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ORIGINAL RESEARCH

Qualitative Study on the Real Experiences of Patients with Meige Syndrome Based on the Individual and Family Self-Management Theory

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Objective: This study aimed to analyze the real experiences of patients with Meige Syndrome, which is an idiopathic dystonia, during the perioperative period and to explore the practical application and effectiveness of Individual and Family Self-Management Theory (IFSMT) in improving patient experiences.

Methods: A qualitative descriptive research methodology was employed to elucidate the intricate psychological and social experiences encountered by patients with Meige Syndrome throughout the perioperative phase. This study conduct face-to-face, one-on-one, semi-structured interviews with 16 Meige Syndrome patients to gain an in-depth understanding of the patients' true feelings and needs. Interview data were organized and analyzed using Colaizzi's method, and themes were refined in conjunction with IFSMT to reveal patients' self-management practices and influencing factors.

Results: Through in-depth analysis using Colaizzi's method and the application of IFSMT to the perioperative experiences of patients with Meige Syndrome, and reported according to COREQ standards, three core themes were identified: (1) Context Dimension (specific disease factors, physical and social environmental factors, personal and family factors), (2) Process Dimension (knowledge and beliefs, self-regulation and self-efficacy, social facilitation), and (3) Outcome Dimension (proximal and distal outcomes of self-management behaviors).

Conclusion: This study demonstrates that IFSMT has significant application value in the perioperative experiences of patients with Meige Syndrome. Enhancing patients' knowledge, beliefs, self-regulation abilities, and social support can promote effective self-management behaviors, thereby improving their quality of life and health status. Additionally, the study reveals the complexity of self-management in perioperative patients, emphasizing the importance of interdisciplinary collaboration and comprehensive interventions in enhancing patient experiences. Future research can further explore how to apply these theories in clinical practice to optimize perioperative management and rehabilitation processes for patients with Meige Syndrome.

Keywords: Meige Syndrome, individual and family self-management theory, IFSMT, qualitative study, real experiences

Introduction

Meige Syndrome

Meige Syndrome, also known as idiopathic blepharospasm-oromandibular dystonia, Brueghel's syndrome, or oral facial dystonia, was first identified and named by the French neurologist Henri Meige in 1910.[1] It primarily manifests with a variety of ocular and mandibular symptoms, including increased blinking, photophobia (sensitivity to light), and

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chewing-induced spasmodic dystonia affecting the eyes, as well as difficulties in opening the mouth, bruxism (teeth grinding), and jaw spasms.[2] According to a study in the United States, the prevalence of Meige Syndrome is estimated to be 5–10 per 100,000 individuals.[3] The majority of patients are aged between 40 and 70, with a higher incidence in women compared to men, at a ratio of 1:3.[4,5] Additionally, patients may experience emotional disorders such as depression and anxiety,[6] which significantly disrupt their daily lives and present considerable challenges.[7] Furthermore, due to limited access to medical care and scarce medical resources, families of patients with rare diseases like Meige Syndrome may face substantial economic burdens.[8] Government policies aimed at providing support for rare diseases, including Meige Syndrome, can also impose significant financial pressures on public budgets.[9,10]

Previous research has primarily focused on the pathophysiological mechanisms,[5,11] medical treatments,[12,13] and rehabilitation measures for Meige Syndrome.[14] However, there is relatively little research on the real experiences of patients with Meige Syndrome. Understanding the challenges these patients face in their daily lives, their coping strategies, and psychological distress is crucial for improving their quality of life and providing targeted support.

Theory of Individual and Family Self-Management Theory (IFSMT)

IFSMT was proposed by American clinical nursing expert Ryan as an innovative self-management theory.[15] This theory is based on the integration of health behavior change theories and the ecological model of conditional adaptation. It aims to promote health behavior changes in patients, reduce medical costs, and improve patients' quality of life and well-being. The theory defines self-management behavior as a complex phenomenon driven by intrinsic motivation. It includes three components: context, process, and outcomes. It posits that the context and processual conceptual factors are closely related to both proximal outcomes (self-management behaviors) and distal outcomes (health status, quality of life, and healthcare costs).

The development of IFSMT serves as an important complement to the traditional medical model. The traditional medical model emphasizes the authoritative role of doctors and views patients as passive recipients of treatment, especially when dealing with chronic illnesses. However, in the context of chronic diseases, individuals and families need to actively participate in management and decision-making to better cope with challenges and achieve optimal health outcomes.

IFSMT is a theoretical framework that addresses how individuals and families effectively manage and cope with chronic illnesses.[16] In this theory, individuals and families are seen as central to disease management, possessing the initiative and responsibility to take control of their health status.[17] According to this theory, individuals and families need to acquire a range of skills and knowledge, including disease self-monitoring, medication management, dietary adjustments, psychological coping, and seeking social support. By enhancing these self-management capabilities, individuals and families can effectively address various aspects of the disease and maintain a relatively stable health condition in their daily lives.

In previous studies, most researchers have applied IFSMT to populations with conditions such as epilepsy,[11] HIV/AIDS,[18] adolescent polycystic ovary syndrome (PCOS),[19] and heart failure.[20] However, there has been no research found that applies this theory to patients with Meige Syndrome.

