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ORIGINAL RESEARCH

The Patient Persona of the Self-Management Experience of Home-Based Rehabilitation for Spinal Cord Injury Patients: A Qualitative Study

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Purpose: To understand the real experience of self-management in home-based rehabilitation for spinal cord injury patients, and to investigate population differences and characteristics in self-management experiences and create tailored patient personas.

Patients and Methods: A descriptive qualitative study was designed, and purposive sampling was utilized to choose 17 spinal cord injury patients for semi-structured interviews, guided by the concept of precision nursing. Colaizzi's seven-step analytical approach was applied to review the data. The label system for the self-management experience of home-based rehabilitation for spinal cord injury patients was refined and summarized, and then the patient persona was constructed. Figures and tables were combined to visualize patient personas.

Results: The patient persona labels for spinal cord injury patients' self-management of home-based rehabilitation were distilled into six dimensions: basic characteristics, cognitive characteristics, behavioral characteristics, psychological characteristics, social support, and medical resource status. Three categories of patient personas were created: patients who are autonomy-driven, patients who are passively dependent, and patients who are suffering and conflicted.

Conclusion: Patients with spinal cord injuries have a variety of home-based self-management experiences. To improve disease prognosis and patients' capacity for self-management during home rehabilitation, healthcare professionals must thoroughly evaluate patients' attribute features and create tailored intervention programs.

Keywords: spinal cord injury, home-based rehabilitation, self-management, patient persona, heterogeneity, tailored interventions, qualitative study, locus of control

Introduction

Spinal cord injury (SCI) is described as structural or functional damage to the spinal cord produced by a variety of factors that results in motor, sensory, and autonomic dysfunction below and at the site of the injury.[1] In recent years, the worldwide incidence of spinal cord injuries has been increasing annually, ranging from 3.6 per million to 195.4 per - million.[2] Of these, China has a greater incidence rate of spinal cord injuries than developed countries, ranging from 14.6% to 60.6%.[3,4] Against the background of the current relative shortage of medical resources, the inpatient rehabilitation model makes it difficult to meet the patients' long-term rehabilitation needs. This is particularly true for patients with spinal cord injuries, whose rehabilitation cycle is lengthy, treatment costs are high, and regression effects are poor, placing a significant financial burden on the patient, caregiver, and society.[5,6] Therefore, the majority of patients prefer home-based rehabilitation.[7]

The core of home-based rehabilitation management for patients with spinal cord injuries is a patient-led, caregiver-assisted collaborative care model, whose primary goal is to maximize autonomy and dignity in the face of functional

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limitations, with a focus on facilitating functional reconstruction of the limb and reducing complications.[8] However, the lengthy rehabilitation process tends to trigger frustration in patients, which in turn leads to self-doubt and eventually may lead to physical, psychological, social, and other health problems.[9] Self-management, which encourages people to actively participate in and maintain their health condition, is a significant factor in home rehabilitation outcomes.[10] Self-management is the process by which an individual actively uses cognitive and behavioral strategies to manage their thoughts, feelings, actions, and surroundings.[11] When patients and caregivers return home after being discharged from the hospital and must manage several new health issues on their own due to changes in physiological or psychological function, at which time effective self-management is essential to the patient's prognosis and recovery.[12] Previous studies have found that spinal cord injury patients generally have low adherence to rehabilitation training during the home-based rehabilitation phase, and the underlying reason may be the lack of self-management ability. In-depth analyses revealed that individual psychological factors are considered important determinants of self-management and that patients' attitudes and beliefs regarding self-management similarly influence rehabilitation outcomes.[13] Among these factors, locus of control stands out as a critical personality trait that affects how patients practice self-management.[14] Locus of control refers to an individual's belief in their ability to control events in their surroundings. Individuals who have an internal locus of control are confident in their ability to make decisions about their own health and take responsibility for their overall health condition; they often adopt proactive coping strategies in self-management. However, people with an external locus of control perceive that their health is determined by external factors such as fate, chance, or medical professionals, etc.[15] According to research, people who have a high degree of internal locus of control may have better health outcomes and be more inclined to make decisions that would benefit their health.[16]

