

Exploration of Reasons for Patient Loss to Follow-Up Management—A Cross-Sectional Study of Patients with Rosacea

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Background: Rosacea is a chronic skin condition requiring long-term management and regular follow-up for treatment optimization. However, significant patient loss to follow-up in clinical practice hinders the collection of essential clinical data. This study aims to investigate the reasons for patient attrition to inform improved retention strategies and patient management.

Methods: We randomly selected 100 lost-to-follow-up patients with rosacea and 100 rosacea patients who adhered to regular follow-ups from our outpatient system and conducted a survey and interviews with them based on their basic information, disease and treatment status, exploration of reasons for loss to follow-up, and assessment of disease status and willingness to return for follow-up.

Results: The results indicated that demographic factors, such as gender and education level, are not the primary reasons for patient loss to follow-up. The lost-to-follow-up group exhibited milder symptoms ($p < 0.001$) and lower treatment willingness ($p < 0.001$), while the regular follow-up group had a higher level of disease awareness. The main reasons for patient loss to follow-up were improvement in condition and dissatisfaction with treatment outcomes. Most patients expressed satisfaction with our follow-up services. Patients desire more personalized and flexible follow-up services and patient education.

Conclusion: Demographic factors are not the primary reasons for patient loss to follow-up, but milder symptoms and dissatisfaction with treatment outcomes are the main reasons for patients discontinuing follow-up. Effective patient education enhances patients' understanding of their condition, which encourages them to adhere to follow-up appointments.

Keywords: rosacea, patients education, patients management, follow up, chronic conditions

Introduction

Rosacea is a common chronic skin condition that primarily affects the facial area. Patients may experience symptoms such as flushing, erythema, papules, telangiectasia, along with sensations of burning or stinging.¹ The treatment of rosacea is complex and requires an assessment of the condition to develop a comprehensive treatment plan.^{1,2} As a chronic disease, patients with rosacea often need long-term treatment and adjustments to their treatment plans based on changes in their condition. Patient management and education are particularly important in the treatment of rosacea; regular follow-ups and patient education can effectively reduce confusion about the disease, improve medication adherence, and foster a positive doctor-patient relationship.^{3,4} However, during follow-up, many patients still experience loss to follow-up, leading to interruptions in treatment.

Loss to follow-up is a common challenge in chronic disease management, with numerous studies examining its contributing factors and adverse outcomes across various conditions. For instance, a study of 298 patients with chronic pulmonary aspergillosis identified advanced age (>60 years), low education level, and non-local residence as significant risk factors for loss of follow-up. Notably, the 180-day mortality rate was 19.65% among loss of follow-up patients compared to 0% in those

adhering to follow-up.⁵ Similarly, research in pediatric oncology found higher loss of follow-up rates in clinical trials among adolescents and young adults (15–39 years), ethnic minorities, and patients from low socioeconomic status areas.⁶ While loss of follow-up in chronic dermatologic conditions like rosacea may lead to recurrence or exacerbation, studies specifically investigating loss to follow-up within dermatology remain unexplored. This study aims to investigate the reasons for loss to follow-up among rosacea patients to enhance the management process and improve the treatment experience for patients.

Methods

This study included patients diagnosed with rosacea at our outpatient clinic in the past five years who voluntarily participated in the management of rosacea. These patients were incorporated into the patient management system at the time of their initial diagnosis. Specific patient inclusion and exclusion criteria are detailed below.

Inclusion Criteria: i) Patients diagnosed with rosacea by dermatologists during outpatient consultations, meeting the diagnostic criteria established in the 2019 Global ROSacea COnsensus (ROSCO).⁷ ii) Provided written informed consent, expressed willingness to enroll in the outpatient follow-up system, and committed to attending scheduled follow-up visits. iii) Possessed adequate comprehension and communication abilities to interact effectively with healthcare providers.

Exclusion Criteria: i) Individuals not definitively diagnosed with rosacea, including those presenting solely with facial flushing or persistent erythema without a confirmed rosacea diagnosis. ii) Individuals unable to comprehend questionnaire content or collaborate with the research team.

