*Research Article*

# More Than Meets the Eye: A Qualitative Exploration of the Experience of Remission in Chronic Skin Disease

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## Abstract

This study explores the lived experience of remission in chronic skin disease (CSD), a clinically significant but underexamined phase of the chronic relapse–remission cycle. Although the psychological burden of active CSD is well established, far less is known about how individuals experience periods of skin improvement or clearance. Using interpretative phenomenological analysis, semi-structured interviews were conducted with six participants previously discharged from a London-based National Health Service (NHS) psychodermatology service. Four themes were developed: (1) *More than meets the eye* captured a dissonance between physical and psychological recovery, with ongoing shame, vulnerability, and treatment burden despite visible improvement. (2) *A wordless experience* reflected the difficulty of accessing, naming, and retaining remission experiences, in contrast to vivid accounts of flare-ups. (3) *All-consuming: overwhelmed by fear and powerlessness* described remission as marked by sustained vigilance, anticipation of relapse, and vulnerability to withdrawal of care; within this, the study introduces the concept of 'Relapse Anxiety' to capture the persistent expectation of symptom recurrence. (4) *Unsolvable dilemmas of remission* captured treatment-related harms, attempts to regain agency, and harsh self-judgements surrounding the pursuit of relief. Remission was not experienced as a straightforward endpoint of recovery but as a psychologically active and poorly understood phase of adjustment. Visible improvement coexisted with ongoing distress, identity-level impacts, and treatment burden. Greater conceptual and clinical attention to remission may support more nuanced, patient-centred understandings, with further qualitative research needed to inform measurement and intervention.

## Keywords

qualitative analysis, chronic skin disease, dermatology, interpretative phenomenological analysis, remission

## Introduction

Chronic skin disease (CSD) refers to dermatological conditions characterised by recurrent cycles of relapse and remission, including plaque psoriasis (PS), atopic dermatitis (AD), and acne vulgaris (AC) (Leung & Guttman-Yassky, 2014; Lowes et al., 2014; Silverberg, 2017; Zouboulis, 2014). Although these conditions differ in aetiology and immunopathology, they are commonly grouped under the transdiagnostic umbrella of CSD in both research and dermatology care pathways (e.g., Hong et al., 2008; Richard et al., 2022; Richard et al., 2023; Schofield et al., 2011; Silverberg et al., 2025).

The psychological burden of CSD is well established within psychodermatology. Research has documented elevated rates of depression (Bao et al., 2018), anxiety (Fleming et al., 2017), suicidal ideation (Ra et al., 2020; Singh et al., 2017), poor body image (Khoury et al., 2014), and low self-esteem (Papadopoulos et al., 1999). Despite the chronic, relapsing course of these conditions, research and clinical attention have focused predominantly on active disease. Far less is known about how

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remission is experienced or what remission denotes beyond visible skin improvement.

This gap is notable given longstanding evidence that physical and psychological symptom severity in CSD is only weakly correlated (Fortune et al., 2002; Kokandi, 2010; Law et al., 2010; Walker, 2005), while clinical assessment and treatment outcomes continue to rely heavily on visible severity indices such as the Psoriasis Area and Severity Index (PASI; Fredriksson & Pettersson, 1978) and the Eczema Area and Severity Index (EASI; Hanifin et al., 2001). Despite their widespread use, there is little consensus as to what degree of improvement on these measures constitutes remission (Balak et al., 2022; Silverberg et al., 2020).

The issue is further complicated by persistent misalignment between clinician and patient perspectives on disease burden (Perrott et al., 2000; Talamonti et al., 2021), alongside evidence that CSD-related distress is often under-recognised in practice (Augustin et al., 2022; Dalgard et al., 2018; Sampogna et al., 2003). Self-reported quality-of-life (QoL) measures such as the Dermatology Life Quality Index (DLQI; Finlay & Khan, 1994) have been incorporated to address this, but these instruments have been criticised for limitations in validity, reliability, and sensitivity to psychological burden (Basra et al., 2008; Nijsten, 2012; Pattinson et al., 2021; Twiss et al., 2012). If remission is inferred primarily from physical improvement, how should patients be understood when ongoing psychological or QoL impairment coexists with skin clearance?

