

“I’m not the same person anymore”: **Sociocultural lived experiences of stroke recovery survivors in Malaysia**

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Abstract

This study used Interpretative Phenomenological Analysis to explore the lived experiences of recovery among 13 stroke survivors in Malaysia, within their sociocultural contexts. Three superordinate themes emerged: making sense of illness and recovery through sociocultural and embodied understandings; reconstructing and negotiating the self within sociocultural contexts; and navigating treatment choices within pluralistic and socioculturally influenced approaches. Findings indicate that recovery is shaped by cultural beliefs, spiritual practices, and social expectations, influencing identity and engagement with treatment. These insights highlight the importance of culturally responsive and person-centred rehabilitation.

Keywords: Stroke survivors; Community reintegration; Sociocultural context; Interpretative Phenomenological Analysis

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1.0 Introduction

Stroke is a leading cause of long-term disability, often affecting individuals' physical abilities, roles, and participation in everyday life (Hussain, 2024). Recovery is commonly understood from a biomedical perspective, focusing on functional outcomes and individual effort. However, such perspectives may overlook how recovery is experienced within everyday social and cultural contexts. Increasingly, there is recognition that recovery is shaped not only by physical changes but also by cultural beliefs, spiritual practices, and social expectations that influence how individuals make sense of their condition and engage in daily life (Rony et al., 2024). In culturally diverse settings such as Malaysia, recovery is closely intertwined with shared beliefs, social norms, and everyday practices. Stroke survivors may draw on a combination of biomedical care, traditional understandings of illness, and religious beliefs as they navigate recovery.

Despite this, limited research has explored how sociocultural influences shape stroke recovery and community reintegration within the Malaysian context. Most existing research on community reintegration is derived from non-Malaysian contexts, such as South Africa (Witt et al., 2024) and India (Nayak et al., 2022), limiting its applicability to Malaysian contexts. Literature also lacks an explicit discussion of sociocultural influences on stroke community reintegration. Furthermore, earlier studies often employ cross-sectional approaches (Honado et al., 2023; Yarfi et al., 2023) that may not adequately capture lived experiences. Therefore, this study aims to explore how stroke survivors make sense of their experiences of recovery towards community reintegration within their sociocultural contexts in

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Malaysia. Specifically, the objective of this study is to interpret how sociocultural influences shape stroke survivors' experiences of recovery towards community reintegration.

2.0 Literature Review

Six major sociocultural factors were identified across the literature: social attitudes and stigma (Aderinto et al., 2025; Song et al., 2025; Zhang et al., 2025); cultural beliefs and practices (Aderinto et al., 2025; Adigwe et al., 2022; Deng et al., 2025); religious and spiritual beliefs (Ambrosca et al., 2024; Laures-Gore & Griffey, 2024; Rony et al., 2024); gender roles and norms (Adigwe et al., 2022; Rony et al., 2024); community and social systems (Rony et al., 2024; Somtua & Nuntaboot, 2025); and knowledge and misconceptions (Njohjam et al., 2025). Social attitudes and stigma encompass both internalised and enacted stigma, which may shape self-perception and participation in social and rehabilitation contexts (Song et al., 2025; Zhang et al., 2025). Internalised stigma (shame and worthlessness) may reduce confidence and engagement in rehabilitation, while enacted stigma from others (blame and negative labelling) may hinder reintegration (Hu et al., 2022; Persson et al., 2024). Conversely, supportive and inclusive attitudes may facilitate recovery by enhancing confidence and participation (Mahmood et al., 2021).

Cultural beliefs and practices include traditional understandings of illness, complementary and alternative medicine, and family caregiving norms shaped by cultural expectations (Aderinto et al., 2025; Adigwe et al., 2022; Deng et al., 2025). These factors may shape illness interpretations and treatment decisions (Aderinto et al., 2025). Preferences for traditional approaches and community norms may delay care or reduce adherence (Njohjam et al., 2025). Family caregiving norms may also lead to overdependence (restrict autonomy) (Aderinto et al., 2025). However, some cultural practices may facilitate recovery by supporting function and meaningful engagement (Aderinto et al., 2025). Religious and spiritual beliefs involve faith-based coping and meaning-making processes that shape how individuals understand and respond to illness (Ambrosca et al., 2024; Laures-Gore & Griffey, 2024; Rony et al., 2024). These beliefs may promote acceptance, hope, resilience, and engagement in rehabilitation (Ambrosca et al., 2024; Laures-Gore & Griffey, 2024). However, spiritual struggles or beliefs that recovery is determined by a higher power may reduce engagement and contribute to distress or isolation (Rony et al., 2024).

