# Care Transition Interventions to Improve Stroke Outcomes: Evidence Gaps in Underserved and Minority Populations

Mathew J. Reeves, PhD; Bernadette Boden-Albala, PhD; Dominique A. Cadilhac, PhD

**ABSTRACT:** In many countries hospital length of stay after an acute stroke admission is typically just a few days, therefore, most of a person's recovery from stroke occurs in the community. Care transitions, which occur when there is a change in, or handoff between 2 different care settings or providers, represent an especially vulnerable period for patients and caregivers. For some patients with stroke the return home is associated with substantial practical, psychosocial, and health-related challenges leading to substantial burden for the individual and caregiver. Underserved and minority populations, because of their exposure to poor environmental, social, and economic conditions, as well as structural racism and discrimination, are especially vulnerable to the problems of complicated care transitions which in turn, can negatively impact stroke recovery. Overall, there remain significant unanswered questions about how to promote optimal recovery in the post-acute care period, particularly for those from underserved communities. Evidence is limited on how best to support patients after they have returned home where they are required to navigate the chronic stages of stroke with little direct support from health professionals.

**GRAPHIC ABSTRACT:** A graphic abstract is available for this article.

n this narrative topical review, we describe the common challenges associated with stroke transitions and highlight the unique vulnerabilities of underserved and minority populations. We describe the wide array of potential interventions that could be adapted and tested to improve care transitions and community reintegration for people living with stroke. We conclude by highlighting the need for researchers to embrace the philosophy of communitybased participatory research, and to develop interventions that are co-designed with, and tested among minority populations and communities. We also call for more research studies designed to understand how eHealth solutions can be successfully applied in underserved populations. The needs of underserved and minority populations during the transitional period are significant and successful transitional care interventions have great potential to benefit patients and their caregivers.

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#### **BACKGROUND AND PURPOSE**

Over the past 25-30 years clinical research on acute stroke has focused heavily on the development and delivery of reperfusion-based treatments which, when given early in the clinical course, have been shown to reduce ischemic damage and improve patient outcomes.1 The development of comprehensive stroke systems-of-care,<sup>2</sup> stroke registries,<sup>3,4</sup> and advancement of multidisciplinary acute stroke care (including the use of Stroke Units) have also improved patient outcomes.<sup>5</sup> In parallel with the development of reperfusion-based therapies for acute stroke, attention have been given to understanding and improving stroke rehabilitation and recovery during the post-acute period. This includes efforts to develop and promulgate clinical guidelines on stroke rehabilitation, 67,8 including stroke transitions, 9 as well as efforts to align priorities for research on stroke recovery and knowledge translation.5,10,11 In most developed countries, hospital length of stay after admission

Correspondence to: Mathew Reeves, PhD, Department of Epidemiology and Biostatistics, Michigan State University, East Lansing, MI 48824. Email reevesm@msu.edu For Sources of Funding and Disclosures, see page 392.

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for acute stroke is typically short (a few days), and the great majority of a stroke patients' recovery occurs after the patient has been discharged from the acute hospital. There remains significant unanswered questions about how to promote optimal recovery from stroke in the post-acute—care period. 12 In particular, relatively little is known about evidence-based strategies that can be implemented to assist stroke patients and their support people (caregivers) after patients return home, and how they can better self-manage their recovery during the chronic stages of stroke with little direct input from health professionals.

There have been recent calls for further research to design intervention studies that combine acute and post-acute phases of stroke care to optimize recovery from stroke.<sup>5</sup> Research that aims to promote stroke recovery must also include the testing of interventions that directly support patients and caregivers during the "care transition" when patients move between different care settings (eg, acute hospital, rehabilitation facilities and services, and home). Improving this phase of the stroke systems-of-care should be centered on the experiences of people living with stroke and their caregivers as they move through the different care environments. 13,14,15 Patient and caregiver challenges associated with navigating the transition period after returning home are multifaceted, and can include accessing rehabilitation services, obtaining information on secondary stroke prevention and lifestyle changes, mitigating emotional and behavioral changes, and reintegration into the community. While we currently lack proven, evidence-based interventions to improve care transitions and support recovery for people living with stroke, there is a particular dearth of transition-related studies addressing the needs of underserved and minority populations who are especially vulnerable to the problems of poor and complicated care transitions.

