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Mapping the Health Management Journey of Patients Undergoing Sacral Neuromodulation: A Descriptive Qualitative Study

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Mapping the Health Management Journey of Patients Undergoing Sacral Neuromodulation: A Descriptive Qualitative Study

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ABSTRACT

Background: Patient journey maps are increasingly used as a tool that enables healthcare providers to refine their service provision to best meet patient needs. SNM treatment features a phased, long - term management approach and device adaptability, which necessitates a dynamic representation of the patient experience. We developed an SNM patient journey map (SPJM) that describes patients' experiences from diagnosis to long - term self - management.

Methods: Based on the patient journey map framework and using a descriptive qualitative research method, maximum variation purposive sampling was used, and recruitment continued until data saturation was achieved, and 17 patients with SNM were selected for semi-structured interviews from March and June, 2026. The Colaizzi's seven-step analysis method was used to analyze the interview data. The journey map was developed by integrating interview themes, observation data, and stakeholder validation.

Results: Seventeen eligible patients participated, and 28 topics were identified across needs, pain points, emotions, and stakeholder involvement. A journey map framework was constructed based

on a literature review, with its horizontal axis divided into diagnosis, stage I surgery, transitional care, stage II surgery, and long-term self-management. Additionally, relevant personnel and their participation time domains were identified, thus forming the SNM disease management journey map.

Conclusions: This descriptive qualitative study mapped the complete health management trajectory of patients receiving SNM. The SPJM serves as a practical reference and framework for developing phase-based, full-cycle nursing interventions, which can effectively improve patients' treatment experience and quality of life. Clinicians are encouraged to further optimize and disseminate standardized staged health management strategies based on this model in routine practice.

Keywords: Sacral neuromodulation; patient journey map; disease management; qualitative research; precision management

Introduction

Sacral neuromodulation (SNM)[1],is an emerging neuromodulation therapy for refractory lower urinary tract dysfunction. This surgical intervention involves the continuous delivery of low-voltage, short-pulse electrical currents to the sacral nerves via an implanted pulse generator, thereby modulating their electrophysiological properties and influencing the innervated pelvic organs[2]. The standard clinical protocol is a two-stage process[3, 4]external pulse generator to assess therapeutic efficacy over 3-4 weeks, followed by permanent implantation of the device in responders, defined as those achieving ≥50% improvement in symptoms. SNM is indicated for conditions such as urgency urinary incontinence, non-obstructive urinary retention, and overactive bladder syndrome[5]. Patients can manage symptoms by controlling and adjusting stimulation

parameters via an external programmer.

As an invasive chronic therapy, SNM treatment consists of multiple phases and requires long-term adherence, covering diagnosis, staged surgical treatment and continuous self-management. During the whole process, patients suffer from both physical issues and prolonged psychosocial pressures, such as worries about treatment effects, poor adaptation to implants, stigma and restricted daily and social activities. Given the obvious phased features of patient experience, it is essential to develop a corresponding health management journey map[6, 7].

However, existing quantitative studies on SNM, while confirming safety and efficacy, rely on static outcome measures that fail to capture patients' continuous experiences—the evolving needs, emotions, and practical challenges across diagnosis, surgery, and long-term self-management. These experiences fluctuate significantly, yet no current evidence tracks them continuously over time. As a result, it remains unclear how diagnostic phase experiences shape surgical decisions, and how early postoperative burdens affect long-term adherence and coping.

Patient journey mapping has already demonstrated notable success in chronic disease management and surgical continuity of care. For example, Bharatan [8]applied quantitative patient journey mapping across different illness stages among chronically ill patients in low - and middle - income countries, which enhanced patient engagement in self - management and provided effective guidance for integrating care resources and improving care quality. Similarly, a study on the full - journey experience and multidimensional health management needs of young and middle-aged colorectal cancer patients with ostomy provided insights for optimizing continuity and holistic care for this specific population[9].

Therefore, this study aims to employ a descriptive qualitative research method to construct a

comprehensive health management journey map for SNM patients from their own perspective. By systematically exploring and analyzing this complete trajectory, the study further seeks to identify the multifaceted needs and challenges that patients face at various stages, thereby pinpointing precise intervention targets and providing an empirical foundation for personalized, whole-cycle, and responsive SNM health management interventions.

Methods

Study design

The patient journey map was constructed through a three-phase methodology: (1) a desktop review of clinical protocols and workflows, (2) participant observation to establish the initial journey framework, and (3) semi-structured patient interviews to refine experiential details and identify innovation opportunities[10]. Following thematic analysis of the interview data, collaborative evaluation was conducted with key stakeholders, including patients and family caregivers, to finalize validation of the journey map, serving as a supplementary step after the third phase.

This study adopts a descriptive qualitative design, with the aim of providing a straightforward description of patients' real-world experiences , rather than constructing theoretical models. Guided by this stance, we focused on capturing the complex real-world experiences of SNM patients to generate actionable insights for clinical practice. This approach is well-suited for exploring cases where a direct description of the relevant phenomena is required[11] SNM management involves critical transitions-from disease diagnosis and surgical intervention to rehabilitation and long-term follow-up-each shaped by unique physical, emotional, and social challenges.

In-depth interviews were conducted with participants, and the interview data were analyzed using Colaizzi's seven-step method with the assistance of NVivo 15.0. This qualitative design enables patients to narrate their experiences holistically, revealing nuanced insights into their decision-making processes, barriers to care adherence, and evolving support needs. The Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines were applied to evaluate the qualitative research reports produced for this study[12]

Study Setting and Recruitment

Participants were recruited using maximum variation purposive sampling. Sampling dimensions were selected according to their potential to shape patients' experiences, including age, marital status, gender, educational level, household income, disease category, treatment stage, and treatment outcome. To ensure the adequacy of this strategy, we subsequently reviewed the achieved sample and confirmed that it spanned a wide range of values across all these dimensions. Recruitment was completed in the Department of Urology at a tertiary hospital in Hefei, China, from March and June, 2026. Inclusion criteria were as follows: (1) Scheduled for SNM surgery; (2) aged >18 years; (3) undergoing Stage I or Stage II implantation, or within one month postoperatively; (4) with normal cognitive and communication abilities; and (5) voluntary participation with signed informed consent.

Exclusion criteria included:(1) patients with unstable conditions preventing their prolonged communication; (2) patients with malignant tumours or other serious physical conditions; and (3) patients in the terminal phase of the illness; and (4) patients with psychological or psychiatric disorders . The sample size was determined based on the principle of data saturation. After each interview, the research team immediately conducted debriefing sessions and initiated preliminary

coding. Data saturation was considered reached when no new themes emerged from three consecutive participants, at which point further interviews were terminated[13].To mitigate potential recall bias, we employed the following strategies[14]. First, we aimed to conduct interviews as soon as possible after each key time point—namely, following the first-stage surgery, the second-stage surgery, and the one-month postoperative follow-up-to minimize the interval between events and their recollection; the maximum postoperative interval was limited to one month[15]. Second, we facilitated memory retrieval by utilizing time anchors and probes: participants were provided with prompts and an optional time frame and were asked to structure their narratives around these frames, which helped them pinpoint specific temporal events rather than reporting inaccurate memories[16].

Research team

We established a multidisciplinary research team comprising one principal investigators, three research assistants , and two supervisor . The research workflow was structured as follows: principal investigators were responsible for study design, interview implementation, and data analysis. Specifically, investigators collaboratively conducted all interviews. The three research assistants were tasked with organizing interview content and processing raw data. The two supervisors oversaw the entire analysis process and resolved any ambiguities to ensure the accuracy and reliability of the data analysis.