Although remission in CSD has not been examined phenomenologically, biologic trial data, where remission is inferred from clinical endpoints, demonstrate that skin clearance and lived recovery are not equivalent. In PS, PASI improvement is strongly associated with DLQI improvement (Mattei et al., 2014; Reich & Mrowietz, 2007), but this relationship is not absolute. In a sample of 365 patients, Nishida and Morita (2025) found that 1.0% ($n$ = 8) of observations with an absolute PASI score of 0, indicating complete skin clearance (Naldi, 2010), were associated with DLQI ≥10, suggesting at least moderate QoL impairment (Hongbo et al., 2005) despite remission. Similarly, pooled analyses of biologic treatment trials found that 74.9% of patients achieving PASI 100 (100% improvement from baseline) achieved DLQI 0/1 at week 12 and 79.7% at week 52, leaving over 20% with residual QoL impact (Elewski et al., 2017). Likewise, pooled analyses of patients with PS found that 8%–17% of PASI 100 responders continued to report DLQI scores greater than 1, suggesting ongoing, albeit low, QoL impairment despite complete clearance relative to baseline disease severity (Blauvelt et al., 2019). Comparable patterns are observed in AD, where substantial EASI responses do not uniformly translate into meaningful QoL improvement (e.g., Simpson et al., 2023).

Existing qualitative research suggests that skin clearance and psychological recovery may unfold differently over time. Studies of biologic treatment suggest that social withdrawal, altered self-perception, and reduced confidence may persist despite clinical improvement (Moschogianis et al., 2025; Narayanan et al., 2014; Trettin et al., 2020). Other research indicates that CSD may become integrated into identity over time, complicating adjustment during periods of improvement (Bundy et al., 2014; Sarkar et al., 2016; Uguz et al., 2008). A case report of depressive adjustment disorder following successful dupilumab treatment similarly raises questions about the psychological impact of rapid, treatment-induced clearance (Ridge et al., 2018). These findings suggest that psychological recovery may not proceed in line with physical improvement, but do not address the experience of remission as a distinct phenomenon.

The experience of remission therefore remains underexamined in both qualitative and quantitative research. As a result, little is known about its psychological dimensions, how individuals make sense of skin clearance, or what support needs may arise during improvement or discharge from care. This study therefore aimed to explore the lived experience of remission in CSD, specifically how individuals experience episodes of partial or complete skin clearance. The guiding research question was: *What is the experience of remission in chronic skin disease?*

## Method

### Counselling Psychology Framework

The study was conducted within a Counselling Psychology framework, which privileges reflexive, relational, and contextual understandings of psychological experience (Strawbridge & Woolfe, 2010). The researchers adopt a humanistic and phenomenological orientation, viewing individuals as experts in their own experience and prioritising collaborative researcher–participant relationships. Counselling Psychology's dual scientist–practitioner identity (Jones Nielsen & Nicholas, 2016) shaped methodological decisions, emphasising holistic and nuanced understandings of patient experience. This stance was also adopted to challenge traditional expert-led models in dermatology.

### Theoretical Foundation

A critical realist ontology underpinned the study, holding that reality exists independently of individual perception while recognising that knowledge of it is socially and contextually mediated (Bhaskar, 2013; Danermark et al., 2019). Positioned between naïve realism and relativism,

critical realism maintains that experiences are shaped by underlying mechanisms, even if these are only partially accessible through interpretation. This ontological position acknowledges both an experiential world and the mediated nature of its interpretation (Fletcher, 2017).

The epistemological stance was phenomenological, grounded in the philosophical tradition of Husserl (1913) and interpretative developments in Heideggerian thought (Heidegger, 1962; Smith et al., 2021), and aimed to capture the richness and "quality and texture" of lived experience (Willig, 2012, p. 11).

## *Methodological Approach: Interpretative Phenomenological Analysis (IPA)*

Interpretative phenomenological analysis (IPA; Smith et al., 2021), rooted in phenomenology, hermeneutics, and idiography, was selected because of its capacity to generate detailed, interpretative accounts of lived experience while explicitly acknowledging researcher subjectivity. IPA's emphasis on individual meaning-making, situated within relational and socio-cultural contexts, closely aligned with the study's aim of exploring how remission is experienced and understood by individuals with CSD. Its commitment to idiographic analysis allowed for careful attention to convergence and divergence across a small sample, while retaining the depth and texture of individual accounts. In foregrounding interpretation as an active, reflexive process, IPA provided a methodologically coherent framework for examining the meanings attributed to skin clearance and for addressing the current empirical gap regarding the experience of remission in CSD.

## *Researcher Reflexivity*

Reflexivity was treated as integral to the analytic process. The primary researcher's clinical background in psychodermatology enhanced contextual sensitivity but also introduced potential preconceptions about the remission experience. For instance, the primary researcher had repeated clinical contact with patients in the psychodermatology service whose physical symptoms had subsided by the time they were referred for therapy yet were still in need of psychological treatment.

Assumptions arising from clinical work were actively examined through a reflexive journal and analytic memoing, alongside regular clinical and academic supervision with the co-authors, focusing on how clinical knowledge may shape interpretation. Peer supervision with doctoral colleagues contributed an independent perspective, enabling external scrutiny of process – for example, the development of the interview guide (Appendix 1) and analytic process. Analytic decisions were documented to support transparency and an audit trail, and interpretations were repeatedly checked against transcripts to ensure themes remained grounded in participants' accounts.