The objectives of this narrative topical review are to describe the common challenges with stroke transitions and recovery, and to highlight the unique vulnerabilities of underserved and minority populations. We also discuss the array of potential interventions that could be adapted and tested to improve care transitions for stroke, and highlight the need for intervention studies to be codesigned with, and tested among, relevant minority populations and communities.

# CARE TRANSITIONS AND COMMUNITY REINTEGRATION FOR PEOPLE AFTER ACUTE STROKE

Care transitions occur when there is a change in, or handoff between 2 different care settings or providers, and transitional care has been defined as a set of actions designed to ensure coordination and continuity of health

care as patients transfer between different settings or levels of care. 16 Care transitions represent an especially vulnerable period for patients. In the simplest scenario after an acute stroke, a patient might have to navigate only a single transition from the acute hospital to home, although even this transition may be associated with significant challenges for patients and caregivers. 19,17,18 However, for many patients the post-acute stroke care period involves a more complex series of transitions between several different care settings - for example, from the acute hospital to acute institutional rehabilitation, to nursing home, to home. Each of these changes in physical location are accompanied by concomitant changes in medical care characterized by different types of providers (ie, therapists, nurses, home health aides, physicians), levels of care, and goals. It is during these care transitions that care can be become fragmented or discontinued resulting in lapses in quality of care that can adversely affect patient outcomes.<sup>16</sup> The type and quality of care transitions experienced by stroke survivors will be dictated in large part by the organizational structure of the local healthcare system and particularly postacute care services. For example, the organization of and access to rehabilitation services varies markedly across countries and healthcare systems, 20 which can directly impact the transition experience of patients.

While the primary goal of rehabilitation care for acute stroke is to restore physical function, mobility and self-care so that patients can return safely to home, community reintegration refers to the re-establishment of usual social and community relationships, roles and activities after a health event such as a stroke.<sup>21</sup> While community reintegration is not the immediate goal of stroke rehabilitation care it should be viewed as the ultimate marker of successful recovery from stroke and the goal of successful multidisciplinary stroke systems-of-care.<sup>6,9,22</sup> Patients often report dissatisfaction with community reintegration, and poor transitions whether they directly reflect rehabilitation care or not have been shown to negatively affect the level of community reintegration a patient achieves.<sup>21,23,24</sup>

# COMMON CHALLENGES ASSOCIATED WITH STROKE TRANSITIONS, RECOVERY, AND COMMUNITY REINTEGRATION

In the United States, after an acute stroke the median length of stay in the acute hospital is only 4 days<sup>25</sup>; short hospital stays are also common in other high income countries.<sup>26</sup> The obvious implication of this is that the majority of a stroke patients' recovery occurs after the patient has been discharged, and is therefore directly affected by the quality of care provided during the transitional care period. For some patients with stroke the return home is associated with substantial psychosocial and health-related

challenges.<sup>17</sup> People living with stroke are challenged by an array of issues during the transition period including poor access to rehabilitation care, 27-29 a wide range of unmet needs,30-32 educational and informational challenges, 33,34 and poor medication adherence. 35,36 In turn these issue can lead to poor patient outcomes including hospital readmissions,<sup>37</sup> slow recovery,<sup>38-40</sup> depression,<sup>41</sup> and dissatisfaction with care. 42 Similar high levels of burden can be found in stroke caregivers. 43,44 The challenges associated with care transitions have a cumulative negative effect on a patient's well-being through the added workload that is placed on the stroke survivor: a phenomenon referred to as treatment burden.<sup>45</sup> The challenges people living with stroke face when navigating the transitional care period are exacerbated by the fragmented and poorly coordinated nature of existing post-acute care services which frequently provide inadequate access to community resources and services. 13,46-48 These limitations in care, in turn, lead to poorer levels of community reintegration<sup>21,24</sup> and substantial long-term unmet needs for themselves and their caregivers. 49,50

Findings from a comprehensive study of patient and caregivers' perspectives on care transitions conducted in a broad sample of US patients and family caregivers who had recently experienced an acute hospitalization are particularly noteworthy for healthcare systems who want to improve transitional care.14 The participants in this study identified 3 desired outcomes of care transitions: that patients wanted to feel cared for and cared about by medical providers, have unambiguous accountability from the healthcare system, and to feel prepared and capable of implementing care plans. To achieve these aims, the authors suggested that health systems better prepare patients and caregivers for self-care at home, include a process for collaborative discharge planning, provide more actionable information, and ensure uninterrupted care with minimal handoffs.