Notably, the interviewers had no clinical care relationship with the participants, which avoided any potential conflicts of interest. All team members received training in qualitative research methods and had extensive clinical experience, laying a solid foundation for the rigor and scientific validity of the study.

Research method

1) Desktop review research

The research team conducted a desktop review of relevant guidelines, clinical pathways, nursing procedures, device manuals, and our institutional workflow to aggregate available clinical data on patients with SNM implantation[17]. Through iterative discussions,we developed a patient journey timeline identifying five critical stages: diagnosis, stage I surgery, transitional care, stage II surgery, and long-term self-management.

2) Participatory observation method

A structured participant observation was conducted to supplement the interview data and capture real-time perioperative interactions. All observations were conducted after obtaining written informed consent from the patients. Two registered nurses served as observers; they had completed one week of qualitative observation training and were not involved in the clinical care of the participants. Three patients diagnosed with SNM who underwent surgical management were purposively selected as observation subjects. These three patients constituted a subset of the 17 interview participants, and were selected to ensure diversity in clinical characteristics including sex, disease stage, and treatment response. Observations were performed in the operating room and postoperative ward, covering key perioperative time points such as preoperative consultation, intraoperative procedures, postoperative care, and device parameter adjustment. For each patient, three observation sessions were conducted, each lasting approximately 2 hours, resulting in a total of 9 observation sessions. Observers adopted a structured observation form combined with field notes to record task flows, emotions, pain points, and stakeholder interactions in real time. All notes were transcribed into electronic documents within 24 hours after each session. Observers

maintained a neutral, non-participatory stance and did not intervene in clinical procedures. To ensure accuracy, audio recordings were used as a supplement for key interactive segments, and verbal consent was obtained from all observed individuals.

Given the heterogeneity of the data, analytical methods were selected based on their respective strengths: Interview data were analyzed using Colaizzi's descriptive qualitative research method, which is well-suited for interpreting lived experiences, while observation data were independently coded using thematic analysis.which is effective for capturing structured patterns of behavior and interaction. The findings from both datasets were integrated through a triangulation approach: data from the two datasets were first analyzed separately, then compared and contrasted to identify convergent and divergent themes. Discrepancies were resolved through iterative team discussions, leading to the refinement of a unified multidimensional journey map supported by evidence from both data types. All identifiable information was anonymized to protect participant confidentiality.

3) Semi-structured interviews

(1) Interview guide

The interview guide was developed based on the research objectives, a review of the literature, and group discussions. It was subsequently revised and refined following a pilot interview with three patients. For example, the original question “Did you feel pain after surgery?” was too broad, yielding vague responses, and was therefore split into two more specific questions: “What did you feel after surgery?” and “How did this sensation affect your daily activities?” Another question, “What do you think about wearing the device long-term?” was rephrased to “What feelings or thoughts do you have about the long-term use of the device after discharge?” because the initial wording was overly technical. The remaining questions (covering symptom detection,

surgical decision-making, perioperative experiences, adaptation, and long-term adjustment underwent only minor wording adjustments. Two experts in qualitative research and urinary surgery nursing were invited to review the interview guide, and further revisions were made based on their feedback.(Table 1)

Table 1 Semi-structured interview guide and its targeted constructs

Interview Question	Targeted Constructs
(1) What experiences, thoughts, and feelings did you have from noticing physical abnormalities to deciding to seek medical care? (2) What were your initial reactions and inner feelings when being informed that surgery could treat your disease? (3) What experiences or feelings during the perioperative period and hospitalization remain memorable to you? (4) How did you adapt to physical changes and cope with discomfort or life inconveniences during postoperative recovery? (5) How did you make decisions and adjust your mindset and living status when facing the choice of secondary surgery or long-term post-discharge rehabilitation? (6) What is the most influential experience throughout your entire treatment journey,and why?	● Symptom recognition and perception ● Disease cognition healthcare-seeking behavior ● barriers to healthcare ● Surgical cognition ● treatment decision-making and motivation ● trust in healthcare providers and recommendations ● Perioperative psychological state; Healthcare provider support experience ● Satisfaction with inpatient care ● Perioperative coping strategies ● Device adaptation ● symptom perception improvement ● maladaptation to lifestyle modification ● Adherence to rehabilitation Post-discharge self-health management capacity ● Utilization of social support ● Psychological adjustment during the rehabilitation period ● Health management optimization recommendations ● changes in quality of life after treatment

4) Data collection

First, data were collected through face-to-face semi-structured interviews. Two principal investigators who had received training in qualitative research conducted all interviews. Prior

permission was obtained from the nursing managers of the participating department.

Second, the researchers informed eligible participants of the study's objectives and clinical significance, and ensured anonymity while strictly protecting participants' privacy. Interviews were scheduled at locations and times preferred by participants to ensure their comfort and convenience. During the interviews, participants were encouraged to share their personal experiences. All sessions were conducted without any third parties present, with only the participant and the researchers in attendance.

Finally, confidentiality was guaranteed through anonymized data handling and secure information storage. Each interview, carried out by two principal investigators, lasted approximately 30 to 40 minutes and was audio-recorded in its entirety.

5) Data analysis

Within 24 hours after the interview, two research assistants listened to the audio recordings repeatedly, transcribed them verbatim, and cross-checked the transcripts against the original recordings for accuracy. The transcripts were further supplemented with on-site notes to ensure completeness. Data were analyzed using Colaizzi's seven-step method[18], facilitated by NVivo 15.0 for coding. The steps included:① Listen attentively to patients' specific statements and discern their perspectives and attitudes by observing tone and intonation variations.② Analyze and distill key statements.③ Conduct statistical analysis and define recurring viewpoints.④ Consolidate frequently repeated perspectives into meaningful thematic clusters.⑤ List detailed descriptions and identify similar viewpoints based on them.⑥ Group similar viewpoints into comparable survey themes.⑦ Strive to obtain final validation from respondents.

Subsequently, the emerging themes were integrated with a pre-constructed journey map

framework to capture changes in patients' disease - management needs across different stages of SNM. The journey map was used to visually present the results.Finally, researchers and patients jointly reviewed the findings through thematic discussions, refining the journey map content to ensure comprehensiveness and consistency.

Rigour and reflexivity

This study complied with the Standards for COREQ[12] and systematically ensured trustworthiness through credibility, transferability, dependability, and confirmability. Credibility was established by ensuring no prior relationship with participants, employing a dual - researcher strategy (one leading interviews, one observing non - verbal behaviours), actively listening, avoiding leading language, and clarifying ambiguous content to minimize social desirability bias. Collaborative interview notes captured insightful perspectives, and triangulation was achieved through the integration of participant validation, researcher analysis, and expert evaluation[19]. Transferability was supported by documenting procedures such as the interview guide, data transcription, and analysis steps, enabling readers to assess applicability to similar contexts. Dependability was ensured through reflexive practices throughout data collection and analysi[20], secure storage of all records, and transparent documentation to facilitate reproducibility. Confirmability was reinforced by maintaining researcher neutrality during data collection and analysis, and by grounding findings in participant data rather than preconceptions, with external expert evaluation further verifying the correspondence between data and conclusions.