This study aims to deeply explore the real experiences of patients with Meige Syndrome through qualitative research methods. IFSMT will be used as the theoretical framework, which emphasizes the active role of individuals and families in coping with chronic illnesses.[21] The theoretical model of IFSMT for patients with meige syndrome is shown in Figure 1. By exploring patients' self-management strategies and experiences at the individual and family levels, a better understanding of the challenges they face and how they cope with these challenges will be gained.

This study innovatively applies IFSMT to deeply explore the real experiences of patients with Meige Syndrome (ocular disease) to better understand the challenges they face in managing a chronic illness. Qualitative research methods and conducting in-depth interviews with patients are employed to investigate their experiences and perspectives on self-management. This will help identify the difficulties, challenges, and successful strategies patients encounter when dealing with Meige Syndrome, providing practical information for developing more effective support strategies. Through the analysis and interpretation of these real experiences, this study aims to expand the understanding of IFSMT and provide practical support for patients with Meige Syndrome.

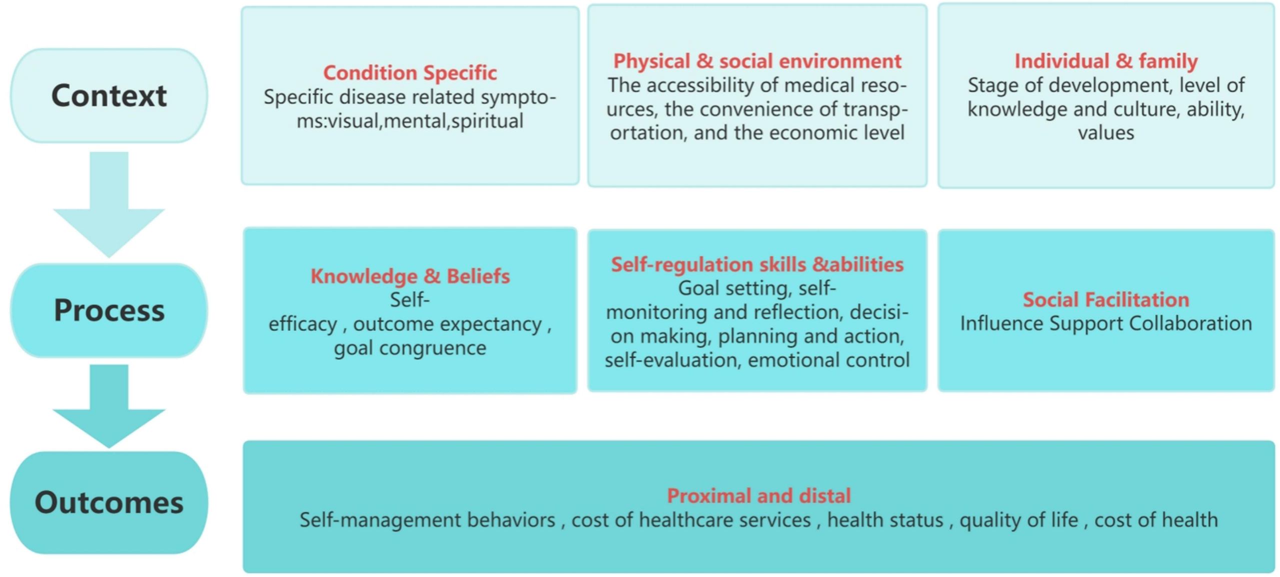

Figure 1 Theoretical Model of Individual and Family Self-Management Theory(IFSMT) in Patients with Meige Syndrome.

Materials and Methods

Participants

This study employed face-to-face interviews, each conducted individually. Participants were selected through convenience and purposive sampling and were from the Third Provincial People's Hospital of Henan Province. The inclusion criteria were: 1) Diagnosis of Meige syndrome in accordance with the "Chinese Expert Consensus on the Diagnosis and Treatment of Meige Syndrome (2018);"[22] 2) Clear diagnosis of Meige syndrome confirmed by joint neurology and neurosurgery departments; 3) No severe mental disorders or other serious diseases affecting the patient's health. The exclusion criteria were: 1) Patients with poor general health or severe internal diseases unable to withstand surgical intervention; 2) Patients unable to live independently and bedridden; 3) Patients with severe mental disorders such as dementia or suicidal tendencies. The sample size was determined by data saturation. Ultimately, 16 subjects participated in this study.

Methods

Confirmation of the Interview Outline

According to the purpose of the study, a preliminary outline of the interview was developed through literature review and discussion with the research group. Three patients in the first round of interviews helped to fine-tune the format and guarantee flexibility up until data saturation was reached.

All participants signed informed consent after being informed of the purpose of the study. The study followed the comprehensive Criteria for qualitative research (COREQ) and trustworthiness indicators for reporting.[23,24] To ensure credibility, field recordings and audio captures from the interviews were included, followed by a team analysis to derive themes, which participants then authenticated.

Transferability was addressed by providing a detailed description of the study environment, including participant demographics, sampling logic, and procedural details. Dependability was maintained through an external academic review, ensuring adherence to qualitative research principles. Confirmability was achieved using triangulation to reduce researcher bias and self-selection to ensure awareness of potential limitations and maintain the study's integrity.

