

Caregiver Empowerment Interventions for Post-Stroke Incontinence: A Narrative Review of Chinese and International Practices

Yuping Jiang^{1,2}, Lihua Wang^{1,3}

¹School of Nursing and Rehabilitation, Nantong University, Nantong, 226001, People's Republic of China; ²Department of Neurology, Nantong First People's Hospital, Nantong, 226001, People's Republic of China; ³Department of Nursing, Nantong First People's Hospital, Nantong, 226001, People's Republic of China

Correspondence: Lihua Wang, Department of Nursing, Nantong First People's Hospital, No. 666 Shengli Road, Chongchuan District, Nantong, 226001, People's Republic of China, Tel +8613815219995, Email lihuawangwh07@126.com

Abstract: This review systematically analyzes the current status and characteristics of caregiver empowerment interventions for post-stroke incontinence (PSI) globally, with a focus on Chinese and international practices. Key research dimensions include: the types, manifestations, and impacts of caregiver burden; the classification and implementation features of empowerment intervention models; the effectiveness of evidence-based empowerment nursing strategies; and emerging development trends in this field. The findings reveal that PSI caregivers commonly face multi-dimensional burdens, which significantly impair their quality of life and long-term caregiving sustainability. Empowerment-oriented nursing interventions have shown consistent positive effects in improving caregivers' care competence, reducing care-related stress, and enhancing the quality of PSI care. However, three critical limitations persist: the absence of unified standardized intervention protocols, large variability in the selection and application of caregiver/patient assessment tools, and insufficient long-term outcome evaluations. Future research should prioritize three directions: developing personalized intervention frameworks tailored to caregiver burden types and patient incontinence severity; constructing integrated multidisciplinary collaboration models; and promoting the application of digital health tools to address time/geographic barriers. Additionally, greater attention should be paid to strengthening caregivers' mental health support systems and optimizing social assistance mechanisms. This review provides a solid theoretical basis and practical strategic references for guiding subsequent research on PSI caregiver empowerment and promoting the translation of research findings into clinical and community practice.

Keywords: caregiver, empowerment nursing, incontinence, intervention research, stroke, narrative review

Introduction

Stroke, a cerebrovascular disorder marked by high incidence, disability, and mortality, ranks among the top global causes of death and long-term disability—with distinct burden patterns across regions.¹ Globally, the World Health Organization estimates 15 million new stroke cases annually, leading to 5 million deaths and 5 million permanent disabilities; these figures reflect consistent challenges in high-, middle-, and low-income countries, where post-stroke care often relies on a mix of institutional and community-based services.² In China, however, the stroke burden is uniquely pronounced due to rapid aging and epidemiological transitions: there are 2.7 million new cases each year, with approximately 13 million individuals living with stroke-related conditions, and care provision remains predominantly family-centered, differing from the more diversified care systems in many high-income countries.³ A critical yet underaddressed complication of stroke is post-stroke urinary and fecal incontinence (PSI), which affects 29% to 58% of survivors globally—a prevalence range that overlaps in Chinese and international studies, but with divergent care challenges.⁴ Internationally, PSI management often integrates multidisciplinary teams into post-acute care, while in China, the lack of widespread formal long-term care services means most PSI care falls to untrained family caregivers, exacerbating care difficulty. This discrepancy in care delivery models directly amplifies caregiver burden: globally, caregivers face physical fatigue and psychological stress, but Chinese caregivers additionally contend with