Ethical considerations

This study received ethical approval from the Institutional Review Board of The Second Affiliated Hospital of Anhui Medical UniversityYX2026-276. Written informed consent,including

permission for audio-recording, was obtained from all participants prior to data collection. Participants retained the right to with draw from interviews at any time without penalty, though no withdrawals occurred.

To ensure participants' privacy and data confidentiality throughout the research process, the following measures were implemented: (1) The social media application WeChat was used solely for initial contact and scheduling interviews, not for data collection. Participants' We Chat IDs and phone numbers were stored separately from their research data and were accessible only to the principal investigator. (2) All participant identifiable information was removed and replaced with a unique study code (e.g., P1, P2) during transcription and data analysis. All digital records (audio recordings, transcripts) were stored under this anonymous code. (3) All electronic data are stored on a secure, protected hard disk.

Results

1) Characteristics of the study population

A total of 17 patients were enrolled in this study. Among them, 14 patients successfully completed both Stage I surgery and Stage II surgery, whereas the remaining 3 patients opted to ab andon the Stage II surgery because the Stage I surgery had not achieved the expected outcomes. including 9 males and 8 females. The age of the patients ranged from 27 to 84 years, with a mean age of (61.59±13.72) years. In terms of educational level, 5.88% of the patients had received higher education. Additionally, 88.24% of the patients were married. The patients were investigated during the first stage of SNM surgery, the second stage of SNM surgery and the rehabilitation period, with a total of 45 interviews conducted. Among them, 14 patients completed three interviews. A total of 17 patients underwent primary surgery, among whom 14 underwent

secondary surgery. Detailed information is shown in the table 2

Table 2: Demographic characteristics of participants (n = 17)

Variable	Category	Frequency (n)	Percentage (%)
Age (years)	≤40	1	5.88
	41-60	10	58.82
	61-79	4	23.53
	≥80	2	11.76
Gender	Male	9	52.94
	Female	8	47.06
Educational Level	No formal education	5	29.41
	Primary school	5	29.41
	Middle school	6	35.29
	Higher education	1	5.88
Marital Status	Unmarried	2	11.76
	Married	15	88.24
Employment Status	Unemployed	14	82.35
	Retired	3	17.65
Treatment Phase	Stage I surgery	17	100%
	stage II surgery	14	82.35%
	Long-term self-management	14	82.35%
Treatment Outcomes	effective	14	82.35%
	inefficient	3	17.64%

Table 2: Demographic characteristics of participants (n = 17)

2) Construction of the journey framework

The patient journey map was organized using a dual-axis structure: time progression (horizontal axis) and functional dimensions (vertical axis). Guided by clinical expert consensus, the timeline was divided into five stages: diagnosis, stage I surgery, transitional care, stage II surgery, and long-term self-management. The vertical axis comprises four functional areas critical to the health management trajectory: tasks, emotions, pain points, and stakeholder interactions.

Based on the established journey framework, we conducted in-depth thematic analysis of interview data across four dimensions: clinical tasks, emotions, pain points, and stakeholder interactions. Through rigorous coding, 727 codes were aggregated into 58 sub-topics, which were eventually integrated into 28 topics, systematically documenting behavioral adaptation, emotional transitions, and care barriers across all stages of health management.

This process enables the construction of a multi-dimensional storyline, resulting in a comprehensive SNM health management journey map (Figure 1), which intuitively integrates the health management trajectory of patients at each disease stage.

Figure 1：Health management journey map of patients undergoing sacral neuromodulation.

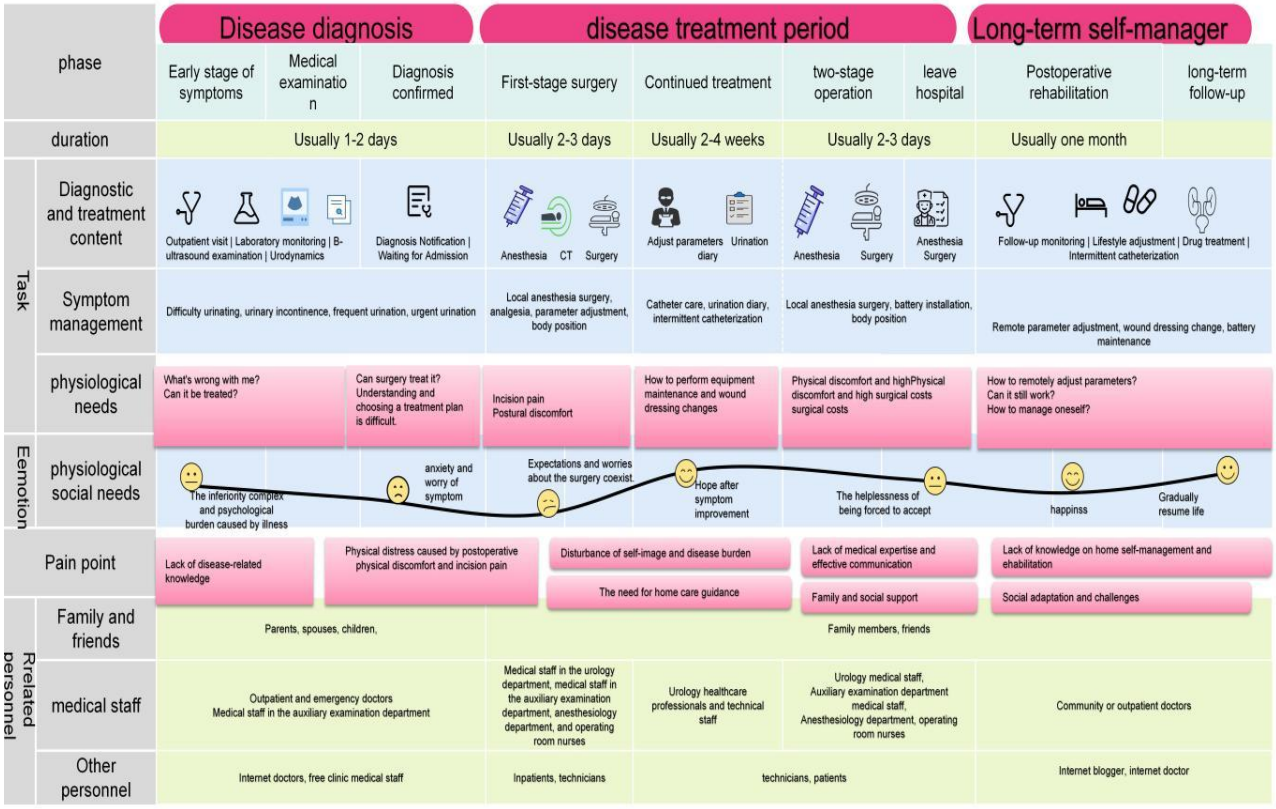


Figure 1：Health management journey map of patients undergoing sacral neuromodulation.

Diagnosis

Tasks

①Participation in diagnostic assessment and treatment planning

The patient showed good compliance and cooperated in completing all examinations and evaluations, including urodynamics and ultrasound. These findings offer a clinical basis for disease diagnosis and the formulation of individualized treatment strategies, while also guaranteeing the implementation of standardized clinical practices.

P5 stated: “All routine examinations have been completed, including urodynamic and bladder-related tests.”

P17 stated: “Urodynamic ,ultrasound, and residual urine volume measurements were performed.”

② Selection of medical resources.

Patients' decision-making regarding healthcare resources is influenced by multiple factors. The core determinants can be summarized as medical capacity, accessibility of healthcare services, and recommendations from others. This reflects patients' rational judgment in selecting healthcare resources, and their preferences also provide references for optimizing clinical medical services.

