



Development and Content Validation of a Semi-Structured Interview Guide for Exploring the Lived Experiences and Unmet Needs of Stroke Survivors after Physiotherapy

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(Received: 27 September 2025 Revised: 05 October 2025 Accepted: 18 November 2025)

KEYWORDS

stroke survivors, lived experiences, physiotherapy, interview guide, content validity, Qualitative research.

ABSTRACT:

Background: Stroke survivors often encounter persistent challenges and unmet rehabilitation needs after completing physiotherapy, yet there is no validated tool to comprehensively capture these experiences. Understanding their lived experiences is essential for improving rehabilitation outcomes and identifying gaps in care.

Objectives: To develop and content-validate a semi-structured interview guide to explore the lived experiences and unmet needs of stroke survivors following physiotherapy.

Methods: A mixed-methods approach was used, beginning with interview-guide development through a comprehensive literature review and consultation with multidisciplinary experts. Content validity was established through expert evaluation using item- and scale-level Content Validity Index (CVI) calculations.

Results: The final interview guide comprises 14 open-ended questions organized into five thematic domains: (1) post-physiotherapy physical and functional status, (2) psychological and emotional well-being, (3) social participation and community reintegration, (4) unmet rehabilitation needs, and (5) healthcare system experiences. Content validity analysis demonstrated excellent agreement, with item-level CVI values ranging from 0.88 to 1.00 and a scale-level CVI/Ave of 0.96.

Conclusions: This validated interview guide provides researchers and clinicians with a structured tool to systematically explore the lived experiences and unmet needs of stroke survivors after physiotherapy, supporting evidence-based improvements in post-stroke care and rehabilitation services.

1. Introduction

Stroke remains one of the leading causes of long-term disability worldwide, affecting approximately 15 million people annually [1]. While advances in acute stroke care have significantly improved survival rates, the majority of stroke survivors face ongoing challenge that persist well beyond their initial rehabilitation period [2]. Despite the critical role of physiotherapy in stroke recovery, evidence suggests that many survivors

continue to experience significant unmet needs after completing formal rehabilitation services [3,4]. The lived experience of stroke survivors encompasses the complex interplay of physical, psychological, social, and functional challenges that individuals face as they navigate their post-stroke journey [5]. Research has consistently demonstrated that stroke survivors encounter multifaceted difficulties including motor impairments, cognitive deficits, emotional disturbances,



social isolation, and barriers to community reintegration[1,3,6]. These challenges are particularly pronounced in the period following discharge from physiotherapy services, where survivors often feel abandoned by the healthcare system and struggle to maintain functional gains [7,4]. Current literature reveals substantial evidence of unmet needs among stroke survivors, with studies reporting that 30-49% of individuals identify specific unmet physiotherapy needs even one year after hospital discharge [3]. These needs span across multiple domains including mobility enhancement, balance training, fatigue management, and access to ongoing therapeutic services[3,4]. Qualitative research has highlighted that stroke survivors particularly struggle with higher-level mobility skills necessary for community ambulation, yet current rehabilitation approaches often fail to address these complex functional requirements[3]. The phenomenon of post-stroke unmet needs has been explored through various research methodologies, yet there remains a significant gap in validated instruments specifically designed to comprehensively explore the lived experiences of stroke survivors following physiotherapy completion[4,6]. Existing assessment tools often focus on standardized outcome measures rather than capturing the nuanced, subjective experiences that are central to understanding the full impact of stroke on individuals' lives [5,8]. Phenomenological research approaches have emerged as particularly valuable for understanding the lived experiences of stroke survivors, as they allow for deep exploration of how individuals make sense of their post-stroke reality[5,8,9]. However, the lack of validated interview guides specifically designed for this population has limited the systematic investigation of post-physiotherapy experiences and hampered efforts to develop targeted interventions[6].