This study adopted a descriptive qualitative research design, using semi-structured interviews as an effective strategy to obtain qualitative research data. This approach helps to explain, understand, and explore the perspectives, behaviors, and experiences of the subjects, narrowing the research area of interest while listening to their participatory conversations. The research team members were all healthcare professionals who had received training related to qualitative research. The finalized interview outline included the following questions: 1) Can you describe your feelings when you were diagnosed with Meige syndrome? 2) What difficulties and challenges did you experience while waiting for surgery and during the surgical process? How did you cope with these challenges?3) How has your life changed after the surgery? 4) How satisfied are you with the overall treatment process? 5) Can you share how you received support from family and friends during your treatment for Meige syndrome? What significance did this support have for you? The interview outline was used as a reference and adjusted according to the actual situation during the interviews to ensure an in-depth understanding of the real experiences of patients with Meige syndrome and the application of individual and family self-management in this context.

Data Collection

Data were collected through face-to-face, one-on-one, semi-structured interviews. Semi-structured interviews are a method of in-depth communication designed to understand participants' experiences, attitudes, and perspectives through open-ended questions and a flexible feedback mechanism.[25] The researchers acted as interviewers and scheduled the time and place for the interviews with the participants.

The interviews were conducted from December 9, 2023, to March 9, 2024, in the education room of the Meige Center ward. Each participant was briefed by the researchers about the study and informed of the interview location and time. Each participant was interviewed for 30 minutes during their free time. First, the researchers introduced themselves to the participants and recorded the interview location and time. Before the interviews began, the interviewer explained the informed consent form to each participant and requested that they sign and date the document to confirm their informed consent. Next, the interviewer posed questions based on a pre-prepared interview guide and adjusted the questioning strategy flexibly according to the participants' feedback to ensure the collection of comprehensive information. Finally, at the end of the interview, the interviewer expressed gratitude to each participant, thanking them for their participation and for sharing their experiences.

Data Analysis

Data collection and analysis proceed concurrently. Within 24 hours following the conclusion of each interview, the audio recordings are reviewed multiple times, and the content is meticulously transcribed verbatim into text. Key non-verbal cues exhibited by the interviewees during the session, such as pauses, tonal shifts, facial expressions, and bodily gestures, are annotated alongside the transcription. Additionally, contemporaneous notes and reflective journals pertaining to the interviewees are amalgamated into their respective data sets. Each participant is assigned an individual file, with a unique identifier in the format of "N1, N2, N3. N15, N16". This study employed the Colaizzi qualitative analysis method:[26,27] 1) Carefully read all materials; 2) Extract significant statements; 3) Encode recurring themes; 4) Assemble the encoded themes; 5) Write a comprehensive and detailed description, ensuring no omissions; 6) Write a comprehensive and detailed description, ensuring no omissions; 7) Return to the participant for verification. The detailed steps are shown in Figure 2.

Results

Demographic Characteristics of Participants

This study collected data from 16 participants, including 10 female and 6 male patients, with an average age of 44.19 years and an average disease duration of 1.5 years. Detailed demographic characteristics of all participants were documented. The data are shown in Table 1.

Three core themes were identified from the analysis. Themes and Subthemes are shown in Table 2.

Theme 1: Context Dimension

Specific Disease Factors – Impact of Meige Syndrome on Patients' Vision, Psychology, and Quality of Daily Life

Due to factors such as ptosis, diplopia, and ocular motor dysfunction, Meige syndrome can easily lead to decreased vision in patients. The weakness and impaired movement of the eye muscles affect the clarity and stability of vision, making it difficult for patients to see objects clearly or maintain focus.