# CARE TRANSITIONS AND COMMUNITY REINTEGRATION IN UNDERSERVED AND MINORITY POPULATIONS

The system level limitations commonly observed in transitional care are exacerbated in underserved and minority populations who face a host of challenges as a consequence of their exposure to adverse social determinants of health, which include poor environmental, social, and economic conditions combined with the effects of structural racism, discrimination, and disadvantage.<sup>51</sup> The particular characteristics of medically underserved populations will vary between different countries and regions,<sup>52</sup> but can include racial and ethnic minorities,<sup>53,54</sup> indigenous populations,<sup>55</sup> immigrants (especially nonnative language speakers),<sup>56</sup> those with low-income, poor housing, or homelessness.<sup>57</sup>

In the United States, underserved patients are common, comprising an estimated 30% of all hospital discharges.<sup>58</sup> Underserved and minority populations often have high rates of chronic illness and medical comorbidities, lack health insurance (or are under-insured), and may not have a routine place of primary care.59 Lack of access often leads individuals to defer seeking medical care and to rely on care from emergency departments.60 Underserved populations often have low levels of education or poor health literacy, and may not communicate in English. Further, negative health beliefs, including fatalism and lack of trust in the health system, may be more common in underserved populations and have been associated with poorer risk factor control, including blood pressure. 61 Multiple employment obligations of minority caregivers and other competing responsibilities may also result in missed appointments, and the need for additional resources and support during the transition period. Stigma related to disability along with limitations in participation around work and other responsibilities may further exacerbate disparities related to transitions of care.62 The effect of this constellation of individual patient-level factors in underserved and minority populations are further exacerbated by the fact that they often live in disadvantaged neighborhoods that are poorly resourced, unsafe, and lack convenient access to grocery stores and pharmacies. In fact, neighborhoods characterized by food deserts and those with higher density of fast food restaurants (referred to as food swamps) have been shown to be associated poorer dietary patterns, and higher cardiovascular disease risks including stroke. 63-65 The lack the community-level resources results in a strong negative cycle whereby residents are unable to find the critical resources (eg, social services, transportation, community health clinics, home-based services) necessary to support the return to home and successful community reintegration.58

### CURRENT CARE TRANSITION INTERVENTION STUDIES: LIMITATIONS AND EVIDENCE GAPS

To correct the problems associated with transitional care a wide variety of intervention strategies designed to improve communication, care coordination, and continuity as patients move across different care settings have been proposed and tested. Specific intervention strategies, which have tended to be implemented in the acute hospital setting, include the use of multidisciplinary care teams, tailored hospital discharge planning (that emphasize early patient contact and pre-set primary care appointments), enhanced patient education, self-management skill development, medication reconciliation, and care management programs that rely on care navigators. The many different types of

intervention strategies tested illustrate that transitional care programs can target a broad range of potential elements or domains including patient-level interventions (ie, education, self-management, medication management, and caregiver engagement), or systems-level and/or provider-level interventions designed to improve case management, care continuity, communication, cooperation, and accountability.<sup>66</sup>