Gender roles and norms are socially constructed expectations that shape responsibilities, behaviours, and participation (Adigwe et al., 2022; Rony et al., 2024). Fulfilling expected roles may support motivation and mental well-being, whereas the inability to fulfil roles, such as breadwinning or domestic responsibilities, may lead to distress and reduced self-worth (Adigwe et al., 2022; Prakash & Ganesan, 2021). Community and social systems, including support networks, community attitudes, and healthcare structures, may influence access to resources and reintegration experiences (Rony et al., 2024; Somtua & Nuntaboot, 2025). Community-based support may facilitate recovery through emotional and practical assistance (Somtua & Nuntaboot, 2025), while systemic attitudes and differences in professional practices may shape how rehabilitation is delivered and limit consistency in care (Rony et al., 2024). Lastly, knowledge and misconceptions about stroke, including inaccurate beliefs and limited awareness, may reduce help-seeking behaviours and poor attitudes towards recovery (Njohjam et al., 2025).

Overall, these findings highlight that sociocultural influences interact in complex ways to shape stroke recovery experiences, functioning as both barriers and facilitators. While these factors have been identified, existing studies often treat them as static variables rather than dynamic processes shaped through lived experience. Furthermore, many studies do not explicitly use the term "sociocultural" and instead refer to related concepts, such as stigma or cultural beliefs. This suggests sociocultural influences are rarely recognised as a unified concept. Therefore, this study adopts the term "sociocultural" in one lens to bring these related aspects together in understanding recovery.

3.0 Methodology

3.1 Study design and participants

This study employed a qualitative research design using Interpretative Phenomenological Analysis (IPA) to explore how stroke survivors make sense of their recovery and community reintegration experiences within their sociocultural contexts. IPA was selected because it acknowledges the double hermeneutic process, in which participants attempt to make sense of their experiences while the researcher simultaneously interprets how they make sense of those experiences. A total of 13 stroke survivors participated in this study, and the sample was considered sufficient based on the concept of information power, which holds that participants with specific and relevant experiences can provide rich, in-depth insights into the phenomenon being explored.

The study was conducted in Kuala Selangor, which comprises both urban and rural communities, enabling exploration of diverse sociocultural experiences. Inclusion criteria were stroke survivors aged between 18 and 60 years who had experienced a first or recurrent stroke within 6 months to 2 years prior to the study, had moderate dependence to independence in activities of daily living (Barthel Index scores of 61–100), and were able to communicate in Malay or English. Exclusion criteria included individuals with severe sensory deficits (e.g., significant hearing or visual impairments), severe musculoskeletal or neurological conditions (e.g., contractures, severe aphasia), and non-Malaysian citizens.

3.2 Data collection and analysis

Data collection commenced following ethical approval from Universiti Teknologi MARA (REC/06/2025 [ST/MR/115]) and the Medical Research and Ethics Committee, Ministry of Health Malaysia (NMRR ID-25-02469-T0C [IIR]). Participants were recruited using purposive sampling through selected healthcare facilities and rehabilitation centres, with healthcare practitioners assisting in identifying eligible individuals. Upon consent, individual semi-structured interviews were conducted at a convenient time and location, audio-recorded, and transcribed verbatim. An interview guide was used to maintain consistency with the study objectives.

Data was analysed using Interpretative Phenomenological Analysis (IPA), following Pietkiewicz and Smith (2014). Analysis involved repeated readings of transcripts, initial noting of descriptive, linguistic, and conceptual insights, and development of emergent themes within each case. Themes were then clustered and compared across cases to identify similarities and differences, leading to the development of cross-case superordinate themes. This process facilitated understanding of how participants made sense of recovery and community reintegration within their sociocultural contexts.

3.3 Translation of quotes

Interviews were conducted in Malay and later translated into English for reporting purposes. Emphasis was placed on maintaining semantic equivalence and preserving culturally nuanced expressions to ensure participants' intended meanings were accurately represented in the translated quotations.

3.4 Trustworthiness of study

Trustworthiness was established through credibility, transferability, dependability, and confirmability. Credibility was enhanced through prolonged engagement and repeated immersion in the data. Transferability involved providing contextual descriptions of the participants and research process. Dependability was maintained through clear documentation of data analysis and peer discussions among the research team. Confirmability involved reflexive practices and documentation of analytical decisions throughout the study.

