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# Understanding Emotional Needs Across Stroke Rehabilitation Phases for Affective Design

**Yixuan Lyu and Yue Chen**

East China University of Science and Technology, Shanghai 200237, China

## ABSTRACT

Despite significant physical and psychological challenges, stroke patients often face overlooked emotional needs in rehabilitation. Such emotional needs can be satisfied by the innovative design of rehabilitation equipment, but the specific patient needs across recovery phases (acute, stable, and maintenance) remain unclear for targeted emotional design. This study aims to identify pain points and emotional needs in each recovery phase through observations and interviews with 31 participants and 60 hours of data. Acute-phase patients struggled with both communication challenges and psychological barriers from disability and identity shifts. Stable-phase patients experienced loneliness, self-blame, and boredom during intense therapy. Maintenance-phase patients, while physically improving, felt hospital fatigue, desired social interactions and entertainment, and worried about reintegration. Based on these findings, we also discuss emotional design implications and examples tailored for each stage.

**Keywords:** Emotional needs, Stroke rehabilitation services, Graded rehabilitation

## INTRODUCTION

Stroke is characterized by high incidence, high disability rate, high mortality rate, and high recurrence rate (Kolmos et al., 2021). World Stroke Organization (WSO) suggests that stroke has become the second leading cause of death in humans and a major cause of acquired disability in adults (Feigin et al., 2022). Humanity loses nearly 69 million years of healthy life due to stroke-related diseases' deaths and disabilities every year., with approximately 80% of stroke patients facing severe physical, cognitive, and emotional impairments (Feigin et al., 2022; She et al., 2022). However, such impairments can be alleviated by effective rehabilitation therapy and recovery training (Teasell et al., 2020).

Recent rehabilitation therapy, in addition to focusing on physical functions, increasingly addresses mental health and the satisfaction of emotional needs. The reason is that the sudden disability and the long-term rehabilitation can cause various psychological problems, such as depression, guilt, loss of self-confidence, and loneliness. It has been shown that about 11%-41% of stroke patients experience post-stroke depression (Guo et al., 2022). These psychological problems also distress caregivers (Kim, 2017) and decrease

 

the patients' trust in rehabilitation methods, willingness to recover, and the effectiveness of rehabilitation therapy. Therefore, it is necessary to identify patients' psychological and emotional needs during rehabilitation.

Patients can have different needs in different recovery phases. In the current practice, increasing patients receive standardized graded rehabilitation, in which their treatment plans are tailored to the different phases from a severe state to full recovery (Huang et al., 2023). Therefore, this study aims to understand patients' phase-specific psychological and emotional needs by qualitatively observing and interviewing patients in the different phases and relevant stakeholders. The findings can be used for the design of rehabilitation therapy and related products in different recovery phases in the future.

## LITERATURE REVIEW

### Graded Rehabilitation for Stroke Rehabilitation

The primary goal of stroke rehabilitation is to maximize the improvement of patients' motor function, enhance their activities of daily living capabilities, and reintegrate them into social activities (Shahid et al., 2023). To achieve this goal, a widely used rehabilitation solution is the three-level graded rehabilitation model, which significantly promotes the recovery of neurological function and reduces complications (Huang et al., 2023).

The graded rehabilitation model proposes three levels of therapy corresponding to the three phases of recovery. Level 1 rehabilitation targets the acute phase of patients admitted within days to weeks after the stroke. The goal of this phase is to prevent complications and maintain stable vital signs. Patients have mostly lost movability and stay in bed. They can only take basic passive exercise and physical therapy to restore physical abilities. Level 2 rehabilitation targets patients in a later stable phase. During this phase, patients typically undergo various rehabilitation interventions, such as speech therapy, muscle rehabilitation training, and balance and coordination training to gradually regain physical functions and relearn how to speak, stand, and walk (Kinoshita et al., 2022). Level 3 rehabilitation targets patients in the maintenance phase and provides ongoing support to maintain the effects of rehabilitation and prevent disease recurrence. Patients need to keep regular exercise, rehabilitation training, and healthy lifestyle habits. The focus shifts to fine motor skills training, posture correction, obstacle avoidance, and the integration of rehabilitation training activities with daily life activities (Shahid et al., 2023).