In principle, each patient was required to have follow-up visits every month after diagnosis to adjust their treatment plan until their rosacea assessment scores (using the rosacea self-assessment tool (RSAT) scale and (investigator's global assessment (IGA) scale) were both 0, indicating complete remission of rosacea. If a patient's assessment scores were not 0 and they had not returned for a follow-up visit for more than 6 months, they were classified as lost to follow-up and included in this study's lost follow-up group. The control group consisted of patients who adhered to regular follow-up, meaning they had monthly follow-up visits and continued for more than 6 months or until remission was achieved.

We developed a questionnaire based on: (a) Rosacea disease manifestations outlined in the ROSCO (Rosacea International Consensus) standards, and (b) Clinically relevant issues prioritized by both outpatients and clinicians. The questionnaire was created to investigate patients based on their basic information, disease and treatment status, exploration of reasons for loss to follow-up, and assessment of disease status and willingness to return for follow-up. Telephone or Email surveys were conducted with patients in both the lost follow-up group and the regular follow-up group, and the collected questionnaires were analyzed statistically.

All statistical procedures were performed in IBM SPSS Statistics (v28). Continuous measures are summarized using means $\pm$ standard deviations. Counts and percentages describe categorical variables. For comparisons involving categorical data, either the χ^2 -test or Fisher's exact test was applied as appropriate. Analysis of variance (ANOVA) was employed to assess differences in continuous measures across three or more groups, preceded by a test for variance homogeneity. When quantitative data violated normality assumptions, the Kruskal–Wallis test was used for group comparisons.

Results

Demographic Baseline and Disease Consultation Status

A random sample of 100 patients each from the lost to follow-up group and the regular follow-up group was drawn from the outpatient management system, and questionnaires were distributed and followed up by phone. In the lost to follow-up group, 91 patients (91.0%) completed and returned the questionnaire, while in the regular follow-up group, 95 patients (95.0%) did the same. The results indicated that there were no differences in demographic baselines, such as gender, age, education level, employment, and marital status, between the two groups; however, there was a difference in the severity of rosacea. Compared to the regular follow-up group, the lost to follow-up group had a lower initial IGA score, with most patients experiencing mild to moderate rosacea, while the regular follow-up group had a greater number of moderate to severe cases ($p < 0.001$). Similarly, patients were asked to rate their current rosacea symptoms using the RAST scale, and the results showed that the lost to follow-up group had a lower total score than the regular follow-up group (1.12 vs 1.96,

$p<0.001$). Regarding consultation status, the regular follow-up group also demonstrated a higher willingness to seek treatment; even though there was no difference in the total treatment duration between the two groups ($p=0.32$), the regular follow-up group had more outpatient visits within one year (6.02 vs 3.31, $p<0.001$) and shorter time since the last visit (2.42 vs 11.87, $p<0.001$) (Table 1).

Table 1 Basic Demographic Information of Patients and Their Disease Consultation Status