P11 stated: “Certainly, the large hospital is superior. Additionally, my daughter resides near this hospital. I trust your hospital.”

P4 stated: “The primary reason is its proximity to my residence. In fact, I chose this physician due to a recommendation from a physician at a county-level hospital.”

1) Emotions

① Anxiety and worry

Patients experience intense psychological stress due to their first encounter with the diseaseand lack of disease-related knowledge, manifesting as nocturnal insomnia and emotional lethargy. Secondly, patients develop a desire for urgent treatment due to concerns about disease progression. Such emotional responses not only affect the patients' psychological state but may also potentially impact treatment adherence, providing a practical basis for clinical psychological intervention.

P12 reported: “feeling extremely depressed and demoralized. At that time, I had never heard of this disease. I was unable to sleep at night”.

P13 said：“It was like grabbing a lifeline-treat him immediately”.

② Symptom-related inferiority and psychological burden

Patients reported inferiority, fear of negative evaluation, and embarrassment caused by urinary

symptoms. This constant psychosomatic interplay created a negative feedback loop: psychological distress amplified symptom perception, which in turn worsened daily functioning and emotional burden.

P9 stated: “Lack of self-esteem. Fear of being criticized by others, which causes significant distress. Inferiority complex”.

P5 described:“the most embarrassing situations as walking or changing clothes. Urinary incontinence led to accidental soiling. Tell me, for a normal person—not Alzheimer's disease—how embarrassing is that?”

2) Pain points

Lack of disease-related knowledge

Lack of disease-related knowledge was a core pain point, which led to cognitive bias and delayed attention to early symptoms. When initial symptoms appear, patients often attribute them to normal physiological phenomena; additionally, elderly patients may perceive these symptoms as natural aging-related manifestations and fail to seek immediate medical attention. This cognitive deficiency not only delays optimal diagnostic and therapeutic opportunities but may also exacerbate psychological burdens during symptom progression.

P12 reported：“initial difficulty in urination, which I initially attributed to prostatic issues, given that benign prostatic hyperplasia is a common condition in males. I considered this to be a normal physiological phenomenon.”

P11 remarked, “I just thought it was normal for older adults and didn't take it seriously.”

Stage I surgery

1) Tasks

① Treatment decision-making and adherence

Patients' treatment decision-making and adherence were non-autonomous, being heavily influenced by family and healthcare professionals. They prioritized fulfilling family roles rather than actively participating in decisions.

P2 stated: “The surgery was a joint decision made by the children, and I was unwilling to undergo the procedure”.

P3 stated: “ In the hospital, it's all about the doctors”.

P4 stated: "Initially, I considered conservative treatment, but my family insisted on undergoing this surgery, so we proceeded with it."

② The role of physicians and nurses in treatment

Physicians and nurses play a pivotal role in treatment decision-making and adherence, assuming distinct responsibilities: physicians are primarily responsible for explaining treatment protocols-clarifying the rationale, risks, benefits, and alternative options to ensure informed decision-making—whereas nurses focus on device guidance (training patients to correctly use medical equipment such as urinary incontinence management devices) and perioperative care, including preoperative preparation, postoperative monitoring, and complication prevention. Together, they serve as the key agents driving the scientific implementation of treatment decisions and enhancing patients’ treatment awareness and adherence.

P7 stated: "We basically followed the doctor's advice. They proposed three options: one was clean intermittent catheterization, the second was permanent suprapubic cystostomy, and the third was SNM， The doctor recommended SNM for us."

P8 stated: “I reviewed some materials, but still did not understand. Later, upon arriving at the

hospital, the physician provided me with a detailed explanation."

Emotions

① **Expectations and concerns coexist regarding the surgical procedure.**

Many patients view the surgery as a final option after the failure of existing therapies-a perception that fosters strong hopes for success while also generating profound unease about the uncertain outcome. This uncertainty is heightened by the experimental nature of the treatment, as patients lack sufficient evidence regarding its efficacy and long-term safety. At the same time, awareness of surgical risks contributes to notable anxiety, reflecting a shared recognition among participants of the inherent unpredictability of the procedure. Thus, the emotional core of the decision-making stage lies in balancing the "grasp for a cure" against the "acceptance of trial risks."

P12 described it as "the last method, clinging to a sliver of hope."

P11 expressed an urgenst wish: "We also hope the surgery will be effective."

P3 noted: "Worried about the outcome. Since the surgery has been performed, it's only natural to expect good results." She also remarked, "It i said that surgery is not 100% successful; it can only be regarded as a trial,"

② **Gratitude and Trust for Postoperative Symptom Improvement**

During the postoperative recovery phase following SNM, when patients experience clear symptomatic improvement-such as better urinary control, resolution of urinary retention, and reduced leakage-the core characteristic of their emotional experience is profound gratitude arising from treatment efficacy and trust in the medical team. The successful surgical experience is constructed by patients as a positive outcome achieved through the combined support of family and professional medical care, thereby strengthening the bond of trust between patients and

healthcare providers.

P9 stated: “The only improvement is that urination has become slightly easier. I would like to express my gratitude first and foremost to my spouse and the physician.”

P11 stated: “At that time, I felt that I could hold my urine and no longer experienced leakage. Previously, I was unable to control urination and often had urinary incontinence.”

3) Pain points

① Lack of knowledge about disease management

A lack of knowledge regarding disease management is common during the postoperative phase. SNM patients and their families typically have a significant gap in knowledge related to long-term disease management and device maintenance, which represents a major unmet informational need. Their uncertainties center on the specific impact of the procedure on daily life, requirements for wound care, and the long-term functionality of the implanted device .

P6 : "Will postoperative life be affected? Can the inflammation improve? Will creatinine levels decrease?"

P4: "The wound doesn't require any special care. I'm not sure."

P6: "I'm a bit concerned about how long the battery will last after the surgery."

② Incision pain

During device placement under local anesthesia, the surgical process involves repeated steps of localization, needle puncture, and electrical testing to identify the optimal lead position. These procedures cause significant acute pain both intraoperatively and postoperatively.

P17: "Currently, the incision site is still very painful. The surgical procedure was also extremely painful, so I subsequently requested assistance from the anesthesiologist."

P7: There's no particularly unusual sensation. The wound causes mild pain, but it's tolerable and manageable.

P8: “Even during nighttime bed rest, I still experience a certain degree of pain. When it became intolerable, I received an analgesic injection.”

③ Postural intolerance

During the procedure, patients are required to maintain a prone position for an extended period to facilitate the surgeon's operation. Postoperatively, due to device retention and incision protection, patients must continue to lie prone for approximately 2 hours. This prolonged forced posture leads to persistent muscle tension and soreness in areas such as the neck, shoulders, lower back, and spine. For many patients, this discomfort accumulates to an intolerable level, significantly impairing intraoperative cooperation and the postoperative recovery experience.

P2: “I feel somewhat uncomfortable. This procedure is particularly challenging as it requires me to sleep in a prone position, which I cannot maintain for an extended duration. Moreover, the device cannot be properly compressed while maintaining this position, causing significant discomfort.”

P16 reported: “I was lying on the operating table for over two hours, which was extremely uncomfortable. I trembled violently and felt terrified, but I had to endure it alone.”