## *Ethical Approval and NHS Collaboration*

Ethical approval was obtained from a UK National Research Ethics Committee (REC), the host university research ethics board, and collaborating NHS Trust. Institutional identifiers have been removed to preserve double anonymity. Recruitment procedures were reviewed and approved through the Integrated Research Application System, including amendments permitting contact via the NHS-NoReply text messaging system.

Participants' informed consent was obtained following screening calls and signed consent forms. Confidentiality was maintained through secure NHS data systems, anonymisation procedures, and participant-selected pseudonyms. Participants were informed of their right to withdraw up to two weeks post-interview. GPs were notified of participation, as recommended by the REC. Distress protocols included screening for capacity and emotional readiness, reminder of voluntary participation, and debrief procedures.

## *Sampling and Participants*

All patients discharged from the specialist psychodermatology service within the previous 5 years were eligible for contact. A total of 169 records were screened; following exclusions (deceased, inaccessible records, or no clinical contact prior to discharge), 149 individuals received a recruitment text via the NHS-NoReply system.

Fifteen individuals expressed interest. Eleven confirmed willingness to participate after reviewing the Participant Information Sheet; the remaining four did not respond. These 11 individuals were listed in order of response date and allocated a random number between 1 and 11 using a random number generator (Calculator.net, n.d.). Those allocated numbers 1–6 were selected to participate. Although 11 participants expressed willingness to participate, a sample of 6 was selected to preserve the depth of idiographic engagement required for IPA and to ensure analytic manageability within a single-researcher doctoral project. All respondents were informed whether they had been selected.

Only discharged patients were eligible to prevent boundary confusion between research and clinical care, as the primary author was working clinically within the service. All participants had experienced CSD and received psychological intervention through the same NHS psychodermatology service, providing the experiential

homogeneity typically sought in IPA (Smith et al., 2021). In IPA, homogeneity refers primarily to a likely shared experiential relationship to the phenomenon of interest (Larkin et al., 2019), rather than strict demographic matching. No further demographic exclusion criteria were applied because the study sought to avoid presupposing which social categories would be most relevant to remission. This does not imply that demographic factors were considered unimportant; rather, they were not used to structure sampling in advance.

While disease duration was not collected as a metric, during the interviews it emerged that participants had suffered with CSD for extended periods (range: several years to multiple decades).

### Sample Size

Six participants were recruited. IPA prioritises idiographic depth over breadth, recommending small, homogeneous samples to enable detailed case-by-case analysis before cross-case synthesis (Smith et al., 2021). Sample sizes between four and ten are typical for doctoral-level IPA research of this kind (Noon, 2018). A sample of six allowed sufficient depth of analysis while retaining analytic manageability.

### Data Collection

Semi-structured interviews were employed to investigate participants' lived experience of remission. Given the study's aim to explore the meanings attributed to partial or complete skin clearance, an approach enabling detailed, participant-led accounts was required. Semi-structured interviewing allows exploration of personally salient aspects or "expressed interests" (Biggerstaff & Thompson, 2008, p. 217) of experience while maintaining coherence around the research question (Smith et al., 2021).

An open-ended interview guide was developed iteratively through academic supervision and peer review within a doctoral research group. Questions were designed to elicit detailed experiential accounts of remission and included prompts such as: "Can you tell me what 'being in remission' means to you?", "Can you tell me about a time when your skin has improved?", and "How did your experience of remission compare to how you expected it to be?" The full interview guide is available as supplementary material (Appendix 1). Interviews were conducted by the primary author, either in person or online, depending on the participant's preference; five were via secure video platform and one in person. Interviews were audio-recorded and averaged 72 min in duration.

### Data Analysis

Interviews were transcribed verbatim and analysed using guidelines proposed by Smith et al. (2021). Analysis began with rigorous immersion in the data through multiple readings and listenings of the interview recordings, fostering familiarity with the narratives and emotional nuance. Detailed reflexive and exploratory notes were systematically made, capturing descriptive, linguistic, reflexive, and conceptual observations within each transcript.

Exploratory notes were then synthesised into concise experiential statements and clustered to form personal experiential themes (PETs) within each participant's account. Cross-case analysis was conducted, consolidating PETs into group experiential themes (GETs) to highlight shared and divergent elements across participants' experiences.

## Findings

Table 1 summarises the GETs and subthemes (STs) generated in the analysis. One participant selected a pseudonym including an initial ('Thomas C'), which has been retained. Across the sample, conditions varied in symptom presentation and patterning (e.g., inflammatory flares, itch, pain, scarring, and periods of partial or

**Table 1.** Group Experiential Themes (GETs) and Subthemes (STs)

| GET 1 | GET 2 | GET 3 | GET 4 |
|---|---|---|---|
| More than meets the eye | A wordless experience | All-consuming: Overwhelmed by fear and powerlessness | Unsolvable dilemmas of remission |
| | | STs | |
| (1) "It's not what you see, it's what inside" | | (1) "Constantly on alert": Ever-present relapse anxiety | (1) The price of relief: "A cure worse than the disease?" |
| (2) Healing but never healed: "I carry it with me" | | (2) Swallowed by the system: "it feels like you're being dismissed" | (2) Surviving powerlessness: Acceptance, action, accountability |

substantial clearance), shaping what could be experienced as remission for each individual.