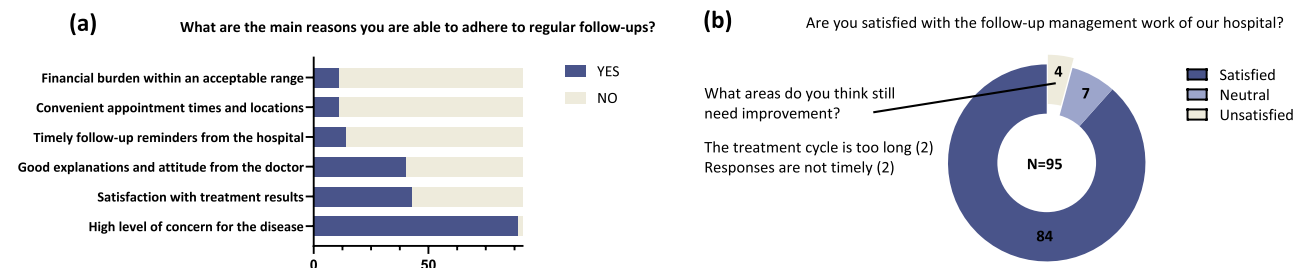
Characteristics	Loss of Follow Up Group (n=91)	Regular Follow Up Group (n=95)	P-value
Gender			
Female	80 (87.9%)	87 (91.6%)	0.55
Male	11 (12.1%)	8 (8.4%)	
Age	36.08 (9.26)	39.98 (10.16)	0.16
Educational Level			
Elementary School and Below	1 (1.1%)	3 (3.2%)	0.07
Middle School	9 (9.9%)	21 (22.1%)	
High School	13 (14.3%)	18 (18.9%)	
Associate Degree	27 (29.7%)	23 (24.2%)	
Bachelor's Degree and Above	41 (45.0%)	30 (31.6%)	
Occupation			
Agricultural production personnel	7 (7.7%)	6 (6.3%)	0.2
Industrial or transportation personnel	6 (6.6%)	4 (4.2%)	
Professional and technical personnel	12 (13.2%)	14 (14.7%)	
Administrative and related personnel	10 (11.0%)	9 (9.5%)	
Business/service industry workers	7 (7.7%)	17 (17.9%)	
Government or other organization leaders	10 (11.0%)	3 (3.2%)	
Students	7 (7.7%)	4 (4.2%)	
Retired individuals	3 (3.3%)	7 (7.4%)	
Others	29 (31.8%)	31 (32.6%)	
Marital Status			
Married	77 (84.6%)	74 (77.9%)	0.35
Unmarried	13 (14.3%)	17 (17.9%)	
Divorced	1 (1.1%)	4 (4.2%)	
IGA Score at Initial Diagnosis ^a			
1	10 (11.0%)	4 (4.2%)	<0.001
2	35 (38.5%)	22 (23.2%)	
3	41 (45.0%)	39 (41.1%)	
4	5 (5.5%)	30 (31.6%)	
Current total score on the RSAT scale ^b	1.12 (1.42)	1.96 (1.28)	<0.001
Total duration of treatment (months)	15.03 (11.41)	16.90 (13.56)	0.32
Number of outpatient visits ^c	3.31 (3.24)	6.02 (3.66)	<0.001
Time since last outpatient visit (months)	11.87 (7.37)	2.42 (2.85)	<0.001

Notes: Statistically significant p values are in bold. ^aIGA, Investigator's Global Assessment, is rated on a scale from 0 to 4, where 0 indicates no symptoms of rosacea and 4 indicates severe symptoms of rosacea, with increasing severity. ^bRSAT, Rosacea Self-Assessment Tool, is a questionnaire for patients to self-evaluate the symptoms and severity of rosacea, used to assess the severity of erythema, papules and pustules, phymatous changes, and ocular rosacea. A higher score indicates more severe rosacea symptoms. ^cThe number of visits includes the total number of visits to our hospital as well as visits to other hospitals.

Exploration of Reasons for Loss to Follow-Up and Assessment of Re-Consultation Willingness

Surveys regarding the reasons for regular follow-up or loss to follow-up were conducted among patients. The results indicated that the main reason the regular follow-up group was able to maintain consistent follow-up was their higher level of disease awareness, followed by satisfaction with treatment outcomes and satisfaction with the services provided by the doctors (Figure 1a). Additionally, 88.4% of regular follow-up patients expressed satisfaction with the patient management services at

