

Economic Burden of Long-Term Care (LTC) in Patients with Advanced Huntington’s Disease (HD) and the Impact on Caregivers in North America: A Systematic Literature Review (SLR)

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Introduction and Objective

- HD is a rare autosomal dominant, neurodegenerative disorder caused by a CAG expansion in the *HTT* gene, resulting in the expression of mutant huntingtin protein¹.
- The disease is characterized by cognitive and motor decline, and behavioural symptoms that lead to loss of independence and severe disability². HD is terminal, with onset usually between 30-50 years of age and death occurring ~15 years after diagnosis².
- Currently there are no FDA approved treatments to prevent or slow the progression of HD, meaning treatment focuses on managing the manifestations of disease to maximize quality of life.
- The progressive decline in HD leads to increasing need for care, with greater likelihood of placement into LTC as patients progress to an advanced stage of disease. This need for LTC puts a significant financial burden on patients, families, caregivers, and the healthcare system³.
- To understand further the LTC needs of patients with HD and the resulting impact on caregivers and the healthcare system, this study aimed to investigate healthcare resource utilization (HCRU) and costs related to LTC in HD in North America.

Methods

- A broad SLR was conducted in Embase in March 2023 to evaluate the economic burden associated with HD.
- Eligible articles were full-text papers published 2008-2023 and conference proceedings published 2020-2023 that presented data relating to HCRU, disease-related direct or indirect costs, or impact on caregivers.
- This sub-analysis was focused on LTC for patients with HD in North America, and the impact this need for care has on caregivers and the healthcare system. Economic data associated with HCRU, care costs, and the impact on caregivers’ work and productivity were extracted.
- Studies were screened by two reviewers and reconciled by a third. Data was extracted by a single reviewer, with data number-checked by a second reviewer.



Results

The SLR yielded 8 papers from North America reporting data on LTC, 6 from the US^{4-7,9,10} and 2 from Canada^{3,8}.

Setting of Care and Length of Stay

- Most patients with advanced HD receive LTC in a nursing home (35%) or at home (32%), with fewer patients receiving LTC from hospitals, hospices, and multi-setting facilities (Figure 1)⁷.
- Patients receiving formal LTC spend most time in a nursing home before relocating to a hospice to receive end-of-life care (Figure 2)^{4,7}.

Figure 1: Setting of care for patients with HD before end-of-life hospice care (n=550, 2016-2019)⁷