heavier economic strain and social withdrawal.^{5,6} PSI care is defined by qualitative uniqueness that sets it apart from general stroke care—demanding specialized intervention strategies often overlooked in existing research. Stigma pervades PSI care, creating psychological barriers distinct from other stroke-related needs. In China, this stigma is amplified by traditional cultural norms emphasizing “dignity in bodily control”—PSI is often viewed as a “private shame” rather than a medical symptom, leading caregivers to delay seeking help or downplay their own psychological distress. Besides, PSI care requires direct bodily contact—cleaning soiled clothing/bedding, assisting with toileting, or managing catheters. Against this backdrop, empowerment-based nursing interventions have emerged as a promising solution to alleviate caregiver burden—though their development and application also differ across contexts. Internationally, such interventions often follow standardized frameworks that combine knowledge transfer, skill training, and social support system linkage; health empowerment (HE), defined as enhancing individuals’ capacity to manage health through targeted knowledge and skills for informed decision-making, has been widely applied to caregiver support, with a focus on long-term sustainability.^{7,8} In China, by contrast, existing HE-related research for stroke caregivers primarily focuses on general nursing skills rather than PSI-specific needs, and lacks integration with community or policy support systems.⁹ Despite growing global interest in stroke caregiver interventions, three critical gaps persist—with distinct nuances in Chinese versus international contexts: (1) Internationally, while some studies address incontinence care, few focus on empowerment strategies tailored to PSI’s unique demands; in China, this gap is wider, as PSI is often overlooked in caregiver training. (2) Internationally, researchers explore adapting empowerment models to diverse care settings; in China, adaptation is limited by reliance on family care and scarce formal support. (3) Globally, evidence on HE effectiveness for PSI caregivers is sparse, but in China, this evidence is further fragmented by small sample sizes and lack of cross-regional studies. These gaps are consequential because PSI management is one of the most distressing and resource-intensive aspects of post-stroke care worldwide—yet its impact varies by care context: in China, for example, family-centered care means caregiver burden directly affects both patient outcomes and household stability, more so than in contexts with robust formal care.^{10,11} To address this, the present review comprehensively evaluates empowerment-based nursing interventions for PSI caregivers, with explicit attention to Chinese and international practices. By systematically analyzing global literature, comparing implementation challenges across contexts, and proposing evidence-based recommendations tailored to diverse care systems, this review aims to fill context-specific gaps, inform clinical nursing practice, and advance caregiver empowerment globally for PSI care. This review will also explore how digital health solutions, including telemedicine, smartphone applications, and online training platforms, could help address care gaps.

Assessment of Caregiver Burden Associated with Post-Stroke Incontinence

Physical Burden

Caregivers supporting individuals with post-stroke incontinence frequently experience physical burden, primarily manifested as sleep disturbances, physical exhaustion, and chronic fatigue. In a survey conducted by Paterson et al involving 126 primary caregivers of stroke survivors, 78.6% reported sleep-related issues, while 63.5% experienced chronic pain.¹² Liu et al observed that the specific care demands associated with incontinence such as frequent changes of diapers and bed linens, as well as nighttime urinary management, resulted in caregivers averaging only 5.2 hours of sleep per day, which is significantly below the recommended duration for healthy adults.¹³ Physiological monitoring data indicated that prolonged caregiving responsibilities led to reduced heart rate variability and increased cortisol levels, reflecting dysfunction of the autonomic nervous system and heightened stress responses. Musculoskeletal issues, particularly lower back pain and joint injuries, are also common due to repetitive physical activities such as bending and lifting. A cross-sectional study conducted by Sahbaz et al reported that 62.7% of family caregivers experienced lower back pain and 45.3% reported knee pain. The severity of these symptoms was positively associated with the duration of caregiving.¹⁴ These physical health challenges not only reduce the quality of life of caregivers but also compromise the quality of care, potentially leading to a detrimental cycle.

In light of these findings on the substantial physical demands placed on caregivers in this population, targeted interventions are warranted to alleviate the physical demands on caregivers. Recommended strategies include: (1) enhancing caregiving efficiency and minimizing physical burden through training in specialized nursing techniques, including the use of assistive devices, and the optimization of nocturnal care routines; (2) implementing physical support equipment, such as nursing beds,

and providing individualized exercise guidance to reduce the incidence of joint injuries; (3) integrating stress management approaches such as mindfulness training and sleep hygiene programs to support autonomic function; and (4) providing structured respite care through community-based programs or formal respite services to alleviate the cumulative physical load on caregivers.

Psychological Burden

Caregivers of individuals with post-stroke incontinence frequently experience psychological burden, including symptoms of anxiety, depression, stress, and burnout. In a study using the Hamilton Anxiety Rating Scale and the Hamilton Depression Rating Scale, Yuliana et al reported that 56.2% of 153 caregivers experienced anxiety, while 62.7% exhibited symptoms of depression.¹⁵ Similarly, Hu et al reported incidence rates of 43.9% for anxiety, 26.5% for mild-to-moderate depression, and 27.4% for severe depression among caregivers of stroke survivors.¹⁶ A systematic review conducted by Li et al indicated that the prevalence of depression among caregivers of individuals who experienced a stroke ranged from 30% to 55%, markedly exceeding rates observed in the general population.¹⁷ The psychological burden is further exacerbated in caregivers managing incontinence, due to the emotional strain, embarrassment, and stigma associated with excretory care. Zhou et al, using the Caregiver Burden Scale and the Caregiver Strain Index, identified incontinence as a significant contributor to elevated stress levels among caregivers.¹⁸

