


Perspectives of Chinese Adult Patients with Alopecia Areata on Janus Kinase Inhibitors Therapy: A Qualitative Analysis Based on Social Media Platforms

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Background: Alopecia areata (AA) is a common autoimmune disorder causing non-scarring hair loss. Janus kinase (JAK) inhibitors have emerged as a promising new treatment approach for AA. This study aimed to investigate the perspectives of Chinese adult AA patients on JAK inhibitor therapy through a qualitative analysis of social media discussions.

Methods: Keyword searches were conducted on two major Chinese social media platforms, Baidu and Sina Weibo, to retrieve AA-related discussion posts within China. A total of 300 posts met the inclusion criteria and were analyzed using natural language processing techniques. All data used in this study were publicly available, anonymized, and obtained without interaction with human subjects, ensuring compliance with ethical standards. High-frequency terms were categorized into four main themes: drug information, efficacy and side effects, shared experiences, and treatment choices.

Results: Tofacitinib and baricitinib were the most frequently mentioned JAK inhibitors. Patients' discussions focused on treatment efficacy, relapse after discontinuation, and side effects. Specific attention was given to treatment effects at different time points. The psychological burden and emotional impact of AA emerged as significant themes in patients' shared experiences. Patients' discussions on treatment choices and brand selection reflected their active involvement in decision-making and desire for personalized treatment options.

Conclusion: This study reveals the significant interest and hope that Chinese adult AA patients have in JAK inhibitor therapy. The findings underscore the importance of comprehensive patient education, individualized risk assessment, and shared decision-making in the management of AA. Understanding patients' perspectives is crucial for developing patient-centered care strategies and improving treatment outcomes. Previous studies have demonstrated the feasibility and value of using social media data to explore patient perceptions and health behaviors in various diseases.

Keywords: alopecia areata, janus kinase inhibitors, qualitative analysis, patient needs

Introduction

Alopecia areata (AA) is a common autoimmune disorder characterized by non-scarring hair loss, affecting approximately 2% of the general population.¹ It can occur at any age, but is most prevalent among young adults, leading to significant cosmetic concerns and psychological distress, which negatively impacts their quality of life.² The pathogenesis of AA involves a complex interplay of genetic, environmental, and immunological factors. Research has revealed that AA stems from the collapse of immune privilege within the hair follicle, triggering an autoimmune attack primarily mediated by autoreactive T cells. The involvement of cytokines such as interleukin-15 (IL-15) and interferon-gamma (IFN- γ) plays a crucial role in promoting this immune response, ultimately leading to hair follicle destruction.³ The immune response is further amplified by a variety of chemokines and cytokines, creating an environment that sustains the autoimmune attack.⁴

Managing AA presents a considerable challenge due to its unpredictable nature, high recurrence rates, and limited treatment options. Traditional therapies, including corticosteroids and immunosuppressants, often require prolonged use and come with substantial side effects, diminished efficacy, and the development of resistance over time.⁵ This underscores the need for alternative treatment approaches that can provide sustained benefits without the drawbacks associated with conventional therapies.

In recent years, the discovery of Janus kinase (JAK) signaling's involvement in AA pathogenesis has opened up new avenues for treatment. JAK inhibitors (JAKi), such as tofacitinib, ruxolitinib, and baricitinib, have emerged as promising therapies due to their ability to selectively inhibit the JAK-STAT pathway. This pathway is critical in mediating the immune system's attack on hair follicles, making JAK inhibitors effective at curbing disease progression and facilitating hair regrowth.⁶ Clinical trials have demonstrated significant improvements in patients treated with JAK inhibitors, including hair regrowth, prevention of disease relapse, and enhanced quality of life.^{7,8}

Despite the growing interest and optimism surrounding JAK inhibitors for AA treatment, there remains a notable gap in understanding the perspectives and experiences of patients undergoing this therapy. Studies have largely focused on clinical outcomes, with little emphasis on how patients perceive the efficacy, safety, and long-term use of these treatments. Understanding patients' concerns, expectations, and real-world experiences is crucial for developing tailored, patient-centered management strategies. Additionally, patients' psychological burden and their need for emotional support during treatment are often underexplored in clinical research.⁹