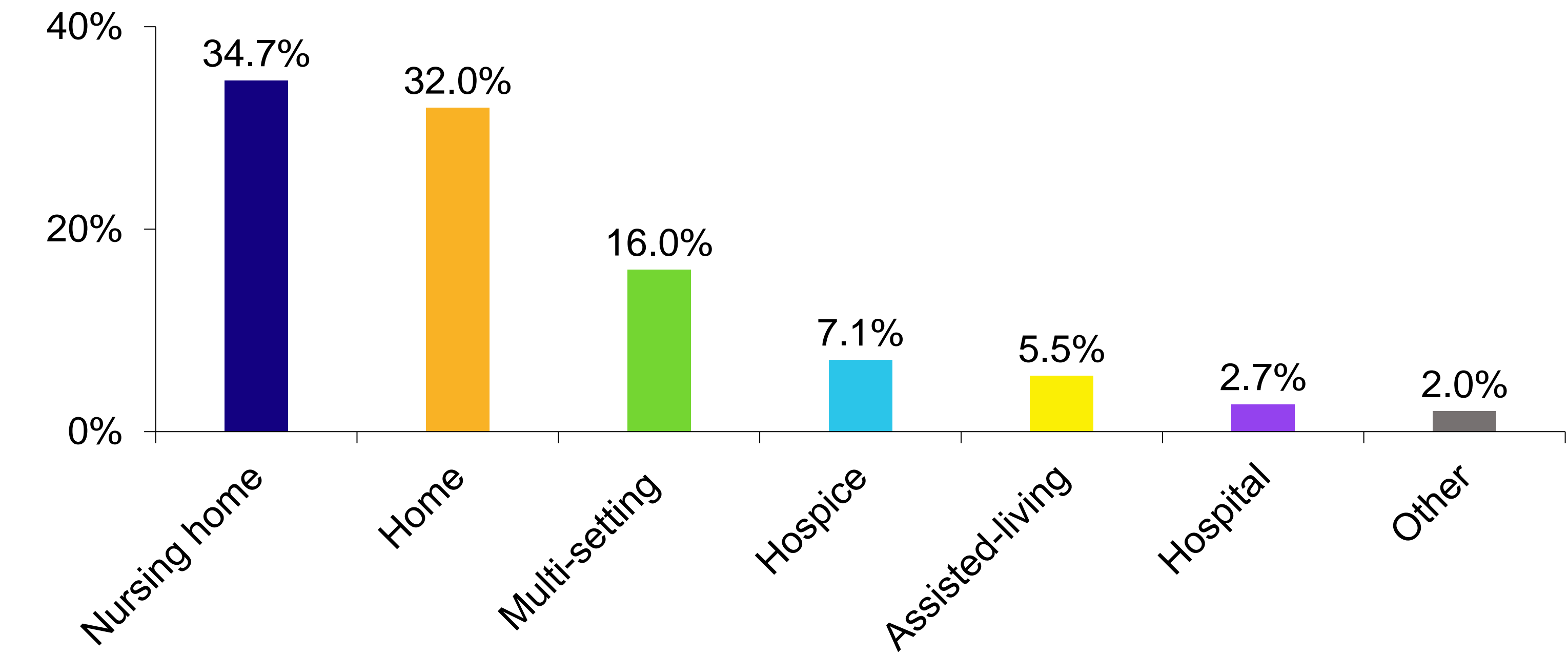
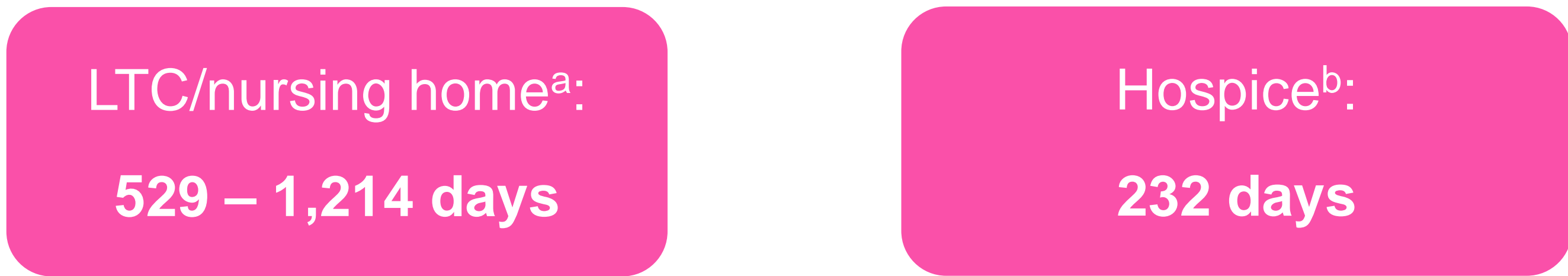