Although the locus of control theory has clearly revealed the profound influence of personal beliefs on healthy behaviors, in the context of home rehabilitation for patients with spinal cord injuries, there is still a lack of in-depth exploration on how control points affect their self-management practices. Understanding the patient's genuine experience and subjective feelings during this process is critical for cultivating and developing their tendency towards internal locus of control. At present, there is a lack of clarity about the genuine experience of self-management of home rehabilitation for people with spinal cord injuries, with a disregard for the patient's perspective on how self-management is experienced and felt. Knowing the patient's actual experience with this procedure not only assists medical professionals in offering more specialized care, but also helps to improve the patient's long-term self-management awareness and skills. According to clinical research, the intervention can greatly increase patients' self-efficacy and self-management skills.[17] The majority of current research focuses on creating universal management frameworks,[18] like standardized health education programs, which unexplained individual differences and diverse needs of patients. As a result, creating tailored and accurate intervention plans for individuals with various types of spinal cord injuries is essential. Patient Persona, a virtual model of user information, has been introduced into the nursing field in recent years as a data analytics tool that focuses on patients, categorizes people with comparable traits, and then extracts labels from the traits to show the group as a whole.[16,17]

With the rise of the concept of precision nursing,[19] healthcare professionals construct tailored patient persona models by thoroughly evaluating the patient's psychological condition, cognitive ability, behavior, and other trials to achieve stratified and classified health management strategies for patients and to promote the paradigm shift from "standardized intervention" to "tailored intervention." Consequently, this study adopts a descriptive qualitative research approach and utilizes the patient persona technology to investigate the needs and experiences of spinal cord injury patients who self-manage at home based on the precision nursing concept and the locus of control theory.

Methods

Design

Through semi-structured interviews, this study employed a descriptive qualitative research approach to investigate the experiences of spinal cord injury patients for self-management at home. This study adheres closely to the COREQ (Criteria for Reporting Qualitative Research) checklist for qualitative reporting.[20]

Settings and Participants

The maximum variation purposive sampling method was used to select the study subjects based on the patients' age, gender, education level, ASIA grade, and home-based rehabilitation time to gather as much richer information as possible. This ensured the representativeness and typicality of the interview sample. Interviews were conducted with spinal cord injury patients who, following surgery at the spine surgery in a tertiary-level hospital in Hefei City, Anhui Province, China, from July to September 2024, opted for home-based rehabilitation. The sample size was established under the assumption that the data had reached basic saturation when it was no longer possible to produce new themes or codes from the freshly gathered interview data. The researcher typically adds two to three more interviews to the basic saturation for validation to guarantee data saturation.[21] Data reached basic saturation after interviewing 15 participants in this study. On this basis, data collection was then stopped when no new themes emerged in two successive interviews. Seventeen study volunteers were eventually included, to safeguard patients' anonymity, their numbers were changed from A1 to A17.

Inclusion and Exclusion Criteria

Participants need to meet the following requirements to be eligible: 1) have a spinal cord injury diagnosis based on the International Standard for Neurological Classification of Spinal Cord Injuries;[22] 2) be at least eighteen years of age; 3) have an American Spinal Injury Association (ASIA) grade of A to D;[1] 4) make the decision to undergo home-based rehabilitation following surgery; 5) have clear consciousness, clear speech, and basic reading and communication skills; and 6) permission to participate in the study after being fully informed. Patients with significant cognitive impairments or behavioral disorders are excluded, as are those with comorbidities of other additional significant illnesses of other essential organs.

Data Collection

The first draft of the interview framework was developed after literature review and team collective discussion, taking into account the goals and substance of the study. Two postoperative home-based rehabilitation patients with spinal cord injuries were selected for pre-interviews; the outcomes of the pre-interviews were not incorporated into the results analysis. Following that, the official interview outline was decided upon based on the interview outcomes and expert comments (Box 1). Data was gathered through semi-structured interviews, which were founded on the idea of precision nursing.[19] Prior to the official interview, the researcher gave the patient an introduction, explained the study's goals, methodology, and importance, and got their consent while guaranteeing that all information would be kept private. Following that, the researcher employed a general information questionnaire to gather basic data about the patients, including their age, gender, education level, per capita household income each month, ASIA grade, and home-based rehabilitation time, etc.