Social media platforms have emerged as valuable tools for capturing patient-generated data, offering insights into real-world experiences and perceptions. These platforms provide a space for patients to share their personal experiences, seek advice, and connect with others facing similar challenges. In China, platforms like Baidu Tieba and Sina Weibo have large, active patient communities, making them ideal for studying the perspectives of AA patients.¹⁰ Previous studies have demonstrated the feasibility and value of using social media data to explore patient perceptions and health behaviors in various diseases.^{10,11} By analyzing patient discussions on these platforms, clinicians can gain a deeper understanding of patient needs, preferences, and concerns, which is critical for optimizing treatment plans and improving outcomes.

This study aimed to conduct a qualitative analysis of social media discussions to investigate the perspectives of Chinese adult AA patients on JAK inhibitor therapy. Baidu Tieba and Sina Weibo were selected as data sources due to their widespread use among Chinese patients, offering a broad representation of the AA patient population in the country. By exploring patients' experiences, concerns, and expectations, we aim to assist clinicians in better understanding patient needs and facilitating more effective, patient-centered clinical decision-making. Ultimately, the findings from this study may contribute to the development of more personalized care strategies and inform future research on JAK inhibitor therapy for AA.

Methods

Data Collection

To investigate the perspectives of Chinese adult AA patients on JAK inhibitor therapy, we conducted keyword searches on two major Chinese social media platforms, Baidu and Sina Weibo, to retrieve AA-related discussion posts within China. These platforms were selected due to their large user base and active patient communities, ensuring a representative sample of the broader AA patient population in China.

We used a combination of broad and specific keywords to ensure comprehensive coverage of relevant discussions. The broad keywords included "adult alopecia areata" and "alopecia areata" which were used to identify AA-related discussion communities on the social media platforms. Within these communities, we conducted a secondary search using seven specific keywords related to JAK inhibitors: "tofacitinib" "ruxolitinib" "baricitinib" "abrocitinib" "upadacitinib" "JAK" and "Janus." The keyword searches were conducted in Chinese, and the retrieved posts were limited to those originating from China. The initial keyword searches yielded a total of 628 discussion posts. To ensure data quality and relevance, we applied the following inclusion criteria: (1) posts related to adult AA patients' experiences or perspectives on JAK inhibitor therapy, (2) posts containing textual descriptions of patient experiences or opinions, and (3) posts originating from China. We excluded posts that were unrelated to adult AA, lacked textual descriptions, or were duplicate entries. Two dermatologists independently reviewed and sampled the raw data based on the inclusion and exclusion criteria. Discrepancies were

resolved through discussion and consensus. After the screening process, a total of 300 posts met the inclusion criteria and were included in the final analysis. All data used in this study were publicly available, anonymized, and obtained without interaction with human subjects, ensuring compliance with ethical standards.

Data Analysis

The included posts were analyzed using a qualitative approach based on natural language processing (NLP) techniques. We utilized the Jieba Database for Chinese word segmentation, which is a widely used NLP tool for processing Chinese text data.¹² The Jieba Database allowed us to tokenize the text data into individual words and phrases, enabling further analysis. It is important to note that the Jieba Database, like other NLP tools, may have limitations in accurately segmenting certain colloquial expressions or medical jargon specific to the AA patient community. To mitigate potential biases, we manually reviewed and validated the segmentation results to ensure the accuracy and reliability of the analysis.