Investigation of Patients in the Regular Follow-up Group



Investigation of Patients in the Loss Follow-up Group

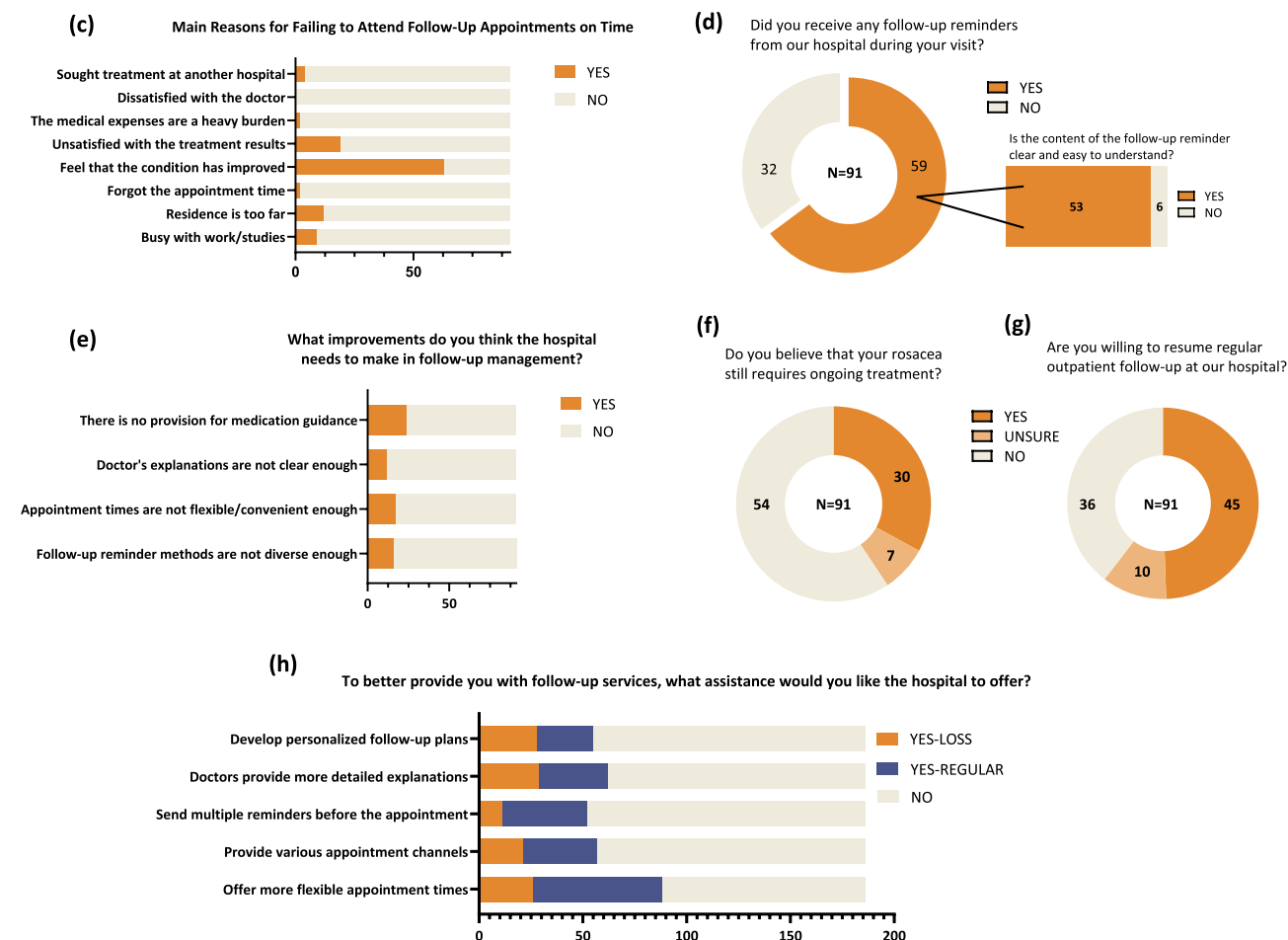


Figure 1 Investigation of Reasons for Loss to Follow-Up. Survey of the Regular Follow-Up Population: (a) Reasons for being able to maintain regular follow-up; (b) Are you satisfied with the follow-up services provided by our hospital? Survey of the Lost to Follow-Up Population: (c) Reasons for interrupting follow-up; (d) Have you received follow-up reminders? If so, were these reminders easy to understand?; (e) What improvements do you think our follow-up services need?; (f) Do you believe you need to continue treatment for rosacea?; (g) Are you willing to continue follow-up at our hospital? Joint Survey of Both Patient Groups: (h) What suggestions do you have for improving follow-up services?