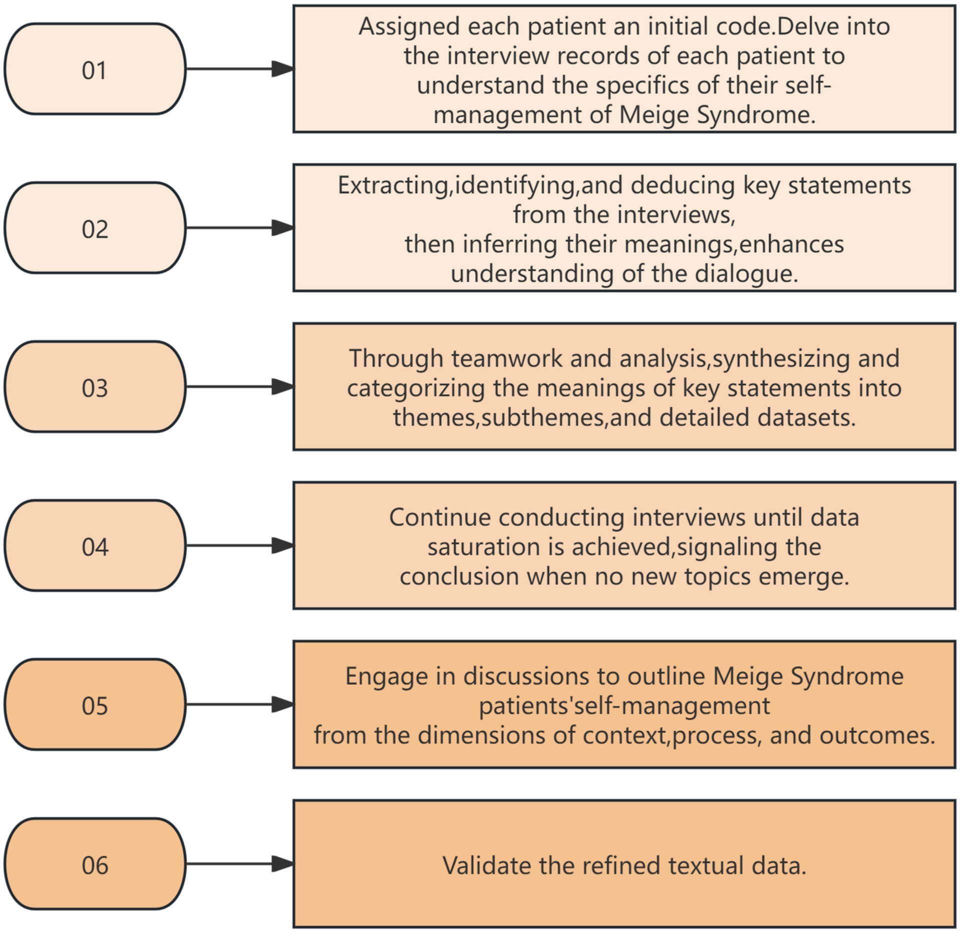

Figure 2 Steps of Colaizzi's qualitative analysis.

> Meige syndrome has been very distressing for me; my eyes cannot close properly, which leads to decreased vision. (N1)

Additionally, in the interviews, most Meige syndrome patients reported experiencing significant mental stress due to the condition. The symptoms of blepharospasm and oromandibular dystonia are often difficult to control. Patients expressed feelings of embarrassment, anxiety, and depression, worrying that their appearance would affect how others perceive them, leading to a decreased sense of self-worth and social isolation.

Table 1 Demographic Characteristics

Demographic Characteristics	**n(%)**
Age	
<30	1(6.25%)
31–40	5(31.25%)
41–50	5(31.25%)
51–60	4(25.00%)
>60	1(6.25%)

(*Continued*)

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Table 1 (Continued).

Demographic Characteristics	**n(%)**
Sex	
Women	10(62.50%)
Man	6(37.50%)
Educational Level	
Junior and primary schools	2(12.50%)
High school and technical secondary school	5(31.25%)
Junior college	6(37.50%)
Bachelor degree	2(12.50%)
Master degree or above	1(6.25%)
Marital status	
Married	13(81.25%)
Unmarried	1(6.25%)
Divorce	1(6.25%)
Bereaved spouse	1(6.25%)
Monthly income	
1000–4999	9(56.25%)
5000–9999	5(31.25%)
>10,000	2(12.50%)
Illness duration (year)	
<0.5	2(12.50%)
0.5–1	3(18.75%)
1–2	5(31.25%)
2–3	3(18.75%)
>3	3(18.75%)

> The progression of Meige syndrome is very rapid. I often feel anxious and uneasy, worrying that my vision will further deteriorate. (N4)
>
> This disease also puts a lot of psychological pressure on me. I often feel inferior and helpless. (N5)
>
> Every morning when I wake up, my eyes can't fully open, which makes me very uneasy. (N6)
>
> In public places, I am always afraid that others will notice the abnormality of my eyes, which makes me feel very embarrassed. (N7)

Due to physical discomfort and psychological stress, patients may be unable to work or study normally. Prolonged physical discomfort and mental burden can further deteriorate their quality of life, potentially leading to additional problems.

Table 2 Themes and Subthemes

Themes	**Subthemes**
1. Context Dimension	1.1 Specific Disease Factors - Impact on patients' visual, psychological, and quality of daily life.
	1.2 Physical and Social Environmental Factors
	1.3 Influence of Personal and Family Factors on Self-Management
2. Process Dimension	2.1 Knowledge and Beliefs: Understanding and exploration of Meige Syndrome
	2.2 Self-regulation and Self-efficacy
	2.3 Social Facilitation: Accessing professionals and authoritative knowledge
3. Outcome Dimension	3.1 Proximal Outcomes of Self-Management Behaviors
	3.2 Distal Outcomes of Self-Management Behaviors

> This disease has greatly impacted my daily life. I am unable to work or study normally. (N2)
>
> I often miss important information because of my limited vision, which causes significant trouble in my work and life. (N8)
>
> This disease has had a huge impact on my work and life. I can't use the computer for long periods, and reading has become difficult. (N10)

Physical and Social Environmental Factors – Impact on Self-Management of Meige Syndrome Patients

Currently, the unequal distribution of medical resources can prevent some patients from receiving timely and effective diagnosis and treatment. Here are some situations where patients have difficulty accessing medical care due to resource shortages.

> Residing in rural areas, I perceive significant inconvenience. In the event of illness, one must travel long distances to access medical care, which proves overly burdensome. There is a compelling need for the enhancement of healthcare services, ensuring timely access to requisite medical assistance for all individuals, irrespective of their financial status or geographical location. (N11)
>
> I reside in a remote village in Henan province. Approximately one year ago, I learned that Dr. Liu is offering free medical services in our village, eliciting genuine delight as it heralded the prospect of treatment. Due to the lack of convenient transportation, individuals inhabiting remote regions such as ours encounter substantial challenges in obtaining essential medical care. (N14)

Additionally, stable medical relationships can lead to better medical care for patients, and a healthy living environment can effectively reduce the risk of illness.