④ Discomfort during parameter adjustment

Parameter adjustment occurs both during intraoperative testing and postoperative external device connection. Adjustment of stimulation parameters directly stimulates the sacral nerve roots, eliciting intense physiological responses. Patients commonly report distinct electrical sensations, muscle twitching or spasms in the lumbosacral or perineal regions, and some experience sharp pain or stabbing discomfort. Due to individual differences in neural sensitivity, the degree of

reaction varies greatly, often causing anxiety and affecting cooperation, sometimes requiring repeated adjustments to balance tolerability and therapeutic efficacy.

P9 described: “My leg kept twitching , and I couldn't sleep at all last night.”

P15 stated: “The programming process was quite painful. The pain from the electrical stimulation, the bladder fullness, and the leg pain/numbness were really unbearable.”

transitional care

1) Tasks

① home-based self-management challenges

Patients families face specific and persistent practical challenges. They are required to perform medical care tasks such as device maintenance, symptom monitoring, and possibly intermittent catheterization. This process often relies on self-learning, as well as support from family members and healthcare professionals. This highlights the need for practical guidance and continuous professional support for patients during the transition from hospital-based professional care to home self-management.

P7 mentioned: "The urinary catheter was removed after about one week at home, and a voiding diary was then started."

P11 stated: "My son purchased adhesive tape to secure the device, gradually overcoming the procedure during bathing. The first attempt was also self-directed. The parameters remained unchanged postoperatively, with the voltage set at 3.5V."

P17 reported: “The physician recommended intermittent catheterization as an adjunctive measure. Initially, three catheterizations per day were performed, with the frequency gradually reduced based on symptoms."

2) Emotions

① Hope

During the postoperative recovery period at home, patients and their family members express hopeful expectations regarding functional recovery and treatment outcomes. The focus is on the smooth resolution of specific symptoms and the overall effectiveness of the surgery.

P2: “After discharge and returning home, the urinary catheter can be removed, and urination will become smooth. That should be sufficient.”

P1: “we hope for effective postoperative outcomes to achieve full recovery.”

② Happiness

During the transition from hospital care to home self-management, patients and their families frequently experience positive moments that signify progress in rehabilitation. For example, the first successful restoration of anticipated physiological functions can bring significant relief and positive emotions.Such positive experiences inject confidence and hope into the subsequent rehabilitation journey.

P9: Initially after catheter removal, he had difficulty initiating urination with minimal flow and mild urethral irritation. At 12:30, he instructed me to examine the urine collection bag, which resulted in a sudden void of 200 mL. This was the most unobstructed voiding experience he had ever experienced.

3) Pain points

① The need for home care guidance

Patients have two main areas of concern regarding device usage: (1) safety, durability, and daily maintenance (e.g., waterproofing, impact resistance, cable management); (2) the device’s

significant limitations on personal quality of life and freedom of movement. These concerns highlight a strong unmet need for ongoing, meticulous professional guidance. Without such support, these worries may become psychological burdens, ultimately undermining patients' confidence in recovery and hindering daily activities.

P11: "I carry the device, but I'm worried about not being able to take a shower. It also affects my sleep. I'm concerned about bumping into it, mainly fearing damage. I'm constantly worried that the wires need to be extended, otherwise they may stretch and cause incision pain."

P2: "What if the battery runs out? Should I replace it? Carrying this device is quite troublesome; I can't move around freely and can't go anywhere."

② Body image disturbance and disease burden

During the prolonged postoperative recovery phase, the burden patients endure has extended from significant physical suffering to profound psychological and social dimensions. Interviews revealed that self-image disturbances accompanied by shame and social anxiety constitute a heavy and persistent psychological dimension in their disease experience.

P11: It's a burden. I feel like this is just a burden. I'm embarrassed to bring the machine home.

P2: I'm too scared to go out. Wearing this makes me look awful. I'm worried people will gossip about me.

P12: I fear sudden urination because I am overly concerned about indwelling catheterization. The frequent urination and polyuria are extremely distressing, and so is the catheterization itself.

Stage II surgery

1) Tasks

① Individualized parameter programming and adjustment

Parameter adjustment for medical devices is a critical component that enables patients to access personalized treatment, improve their self-management capabilities, and optimize long-term therapeutic outcomes.Some patients have mastered parameter adjustment skills through professional authorization and guidance. This not only gives them a greater sense of control over their treatment process, but also reflects their proactive planning for long-term device use.

P4: "They authorized me to teach me parameter adjustment. I learned how to adjust, and now I can perform it independently with remote guidance."

P17: "The parameters for Phase I are 1.0V amplitude and 35Hz frequency. For Phase II, the parameters are 0.8V amplitude and 20Hz frequency. I discussed with the director yesterday regarding Phase II, and we aim to adjust the parameters to a relatively smaller value. This will be beneficial for battery life."

② Family care and burden

Family caregiving plays a vital role during the perioperative period, primarily reflected in ensuring patient safety, monitoring changes in the patient's condition, and providing emotional comfort. In response to their family's hard work and excessive care, patients feel both profound gratitude and heartache. However, this level of care also places a heavy burden on both patients and their families. A patient's illness consumes extensive amounts of the family's time, energy and financial resources, and significantly disrupts their daily lives.. As a result, patients experience intense "disease guilt"-a conflicted emotional state in which they feel remorse and self-blame for the family's sacrifices, yet are unable to escape their dependency on care, leading to persistent psychological distress and emotional conflict.

P5: "During this period, my wife treated me like a deity, even forbidding me from sweeping the floor, and would argue with me if I did. The whole family took care of me—she prepared meals, and I had to eat them. My wife has suffered all her life, enduring hardships with me." P12: “Family members are very important, especially the couple. As for the child, I still avoid causing them trouble.”

P17: “I still feel it adds a burden to the family. My spouse said, "If you borrow money, we'll pay for the treatment.”

2) Emotions

① Helpless acceptance

A complex psychological state experienced by patients after undergoing second-stage surgery when treatment outcomes fail to meet expectations. This state is not characterized by intense resistance, but rather a "calm resignation" that blends disappointment, comparison, rational cognition, and eventual compromise. However, it fundamentally represents a "Resigned acceptance after unmet expectations" or "alternative" acceptance.

P4: No significant sensation, including during this second-phase period, when there was a slight sensation. Currently, no sensation is present. During initial installation, there was electrical stimulation upon power-on, but now no sensation is observed.

P5: What should I do if the outcome is unsatisfactory? Regardless of the result, it must be accepted. Who can claim a 100% efficacy rate? Others have demonstrated effectiveness, but in my case, it is only 60%.

② Satisfaction

As evidenced by the enhancement of clinical indicators, satisfaction was mainly reflected in

functional improvement rather than complete symptom resolution.This underscores the importance for healthcare providers to emphasize communication with patients, openly discussing individual variations in treatment outcomes and the potential range of results during the early stages of therapy.

P11 : “Although the symptoms did not show significant improvement after this surgery, the residual urine volume has been markedly reduced. It still demonstrates therapeutic efficacy”.

P17: “After returning home from the first-stage surgery, I required self-catheterization. This time, I no longer need catheterization upon hospital admission, which is highly satisfactory.”

2) Pain points

① Family and social support

The cost of SNM treatment is high, and the recovery period is lengthy. Patients face significant economic challenges and require support from both family and society. The social medical security system provides essential support for patients to cope with enormous medical expenses; the family is the most critical entity within the support system, with its role encompassing financial assistance, decision-making support, and the maintenance of emotional bonds.

P5: The surgery was recommended by my family. My sisters also contributed financially.