Given the high prevalence of psychological distress in this caregiver population, targeted interventions are essential. Recommended interventions include the provision of psychological support, the implementation of stress management training programs, and the development of peer support groups facilitated through community-based or digital platforms. Such peer networks help alleviate emotional isolation by fostering shared experiences and mutual understanding. Incorporating health empowerment principles into these interventions may further mitigate feelings of helplessness and frustration and improve caregivers' incontinence management skills and self-efficacy. Moreover, regular psychological follow-up is recommended to monitor for the emergence of severe psychological outcomes, such as caregiver abuse or suicidal ideation. These comprehensive strategies aim to enhance both psychological resilience and the overall quality of care.

Social Burden

Caregivers of individuals with post-stroke incontinence often experience social burden, primarily characterized by role conflict, reduced social support, and social isolation. The demands of caregiving frequently require caregivers to reduce or forgo employment, social engagements, and recreational activities, thereby limiting overall social functioning. Li et al, using the Social Support Rating Scale, reported significantly lower levels of social support among caregivers of individuals with stroke compared to those in the general healthy population.¹⁹ Similarly, Liu et al observed a negative correlation between levels of social support and psychological stress in this caregiver population.²⁰ A lack of adequate social support and resulting isolation not only intensifies psychological strain but also reduces access to caregiving information and assistance, perpetuating a cycle of burden.

To address the social challenges encountered by caregivers of individuals with post-stroke incontinence, targeted interventions should aim to enhance social support networks. Recommended strategies include: establishing peer support groups to facilitate the exchange of experiences and emotional support; promoting flexible caregiving arrangements to encourage participation by additional family members; and integrating community-based services to provide accessible caregiving services. These measures collectively support the social reintegration, promote a balanced lifestyle, mitigate the cumulative social burden associated with caregiving.

Economic Burden

The economic burden associated with caregiving for individuals with post-stroke incontinence primarily arises from medical expenses, the cost of care-related supplies, and loss of work-related income. A qualitative study conducted by Guo et al reported that the average annual direct medical expenditure for individuals with stroke was approximately RMB 25,800, with those experiencing incontinence incurring costs approximately 30% higher than individuals without incontinence.²¹ Monthly expenditures for incontinence-specific supplies such as diapers, nursing pads, and cleaning products ranged from RMB 800 to RMB 1,500, imposing additional financial strain on families. This economic pressure

not only adversely impacts household quality of life but may also hinder access to adequate medical and rehabilitation services, thereby exacerbating the overall caregiving burden.

Although existing measures to mitigate the financial burden on families caring for individuals with post-stroke incontinence remain limited, several long-term strategies have been proposed. These include the expansion of long-term care insurance within the social security system to provide sustained economic support for incontinence-related care. Additionally, advocating for increased corporate social responsibility such as providing caregiving leave and flexible work arrangements may help mitigate income loss resulting from caregiving responsibilities. The successful implementation of these strategies requires coordinated efforts across multiple sectors and long-term policy development; nevertheless, they represent potential pathways to reducing the economic challenges faced by caregivers.

Current Status of Nursing Empowerment Interventions for Caregivers of Individuals with Post-Stroke Incontinence

Theoretical Foundation

Nursing empowerment interventions for caregivers of individuals with post-stroke incontinence are primarily grounded in the following theoretical frameworks:

Self-efficacy theory: Bandura's self-efficacy theory constitutes the foundational framework for many empowerment interventions.²² Zhang et al developed a caregiver skills training program guided by self-efficacy principles, aiming to enhance caregiver confidence through four mechanisms: verbal persuasion, vicarious experience, mastery experience, and emotional regulation.²³ Participants in the intervention group exhibited significant improvements in self-efficacy and caregiving competence.