After word segmentation, we performed a word frequency analysis to identify the high-frequency terms in the dataset. Terms with a frequency greater than 10 ($N > 10$) were considered high-frequency terms and were included in the subsequent qualitative analysis. This frequency threshold was determined based on the distribution of the data and the need to focus on the most salient themes in the discussions. The high-frequency terms were then categorized into four main themes based on their semantic meanings and the context in which they appeared in the posts. We generated a word cloud to visually represent the high-frequency keywords in the discussions. The size of each word in the word cloud reflects its frequency in the discussions, with larger words indicating more frequent mentions (Figure 1). The four themes were: (1) drug information, (2) efficacy and side effects, (3) shared experiences, and (4) treatment choices. These themes were determined through an iterative process of coding and discussion among the research team. To ensure the reliability and validity of the qualitative analysis, two researchers independently coded the high-frequency terms into the four themes. Disagreements were resolved through discussion and consensus. The final coding scheme was reviewed and approved by a senior dermatologist with expertise in AA management.

Results

Drug Information

The word frequency analysis revealed that tofacitinib ($N=124$, 14.71%) and baricitinib ($N=70$, 8.30%) were the most frequently mentioned JAK inhibitors in the social media discussions (Table 1). Tofacitinib is an oral JAK inhibitor that selectively inhibits JAK1 and JAK3, while baricitinib is a selective JAK1 and JAK2 inhibitor. Both drugs have demonstrated efficacy in treating AA in clinical trials.^{6,8} Patients expressed a strong interest in understanding the differences between these two drugs, as evidenced by questions such as “What are the differences between tofacitinib and baricitinib?” and “Which drug is more suitable for treating severe alopecia areata?” These findings suggest that patients have a basic understanding of JAK inhibitor therapy for AA but desire more information on the specific indications and characteristics of each drug.

Efficacy and Side Effects

Patients' discussions on JAK inhibitor therapy for AA focused heavily on treatment efficacy ($N=87$, 10.32%), relapse after discontinuation ($N=76$, 9.02%), and side effects ($N=34$, 4.03%) (Table 1). Many patients reported experiencing little improvement with conventional treatments before attempting JAK inhibitors, highlighting their hopes and expectations for this new treatment approach. The high frequency of discussions on relapse after discontinuation indicates patients' concerns about the long-term sustainability of treatment effects and the need for maintenance therapy.

Patients also showed a keen interest in the timing of treatment effects, with specific attention to efficacy in the first month ($N=21$, 2.49%), six months ($N=19$, 2.25%), and one year ($N=18$, 2.14%) of JAK inhibitor therapy (Table 1). These time points reflect patients' desire to understand the expected trajectory of treatment response and to set realistic expectations for their treatment journey.

Side effects were another important concern among AA patients discussing JAK inhibitor therapy. Patients frequently sought information on the potential adverse effects of JAK inhibitors and shared their personal experiences with side effects. The discussions highlighted the importance of patient education and individualized risk assessment in the context of JAK inhibitor therapy for AA.

Table 1 Word Frequency Analysis Results

Category	Vocabulary	Part of Speech	Frequency (N, %)
Drug-Related Information	Tofacitinib	x	(124,14.71%)
	Baricitinib	x	(70,8.30%)
Efficacy, duration, and side effects	Therapeutic effects	n	(87,10.32%)
	Relapse after discontinuation	v	(76,9.02%)
	Side effects	n	(34,4.03%)
	Administration method	vn	(25,2.97%)
	First-month efficacy	m	(21,2.49%)
	Total treatment duration	m	(19,2.25%)
	One-year course of treatment	m	(18,2.14%)
	Treatment progress	n	(18,2.14%)
	Ancillary examinations	vn	(16,1.90%)
	Recovery status	v	(14,1.66%)
Shared experiences	Effect after six months	m	(12,1.42%)
	Recurrent hair loss	n	(69,8.19%)
	Severe alopecia areata	z	(64,7.59%)
	Eyebrow conditions	n	(25,2.97%)
	Seeking communication with fellow patients	n	(20,3.37%)
	Planning to try	vn	(13,1.54%)
Other treatment methods and brand choices	Psychological burden	v	(36,4.27%)
	Drug brand selection	n	(24,2.85%)
	Hormone therapy	n	(17,2.02%)
	Original research drug	n	(16,1.90%)
	Traditional Chinese medicine treatment	n	(14,1.66%)
	Hospital recommendation	n	(11,1.30%)

Notes: Through the word frequency analysis of discussion posts on “Chinese adult alopecia areata patients’ perspectives on Janus kinase inhibitor treatment” we have identified 24 high-frequency vocabulary items (N>10). The qualitative analysis results of all high-frequency terms are summarized into four main categories, including “Drug-Related Information” “Efficacy, duration, and side effects” “Shared experiences” and “Other treatment methods and brand choices.”