There are certain difficulties in conducting qualitative research due to the distinctive traits of people with spinal cord injuries. First, patients' limited mobility restricts in-person recruitment and interviews, which are constrained by geographical location and physical conditions. Second, some patients are undergoing long-term rehabilitation cycles, making interview schedules prone to conflicts with rehabilitation plans. To overcome these obstacles, the research team broadened recruitment channels by employing online patient support groups. Semi-structured interviews were then performed with patients via telephone or in-person interviews, arranging interview times beforehand with participants

Box 1 Interview Framework

- How much do you know about the illness known as spinal cord injury?
- Do you have any prior knowledge of home-based self-management? What are your thoughts on home-based self-management?
- What is your self-management strategy when you live at home? Can you keep it going? In your perspective, what are the benefits of self-management at home?
- What do you think facilitates or impedes your practice of self-management?
- When you live at home, do you get help and support managing your illness?
- What aspects of your self-management process would you like assistance with?

to guarantee efficient data gathering. The in-person interviews were held in a separate room within the patient's review clinic, maintaining a calm and private setting to preserve the confidentiality and reliability of the data collected. The patients selected the time for the interview, and the entire procedure was audio recorded, along with the patient's body language, emotional changes, and other nonverbal cues. The telephone interview was audio recorded, and the patient's voice and tone shifts were captured. Two lead investigators were involved in this study; one was primarily in charge of conducting the interviews, while the other was in charge of watching and documenting the interviewees' nonverbal cues. Each research participant had a 20–30 min interview, and the interviews were conducted with a neutral attitude. The interviews were conducted so that the interviewers could restate, ask rhetorical questions, and follow up based on their statements, and the contents of their ambiguous expressions were checked in time to confirm the patient's statement. When the amount of data gathered reached saturation and no further information could be gleaned from the interviews during the data-gathering documentation phase, the interviews were closed.

Data Analysis

Establishing Patient Persona Labeling Dimensions

The data from the interviews was analyzed using the Colaizzi's seven-step analysis approach.[23] The researcher who conducted the interviews transcribed, arranged, and imported the audio recordings into the NVivo12 Plus software within 24 hours of the interviews concluding. Two researchers independently examined each interview multiple times to verify the data's validity and accuracy. The statements about the experience of spinal cord injury patients managing their care at home were then taken out and labeled appropriately. If there were any questions concerning the interview data, the patients were called to confirm; if there were disagreements between the two researchers during the labeling process, the team members discussed the findings to decide on the outcome. After aggregating all the portrait labels, the labeling dimensions of the patient persona were summarized following a group discussion to develop a labeling system for the patient persona of spinal cord injury patients' home-based self-management experience.

Manual Extraction of Features to Build Patient Persona

The researcher used manual techniques to extract patient persona attributes based on the patient persona labeling system and the locus of control theory. To create a customized, multifaceted patient persona of the self-management experience, following preliminary coding, based on locus of control theory and through collaborative discussion within the research team, combined with the researchers' expertise and experience, a systematic analysis of labels under each dimension was conducted according to their manifested control point tendencies. We then group patients whose labels share similar characteristics into a single category. The created patient personas were then returned to the participants for confirmation that they appropriately captured their traits and experiences.

Expression of Home-Based Self-Management in Patient Persona

This study aggregated various label sets and extracted representative and typical phrases as labels from patient characteristics to visually display the distinct characteristics of different groups of spinal cord injury patients' experiences with home-based self-management. Figures and tables were combined to illustrate the home-based self-management experience of spinal cord injury patients.

Rigor of the Study

All researchers received training in qualitative research definitions, interview outline creation, interview methodologies and observation points to improve the depth of the interviews and guarantee the study ran smoothly before the formal interviews began. Two primary investigators took part in the interviews to guarantee the study's validity and reliability. One researcher conducted the interviews, with the other researcher's primary responsibility being to observe and document the participants' nonverbal behavior. The study team maintained objectivity during the collection and analysis of data. The pair transcribed audio-recorded interviews and recorded nonverbal information (changes in facial expressions, emotional states, body movements, etc.) of the study participants into textual information to be stored within 24 hours. To prevent bias in the data analysis caused by the researcher's subjective perception of worth, two researchers

independently examined the identical data. Meetings with the research team were conducted to settle disagreements that arose at various points during the study to guarantee its dependability. To further validate the researcher's findings, the three study participants received the outcome of the investigation via WeChat. After reading the results carefully and giving them some thought, the study participants decided that they could accurately represent their opinions and experiences.