The early transition-based intervention studies focused mostly on complex elderly patients with chronic conditions such as heart failure or chronic lung disease that have a high risk of hospital readmission (these studies typically excluded stroke patients). While some of these early studies were effective in reducing readmissions and improving patient outcomes, 67,68 readmission prevention studies conducted in later years have been less successful.69 The limitations of using hospital readmissions as the primary marker of success for transition-based intervention studies has been noted previously.70 Readmissions occur due to a multitude of complex factors that are usually beyond the direct control of the provider or patient. Also by only focusing on readmissions we fail to acknowledge the wide range of other patient experiences that occur during care transitions which include practical, economic, psychosocial and mental health concerns. 70 However, there is now a growing number of intervention studies conducted in stroke patients or caregivers that address transitional care challenges more broadly, and do not rely solely on readmissions as a measure of success. These include the use of post-acute multidisciplinary care teams,71 early supported discharge programs,72 tailored hospital discharge planning,73 enhanced patient or caregiver education and information,33,74 self-management support or skill development,75-77 and care management programs that rely on care navigators or other patient advocates (including social workers,78 nurses,79 peer mentors,80 and community health workers<sup>81,82</sup>). Most recently there has been the introduction of technology or eHealth-based approaches to improve provider communication and patient selfmanagement.78,83 But as noted earlier, we currently lack proven, evidence-based interventions to improve care transitions and support recovery for people living with stroke which reflects that fact that the stroke-related transition studies conducted to date have not identified efficacious approaches that have been shown to be replicable across study populations. This is due largely to the limitations of the current evidence-base; transitionbased intervention studies conducted across a wide range of medical conditions (both stroke and nonstroke) suffer from similar methodological limitations characterized by small non-representative patient samples, heterogeneous study designs, interventions that are often too short or limited in scope, and that are undertaken in different medical contexts or environments (eg, specific medical care systems or populations).84 A review of 27 transitional care intervention studies conducted in stroke survivors found no single strategy had a consistent, clinically meaningful effect, and most studies had significant methodological limitations. Studies also often fail to describe what the components of usual (control) care are, and often test multiple different intervention components at the same time, making it difficult to make firm conclusions about which specific interventions are likely to work and in which type of patient populations and contexts. Overall, the variability in approaches, designs, and results of transitional care intervention trials emphasize the importance that contextual factors, including social determinants, community resources, health delivery systems, and external policy factors, have on the final conclusions.

### EVIDENCE GAPS IN UNDERSERVED AND MINORITY POPULATIONS

A further challenge with the existing literature is that there has been little work done to date in underserved and minority populations that specifically develop, and test interventions designed to improve care transitions or community integration. Conclusions from the recent work of the Patient-centered Outcomes Research Institute (PCORI) transition network84 has placed a strong emphasis on the need for early stakeholder engagement (ie, patient, caregiver, healthcare provider) to ensure that the health problems, challenges, and perspectives of the affected populations are captured prior to the development of potential solutions. 14,87 It is important that prior to testing that interventions should be co-designed with input from patients, families, health professionals, community members, and other stakeholders responsible for care transition support. In this way interventions can better meet patient needs, and increase the chances of adoption and embedding within the healthcare system if found to be more effective than current practice options. 10,88 A common limitation of many intervention studies is that they are too short or represent only single point-in-time actions (eg, discharge planning, provision of patient educational materials). Ideally interventions should last several months and be co-designed with stakeholders so that they can adapt to the changing needs of patients and caregivers as they progress through the transition period. The emphasis on co-design is especially important when dealing with population groups that have been historically marginalized who have greater unmet medical and social needs, as well as skepticism of the value of participating in clinical research.89 The approach of stakeholder engagement is closely aligned with the notion of community-based participatory research that traditional has been emphasized in public health intervention work.90

Theoretically, given the greater needs of underserved and minority populations, it should be easier to identify

interventions that have a demonstrable clinical benefit. However, it could also be the case that it might prove difficult to implement interventions in patient populations that have multiple limitations and challenges (eg, poor health literacy, high disease burden, inadequate health care, transportation challenges) and who are living within communities that lack important supporting structures and assets. Thus, the need for further research.

# EXAMPLE STROKE INTERVENTION STUDIES RELEVANT TO TRANSITIONAL CARE AND UNDERSERVED POPULATIONS

In this section we provide summaries of a select few intervention studies that have been specifically designed to addresses either challenges with stroke transitions, or community-based secondary stroke prevention studies undertaken in underserved or high-risk populations. Interestingly, we know of no study that has done both, that is, a transitional care intervention study conducted in an underserved population. We hope that providing a summary of these existing studies will offer the opportunity to blend both approaches in future studies.

