then that’s when it’s different.’

The sense of helplessness or frustration was expressed by HPs: 30-year-old doctor, ’We [are] also very helpless ... [with] nothing to offer them [patients with high symptom burden].’ HPs may attempt to ‘change the medication’ or ‘cycle treatment’ as a solution, however, this itself does not address many of the causes of DSG: 34-year-old doctor, ’When you cycle treatment and say this has failed, that has failed, and you keep going up [escalating treatment], that is the easiest thing to do.’

Finally, time was a common limiting factor: 31-year-old doctor, ’I’m guilty of that [not listening enough] .... I’ll lead the consult quite a bit so that we can all reach our aim quite quickly.’ This could mean that doctors were not always able to listen as carefully to their patients as they may have preferred.

**Selection bias from patients who present to dermatological clinics**

The HP interviews suggest a possible selection bias in who they see, as patients who tend to under-grade their severity are more likely to be managed in a primary care setting, or not see, as patients who tend to under-grade their severity are more likely to be managed in a primary care setting, or not.

**Framework for explaining DSG**

Figure 1 summarizes our findings in a framework. Discordance starts when the same objective disease may have different physical, emotional, and functional consequences for a patient. These are moderated by the patient’s resilience and coping abilities, such as their mindset and reserves of capital. Factors as the ability to communicate, self-consciousness, and underlying motives subsequently influence the reporting of symptoms to HPs. Concurrently, patients and HPs have disparate cognitive and experiential perspectives of disease, with differences in constructs used to grade severity (e.g. weights given to objective and subjective criteria). Finally, the context of the consult is shaped by such factors as rapport, empathy, and time constraints.

**Discussion**

Overall, it may be tempting for a physician to attribute a patient’s reported high symptom burden to anxiety or low threshold for discomfort, or for a patient to presume that the doctor is uncaring. Our data suggest that DSG is a complex phenomenon with many causes. Our framework suggests areas that can be targeted for reducing DSG.

The first pertains to HP’s predominant emphasis on objective assessments of disease. Medical education trains doctors to diagnose, prescribe evidence-based treatment, and employ communication protocols (e.g. SPIKES (24)) when breaking bad news or delivering unfavorable information. The lack of confidence and comfort in identifying and addressing the psychosocial aspects of disease may result in HPs falling back on the familiar biomedical predicates of the disease (25), such as the focus on prescriptive therapeutics.

DSG also arises from patient-HP differences in perspective, outcome expectations, and the grading of severity relative to different comparison groups. As such, it follows that reframing the patient’s mindset and realigning treatment goals may help to reduce DSG. However, our data show that such attempts to shift and correct the patient’s views may result in the HP being perceived as unempathetic. This affirms the importance of a multi-pronged approach including individualized treatment plans (26,27), patient education (28,29), HP training (30,31), empathy (6,26,29,32,33) tacit communicative (1,34), and continuity of care (35–37) in achieving patient-centered care to improve satisfaction (3,38–40). The data also suggest that these approaches need to be conjoint. Although longer consults are resource-intensive in the short term, there is value in closing the DSG gap early because future encounters may be more productive and time-efficient in the long term when patients become their own cheerleaders as a result.

The strength of qualitative studies lies in the acquisition of rich and deep information, with recommended sample sizes ranging from 20 to 30 participants for grounded theory (41,42). Interviews with patients gave us person-specific experiential information, while interviews with HPs helped us understand the cohort-specific factors contributing to DSG. The two levels of analysis (person and group) provided complementary data for a comprehensive and nuanced view of the phenomenon. This allowed us to explore themes and constructs that cannot be obtained through structured questionnaires. The caveat of grounded theory is the assumption that informants accurately report the phenomenon. To address this limitation, we used iterative interviewing to reveal contradictions and similarities in the accounts. While we recruited a diverse group of patients (demographics, disease type, and severity) and healthcare professionals (age, profession, years of experience) to ensure that the results generalize to various dermatological settings, the derived themes are contextually situated (43,44). Cultural norms shape behavior (45–48), perceptions of pain, and social stigmatization (45–48), and although we believe this framework is ultimately generalizable, the specific ways the factors interact, and their relative importance could be unique to the present study. For example, while previous studies have shown that patients of color tended to be under-treated for pain (18–20), our data did not reveal any systematic differences in DSG discordance. But this is a qualitative study, and so we cannot be sure if racial factors may be present in the phenomenon, especially given that, as previously noted, patient self-selection for
the initial consult may bias our study sample to those with greater symptom burden, disease severity, or willingness to share their experiences.

Finally, addressing DSG would first require a greater awareness of this concept and an improved ability to detect DSG in clinical practice. Interventions based on aspects of the framework, such as creating a shared standard of reference for disease severity, eliciting underlying motives for symptom reporting, and developing a treatment plan that focuses on more than just the subjective disease state may help to reduce DSG. We are currently embarking on further research to assess the prevalence of DSG, operationalize our concepts into measurable constructs and quantify the relative importance of these contributory factors. This would allow us to objectively measure the effectiveness of subsequent interventions.

Conclusions

DSG is a major cause for concern in dermatology as many skin conditions are chronic and are associated with emotional and functional impairment that can easily be trivialized. Our research provides insight into the contributing factors, an important first step toward achieving mutual respect, shared understanding, and collaborative patient-centered care.

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Disclosure statement

There are no financial or personal conflicts of interest to declare.

Ethical approval

The study was approved by the hospital institutional review board (DSRB Reference: 2019/00880).

Author contributions

EC designed, implemented the study, and wrote the first draft. EC, LT, and FY conducted the interviews and coded the data. PP, EC, LT, and FY interpreted the data and wrote subsequent drafts. All approved the manuscript for submission.

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Data availability statement

Deidentified datasets are available from the corresponding author upon reasonable request.

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