Postprint of a Meta-Synthesis of Qualitative Research on the Fatigue Experience of Patients with Post-Stroke Fatigue

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Abstract

Background Previous studies have shown that the incidence rate of post-stroke fatigue (PSF) in stroke patients ranges from 25% to 85%. Persistent fatigue severely impacts patients' daily lives and rehabilitation processes. Therefore, there is an urgent need to understand the psychological experiences and needs of these patients. However, findings from single qualitative studies conducted previously may lack representativeness.

Objective To systematically evaluate and integrate qualitative studies on the fatigue experience of PSF patients, providing evidence for developing fatigue management strategies for this population.

Methods Computerized searches were conducted in PsycINFO, PubMed, Web of Science, CINAHL, Cochrane Library, Scopus, the Joanna Briggs Institute (JBI) evidence-based healthcare database, as well as CNKI, Wanfang Data Knowledge Service Platform, VIP, and the Chinese Biomedical Literature Database to collect qualitative studies related to the fatigue experience of PSF patients. The search timeframe spanned from database inception to July 5, 2023. Quality assessment was performed using the JBI Critical Appraisal Checklist for Qualitative Research (2016), and a meta-aggregative approach was employed for meta-synthesis.

Results A total of 10 articles were included, from which 22 main findings were extracted, categorized into 8 categories, and synthesized into 4 integrated findings: severe lack of knowledge regarding PSF; complex negative physical and psychological experiences; diverse self-adjustment strategies for PSF; and multiple rehabilitation needs for PSF.

Conclusion PSF patients exhibit insufficient knowledge about fatigue and experience significant negative physical and psychological effects. Therefore, early identification and screening of PSF patients should be implemented, fatigue education should be strengthened, and personalized fatigue management strategies should be developed. Simultaneously, the role of community and family in fatigue management for PSF patients should be emphasized, enabling them to collaborate with healthcare professionals to provide a supportive rehabilitation environment for PSF patients.

Full Text

Meta-Integration of Qualitative Research on Fatigue Experience in Patients with Post-Stroke Fatigue

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Abstract

Background: Previous studies have reported that 25%-85% of stroke patients develop post-stroke fatigue (PSF), with persistent exhaustion severely impacting daily life and rehabilitation. Understanding the psychological experiences and needs of these patients is urgently needed, yet individual qualitative studies may lack representativeness. **Objective:** To systematically review and integrate qualitative studies on fatigue experiences in PSF patients, providing evidence for constructing fatigue management strategies.

Methods: We searched PsycINFO, PubMed, Web of Science, CINAHL, Cochrane Library, Scopus, Joanna Briggs Institute (JBI) Evidence-Based Health Care database, CNKI, Wanfang, VIP, and CBM for qualitative studies on PSF patients' fatigue experiences from inception to July 5, 2023. Quality assessment used the JBI Critical Appraisal Tool for qualitative studies (2016), with meta-synthesis following the JBI convergent integration approach.

Results: Ten papers were included, yielding 22 primary findings grouped into 8 categories and synthesized into 4 integrated outcomes: (1) profound lack of PSF awareness; (2) complex negative physical and psychological experiences; (3) diverse self-regulation strategies for PSF; and (4) multiple rehabilitation needs related to PSF.

Conclusion: PSF patients demonstrate insufficient fatigue cognition with significant negative physical and psychological experiences. Early identification and screening of PSF patients should be implemented, with enhanced fatigue education and personalized management strategies. The role of community and family in PSF management should be emphasized to create supportive rehabilitation environments alongside healthcare professionals.

Keywords: Stroke; Post-stroke fatigue; Experience; Coping style; Needs; Qualitative research; Meta-integration

Introduction

China faces the highest lifetime risk of stroke globally at 39.3% [1]. Beyond functional disabilities, stroke survivors commonly experience fatigue during rehabilitation [2]. Post-stroke fatigue (PSF) is defined as a pathological state of persistent weakness and low energy [3], affecting 25%-85% of stroke patients [4]. PSF contributes to sustained negative emotional states, delays rehabilitation, and severely compromises quality of life [5]. Understanding PSF patients' experiences and needs is essential for developing targeted interventions. While existing qualitative studies [6-7] have explored these experiences, variations in time since diagnosis and sociocultural backgrounds limit the generalizability of individual findings. This meta-integration systematically analyzes qualitative research on PSF patients' fatigue experiences to inform comprehensive and personalized interventions.

