






RESEARCH LETTER

# Low Engagement of Advance Care Planning Among Patients Who Had a Stroke or Transient Ischemic Attack

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**T**he goal of advance care planning (ACP) is to ensure that medical care is consistent with patients' values and preferences.<sup>1</sup> ACP is a process and should be reviewed after a change in health, such as a stroke, as preferences may have changed.<sup>1</sup> Yet, among stroke survivors, only 45% reported having an advance directive, and whether this was completed pre or post stroke is unknown.<sup>2</sup> We sought to explore ACP engagement among patients with stroke/transient ischemic attack (TIA).

The data that support the findings of this study are available from the corresponding author upon reasonable request. We conducted cross-sectional structured telephone interviews of patients with stroke/TIA admitted to a Comprehensive Stroke Center from November 2019 to November 2020 until we reached 50 respondents. We excluded patients with stroke/TIA who had hearing, vision, cognitive, or language deficits. We queried demographics, health literacy (confident with forms by self-report),<sup>3</sup> and modified Rankin Scale score. Our primary outcome was the validated 4-item Advance Care Planning Engagement Survey.<sup>4</sup> The survey assesses 4 critical ACP elements on a 5-point Likert scale that reflect behavior change: (1) signing official papers (durable power of attorney) naming a surrogate decision-maker; (2) discussion of patients' wishes with surrogate decision-maker; (3) discussion

of patients' wishes with medical provider; and (4) completion of an advance directive. Responses were dichotomized as "I have already done it" versus other stages of engagement (never thought about it; thought about it, but I am not ready; thinking about it in the next 6 months; definitely planning to it in the next 30 days). For those who engaged in ACP, we asked whether this was before or after their stroke/TIA and whether they had uploaded the ACP documents (durable power of attorney or advance directive) into their patient portal. Secondarily, we scored the 4 Advance Care Planning Engagement Survey questions as an average 5-point Likert scale (scored 1–5). If a respondent indicated prior designation of a surrogate decision-maker, we also attempted to enroll the surrogate. Patients with stroke/TIA and surrogates were queried about life-prolonging treatment (LPT) preferences. Specifically, participants with stroke/TIA were asked whether they would want to receive or stop/reject all life-prolonging treatments if they had a serious or terminal illness and were experiencing either of these hypothetical scenarios: (1) they could speak, walk, and recognize others but were in constant, severe physical pain; and (2) they were not in pain, but could not speak, walk, or recognize others.<sup>5</sup> Surrogates were asked what the patient would want in these scenarios. Descriptive statistics were used to characterize study participants and describe ACP

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**Table. Elements of Advance Care Planning: Overall and After Stroke/TIA\* (n=50)**

	Designation of a surrogate	Discussed wishes with surrogate	Discussed wishes with provider	Completed advance directive
Overall	23 (46%)	25 (50%)	5 (10%)	17 (34%)
Performed after stroke/TIA*	6 (12%)	7 (14%)	1 (2%)	5 (10%)

\*TIA indicates transient ischemic attack.

engagement. Unweighted Cohen's Kappa was used to assess agreement between patient and surrogate for LPT scenarios. The study was deemed exempt from review by the University of Michigan institutional review board. Participants gave informed consent to participate.

Between January and February 2021, we attempted to contact 196 patients with stroke/TIA; 26 were excluded due to cognitive or language deficits, 23 had invalid contact information, and voicemails were left with 70 people. Of the 77 people with whom the research team spoke, 27 (35%) declined. Among the 50 participants, 60% had a stroke, 24% had a TIA, and 12% had both. Mean age of participants was 68.1 (SD=12.8) years; 13% were Black Americans, and 54% were women; all received at least a high school diploma/general educational development certificate, and 17% reported limited health literacy. The median modified Rankin Scale score was 0 (interquartile range 0–1). A total of 23 (46%) participants with stroke/TIA reported designating a surrogate decision-maker; 17 (34%) surrogate decision-makers participated in the study.

Only 10% to 50% of patients with stroke/TIA reported completion of the individual 4 ACP behaviors (Table), and the overall mean 5-point Advance Care Planning Engagement Survey score was 3.3 (SD=1.1). Few (2%–14%) reported completion of any ACP behavior after the stroke/TIA (Table). Eight (35%) of those with a durable power of attorney and 4 (24%) of those with an advance directive reported patient portal deposition.

Limiting to those patients with stroke/TIA who identified a surrogate, for the severe pain LPT scenario, 4 (25%) reported wanting to stop/reject treatments, and 63% of patient/surrogate pairs agreed (n=16, Kappa=0.32, P=0.08). For the severe disability LPT scenario, 9 (56%) reported wanting to stop/reject treatments and 44% of patient/surrogate pairs agreed (n=16, Kappa=-0.13, P=0.43).

Our findings suggest that ACP is underused among patients with stroke/TIA, particularly after the stroke. Only 14% of patients with stroke/TIA discussed their wishes with a surrogate decision-maker after their stroke/TIA. Furthermore, among patients with stroke/TIA who designated a surrogate medical

decision-maker, the agreement between patients and surrogate LPT preferences was low.

Our work is limited by nonresponse, self-report of ACP document upload, variable time between stroke/TIA and interview, sample size, and its single-center convenience center nature. Furthermore, we cannot exclude that the patients with stroke/TIA engaged in ACP with their surrogate between the patient and surrogate interview. We also cannot exclude that patients had stable poststroke preferences and did not need to update their ACP documents. Nonetheless, discussion with surrogates and providers would need to be updated.

Our results suggest that efforts to increase ACP among patients with stroke/TIA and optimization of discussions between patients and surrogates may represent novel targets to promote patient-centered care.

## ARTICLE INFORMATION

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### Disclosures

None.

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