

International Journal Of Multi Research

Online ISSN: 3107 - 7676

IJMR 2026; 2(4): 50-52

2026 July - August

www.allmultiresearchjournal.com

Received: 02-06-2026

Accepted: 05-07-2026

Published: 15-07-2026

DOI: <https://doi.org/10.54660/IJMR.2026.2.4.50-52>

A Home Life After Stroke: A Review on Perspectives of Domestic Life Among Post-Stroke Individual

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Abstract

Returning to domestic life after stroke represents a critical but often poorly understood transition. This narrative review synthesizes qualitative and quantitative evidence on how post-stroke individuals perceive their daily lives within the home environment. Key themes include disrupted domestic competence, the home as both a facilitator and barrier to participation, and the psychosocial consequences of altered roles. A significant gap remains in quantifying the relationship between specific environmental features, support dynamics, and mental health outcomes. Accordingly, a future cross-sectional study is proposed to examine these associations systematically.

Keyword: Stroke, Domestic Life, Home Environment, Participation, Activities of Daily Living, Psychosocial Adjustment

Introduction

Stroke is a leading cause of long-term disability worldwide, with over 80% of survivors experiencing residual impairments that affect daily functioning (GBD 2019 Stroke Collaborators, 2021). There has been a significant body of rehabilitation research focused on acute recovery and community ambulation, with relatively little research conducted in the home environment where people spend most of their time after discharge. The home is not simply a place of recovery but a site of identity, independence and social relationships that are continually negotiated. Up to 65% of stroke survivors report difficulty reintegrating into desired domestic activities within six months post-discharge, and these difficulties persist for many years (Twigge *et al.*, 2020)^[6]. Unlike mobility or speech, the ability to engage in meaningful home-based activities is often assumed to "recover naturally" or be managed by family members. This assumption is increasingly challenged by patient-reported outcome studies.

The International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001) distinguishes between body functions/structures (e.g., hemiparesis), activities (e.g., lifting a pot), participation (e.g., cooking a meal for family), and contextual factors (environmental and personal). After stroke living in home is like doing tasks and being part of daily life. However, stroke survivors often say that what matters most is not just finishing chores, but feeling useful, feeling like they belong at home, and feeling capable — even if they need help or do things differently (Satink *et al.*, 2016)^[5].

For people after stroke things that used to be automatic can now be physically tiring, mentally taxing, or emotionally difficult. Despite advances in rehabilitation, many survivors say they were not prepared for the realities of home life (Pettersson *et al.*, 2019)^[4]. Grasping their subjective views is essential for the design of client-centered interventions. The aim of this narrative review is to synthesise the literature on perspectives of domestic life among post-stroke individuals and identify key themes, gaps and methodological

limitations. It will suggest a particular research question for a future cross-sectional study to fill a gap identified.

Methods

This narrative review used a structured, but non-systematic, approach consistent with the synthesis of diverse evidence on a lived-experience topic. Literature was searched in PubMed, CINAHL, PsycINFO and Scopus for articles published between January 2010 and December 2025. The search terms used were combinations of the following: stroke, cerebrovascular accident, domestic life, home environment, activities of daily living, participation, perspective, qualitative, lived experience, and occupational performance. We included peer-reviewed original research (qualitative, quantitative, or mixed methods) and review articles

published in English that focused on adult stroke survivors (≥ 18 years) living in community settings and reported perspectives on domestic activities or home participation. Studies that focused exclusively on institutional care (nursing homes, inpatient rehabilitation), acute hospitalisation, or the perspectives of carers without survivor input were excluded from the study. Thematic synthesis was used. Relevant findings were extracted first. Second, common themes were coded. Third, themes were then clustered into larger interpretive categories. Studies were assessed for methodological transparency and relevance, but quality appraisal was not formally scored. After the screening, 34 studies (28 qualitative, 4 quantitative, 2 mixed-methods) and 3 systematic reviews were included.

Total 1: Articles were included for final results.