Participant extracts are presented as spoken. Ellipses ("…") indicate where words have been omitted for brevity while retaining the original meaning. Square brackets indicate clarifications added for readability and "[pause]" reflects a brief pause in speech. Text in bold reflects the authors' emphasis.

## *GET 1: More Than Meets the Eye*

This GET captures a central dissonance running through participants' accounts. Remission was repeatedly described as a phase in which visual improvement could coexist with ongoing psychological distress, bodily discomfort, and a heightened awareness of what could not be seen by others. Participant narratives challenged assumptions that skin improvement necessarily signalled recovery, suggesting instead that remission could be an external change with no equivalent internal shift.

*ST 1: "It's Not What You See, It's What's Inside".* Participants repeatedly positioned the "surface" as an unreliable guide to severity. For Angela, the dramatic appearance of open skin did not correlate with pain and healing could paradoxically feel worse than more extreme looking flares:

> I can have days where my skin would be really open, and it **looks horrific**. But it's **not as painful** because … when you have really deep sores, it's gone past the nerves. When it's on the surface, it's much sorer … and much more painful. (Angela, AD)

Angela's account disrupts a straightforward visual logic of remission by locating suffering in sensation and cutaneous depth rather than appearance. It also points to the interpretive risk of clinical assessments that privilege what can be seen, particularly when remission is implicitly treated as a less significant clinical phase. This theme was echoed in Izzy's explicit appeal to clinicians to attend to internal impacts rather than visible presentation, stating, "They need to listen to what it's doing to people, not what they see. Because **it's not what you see**, **it's what's inside**" (Izzy, AC).

Across accounts, participants described how visible improvement did not necessarily quieten entrenched self-criticism. Izzy reflected on the relief of looking clearer while still feeling psychologically marked when she remarked, "It was lovely to look in the mirror and go, 'Oh yeah … I'm not spotty' … but that **didn't stop the psychological thoughts.** I've still got holes, I'm not good enough" (Izzy, AC). Peter similarly framed remission as requiring a broader lens than surface change. His comments positioned physical treatments as redundant for psychological aspects noting, "Eczema creams, steroid creams are really not a solution … There's no cream that's gonna be fixing … the problem in my mind" (Peter, AD). Taken together, these accounts suggest remission was often experienced as a partial bodily easing alongside a continuing internal struggle, where emotional sequelae were less visible, less discussable, and less readily treated.

*ST 2: "Healing but Never Healed, I Carry It With Me".* Participants described remission not as a return to a pre-illness self but as a modified state that retained vulnerability, shame, and a fragile relationship with the body. Harold captured this continuity directly, describing how vulnerability persisted even during physical improvement:

> **I carry with me** this sense of vulnerability … so even when there was remission, I had the sense that I may not be aware that I actually have [psoriasis] … unless I was inspecting myself everywhere – there might, might be the plaques showing to someone else. So … **that never went away.** (Harold, PS)

Here, remission is an uneasy interval with little stability or ease. Harold described increased skin monitoring in remission, where reduced symptom visibility made it harder to feel certain that the condition had truly subsided.

In Harold's account, the psychological residue of psoriasis also appeared entwined with identity and self-evaluation, when he reflected, "There was a feeling of, **I have a defect, I'm imperfect"** (Harold, PS). Other participants also described CSD as constitutive of identity rather than a condition that could be separated from the self. Izzy articulated this fusion, noting, "It becomes part of who you are … **It's like it's inbuilt.** You don't just switch it off and go back to how you were before because **there isn't really a before**." Angela's account similarly reflected a developmental embedding of illness identity, describing early onset AD: "**I don't know any differently**, really… I was five months old…" (Angela, AD).

Izzy's account of scarring further illustrates how CSD remained inscribed in both body and self. For Izzy, lasting scarring complicated remission, as clearance still left a permanent record of illness: "Because of my scars . . . they're always going to be there now. So they're never going to be in remission, are they" (Izzy, AC). Here, scarring functions as both material and symbolic evidence that CSD persists, reinforcing established patterns of self-evaluation and complicating any definition of remission based solely on the absence of active symptoms.

