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Original Reports: Pragmatic Trials among Older Adults

Assessing Representativeness of Seriously Ill Patient Survey Responders in a Pragmatic Clinical Trial

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Objective: Pragmatic trials often implement an intervention across a population of patients but require information unavailable at the population level that must be reported by a subset of patients. In this pragmatic clinical trial, we compared characteristics of seriously ill patients with those who completed a survey evaluating advance care planning across 3 academic health systems.

Methods: A deliberate process including health system and external stakeholders and patients was used to design materials for and the approach to seriously ill patients. We developed a survey and conducted a multistep process to identify seriously ill primary care patients. We evaluated the relationships of age, gender, race and ethnicity, and vulnerability using the social vulnerability index in this population, and explored the representativeness of survey respondents compared with the underlying seriously ill population in terms of age, race and ethnicity, and vulnerability measured.

Results: About 5% (8707 patients) of the primary care population was classified as seriously ill, 5351 were mailed a survey and 1100 provided survey responses. Hispanic and Black patients were younger than White patients, and Black and Hispanic patients were more vulnerable than White and Asian patients and patients of other races. Representativeness was high across age and race and ethnicity, although White and Hispanic patients were more likely to respond than Black and Asian patients and patients of other races. Vulnerability in the surveyed sample was nearly identical to the population.

Conclusions: A tailored survey and recruitment strategy yielded a representative sample of seriously ill, largely older, primary care respondents in the context of a pragmatic clinical trial. *Ethn Dis.* 2023;33(2/3):91–97; doi:10.18865/ed.33.2-3.091

Keywords: Pragmatic Clinical Trial; Serious Illness; Representativeness; Survey; Advance Care Planning ¹ Division of Geriatric Medicine and Gerontology, Department of Family Medicine, University of California, Irvine, Irvine, CA ² Department of Medicine, University of California, Los Angeles, CA

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INTRODUCTION

Seriously ill patients are a prime target for health care system interventions. They require medical care focused on their clinical conditions, coordination of care, and a disproportionate use of resources.¹ Patients in lower socioeconomic strata of minority races and ethnicities are overrepresented among the seriously ill.^{2,3} To identify unmet need and to target interventions, it is important to elicit the perspectives of seriously ill patients.⁴ Furthermore, in the context of a pragmatic trial, it is often important to obtain patient reports to obtain information unavailable in routinely collected clinical and administrative data. Patient perspectives are often captured by surveys, and including a representative sample of different ages, genders, and race and ethnic subgroups is important.⁵ However, ensuring survey participation that represents the underlying population is challenging in a pragmatic trial.

One topic of importance to seriously ill patients is advance care planningconsideration of clinical circumstances and prognosis in discussion about goals for future medical care, specification of a health care agent, and completion of an advance directive. Advance care planning is a sensitive topic for many patients. Encouraging advance care planning is of importance to health care systems,⁶ but the attitudes and level of engagement of seriously ill patients who have not completed the advance care planning process are unknown. Furthermore, it is not known what approaches are acceptable and engaging for these patients. The context for this report is a pragmatic clinical trial to improve advance care planning for all seriously ill patients receiving primary care across 3 academic health systems. To evaluate the impact of the trial, we fielded a survey to understand levels of engagement in advance care planning and to elicit patient preferences among primary care patients with serious illness. The survey aimed to accommodate the language and reading level of the target population and be available in multiple modes of administration to accommodate patient preferences. In this

report, we evaluated how well the surveyed sample represented the population of seriously ill patients.

METHODS

We evaluated the capability of a mailed survey and telephone follow-up to capture a representative sample of a population of seriously ill patients across 3 health systems with a focus on representativeness by age, race and ethnicity, language, and vulnerability. This effort aimed to elicit patient-reported information to understand the effect of health system-wide interventions implemented in a pragmatic trial of advance care planning conducted at the health system population level.⁷

Population

The patient population was all patients aged 18 years or older who had a serious illness and who attended at least two primary care office visits during the prior 12 months in 50 clinics across 3 health systems. Serious illness was defined using administrative billing codes, encounter data, and clinical information available in the electronic health record. The definition of serious illness required an at-risk medical diagnosis (cancer, heart failure, chronic obstructive pulmonary disease, end-stage liver disease, end-stage renal disease, or amyotrophic lateral sclerosis) at a level of illness severity such that advance care planning would be a priority or 1 of these conditions linked with age 75 years or older. The serious illness algorithm was validated by chart review with 98% of identified patients meeting the criteria.⁷