Key Finding	Study Design	Sample Size
Stroke survivors experience loss of domestic competence as a threat to personal identity, not merely a functional limitation.	Qualitative (Phenomenology)	N = 16-20 (typical)
Completing tasks with assistance does not fully restore the sense of being a capable homemaker or contributor.	Qualitative (Thematic analysis)	N = 22
Common environmental barriers include stairs, narrow doorways, slippery floors, and poorly designed bathrooms.	Cross-sectional survey	N = 317
Home modifications (e.g., grab bars, shower chairs) improve safety but are often perceived as stigmatizing reminders of disability.	Qualitative (Phenomenology)	N = 12
Survivors prefer discreet home adaptations that preserve normalcy and aesthetic privacy.	Qualitative (Phenomenology)	N = 12
Supportive caregiver behavior (assisting only when requested, allowing slow task completion) is associated with better mood and self-efficacy.	Qualitative (Thematic analysis)	N = 22
Overprotective caregiving (taking over tasks preemptively) leads to survivor passivity, frustration, and de-skilling.	Qualitative (Thematic analysis)	N = 22
Survivors consistently prefer "supported independence" — the ability to attempt tasks with backup available — over complete delegation.	Qualitative (Longitudinal)	N = 18
Dissatisfaction with domestic participation is associated with higher rates of post-stroke depression.	Cross-sectional survey	N = 317
Perceived loss of control over domestic routines predicts lower quality of life, sometimes more strongly than physical impairment severity.	Cross-sectional survey (SEM analysis)	N = 317
Lack of meaningful domestic activity contributes to social withdrawal and isolation.	Scoping review	14 studies
Home care services have a direct positive effect on perceived self-management support, functional status, and quality of life ($\beta = 0.39, 0.12$, and 0.11 respectively).	Cross-sectional (Structural Equation Modeling)	N = 317
Older stroke survivors report that home environmental modifications are needed but often lack knowledge about available options.	Qualitative (Phenomenology with semi-structured interviews)	N = 12
The transition from hospital to home involves distinct but interconnected experiences: survivors express physical and emotional struggles while caregivers highlight need for preparation and support.	Qualitative (Multimethod with Automatic Textual Analysis)	N = 19 survivors, 18 caregivers
Engagement in physical activities and activities of daily living is associated with reduced subsequent post-stroke pain ($\beta = -0.052$ and $\beta = -0.038$ respectively).	Prospective observational (Ecological Momentary Assessment)	N = 202
Spending time with friends, spouses, and coworkers is associated with decreased pain, while time with care providers is associated with increased pain.	Prospective observational (Ecological Momentary Assessment)	N = 202

Results

Three major thematic domains emerged from the literature.

Disrupted Domestic Competence and Identity

In almost all qualitative studies, stroke survivors described a deep sense of loss of competence in familiar domestic tasks. Most commonly reported activities that became too much or impossible were cooking, cleaning, laundry and childcare (Satink *et al.*, 2016) ^[5]. This was a loss that was not only functional but a threat to personal identity. Participants who had identified themselves as homemakers, cooks or independent householders experienced grief that was similar to the loss of employment (White & MacKenzie, 2021) ^[7]. One of the key findings was the distinction between doing (completing the task) and being (a sense of role fulfilment). Many survivors could do tasks with support but still felt

marginal in-home life, as their input was seen as not enough or different (Twigge *et al.*, 2020) ^[6].

The Home Environment: Facilitator, Barrier, and Emotional Reminder

Facilitators included: single floor living, modified bathrooms, lever handles and unobtrusive grab bars. Barriers included stairs, narrow doors, slippery surfaces and poorly placed furniture (Noreau *et al.*, 2018) ^[3]. However, finding was the emotional valence of the modifications. Survivors appreciated safety features, but many found grab bars, shower chairs and elevated toilet seats to be stigmatising, as visible markers of disability that were at odds with the domestic aesthetics of pre-stroke life (Pettersson *et al.*, 2019) ^[4]. The ideal home was described as one where adaptations were discreet and integrated seamlessly into existing decor.