2. Methods

Phase 1 Initial Interview Guide Development

Literature Review and Theoretical Framework:

A comprehensive literature review was conducted using PubMed, CINAHL, PsycINFO, and Cochrane databases with search terms including "stroke survivors," "lived experience," "unmet needs," "physiotherapy," "rehabilitation," and "qualitative research." The search encompassed articles published between 2010-2023 to ensure contemporary relevance while maintaining sufficient depth of evidence[1,2,3,4,5].

The initial guide was developed was grounded in phenomenological research principles[8,9], specifically Diekelmann's hermeneutic approach, which emphasizes understanding the meaning individual's attribute to their lived experiences[5]. The theoretical framework also incorporated elements from the International Classification of Functioning, Disability and Health (ICF) model to ensure comprehensive coverage of physical, psychological and social dimensions of post-stroke experiences[3].

Initial Question Development:

The initial pool of interview questions was generated through synthesis of findings from the literature review, clinical expertise of the research team, and adaptation of questions from validated instruments used in similar populations[12,13,14]. Questions were formulated as open-ended to facilitate in-depth exploration of participants' experiences while maintaining sufficient structure to ensure consistent coverage of key topics[12,15].

The preliminary guide included 16 questions organized into three preliminary thematic domains: lived experiences, unmet needs, and future perspectives. Questions were designed to progress from broad, descriptive inquiries to more specific, focused explorations of particular experiences [12].

Phase 2 Content Validation

Expert Panel Selection:

Content Validation was conducted using Lawshe's methodology [10], which requires assessment by subject matter experts to determine the essential nature of each interview question. A panel of 9 multidisciplinary experts was recruited using purposive sampling based on predefined criteria [11]. Minimum 8 years of clinical or research experience with stroke populations. Advanced degree in relevant discipline (physiotherapy, occupational therapy and medicine). Demonstrated expertise through peer-reviewed publications or clinical leadership roles. Availability and willingness to participate in the validation process.

The expert panel comprised 5 physiotherapists, 1 occupational therapists, 2 stroke physicians and 1 Physiatrist Panel members represented diverse healthcare settings including acute care, rehabilitation centers, and community-based services.

Content Validity:

A Delphi survey was conducted to establish the content validity of the newly developed interview guide, following established recommendations (Polit 2006; Zamanzadeh, 2016). The multidisciplinary expert panel



comprised physiotherapists, occupational therapists, and neurologists with extensive experience in stroke rehabilitation (Paredes 2021). Initially, 25 potential experts were identified. They were screened using two criteria: a minimum of 6 years of clinical experience in stroke rehabilitation and at least one published article on the subject. From this pool, 15 experts were invited to participate and received the questionnaire via Google Forms, shared through email, WhatsApp, and personal messages. The form included the draft interview guide and a cover letter explaining its purpose and background, along with clear instructions for rating each item's relevance, clarity, and essentiality. Relevance was rated on a 4-point Likert scale (1 = not relevant to 4 = very relevant) (Polit 2006; Yusoff 2019; Zamanzadeh 2016). Essentiality was assessed on a 3-point scale (1 = not essential to 3 = essential), and clarity on a 3-point scale (1 = not clear, 2 = needs revision, 3 = clear). Space was provided for experts to suggest wording changes or other improvements for each item. Following Lynn's guideline that at least six experts are required for scale validation, nine experts with an average of eight years' experience in stroke rehabilitation completed the survey and offered detailed feedback.

Initial Interview guide draft

Lived Experience

1. Before you began physiotherapy after your stroke, what went through your mind? Can you share the thoughts or feelings you had when the doctor or therapist first suggested it? What were you hoping it might help you achieve---such as walking again, gaining independence, or simply feeling stronger?

2. When you started your very first sessions, what specific goals did you set for yourself, and what outcomes did you imagine at that time? Were there things you worried about or looked forward to?

3. Please walk me through your entire journey with physiotherapy so far. Were there moments that were particularly uplifting, discouraging, or surprising? How did the environment, the staff, or the routine make you feel on a daily basis?