Ethical Considerations

The study received permission from Anhui Medical University's Biomedical Ethics Committee (approval number: 82240202), and it complies with the Declaration of Helsinki. All participants provided informed written consent, including permission to publish their anonymized responses. Adhere to strict privacy protections for all research participants, guarantee that all research recordings and transcribed texts will be used exclusively for this study, anonymize participant information from the interviews, and prevent unauthorized access to the study's audio, text, and data without the researcher's permission.

Results

Demographic Characteristics of Participants

The study included a total of 17 patients who self-managed at home, 6 females and 11 males were present. The average age of the participants was 50.82±6.44 years, with a range of 41 to 62 years. Patients were married in 94.12% of cases, and 41.18% of them were permanent residents of rural areas. In terms of occupation, the majority of the patients were workers before their injuries (52.94%); also, falls were the primary cause of injury for 58.82% of the patients. Approximately 29.41% and 52.94% of the patients had mild injuries, primarily grades C and D, and most patients' home-based rehabilitation time is more than 6 months, accounting for 64.71% (Table 1).

Table 1 Demographic Characteristics of Participants (n=17)

Variable	Frequency (n)	Percentage (%)
Age (year)		
<50	8	47.06
50-60	7	41.18
>60	2	11.76
Gender		
Male	11	64.71
Female	6	35.29
Educational level		
Primary school	4	23.53
Junior high school	11	64.71
High school or technical secondary school	1	5.88
Junior college and above	1	5.88
Marital status		
Married	16	94.12
Unmarried	1	5.88
Occupation[a]		
Worker	9	52.94
Farmer	4	23.53
Office worker	1	5.88
Workless	3	17.65

(*Continued*)

Table 1 (Continued).

Variable	Frequency (n)	Percentage (%)
Place of residence		
Countryside	7	41.18
Township	6	35.29
City	4	23.53
Cause of injury		
Traffic accident	4	23.53
Fall	10	58.82
Fall from a height	3	17.65
ASIA grade		
Grade A	2	11.76
Grade B	1	5.88
Grade C	5	29.41
Grade D	9	52.94
Per capita household income each month (yuan)		
<3000	5	29.41
3000 ~ 5000	7	41.18
>5000	5	29.41
Home-based rehabilitation time (month)		
<3	1	5.88
3 ~ 6	5	29.41
>6	11	64.71

Note: [a]Represents the patient's occupation prior to injury.

A System for Labeling Patient Personas for Spinal Cord Injury Patients' Self-Management Experience in Home-Based Rehabilitation

Based on the findings of the interviews, six dimensions were identified from the patient persona labels of spinal cord injury patients' experiences with home-based self-management: basic characteristics, cognitive characteristics, behavioral characteristics, psychological characteristics, social support and medical resource status.

Patient Personas for the Home-Based Self-Management Experience of Individuals with Spinal Cord Injury

According to the label characteristics of the patients, the patient personas of home-based rehabilitation self-management experience for spinal cord injury patients were categorized into three categories: patients who are autonomy-driven, patients who are passively dependent, and patients who are suffering and conflicted. Table 2 provides a detailed description of the requirements and traits of each role (For more information on patient quotes, see Supplementary File 1).

Theme 1: Patients Who are Autonomy-Driven

This group is primarily found in cities and has a stronger desire for rehabilitation and a better family financial situation. Their self-management behaviors comply with internal locus of control, and home-based self-management activities are characterized as wall-breaking activism - "there are always more solutions than difficulties." They place a strong emphasis on managing their health, actively seek out information from family members, healthcare professionals, telemedicine platforms, etc. regarding illness management and rehabilitation, and can continuously obtain health information (see Figure 1).

The patient quotes are as follows:

Patient A1: I usually learn quite a lot online, such as doing physical exercises, blowing up balloons, strength training, etc., and I insist on doing it every day, and I feel that rehabilitation is still mainly dependent on myself.