> When I went to the hospital, I understood one thing: to receive the best medical care, maintaining a long-term stable relationship with the doctor is crucial. Frequently changing doctors may affect the effectiveness and continuity of treatment. Therefore, I intend to continue treatment at this hospital in the future and establish a long-term cooperative relationship with a fixed doctor. (N13)
>
> The environment has a significant impact on health, whether it's the living or working environment. Environmental factors for this disease mainly include infections, poisoning, radiation, especially viral infections. Long-term stress and emotional fluctuations may also lead to worsening symptoms. (N16)

Ensuring a healthy and livable living and working environment is crucial. Communities can not only provide essential medical assistance to patients with Meige Syndrome but also establish corresponding social support networks for them.

> Communities provide various activities and education, and they also offer us a lot of support, which has been very helpful. These resources not only help me understand Meige Syndrome better but also guide me on how to lead a healthy life. (N12)

> By participating in community activities, I have met other patients, and we share experiences and support each other. Here, I no longer feel lonely. Although Meige Syndrome sometimes troubles me, with the help and support of the community, I believe I can overcome it and regain health and happiness. (N15)

In the workplace environment, the employer should also enhance their attention to employees' health and respect for those who are ill.

> One time while I was at work, my face started twitching, my eyelids spasmed, and my lips twisted outward, which made me feel very embarrassed. My colleagues even mocked me, and it was really painful. (N6)

> I feel that a good company should not only care about the employees' job performance but also pay attention to their health and happiness. (N7)

The Influence of Personal and Family Factors on Self-Management

Personal and family factors refer to individual and family characteristics that enhance or diminish self-management, such as personal cognitive status, attitudes, information processing ability, developmental stage, and personal and family capabilities, cohesion, cultural level, and intelligence.

A positive and optimistic mindset, along with a calm and stable attitude towards illness, can help patients engage in better self-management.

> As a Meige Syndrome patient, I know that this condition's recurrent flare-ups have caused me a lot of trouble in life. However, this challenge has also taught me patience and resilience. Now, when I face difficulties, I no longer react impulsively but have learned to confront them calmly. (N2)

> Throughout the battle against the illness, I've learned to manage my emotions better, no longer allowing the troubles of the disease to affect my mindset. (N5)

> Despite the many troubles that Meige Syndrome has brought into my life, I always believe that the struggle against it is not just a physical battle but also a battle of the spirit. I want to confront it with a positive attitude. (N7)

Some patients express that the support and assistance from their families are crucial forces that help them face their illness positively and improve self-management. Similarly, sharing experiences with fellow patients who have gone through similar struggles can alleviate the psychological burden for Meige Syndrome patients and provide strong support for their self-management.

> As a patient, I deeply appreciate the warmth and support of my family. After surgery, my vision was very poor, and I could hardly see anything. But my husband didn't reject me; instead, he helped me with meals every day, told me stories, making me feel very comforted and warm. (N6)

> The love and understanding from my family are my greatest sources of motivation. They let me know that I'm not alone in this battle; I have them by my side, supporting and encouraging me. (N7)

> There is a cultural wall in the hospital corridor, where the stories of other patients are recorded. These stories are genuine and touching, showing me how bravely other patients face their illnesses and strive to live. (N9)

> On the cultural wall of Meige patients, I saw and experienced that each of us has our own story. We share and encourage each other. (N10)

Theme 2: Process Dimension

The concept of the process dimension aligns with reports from medical research institutions regarding health and behavior. It includes three aspects: knowledge and beliefs, self-regulation abilities and skills, and social facilitation.

Knowledge and Beliefs: Understanding and Exploring Meige Syndrome

For Meige Syndrome patients, knowledge refers to the personalized information provided to them regarding their health. During interviews, some patients expressed affirmation and gratitude for the health education provided to them by hospitals.

> As a patient, I am very satisfied with the practice of the head nurse in establishing personal health records for us. I have received a lot of personalized information related to my health condition. These details not only help me better understand my physical condition but also provide me with treatment advice and health management plans that are more suitable for me. (N12)
>
> Through the health education manuals and videos provided by the hospital, I learned how to change my lifestyle and dietary habits to alleviate these symptoms and improve the quality of life. (N13)

Some patients also expressed an urgent desire to understand knowledge about Meige Syndrome.

> We, the patients, are in great need of understanding this disease. Why do we get Meige Syndrome ? How should Meige be treated? What complications can arise from having Meige? These are all things we need to understand, so that we can better cooperate with doctors' treatments. (N1)

Beliefs refer to patients' views on specific health conditions or health behaviors. Positive beliefs can play a significant role in promoting recovery from the illness.