our hospital (Figure 1b). The primary reasons for loss to follow-up among the patients in the lost to follow-up group were improvement in their condition and dissatisfaction with treatment outcomes (Figure 1c). Correspondingly, only 32.9% of patients in the lost to follow-up group believed that their rosacea required continued treatment (Figure 1f), however, 45.9% of patients were willing to be re-admitted for regular follow-up (Figure 1g). Regarding our hospital's follow-up services, 64.8% of patients in the lost to follow-up group reported receiving follow-up reminders, and among these patients, 90.0% found the reminders to be clear and understandable (Figure 1d). Furthermore, 49.5% of patients in the lost to follow-up group expressed willingness to re-enter follow-up. Both groups of patients provided suggestions regarding our hospital's follow-up services (Figure 1e and h).

Discussion

This study investigated the factors related to loss of follow-up among patients with rosacea by comparing those who were lost to follow-up with those who adhered to regular follow-up.

The results indicated that there were no differences in demographic characteristics between the two groups; however, there were significant differences in their disease conditions. The primary reason for patients in the lost-to-follow-up group discontinuing regular visits was that their rosacea symptoms were mild and tolerable, or they believed that mild symptoms did not require ongoing treatment. The findings showed that the regular follow-up group had a higher level of disease awareness, with most patients hoping to achieve complete remission through consistent follow-up and treatment, demonstrating a strong willingness to undergo treatment and expressing satisfaction with the current follow-up services at our hospital. In contrast, the lost-to-follow-up group often ceased treatment after partial symptom relief and had lower expectations regarding treatment outcomes. As a chronic and recurrent condition, long-term treatment of rosacea is significant for delaying disease progression.⁸ The results of this study also suggest the need for disease-related patient education for rosacea patients to enhance their understanding of the condition and improve treatment adherence.

Loss to follow-up, a prevalent issue in patient management, is often associated with specific demographic characteristics. As previously noted, factors such as age, educational attainment, and income level may influence follow-up adherence. Beyond demographic factors, disease-specific symptom characteristics also contribute to loss to follow-up. For instance, among hepatitis C patients receiving antiviral therapy, loss to follow-up correlates with a history of injection drug use, current opioid substitution therapy, and the degree of liver cirrhosis.⁹ Similarly, in patients with chronic lower extremity wounds, wound location characteristics, such as involving the ankle, knee, or thigh regions, are associated with higher rates of loss to follow-up.¹⁰ Contrastingly, this study found no association between loss to follow-up in rosacea patients and demographic characteristics or social circumstances. Loss to follow-up in rosacea was solely linked to disease symptoms. Notably, and unlike other systemic chronic diseases, it was patients with milder disease severity, rather than severe cases, who were more prone to loss to follow-up. This pattern may reflect the overall nature of rosacea. As dermatological conditions are generally not perceived as life-threatening, and mild symptoms impose a lower burden on quality of life, the primary reason for loss to follow-up appears to be diminished treatment motivation during partial remission, when symptoms improve but resolve incompletely. However, it is crucial to note that discontinuing treatment before achieving complete remission in rosacea may lead to disease recurrence and exacerbation. This underscores the necessity for enhanced patient education to reduce loss to follow-up rates.

Implementing more reasonable patient education and management is essential for follow-up work. Our research shows that patients expect more flexibility in scheduling, more detailed information, additional communication channels, and more personalized approaches. This undoubtedly presents challenges for the current management of patients with rosacea in clinical settings. To our knowledge, this study is the first to specifically address patient loss to follow-up in the management of chronic dermatological conditions. However, a notable limitation is its exclusive focus on the characteristics of patients lost to follow-up and their service preferences, without further assessment of patient-reported outcomes such as quality of life and psychological status. In future research, we urge researchers and clinical managers to create and practice more personalized patient management, such as adopting different management models and follow-up strategies for mild and severe cases. This will facilitate clinical work and benefit more patients.

Ethics Statement

This study was approved by the Medical Ethics Committee of the West China Hospital of Sichuan University (ID: 2024–2499). The work described has been carried out under The Code of Ethics of the World Medical Association (Declaration of Helsinki).

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.

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Disclosure

The authors have no conflicts of interest to declare for this work.

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