



Research Article

Understanding Resistance to Honoring VSED Advance Directives in Dementia Patients: A Cross-Sectional Provider Survey

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Abstract

Context

The prerogative to refuse life-sustaining and life-prolonging interventions via an advance directive is an established legal, ethical, and moral right. Controversy remains as to whether patients with dementia have an equivocal right to refuse assisted feeding at the end of life through an advance directive made when the patient had decision-making capacity.

Objectives

This study reports on an online survey administered to understand whether and why long-term care providers decline to honor an advance directive to voluntarily stop eating and drinking (VSED).

Methods

An IRB-approved online cross-sectional survey was distributed to the Society for Post-Acute and Long-Term Care Medicine (AMDA) listserv. A series of quantitative and qualitative questions collected information on facilities, institutional policies, training protocols, and personal care wishes to assess attitudes and behaviors surrounding VSED and advance directive requests by patients.

Results

138 respondents, primarily long-term care facility medical directors, participated. Among other findings, 79.6% of respondents indicated some level of familiarity with VSED but 23.9% were unsure

if their facility could accommodate a request. The 56% were highly familiar with Immediate Jeopardy regulations but 91% were unaware of Ulysses Clauses. Only 29% felt that their institution provided sufficient training on symptom management for patients and one-quarter were unsure of any facility protocols or trainings pertaining to patient end-of-life care issues. One-fifth were personally uncomfortable caring for a patient who chooses VSED.

Conclusion

A refusal to honor a VSED advance directive is most often precipitated by uncertainties due to inadequate trainings and insufficient guidance on how to apply relevant state and federal regulations rather than personal objection or facility protocol against the practice. Healthcare facilities that can integrate multidisciplinary perspectives during the advanced care planning process, implement effective trainings modules, and incorporate ethical principles honoring the obligation to respect autonomy show promise for improved patient care at the end of life.

Keywords: Alzheimer's disease; Advance care planning; Dementia; End of life; Long term care; Palliative care; Patient autonomy

Introduction

In the United States, patients with Alzheimer's and other dementias make up more than 40% of the residents in care communities, hospices, residential nursing homes, and other care facilities [1]. These institutions collectively hereafter referred to as long-term care facilities (LTCs) and the practitioners within them are legally and morally charged with protecting these patient-residents from harm while respecting their right of autonomy. Capacitated patients may execute an advance directive (AD) to achieve a death in line with their own values and goals, and to avoid prolonged suffering at the end of life. The conceptual foundation of an AD is respect for autonomy. When a person with decision-making capacity provides instructions to guide treatment decisions in future states of cognitive incapacity such as dementia, an AD serves as a valuable tool to ensure respect for the values of the earlier self [2,3].

The right to refuse life-sustaining interventions via an AD has been recognized as a legal, ethical, and moral right for decades. It is concerning that a quarter of providers are unwilling to honor an AD limiting life-sustaining interventions for a patient with dementia [4]. The act of voluntary stopping of eating and drinking (VSED) is a legally permissible option to hasten death for competent adults who find life with a progressive, irreversible disease unendurable. The right to voluntary stop eating and drinking is both a palliative and gerontological care issue. Some legal scholars cite the acceptance of VSED in capacitated patients as the precedent for allowing refusal of food and water by AD [5]. Recognizing that a patient with dementia has an equivocal right to refuse assisted oral feeding via AD is a recently emerging trend that pushes the boundaries of widely accepted medical practice at the end of life. This is known as voluntary stopping of eating and drinking via advance directive, or VSED-AD.

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Citation: Hoffman DN, Strand GR, Bloom RF, Hendley K (2023) Understanding Resistance to Honoring VSED Advance Directives in Dementia Patients: A Cross-Sectional Provider Survey. J Gerontol Geriatr Med 9: 192.

Received: October 23, 2023; **Accepted:** November 03, 2023; **Published:** November 10, 2023

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The premise of a VSED-AD is much the same as any other directive made: an individual who wishes to avoid unwanted prolonged dying can specify a situation in which they would not want assistance or intervention, such as with eating and drinking if they could no longer feed themselves [6]. There remain conceptual disagreements as to whether feeding assistance is a basic personal care need like bathing and dressing, or whether the complex activity required feed a patient with advanced dementia is more advanced than basic care and therefore represents a kind of treatment [7,8]. Legal and ethical scholarship have found no distinction between the limits of bodily integrity from spoon feeding versus feeding tubes, or of the withdrawal of artificial feeding and the withdrawal of hand feeding [9,10].