Stress-coping theory: The stress-coping framework proposed by Lazarus and Folkman has been extensively utilized in caregiver intervention research.²⁴ Wang et al applied this framework in a program that included not only primary caregivers but also secondary caregivers and other family members, thereby facilitating intra-family collaboration and shared resource utilization.²⁵ The intervention outcomes surpassed those of traditional models focused solely on individual caregivers.

Adult learning theory: Knowles' theory of adult learning provides an instructional framework for the design of caregiver education programs.^{26,27} This theory emphasizes the importance of experiential learning and learner autonomy in the acquisition of caregiving knowledge and skills.

Existing studies demonstrate well-defined theoretical foundations and structured intervention approaches. However, several limitations remain. Interventions grounded in self-efficacy theory tend to emphasize individual capability enhancement while overlooking the integration of external resources. While stress-coping interventions provide targeted support, they often lack the specificity required to address psychological stressors unique to incontinence care, such as stigma and emotional discomfort. Applications of adult learning theory prioritize knowledge transmission but are limited in their adaptability to evolving caregiving demands.

These limitations underscore the need for future research to adopt a multidimensional HE approach incorporating stratified intervention designs such as modular frameworks specifically addressing incontinence care and long-term caregiving. Such an approach should aim to establish a comprehensive and systematic empowerment model that accounts for individual capacity, family collaboration, and available social resources, thereby addressing the fragmented nature of current intervention strategies.

Intervention Content and Methods

Knowledge Education

Knowledge education is a core component of empowerment-based nursing interventions, encompassing essential information on disease mechanisms, incontinence management, and safe caregiving practices. Jiang et al developed an educational manual for caregiver of individuals with post-stroke incontinence, which systematically presented information on the etiology, classification, assessment, and management of post-stroke incontinence.²⁸ The effectiveness of the manual was enhanced through the use of illustrated texts and visual aids. Zhuo et al implemented a phased educational model, delivering stage-specific content aligned with the recovery trajectory to minimize the risk of cognitive overload among caregivers.²⁹

Various instructional methods have been used for in delivering educational content, including individualized counseling, group lectures, and video-based instruction. Ugur et al reported that health education directed at caregivers of stroke survivors were associated with a reduction in caregiver burden.³⁰

Despite the development of structured approaches for knowledge dissemination, certain limitations persist. Static educational formats, such as printed manuals, may be insufficient in accommodating dynamic changes in caregiving needs. The phased educational approach, while targeted, rely on accurate assessment of disease progression and may be constrained by interindividual variability. Furthermore, most educational interventions emphasize unidirectional delivery, with limited incorporation of feedback mechanisms.

These observations underscore the need for future educational strategies to incorporate a closed-loop model based on “knowledge–practice–feedback” integration. This approach offers a means to overcome the limitations associated with unidirectional knowledge delivery, facilitating deeper internalization of information and promoting sustained behavioral change.

Skills Training

Skills training within empowerment-based interventions has primarily focused on practical caregiving tasks such as urinary and bowel management, personal hygiene maintenance, and skin protection. The caregiver skills training program developed by Zhu et al incorporated techniques such as bladder training, prompted voiding, and scheduled defecation.³¹ Instruction was delivered using a demonstration–return demonstration–feedback model, which significantly enhanced the practical abilities of the caregivers. A supplementary training module targeting incontinence-associated dermatitis, also developed by Zhu et al, improved the skin care competencies of caregivers through a combination of physical demonstrations and hands-on practice.³¹

Simulation-based instruction has emerged as an effective method in skills training. Wang et al implemented high-fidelity simulators to recreate realistic care scenarios, thereby enhancing the transfer and application of learned skills.³² Complex caregiving procedures were segmented into simplified, manageable steps, which reduced training difficulty, and improved caregiver confidence and performance outcomes.

Despite the intuitive nature and interactive benefits of these instructional approaches, certain limitations were identified. High-fidelity simulation training requires substantial technological and logistical resources, limiting accessibility and hindering widespread implementation, particularly in grassroots or economically disadvantaged settings. Furthermore, existing training modules tended to narrowly focus on specific aspects of care, such as skin integrity or urinary incontinence, with limited inclusion of content related to assistive device utilization, energy-efficient caregiving strategies, or rehabilitation techniques.

These findings indicate that skills training programs for caregivers of individuals with post-stroke incontinence should incorporate modules on rehabilitation methods, including assisted urination and pelvic floor muscle exercises. Additionally, the integration of training modules that simulate home care environments may support the transition of competencies from basic skill acquisition to proficient application.