4.0 Findings

A total of 13 stroke survivors participated in this study. The participants' ages ranged from 24 to 60 years old. They were recruited from the government and semi-government hospitals, government clinics, and private rehabilitation centres in Kuala Selangor. Most participants had experienced a first-ever stroke, while two participants had experienced recurrent strokes. All participants were between 6 months and 2 years post-stroke. Approximately half of the participants were moderately dependent on activities of daily living, while the remainder were independent. Most participants communicated primarily in Malay, while a smaller number communicated in English. Three superordinate themes emerged from the analysis: Making sense of illness and recovery through sociocultural and embodied understandings; Reconstructing and negotiating the self within sociocultural contexts; and Navigating treatment choices within pluralistic and socioculturally influenced approaches. The findings are illustrated in Fig. 1 below.

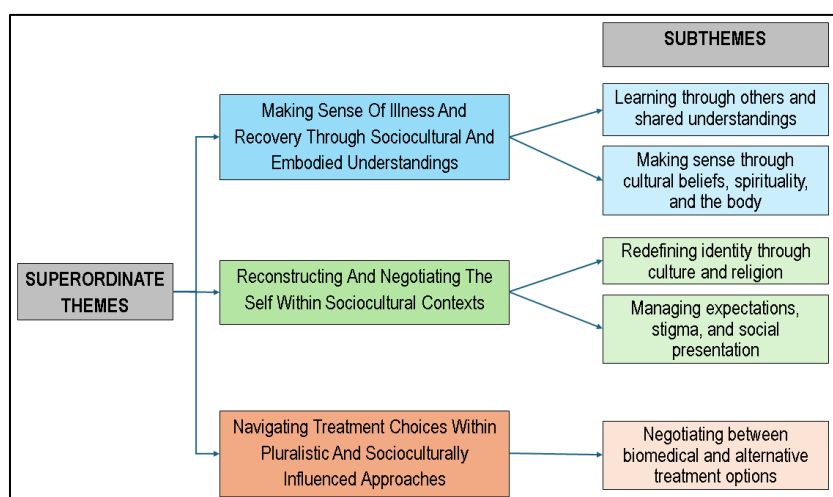


Fig. 1: Overview of Superordinate Themes and Subthemes

4.1 Making sense of illness and recovery through sociocultural and embodied understandings

Participants expressed that making sense of illness and recovery was shaped by interactions with others, cultural beliefs, and spiritual perspectives.

4.1.1 Learning through others and shared understandings

Participants drew on others' experiences and knowledge to reframe or interpret their condition. This can be seen in a participant who compared themselves with others who were more severely affected:

"I prefer the community setting... see that others are going through worse. There was one person who had a stroke and came in a wheelchair, pushed by his wife... ya Allah, I haven't been grateful... I need a walking stick, at least I can still walk."

Another participant shared how others influenced their understanding of stroke:

"My family did tell me that staying up late on the phone and constantly being online makes you think too much. When you keep overthinking like that, eventually something like this happens."

4.1.2 Making sense through cultural beliefs, spirituality, and the body

Participants also interpreted their recovery through cultural and spiritual beliefs and bodily experiences. A participant reflected on their illness through culturally informed beliefs:

"He is a retired teacher who does massage. It was painful because he used the tip of a pencil to press and pull. He said this wasn't a typical stroke, but a 'nerve stroke' because the blood flow was disrupted in the nerve... he has experience."

Another participant reflected on their illness through a spiritual perspective:

"My husband reminded me that when Allah gives happiness, we are grateful, but when hardship comes, we complain and forget His blessings. That made me reflect on my illness differently and see it as a test of faith that taught me gratitude."

4.2 Reconstructing and negotiating the self within sociocultural contexts

Participants expressed changes in their sense of self as an ongoing process of adjusting how they saw themselves and how others saw them.

4.2.1 Redefining identity through culture and religion

Participants expressed continuing cultural and religious practices after a stroke. Religious practices were often adapted to fit their abilities, as shared by a participant:

"I pray sitting down, depending on what I can manage. At first, I was sitting the whole time, but now I can stand a bit, like during bowing. I'm slowly trying to get back to praying like usual."

One participant shared their experience from a cultural perspective:

"I still join cultural celebrations with my family, like going to Batu Caves during festivals. Even though they were worried about me climbing the stairs after the stroke, I wanted to do it myself."