Participants also described lasting psychological injury linked to clinical encounters. Angela's account, in

particular, foregrounded how medical interactions could embed enduring shame, leaving effects that did not remit alongside skin:

> You have a roomful of people talking about every single thing that is wrong with your body … these words … have a huge impact on you. You start to think about how ugly you are, how undeserving you are. (Angela, AD)

Likewise, Izzy described close medical scrutiny as "quite **traumatic** in itself," suggesting that the shame and vulnerability produced in clinical care could persist beyond the consultation and beyond the skin.

## *GET 2: A Wordless Experience*

This GET examines how experiences of remission were more difficult to access, name, and communicate than episodes of flaring skin, consistent with features of alexithymia, characterised by difficulties identifying and describing emotional experience (Preece & Gross, 2023). Participants often spoke of remission through absence, comparison, or retrospective recognition, suggesting it lacked the same emotional and linguistic availability as relapse.

Some participants faltered when asked for concrete examples of remission, describing an absence of recall rather than a distinct remembered state. Angela's response captured this hesitancy, "Umm . . . I'm drawing a blank . . . oh! I went to the theatre about two weeks ago . . . my skin was quite good" (Angela, AD). Here, remission is located through incidental memory rather than a readily accessible narrative. Thomas C similarly responded with stalled searching, "That's a good question. I mean . . . [pause] yeah, it's a good question" (Thomas C, PS), highlighting the relative inaccessibility of remission compared to the more readily articulated accounts of flares.

For some, remission appeared to be defined more by the absence of suffering, rather than a conscious ease. Participants often described remission using terms of negation. For instance, Peter (AD) spoke of being "**not** red or flared up," Izzy (AC) as "**not** having that fear," and Charles (AD) as "**not** distracted by worrying." In this way, remission could read as a temporary absence of flares rather than a recognised state of clearance.

More direct accounts of remission were often translated into figurative language and embodied imagery. Employing simile, Angela (AD) described healing as "like sunburn," while Peter (AD) referred to it as "like a stinging nettle." This language highlighted participants' difficulty in clearly describing remission, suggesting a possible linguistic or conceptual gap around the experience.

Across the sample, remission was difficult to articulate as a direct experience and was more readily accessed through contrast with relapse or through metaphor to convey internal states via the body.

## *GET 3: All-Consuming: Overwhelmed by Fear and Powerlessness*

This GET captures how remission could intensify vigilance and emphasise vulnerability. Two interconnected dynamics were central: The ever-present fear of relapse that shaped daily life and feeling vulnerable to systemic abandonment during periods of improvement.

*ST 1: Constantly on Alert, Ever-Present Relapse Anxiety.* All participants described remission as shadowed by the sense that improvement could be revoked at any moment. Even when symptoms were better managed, the possibility of return remained psychologically active. Izzy framed remission through the metaphor of cancer, noting that "all clear" does not eliminate psychological dread: "It's like cancer. If you've had cancer, you get the all clear . . . the fear of it returning must be exactly the same" (Izzy, AC). Thomas C similarly described this anticipation as persistent and automatic: "**always kind of there**, something that might happen again" (Thomas C, PS).

For others, this anticipation was less overt but remained present as a background state. Charles described it as "**always in the back of my mind** . . . which was unsettling" (Charles, AD), while Peter conveyed a more conditional sense of improvement, "I'm fine at the moment . . . but **I know it can come back"** (Peter, AD). Harold's account further suggested that remission did not bring full psychological release, noting, "Well, I'd like to say it [remission] was liberating, but I don't think that's true . . . because I think **I've always felt it could come back"** (Harold, PS). Across these accounts, improvement was accompanied by an ongoing expectation of recurrence.

Angela's account extended this anticipation into everyday experience, describing a constant scanning of the environment for potential triggers. Her account conveyed remission as a state of sustained alertness:

> There's always that niggling thing in your head, and you're **constantly on alert** looking around for the next problem that's gonna happen . . . you can't relax and just sit down . . . because it could happen at any second. (Angela, AD)

The accounts depict remission as a state organised around anticipation, in which the possibility of relapse remained psychologically present and shaped how improvement was experienced.

*ST 2: Swallowed by the System; "It Feels Like You're Being Dismissed".* Alongside concerns about recurrence, participants described feeling vulnerable to systems of care. Remission, in this sense, could create uncertainty, as it was associated with discharge, reduced monitoring, and delayed re-entry into specialist support.

Angela described how discharge during periods of "good skin" could be experienced as a withdrawal of care that failed to account for the chronic and fluctuating nature of CSD:

> As soon as somebody hits a period of good skin, doctors are supposed to discharge them . . . I think it's really dangerous because what you're basically saying . . . is that . . . you're not worthy of the treatment. You're not bad enough. (Angela, AD)

Charles articulated a similar concern, describing the potential difficulty of re-accessing care: "I'd have to sort of really wait a long time maybe to get back into the system. So it is a concern" (Charles, AD). Thomas C linked remission to systemic thresholds for intervention: "Things have to kind of get worse before you actually get any further treatment. That's not great" (Thomas C, PS). Together, these accounts positioned remission as a state in which access to care could become more uncertain.