Methods

1.1 Search Strategy

We searched English databases (PsycINFO, PubMed, Web of Science, CINAHL, Cochrane Library, Scopus, JBI Evidence-Based Health Care database) and Chinese databases (CNKI, Wanfang, VIP, CBM) from inception to July 5, 2023. English search terms included: "stroke/cerebrovascular stroke/cerebral stroke/acute stroke/cerebrovascular accident/brain vascular accident/acute cerebrovascular accident"; "post stroke fatigue/fatigue/PSF"; "psychological/experience/needs/perception/*feeling*"; and "qualitative research/qualitative study/qualitative methods/interview/phenomenon/grounded theory/ethnographic research". Chinese search terms included equivalents for stroke, post-stroke fatigue, experience/needs, and qualitative research methods. The PubMed search strategy is detailed in .

1.2 Inclusion and Exclusion Criteria

Using the SPIDER framework [8], inclusion criteria were: (S) PSF-diagnosed patients; (PI) PSF experiences and perceptions (no time limit); (D) phenomenology, grounded theory, ethnography, case studies; (E) fatigue experience, needs, expectations; (R) qualitative or mixed-methods studies with separable qualitative data; and context: during PSF rehabilitation. Exclusions: duplicates, incomplete information, unavailable full text, non-Chinese/English publications, and mixed-methods studies with inseparable qualitative data.

1.3 Literature Screening and Data Extraction

Two researchers independently screened literature and extracted data after consulting evidence-based practice experts, with disagreements resolved by a third researcher. NoteExpress 3.8 managed references. Screening proceeded through title/abstract review to full-text assessment. Extracted data included first author, country, qualitative method, phenomenon of interest, context, and findings.

1.4 Quality Assessment

Two evidence-based nursing-trained researchers independently evaluated included studies using the JBI Critical Appraisal Tool for qualitative research [9], comprising 10 items rated as "yes," "no," "unclear," or "not applicable." Studies meeting all criteria received A-level rating; partially meeting criteria received B-level; and not meeting criteria received C-level. Disagreements were resolved by a third researcher. Only A- and B-level studies were included.

1.5 Meta-Integration

We employed JBI's convergent meta-integration approach, repeatedly reading and analyzing included studies to extract themes, implicit meanings, and categories. Researchers synthesized similar findings into new categories, then analyzed relationships between categories to generate integrated outcomes with greater generalizability and persuasiveness.

Results

2.1 Literature Search Results

The initial search yielded 726 records. After removing duplicates, 575 remained. Following title/abstract screening, 21 articles were reviewed in full text, ultimately yielding 10 included studies [6-7,11-18]. The screening process is illustrated in [Figure 1: see original paper].

2.2 Characteristics and Quality of Included Studies

The 10 studies involved 161 stroke patients. Basic characteristics are summarized in . All studies received B-level quality ratings, as detailed in .

2.3 Integration Results

Through repeated analysis, we extracted 22 primary findings (Findings 1-22), organized into 8 categories (Categories 1-8), and synthesized into 4 integrated outcomes (Integrated Outcomes 1-4) without mutual exclusivity, as shown in [Figure 2: see original paper].

2.3.1 Integrated Outcome 1: Profound Lack of PSF Awareness Category 1: Patient Factors. PSF patients often perceived their symptoms as inconspicuous, initially attributing fatigue to normal post-stroke recovery ("We didn't call it fatigue, didn't even think about it, because we thought it was normal" [6]). Some patients, lacking knowledge, misattributed fatigue to other conditions ("When I felt fatigued, I thought I had something else wrong" [11]).

Category 2: Healthcare Provider Factors. Patients reported that healthcare professionals rarely mentioned potential fatigue symptoms ("They [healthcare staff] tell you other things to watch for, but they never mentioned fatigue" [11]). When patients reported fatigue, providers often dismissed or misattributed it ("They either didn't mention fatigue or attributed it to other factors like medication reactions" [15]).