P6 : It's been over a decade now, and rural residents still earn relatively low incomes with limited financial resources. Fortunately, there's a subsistence allowance program; otherwise, the surgery wouldn't have been performed.

P9: The cost of the second-stage surgery. We have employee medical insurance, which covers a portion of the expenses, and I personally contribute an additional amount.

② Lack of medical expertise and effective communication

Due to a lack of medical expertise and effective communication, there are significant gaps in both the "quantity" and "quality" of information transmission in doctor-patient communication. Patients are unable to obtain comprehensive disease-related information (e.g., details of treatment plans, expected outcomes, potential risks, rehabilitation procedures), remaining in a state of cognitive ambiguity and lacking the foundational knowledge needed for decision-making. due to the lack of clear, understandable, and personalized professional explanations, patients struggle to truly comprehend medical terminology or complex logic. Communication efficacy is low, failing to alleviate their confusion and uncertainty. This dual gap leaves patients in a state of passive dependence and latent anxiety, severely hindering their treatment experience, self-management capacity, and rational evaluation of treatment outcomes.

P4: The specific surgical procedure was only known from the physician, who provided a brief overview without detailed explanation, merely describing a simplified process.

P17: What if the surgery is ineffective? What if the effect is not sustained for a period of time? Fear of the device affecting daily life, inability to bend over, or perform household chores.

P9: The number of patients undergoing this procedure will continue to increase in the future. It is hoped that the therapists can provide comprehensive services and offer more thorough explanations.

Long-term self-management

1) Tasks

① Regular follow-up and management of complications

Regular follow-up-typically scheduled at key time points such as 1 month, 3 months, and 6

months postoperatively-is the cornerstone for ensuring the long-term safety and efficacy of surgical procedures. Follow-up examinations include standardized tests such as ultrasound, renal function assessment, and residual urine volume measurement. The core value lies in proactive screening and early management of complications, including: Local complications (e.g., wound infection, device-related abnormalities) Systemic complications (e.g., urinary tract infection, renal impairment).

P2: One month after surgery, I returned to the outpatient clinic for an ultrasound and urinalysis.

P6 : “The recovery is not complete; there is urethritis. The wound is red and swollen, and the inflammation has not fully subsided. His creatinine level is slightly elevated, indicating suboptimal renal function”.

P13: The outpatient follow-up ultrasound was performed approximately one month ago. The residual urine volume at that time was estimated to be 25 mL. A follow-up examination will be scheduled after the Spring Festival.

② **Long-term symptom management**

Long-term symptom management is a dynamic adaptation process centered on symptom management, transitioning from professional hospital care to home-based self-management. Simultaneously, the patient's role undergoes a fundamental shift from passive treatment recipients to active health co-managers serving as the driving force for improving treatment adherence and long-term quality of life.

P17: Urination is also satisfactory, with a significant volume each time. Currently, a single catheterization per night suffices.

P9: I have limited mobility in my left leg, and battery installation is somewhat stressful. I'm

599 hesitant to exercise and even avoid supermarkets, steering clear of areas near cash registers due to
600 electromagnetic interference.
601 P10: I contacted Mr.Zhou. He initially used remote control, then authorized me to adjust the
602 parameters myself. I made multiple adjustments to the settings.
603 **2) Emotions**
604 **① Complaints and unmet expectations**
605 Expressions of dissatisfaction represent the genuine psychological response of patients and their
606 families when treatment outcomes fail to meet expectations. Through follow-up visits, we provide
607 a channel for these unmet expectations to be expressed and articulated.
608 P10: Since it's pointless anyway, I might as well vent. But since you're calling back, I'll tell you
609 everything I know.
610 P5: Now there's no sensation at all. Previously, the muscles would still twitch before adjustment.
611 After this parameter adjustment, the muscles no longer twitch.
612 P14 : After returning home, the urine still cannot be controlled at all. Sometimes the pants get wet
613 frequently.
614 **Positive experiences of symptom improvement and functional recovery**
615 Therapeutic efficacy appears to be a key element of patient satisfaction. SNM effectively
616 improves symptoms and restores function, ultimately translating into enhanced quality of life and
617 highly satisfying positive experiences for patients. They are able to go out and resume daily
618 activities without fear of urgency or incontinence, the frequency of intermittent catheterization is
619 reduced, and sleep quality improves due to fewer episodes of nocturia. These tangible
620 improvements in daily life not only alleviate physical discomfort but also restore social confidence

and emotional well-being, laying the foundation for a positive treatment experience.

P9: “Currently, daytime duration is three to four hours. The last time I used the bathroom, I was quite satisfied with the urination process.”

P6 Brother: Now I finally don't need a urinary catheter anymore, which makes both daily life and work much more convenient.

P17: “Urination has become significantly more comfortable and effortless. Previously, urine would flow down the thigh, but now I can feel the urge to urinate when it occurs.”

3) Pain points

Social adaptation and challenges

The postoperative rehabilitation of patients extends beyond physiological improvement; it constitutes a process of social and psychological re-adaptation. Patients may face restricted mobility or discomfort due to the implanted device, limiting their ability to engage in daily or social activities. Such concerns further hinder social participation. They may feel ashamed or embarrassed by symptoms such as urinary incontinence or voiding difficulties caused by the disease. This stigma can lead to social withdrawal, avoidance of public places, and reluctance to discuss their health status with others. At the same time, out of care and concern, family members may excessively restrict the patient's activities, unintentionally limiting their independence. Although, this "protective" behavior can reinforce the patient's sense of dependence and hinder their psychological re-adaptation to normal life.

P1: “I haven't done anything yet. My kid doesn't want me to work, so I haven't done anything.

P5: These days I hardly go out. Since I'm getting older, I can't do much work anymore, so I just do some housework at home.”

P8: “I hope to recover soon, so I can go out to work and earn more money. (The patient expresses profound helplessness with a sigh.”

P14 : “Currently, he does not go far outside; he mainly stays at home and wanders around the nearby residential areas.”

P16: “I usually sleep on my side and avoid lying flat.”

Discussion

4.1 The SNM patient journey map provides evidence for service optimization.

This study uses the patient journey mapping tool, with timeline as the horizontal axis and tasks, emotions, and pain points as the vertical axes. It systematically presents the health management needs of patients with SNM implantation identified through interviews.

A comprehensive health management journey map is constructed, covering the diagnostic phase, primary surgical phase, extended care phase, secondary surgical phase, and long-term self-management phase. This study identifies 28 core themes across four dimensions-asks, emotions, pain points, and stakeholder interactions-comprehensively revealing the dynamic health management needs and core challenges of SNM patients at different disease stages.

Current domestic and international research on SNM patients predominantly focuses on surgical efficacy, complication prevention, and short-term rehabilitation care[21–23], while systematic exploration of patients' subjective experiences, psychological changes, and phased care gaps throughout the entire disease course remains limited. This study provides initial evidence to address via a visualized journey map, providing a foundation for developing patient-centered targeted nursing intervention strategies.

4.2 Lack of disease-related knowledge: a core obstacle throughout disease health management

The study identifies knowledge deficit as acommon pain point, yet its manifestation differs qualitatively across phases. During the diagnostic phase, the deficit concerns 'illness representation'-patients misinterpret urinary symptoms as normal aging or benign prostatic hyperplasia, leading to care-seeking delay. In contrast, during the long-term self-management phase, the deficit shifts to 'procedural knowledge'-patients lack skills in device maintenance, parameter adjustment, and symptom logging, leading to unsafe practices and anxiety. This distinction is critical: interventions for the first require public health campaigns and primary care education, while those for the second demand specialized, hands-on training and telenursing support.