Within this context, ongoing clinical contact was described as itself preventative, not only physically but psychologically. Izzy explained that simply knowing support was available could reduce anxiety, even in remission: "If you have a beta blocker in your purse, you don't necessarily need to take the beta blocker . . . knowing you have it . . . will stop it in its tracks" (Izzy, AC). The relational dimension of care was also emphasised. Even with symptom improvement, discharge could feel like a loss of safety: "I feel scared to let [my dermatologist] go . . . He supported me through quite a lot" (Izzy, AC).

Charles made explicit the importance of support during remission, stating, "My main message is to say that please, please do more of that . . . I think, remission, perhaps is as important as when you're actually having your treatment, because that gives you a lot of reassurance" (Charles, AD).

## *GET 4: Unsolvable Dilemmas of Remission*

This GET captures the unresolved, sometimes contradictory, choices participants had to grapple with in remission. Remission emerged as a phase of negotiation in which the pursuit and maintenance of improved skin could carry complex costs. In response to these dilemmas, participants adopted differing stances towards powerlessness, ranging from resignation to action to self-blame.

*ST 1: The Price of Relief; "A Cure Worse Than the Disease"?.* Participants questioned whether physical improvement justified the risks and side effects of treatment, particularly where monitoring felt limited or long-term harms were uncertain. Angela described treatment as physically effective but profoundly damaging, recalling that she "couldn't lift [her] head off the pillow . . . [her] hair was falling out in clumps . . . [she] ended up in A&E . . . in unbearable pain and it turned out [she] had viral meningitis" (Angela, AD). She added, "It's not like my skin was completely perfect," underscoring how the costs of treatment outweighed its benefits. Similarly, Harold expressed caution about treatments perceived as excessive, describing himself as "leery of the idea of **a cure that's worse than the disease** . . . there's warnings with the medications that they can cause skin thinning" (Harold, PS).

Others described harm emerging through treatment overuse in the absence of clear guidance. Izzy recalled being given a cream "you're not meant to put . . . on your face," and, at fifteen, "whacking this cream on . . . twenty times a day . . . damaging my skin more because it was thinning my skin" (Izzy, AC). She described similar concerns in relation to phototherapy, which "they didn't monitor . . . properly . . . I just used to go all the time . . . so obviously that was another **damaging** factor" (Izzy, AC). Thomas C likewise described prolonged, unsupervised medication use, noting that "the dermatologist was pretty shocked I'd been using [Tacrolimus] that long without any kind of reassessment" (Thomas C, PS).

Across accounts, treatment was experienced as a complex trade-off between symptom relief and potential harm, with participants often navigating these decisions with limited guidance or ongoing review.

*ST 2: Surviving Powerlessness: Acceptance, Action, and Accountability.* Participants described chronic unpredictability as a persistent constraint of living with CSD, within which three interweaving orientations were evident.

First, some accounts reflected acceptance as a form of accommodation to a volatile disease course. Charles described moving from hoping for a "magic pill . . . that would clear the whole thing up" to having "accepted [his eczema] quite a while ago" (Charles, AD). Angela similarly acknowledged the limits of control, noting, "you try and control as much as you can because you don't really have any control," while Peter conveyed a more resigned acceptance: "it's just one of the things to deal with" (Peter, AD).

Second, participants described action as a way of reclaiming some agency. Izzy recalled pressuring a clinician for treatment, "I begged and begged him . . . said that if he didn't give [Roaccutane] to me, I'd get it off the

internet . . . I would have done whatever" (Izzy, AC). Angela framed remission as a window for preparation: "When your skin is a bit better, it seems like it would almost be a waste to not be using that time to . . . prepare for the next problem" (Angela, AD). For Harold, action took a more paradoxical form, with scratching described as restoring a sense of control: "The psoriasis has given me a sense of control . . . I can scratch my skin [laughs]" (Harold, PS).

Third, participants described forms of accountability that ranged from self-responsibility to self-blame. Peter linked remission to a broader sense of health: "**It starts with me** kind of getting into a place of . . . feeling healthy and robust. And then [the] skin kind of follows" (Peter, AD). Izzy described withholding acknowledgment of improvement: "I won't allow myself to go that's better . . . if I allow myself to go there, then **it might all undo**" (Izzy, AC). Angela's account carried a heavier moral weight, locating treatment harm within personal fault: "I hadn't done my research . . . I felt very much like it was my fault . . . t**his was my punishment** . . . I still definitely hold on to a lot of anger at myself" (Angela, AD).

Across these orientations, remission was shown as a psychologically charged interval involving trade-offs, strategies for managing uncertainty, and, at times, harsh self-judgements about the pursuit of relief.

