Understanding treatment preference heterogeneity in psoriasis:

Insights from a qualitative analysis of social media data

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BACKGROUND

Psoriasis is a **chronic autoimmune condition** that can dramatically affect the health-related quality-of-life of those afflicted

There are numerous treatments available, that have varying features and modalities; and **preferences for these treatments vary**.[1,2]

Social media forums, wherein individuals share perspectives about health, provide a **potentially rich source of data** on how, and the range of reasons why, individuals make health-related decisions.[3]

While we were not able to identify published studies specifically in psoriasis, data from social media have been applied to investigate topics such as the nature of pregnancy considerations among those with rheumatoid arthritis, or the mental health impact of arthritis.[4,5]

Nor have these data been widely published for treatment preference research.

Objective

AIM: understand how social media discussions can inform an understanding of drivers of treatment preferences in psoriasis

OBJECTIVE: explore the range of patient treatment preferences and their drivers, within social media posts from individuals with psoriasis

Methods

We conducted a **hybrid deductive-inductive thematic analysis** of data from the r/Psoriasis subreddit of Reddit

r/Psoriasis

Potentially-relevant posts published between **01/20-10/25** were identified using a search strategy including keywords for psoriasis and treatment

Reddit threads identified by the search strategy were downloaded to Microsoft Excel for screening; the title, original post, and corresponding comments were extracted

Threads were reviewed by one author and those pertaining to preferences for psoriasis treatment were included and loaded in NVIVO14 for qualitative analyses

Data within posts were coded to classify themes
  o The categories of the conceptual model from a previous grounded theory analysis (n=38) were used; these outlined how personal features and contextual factors combine with health priorities to produce treatment preferences in psoriasis.[6]
  o Additionally, new categories were developed for themes not already identified

This research was approved by the University of Glasgow College of Medical, Veterinary & Life Sciences Ethics Committee

RESULTS

90 of 983 potentially-eligible posts were included → Many posts were soliciting feedback on treatment decisions → Thematic analysis identified the heterogeneous treatment priorities and preferences of individuals with psoriasis, and their drivers

Patient treatment priorities and preferences in psoriasis are heterogeneous

Theme 1 there were two governing priorities: controlling symptoms, and minimizing negative treatment impact

• For those interested in controlling symptoms, prioritizing efficacy and controlling other health conditions were common considerations (quote 1); as were avoiding unnecessary treatment and adverse events for those focusing on treatment impact (**Figure 1**).
• We also noted that:
  • **Not everyone prioritizes efficacy**; and people have a range of internally valid reasons for choosing treatments providing less psoriasis control (quote 2)
  • **Avoiding 'unnecessary' medical treatment** is a common priority among those focused on minimizing negative treatment impact (quote 3)
• Among those interested in minimizing negative treatment impact, interest in alternative therapies and dietary control of psoriasis were common

Figure 1: Mechanisms underlying treatment preferences, according to treatment preference category

Treatment priorities

Controlling symptoms
o Adequate and rapid symptom control
o Can manage related health conditions
o Addresses feelings of stigma or embarrassment
o Allows resumption of or supports normal activities

Minimizing negative treatment impact
o Convenient (easy to take)
o Avoids 'unnecessary' medical treatment
o Avoids adverse events and dependence
o Aligns with modality-specific preferences
o Pharmacotherapy fits into lifestyle

(Quote 1, Controlling symptoms: *"I was completely against taking drugs but now I know how much better life can be with them, you'd have to pry them out if my cold, dying hands before I gave them up."*

Quote 2, Priorities other than efficacy: *I'm 34 and female. I've been on Skyrizi for two years and I think it's lowered my immune system too much. I've been getting UTIs, yeast infections, throat infections, and just overall chronic fatigue. I get these infections almost every month…sometimes it's compounded (many infections at once). I can't live like this anymore. I think I might just skip the next dose. This drug has kept me in remission successfully for two years…but it might be time for a break…I'm just scared cuz my psoriasis was really bad before all this. \reddit_thread_1dczz2iu>*

Quote 3, Avoiding 'unnecessary' treatment: *"I now have coverage again and am also questioning on if I want to get back on the [biologic]…I am convinced that whatever damage is being presented on the exterior of your body; there is likely interior inflammation that may be causing damage that is unseen on the inside. I generally think the medication is safe, but something about prolongedly dosing your immune system for years at a time seems like it could have some sort of unforseen long term effects. If my symptoms came back as bad as they used to be, I would definitely get back on it, but in my current state I think I will pass on it until I really need it." (PsO row 20)*