The ongoing clinical and scholarly debates around VSED-AD entered public discourse in the recent highly publicized case of Susan Saran [11]. Diagnosed with frontotemporal dementia, a progressively fatal brain disease, Saran worked in conjunction with a lawyer to complete an AD that instructs caregivers to withhold hand feeding and fluids at the end of life. Her continuing care retirement community refused to honor the AD, incorrectly citing a federal requirement that they must provide her nutrition and hydration. However, that assertion was made in error. Medicare (CMS) requires that patient-residents are offered at least three meals per day at regular intervals and are provided help eating, if needed [12]. A patient is not required to consume the food. Misunderstanding the nature of *offer* versus *obligation* leads care facilities and providers to forcefully feed residents against a patient’s explicit written refusal of assistance out of fear that the facility will be issued an immediate jeopardy sanction [13]. Immediate Jeopardy (IJ) occurs when an entity’s noncompliance with one or more Conditions of Participation (CoP) has placed the health and safety of patient-residents at risk for serious injury, serious harm, serious impairment, or death. IJ noncompliance is among the most serious deficiency types and carries significant sanctions for providers and care-providing entities.

We hypothesize that these persistent knowledge gaps and misunderstandings are directly affecting bedside care. There is some evidence that forgoing artificial or assisted hydration in patients with severe dementia is not associated with high levels of discomfort but there is minimal literature measuring the willingness of institutions to accept VSED-AD [14]. Previous studies of provider attitudes have been limited by a focus on hypothetical patient scenarios rather than real-world experiences [15].

This study intends to advance the current body of knowledge by surveying clinical providers about their actual practice experiences. We hypothesize that medical directors and the LTC institutions themselves do not commit to respecting a VSED-AD due to a misinterpretation of relevant federal regulations regarding immediate jeopardy and a misunderstanding of the interplay between federal regulations, state statutes, and case law [16]. The aim of this cross-sectional survey study is to identify and quantify the range of reasons given for (dis) honoring a patient’s VSED-AD, to clarify misinformation, and to offer actionable policy solutions to address the patient care barriers experienced by long-term care providers.

Methods

The survey was designed following a review of the literature and discussion among the research team to rank important topics. Survey responses were anonymous and respondents provided informed consent. The Columbia University Institutional Review Board granted

approval for this study. The survey tool was distributed via email link to the entire membership of The Society for Post-Acute and Long-Term Care Medicine (AMDA) in February 2022. Reminder emails were sent over the subsequent three weeks. Respondents were limited to those with specific professional roles at long-term care facilities based in the United States (Table 1). The survey consisted of a total of 66 questions. Fourteen questions were conditional and were only presented to a respondent based on their answer to a preceding question. Respondents could decline to continue the survey at any point.

Primary Professional Role at LTC (n = 138)		
	%	n
Administrator	3.62	5
Clinical Practitioner	32.6	45
Medical Director	62.3	86
Medical Officer	1.45	2
Owner	0	0
Secondary Professional Role at LTC (n = 138)		
Administrator	0	0
Clinical Practitioner	46.4	64
Medical Director	13.8	19
Medical Officer	6.52	9
Owner	0	0
No Secondary Role	23.9	33
Other	9.42	13
Total Patient-Facing Practitioners at LTC (n = 83)		
0-10	84.3	70
10-25	13.3	11
25-50	2.41	2
>50	0	0

Table 1: Survey Respondent Professional Characteristics.

Results

We received 291 survey responses and 138 respondents proceeded to full questionnaire based on their primary professional role (response rate 7.16%). Respondent characteristics are outlined in Table 1. All respondents are members of AMDA. Additional professional society memberships were reported to the American Geriatrics Society ($n = 50, 36.23\%$), the American Academy of Hospice and Palliative Medicine ($n = 25, 9.16\%$), and the Gerontological Society of America ($n = 6, 2.19\%$). Eighty-four percent practice in some clinical capacity ($n = 116$) while 76.09% ($n = 105$) serve as the medical director in their primary or secondary role. Most work alongside less than 10 patient-facing practitioners at their facility. No facility had greater than 50 patient-facing practitioners.