## Discussion

This study explored how people living with CSD experience periods of remission. Remission was described as a psychologically active phase, shaped by anticipation of relapse, enduring impacts on identity and treatment-related burdens. The findings extend evidence that physical severity does not predict psychological distress in CSD, illustrating how this asynchronicity may persist, and in some cases intensify, during remission.

### *'Relapse Anxiety' in Remission*

The most distinctive contribution of this study is the proposition of 'Relapse Anxiety' in CSD as a potentially usable clinical construct warranting further investigation. While anxiety in CSD is typically understood as a response to active symptoms and visibility (Fleming et al., 2017; Salari et al., 2024), participants described remission as characterised by sustained vigilance, including ongoing monitoring of skin and heightened attention to triggers. Remission may therefore involve its own psychological demands, centred on uncertainty management and attempts to maintain control within an unpredictable relapse–remission cycle.

This resonates with the psycho-oncology construct of 'Fear of Cancer Recurrence' (FCR), which captures persistent worry and bodily monitoring following remission (Butow et al., 2018; Simonelli et al., 2017). This has been operationalised via the FCR Inventory (Simard & Savard, 2009), which is widely used in psycho-oncology research (Smith et al., 2020). Dermatology may benefit from similar adjustment-focused frameworks that recognise remission as a distinct psychological phase, alongside the development of measures to assess 'Relapse Anxiety' in CSD.

A trauma-informed lens may help conceptualise the hypervigilance described by participants, as a persistent expectation of threat and attempts to prevent re-exposure (American Psychiatric Association, 2013). Repeated experiences of inflammation, pain, itch, social rejection, and high-stakes treatment decisions may accumulate as threat over time, alongside, in some cases, exposure to life-threatening complications or suicide risk (Buckley, 2021; Hrvatin Stancic et al., 2026). From this perspective, remission does not necessarily confer a sense of safety or resolution.

This formulation also helps to contextualise participants' fears that remission would lead to premature discharge. Ongoing clinical contact appeared to provide reassurance and containment, consistent with attachment-informed accounts of clinicians as 'secure bases' (Salmon & Young, 2009). Discharge may therefore represent not only a service transition but a perceived loss of safety in the context of persistent threat anticipation. These findings suggest the value of integrating trauma- and attachment-informed approaches in psychodermatology, including attention to discharge planning and clear re-access pathways.

Clinically, psychologists may use the International Trauma Questionnaire (Cloitre et al., 2018) to identify trauma-related experiences and consider trauma-focused interventions (e.g., Ehlers & Clark, 2000; NICE, 2018) where appropriate.

### *Remission, Psychological Recovery, and Identity Over Time*

A second point concerns the dissociation between skin clearance and psychological recovery. Consistent with existing literature demonstrating misalignment between clinical severity and psychological burden (Fortune et al., 2002; Kokandi, 2010; Law et al., 2010; Perrott et al., 2000; Talamonti et al., 2021; Walker, 2005), this discrepancy persisted into remission for participants. Participants described ongoing shame and interpersonal guardedness despite visible improvement, indicating that symptom resolution did not equate to psychological recovery. Symptom relief was also frequently accompanied by treatment burden, including adverse effects and anxiety about long-term risks.

This persistence of distress may be understood through identity-based and schema-oriented accounts of CSD. Participants' accounts suggested that living with a visible, chronic condition continued to shape self-concept beyond periods of active disease. This is consistent with literature indicating that CSD may influence personality organisation (Sarkar et al., 2016; Uguz et al., 2008) and identity (Bundy et al., 2014). Illness-related experiences may consolidate enduring patterns of shame, defectiveness, and threat sensitivity (Mizara et al., 2012; Young et al., 2006), such that psychological and interpersonal patterns persist despite physical improvement.

### Treatment Burden in Remission

Participants described treatment side effects ranging from mild to severe, with some perceiving interventions as more harmful than beneficial. In several cases, improvements in skin were accompanied by lasting physical and psychological impacts, raising questions about the adequacy of patient education and support. Although existing literature emphasises clear guidance and monitoring (Bewley & Dermatology Working Group, 2008; Charman & Williams, 2003), participants reported self-administering potent therapies with limited support, despite evidence that safe use depends on adequate understanding and adherence (Krenitsky et al., 2020; Patrizi et al., 2017).

Psychological distress appeared to contribute to patterns of misuse. While prior research has focused on underuse (Aubert-Wastiaux et al., 2011; Dréno et al., 2010, 2018), these findings highlight the need to examine overuse, particularly in patients with high emotional burden. Psychologists within multidisciplinary teams may play a key role in addressing these processes, and future research could examine treatment burden alongside QoL trade-offs, drawing on models from transplantation medicine (Dobbels et al., 2008; Winsett et al., 2004).