> I believe I can overcome this disease as long as I actively cooperate with the doctors and maintain an optimistic attitude. (N7)
>
> I have realized the importance of confidence. Confidence gives me more motivation to cope with the disease, actively cooperate with treatment, and maintain a positive mindset. (N10)

Self-Regulation and Self-Efficacy

Self-efficacy is a behavior-specific concept that refers to the degree of confidence individuals have in their ability to successfully engage in a particular behavior under normal and stressful circumstances. In interviews, some patients demonstrated a high sense of self-efficacy, which played a crucial role in promoting health, coping with challenges, and improving the quality of life through personal and family self-management.

> I take my medication on time and follow the doctor's instructions for treatment, not giving up on any opportunity for recovery. (N4)
>
> I strive to maintain a positive attitude, trust in the doctor's treatment plan, and believe that I can overcome the illness. (N9)

Self-regulation is an iterative process that individuals engage in to promote healthy behavior improvements. It involves setting clear and achievable goals, using effective strategies to achieve these goals, and evaluating one's success in reaching them.

Self-regulation is crucial for the self-management of Meige Syndrome. In interviews, patients demonstrated effective coping strategies by controlling their lifestyle, dietary habits, and maintaining a positive mindset. Adhering to these measures requires persistent effort and patience, with the determination of the patients and the support of family and friends being key factors for success.

> I have gradually mastered self-regulation methods suitable for me through continuous learning and practice. I try to avoid factors that trigger Meige Syndrome, such as strong light and irritating smells. (N3)
>
> As a Meige Syndrome patient, I deeply understand the pain of the condition. I used to be a workaholic, relying on strong tea and coffee to stay awake. But now, to control my condition, I have to give up these habits. (N5)
>
> The doctor advised me to avoid consuming irritants, and I must strictly adhere to this. Although life is a bit dull, I believe it is worth it for my health. (N14)

> The process of self-regulation requires continuous patience and perseverance. The support of my family and friends is very important, as they have always encouraged me. Self-regulation is crucial for health. Through comprehensive measures, I successfully regained my health, and it was all worth it. (N15)

Social Facilitation: The Need for Professionals and Authoritative Knowledge

Patients with Meige Syndrome expressed a need for both societal support and professional treatment. They seek increased public awareness and understanding of the condition to reduce discrimination and improve acceptance in daily life. Patients also emphasize the importance of expert knowledge and authoritative institutions in managing their rare disease.

> Meige Syndrome has caused me a lot of psychological stress and distress. I really wish people could learn more about this disease and give us patients more care and support. (N1)

> I sincerely hope more people can understand us and give us care and help. This way, we can overcome the difficulties together. (N11)

Some patients who have received support from their families and society also express gratitude for this support.

> Fortunately, I have encountered some kind-hearted people. They accompanied me through the most difficult times, giving me encouragement and support. Their care has strengthened my confidence in overcoming the disease. (N13)

> During this journey of battling the disease, I deeply felt the love and support of my family and friends. They gave me strength when I was at my most vulnerable, giving me the courage to face the pain. (N15)

> As a Meige Syndrome patient, I am very grateful for the knowledge shared by my friends through the internet and other means. This information has been very helpful in coping with the disease. (N 16)

Patients with Meige Syndrome need professional care from doctors, ophthalmologists, and medical staff, including personalized treatment plans and regular follow-ups to manage and improve the condition.

> The support from doctors, family, and friends has been very helpful to me. When determining treatment and lifestyle plans, they always communicated with me, respecting my opinions and needs. I believe that as long as we work together, we can definitely overcome this disease. (N2)

Patients need reliable information from expert institutions on the causes, symptoms, and treatments of Meige Syndrome to make informed decisions and better manage the disease.

> Authoritative guidance has been crucial for me in the fight against Meige Syndrome. It helps me understand the disease better and aids in developing a more effective treatment plan. (N7)

Theme 3: Outcome Dimension

In IFSMT, the outcomes of self-management are divided into proximal and distal outcomes. Proximal outcomes in IFSMT involve self-management behaviors such as participation in treatment, symptom management, and adherence to medications or healthcare services. Distal outcomes include health status (disease prevention, alleviation, stabilization, or worsening), quality of life (overall well-being), and costs (both direct and indirect).

Proximal Outcomes of Self-Management Behaviors

For patients with Meige Syndrome, they often feel frustrated and helpless, especially considering the impact of the disease on their daily lives and work.

> I am a Meige Syndrome patient, and this disease has brought great trouble to my life. I feel very helpless and frustrated. (N3)

> The symptoms of my eye disease prevent me from working and living normally. I feel very helpless and frustrated. (N4)

Patients maintain a positive attitude and cooperate with treatment, emphasizing the importance of self-management and family support in coping with Meige Syndrome, which helps them adapt to and alleviate the challenges of the disease.

> In the course of treatment, I actively cooperate with the doctor's treatment plan, take my medication on time, and also manage myself at home, such as through eye massages. (N4)

> Although the treatment process is difficult, through self-management and family support, I have gradually adapted to the changes brought by the disease. (N8)

> My experience has made me deeply aware that for patients with eye diseases, self-management and family support are extremely important. (N10)

Distal Outcomes of Self-Management Behaviors

Patients reported positive changes after surgery for Meige Syndrome, including symptom relief, improved quality of life, and reduced financial pressure. These improvements gave them hope and satisfaction, with family, friends, and doctors providing crucial support in the recovery process.