Discussion

Patients’ Interest in Tofacitinib and Baricitinib

This qualitative analysis of social media discussions provides valuable insights into the perspectives of Chinese adult AA patients on JAK inhibitor therapy. The high frequency of discussions surrounding tofacitinib and baricitinib reflects patients’ awareness of these two JAK inhibitors as the most widely studied and promising treatment options for AA. Patients expressed a strong desire to understand the differences between these drugs, particularly in terms of efficacy, side effect profiles, and their suitability for specific AA subtypes. This highlights the need for more tailored patient education and decision-support tools that can aid in personalized treatment choices. Providing clear comparisons of these JAK inhibitors, including specific patient-reported outcomes and clinical trial results, will allow patients to make informed decisions that align with their individual needs and expectations.

Efficacy, Adverse Reactions, and Empathetic Communication

Patients’ focus on treatment efficacy, relapse after discontinuation, and side effects emphasizes the importance of setting realistic expectations and offering individualized risk-benefit assessments when considering JAK inhibitor therapy. Clinical data have shown that while JAK inhibitors can induce significant hair regrowth, the possibility of relapse upon discontinuation remains a major concern.^{6,7} This recurring theme in patient discussions suggests that patients highly value transparent and empathetic communication about the expected treatment course and the potential need for long-term maintenance therapy to sustain results.

In addition to treatment efficacy, side effects such as infections, gastrointestinal disturbances, and fatigue were frequently mentioned. Patients often sought peer experiences to understand how others managed these adverse reactions,

underlining the importance of detailed patient counseling and monitoring during JAK inhibitor therapy. Clinicians should actively engage with patients in conversations about potential side effects and work collaboratively to manage them, which can improve adherence and overall satisfaction with treatment.

Psychological Burden and Emotional Impact

The psychological burden of living with AA was another prominent theme in patients' shared experiences. AA, particularly in its severe forms, can lead to significant emotional distress, impacting self-esteem and social interactions. Many patients described feelings of anxiety, frustration, and depression related to recurrent hair loss, emphasizing the need for psychological support and counseling in the management of AA.⁹ Given the chronic and unpredictable nature of AA, integrating psychological support into treatment plans is crucial. Clinicians should be mindful of the emotional challenges patients face and offer resources for coping, such as referrals to mental health professionals or support groups.

The high frequency of discussions regarding peer support highlights the role of social media platforms as critical spaces where patients can connect, share experiences, and provide emotional support to one another. Such interactions help patients feel less isolated in their condition and can foster a sense of community. Encouraging patients to seek peer support or participate in online patient communities may provide them with additional emotional and practical coping mechanisms.

Empathetic Communication and Patient-Centered Care

Empathetic communication plays a key role in managing the psychosocial aspects of AA. Clinicians should be attentive to patients' concerns, offering reassurance and maintaining open lines of communication throughout the treatment process. Listening to patient feedback and providing individualized care that aligns with patients' values and preferences can significantly improve patient outcomes and satisfaction. Engaging patients in shared decision-making about JAK inhibitor therapy is essential, as it not only respects their autonomy but also helps to address their specific treatment concerns.

Shared Decision-Making and Patient Education

Patients' discussions on treatment choices and brand selection reflect their active involvement in decision-making and their desire for personalized treatment options. The findings of this study underscore the importance of shared decision-making in the management of AA. Clinicians should engage patients in open discussions about the various available treatment options, including JAK inhibitors, and provide balanced, clear information on the potential benefits and risks associated with each therapy. Providing detailed, patient-friendly education materials—such as infographics or interactive online resources—can help patients understand the differences between JAK inhibitors and their expected outcomes, thus facilitating more informed decision-making. These decision-support tools should include clear explanations of the efficacy, side effect profiles, and appropriate use cases for each JAK inhibitor, as well as other treatment options available for AA. Such tools will not only enhance patient engagement but also ensure that patients are better equipped to navigate their treatment journey.