2.3.2 Integrated Outcome 2: Complex Negative Physical and Psychological Experiences Category 3: Severe Impact on Daily Life, Work, and Social Activities. PSF patients experienced profound physical fatigue requiring frequent rest ("Now whenever I have a second, I go to sleep" [16]), with intensity varying diurnally ("It's severe in the morning, gets better, best around noon, but by evening I've used all my energy and am exhausted" [6]). Fatigue severely impaired activities including reading ("I used to read a lot, but now I can't even finish a chapter—no, not a chapter, after a few pages my mind goes blank" [17]), caregiving ("When caring for my grandchildren, I often tell them Grandma needs to sleep and they should play by themselves" [10]), and driving ("I have to drive to the city but often don't dare, needing coffee to stay alert—I'm worried about my safety" [10]), consistent with quantitative findings [19-20]. Returning workers faced "invisible" impairments hindering previous capacity ("I used to work all day; now I'm exhausted after one hour" [10]). Social activities were also affected, with some patients avoiding social interaction entirely ("I can't talk with people for long" [16]).

Category 4: Persistent Feelings of Frustration, Guilt, and Anxiety. Patients experienced frustration from inability to recover pre-stroke roles ("I worry I can't return to how I was before the stroke, needing more sleep now" [13]). Dependence on family and friends generated guilt ("Needing to rely on my partner makes me sad" [15]). Most developed negative emotions ("I have to say it's really depressing—like that Sunday, you know, I wasted a whole day doing nothing" [6]). The unpredictable, diurnal nature of fatigue created anxiety ("When I have things to do, I don't know when it [fatigue] will come or if I'll feel fatigued by what's ahead" [6]), leaving patients feeling trapped between self-expectations and unpredictable symptoms (“My inner self, my expectations, and the unknown fatigue conflict and fight each other, and I’m stuck in the middle” [15]).

2.3.3 Integrated Outcome 3: Diverse Self-Regulation Strategies for PSF

Category 5: Psychological Adjustment. Most patients gradually accepted fatigue’s impact [7], with three adjustment patterns: active coping, passive coping, and stagnation. (1) Active copers focused on self-reconstruction (“I have to solve it myself. I try to exercise daily, cycle…read papers to maintain my reading ability, eat healthy food—I concentrate on all these” [12]). Family and friends provided emotional support (“My family and friends ease my anxiety” [16]). (2) Passive copers resigned themselves to fatigue, reducing activity (“I do less than before—if I don’t do it today, I’ll do it tomorrow” [13]) and increasing rest (“If I’m tired, I don’t fight it, I lie down, and after an hour I’m recovered and can do what I want” [13]). (3) Stagnant patients felt out of control (“I want to do everything at once…I can’t do it, it really tires me. I can’t do anything, really, sometimes…what should I do now?” [12]).

Category 6: Behavioral Adjustment. Most patients reduced activities and increased rest. Many established daily “rhythms” (“Rhythm helps—if we have evening plans, I know it’ll be busy, so I don’t do much at noon or afternoon” [7]). Engaging in beloved past activities helped prevent and manage fatigue (“What works for me—mindfulness, meditation, deep breathing” [7]), with diverse forms including crossword puzzles, swimming, walking, and tai chi. Patients sought social support, using the internet for PSF information (“I learned management online, you can check blogs” [15]). Only one study mentioned pre-discharge provider education (“They explained many things…told me if you’re tired, rest” [13]).

2.3.4 Integrated Outcome 4: Multiple Information and Emotional Support Needs

Category 7: Healthcare Support. Patients wanted providers to prioritize fatigue assessment alongside other symptoms (“It needs to be observed and treated like all my other symptoms, with goal-setting equal to other rehabilitation goals” [18]). They desired pre-discharge professional support (“I wish I’d known what PSF was before going home—not knowing what this [fatigue] is makes me more anxious” [7]), with information tailored to individual needs and abilities (“Given my memory, they can’t just give me lots of materials—they must tell me in a meaningful way, otherwise it’s useless” [18]).

Category 8: Family Support. Family support is a known PSF influencing factor [22]. Patients wanted relatives to understand their condition (“I hope my family understands my illness, helps me find solutions, discusses treatment plans” [17]) and provide more emotional support (“Sometimes my family doesn’t believe I’m tired. I think what’s important is telling them my situation so they understand me better” [7]).