4. Out of all the activities---exercises, balance training, mobility drills, or use of equipment---what parts felt most valuable or meaningful to you? Were there any that you found confusing or not very helpful?

5. In what ways has physiotherapy affected your everyday activities such as bathing, dressing, cooking or getting around? Have you noticed changes in confidence, independence, or your ability to manage at home?

6. How has physiotherapy influenced your mood, motivation, or relationships? Did it help you feel more connected with others or sometimes more isolated?

7. Who or what has been the biggest support for you in sticking with your physiotherapy plan---family members, friends, other patients, your therapist, or even your own determination? Can you describe a moment when that support really mattered?

8. Tell me about any times when you felt very involved--or maybe not involved enough---in decisions about your therapy schedule, exercises, or goals. What difference did that make for you?

9. After you left the hospital or inpatient program, did you feel you had enough emotional support? For example, did you experience feelings such as confusion, sadness, or anxiety, and if so, how were they addressed?

10. Have you faced any challenges in reconnecting socially---like meeting friends, joining community events, or simply feeling part of everyday life again? What helped or hindered that process?

Unmet Needs

11. Thinking about your physiotherapy journey, were there any services or types of therapy you expected but did not receive? Maybe certain equipment, counselling, or specialized sessions?

12. What were the toughest challenges while attending therapy such as pain, fatigue, travel issues, or financial strain? How did you cope with them?

13. Looking more broadly, what outside factors---like transportation problems, lack of home adaptations, or limited caregiver help---have made recovery harder for you?

14. What do you know about government policies, insurance coverage, or financial benefits that could support stroke rehabilitation? Who first told you about them, and did you find the information easy to understand?

15. Have you tried to apply for any of these supports? Please describe what that process was like---smooth, frustrating, or something in between.

16. If you could design the perfect rehabilitation service for someone in your situation, what would it look like? Are there services or resources you feel should exist but currently do not?



3. Results

Revisions to the stroke-survivor interview guide were made after collecting expert feedback through the Delphi survey. Experts suggested rephrasing several questions to a more open-ended style (changing “Do/Are/Have” to prompts such as “Can you describe...” or “Tell me about...”), merging overlapping questions, and simplifying wording for clarity. Specific modifications included- Initial Q1 and Q2 (first impressions and early expectations) were combined into the final Item 1: “Before starting physiotherapy, what were you hoping to get out of it?”. Initial Q3 and Q4 (overall journey and therapy components) were condensed into final Items 2 and 3 focusing on overall experience and most helpful parts of physiotherapy. Initial Q5 and Q6 (impact on daily life and emotional/social influence) were streamlined and partially merged into final Item 4. Initial Q7 (support systems) became final Item 5, with shorter probes. Initial Q8 (participation in planning) was retained as final Item 6, but wording was simplified. Initial Q9 (transition after discharge) was refined to emphasize emotional support and placed as final Item 7. Initial Q10 (community/social reintegration) became final Item 8. For the Unmet Needs domain, overlapping questions on missing services, challenges, and barriers (Initial Q11–Q13) were merged and re-ordered as final Items 9–11. The two questions on government awareness and accessing benefits (Initial Q14 and Q15) were combined and tightened into final Items 12 and 13. Initial Q16 (ideal rehabilitation services) was streamlined into final Item 14. During this process, long or repetitive wording was shortened, and redundant probes were removed. The resulting validated interview guide therefore contains 14 concise, open-ended questions: seven under *Lived Experience* and seven under *Unmet Needs*, each with clear probes for richer qualitative responses.