Table 2 Patient Personas of the Home-Based Self-Management Experience of Spinal Cord Injury Patients

Name	**Patients Who are Autonomy-Driven**	**Patients Who are Passively Dependent**	**Patients Who are Suffering and Conflicted**
Representative individual	A1, A5, A7, A8, A12	A3, A4, A6, A10, A11, A16	A2, A9, A13, A14, A15, A17
Basic characteristics			
Age	• 41-58	• 44-61	• 46-62
Gender	• Male 4 • Female 1	• Male 5 • Female 1	• Male 2 • Female 4
Education level	• Primary school 1 • Junior high school 3 • Technical secondary school 1	• Primary school 2 • Junior high school 4	• Primary school 1 • Junior high school 4 • Junior college 1
Place of residence	• City 3 • Township 1 • Countryside 1	• Township 1 • Countryside 5	• City 1 • Township 4 • Countryside 1
Per capita household income each month	• 3000 ~ 5000 yuan 2 • >5000 yuan 3	• <3000 yuan 3 • 3000 ~ 5000 yuan 2 • >5000 yuan 1	• <3000 yuan 2 • 3000 ~ 5000 yuan 3 • >5000 yuan 1
ASIA grade	• Grade B 1 • Grade C 1 • Grade D 3	• Grade A 2 • Grade C 1 • Grade D 3	• Grade C 3 • Grade D 3
Home-based rehabilitation time	• 4-8 months	• 2-8 months	• 6-8 months
Unique labels	Wall-Breaking Activism - "There are always more solutions than difficulties"	Misty Prowler - "I don't know what to do"	Swinging Pendulum - "I'm holding on, but it's so hard"
Cognitive characteristics			
Attitude of cognition	Proactively	Involuntary and having poor self-management abilities	Both intermittently proactive and reactive
Degree of awareness	More	Fewer and cognitively biased	Fewer and cognitively biased
Cognitive pathway	Buddies, ward mates, healthcare professionals, networks, recovery apps and applets	Ward mates, healthcare professionals, and networks	Ward mates, networks, and healthcare professionals
Information Availability	• Possess discriminating awareness, • Information from multiple sources that is complicated and hard for patients to understand	• Passive access to dispersed information from the outside world • Limited acceptance of disease knowledge	• Skeptical of outside information

(*Continued*)

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Table 2 (Continued).

Name	Patients Who are Autonomy-Driven	Patients Who are Passively Dependent	Patients Who are Suffering and Conflicted
Behavioral characteristics	• Regular exercise and consistent diversification • When complications arise, proactively seek medical attention and take specific actions	• Inadequate self-control and merely basic, low-intensity training • When health problems arise, take simple actions based on conventional wisdom or let them grow	• Phase-based fundamental training that is hard to persist and readily altered by physical functionality • When complications arise and targeted measures are initiated but are not effective, it can be discouraging.
Psychological characteristics	• Self-sufficient and maintain a cheerful and upbeat attitude while managing their physical symptoms • Strong desire for rehabilitation • Occasional phases of frustration but positive self-adjustment	• Reliance on others for help and limited positive coping strategies • Prone to negative emotions such as irritability, depression and frustration • Apparent social avoidance tendencies	• Complex and conflicted psychological condition that is simultaneously positive and negative • The demands of society and stigma are at odds • Cognitive-behavioral fragmentation, including the desire for and difficulty maintaining recovery
Social supports			
Family supports	• Much	• General	• Much
Healthcare supports	• Less	• Less	• Less
Other supports	• General	• Less	• Less
Medical resource status	• Easy access to healthcare • Absence of expert and tailored advice • Absence of specialized equipment for exercising	• Inconvenient access to healthcare elsewhere • Absence of expert and tailored advice • Absence of specialized equipment for exercising • Insufficient medical resources in rural regions	• Inconvenient access to healthcare elsewhere • Absence of expert and tailored advice • Absence of specialized equipment for exercising • Insufficient medical resources in rural regions

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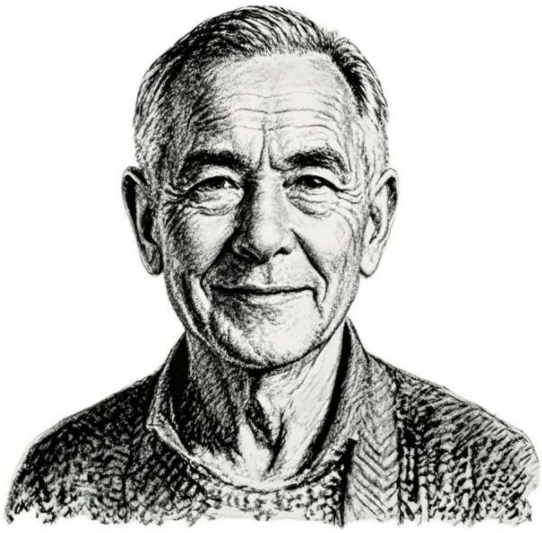

Figure 1 The patient persona of patients who are autonomy-driven.