Discussion

3.1 PSF Symptoms Are Insidious and Difficult to Self-Identify, Requiring Enhanced Education for Both Patients and Providers

Most PSF patients could perceive fatigue but struggled to identify it, possibly because PSF resembles physiological fatigue [23] and is more insidious than other post-stroke deficits. Healthcare providers rarely mentioned PSF, contributing to patients' insufficient or erroneous cognition. Screening and assessment are prerequisites for effective PSF management. Education should target both providers and patients: (1) Provider training through scenario-based models covering pathophysiology, clinical manifestations, risk factors (gender [24], personality traits [25], vision problems [26], pre-stroke fatigue [25], depression [25], sleep disorders [25], coronary disease [25], diabetes [25]), and management strategies, using the Fatigue Severity Scale recommended by the American Heart Association [27] to improve current low utilization of assessment tools [28]. (2) Patient education through fatigue training courses to enhance self-identification and prompt medical consultation.

3.2 Fatigue Creates Multiple Negative Impacts, Necessitating Dynamic Comprehensive Assessment

PSF severely affected patients' lives, work, and social activities, generating persistent frustration, guilt, and anxiety. The diurnal variation of fatigue intensified uncertainty and worry. PSF pathophysiology remains unclear, likely involving biological, behavioral-psychological, and social factors [29], warranting comprehensive assessment of physiological, psychological, and social dimensions using multidimensional fatigue instruments [30]. Longitudinal studies show PSF is most severe in the acute phase, with severity remaining largely unchanged from baseline up to 18 months post-stroke [31]. Therefore, dynamic in-hospital assessment should help patients identify symptom patterns, with post-discharge follow-up evaluating activity-rest balance, activity interruption improvements, work efficiency, social participation, and psychological changes for targeted guidance.

3.3 Psychological and Behavioral Adjustment Strategies Are Highly Individualized, Requiring Personalized Guidance

Patients exhibited distinct psychological adjustment patterns. Active coping, shown to enhance post-traumatic growth [32], contrasted with passive coping, which psychological stress theory [33] links to increased negative emotions and depression risk. Some patients remained "stagnant." Healthcare providers should classify patients by adjustment type for targeted intervention. Learned optimism improves fatigue [25]; thus, extraverted group therapy [34] could pair active and passive copers to share strategies. Behavioral adjustments were also highly specific, requiring providers to understand patients' interests and habits for personalized guidance. Emerging health empowerment concepts suggest building individualized interventions based on empowerment theory [35] to enhance management motivation.

3.4 PSF Patients Have Diverse Information and Emotional Support Needs, Requiring Multi-System Support Strategies

PSF patients need support across healthcare and family systems [36], consistent with previous research. Multi-system strategies should enhance self-management and rehabilitation self-efficacy. Healthcare providers should offer professional information support to help patients recognize PSF, alleviate anxiety about symptom origins, and teach management methods. Cognitive-behavioral therapy—comprising psychoeducation, activity scheduling, energy conservation, and cognitive restructuring—is recommended [37], with fatigue assessment integrated into stroke rehabilitation. Hospital-community-family partnerships should expand access to professional information, with community health workers adding PSF monitoring to post-discharge management using guidelines like the American Stroke Association's fatigue management handbook [38]. Providers should educate families about support importance, encouraging empathetic listening and emotional support.

Conclusion

This meta-integration of qualitative research reveals that PSF patients have poor fatigue-related knowledge and significant negative experiences. While developing adaptive strategies, they have multifaceted support needs. Future interventions should address knowledge gaps through provider education, early PSF identification, and personalized management strategies. Family emotional support is crucial for creating optimal rehabilitation environments and enhancing coping capacity. Limitations include inclusion of older studies potentially affected by temporal changes, and all included studies being B-level quality, which may influence interpretation.

Author Contributions: WANG Xiaoxuan conceptualized the study, designed the methodology, and drafted the manuscript. ZHANG Zhenxiang supervised quality control and revision, taking overall responsibility. ZHAO Zhixin, JIANG Hu, WANG Jiajia, and LIN Beilei collected and organized literature. WANG Wenna and CHEN Suyan revised the manuscript.

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