Social Negotiation of Domestic Autonomy

Domestic life is relational by nature. The home, after stroke, becomes a micro-political space where autonomy is negotiated on a daily basis with family caretakers, usually spouses or adult children. Three relational patterns were identified:

Supportive pattern: Care taker assists only when asked, allows survivor to work slow, and honors survivor's ways. Related to improved mood and self efficacy.

Overprotective pattern: Caretakers anticipates tasks, leading to survivor passivity, de-skilling and frustration.

Conflictual pattern: Open disagreement about who should do what, often associated with pre-stroke relationship dynamics (White & MacKenzie, 2021) [7]. Survivors consistently expressed a preference for supported independence (the ability to attempt tasks, even imperfectly, with backup) over total delegation to others.

Psychosocial Consequences

Longer-term studies (≥ 12 months post-stroke) found that dissatisfaction with domestic participation was associated with higher rates of depression, social withdrawal, and reduced quality of life (Noreau *et al.*, 2018) [3]. Interestingly, functional impairment severity was not the strongest predictor. Instead, perceived loss of control over domestic routines and lack of meaningful activity were more strongly associated with poor psychological outcomes.

Gaps in the Literature

Several limitations were evident:

Most studies used small, purposive samples ($n = 6-20$), limiting generalizability. Few quantitative studies examined dose-response relationships between domestic participation and mental health. Cross-cultural data are sparse; most research comes from Western, individualistic societies. The interplay between specific home features, caregiver support patterns, and depressive symptoms has not been quantified.

Discussion

This narrative review demonstrates that domestic life after stroke is a complex psychosocial domain, not merely a collection of daily tasks. Survivors navigate a tension between wanting to remain active in their homes and facing physical, emotional, and relational barriers. The findings align with the Person-Environment-Occupation (PEO) model (Law *et al.*, 1996) [2], where optimal participation occurs when the person's abilities, the environment's demands, and the occupation's meaning are aligned. Post-stroke, a mismatch across these dimensions is common.

Several clinical implications emerge. First, discharge planning should include detailed home environment assessments that go beyond safety to consider aesthetics, privacy, and emotional comfort. Second, caregivers should be trained in supportive rather than substitutive approaches. Third, rehabilitation goals should include domestic role negotiation—helping survivors redefine what “doing” means post-stroke (e.g., supervising a meal rather than cooking it entirely).

However, current evidence is largely descriptive. What remains unknown is the prevalence and strength of associations between specific domestic variables (e.g., number of home barriers, type of caregiver support, perceived domestic autonomy) and clinical outcomes like depression or quality of life. Most existing studies lack sufficient sample sizes or statistical power to control for confounding variables such as age, stroke severity, and time since stroke.

Based on the identified gap, the research question proposed is among community-dwelling stroke survivors (≥ 6 months

post-stroke), to what extent are perceived domestic autonomy, number of environmental home barriers, and caregiver support style independently associated with depressive symptoms, after controlling for age, sex, motor impairment severity, and time since stroke?" As a narrative review, this work does not claim to be exhaustive. The search was not systematic, and publication bias (overrepresentation of positive or dramatic findings) may exist. Most included studies were from high-income countries, limiting cross-cultural applicability.

Conclusion

Post-stroke individuals perceive domestic life as a daily negotiation between physical limitations, environmental affordances, and social relationships. Loss of domestic competence threatens identity, while home adaptations can be both enabling and stigmatizing. A future cross-sectional study examining the independent contributions of domestic autonomy, home barriers, and caregiver support to depressive symptoms is warranted. Clinically, rehabilitation must expand beyond functional tasks to address the lived, relational, and emotional dimensions of home life.

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How to Cite This Article

Desai A, Rathod V. A home life after stroke: A review on perspectives of Domestic Life Among Post-Stroke Individual. *International Journal of Multi Research.* 2026; 2(4): 50-52.

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