Patient A1: I think my mindset has always been pretty good, and I feel like working out is definitely better than not working out, and the key is just to get in the right frame of mind and then just be active.

Patient A5: Usually I would meet patients in the neighborhood and we would talk to each other and we could learn some new exercises that I felt would help with recovery.

Patient A8: I have learned about remote rehab apps or applets on my phone, I have watched some science videos, and I keep working out every day no matter how long it takes.

Patient A12: My daughter learned about the medication for constipation from the Internet and bought it for me from Japan, and she feels that it works pretty well. I do not have any financial pressures either, and my moods and all that are fine.

Theme 2: Patients Who are Passively Dependent

This group tends to reside in rural locations where transportation is difficult and economic pressure is great, and they generally have poor self-management abilities and must rely on others for assistance. Their self-management behaviors align with external locus of control and home-based rehabilitation self-management manifests as misty prowlers - "I don't know what to do." They lack self-control and engage in only easy, low-intensity fundamental exercise. There is a severe lack of knowledge about rehabilitation management, the major source of information is passive, and the symptom management of disease is often not emphasized. When confronted with health problems, they frequently use negative coping strategies and allow symptoms to grow; they are psychologically burdened and frequently experience unpleasant feelings such as irritation and depression, which are accompanied by a strong inclination to avoid social situations (see Figure 2).

The patient quotes are as follows:

Patient A3: Did the glute bridge workout while recovering in the hospital, did it earlier in the day back home, and stopped doing it later. Just us rural folk, we cannot keep it up.

Patient A4: I did not go for a review before, transportation was very inconvenient, and my children were usually busy, so I was too embarrassed to ask them to help me more for fear of burdening them.

Patient A6: Feeling of stiff neck, have not done much exercise; usually just walk back and forth, have not done any other targeted exercise or used exercise equipment. Struggling to urinate can make me feel irritable and I do not know what to do.

Patient A10: My shoulders and arms usually hurt a lot and I do not know how to relieve them? I just let it hurt! The nerves hurt too. I am afraid to exercise for fear of being crippled.

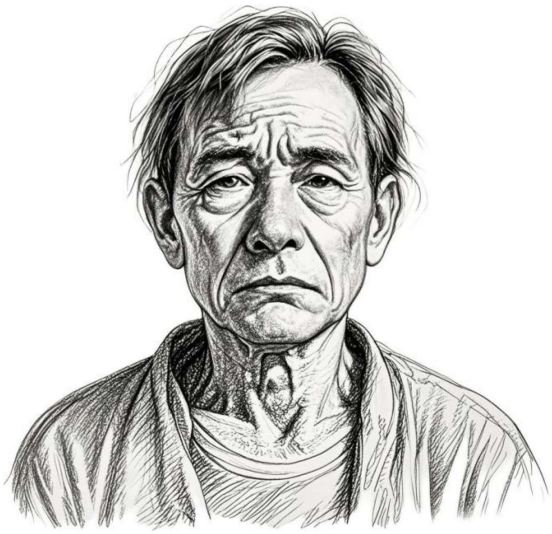

Figure 2 The patient persona of patients who are passively dependent.

Patient A11: My family is busy, if I go to a rehabilitation hospital, there is no one to take care of me, the caregiver is expensive, and I cannot keep up with the economy, otherwise I would still want to go to a rehabilitation hospital. I have poor self-discipline at home, sometimes I am lazy and do not want to exercise.

Theme 3: Patients Who are Suffering and Conflicted

The majority of this group, who lack disease awareness and are prone to cognitive biases, reside in townships. Their home-based self-management was defined by a swinging pendulum - "I'm holding on, but it's so hard." That is, positive and negative coping coexisted. This includes both proactive attempts at symptom management and challenges in sticking to them due to changes in psychological status, physical functionality, and other reasons. They have stronger compliance but are less autonomous. At the same time, there is a contradiction between social demands and stigma, with both needing help from the outside world and fearing causing trouble for others, which amounts to an external locus of control (see Figure 3).