Psychological Support

Psychological support is a key component of empowerment-based nursing interventions, encompassing emotional regulation, stress coping strategies, and self-care practices.³³ A psychological support program for caregivers developed by Wang et al used cognitive restructuring, relaxation training, and the cultivation of positive thinking to assist in managing negative emotions, resulting in reduced levels of depression and anxiety among participants.³⁴

Existing research has explored the development of multi-dimensional psychological support systems utilizing methods such as cognitive restructuring, mindfulness-based stress reduction, and peer support mechanisms.³⁵ However, mindfulness-based stress reduction techniques have demonstrated high dependency on individual cognitive capacity and cultural context, which may limit sustained engagement and internalization among certain caregiver populations.³⁶ In addition, current psychological interventions have not sufficiently addressed the unique psychological burden associated with incontinence care, including feelings of embarrassment, stigma, and the need for privacy.

These observations highlight the necessity for tailoring future psychological empowerment interventions to reflect the cultural backgrounds and cognitive capacities of caregivers. Developing stratified and personalized psychological adjustment strategies may enhance the relevance, accessibility, and overall impact of these interventions in supporting caregivers managing the challenges of post-stroke incontinence.

Assessment Indicators and Tools

Caregiver Level

At the caregiver level, evaluation of empowerment-based nursing interventions has primarily focused on outcomes such as mastery of knowledge and skills, self-efficacy, caregiver burden, and quality of life. Zhang et al used the Caregiver Self-Efficacy Scale to assess outcomes and reported significantly higher self-efficacy scores in the empowerment intervention group compared to the routine guidance group ($p < 0.01$). These improvements were maintained at a six-month follow-up.³⁷ Notable improvements in caregiver burden and mental health were also observed as a result of the intervention. In a randomized controlled trial conducted by Deyhoul et al, implementation of empowerment interventions was associated with enhanced quality of life for individuals with stroke and a significant reduction in the caregiving burden experienced by family members.⁶

Patient Level

At the patient level, evaluation of caregiver empowerment interventions has primarily focused on outcomes such as incontinence severity, skin integrity, quality of life, and the incidence of complications. Zhang et al reported that following caregiver empowerment interventions, incontinence scores measured by the International Consultation on Incontinence Questionnaire - Short Form decreased by an average of 3.2 points, and the number of urine leakage episodes recorded in voiding diaries was reduced by 41.5%.³⁸ Similarly, Arkan et al found that caregiver empowerment interventions contributed to improvements in urinary incontinence symptoms and quality of life among individuals with stroke.³⁹ Additionally, these interventions were associated with significant reductions in the incidence rates of urinary tract infections and constipation ($p < 0.05$).

Emerging Trends and Future Directions in Caregiver Empowerment Nursing Interventions

Design and Implementation of Personalized Precision Intervention Strategies

The development of stratified and classification-based precision nursing interventions has been identified as a key direction for future research and practice.^{40–42} Ma et al proposed a “two-dimensional classification management model” structured around caregiver characteristics (eg, age, educational background, caregiving experience) and patient conditions (eg, type and severity of incontinence, presence of comorbidities), enabling the delivery of targeted interventions tailored to distinct caregiver groups.⁴³ Rao et al established a caregiver intervention decision-support system using machine learning algorithms that adaptively refine intervention recommendations based on caregiver profiles, needs assessments, and feedback data, thereby achieving dynamic personalization.⁴⁴

These developments indicate that big data analytics and artificial intelligence technologies will play an increasingly prominent role in the future of caregiver empowerment interventions. These technologies enhance the precision of interventions by enabling the analysis of large-scale datasets to identify key influencing factors and determine optimal intervention strategies.^{45–47}

Advancements in Multidisciplinary Collaborative Care Models

The establishment of standardized multidisciplinary collaboration mechanisms is a key component in advancing caregiver empowerment interventions. Zhou et al proposed a “Multidisciplinary Team + Caregiver” collaboration model, which integrates caregivers into the clinical decision-making process, thereby enhancing caregiver engagement and active participation.⁴⁸ Chen et al developed a model of multidisciplinary team-based continuity of care supported by smart cloud platforms.⁴⁹ This model delineated professional roles, responsibilities, and collaborative procedures within

caregiver empowerment interventions, effectively reducing procedural redundancies and omissions while improving the overall efficiency of interdisciplinary cooperation.