Content Validity : The content validity index (CVI) was derived at both the item and scale levels. The item-level CVI (I-CVI) for each of the 14 final questions was calculated as the proportion of the nine experts who rated that item as “quite relevant” or “very relevant.” With nine experts, an I-CVI ≥ 0.78 indicates adequate relevance (Polit, 2006; Yusoff, 2019). In our guide, four items (Q3, Q4, Q6, Q10) showed I-CVI values of 0.88, while the remaining ten items achieved perfect agreement (I-CVI = 1.00) (Table 2). The scale-level CVI (S-CVI) was calculated by the average method (S-CVI/Ave) by summing all I-CVI scores and dividing by the total number of items. The overall S-CVI/Ave was 0.96, and the universal-agreement S-CVI (S-CVI/UA) was 0.85, both demonstrating excellent content validity for the final 14-item interview guide.

The preliminary draft and the validated final guide are presented in Tables 1 and 2 of this manuscript.

Table 1 : Final interview guide with Scale-level and Item-level Content Validity Index (CVI)

Sr. No.	Final Interview Guide Item	I-CVI
1	Before starting physiotherapy, what were you hoping to get out of it?	1.00
2	Tell me about your overall experience with physiotherapy.	1.00
3	In your opinion, which parts of physiotherapy were most helpful (e.g., exercises, support, tools)?	0.88
4	How has physiotherapy contributed to your daily activities (ADLs), movement, balance, or social life?	0.88
5	What supported you most in sticking with physiotherapy (family, friends, spouse, team)?	1.00
6	Can you describe any situation where you felt very involved—or not involved—in planning your care?	0.88
7	After leaving the hospital, did you feel supported emotionally (confusion, distress, depression)?	1.00
8	Can you describe any difficulties with social interactions or feelings of isolation?	1.00
9	What rehabilitation needs or preferences were not included in your physiotherapy care plan?	1.00
10	What challenges have you faced during physiotherapy after your stroke (e.g., pain, fatigue)?	0.88
11	What barriers have you faced in your recovery journey (transport, equipment, home help)?	1.00
12	Can you share what you know about government policies, insurance, or financial support for rehabilitation?	1.00
13	Have you been able to access these services or benefits easily? Describe challenges, if any.	1.00



14	Are there services you feel should be available but currently are not?	1.00
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4. Discussion

This study generated and content-validated a semi-structured interview guide designed to explore the lived experiences and unmet rehabilitation needs of stroke survivors following physiotherapy. The guide captures not only patients’ personal experiences with physiotherapy but also their perceptions of barriers, facilitators, and areas where services could be improved. Although developed specifically for the Indian context, the guide can be adapted and validated for use in other low-, middle-, and high-income settings. To our knowledge, this is the first validated interview guide focusing on stroke survivors’ post-physiotherapy experiences and unmet needs. It provides a structured framework for qualitative research aimed at understanding recovery from the patient perspective and for evaluating service delivery in outpatient, inpatient, and community rehabilitation programs. Through this guide, researchers and clinicians can systematically explore how physiotherapy influences daily activities, emotional well-being, and social participation. It also offers a tool to gather patient-centred feedback about obstacles such as transportation, equipment availability, or financial support, and to identify supports that enhance adherence and outcomes. The validated guide can be applied across diverse care settings—including in-person and tele-rehabilitation—to inform policy, refine physiotherapy services, and improve long-term quality of life for stroke survivors.

Table 2 : Interview guide with initial and final items.

Initial Item	Final Item
1. Before beginning physiotherapy after your stroke, what were your first thoughts and hopes? What did you expect therapy to help you achieve, such as walking again, gaining independence, or simply feeling stronger?	1. Before starting physiotherapy, what were you hoping to get out of it?• Initial thoughts about physiotherapy• Hoping to achieve something
2. When you first started your sessions, what specific goals or concerns did you have? Were there things you worried	2. Tell me about your overall experience with physiotherapy. • Any moments that stood out • Positive or challenging