### Systemic Wordlessness?

Participants found remission difficult to articulate, often relying on absence-based language, in contrast to vivid accounts of flares. Alexithymia, defined as difficulty identifying and describing emotions (Preece & Gross, 2023), is well documented in patients with CSD (e.g., Chiricozzi et al., 2020; Tang et al., 2022). These findings suggest that these difficulties may not solely reflect individual patient traits, but also systemic and linguistic gaps within dermatology, where clinical discourse prioritises visible pathology over recovery.

This raises questions about the validity of commonly used alexithymia measures, such as the Toronto Alexithymia Scale-20 (TAS-20; Bagby et al., 1994), in this context, as difficulties identifying and describing internal states may partly arise from a lack of shared language for remission. The alexithymia observed here may therefore be, in part, a property of the wider clinical system, highlighting the need to develop language that captures patients' lived experience of remission.

### Defining Remission

While grounded in a small sample, these findings invite reconsideration of assumptions that remission can be adequately defined through physical benchmarks or routine QoL instruments. The phenomena described by participants are not readily captured by measures such as the DLQI, which are oriented towards symptoms and functional impact rather than the enduring, identity-level, and threat-based experiences described in this study.

Conceptually, these findings point to the need for a more patient-informed understanding of remission, encompassing visible and sensory change, psychological recovery, and treatment-related burden. Complementing existing measures with more emotionally sensitive tools, such as the Skindex-29 (Chren et al., 1996) or Skindex-17 (Nijsten et al., 2006), may better capture this experience. This study represents an initial idiographic exploration of remission from the patient perspective. Further qualitative research is needed to clarify this experience and inform the development of appropriate measures.

### Implications for Clinical Practice

The findings support existing recommendations for psychological screening and access to specialist support within CSD pathways (British Association of Dermatologists & Primary Care Dermatology Society, 2009; NICE, 2012, 2020), and suggest that remission warrants more explicit consideration within psychological monitoring. Improvements in skin appearance may currently be taken as a proxy for recovery, with the potential for premature discharge and overlooked distress.

A practice-relevant insight, articulated by Angela, was that remission may represent an under-recognised window for psychological input. If physical severity is prioritised, referral to psychodermatology services may be driven by periods of acute skin severity. Participants' accounts suggested that active flares were characterised by crisis-oriented coping, whereas remission may afford greater psychological capacity for reflection. These findings suggest remission may represent a more

conducive window for psychological intervention than periods of active flare.

### Quality and Limitations

Using Smith's (2011) criteria for evaluating IPA, the study demonstrates sensitivity to the clinical context of psychodermatology care and idiographic commitment in its attention to individual sense-making. Its transparency and coherence rest on clear reporting of analytic procedures and reflexive decision-making, and its impact lies in the proposition of 'Relapse Anxiety' as a potentially usable clinical construct.

Several limitations should be acknowledged. The small, single-site sample means the findings are not intended to be statistically generalisable and may be most applicable to patients with CSD who have engaged with specialist psychological services. The transdiagnostic approach enabled convergence across conditions to be explored but may have obscured diagnosis-specific features of remission. The absence of detailed demographic and clinical information limited attention to variability across social location and medical presentation, including lesion location and visibility, which may shape stigma experiences and the meaning of clearance. These limitations sharpen priorities for future research.

### Conclusion

This study offers an initial qualitative account of remission in CSD, highlighting it as a psychologically active phase rather than a discrete endpoint of recovery. The findings suggest that distress may persist, and in some cases intensify, despite visible skin improvement, with remission shaped by ongoing vigilance, identity-related processes, and treatment burden. In doing so, the study draws attention to a largely unexamined phase of the disease course. Greater conceptual and clinical attention to remission may support more nuanced, patient-centred understandings of recovery in CSD.

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## Ethical Considerations

Ethical approval was obtained via the Health Research Authority (HRA), Camden & King's Cross Research Ethics Committee (REC), City, University of London's Ethics Committee, and the collaborating National Health Service (NHS) Psychodermatology service.

## Consent to Participate

All participants provided written informed consent. Those who participated in the study gave written informed consent. IRAS Project ID: 305600; REC Reference: 21/LO/0904.

## Author Contributions

**Daniella Allard**: Conceptualisation, Methodology, Investigation, Formal Analysis, Data Curation, Project Administration, Resources, Writing – Original Draft, and Visualisation. **Alexandra Mizara**: Resources, Supervision, Methodology, and Writing – Review and Editing. **Trudi Edginton**: Conceptualisation, Resources, Supervision, and Writing – Review and Editing.

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The authors declared the following potential conflicts of interest with respect to the research, authorship, and/or publication of this article: Daniella Allard was a trainee within the psychodermatology service at the time of the study but had no clinical relationship with any participants, and declares no conflicts of interest. Trudi Edginton declares no conflicts of interest. Alexandra Mizara declares no conflicts of interest.

## Supplemental Material

Supplemental material for this article is available online.

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