4.2.2 Managing expectations, stigma, and social presentation

Participants shared that having awareness of how they were perceived led them to adjust their social presentation, as conveyed by a participant:

"I actually didn't want people to know I had a stroke because I didn't want them to see me as incapable or feel sorry for me... I didn't tell anyone because if they knew, they would usually come over to visit."

A participant expressed struggling with self-expectations in fulfilling her role within the family following a stroke:

"My siblings said my husband was very patient because he had to take care of the family for six months. All these years, I was the one managing the family, but after the stroke, I felt useless just staying at home."

4.3 Navigating treatment choices within pluralistic and socioculturally influenced approaches

In Malaysia, while biomedical treatment is widely recognised, alternative and traditional practices remain embedded in everyday health practices. In this context, participants shared their experiences navigating different treatment approaches during their recovery.

4.3.1 Negotiating between biomedical and alternative treatment options

Participants expressed trying both medical and alternative treatments, often using them together based on what they felt worked. As reflected in one participant's account:

"For me, there's no one that's better. Each has its own strengths... When I was in the ward, I followed the hospital treatment... At the same time, I also took herbal tea, such as 'misai kucing'... To me, both complement each other."

Others leaned more towards alternative treatments, often trying these first before seeking medical care:

"When it first happened, we tried treatments like bloodletting and cupping before going to the hospital... The bloodletting was performed using a method called fashdu... After that, the doctor confirmed it was a minor stroke."

In other cases, a participant engaged in alternative practices but remained distanced, participating out of respect rather than belief:

"My mother called someone to do a 'wind release' ritual, saying it was to remove bad things. I just went along with it, but honestly, it was hard to believe. They were blowing and tapping... After that, we just laughed about it, like we weren't even sure if it was real."

5.0 Discussion

This study delved into how stroke survivors interpret their recovery journeys within their unique cultural and social settings. Consistent with previous literature, the findings suggest that sociocultural influences function as both barriers and facilitators in shaping recovery experiences. However, this study further highlights how these influences are actively interpreted, negotiated, and embodied by stroke survivors in daily lives rather than passively experienced.

5.1 Making sense of illness and recovery through sociocultural and embodied understandings

Participants made sense of their illness and recovery through shared understandings, cultural beliefs, spirituality, and embodied experiences. This aligns with previous literature highlighting the influence of sociocultural contexts on how individuals interpret illness, engage with recovery, and participate in rehabilitation (Aderinto et al., 2025; Adigwe et al., 2022; Deng et al., 2025). Existing studies have also shown that community influences (Somtua & Nuntaboot, 2025), cultural beliefs (Aderinto et al., 2025), and spirituality (Ambrosca et al., 2024) shape how stroke survivors understand their condition and cope with recovery.

This study further illustrates how participants constructed meaning through social, cultural, and spiritual perspectives. For some participants, comparing themselves with others who were perceived as more severely affected appeared to promote gratitude and acceptance, reflecting the role of shared social understandings in shaping recovery experiences. Similarly, beliefs shared within social settings influenced how participants explained the causes of stroke, particularly through ideas surrounding stress, overthinking, and lifestyle practices. Furthermore, some participants drew on culturally informed explanations, such as viewing stroke as a "nerve stroke" based on traditional understandings and experiential knowledge from alternative practitioners. This reflects previous findings that sociocultural beliefs may shape how individuals interpret illness and recovery beyond biomedical understandings (Deng et al., 2025).

In addition, spiritual reflections appeared to help some participants make sense of suffering by viewing illness as a test of faith or a reminder of gratitude, supporting earlier literature that identified spirituality as a source of meaning-making, hope, and psychological resilience during recovery (Ambrosca et al., 2024; Laures-Gore & Griffey, 2024). These findings suggest that recovery was not understood solely as a physical process, but as an experience continuously interpreted through participants' sociocultural contexts.

5.2 Reconstructing and negotiating the self within sociocultural contexts

The findings suggest that recovery involves an ongoing process of reconstructing and negotiating the self within sociocultural contexts. Consistent with previous literature, participants experienced disruptions in identity, roles, and social participation following stroke (Adigwe et al., 2022). Existing studies have also shown that stigma and social attitudes (Aderinto et al., 2025), as well as gender expectations (Rony et al., 2024), may influence self-worth, psychological well-being, and reintegration.