Although the full seriously ill primary care cohort was the target of intervention for this health system-wide quality improvement pragmatic clinical trial, we also aimed to enroll a representative sample of this seriously ill population to provide patient-reported information that was unavailable in the electronic medical record. This survey sample was comprised of the 7785 seriously ill primary care patients across the 3 health systems at the time that the survey was prepared. We excluded 1631 patients who already had a recent advance directive or physician order for life sustaining treatment form available in the electronic health record, and 803 patients were excluded from the survey by their physician because of language, cognitive impairment, or concern that the survey might harm the patient, or because of invalid patient information. Among the 5351 patients who were mailed a survey, 1100 patients returned a survey. Between the time that the surveys were mailed to the sample and when the health systems introduced the intervention across the 50 clinics (1 to 9 months across the 50 clinics, in part related to coronavirus disease 2019 [COVID-19]), an additional 922 seriously ill primary care patients were identified. In this report, we compare the 1100 patients who responded to the survey with the 8707 patients comprising the seriously ill primary care population in these health systems.

Recruitment and Survey Instrument

Seriously ill primary care patients with an English or Spanish language preference were mailed a survey in their preferred language. The survey content and approach were guided by an active community advisory group that reviewed (and edited) materials, provided insight concerning content and design, and suggested and approved a logo. Materials were iteratively modified with piloting and cognitive interviews. The study team worked closely with multiple stakeholders at the 3 health systems to align the intervention and recruitment with local clinical, administrative, and information technology workflows. The cover letter signed by the health system explained that advance care planning is an important aspect of care, and the system wants to understand patients' levels of awareness and engagement. Surveys were

mailed in the final quarter of 2019 and first half of 2020. Patients who did not respond to the mailed survey were called by staff up to 3 times to remind them of the mailed survey or to help complete the survey over the phone. At each site, patients were called in the order of their medical record numbers. Because the number of patients not returning surveys exceeded the available time for phone calls, not every patient received a phone call. Patients who received a phone call were more likely to complete a survey; including phone calls improved representativeness of the underlying population.⁸ A second survey with the same introductory letter was mailed to nonrespondents. Patients could also complete an electronic version of the survey if they indicated this preference during a telephone contact. The study was approved by the Institutional Review Board at University of California, Los Angeles (18-001612), with delegation from the other 2 health systems.

The survey instrument was written for the fifth grade reading level and printed in 14-point type using welcoming introductions and instructions. The survey assessed level of engagement in advance care planning, preferences for medical care and future health states, confidence that future care will match goals, desired role in decisions, and physician communication. Patients provided written informed consent and received a \$30 gift card for completing the survey.

Statistical Analysis

Patient demographics were obtained from the electronic health record. We computed the Social Vulnerability Index (SVI), an indicator of potential negative effects from external stress on health. SVI is based on 15 US Census variables, such as income, educational level, employment, crowding, and vehicle access.^{9,10} SVI scores are computed for each census tract and range from 0 to 1, with 1 being the most vulnerable. Patient home addresses were geocoded using ArcGIS Pro to obtain geographical coordinates. The coordinates were binned into census tracts, which allowed SVI scores to be matched to most patients (N=7981).

We evaluated the representativeness of the surveyed sample compared with the full population of seriously ill patients in terms of age (<60, 60 to 80, and >80years), gender, race and ethnicity (White, Hispanic, Black, Asian, and other), language (English, Spanish, and other), and SVI (<0.5 SVI and \geq 0.5 SVI). The "other" race and ethnicity category includes Native Hawaiian, Pacific Islander, American Indian, Alaskan Native, multiple, and other. We evaluated variation in the composition of the seriously ill population. Representativeness of the survey sample across categories of age, race and ethnicity, and SVI was evaluated using chi-square goodnessof-fit tests. Due to multiple comparisons, the level of significance was set at P < .01.