Limitations and Future Directions

The limitations of this study include potential selection bias inherent in using social media data, as the perspectives of patients who do not participate in online discussions may not be fully represented. Moreover, the qualitative nature of the study may limit the generalizability of the findings to the broader AA patient population. The authenticity and accuracy of online posts are difficult to verify, which may introduce bias into the analysis. Despite these limitations, this study offers valuable insights into the real-world experiences of Chinese AA patients undergoing JAK inhibitor therapy. The findings can inform the development of patient-centered care strategies, educational interventions, and decision-support tools for AA management. Future research should aim to explore the perspectives of AA patients in different cultural contexts and investigate the long-term outcomes of JAK inhibitor therapy, particularly in real-world settings. Additionally, examining patient-reported outcomes over time will be critical in understanding how patients' expectations and experiences evolve as they undergo treatment.

Ethical Considerations

The use of social media data in research raises important ethical considerations. In this study, all personal information was anonymized to protect patient privacy, and the data were used solely for research purposes. Since the data were obtained from publicly available sources, no direct interaction with human subjects was required. However, researchers should remain mindful of the sensitivity of the topics discussed and take measures to respect the privacy and confidentiality of the individuals whose experiences are shared online. Further ethical considerations should include gaining patient consent if more direct or identifiable data are used in future research.¹⁶

Conclusion

This qualitative analysis of social media discussions reveals the significant interest and hope that Chinese adult AA patients have in JAK inhibitor therapy as a new treatment approach for AA. The findings highlight the importance of patient education, individualized risk assessment, and shared decision-making in the management of AA. The study underscores the value of social media platforms as a space for patients to connect, exchange information, and provide emotional support to one another. The psychological burden and emotional impact of AA emerged as significant themes, emphasizing the need for integrating psychological support and counseling into AA management. Understanding patients' perspectives is crucial for developing patient-centered care strategies and improving treatment outcomes. This study provides valuable insights for clinicians, researchers, and policy-makers involved in the care of AA patients and highlights the importance of engaging patients as active partners in their treatment journey.

The innovative use of social media data in this study demonstrates the potential of leveraging patient-generated content to gain insights into real-world patient experiences and inform clinical practice. Future research should explore the long-term outcomes and patient-reported experiences with JAK inhibitor therapy, as well as the perspectives of AA patients in other cultural contexts.

In conclusion, this study contributes to the growing body of literature on patient-centered care in AA management and underscores the importance of understanding and addressing patients' needs, concerns, and expectations. By incorporating patients' perspectives into clinical decision-making and research priorities, we can work towards improving the quality of life and treatment outcomes for individuals living with AA.

Ethics Statement

This study has been reviewed and approved by the Ethics Committee of Deyang People's Hospital, with the ethics approval number (2024-122302). The research is based on user-generated posts from open social media platforms, Baidu Tieba and Sina Weibo, which are publicly accessible. The data collection and usage strictly adhered to the terms of service and platform usage agreements of both Baidu Tieba and Sina Weibo, without violating any data usage clauses. As this study only involves analysis of publicly posted content and does not involve the collection or disclosure of users' private information, no additional permissions were required. The research process and the published content do not contain any personally identifiable information. All data have been anonymized to protect user privacy.

Acknowledgments

The data used in this study was obtained from publicly available social media platform posts. We extend our gratitude to all the users whose posts contributed to this research. We recognize the value of openly shared information and appreciate the insights it has provided. Additionally, we thank the social media platforms for maintaining and providing access to this valuable data. This study would not have been possible without the contributions of these individuals and platforms.

Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

Disclosure

The authors report no conflicts of interest in this work.