This study further highlights how participants actively adjusted their sense of self in response to these changes. Some participants adapted religious and cultural practices to fit their physical abilities, suggesting attempts to preserve continuity in identity despite functional limitations. Continuing participation in cultural and religious activities also appeared to help participants maintain familiarity and connection with their previous roles and routines. These findings support earlier literature suggesting that cultural and spiritual practices may provide meaning, continuity, and emotional support during recovery (Ambrosca et al., 2024; Laures-Gore & Griffey, 2024).

At the same time, participants expressed awareness of how they were perceived by others, particularly concerns about appearing weak or pitied. In response, some manage their social presentation by concealing their condition or attempting to maintain a sense of normality. Participants also appeared to struggle with self-expectations related to their roles within the family, particularly when they were no longer able to fulfil responsibilities they previously managed. This reflects previous findings that stigma, social expectations, and gendered roles may shape how stroke survivors negotiate identity, self-worth, and social participation following stroke (Adigwe et al., 2022; Zhang et al., 2025). Overall, these findings suggest that identity reconstruction following stroke was shaped not only by physical changes but also by ongoing negotiation within participants' sociocultural environments.

5.3 Navigating treatment choices within pluralistic and socioculturally influenced approaches

Participants shared that they navigated between biomedical and alternative treatment approaches throughout their recovery. This supports previous findings that cultural beliefs and traditional practices may shape treatment preferences and rehabilitation engagement

(Aderinto et al., 2025; Adigwe et al., 2022; Deng et al., 2025). Existing literature has also highlighted how sociocultural contexts influence the use of complementary and alternative medicine alongside conventional healthcare approaches (Aderinto et al., 2025).

This study further shows that participants did not simply choose between biomedical and alternative treatments but actively negotiated among different approaches based on perceived effectiveness, family influence, cultural practices, and personal beliefs. Some participants viewed both approaches as complementary, combining hospital treatment with traditional remedies during recovery. Others prioritised alternative practices before seeking medical care, reflecting the ways culturally embedded understandings of illness shape help-seeking behaviours. At the same time, some participants engaged in alternative practices more distantly, participating out of respect for family beliefs despite personal uncertainty. This suggests that engagement with alternative practices was not always driven by personal belief but could also reflect negotiation within family and sociocultural expectations.

Overall, these findings reflect the pluralistic nature of healthcare practices within sociocultural contexts in Malaysia, where biomedical and traditional understandings of illness frequently coexist and influence recovery experiences.

To conclude, the findings highlight the importance of culturally responsive and person-centred rehabilitation approaches that recognise the role of sociocultural influences in shaping recovery experiences. For practice, healthcare practitioners such as occupational therapists should consider stroke survivors' cultural beliefs, spirituality, self and family expectations, and healthcare preferences when planning interventions to support meaningful participation and community reintegration. At the service level, rehabilitation services should incorporate sociocultural considerations into client-centred care to enhance engagement in rehabilitation and recovery outcomes. The findings also support achieving the Sustainable Development Goals (SDGs), particularly SDG 3 (Good Health and Well-being) and SDG 10 (Reduced Inequalities), through more culturally responsive rehabilitation treatments.

6.0 Conclusion & Recommendations

This study highlights that stroke recovery is not just a biomedical or individual process, but is also shaped by cultural beliefs, spiritual practices, and social expectations. The findings show how participants interpreted illness, negotiated identity, and navigated treatment within their sociocultural contexts. This study has several limitations. The findings are based on participants' personal accounts and the researcher's interpretation, which may influence how the data is understood. In addition, some participants were accompanied by caregivers during interviews, mainly due to caregiver concern and participants' own limitations, such as mobility difficulties. This may have influenced how openly they shared their experiences.

To improve the quality of research findings in future studies, interviews could be conducted without caregiver presence where appropriate, while still ensuring participants feel safe and comfortable. Additionally, incorporating multiple data sources or perspectives may help enhance the depth and credibility of the findings. Future research could specifically explore the experiences of caregivers and healthcare professionals to provide a more comprehensive understanding of stroke recovery. Studies involving more diverse populations may also offer further insight.

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Paper Contribution to Related Field of Study

This study contributes to rehabilitation, particularly occupational therapy, by showing how stroke recovery is shaped not only by medical factors but also by sociocultural influences. It highlights how cultural beliefs, spiritual practices, and social expectations influence how individuals engage in daily activities and make treatment decisions. The findings offer insight into how stroke survivors make sense of recovery in their everyday lives. Overall, this study underscores the importance of culturally responsive and person-centred rehabilitation, supporting occupational therapists to provide care that aligns with clients' beliefs, values, and lived experiences.

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