RESULTS

Among approximately 192,000 primary care patients across the 3 health care systems, 8707 individuals (5%) were identified as seriously ill patients. Among seriously ill patients, 20% had advanced cancer, 23% had advanced heart failure, 11% had advanced chronic obstructive pulmonary disease, 6% had decompensated liver disease, 16% had end-stage renal disease, 0.3% had amyotrophic lateral sclerosis, and 34% had heart, lung, liver, or renal disease or cancer and were 75 years or older. Among seriously ill patients, 1100 provided patient reports by paper (mailed) survey, telephone interview, or electronic survey completion. The mean age of respondents was lower than that of the seriously ill population (70.0 versus 73.2 years), but they were similar in terms of gender (52.1% versus 50.1%). White (60.5% versus 54.2%) and Hispanic (18.0% versus 16.8%) patients were more likely to respond than the underlying population, whereas Asian

(9.1% versus 12.4%), Black (6.6% versus 8.3%), and patients of other races (5.8% versus 8.3%) were less likely to respond (overall P<.01). Respondents were less likely to prefer a language other than English or Spanish (as expected because the survey was available only in those languages). Insurance status and SVI were not different between the survey sample and the underlying seriously ill population (Table 1).

Composition of the Seriously Ill Population

In the seriously ill population, patients 80 years and older were more likely than those in the younger age groups to be female (youngest 47.1%, middle 47.0%,

and oldest 54.2%). There was a gradient across increasing age category of a greater proportion of White patients (youngest 36.9%, middle 55.7%, and oldest 60.1%) and a smaller proportion of Hispanic (youngest 33.1%, middle 16.1%, and oldest 10.8%) and Black (youngest 9.6%, middle 9.2%, and oldest 6.8%) patients. Similarly, younger patients were more likely to prefer Spanish (youngest 12.3%, middle 9.1%, and oldest 6.5%). According to SVI, the oldest age group was less vulnerable, particularly in the socioeconomic and minority and language subscales (Table 2).

The White, Asian. and other race patients were of similar age, but Hispanic and Black patients were younger

Table 1. Comparison of demographic characteristics of the surveyed sample to
the underlying seriously ill patient population

	Surveyed sample (n=1100)	Population of seriously III patients (n=8707)
Age, mean (SD)	70.0 (15.3) ^a	73.2 (14.4)
Gender, N (%)		
Male	573 (52.1)	4362 (50.1)
Female	523 (47.5)	4341 (49.9)
Nonbinary	4 (0.4)	4 (0.0)
Race/ethnicity, N (%)		
White	665 (60.5) ^a	4717 (54.2)
Hispanic	198 (18.0) ^a	1462 (16.8)
Asian	100 (9.1) ^a	1084 (12.4)
Black	73 (6.6) ^a	721 (8.3)
Other ^b	64 (5.8) ^a	723 (8.3)
Language, N (%)		
English	963 (87.5) ^a	7360 (84.5)
Spanish	114 (10.4) ^a	748 (8.6)
Other	23 (2.1) ^a	599 (6.9)
SVI, mean (SD) ^c		
Overall	.37 (.27)	.37 (.27)
Socioeconomic	.35 (.25)	.35 (.26)
Household composition	.37 (.25)	.37 (.26)
Minority and language	.41 (.27)	.42 (.27)
Housing and transportation	.47 (.29)	.46 (.29)
Insurance, N (%)		
Commercial	310 (28.2)	2404 (27.6)
Medicare	420 (38.2)	3412 (39.2)
Medicaid	205 (18.6)	1646 (18.9)
НМО	60 (5.5)	378 (4.3)
Other	105 (9.5)	867 (10.0)

HMO, Health Maintenance Organization

^a P<.01 for the goodness-of-fit chi-square test comparing the surveyed sample to the population of seriously ill patients

^b Other race includes Native Hawaiian/Pacific Islander, American Indian/Alaskan Native, and multirace/ethnicities

^c Social vulnerability index scores range from 0 to 1, with 1 indicating higher vulnerability (N=7981)