Figure 2: Length of stay in different care settings for patients with HD^{4,7}

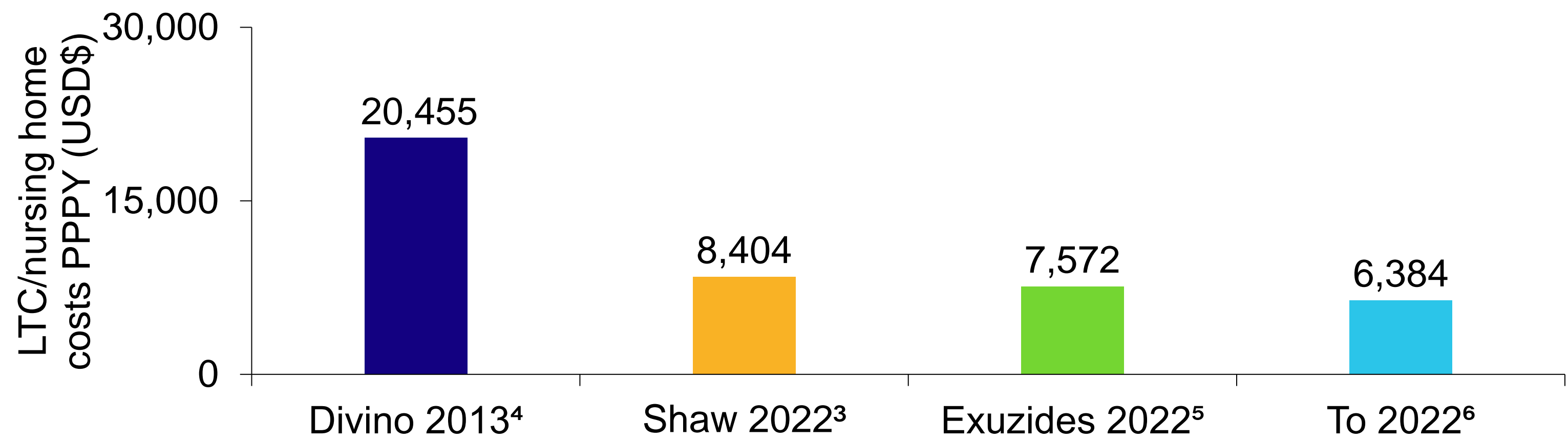


Note: a) Reports the average length of stay during a timeframe of 2002-2009 for commercial vs Medicaid patients. The lowest range reports commercial patients and the largest range reports Medicaid patients. b) Reports the average length of stay in a hospice before patients died in a 3-year timeframe (2016-2019).

Formal LTC Costs

- The average annual cost associated with LTC in a nursing home per patient with advanced HD ranged from \$6,384⁶ to \$20,455⁴ (Figure 3).
- Patients with HD in LTC experience longer LOS and more frequent hospitalizations as well as more Physician visits compared to patients with HD not receiving LTC³.
- LTC costs differ between studies, with one study of Medicaid patients reporting much higher costs⁴ than two studies involving patients across a mixture of US insurance types (Commercial, Medicare, and Medicaid)^{5,6} and one study conducted in Canada³.

Figure 3: Annual long-term care/nursing home costs per patient with advanced HD (USD)



Note: Costs reported in the supplementary from Shaw 2022 were in Canadian dollars. This cost was converted (11,426) into US dollars using March 2024 currency rates via <https://www.google.com/finance/> where 1 CAD = 0.74 USD. Two studies reported cost adjustments to 2018^{5,6}, the other 2 studies did not report cost adjustments^{3,4}. Divino 2013 reported Commercial costs (\$1,039), however, these were removed as the results weren't representative to the Commercial insurance population⁴. Exuzides 2022 and To 2022 reported monthly costs which was converted to yearly costs.

Effect of Home-Based LTC on Caregivers

- The LTC needs of patients with HD puts a significant burden on caregivers (Table 1).

Table 1: Effect of advanced HD care on caregivers

Effect on Caregiver	
Mean time spent as primary carer (years) ^a (n=36) ⁸	10.2 years
Total hours of formal care per week (n=17) ¹⁰	43 hours
Total hours of informal care per week (n=83) ¹⁰	41 hours
Worry about finances (yes) (out of a score of 16) ^a (n=118) ⁹	5.7
Prevented career progression (yes) (n=77) ¹⁰	51%
Prevented from working more hours (yes) (n=67) ¹⁰	70%
Overall work productivity loss (yes) (n=93) ¹⁰	54%

Note: a). Reports on all stages of HD including advanced HD

Conclusions

- The economic burden of care among patients with advanced HD is substantial, both for healthcare systems and caregivers.
- Most patients with advanced HD require LTC, predominantly in a formal/nursing home setting or at home before the patient moves to end-of-life hospice care. A long period of time is spent in both nursing home and hospice care, leading to sizeable annual costs for this care provision.
- The need for care at home puts a significant burden on caregivers as patients are often require full-time care before they move into more formal LTC or end-of-life care. As a result, caring for patients with advanced HD puts significant burden on a caregiver's career and finances. Caregivers often give up their job, change careers, or reduce their hours to accommodate the long hours required to provide LTC. Caregivers who continue in employment often see a reduction in their overall work productivity.
- As a result, future treatments that can prevent or slow the progression of HD could reduce the number of patients reaching advanced HD, ultimately reducing caregiver burden, HCRU, and LTC costs.

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2. Exuzides, A., et al. (2021). J Med Econ 24(1):1327-1336.
3. Shaw, E., et al., (2022). J Med Econ, 25(1):212-219.

4. Divino, et al., (2013). J Med Econ, 16(8):1043-1050.
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6. To, T M., et al (2022). JMCP 28(11):1228-1239

7. Parast, L., et al (2022). J Pain Symptom Manag. 64(1):70-79
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9. Williams, J., et al (2012). Journal Adv Manag 68(1):137-146

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