Theme 2 contextual and personal factors intersect with treatment goals to produce treatment choice

• Considerations around the **lifelong nature of psoriasis treatment**, the perceived **impact of treatment on overall wellbeing**, and **past treatment experiences**, contextualize proffered explanations of patient preferences (quote 4)
  • A desire to be **in control of treatment**, or to **limit the impact of psoriasis**, were also common personal drivers
• Modifying treatment because of adverse events or to accommodate life events highlight that **treatment choice can run contrary to stated treatment preferences**; for example, among people who choose to stop biologics in pregnancy
• Affordability and insurance can be key barriers (quote 5)
  • High degrees of personal agency around health can be needed to navigate these
  • These factors can also influence life choices

Quote 4, The lifelong nature of psoriasis treatment: We are approved for Stelara by insurance and now have to make the decision to try to fight his [psoriasis] with diet or using biologics. Our primary concern is the lack of long-term research around the effects of biologics on pediatric patients (or, frankly, adults), impact during adolescence, etc. We are leaning towards 'yes' but I'd appreciate the community's thoughts.

Quote 5, Insurance, and the need for agency: "My insurance got to decide which medications I can ultimately take. My derms first pick was approved but when I needed to switch it was declined and my doctor and I were provided a list of the medications I had to try before they would approve others. It might be worth calling your insurance company and asking them. Having a list made things go smoother for me and my derm." (1ens3s4)

Theme 3 peer feedback on treatment experiences influences priorities and perceptions

Real-life treatment experience is seen as a valuable source of information, and influencer of patient preferences and choice

A lack of familiarity with, or distrust of, the medical system can also fuel direct peer consultation

Online discussion reveals how individuals balance trade-offs between short- and long-term safety and effectiveness, or effectiveness and convenience, when selecting treatments (quote 6)

Quote 6, <In response to a post on whether you would start your child on a biologic>: I started my first biologic at 11 years old, since then I am now on my 5th type… The biologics definitely improved my quality of life. My doctors were trying to control through steroids and topicals but from the ages of 6-10 I was miserable and I wish these options had been made available sooner… I would strongly encourage from experience that biologics turned my life around. I know they have side effects, as i am living with numerous. However I'll take the side effects over how I felt before treatment any day. As soon as I started biological treatment, I was no longer being bullied, I felt confident, I felt pretty, I felt like I wasn't a pain to my mum for all the mess my skin created. I felt relieved. I hope this is helpful from the child's [point of view]. reddit_thread_14xxvpb>

Discussion

• We summarized the heterogeneous treatment preferences of individuals with psoriasis discussing their treatment online
  • Priorities governing treatment preferences included the desire to control symptoms, vs. minimize negative treatment impact
• We identified contextual and personal factors contributing to these priorities
  • Data to understand personal and contextual factors were not always explicitly stated in an original post but the dialogue between posters can facilitate a more holistic understanding

• Individuals posting on Reddit sought feedback from others with psoriasis to help navigate competing trade-offs, and used these details to guide treatment decisions
• Analyses of data from social media are well suited to understanding drivers of heterogeneity in preferences, as the aim is to understand the range of experiences rather than estimating a central tendency
  • These data can give us insight into what patients perceive as barriers; and the kinds of information that would be needed to help them make treatment decisions

