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Perspectives

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Topical steroid withdrawal syndrome and the transformation of the 'sick role' in the digital era

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The 'sick role' is a concept, originally described by Parsons, that frames illness as a social contract granting exemption from normal responsibilities in exchange for seeking treatment and recovery.[1] Primary and secondary gain refer to unconscious motivations that reinforce the sick role. Primary gain is internal psychological benefit, and can serve to keep internal conflicts or anxieties out of conscious awareness: by focusing on physical symptoms, the person avoids dealing with deeper emotional distress. Secondary gain refers to the rewards and benefits that the sick role provides in the social environment, including receiving care, attention or sympathy from others, and the legitimate avoidance of unpleasant responsibilities.

In recent times, the role of doctors as the sole gatekeepers of the sick role has diminished, with online communities and influencers increasingly validating and shaping illness identity. While social media increasingly empowers patients through connection, education and shared experiences, it is also reshaping how individuals adopt the sick role by reinforcing identification with illness and contributing to the development of a more enduring illness identity.[2]

Dermatology may be particularly susceptible to these dynamics in the digital era because skin disease is visible and easily shared on image-driven platforms. Topical steroid withdrawal (TSW) syndrome, which has increased exponentially in recent years, provides a useful example through which to examine these dynamics. It remains largely self-diagnosed, with clinical perspectives on the condition varying, which contributes to blurred clinician–patient roles.[3]

Increased awareness of TSW has been driven by individuals sharing their experiences on social media, with #TSW generating more than 1.1 billion views on TikTok.[4] Discussions relating to TSW are also widely shared across other platforms including Instagram and Twitter.[5] This context is important given the psychological burden associated with TSW syndrome: in one retrospective series, 26% of patients reported mood disturbance and 16% expressed suicidal ideation.[6] Much of the online content relating to TSW focuses on beliefs about its clinical and physical manifestations, which have been summarized previously.[7] However, comparatively little attention has been given to the behavioural and emotional narratives within these posts. To explore this perspective, we reviewed 50 consecutive TikTok posts relating to TSW syndrome, assessing content across ten predefined domains (Table 1).

Some posts reflected positive psychological adjustment, including hope, humour and resilience, while others conveyed anger, fear, sadness and helplessness. Emotional expression was common, with venting observed in 36% of posts, often alongside coping-oriented or 'warrior' narratives (32%). These emotions were reflected in narratives describing perceived dismissal by healthcare professionals, with comments such as 'Why aren't doctors listening?' and 'This is not eczema'. Some users described feeling 'gaslit' by clinicians, or framed the condition using battle metaphors that positioned the TSW community in opposition to the healthcare profession.

In some cases, mistrust towards healthcare providers, observed in 18% of posts, was accompanied by alternative explanations for the condition, including suggestions that TSW syndrome represents a problem created or perpetuated by pharmaceutical interests. Seeking validation of TSW syndrome as a distinct condition was observed in 14% of posts and often co-occurred with such narratives.

Table 1 Thematic analysis of 50 TikTok posts relating to topical steroid withdrawal syndrome

Domain	Number of posts, *n* (%)
Symptoms perception	29 (58)
Information seeking/sharing	23 (46)
Venting (emotional expression)	18 (36)
Warrior narrative (coping/optimism)	16 (32)
Advocacy	13 (26)
Prognostic anxiety	9 (18)
Conflict with medical system	9 (18)
Validation seeking	7 (14)
Moral reflection	6 (12)
Fatalism	3 (6)

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The motivations for sharing such content appeared varied, including seeking community support, reducing isolation, and sharing experiences with healthcare or symptom management. Information sharing was a prominent feature (46%), alongside detailed descriptions of symptoms (58%). Advocacy and community-oriented behaviours were observed in 26% of posts. Participation in these communities sometimes appeared to strengthen individuals' confidence in discussing the condition with healthcare providers and shape how individuals interpret and evaluate their own experiences of illness.

Prognostic anxiety was observed in 18% of posts, with some individuals expressing uncertainty about recovery trajectories, while fatalistic narratives were less common (6%). In several posts, individuals compared their progress with that of others in the community, sometimes expressing guilt or inadequacy when they perceived themselves as recovering more slowly. Moral reflection was observed in 12% of posts.

Repeated exposure to accounts describing severe or prolonged illness appeared to strengthen expectations about the likely course of the condition, which may create a self-reinforcing narrative environment. In some cases, illness appeared to become increasingly central to personal identity, aligning with the concept of illness engulfment, in which the condition comes to dominate how individuals see themselves and organize their lives. Illness engulfment has previously been associated with poorer psychological functioning in individuals living with chronic disease.[3,8]

When illness becomes central to personal identity, clinicians may need to address the resulting identity disruption rather than focusing solely on the physical disease. Maintaining an open, nonjudgemental approach and recognizing the influence of online illness communities may help clinicians better understand the perspectives patients bring to consultation. Tools designed to explore illness identity, such as the Illness Identity Questionnaire,[2] or broader cognitive–behavioural approaches, may help support patients who feel overwhelmed by their condition. Our observations do not diminish the severity or legitimacy of patients' symptoms with TSW – as it is clear that many appear to be significantly affected – but rather aim to better understand the broader context in which they are experienced. Greater attention to illness identity may represent an important area for future research as the sick role continues to evolve in the digital era.

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