	Age 18 to <60 years		Age 60 to 80 years		Age >80 years	
	Surveyed sample (N=248)	Population (N=1443)	Surveyed sample (N=518)	Population (N=3809)	Surveyed sample (N=334)	Population (N=3432)
Age, mean (SD)	46.8 (9.3)	47.9 (9.5)	71.2 (6.0)	71.4 (5.8)	85.3 (3.6)	85.9 (3.6)
Gender, N (%)						
Male	107 (43.1) ^a	762 (52.8)	288 (55.6)	2018 (53.0)	178 (53.3)a	1570 (45.7)
Female	140 (56.5) ^a	680 (47.1)	228 (44.0)	1789 (47.0)	155 (46.4) ^a	1861 (54.2)
Nonbinary	1 (.4) ^a	1 (.1)	2 (.4)	2 (.1)	1 (.3) ^a	1 (.0)
Race/ethnicity, N (%)						
White	93 (37.5)	533 (36.9)	340 (65.6) ^a	2122 (55.7)	232 (69.5) ^a	2062 (60.1)
Hispanic	94 (37.9)	478 (33.1)	73 (14.1) ^a	615 (16.1)	31 (9.3) ^a	369 (10.8)
Asian	30 (12.1)	172 (11.9)	44 (8.5) ^a	439 (11.5)	26 (7.8) ^a	473 (13.8)
Black	16 (6.5)	138 (9.6)	35 (6.8) ^a	351 (9.2)	22 (6.6) ^a	232 (6.8)
Other ^b	15 (6.0)	122 (8.4)	26 (5.0) ^a	282 (7.4)	23 (6.9) ^a	296 (8.6)
Language, N (%)						
English	207 (83.5)	1239 (85.9)	461 (89.0) ^a	3256 (85.5)	295 (88.3) ^a	2865 (83.5)
Spanish	40 (16.1)	178 (12.3)	50 (9.7) ^a	348 (9.1)	24 (7.2) ^a	222 (6.5)
Other	1 (0.4)	26 (1.8)	7 (1.4) ^a	205 (5.4)	15 (4.5) ^a	345 (10.1)
SVI, mean (SD)						
Overall	.48 (.28)	.46 (.28)	.37 (.27)	.38 (.28)	.29 (.23)	.32 (.25)
Socioeconomic	.45 (.27)	.44 (.27)	.35 (.25)	.37 (.26)	.26 (.21)	.30 (.23)
Household Composition	.40 (.26)	.39 (.26)	.36 (.26)	.37 (.26)	.35 (.25)	.36 (.25)
Minority and language	.53 (.27)	.52 (.28)	.41 (.27)	.43 (.28)	.33 (.25)	.36 (.25)
Housing and transportation	.55 (.29)	.52 (.29)	.47 (.29)	.47 (.29)	.41 (.28)	.44 (.28)

SD, standard deviation; SVI, social vulnerability index

^a P<.01 for the goodness-of-fit chi-square test comparing the surveyed sample to the population of seriously ill patients

^b Other race includes Native Hawaiian/Pacific Islander, American Indian/Alaskan Native, and multirace/ethnicities

(White/Asian/other 73 to 75 years versus Hispanic 66 years versus Black 71 years). Black seriously ill patients were more likely than the other race and ethnicity groups to be female (White/Hispanic/Asian/other 48% to 51% versus Black 57%). Nearly all of the White and Black patients preferred English, whereas 49% of Hispanic patients preferred Spanish; 33% of Asian patients and 16% of other race patients preferred 1 of 66 languages different from English or Spanish (Table 3).

Thirty-one percent of the seriously ill population had an SVI in the upper half of the vulnerability scale. Younger patients tended to be more vulnerable (mean SVI: youngest = 0.46, middle = 0.38, and oldest 0.32; Table 2). White seriously ill patients were far less likely to be in the more vulnerable group, as were Asian and other race patients, whereas Hispanic and Black patients were more likely to be in the more vulnerable group (mean SVI: White = 0.28, Hispanic = 0.57, Asian = 0.40, Black = 0.56, and other = 0.33; Table 3). Patients preferring Spanish were more likely to be in the more vulnerable group (Table 4).

Representativeness of the Surveyed Sample

Men were less likely than women to respond among patients less than 60 years old and more likely to respond among the eldest age group. The group consisting of individuals less than 60 years old was generally representative by race and ethnicity. However, in the older age groups, White patients are overrepresented, with Asian patients particularly underrepresented. Survey respondents were representative of the population by SVI with slightly less vulnerability with increasing age (Table 2).