A diverse range of LTC facility types were represented in the study sample (Table 2). The median bed count was 179 (range 24-500). Municipally owned LTCs ($n = 5, M = 314.00, SD = 185.42$) had on average more beds than non-profit ($n = 47, M = 205.30, SD = 139.73; p = .05$), for-profit ($n = 67, M = 152.61, SD = 90.82; p = .004$), and other facilities ($n = 9, M = 167.89, SD = 146.96; p = .029$). For-profit facilities had fewer beds than non-profit facilities ($p = .021$).

Patient-Resident Population at Intake

CMS is the primary patient insurer at 72.33% ($n = 81$) of LTCs. Additional payer distribution is described in Table 3. A mean of

Facility Type (n = 132)	%	n
Skilled Nursing Facility (SNF)	55.3	73
Full Continuum of Care	25.76	34
Long Term Post-Acute Care	15.015	20
Assisted Living	3.79	5
Independent Living	0	0
Facility Affiliation Structure (n = 132)		
Independent Facility	34.85	46
Regional Chain	37.88	50
National Chain	17.42	23
Other	9.85	13
Funding Structure (n = 132)		
For-profit (publicly traded or privately held)	52.27	69
Non-profit	37.12	49
Municipally-owned	3.79	5
Other	6.82	9
Religious Affiliation (n = 128)		
Faith-based	18.75	24
Secular	76.56	98
Other	4.69	6

Table 2: Facility Demographics.

53.57% of patients enter the LTC with dementia (range 15-100%) while an additional 41% of patients develop a diagnosis of dementia while under the care of the LTC (range 0-98%).

The majority of LTCs (95.69%, $n = 89$) asks a patient or their family about an advance care plan (ACP) at intake or shortly after admission. This is a requirement of the federal Patient Self Determination Act for all healthcare agencies receiving CMS reimbursement [17]. ACPs include ADs, living wills, and other documents specifying care wishes. Fewer than half of facilities (48.05%, $n = 37/77$) discuss oral nutrition and hydration at intake. Fifty-seven percent ($n = 53/93$) of respondents indicated that they or other staff at their facility have made use of CMS Code 99497 to reimburse for services related to voluntary ACP meetings. Sixty percent ($SD = 24.32$, range 5-100) of patients enter the LTC with an ACP document and 9.01% of documents mention VSED. Forty-five percent of respondents ($n = 42/93$) were “familiar” or “very familiar” with VSED, 35.56% ($n = 32$) were “a little” or “somewhat” familiar, and 20.43% ($n = 19$) were not at all familiar.

Bed Type (n = 128)	M	SD	Range
Total Beds	179.34	122.61	24-500
Independent Living	25.55	82.44	0-400
Assisted Living	16.07	42.11	0-349
Memory Care	16.11	28.58	0-150
Skilled Nursing	118.02	84.96	0-500
Primary Payer Distribution (n = 112)			
	%		n
Private pay/long term care insurance	23.21		26
Medicare	33.04		37
Medicaid	39.29		44
Veteran’s Affairs	2.68		3
Indian Health Service	1.79		2

Table 3: LTC Bed Size and Resident Payer Distribution.

Regulation Familiarity

More than half of respondents ($n = 46/82$, 56.10%) reported high levels of familiarity with IJ regulations. Only a small percentage ($n = 8$, 9.76%) reported no familiarity with the CMS regulations. There was no correlation between bed size or faith affiliation and familiarity with IJ regulations. Eighty-one percent ($n = 66/81$) correctly identified that an IJ finding should not be found in cases where a patient declined assisted oral feeding through an AD. Fifty-eight percent ($n = 47$) indicated that an IJ finding was not a concern for honoring a VSED-AD. Twelve respondents (14.81%) indicated that a potential finding of IJ was their primary concern and would stop the implementation of a patient’s request to withhold nutrition or hydration. Approximately one-fifth of respondents ($n = 17/74$; 22.97%) indicated that a regulatory accusation of patient neglect was a significant concern.