#### **Transitional Care Studies in Stroke**

COMPASS (Comprehensive Post-Acute Stroke Services) was a large-scale, cluster-randomized, pragmatic trial designed to address transitional care in stroke patients.91 The COMPASS trial enrolled 40 North Carolina hospitals and over 6000 acute stroke or TIA patients. The 20 intervention hospitals utilized an onsite outpatient clinic staffed by existing hospital personnel to deliver comprehensive individualized care plans that addressed transitions including stroke education, secondary prevention, rehabilitation and recovery, and referral to community services. Critically, COMPASS used co-design methods by seeking input from a wide range of stakeholders (patients, caregivers, and providers) prior to implementation. Despite its carefully designed pragmatic approach, COMPASS faced a series of challenges. Hospitals had difficulty maintaining adequate staffing; and only 35% of patients completed the in-person clinic visit. Outcomes data were collected from only 59% of enrolled patients and based on the primary outcome (Stroke Impact Scale [SIS-16]) collected at 90-days, the study did not find any significant intervention effect.91

MISTT (The Michigan Stroke Transitions Trial) was a pragmatic, open, randomized trial of 265 acute stroke patients discharged from 3 Michigan hospitals. MISTT was designed to improve stroke transitional care through 2 complementary interventions: (1) a home-based social worker-led stroke case management program focused on support, preparedness, unmet needs, and stroke prevention, and (2) access to a patient-centered online

information and support resource. Final patient outcomes, collected 90-days after participants returned home, included Quality-of-Life (PROMIS Global-10 physical and mental health subscales) and the Patient Activation Measure (PAM). The study found that the group that received the combination of social work case management and website access, had clinically and statistically significant improvements in PROMIS physical health scores (*P*=0.0025) and PAM scores (*P*=0.04), but no significant changes in PROMIS mental health scores. There was no detectable effect of receiving social work case management alone when compared with usual care.

The ReCAPS trial (Recovery-Focused Community Support to Avoid Readmissions and Improve Participation After Stroke)93 is currently in progress after the successful development and feasibility testing of a codesigned novel electronic communication technology intervention to support the transition to home after an acute stroke.83,94,95 The eHealth intervention is designed to provide a range of messages sent via SMS or email to support person-centered goal attainment, self-management support and secondary stroke prevention. The intervention group receives 12 weeks of personalized, goal-centered, and administrative electronic messages, while the control group only receives administrative messages. An obvious advantage of this and other eHealth-based interventions is that they can be delivered efficiently in the community setting. However, a critical need is to understand whether digital health interventions could increase rather than decrease health inequities in underserved populations. For example, if a person does not have access or experience with a smart phone or computer or internet they may find an eHealth-based intervention difficult to participate in. The ReCAPS investigators have offered various options to avoid selection bias based on access to technology.96

### Community-Based Secondary Stroke Prevention Studies Conducted in High-Risk Populations

DESERVE trial (The Discharge Educational Strategies for Reduction of Vascular Events) was a 2-arm randomized controlled trial designed to test a culturally tailored-skills-based approach to reduction of blood pressure at 1-year post stroke among 552 mild/moderate stroke or TIA survivors recruited from 4 New York City medical centers. 62 There was an equal proportion of Black, Hispanic, and White patients enrolled. DESERVE was designed in partnership with community stroke survivors and sought to improve patient—physician communication, medication adherence, and stroke risk perception through a discharge centered interactive educational session, a patient-paced tailored workbook, patient narrative videos, and follow-up calls. After 12-months compared with

usual care, the intervention resulted in a modest reduction in systolic blood pressure (mean, 2.5 mm Hg), which was not statistically significant; however, in subgroup analysis, a statistically and clinically significant reduction in systolic blood pressure (9.9 mm Hg) was observed among Hispanics. In a secondary analysis, a significant association was found between greater reductions in systolic blood pressure among those reporting higher self-efficacy and stronger social networks.<sup>61</sup>

The SUCCEED trial (Secondary Stroke Prevention by Uniting Community and Chronic Care Model Teams Early to End Disparities) was conducted in a high-risk underserved population in Los Angeles county.97,98 The trial tested a team-based multilevel intervention that included clinic visits, community health worker home visits, Chronic Disease Self-Management Program (CDSMP) workshops, telephone-based care coordination, and culturally and linguistically tailored education materials. The primary outcome was blood pressure reduction. The study randomized 487 subjects who had ischemic or hemorrhagic stroke or TIA within the last 90 days. At 12 months, SBP had improved in both arms (10 and 8 mmHg decline in intervention and control groups, respectively), but there was no significant difference between them.98 Although 90% of the intervention group received some of the 3 core components, only 15% received the intended full dose. Barriers to engagement were higher life chaos scores and transportation.