### Treatment for Post-Stroke Emotional Disorders and Psychological Problems

A comprehensive study indicates that the overall prevalence of poststroke depression is 27% (Liu et al., 2023). It can further lead to problems such as noticeable weight loss or gain, decreased attention and appetite, sleep disturbances, fatigue, feelings of worthlessness, and loss of energy (Frank et al.,

2022), greatly hindering the recovery progress. More severely, psychological problems are harder to diagnose than physical ones (Khedr et al., 2020). Many healthcare staff and caregivers lacked psychological expertise, leading to the overlooking of patients' emotional needs.

Several factors contribute to post-stroke emotional disorders. First, the sudden loss of body functions can change the patient's social role definition and self-identity, which can induce depression (Munshi and Harwood, 2020). Second, patients in the acute phase have a feeling of 'losing themselves' and 'being trapped' in a new world (Kouwenhoven et al., 2012). As a result, despite being surrounded by medical staff and caregivers, many stroke patients still experience unprecedented loneliness and a sense of helplessness (Gill et al., 2016). Third, post-stroke depression is also related to various complex factors, including the patient's personality, living habits, physical and cognitive impairments, family, social and nursing environment (De Ryck et al., 2014).

Currently, the treatment for these psychological problems is still limited. A guidance in the United Kingdom (UK) recommends a comprehensive approach to psychological care and a 'stepped care' model of psychological support, similar to the graded rehabilitation scheme (Harrison et al., 2017). However, due to the personnel shortage in practice, patients rarely receive specialized psychological rehabilitation therapy. Currently, the most widely used approach is medication, typically involving the use of benzodiazepines. However, long-term use of benzodiazepines can lead to fatigue, slurred speech, drowsiness, and an increased risk of falls (Ma et al., 2021). To provide a safer, long-lasting, and cost-effective treatment, some other researchers attempted to design rehabilitation assistive devices or equipment for psychological recovery.

## Current Rehabilitation Equipment

In most cases, rehabilitation equipment is developed to assist or substitute therapists. In hospitals and rehabilitation facilities, widely used rehabilitation equipment for stroke patients can be divided into three categories: PT (Physical Therapy), OT (Occupational Therapy), and ST (Speech Therapy). PT aims to help patients recover muscle atrophy, relax spastic muscles, restore nerve conduction, and improve joint and muscle movement through various methods such as force, electricity, light, sound, magnetic fields, and thermal therapy. OT focuses on speech therapy, swallowing therapy, and cognitive impairment treatment. ST emphasizes patients' self-care abilities, fine motor skills in the upper limbs, and communication skills (Gunduz et al., 2023; Shahid et al., 2023). However, most current equipment focuses less on patients' emotional needs.

We found a few rehabilitation products considering emotional factors by incorporating interactive and gamified design features. For example, Kynan et al. developed a gamified virtual reality application for upper limb rehabilitation with graded exercises. They found that the application had a pleasant and positive impact on patients and could motivate patients in rehabilitation compared to the dull and monotonous traditional training methods

(Eng et al., 2007). Pedro KirK designed a home drumming instrument device with simple and effective rehabilitation exercises. It engaged users in independent training at home during the maintenance phase (Kirk et al., 2016). The UNI-ONE wheelchair from Honda Robotics allowed users to adjust the height of the wheelchair and have the same eye level as those who are standing (Hands-free personal mobility: UNI-ONE, n.d.). It could facilitate natural communication and a greater sense of equality. In addition, several research reports suggest that using rehabilitation equipment itself has a positive impact on patients' mental well-being because it makes them feel less burdensome during treatment or daily activities, reducing feelings of guilt and enhancing their sense of control. However, there is a limited number of stroke rehabilitation products designed specifically to address patients' emotional needs (Hy, 1996; Bertisch et al., 2014).