More than 91% of respondents ($n = 74/81$) were not familiar with a Ulysses Clause. A Ulysses Clause is a unique provision a patient can incorporate into an AD request for withholding care even when the patient forgets or objects after they have lost decision-making capacity. This clause serves as a prospective self-binding agreement to safeguard the patient’s “authentic” care wishes from future “inauthentic” changes of the mind [18,19].

Staff Trainings and Site Policy

Seventy-one facilities (86.59%) have specific practices or procedures for providing assisted oral feeding to patients with dementia. For-profit facilities were more likely to have institutional policies about IJ specific to assisted oral feeding compared to non-profits ($p = .008$) and other facility types ($p = .039$). Less than one-third ($n = 23/81$, 28.40%) of respondents had ever held or received staff meetings, trainings, or briefings about avoiding IJ in clinical practice. Approximately 70% of respondents ($n = 56/81$) had never had an opportunity to discuss concerns related to a patient who has declined assistance with eating and drinking in relation to a finding of IJ. Insufficient or absent staff training on patient care issues was a commonly reported experience amongst respondents (Table 4).

Does your facility have specific protocols or rules in regards to preventing IJ or responding to suspected instances? (n = 82)	%	n
Yes	67.1	55
No	6.1	5
Unsure	26.8	22
Has your institution held meetings, staff trainings, or briefings about avoiding IJ in clinical practice? (n = 81)		
Yes	28.4	23
No	46.9	38
Unsure	24.7	20
Does your institution provide training on symptom management for patients who decline assisted oral nutrition and hydration? (n = 77)		
Yes, and it is sufficient	29.9	23
Yes, but it is insufficient	24.7	19
No	31.2	24
Unsure	14.3	11
Do your institution’s policies and practices about IJ include guidance on withholding assisted oral feeding? (n = 55)		

Yes	25.5	14
No	32.7	18
Unsure	41.8	23

Table 4: Respondent Familiarity with Policies and Trainings.

Influence of Personal Beliefs on Care Provision

Of the ninety respondents provided more information regarding their personally held convictions about patient and end-of-life care issues, 90% ($n = 81$) agreed with the statement: “Advance directives are useful for protecting patient wishes and values.” Although 73.33% ($n = 66$) felt that respecting a VSED directive fit into their idea of what “care” entails at the end of life, slightly less ($n = 63$) considered VSED to be a viable and an appropriate option for patients at the end-of-life. Fifty-nine respondents (65.56%) would personally feel comfortable with a patient choosing VSED in their facility while fourteen (15.56%) were neither comfortable nor uncomfortable. Support for VSED in patients with dementia increased from 55.56% ($n = 50$) to 72.22% ($n = 65$) if that patient had a VSED-AD. Although 62.22% ($n = 56$) felt their facility could accommodate patient wishes for VSED, one-fifth were unsure ($n = 17$).

Sixty-nine respondents provided information about their own future end-of-life care planning. The majority reported that they personally would be “somewhat” or “very” willing to consider VSED for themselves in the event of terminal illness ($n = 58$, 84.06%) or in the case of late-stage dementia ($n = 56$, 81.16%).

Discussion

Relation to Other Studies

Our findings affirm those of prior research in this field while adding new quantitative data measuring the willingness of LTC practitioners to honor previously expressed treatment wishes by patients, including those with dementia, at the end-of-life. Four-fifths of respondents in this survey reported familiarity with VSED. This is consistent with previously reported rates among providers [20,21].

Regulatory Misinterpretation and Policy Uncertainty

Our survey did not measure the depth or veracity of self-reported familiarity. One respondent who indicated they were “somewhat familiar” with VSED incorrectly stated that: “CMS guidelines will not allow us not to offer food for at least pleasure feedings, so VSED is not an option in a long term care/SNF” [sic, skilled nursing facility]. This response among others supports our hypothesis that providers are misinterpreting the guidance around offering nutrition. Honoring a VSED-AD in clinical practice does not prohibit an LTC from offering a meal to a patient as required by CMS. Although several states limit the withdrawal of oral nutrition and hydration regardless of the wishes expressed in a directive [22] the salient difference is that VSED is not denying, withholding, or withdrawing food or fluid to a patient. Rather, it is honoring a patient-expressed direction to caregivers. VSED represents part of a broader treatment plan whereby a patient can refuse any unwanted intervention. In 1984, a justice of the Supreme Court of the State of New York in Syracuse ruled that a nursing home was not obligated nor empowered to force-feed a competent man who wished to hasten his death with VSED.