Meanwhile, patients' knowledge acquisition is highly dependent on healthcare providers. However, due to clinical workload constraints, there is significant information asymmetry, characterized by specialized terminology, fragmented guidance, and a lack of seamless education throughout the entire disease course. These deficiencies arise because knowledge transmission from healthcare providers tends to be professionally dense and fragmented, lacking a comprehensive system spanning from admission to post-discharge follow-up. To bridge this gap, nurse-led structured health education-including standardized discharge checklists and video-based follow-up-can ensure patient-centered health education and enhance home-based operational skills. This finding aligns with research conclusions on chronic disease management such as heart failure and diabetes[24–29], confirming that knowledge deficiency is a core bottleneck in self -management for chronic disease patients.

Considering the demographic characteristics of patients with SNM implantation, such as a high proportion of low educational attainment and a majority of middle-aged and elderly people, clinical medical staff need to construct a phased, personalized, and popularized health education system. They should integrate disease knowledge, equipment usage, and long-term self - management skills into various links such as diagnosis, surgery, discharge, and follow - up. At the same time, by means of diversified forms such as graphic manuals, popular science videos, and outpatient follow-up guidance, the effectiveness of health education can be improved to fundamentally make up for the patients' knowledge gap.

4.3 Patient passivity in treatment decision-making: A critical care challenge throughout the entire disease cycle

This study indicates that patients, particularly the elderly, exhibit marked passivity in treatment decision-making, displaying a high degree of dependence on family members and healthcare providers, with very low autonomous participation. This finding is consistent with previous research, which demonstrates that shared decision-making models remain poorly implemented in geriatric care, with decision-making authority frequently shifting to family surrogates[1, 2] The observed passivity can be attributed to multiple factors: limited health literacy, resulting in insufficient understanding of the disease and available treatment options[30] fear of surgical risks and complications, leading patients to avoid decision-making responsibility; and the tendency of family members to adopt a "proxy decision-making" model out of protective intentions, which inadvertently undermines patients' autonomy.

This passive decision-making pattern has multifaceted negative impacts on treatment outcomes, including inadequate comprehension of treatment regimens as well as a significant decline in

postoperative self-management ability and treatment adherence. Therefore, healthcare providers should transition from the traditional informed consent communication model to a patient-centered SDM framework. Particularly during the preoperative period, stratified and accessible health education should be implemented to enhance patients' disease awareness, encourage them to express personal preferences and concerns, and guide family members to shift from "decision surrogates" to "supportive partners," thereby fostering a safe and transparent decision-making environment. Future research should focus on developing validated SDM intervention protocols tailored for elderly urological patients, and exploring how telemedicine-based decision aids may overcome barriers of limited mobility and cognitive decline to promote shared decision-making in routine clinical practice.

4.4 Psychosocial burden: A critical care challenge throughout the entire disease cycle

This study found that patients' psychosocial burden persists throughout the entire disease course, intertwining with and continuously reinforcing physiological discomfort. Its core sources can be summarized into three levels:

First, disease - induced self - image disturbance and stigma (e.g., urinary incontinence, indwelling catheter) constitute persistent psychological stress, which is consistent with previous findings on stigma in chronic diseases[31]

Second, mobility limitations and loss of social roles lead to social adaptation disorders that severely impair quality of life [32].

Third, although the "overprotective" caregiving pattern adopted by family members provides emotional support, it objectively weakens patients' self-care ability and induces feelings of guilt and dependency, forming a vicious cycle where "support leads to reduced capacity, which in turn

increases patients' psychological burden." Related studies have also identified "overprotection" as a key factor undermining self - efficacy in older patients[33, 34]

Furthermore, financial burden is a critical factor exacerbating this psychological load. The cost of secondary surgery is high, with a large proportion requiring out-of-pocket payment. Older patients have limited income, and medical expenses are mostly borne by their adult children. Some patients, due to unsatisfactory primary surgical outcomes compounded by a heavy financial burden, forgo the secondary surgery and fall into a psychological dilemma of "disillusionment with expectations—passive acceptance," developing a "giving up" mindset. They no longer actively seek alternative solutions and eventually drop out of the healthcare system. This psychological mechanism exacerbates health inequalities, creating a vicious cycle that profoundly undermines treatment continuity.

These findings suggest that clinical care must transcend traditional single-dimensional symptom management, and a three-dimensional care model integrating physiological, psychological, and social dimensions is urgently needed. In practice, psychological interventions, such as stigma management and cognitive behavioral therapy, should be prioritized—previous studies have demonstrated the significant efficacy of CBT in improving psychological adaptation among patients with urinary incontinence[35]. Meanwhile, family members should be systematically guided to adopt "empowerment-based" caregiving, gradually fostering patients' self-management abilities. Additionally, a dynamic follow-up mechanism for high-risk patients should be established: during the perioperative period, preoperative communication should be strengthened, and collaborative decision-making models should be employed to enhance patient engagement in treatment and alleviate anxiety about surgical risks. For economically vulnerable groups,

752 healthcare providers should proactively assist with applications for medical financial aid or
753 charitable support to help overcome financial barriers, thereby maintaining treatment continuity
754 and interrupting health inequalities driven by social determinants. Future research should further
755 explore the feasibility of telepsychology interventions and social support networks in reducing
756 psychosocial burden, and develop multidimensional nursing intervention protocols tailored for
757 older urological patients.

758 **4.5 Insufficient home self-management ability and lack of continuity of care**

759 The transition from hospital-based professional care to home-based self-management represents a
760 critical juncture in the rehabilitation of patients with SNM implantation and constitutes a major
761 gap in the existing care system[36, 37]This study reveals that during this transitional period,
762 challenges primarily stem from insufficient patient self-management ability and a systemic lack of
763 continuity of care.
764 Using the patient journey map as an analytical framework, we identified that the most error-prone
765 task node is the adjustment of neurostimulator parameters within the first week after discharge. In
766 this early stage, due to a lack of professional knowledge, patients often experience information
767 asymmetry and may even fall into the misconception that “stronger stimulation yields better
768 outcomes,” leading to frequent and inappropriate parameter adjustments. Such misperceptions can
769 undermine early treatment confidence and efficacy, making this a high-priority target for
770 intervention. Errors in other tasks (e.g., wound care, voiding diary recording) become more
771 prominent in subsequent weeks, suggesting that interventions should be prioritized according to
772 time-sensitive risk, with the initial focus on ensuring safe and standardized device operation.
773 To address these gaps, we propose a three-pronged, multi-level support system to complement the