To summarize, stroke patients face substantial physical and psychological challenges during the three phases of the graded rehabilitation model, but emotional needs are often neglected in the current rehabilitation practices due to a lack of psychological resources. Rehabilitation equipment has the potential to fulfil such emotional needs, but it remains unclear about patients' specific needs in different recovery phases and consequently lacks the emotional design of rehabilitation equipment. Therefore, this study aims to answer the following research questions:

1. What problems related to mental health do stroke patients currently encounter in the three rehabilitation phases?
2. What emotional needs do stroke patients have in the three rehabilitation phases, respectively?

## METHOD

### Participants

To answer the research questions, we conducted observations and interviews in the field with 31 participants, including 19 stroke patients, 2 family members of patients, and 10 healthcare professionals from the Affiliated Hospital of Southeast University in Nanjing, China. The 19 stroke patients aged from 32 to 86 years ($M = 57.11$, $SD = 17.93$) included 7 females and 12 males. Among these participants, 2 were in the acute phase, 12 were in the stable phase, and 5 were in the maintenance phase. Due to the limited cognitive and linguistic abilities of the 2 acute-phase patients, we mainly interviewed their family members.

Among the 10 healthcare professionals, 4 were doctors with ages predominantly in the range of 30 to 31 years. There were 4 nurses, including one head nurse, with ages ranging from 36 to 42 years. Two nursing assistants, aged 57 and 65. Only one nursing assistant was male; the rest of the healthcare participants were female.

### Study Design

The interviews and observations were conducted at the Affiliated Hospital of Southeast University. During observations, we employed the "fly on the

wall" and contextual inquiry methods. Observations primarily focused on patients' daily routines, life conditions, behaviours, emotions, as well as the usage of rehabilitation equipment and the hospital environment.

We also conducted semi-structured in-person interviews with the 31 participants in the hospital. The median duration of the interviews was 41 minutes (ranging from 24 to 58 minutes). Interviews were primarily conducted one-to-one, but in cases where patients were accompanied by family members, the family members were also interviewed to aid the patient in recalling information. We asked the patients and family members questions in the following five aspects: basic information, illness experiences, pain points, needs, and rehabilitation attitudes. The emphasis was placed on exploring the psychological needs of the patients, allowing for unplanned discussions.

Interviews with healthcare professionals included three parts: observations of patient needs, professional advice, and an introduction to the rehabilitation process. The purpose was to gain insights into the perspective of healthcare professionals regarding patient needs and to identify existing issues in the clinical implementation of rehabilitation care plans.

### Analysis

The observations and interviews were recorded and transcribed. The data was analysed by the affinity diagram approach to obtain the patients' pain points and needs in different phrases. The initial 98 pieces of recorded information were distilled into 39 labels at the bottom level of the affinity diagram. The recorded 98 pieces of information were categorized according to different phases. After multiple layers of integration, 8 problem tags and 8 need tags were identified and organized.

## RESULT

We have summarized the different emotional pain points and needs across three phases of rehabilitation as shown in Table 1. The results indicate that emotional disorders are very common among stroke patients. All patients reported experiencing emotional disturbances caused by the stroke, with 16 patients (approximately 85%) indicating that they were in a period of low mood though none of the patients were diagnosed with depression.

**Table 1.** Summary of patients' needs and pain points at different phases.

| | Acute phase | Stable phase | Maintenance phase |
|---|---|---|---|
| Pain points | 1. Panic;<br>2. Wakeful consciousness but loss of physical abilities;<br>3. Shift in social identity. | 1. Self-blame and guilt;<br>2. Loneliness;<br>3. Difficulty in rehabilitation training | 1. Weariness of hospital life;<br>2. Concerns about the future. |
| Needs | 1. Feeling of safety;<br>2. Equality and respect;<br>3. Acceptance of new social identity. | 1. Understanding and comfort;<br>2. Companionship and new social interactions;<br>3. Immediate feedback. | 1. Increasing social and recreational activities;<br>2. Boosting confidence. |