The DESERVE and SUCCEED studies, as well as other similar efforts, 99-101 included those conducted through faith-based organizations, 102 are good examples of intervention studies that are anchored around the frame work of community-based participatory research. 90,103 Each study used patient-centered, culturally tailored interventions to address risk factor control and secondary prevention. Although neither study achieved its pre-specified outcome goals, they illustrate the application of participatory based research methods that will be vital when designing stroke transition studies among similar underserved populations.

### CONCLUSIONS AND FUTURE RESEARCH DIRECTIONS

Clearly there is a need to develop and test transitional care interventions specifically targeted to underserved and minority populations. These studies should embrace the principles of co-design and community-based participatory methods so that patient-centered, culturally tailored interventions can be developed and tested in willing communities and stroke populations. Efficiencies in the design and conduct of transitional care trials could be gained if studies are conducted within learning health systems that already serve vulnerable populations and communities. Several attributes of learning health systems, <sup>104</sup> including robust electronic health records, clinical decision support

systems, combined with the ability to track health care utilization and patient-centered outcomes either directly or through data linkage offer the potential to conduct pragmatic trials more efficiently. Officiently, Officient

As mentioned earlier, it is possible that given the greater needs of underserved and minority populations that intervention effects of transitional care studies will be both larger and more consistent. However, we need to caution that the inherent limitations of working in underserved communities that lack resources and assets may make it challenging to successfully complete clinical trials. More research is needed on eHealth solutions such as video conferencing, mobile phone apps, and text messaging, which offer cost-efficient solutions to support stroke patients who are returning home. Although research on the development and testing of eHealth technologies in the context of transitional care programs for stroke patients are limited, 110 in addition to the ReCAPS study93 there are several other studies currently underway (eq. in Canada, 111 Spain, 112 and New Zealand<sup>113</sup>) that are testing various eHealth solution to improve case- or self-management in stroke patients and/or caregivers. However, a concern remains as to whether the use of eHealth interventions could exacerbate the digital divide in underserved or disadvantaged groups, resulting in more rather than less health inequities.114 The lack of access to or familiarity with digital technology could result in minority populations having less access to relevant information, resources, or strategies necessary to facilitate care transitions, recovery and risk factor control.115,116

More research focused on community reintegration is also needed. Successful community reintegration involves moving from the short term focus of restoring physical function to establishing patient independence while adjusting their expectations.21 The full return to usual community activities should be regarded as the best most comprehensive measure of successful stroke care and recovery.9 Learning how to best support stroke survivors to develop self-management skills and adapt to impairments and activity limitations is essential to returning to community-based activities and establishing prior social and inter-personal relationships.23 As discussed earlier, interventions that address the needs of underserved populations and focus on community reintegration will need to have a sufficient duration (ie, 6-12 months), and be designed so that their services or actions can be adapted to the changing needs of the participants.

In this review, we have stressed the critical need to develop evidence-based interventions that support underserved and minority populations and provide them with meaningful improvements in stroke recovery, independence, and well-being. Although the challenges to achieve this goal should not be underestimated, we caution that providers and healthcare systems do not use this evidence gap as an excuse to avoid making changes to their current approach to care transitions. Many of the needs of underserved populations can and should be addressed by the current standards of clinical practice. At a patient level, we do not need clinical trial evidence to understand the value of patient-centered care, shared decision-making, or improved self-management skills. At the systems level, we do not need state-of-theart evidence to improve care coordination, information exchange, and postdischarge handoffs. Further research can help us identify more efficient and effective care models, but the current needs of patients and communities should not be ignored.

#### **ARTICLE INFORMATION**

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#### **Affiliations**

Department of Epidemiology and Biostatistics, Michigan State University, East Lansing (M.J.R.). Department of Health Society and Behavior, Department of Epidemiology and Biostatistics, Program in Public Health, Department of Neurology, School of Medicine, University of California (B.B.-A.). Stroke and Ageing Research, Department of Medicine, School of Clinical Sciences at Monash Health, Monash University, Clayton, Australia (D.A.C.). Stroke theme, the Florey Institute of Neuroscience and Mental Health, University of Melbourne, Heidelberg, Australia (D.A.C.)

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