about or looked forward to?	
3. Please walk me through your entire journey with physiotherapy. Were there moments that were particularly uplifting, discouraging, or surprising?	3. In your opinion, what parts of physiotherapy were most helpful for you?• Exercises• Support• Any tools
4. Out of all the activities—exercises, balance training, mobility drills, or use of equipment—what parts felt most valuable or meaningful to you?	4. How has physiotherapy played a role in:• ADLs• Thinking and focus• Movement and balance• Socializing
5. Who or what has been the biggest support for you in sticking with your physiotherapy plan—family members, friends, other patients, or your therapist?	5. What supported you the most in sticking with physiotherapy?• Family• Friends• Children• Spouse• Physiotherapy team
6. Tell me about any times when you felt very involved—or maybe not involved enough—in decisions about your therapy schedule, exercises, or goals.	6. Can you describe any situation where you felt either very involved or not involved enough in planning your care?
7. After you left the hospital or inpatient program, did you feel you had enough emotional support—such as help for confusion, sadness, or anxiety?	7. After leaving the hospital, did you feel supported emotionally?Probe: Did you feel you received adequate support for issues such as confusion, emotional distress, depression?
8. Have you faced any challenges in reconnecting socially—like meeting friends, joining community events, or	8. Can you describe any difficulties with social interactions or feelings of isolation?



simply feeling part of everyday life again?	
9. Thinking about your physiotherapy journey, were there any services or types of therapy you expected but did not receive?	1. What were the rehabilitation needs or preferences that weren't included in planning physiotherapy care?
10. What were the toughest challenges while attending therapy—such as pain, fatigue, travel issues, or financial strain?	2. What challenges have you faced during physiotherapy after your stroke?• Pain• Fatigue• Difficulty moving
11. Looking more broadly, what outside factors—like transportation problems, lack of home adaptations, or limited caregiver help—have made recovery harder for you?	3. After leaving the hospital, did you feel supported emotionally? <i>(merged with final Q7 for context if needed)</i>
12. What do you know about government policies, insurance coverage, or financial benefits that could support stroke rehabilitation?	5. Can you share what you know about the government policies, insurance coverage, or any financial support available to you for your rehabilitation?Probe: Have you been able to access these services or benefits easily? Were there any challenges? Share your experience.
13. Have you tried to apply for any of these supports? Please describe what that process was like—smooth, frustrating, or something in between.	6. What barriers have you faced in your recovery journey?• Transport• Equipment• Home help
14. If you could design the perfect rehabilitation service for someone in your situation, what would it look like? Are there services or resources	7. Are there any services you feel should be available but aren't there?

you feel should exist but currently do not?	
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Conclusion

The study demonstrated that the developed interview guide is a valid tool for exploring the lived experiences and unmet rehabilitation needs of stroke survivors after physiotherapy. This 14-item guide provides a structured framework to capture patient perspectives, identify barriers and facilitators to recovery, and generate qualitative insights that can inform future research, clinical practice, and rehabilitation policy.

Acknowledgments

We thank the expert panel members for their valuable time and expertise in validating the interview guide content. We also express our gratitude to the stroke survivors who participated in pilot testing and shared their experiences to improve the instrument's quality and relevance. Special appreciation goes to the rehabilitation staff who assisted with participant recruitment and the research coordinators who facilitated the validation process.

Acknowledgments

The authors would like to thank the experts who contributed in validating the interview guide.

Conflict of interest

The authors declare that they have no conflict of interest to disclose.

Ethics statement

The study was approved by the Institutional Ethical Committee of Maharishi Markandeshwar Institute of Medical Sciences and Research (MMIMSR) (project number: IEC-3453) and registered on CTRI (identifier:CTRI/2025/07/091264).

Data Availability Statement

This study involved the development and content validation of an interview guide and did not include the collection of primary participant data. Therefore, no datasets were generated or analyzed, and data sharing is not applicable to this article.

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Funding

The authors state that they did not receive any financial support for this study.

Informed consent

Informed consent was obtained from all experts prior to participation.

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SP & SC : Conception and design and analysis

SC : Interpretation of the data

SP & S & SB : Drafting of the paper

MS & SC : Revising it critically for intellectual content

SC : Final approval of the version to be published

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