> After the surgery, I felt that my Meige Syndrome symptoms had significantly lessened, which filled me with hope for future recovery. (N9)

> Although the surgery was somewhat painful, seeing such good postoperative results makes me feel that it was all worth it. (N11)

> I sincerely thank the doctors for performing the surgery and my family and friends for their support and encouragement. Without them, I might not have been able to persevere until now. (N12)

Additionally, the support from health insurance policies has alleviated the financial burden, allowing patients to better focus on their lives.

> Thanks to the help from health insurance, most of the medical expenses were reimbursed, which greatly reduced my financial burden. (N15)

Discussion

This study aims to delve into the specific application of IFSMT through in-depth interviews with patients suffering from Meige Syndrome.

Context Dimension of IFSMT

In the interviews, 62.50% of Meige Syndrome patients reported that the disease imposed significant mental stress on them. Meige Syndrome, characterized by factors such as ptosis, double vision, and eye movement disorders, has a huge impact on patients' vision. Symptoms like exophthalmos and ptosis not only alter the patients' appearance but often lead to ridicule and strange outlooks, causing feelings of shame and inferiority. This, in turn, affects their social and emotional well-being.[28,29] However, a previous study indicated that a deeper understanding of the disease and related issues, as well as a "positive reinterpretation" of the pain, can effectively alleviate patients' suffering.[30] Caroline F. Wright's research on rare diseases in children also demonstrated that a better understanding of the genetic basis of rare diseases could translate into more accurate prognosis, management, and monitoring for patients.[31] Therefore, it is evident that understanding and cognition of Meige Syndrome (rare disease) are crucial in the self-management process for patients. This understanding includes not only knowledge about the disease itself but also insights into treatment, prevention, and self-care.

American scholar Lesley Steinman's research on chronic disease self-management points out that integrating self-management into daily life through mobile health methods such as medication reminders and doctor-patient communication helps reduce the consumption of medical resources.[32] Similarly, Ran Li et al indicates that the enrichment of medical resources, such as mobile health, is a crucial factor in improving self-management abilities for hypertension patients.[33] On the other hand, British scholar Sadie Lawes-Wickwar's research on blepharospasm demonstrates that allowing patients to have control over their treatment process can effectively reduce anxiety and other negative emotions.[12] Therefore, ensuring that Meige Syndrome patients have access to sufficient and diverse medical resources, such as convenient medical channels and stable healthcare relationships, can significantly aid in effectively managing their condition.

There is reasonable epidemiological evidence indicating that certain environmental factors, such as the habit of drinking coffee, are risk-modulating factors for specific forms of adult-onset primary focal dystonia.[34] Additionally, research by Ann Abney and others[35] suggests that workplaces should foster a culture that values employee health and respects those who are ill. Therefore, maintaining healthy lifestyle habits and having a supportive work environment are crucial factors for effective self-management. These factors can not only reduce the risk of illness but also encourage patients with conditions like Meige Syndrome to engage in positive self-management.

Research by Indian scholar Sanjay Pandey on Meige syndrome[36] shows that individuals with Meige Syndrome often experience exacerbated symptoms of blepharospasm when facing stress, mental tension, or low mood. Additionally, social support from family and friends is crucial for alleviating negative emotions and aiding postoperative recovery.[37–39]Therefore, maintaining a positive and optimistic mindset, adopting a calm and stable attitude towards the disease, and receiving support and assistance from family are essential forces for patients to actively cope with the disease and enhance their self-management abilities. These factors can significantly help patients better manage their condition.

Process Dimension of IFSMT

In this study, over 90% of patients reported that providing personalized health-related information helps them develop a correct understanding of their disease and fosters a positive attitude towards overcoming it. This also contributes to enhancing patients' self-efficacy, enabling them to better cope with the challenges. Birute Tumiene highlighted the importance of patient- and family-centered medical education to meet the needs of rare disease patients.[40] Similarly, in the field of ocular diseases, Shan Wang et al' research on cataracts[41] confirmed this finding. Therefore, health education for patients with Meige Syndrome can encourage the adoption of appropriate self-management behaviors.

Many studies have shown that good self-regulation is crucial for patient self-management.[42–44] John Allegrante et al, in their research on chronic disease self-management,[45] pointed out that controlling lifestyle, dietary habits, and maintaining a positive mindset are highly effective self-management strategies. In this study, more than 50% of patients effectively alleviated symptoms such as dry eyes and vision decline by improving their dietary habits and eye hygiene. Therefore, self-management plays a significant role in the prevention and treatment of dry eye syndrome. A study from Canada on dry eye syndrome indicated that developing personalized self-management plans is an effective measure to improve or alleviate dry eye symptoms in the workplace.[46] Additionally, Christina Jones, in her research on recovery after intensive care unit stays,[47] demonstrated that encouraging patients to actively adjust their mindset and reduce mental stress also positively promotes disease recovery.

Additionally, research by Qinghua Zhang on hypertensive patients[48] indicated that social support plays a crucial role in patient self-management. For patients with ocular diseases, authoritative institutions should provide reliable disease information[49] to help them better understand the causes, symptoms, and treatment options, enabling them to devise effective strategies for managing their conditions. Medically, patients need to receive treatment and care from a professional healthcare team, including doctors, ophthalmologists, and medical social workers,[50] to ensure their condition is controlled and improved. A study from the United States on rare diseases[51] noted that rare disease patients desire deeper societal understanding of these conditions, along with more support and care. Similarly, a study from Japan on rare diseases[52] highlighted the importance of raising public awareness and understanding of rare diseases. This approach can help patients with rare conditions, such as Meige Syndrome, avoid discrimination in their daily lives and work environments.