Figure 3 The patient persona of patients who are suffering and conflicted.

The patient quotes are as follows:

Patient A2: Nowadays, big data is especially developed, and I usually see some exercise videos from the Internet, and there are also a lot of healthcare professionals who come to add me on WeChat, but I do not believe in any of them. Seeing some patients who are worse than me, I feel that I am still lucky.

Patient A9: Usually at home in the morning to get up to take a walk, every day to walk about 20,000 steps, often use the grip strength machine exercise, but also their own from the Internet to buy electrotherapy apparatus exercise, now feel the hand strength has become bigger. I cannot afford to go to a rehabilitation hospital for rehab, financially.

Patient A13: I always feel stiff in my neck and my doctor told me to do confrontation exercises, but I am doing less of them and I am wondering if there's any benefit to this?

Patient A13:I bought the grip strength machine, but did not use it consistently because my hands felt fine and I did not work out. Sometimes when I feel tired, I quickly want to lie down on the bed and rest, not wanting to work out.

Patient A14:My family always encouraged me to be as comfortable as I wanted to be and told me to move around more and not to be psychologically burdened.

Discussion

Individuals with Spinal Cord Injuries Have Heterogeneous Experiences with Self-Management at Home

According to the findings of this study, individuals with spinal cord injuries have various home-based self-management experiences that vary in terms of their basic characteristics, cognitive characteristics, behavioral characteristics, psychological characteristics, social support, and medical resource status. It is stressed how crucial precision care is for patients' home-based self-management. As of right now, there are neither recommendations nor professional agreements about spinal cord injury self-management at home. As a result, healthcare professionals must carefully take into account each patient's unique demands, psychological state, financial burden, and other variables before creating tailored interventions for the traits and obstacles of various patient groups. This will increase their capacity for self-management at home, improve the prognosis of their illness, and offer a theoretical basis for the development of an accurate home-based rehabilitation self-management program for patients with spinal cord injuries.

Characteristics of Home-Based Self-Management Persona and Coping Strategies for Spinal Cord Injury Patients

Patients Who are Autonomy-Driven

This group of patients showed significant positive home rehabilitation self-management behaviors. Their key traits include autonomous learning inclinations and independent management abilities, as well as significant behavioral patterns and resource advantages. According to survey data, the majority of patients live in cities, are financially secure, have easy access to quality medical service resources, have more time and energy to focus on their own health issues, and are conducive to self-management.[24] A well-developed social support system increases patients' self-efficacy and significantly strengthens the continuity of self-management behaviors.[25] Patients with an internal locus of control and high self-efficacy are more likely to adopt positive coping strategies and fully utilize their subjective initiative, generally exhibiting better health outcomes,[26,27] which is highly consistent with the findings of this study. With the advancement of the living environment and medical information technology, these patients are capable of optimizing their self-rehabilitation management plan by utilizing a variety of avenues such as smart terminals, patient exchange groups, and community rehabilitation services.[28] However, notably, in keeping with the results of other research, this group continues to confront obstacles in the process of self-management, such as absence of expert advice and trouble sifting through internet material.[29,30] As a result, healthcare professionals should focus on answering questions from this population, making supportive comments, and maintaining their self-management motivation through continuous constructive feedback. This can be achieved by the establishment of an online communication platform, the frequent distribution of personalized rehabilitation information, and the provision of online consulting services in real time. By strengthening interaction and communication with patients through the "Internet + application platform" and other

means,[31] provide precise professional guidance based on the stages of the patient's recovery process and tailor rehabilitation management programs to meet the needs of each individual. Strengthening the three-tiered connection between hospitals, community/township hospitals, and families;[32] establishing a comprehensive home-based rehabilitation service system; and ensuring the exact allocation and effective usage of rehabilitation resources.