Respondents tended to be younger than the seriously ill population for all race and ethnicity groups other than Black. White and other race respondents were 2 to 4 years younger than their respective populations, on average, whereas Hispanic and Asian respondents were 5 to 7 years younger than their seriously ill groups. Asian patients were less likely to respond if they preferred a language other than English or Spanish. In terms of vulnerability, responding patients tended to be representative of their underlying race and ethnic groups (Table 3).

A similar proportion of patients with an SVI of ≥ 0.5 responded to the survey compared with those with an SVI of <0.5 (12.8% versus 12.1%, P=.6). High- and low-vulnerability White patients responded to the survey

1		white	HISP	HISPANIC	Aslan	an	Black	JCK	Other race	r race
	Surveyed sample (N=665)	Population (N=4717)	Surveyed sample (N=198)	Population (N=1462)	Surveyed sample (N=100)	Population (N=1084)	Surveyed sample (N=73)	Population (N=721)	Surveyed sample (N=64)	Population (N=723)
	73.1 (13.4) ^a	75.5 (12.8)	60.8 (16.5) ^a	66.1 (16.5)	66.8 (16.3) ^a	74.0 (14.3)	71.5 (13.3)	71.3 (13.9)	69.2 (17.7)	73.4 (15.2)
ueriaer, N (%) Male 3	369 (55.5)	2434 (51.6)	87 (43.9)	711 (48.6)	(0) (60.0)	538 (49.6)	28 (38.4)	313 (43.4)	29 (45.3)	354 (50.6)
4	295 (44.4)	2282 (48.4)	109 (55.1)	749 (51.2)	40 (40.0)	546 (50.4)	45 (61.6)	408 (56.6)	34 (53.1)	345 (49.3)
Nonbinary	1 (.2)	1 (.0)	2 (1.0)	2 (.1)	0 (0)	0(.0)	0(.0)	0	1 (1.6)	1 (.1)
Language, N (%)										
	656 (98.6) ^a	4593 (97.4)	89 (44.9)	739 (50.5)	86 (86.0) ^a	726 (67.0)	73 (100.0)	710 (98.5)	59 (92.2)	592 (81.9)
Spanish	4 (.6) ^a	11 (.2)	109 (55.1)	719 (49.2)	0 (.0) ^a	3 (.3)	0(0)	1 (.1)	1 (1.6)	14 (1.9)
Other	5 (.8) ^a	113 (2.4)	0()0	4 (.3)	14 (14.0) ^a	355 (32.7)	0(0)	10 (1.4)	4 (6.2)	117 (16.2)
SVI, mean (SD)										
Overall .	.28 (.23)	.28 (.23)	.58 (.26)	.57 (.27)	.37 (.21)	.40 (.25)	.61 (.23)	.56 (.27)	.37 (.27)	.33 (.25)
Socioeconomic	.26 (.21)	.27 (.21)	.55 (.26)	.55 (.27)	.33 (.20)	.35 (.23)	.57 (.25)	.54 (.26)	.35 (.25)	.31 (.23)
Household composition	.34 (.25)	.34 (.25)	.40 (.26)	.43 (.26)	.33 (.21)	.33 (.24)	.53 (.28)	.49 (.29)	.41 (.24)	.36 (.25)
•	.30 (.22)	.30 (.22)	.64 (.25)	.63 (.27)	.50 (.22)	.51 (.25)	.65 (.22)	.60 (.24)	.39 (.26)	.38 (.24)
Housing and transportation	.41 (.29)	.41 (.28)	.62 (.26)	.59 (.27)	.44 (.26)	.48 (.29)	.62 (.24)	.56 (.27)	.44 (.29)	.44 (.28)