References

1. Pratt CH, Le K Jr, Messenger AG, Christiano AM, Sundberg JP. Alopecia areata. *Nat Rev Dis Primers*. 2017;3:17011. doi:10.1038/nrdp.2017.11
2. Villasante Fricke AC, Miteva M. Epidemiology and burden of alopecia areata: a systematic review. *Clin Cosmet Invest Dermatol*. 2015;8:397–403. doi:10.2147/CCID.S53985
3. Wang E, McElwee KJ. Etiopathogenesis of alopecia areata: why do our patients get it? *Dermatol Ther*. 2011;24(3):337–347. doi:10.1111/j.1529-8019.2011.01416.x
4. Strazzulla LC, Wang EHC, Avila L, et al. Alopecia areata: disease characteristics, clinical evaluation, and new perspectives on pathogenesis. *J Am Acad Dermatol*. 2018;78(1):1–12. doi:10.1016/j.jaad.2017.04.1141
5. Divito SJ, Kupper TS. Inhibiting Janus kinases to treat alopecia areata. *Nat Med*. 2014;20(9):989–990. doi:10.1038/nm.3685
6. Kennedy Crispin M, Ko JM, Craiglow BG, et al. Safety and efficacy of the JAK inhibitor tofacitinib citrate in patients with alopecia areata. *JCI Insight*. 2016;1(15). doi:10.1172/jci.insight.89776.
7. Mackay-Wiggan J, Jabbari A, Nguyen N, et al. Oral ruxolitinib induces hair regrowth in patients with moderate-to-severe alopecia areata. *JCI Insight*. 2016;1(15). doi:10.1172/jci.insight.89790.
8. Jabbari A, Sansaricq F, Cerise J, et al. An open-label pilot study to evaluate the efficacy of tofacitinib in moderate to severe patch-type alopecia areata, totalis, and universalis. *J Invest Dermatol*. 2018;138(7):1539–1545. doi:10.1016/j.jid.2018.01.032
9. Rencz F, Gulácsi L, Péntek M, Wikonkál N, Baji P, Brodszky V. Alopecia areata and health-related quality of life: a systematic review and meta-analysis. *Br J Dermatol*. 2016;175(3):561–571. doi:10.1111/bjd.14497
10. Shen H, Zhang J, Shang Q, Cai X, Zhu W, Chen M. Mining Twitter to assess the determinants of health behavior towards human papillomavirus vaccination in the United States. *Int J Infect Dis*. 2020;96:288–295. doi:10.1016/j.ijid.2020.05.030
11. McKee M, Makszin L, Jurberg C, et al. “Social media monitoring for public health: ethical challenges and opportunities. *BMC Public Health*. 2021;21:1200. doi:10.1186/s12889-021-11244-7
12. Sun J, Wang X, Lv H, Li B, Zhang Y, Lin H. Qualitative research on health communication in Chinese social media: a scoping review. *J Med Internet Res*. 2020;22(11):e18645. doi:10.2196/18645
13. Patil S, Prasad S, Garg R, Madaan K, Joshi R. The psychosocial impact of alopecia areata: a qualitative study. *Int J Trichol*. 2019;11(5):206–211. doi:10.4103/ijt.ijt_57_19
14. Aldhouse NVJ, Kitchen H, Knight S, et al. ““You lose your hair, what’s the big deal?” I was so embarrassed, I was so self-conscious, I was so depressed:” a qualitative interview study to understand the psychosocial burden of alopecia areata. *J Patient Rep Outcomes*. 2020;4(1):76. doi:10.1186/s41687-020-00240-7
15. Liu LY, King BA, Craiglow BG. Health-related quality of life (HRQoL) among patients with alopecia areata (AA): a systematic review. *J Am Acad Dermatol*. 2016;75(4):806–812.e3. doi:10.1016/j.jaad.2016.04.035
16. Liu X, Kim M-K, Du D, et al. “patient education with new media integration self-management support model improves therapeutic outcomes of rosacea patients.” patient preference and adherence. *Patient Preference and Adherence*. 2023;17(17):2395–2400. doi:10.2147/PPA.S431955

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