Patients Who are Passively Dependent

With fundamental traits of behavioral dependency and cognitive passivity, this group exhibited the most negative home rehabilitation self-management behaviors. According to our research, this patient group has more severe injuries than the others; A4 and A11 are grade A injuries, and they have a much lower capacity for self-management. This could be because grade A injuries result in the total loss of motor and sensory functions in the site of the injury and below. Patients often experience paralysis or paraplegia, are frequently dependent on others for assistance, and are often accompanied by significant psychological stress. They are also more likely to experience psychological issues like depression, helplessness, and frustration.[33] External locus of control is linked to higher levels of stress, increased susceptibility to depression, and generally poorer health.[34] Furthermore, following a thorough analysis, it is discovered that this group encounters several challenges during the home rehabilitation process following hospital discharge: the absence of expert rehabilitation supervision, the scarcity of professional exercise equipment, and the limited availability of medical resources are prominent issues. Research has shown that learning more about the illness helps improve understanding of it.[35] Nevertheless, these patients usually exhibit low disease awareness, limited information access, and low health literacy.[36] Therefore, this category is a crucial and challenging management population for healthcare professionals, and multidimensional intervention strategies are recommended. First, cognitive-behavioral approaches[37] and other techniques can be used to improve patients' intrinsic desire for self-management, guide patients to appreciate the importance of self-management in-home rehabilitation, simplify the substance of health education, and conduct continuous education. Second, it focuses on enhancing patients' self-monitoring skills, strengthening professional skill training for caregivers, and aggressively mobilizing family social support structures.[38] Once more, by enhancing the health insurance policy to suitably raise the reimbursement rate and by instituting a shared leasing system for rehabilitation equipment to lessen the financial strain and improve the long-term sustainability of management. Finally, medical resource allocation should be optimized, the primary medical service network should be improved, tertiary hospitals' resource advantages should be fully exploited, and a long-term and effective doctor-patient communication mechanism should be established via telemedicine, mobile applications, and other information-based methods.

Patients Who are Suffering and Conflicted

This group's home rehabilitation self-management behaviors demonstrated cognitive-behavioral fragmentation, which was manifested by a discrepancy between management willingness and actual behaviors. Although they were aware of symptom management, patients frequently failed to adhere to it due to interference from external factors such as physiological and psychological pressures, making them more likely to exhibit behavioral characteristics linked with an external locus of control. Meanwhile, the majority of patients were female (A2, A13, A14, A17), as reported in this study. This could be because women are more sensitive to emotional shifts and are more likely to become discouraged and use negative coping strategies when confronted with recovery challenges, which in turn impacts their confidence in their ability to recover.[39,40] Additionally, it was discovered that this group's social needs and sense of shame are at odds. They not only want outside assistance but also worry about burdening others. This could be because patients with motor-sensory dysfunction following spinal cord injury have had to alter their original lifestyles and frequently experience low self-esteem and guilt, which can lead to feelings of shame.[41] In light of this, healthcare professionals should perform thorough evaluations of patients at every stage of recovery, assist patients in identifying the reasons behind self-management challenges, promptly modify management techniques, and help them develop a positive outlook to facilitate the group's transition into an "autonomy-driven" group. To optimize the advantages of peer learning through role model education,[42] boosting patients' self-efficacy, motivating patients to take the initiative to engage in self-management decision-making, and encouraging active self-management by patients, regular patient exchange activities should be planned. Establish a professional psychological support team to identify the underlying factors that have a direct impact

on the patient's emotions, provide precise psychological guidance, encourage patients to share their innermost thoughts, schedule frequent mental health lectures so that patients can share their psychological distress and coping mechanisms, and help patients develop their emotional regulation skills.

Limitations

This study has limitations, such as the sample being drawn from only one tertiary hospital and the short home rehabilitation period for the included patients, which may have individual variability. In the future, a multi-center, large-sample cross-sectional survey will be done to validate and refine the results.

Conclusions

Semi-structured interviews with 17 patients who have spinal cord injuries were conducted as part of this study using descriptive qualitative research to extract and analyze the labeling system of patients' home-based self-management experience, construct patient personas of spinal cord injury patients' home-based self-management experience covering three categories—autonomy-driven, passive-dependent, and contradictory-struggling—and provide targeted advice based on the personas. Future efforts should focus on advancing the clinical translation of patient persona. Create standardized clinical assessment checklists to quickly determine the type of patient. Following that, individualized treatment strategies are provided. Simultaneously, patient care records should be created centered on the portrait, incorporating digital health technology to allow for dynamic tracking of management outcomes and plan optimization. This will ultimately establish a precise, closed-loop health management pathway.

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Author Contributions

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

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Disclosure

None of the study's authors declared any conflicts of interest.

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