**The acute phase** generally spans from a few days to weeks post-stroke. We identified three major pain points. First, Sudden illness with direct health and life threats often triggered panic in patients. Over half of the patients and family members mentioned the feeling of 'fear' during the acute phase. Second, patients in the acute phase could regain consciousness two or three days after the stroke but would remain unable to move or speak for an extended period. This state of inability to move and communicate needs lead to feelings of helplessness, anxiety, restlessness, and irritability in patients. Additionally, they needed others' help in private daily activities, such as using the toilet and changing clothes, as well as receiving passive treatments, which further brought feelings of privacy invasion, wounded self-esteem, and even a sense of 'losing human rights.' Some patients could become withdrawn, sensitive, and resistant to contact with others. '*Needing help with toileting makes me feel so embarrassed; it's the thing I hate most every day*,' said an 86-year-old female patient participant who was a retired professor. Third, patients experienced a significant shift in social identity and self-definition. Nearly half of the patients reported difficulty in accepting this with a hopeless feeling during their bedridden days, making this phase a peak period for post-stroke depression.

Based on these problems, we proposed three emotional needs of patients. First, to alleviate panic, patients required rapid and effective treatment that could evoke safe, reliable, and protected feelings. Second, they needed the feeling of being as valued and respected as healthy people and thus required sufficient attention, patience, privacy protection, and personal space. Third, to assist them in accepting their changed social identity and maintaining a positive mindset, family members should offer more understanding and companionship, and if necessary, professional psychological guidance should be sought.

**The stable phase** is a relatively prolonged period during which patients' mental states gradually become more peaceful, and they begin to accept the reality of their illness. Physical functions also gradually recover, enabling extensive rehabilitation training. In this phase, we identified three major pain points. First, some patients, especially those aged over 70, expressed guilt for disrupting the life and work of their children or partners. Second, 13 patients reported extreme loneliness due to the lack of companionship from family and friends, especially at night, when such feelings impeded sleep. Third, most patients had to take rehabilitation training to recover from problems (e.g., incontinence), communication problems due to language difficulties, and discomfort from prolonged illness. However, rehabilitation training was a lengthy, difficult, and tedious process. Many patients expressed losing confidence and motivation due to insignificant improvement in a short time.

Therefore, we proposed three needs of patients in the stable phase. First, medical staff could show more empathy and understanding towards patients in the stable phase by listening patiently, comforting patients, and helping them express their emotions. Second, as patients' social needs increase, they need to communicate more with others and develop new emotional connections in the hospital as well as be accompanied by family members. Third, patients required immediate and encouraging feedback on rehabilitation

progress. Patients needed to understand the effectiveness of rehabilitation training and their recovery dynamics. In addition, our participants suggested that they could feel anxious when comparing with other patients' progress. One patient mentioned, '*Whenever I see others doing better than me in training, I feel very jealous and unhappy*,' [32-year-old male, healthcare worker, patient participant]. In designing rehabilitation training programs, patients' emotional needs should also be considered, enhancing the entertainment value of the programs to make the training process more enjoyable and relaxing.

**The maintenance phase,** as the final period of returning to family and society, is a crucial transitional phase. The focus of training shifts to fine motor skills, posture correction, obstacle avoidance, and integrating rehabilitation exercises with home activities, making the training content more interesting. In this phase, we found two major pain points. First, most patients became weary of hospital life as their physical functions were gradually recovering. Eight participants mentioned a lack of entertainment and social interaction and a desire to be discharged soon. Second, some patients expressed concerns about the quality of life after discharge. '*The thought that I might never be able to make bread again saddens me deeply. You know, I feel like I've lost my worth*,' said a 52-year-old male pastry chef. The keyword '*abandoned by society*' was repeatedly mentioned in interviews with patients in the maintenance phase.