This study found that there was a 16% increase in provider support if a patient’s VSED wishes were expressed in an AD. Increased provider comfort with honoring VSED wishes that are expressed and documented when a patient had decision-making capacity suggests that a VSED-AD may be viewed more as an effective legal defense against a claim of IJ or negligence than as a means of protecting patient wishes and values. This confirms the presence of regulatory misinterpretation as VSED is not an IJ deficiency.

For-profit facilities were more likely to have institutional policies about IJ and assisted oral feeding compared to non-profits and other facility types. This is likely due to more elaborate risk management programs in the for-profit sector. Regardless of funding structure, there was widespread confusion among respondents over permissions and a lack of understanding about how to apply facility standards and relevant policies in clinical and bedside practice (Table 4).

Common Themes	Description	Examples [‡]
Fear of regulatory sanction	Respondents indicated a respect for regulatory protocols but expressed a desire for more consistent adjudication. Fear of sanctions can lead to defensive medicine practices that do not benefit patients.	“Less fear of citation from ill-informed regulators”
		“Making sure that the state surveyors understand end of life care. They focus on the rules and not on the patient’s goals of care.”
		“The focus on regulatory compliance and the inclusion of weight loss as a quality indicator makes facilities almost force-feed people.”
		“CMS clarity in differentiating requirements for LTC from end of life care pts [sic, patients].”
More resources and trainings	Respondents indicated a desire for all levels multidisciplinary staff to receive trainings. Care facilities can implement and host targeted trainings and staff briefings on relevant topics.	“More resources for support and engagement for people at the end of life”
		“Training/understanding among RD and RN staff around forced feeding”
		“More ethics guidance that is practical for dealing with staff supports”
		“Improved education of staff on advance directives and maintaining them with patients”
		“There are many facilities that lack trained medical directors, providers, and staff on end of life issues and do not follow advance directives”
		“I see a need for further education for medical and nursing staff in terms of familiarization with principles of palliative and end-of-life care”
		“Too many healthcare professionals, nurses, social workers, administrators and doctors, are not fully competent asking the difficult questions”
“More education is needed in various options that can be offered a family or patient”		

Hospice integration	Respondents indicated a desire for better support services including hospice integration to assist with symptom management.	“Low utilization of hospice and inconsistent training and comfort level of staff are the main problems”
		“Hospice referrals are often too late”
		“Better integration of hospice services”

Table 5: How long-term care providers can help manage end-of-life issues for patients, including those with dementia.

‡ Responses to survey questions: (a) “What would assist your facility in managing end of life issues for those of your patients with dementia?” and (b) “Do you see room for improvement in how end of life care is managed at long term care facilities in general?”

Provider Biases

Respondents were asked about their individual knowledge and views on VSED to specifically understand whether personally held convictions were affecting the implementation of patient ADs. The results show that respondents were more likely to consider VSED an appropriate end-of-life option for themselves than for their patients. There was no statistically significant relationship between personal willingness to consider VSED for oneself and one’s primary professional role, facility type, funding structure, IJ protocol, or prior receipt of IJ trainings. Respondents were comparatively likely to report a willingness to consider VSED for themselves as they were to support their terminally ill patient who chooses VSED (84% vs 78%, $p = 0.23$). There was a significant difference among providers who would support a VSED directive from a patient with dementia compared to one’s own willingness to consider VSED for oneself in the event of late-stage dementia (55% vs 81%, $p = 0.004$).

This suggests the presence of an action-bias paradox in long-term care practices. This bias refers to a general preference for action over inaction even if acting is likely to result in poorer outcomes, and can lead physicians to recommend treatments for their patients that are different from those they would choose for themselves [23,24].

Recommendations

It is imperative to identify, quantify, and address areas of practice uncertainty. Uncertainty about the validity of medical treatment options leads to over diagnosis, overtreatment, and increased costs [25,26]. This is counterintuitive to the goals of geriatric medicine to optimize the care of older people by preserving function and maintaining autonomy as long as possible [27]. Over-action to appease situational uncertainty may appear to provide a safeguard for physicians from litigation, but it does not improve bedside care or patient outcomes.