	Less vulne (SVI < 0		More vulne (SVI > 0.	
	Surveyed sample (N = 688)	Population (N = 5528)	Surveyed sample ^a (N = 315)	Population (N = 2453)
Age, mean (SD)	72.9 (14.2) ^b	75.3 (13.4)	64.3 (15.5) ^b	69.2 (15.3)
Gender, N (%)				
Male	386 (56.1)	2799 (50.8)	143 (45.4)	1179 (48.1)
Female	299 (43.5)	2710 (49.2)	171 (54.3)	1270 (51.8)
Nonbinary	3 (.4)	3 (.1)	1 (.3)	1 (.0)
Race/ethnicity, N (%)				
White	496 (72.1) ^b	3564 (64.5)	107 (34.0)	757 (30.9)
Hispanic	63 (9.2) ^b	513 (9.3)	119 (37.8)	850 (34.7)
Asian	67 (9.7) ^b	678 (12.3)	25 (7.9)	343 (14.0)
Black	23 (3.3) ^b	294 (5.3)	44 (14.0)	339 (13.8)
Other ^c	39 (5.6) ^b	479 (8.7)	20 (5.7)	164 (5.8)
Language, N (%)				
English	638 (92.7) ^b	4967 (89.9)	236 (74.9) ^b	1734 (70.7)
Spanish	33 (4.8) ^b	190 (3.4)	75 (23.8) ^b	527 (21.5)
Other	17 (2.5) ^b	371 (6.7)	4 (1.3) ^b	192 (7.8)
SVI, mean (SD)				
Overall	.21 (.14)	.22 (.14)	.71 (.14)	.72 (.14)
Socioeconomic	.21 (.14)	.22 (.14)	.65 (.17)	.66 (.17)
Household composition	.29 (.22)	.30 (.23)	.52 (.24)	.53 (.25)
Minority and language	.27 (.18)	.28 (.18)	.71 (.18)	.72 (.17)
Housing and transportation	.34 (.24)	.34 (.23)	.74 (.18)	.74 (.19)

SD, standard deviation; SVI, social vulnerability index

^a Column percent presented in the table

^b P<.01 for the goodness-of-fit chi-square test comparing the surveyed sample to the population of seriously ill patients

^c Other race includes Native Hawaiian/Pacific Islander, American Indian/Alaskan Native, and multirace/ethnicities

about equally (14.1% versus 13.9%, P=.9), but there was a nonsignificant trend toward higher response comparing high vulnerability with low vulnerability Black (13.0% versus 7.8%, P=.035) and other race (12.2% versus 8.1%, P=.12) patients. High versus low vulnerability was not statistically significantly associated with survey completion for English preference (13.6% versus 12.8%, P=.4) or Spanish preference (14.2% versus 17.4%, P=.3) patients (Table 4).

DISCUSSION

This report demonstrates a process that yields a relatively representative sample of seriously ill, largely older, primary care survey respondents in the context of a pragmatic clinical trial. This was the case even though the enrollment period overlapped with COVID-19 clinic closures, and interventions began at clinics at different times. Many of the patients did not receive a survey, which reflects the pragmatic nature of the implementation. This trial intentionally undertook a variety of efforts to enhance the representativeness of the enrolled sample. These efforts include tailoring materials to the population; incorporating intensive guidance from a diverse community advisory group of patients and family members from each health system; maintaining awareness of reading level, language, and presentation; following-up by phone after the mailed surveys; and offering multiple modes of survey completion.¹¹ The representativeness of the survey sample is particularly poignant in the context

of the advance care planning survey content, which is known to cause angst among many¹² and may be less welcomed among non-White individuals.¹³

Subgroup analysis of the seriously ill population reveals stark differences by age, ethnicity, and language. Younger patients were much more likely to be of Hispanic ethnicity and Black race. Accordingly, they were more likely to prefer Spanish language. Black and Hispanic seriously ill patients were much more likely to be vulnerable. These findings from academic health systems, which should provide adequate access to all for needed health services, highlight the greater burden of disease present in Black and Hispanic individuals.

These data also demonstrate that the composition of the population is a greater source of variation than the representativeness of the survey sample. Across age, gender, race, and ethnicity, only minor differences are seen between the composition of the underlying seriously ill population and the surveyed sample.

This report has several limitations. It is a study of 3 academic medical centers and may not reflect other academic centers or community practices. Academic medical centers tend to attract more seriously ill patients.¹⁴ The materials development and method of approaching potential survey respondents was intensive and may exceed that of many pragmatic trials, but this experience demonstrates the level of success that can be achieved in reports from a representative sample of patients. The intervention and survey topic are sensitive, but that is also the case for many aspects of screening and intervention for social determinates of health.^{15,16}

In conclusion, we describe an approach that was successful in eliciting input from a representative sample of patients in a pragmatic trial. It is important to examine whether similar strategies are successful in other contexts.

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CONFLICT OF INTEREST None.

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