Strengths and limitations

Strengths include
• The relatively large sample that is not always feasible to achieve using other qualitative methods
• Reddit posts are anonymous and not limited by word count, which may facilitate honest discussions compared to some other sources of social media
• That spontaneous online narratives can provide insight unlikely to emerge through conventional qualitative approaches.
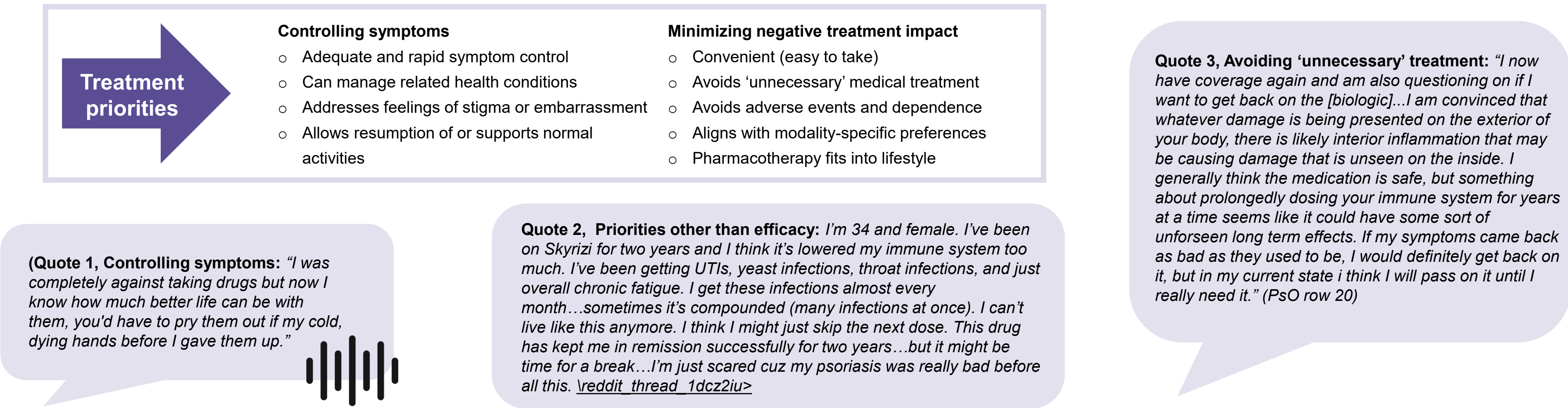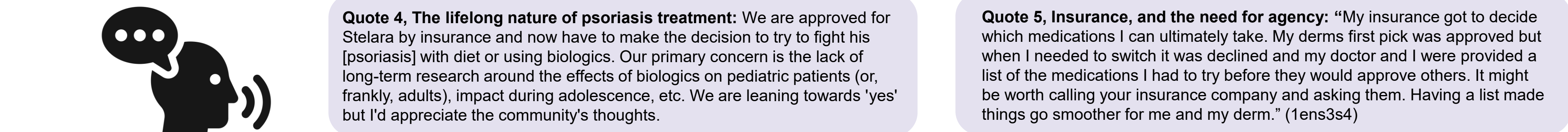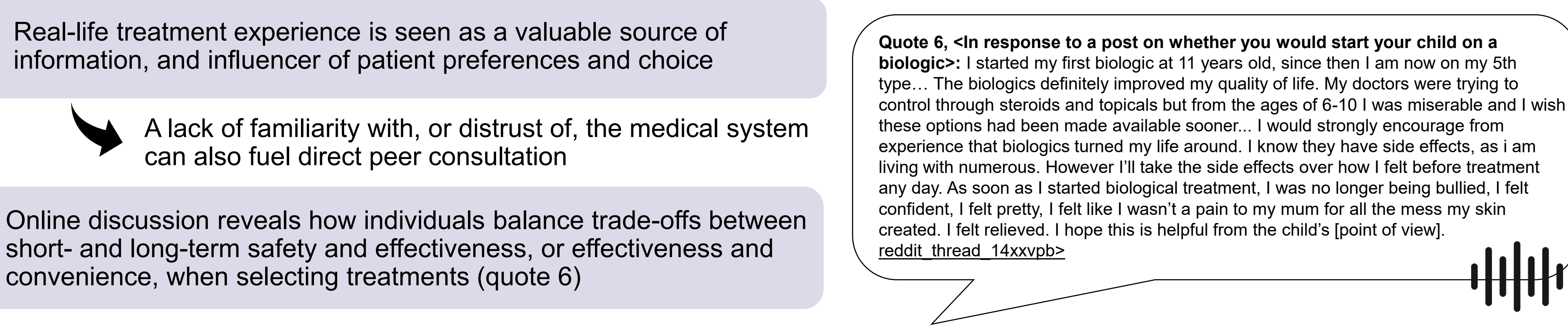
Limitations include
• Posts can lack in sociodemographic and clinical detail; and can be sufficiently narrow in focus to remove the potential for contextual understanding outside of what the poster is directly describing
  • Social media posts give less opportunity to truly understand individuals underlying motivations or drivers, in the absence of them directly stating these motivators within the posts.
• While we limited the posts to those from people who say they have psoriasis, we could not confirm psoriasis diagnosis or severity
• That individuals posting on Reddit may not be generalizable to the larger patient population with plaque psoriasis (6)

Conclusion
• These data corroborate and extend on prior work, further delineating drivers of heterogeneous treatment preferences in psoriasis
• Ideally, these findings can help clinicians and decision-makers better understand patient treatment priorities, providing context for treatment access deliberations

REFERENCES
1. Szabo et al., The Patient 2025 (submitted).
2. Boeri et al., Pharmacoecon 2020;38:593-606.
3. Maynard et al., JDD 2023.
4. Chew et al., ACR Open Rheumatol 2019
5. Park et al., BMC Rheumatol 2020.
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