Outcome Dimension of IFSMT

From the perspective of the outcome dimension, effective self-management behaviors can significantly improve both proximal and distal outcomes. In terms of proximal outcomes, patients' positive attitudes and adherence to treatment plans are key aspects of self-management. Research by Dutch scholar Astrid N. van Smoorenburg on diabetes self-management,[53] and Australian researcher Hang Ding on the impact of remote monitoring,[54] both highlight the importance of patients' positive attitudes and cooperation in the self-management process. Additionally, Wojciech Omulecki's study on cataract patients found that emotional states significantly influence patients' ability to actively cooperate with doctors and nurses during treatment.[55] Thus, for patients with Meige Syndrome, maintaining a positive attitude and actively cooperating with treatment is highly beneficial for gradually adapting to and alleviating the challenges posed by the disease.

In terms of distal outcomes, surgical treatment plays a significant role in patient recovery. Research by Hongying Ma et al on Meige Syndrome suggests that surgery is an acceptable and effective treatment for these patients.[56] Effective surgical methods include GPi-DBS, STN-DBS, pallidotomy, and selective myectomy combined with in situ myotomy.[57,58] Research by Czyz et al suggests that long-term botulinum toxin treatment produces clinical success in the alleviation of facial dystonia symptoms.[3] Research by Duarte et al support that onabotulinum toxin type A(OBTA) seems to be an effective and safe therapeutic option for treating Meige's syndrome, and the effect of OBTA is more pronounced in the treatment of blepharospasm than in oromandibular dystonia.[59] The improvement in postoperative status of Meige patients is a manifestation of their positive response, from symptom relief through medication injections[59] or the aforementioned surgeries, to the alleviation of financial burdens with societal support for patients with rare diseases like Meige Syndrome.[10] These changes not only bring hope to patients but also provide them with greater satisfaction. Health insurance policies that support rare diseases[9] play a crucial role in the treatment and rehabilitation of Meige Syndrome patients. Research by Tulio Reis et al also indicates that including vision services in universal healthcare coverage can reduce the burden of cataracts in Latin America.[60] Support from family, friends, and doctors is also vital in the recovery process,[61] enabling patients to better reintegrate into daily life.

Limitations and Suggestions for Future Research

This study has several limitations. First, the small sample size, due to the rarity of Meige Syndrome, may not fully capture the diverse experiences of the patient population. Future research should aim to increase the sample size for more generalizable results. Second, the study focused solely on the impact of IFSMT, without considering other influencing factors such as medical support, social support, or psychological status. Future studies could explore these factors and their relationship with IFSMT. Third, the use of qualitative methods (face-to-face interviews) may introduce subjectivity, and future research could incorporate quantitative methods to better assess the impact of self-management on patients' quality of life and disease management. Finally, this study concentrated on ocular symptoms, leaving other aspects of Meige Syndrome unexplored. Future studies could apply IFSMT to other patient groups with different manifestations (eg, oral or joint issues) to assess the theory's broader applicability.

Conclusion

In conclusion, this study underscores the importance of understanding the multifaceted psychological and social experiences of patients with Meige Syndrome, particularly during the perioperative period. Our findings, structured through the three dimensions of the Integrated Framework for Self-Management Theory (IFSMT), provide a comprehensive view of the factors influencing self-management behaviors in these patients. Specifically, the "Context Dimension" emphasizes the significant role of personal, social, and environmental factors—such as emotional state, social support, and healthcare accessibility—that shape self-management. The "Process Dimension" highlights the specific actions and strategies employed by patients, such as medication adherence and coping mechanisms, which are crucial for managing their condition. Finally, the "Outcome Dimension" evaluates the results of these self-management efforts in terms of both proximal outcomes (eg, symptom control, emotional well-being) and distal outcomes (eg, long-term health outcomes and quality of life).

The integration of these dimensions offers a more holistic and personalized approach to care, allowing healthcare providers to better support patients' psychological and social needs while improving their overall management of Meige Syndrome. This approach contributes to the existing literature by addressing the gap in understanding the psychological aspects of the disease and proposes a model that can guide clinical interventions aimed at improving both short-term and long-term patient outcomes.

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Abbreviation

IFSMT, Individual and Family Self-Management Theory.

Data Sharing Statement

Due to the sensitive nature of the questions asked in this study, survey respondents were assured raw data would remain confidential and would not be shared, so supporting data is not available.

Ethics Approval and Consent to Participate

This study followed the Declaration of Helsinki and was approved by Medical Ethics Committee of The Third People's Hospital of Henan Province, ethics number: 2024-SZSYKY-023. All participants were informed of the purpose of the study and provided written informed consent. This consent explicitly included the publication of anonymized responses and direct quotes.

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Author Contributions

Meng Li, Qingmiao Li and Junfan Wei contributed equally to this work as the co-first authors.

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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The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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