Therefore, we proposed two major needs of patients in the maintenance phase. First, patients needed more ways of entertainment and social interaction. '*I feel our patients lack recreational spaces. If there were a mahjong room or a book bar to bring together patients with common interests, it would be wonderful. Take mahjong, for example, it not only fulfils social needs but also exercises the patients' fine motor skills, cognitive and verbal abilities, and is more interesting than rehabilitation training*,' said a doctor we interviewed. In addition, patients needed to engage in outdoor activities and interact with people outside the hospital to restore their sense of connection to society. Second, patients needed more training and rehearsals of the activities that they had to perform independently after discharge to boost their confidence in reintegration. This enables patients to return as much as possible to normal life and work, thus reshaping their self-identity.

## DISCUSSION

### Key Findings

This study identified the problems and emotional needs of stroke patients in three phases: acute, stable, and maintenance. In the acute phase, patients primarily face the loss of physical functions and changes in their social identity. They need respect and effective ways to express their needs. In the stable phase, patients encounter difficulties in rehabilitation training and lack motivation, requiring immediate feedback and encouragement. In the maintenance phase, patients grow weary of hospital life and worry about the life after discharge. They need more ways of entertainment, social interaction, and training for independent life.

The finding about the acute phase prioritizes patients' needs of expressing their feelings and having more control over their surroundings. Unmet needs in these areas potentially contribute to patients feeling fearful, disrespected, and disconnected from the world. These results are in line with the previous research finding that 88% of acute stroke patients experienced communication-related impairments, which led to feelings of dissatisfaction and an increased risk of adverse events in the hospital (O'Halloran et al., 2012). It indicates that a potentially effective emotional design strategy for acute patients is to facilitate their expression of intentions and control of surroundings.

The findings about stable and maintenance phases suggest that rehabilitation training is a crucial component of stroke recovery, but current rehabilitation training is often perceived as tedious, unengaging, and feedback-deficient. Another interesting finding about rehabilitation training is the social influence of other patients. Our participants mentioned a sense of competition, anxiety, or peer pressure about the recovery progress. In other health-related fields, such as weight loss, researchers have investigated the positive and negative effects of such social influence and the mechanisms of competition and cooperation (Tsai et al., 2021). The users in these studies have very different physical and psychological features from stroke patients. Therefore, further research needs to investigate how social influence and competition or cooperation affect stroke patients' motivation and willingness to engage in rehabilitation training.

## Design Implications

These findings highlighted a need for emotional design for stroke patients in different phases. Based on these needs, we outlined potential design directions as follows.

In the acute phase, smart technologies in bedside design can support bedridden patients' self-expression, control of the environment, and emotional well-being. For example, patients can express their needs by eye-tracking input technologies. Currently available products include Eyegaze Edge, Tobii Input Method, and Gazepoint Eye Tracking. Besides communication with other people, ceiling and bedside devices with eye-tracking also enable patients to control their environment, such as room lights and curtains, reducing anxiety and fostering autonomy. Additionally, assistive daily living devices (e.g., dressing sticks, button hooks, auto-raising toilet seats) can promote independence in personal care tasks.

In the stable phase, patients take extensive rehabilitation training, and thus the relevant devices need to motivate and engage patients in a safe and pleasant recovery process. Most current assistive devices are made of metal with low-saturation colours and angular shapes, which could lead to difficulties, boredom, and hazards. Therefore, these devices can be improved in both aesthetic and functional aspects. Aesthetically, they can be designed with smoother and more vibrant looks and feels to make patients feel more protected and relaxed during training. Functionally, rehabilitation training can

be incorporated with gamification elements to engage patients and visualization of progress tracking to boost confidence and motivation. For instance, researchers have developed virtual reality training games for stroke patients to take training in home (Chen et al., 2022).

In the maintenance stage, patients can benefit from rehearsal training for independent living skills. This training covers tasks such as cooking, laundry, dressing, bathing, road-crossing, and stair-climbing. The training can be taken in simulated real-life spaces (e.g., kitchens, bedrooms, bathrooms, and streets) using VR/AR technology. These virtual spaces can be integrated with adjustable challenges simulating daily-life obstacles, making training more engaging than conventional exercises. These methods can increase patient confidence and ensure safety during reintegration into home and community life.

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