Emerging trends also highlight the growing importance of community-based multidisciplinary collaboration networks.^{50,51} These networks center on community health service centers which serve as hubs for linking specialized resources from tertiary hospitals with local community services to construct structured caregiver support systems. This framework supports a coordinated cycle of “minor illnesses managed in the community, major illnesses treated in hospitals, and rehabilitation reintegrated into the community.” Furthermore, online platforms have been used to transcend institutional boundaries and integrate diverse professional resources, thereby providing caregivers accessible, continuous, and comprehensive one-stop support services.

Enhancing Mental Health Intervention Strategies for Caregivers

Growing emphasis is being placed on the development of systematic mental health services for caregivers.⁵² Nasreen et al reported that symptoms of depression and anxiety are common among caregivers of individuals with chronic illnesses, and that the implementation of psychoeducational interventions can effectively alleviate caregiver burden and enhance quality of life.⁵³ Gao et al developed a psychological intervention based on acceptance and commitment therapy, adapted to the Chinese cultural context. This intervention supports caregivers in identifying personal values and deriving meaning from the caregiving experience, thereby promoting psychological well-being.⁵⁴ This research also introduced family systems-based psychological intervention programs that emphasize the influence of familial interaction patterns and the cultural construct of filial piety on the psychological status, providing culturally appropriate support strategies of caregivers.

Conclusion

Caregivers of individuals with post-stroke incontinence face a multi-dimensional burden involving physical, psychological, social, and economic challenges. These burdens not only directly impair caregivers' quality of life and physical health but also undermine the stability of long-term care for patients and the sustainability of family care systems—highlighting an urgent need in clinical practice to build a caregiver support framework that addresses these multi-faceted needs.

Empowerment-based nursing interventions have proven effective in enhancing caregivers' competence, alleviating their overall burden, and improving patient outcomes. Importantly, in practical application, such interventions can be integrated into clinical and community care scenarios—for example, through structured training, peer support groups for psychological counseling, and resource-linking services. This integration allows the interventions to be embedded in continuous care programs at community health centers, rehabilitation facilities, or hospitals, directly translating research efficacy into tangible improvements in real-world care.

However, current research has several limitations that hinder its practical translation and long-term impact: The lack of standardized intervention protocols makes it difficult to unify and scale programs across institutions, limiting the widespread adoption of empowerment-based care in clinical practice. Variability in assessment tools reduces the comparability of intervention effects across settings, preventing clinicians from accurately evaluating their real-world value. Insufficient evaluation of long-term outcomes means clinicians cannot confirm the sustained benefits of interventions, making it hard to design sustainable care plans. Inadequate personalization fails to address the heterogeneous needs of caregivers, reducing intervention relevance in diverse care contexts. Suboptimal multidisciplinary collaboration and challenges in resource allocation/sustainability further restrict the integration of comprehensive support into routine care.

To effectively bridge the gap between current research and practical application and promote high-quality development in the field of post-stroke urinary incontinence care, future research should conduct in-depth exploration and breakthroughs from five dimensions: theory, intervention, collaboration, technology, and support systems. It is necessary to clarify the corresponding relationship between the nursing goals at each stage and empowerment interventions. In the acute stage, focus on empowering caregivers' basic nursing skills, and in the recovery stage, strengthen their ability to make autonomous decisions and integrate resources. This will address the problem of inconsistent design in existing intervention plans due to fragmented theoretical support and provide a standardized framework that can be directly referenced by clinical institutions and community services.

By combining data from both Chinese and foreign contexts, this review provides a basis for culturally aware, internationally informed, and sustainable empowerment models” may be added at the conclusion.

Abbreviations

HE, Health Empowerment; HAMA, Hamilton Anxiety Rating Scale; HAMD, Hamilton Depression Rating Scale; CBS, Caregiver Burden Scale; CSI, Caregiver Strain Index; SSRS, Social Support Rating Scale; CSES, Caregiver Self-Efficacy Scale; ZBI, Zarit Burden Interview; ICIQ-SF, International Consultation on Incontinence Questionnaire - Short Form; I-QOL, Incontinence-Quality of Life; MDT, Multidisciplinary Team.

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