774 structured care transition model, which includes pre-discharge assessment, a 1-week post-
775 discharge telephone follow-up, and a 1-month outpatient visit.
776 Additionally, postoperative follow-ups are often standardized, lacking dynamic assessment and
777 continuous guidance on patients' home self-management capabilities. This makes it difficult for
778 healthcare providers to promptly identify care-related issues and thus compromises the
779 effectiveness of continuous nursing care.
780 Furthermore, while some patients possess basic skills in device parameter adjustment, they lack
781 long-term professional guidance and remain confused about device maintenance and daily
782 symptom management. Primary healthcare institutions, due to insufficient SNM-related expertise,
783 are unable to provide effective community care support, further exacerbating the gap in
784 continuous nursing care.
785 First, remote programming under the “Internet + Continuity of Care” model can effectively
786 overcome a major barrier to timely support-specifically, the difficulty patients (especially the
787 elderly or those in remote areas) encounter in attending in - person visits. By enabling real - time
788 voice-and video-guided parameter adjustments, this approach significantly reduces the response
789 time for correcting the most common early errors, thereby enhancing the success rate of initial
790 parameter optimization and alleviating patient burden.
791 Second, dedicated WeChat groups or similar online communication platforms serve as a key
792 bridge for timely knowledge support. This platform enables healthcare providers to instantly
793 answer routine questions regarding device maintenance and symptom monitoring, such as “how to
794 protect the wound while showering” or “what to do when the sensation of stimulation is
795 abnormal.” By providing round - the - clock professional advice, this strategy fills the immediate

information vacuum at home and promotes learning from common mistakes within the group. Third, the involvement of community and primary healthcare institutions is essential for long - term sustainability. Primary healthcare facilities often lack the specific expertise required to manage SNM patients. By training community nurses in basic assessments (e.g., wound inspection, device impedance checks) and establishing a clear two-way referral pathway, we can create a “hospital-community-home” continuum of care. This arrangement allows simple issues to be resolved locally, while complex or urgent conditions (such as infection or parameter abnormalities) can be promptly escalated to the specialist team, preventing delays in care.

4.6 Inadequate family social support system: A significant factor affecting treatment efficacy and quality of life

Research has found that family and social support serve as crucial pillars for the comprehensive management patients with SNM implantation throughout their disease course [38–40].However, the current support system has significant deficiencies, mainly manifested in three aspects:

First, the limited scope of family support. Family members' assistance predominantly focuses on daily care and financial aid, lacking attention to patients' psychological needs. Meanwhile, there coexists excessive protectionism and overwhelming caregiving burdens.

Secondly, as a medical device, SNM shows significant regional differences in insurance coverage. Some regions have included SNM surgical consumables in the scope of medical insurance payment[41], however, other regions still list sacral nerve stimulators as fully self-paid items that have not yet been included in the medical insurance reimbursement catalog. Meanwhile, in regions where such coverage is available, out-of-pocket ratios also vary by insured status[41, 42]employees covered by basic medical insurance generally enjoy a higher reimbursement rate,

while patients receiving subsistence allowances (minimum living guarantee) and other disadvantaged groups face relatively lower out-of-pocket costs, and those enrolled in the basic medical insurance program for urban and rural residents generally bear higher out-of-pocket proportions[43] Owing to differences in policy implementation and funding levels across regions, patients' actual financial burden varies significantly.

Third, the lack of social support. Patients often suffer social stigma due to implant-related concerns and urinary incontinence symptoms. Coupled with restricted mobility, this leads to a significantly reduced social participation. The absence of a robust social support system for these patients hinders effective psychosocial support and social adaptation guidance. The quality of family and social support directly affects treatment adherence, psychological well-being, and quality of life. Patients who receive adequate and appropriate family support demonstrate higher rehabilitation motivation and self-management abilities, whereas those with insufficient support are more prone to negative emotions such as anxiety and depression, which adversely impact treatment outcomes.

In this context, peer support emerges as a valuable and cost-effective intervention. Postoperative experience sharing through patient WeChat groups, social gatherings, and other platforms provides emotional validation, practical coping strategies, and a sense of belonging. Such peer-based programs have been shown to enhance self-efficacy, improve treatment adherence, and facilitate social reintegration. Therefore, integrating peer support into the standard care pathway for SNM patients represents a promising strategy to compensate for the current deficiency in formal social support and to foster a more supportive rehabilitation environment.

This highlights the necessity of addressing social support deficiencies for SNM patients at

multiple levels. At the family level, targeted caregiving training-guiding families toward a "moderate care plus psychological support" model-combined with psychological counseling to alleviate caregiver burden, can improve the quality of home-based care. At the community and peer level, establishing patient WeChat groups for mutual support and regularly conducting free clinics can reduce stigma and facilitate social reintegration. Together with policies to alleviate financial burden, these efforts are essential for improving treatment adherence and postoperative quality of life.

4.7 Limitations and future directions

The findings provide empirical evidence for optimizing comprehensive health management strategies for this patient population, though certain limitations remain:

First, all study subjects were recruited from the urology department of a tertiary (Class III Grade A) hospital in Hefei, resulting in a relatively homogeneous geographical distribution and healthcare resource allocation. This, to some extent, limits the generalizability of the findings and makes it difficult to reflect the characteristics of comprehensive health management among SNM implantation patients across different regions and levels of healthcare resources.

Second, although the study incorporated patients' perspectives, it failed to adequately integrate the viewpoints of healthcare professionals, primary care practitioners, and technical personnel. This renders it difficult to comprehensively illustrate the multi-stakeholder interactions and collaboration barriers in the health management of SNM implantation patients, potentially resulting in incomplete intervention recommendations within the patient journey map.

Third, this study was descriptive in nature, with interviews conducted from diagnosis to one month after implantation. Although it was able to capture patients' initial health management

experiences following implantation, it could not reflect their long-term experiences or the dynamic changes over time:

First, multicenter studies should be conducted enrolling patients with SNM implantation s from medical institutions at different levels and in different regions. This would enhance the representativeness and generalizability of the findings, and by comparing health management characteristics across varying levels of healthcare resources, provide evidence for developing differentiated care strategies.

Second, the research perspective should be expanded to include multiple stakeholders, covering healthcare professionals, family members, primary care practitioners, and device developers. Through multi-source data collection and analysis, the needs, responsibilities, and collaboration mechanisms of each stakeholder can be clarified, thereby further refining the health management journey map.

Third, future longitudinal (follow-up) studies are warranted to capture patients' long-term health management experiences and dynamic changes over time. Based on the themes and key influencing factors identified, predictive models for postoperative rehabilitation outcomes and quality of life can be developed, advancing precision, personalized, and full-cycle health management for patients with SNM implantation .

Conclusions

Through in-depth interviews, this study mapped the complete SNM disease management journey, identifying patients' needs, pain points, and emotional changes across the stages of diagnosis, Phase I surgery, continuity of care, Phase II surgery, and long-term self-management. These insights form the foundation for a patient-centred active disease management model, and provide guidance for developing a timely full-cycle support framework and intervention protocols.

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Author contributions

Study design: Qianqian Yuan， Data collection: Qianqian Yuan , Data analysis Jing Liu, Xiaoyan Tan Bingxue Wang ,Study supervision: Miao Zhang , Yan Liu ,Manuscript writing: Qianqian Yuan Critical revisions for important intellectual content: Miao Zhang , Yan Liu

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Data availability statement

The SNM patient journey map is available on request from the corresponding author.

Ethics approval and consent to participate

This study received ethical approval from the Institutional Review Board of the Second Affiliated Hospital of Anhui Medical University (approval number: YX2026-276) and was conducted in accordance with the principles of the Declaration of Helsinki. Before the interviews, participants were provided with an information sheet detailing the study objectives and procedures. Written and verbal informed consent was obtained before audio recording, and participants confirmed their voluntary participation by selecting the “I agree to participate in the study” option at the beginning of the interview. Participants were informed of their right to refuse to answer any question or withdraw from the study at any time. Confidentiality was strictly maintained, and all personal information was anonymized. Both participants and researchers retained a copy of the signed informed consent form to ensure transparency and compliance with ethical requirements.

Consent for publication

Not applicable.

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