There have been repeated calls in the literature and in clinical practice for the development of policies and trainings to address LTC patient-residents who present with potential end-of-life care concerns like VSED-AD and symptom management [2, 15, 28]. Our research affirms the need for clear policies and improved staff trainings. Up to 41% of respondents were unaware of their facility’s policy or practice guidance on specific patient-care and end-of-life issues. More than two-thirds reported that their facility did not holding trainings on care topics likes oral nutrition and hydration.

These findings can be translated through a model of preventative ethics into clear, actionable processes to assist LTCs in reducing uncertainty when caring for advanced age or cognitively impaired patients. Research-backed examples of implementable improvements include promoting daily staff huddles to provide updates and address specific case-related concerns, and providing more 1:1 engagement between supervisors and staff [28].

There were common themes that respondents provided (Table 5) when asked where they see room for improvement in how care is managed at their LTCs. Additional qualitative analyses, focus group interviews are planned to further assess, and quantify these responses. Until then, these themes can function as an initial framework to recognize, prioritize, and address systemic gaps in bedside care. Proactively formulating relevant policies helps individual clinicians make good decisions and equips staff with the relevant knowledge, skills, and guidelines to appropriately address future patient care requests or concerns that arise [29].

Limitations

This study had several limitations. First, the response rate was lower than other survey studies of medical directors [30]. Response rates can be limited by office and facility policies to not participate in any surveys [31]. This survey was administered during the third wave peak of the COVID-19 pandemic, which we theorize lowered the response rate as clinical practitioners were navigating increased caseloads. Second, due to the anonymous nature of this survey, we cannot assess whether two providers in separate roles at one facility responded. However, the majority of respondents were medical directors and a facility will have only one medical director. Each IP address could only respond once to the survey tool. We feel the risk for such duplication is minimal. Third, the survey was provided to those with AMDA membership and eligibility was limited based on professional role. The sample is not representative of all providers but rather a sampling of those who, in their primary roles as medical directors and lead administrators, should be most informed of the relevant federal regulations, state statutes, case law, and clinical practices surrounding palliative, hospice, and end-of-life patient care issues. Although survey responses reflect the attitudes of a limited professional society, engagement in a professional society indicates that practitioners are engaged in quality of the care provided to gerontological patients in LTCs.

Conclusion

Our study reflects the knowledge variability among clinical providers at long-term care facility about care measures like VSED and how to honor advance directives. Directives are a beneficial communication tool but they must be properly implemented and upheld. There are common misinterpretations about the relevant federal regulations on assisted feeding and imminent jeopardy concerns [32]. This survey study finds that failures to honor a VSED-AD is often a multi-faceted response which begins with a fear of regulatory sanction and is inaccurately perpetuated due to procedural uncertainty and a lack of training. By characterizing common provider experiences in real-world clinical practice, this research identifies areas for direct and indirect training interventions that can improve palliative and end-of-life patient care in all practice settings.

We suggest various approaches to improve gerontological care, specifically among patients with dementia. Gerontological and

primary care providers must begin discussions early with their patients about nutrition and hydration issues that may arise at the end-of-life so that advance care plans contain actionable and intentional care goals that can be discussed if a patient does enter a long-term care facility.

Care facilities would benefit from integrating the perspectives of relevant stakeholders who hold differing expertise in the fields of ethics, law, and medicine when creating standard operating procedures and policies. This diversity of stakeholder input ensures alignment with both professional and clinical best practice standards during the design and regular review of policies. Staff education and trainings on these topics must be prioritized.

The discrepancies found between medical directors' personal willingness to consider VSED compared to their lack of willingness to allow patients to pursue VSED should invite self-reflection and consideration on why providers hesitate to honor patient wishes regarding care decisions they do not conscientiously object to. Without clear guidance on policy, provider training, and actionable protocols on how to honor patient wishes as expressed in an advance directive, individual doubt and uncertainty will continue to unjustly affect patient care.

Acknowledgment

Conflict of Interest

The authors declare no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

This work was funded by the Columbia University School of Professional Studies FY20 Dean's Applied Research Award and a grant from the Faith Sommerfield Family Foundation Inc.

Sponsor's Role

The sponsors had no role in the design, methods, subject recruitment, data collection, analysis, or preparation of this article.

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