Patient-Physician Communication About Health-Related Quality-of-Life Problems: Are Non-Hodgkin Lymphoma Survivors Willing to Talk?

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Published online ahead of print at www.jco.org on September 23, 2013.

Supported by the California Department of Health Services as part of the statewide cancer reporting program mandated by California Health and Safety Code Section 103885, Contract No. N01-PC-35139 from the National Cancer Institute's Surveillance, Epidemiology, and End Results Program awarded to the University of Southern California, Contract No. N02-PC-15105 awarded to the Public Health Institute (PHI), and Agreement No. U55/CCR921930-02 awarded to the PHI from the Centers for Disease Control and Prevention's National Program of Cancer Registries.

Presented in part at the 5th Biennial Cancer Survivorship Research Conference, Washington DC, June 17-19, 2010, and at the 18th Annual Conference of the International Society for Quality of Life Research, Denver, CO, October 26-29, 2011.

The ideas and opinions expressed herein are those of the authors and endorsement by the California Department of Health Services, the National Cancer Institute, and the Centers for Disease Control and Prevention or their contractors and subcontractors is not intended nor should it be inferred.

Authors' disclosures of potential conflicts of interest and author contributions are found at the end of this article.

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0732-183X/13/3131w-3964w/\$20.00

DOI: 10.1200/JCO.2012.47.6705

ABSTRACT

Purpose

To investigate non-Hodgkin lymphoma (NHL) survivors' willingness to discuss health-related quality-of-life (HRQOL) problems with their follow-up care physician.

Patients and Methods

Willingness to discuss HRQOL problems (physical, daily, emotional, social, and sexual functioning) was examined among 374 NHL survivors, 2 to 5 years postdiagnosis. Survivors were asked if they would bring up HRQOL problems with their physician and indicate reasons why not. Logistic regression models examined the association of patient sociodemographics, clinical characteristics, follow-up care variables, and current HRQOL scores with willingness to discuss HRQOL problems.

Results

Overall, 94%, 82%, 76%, 43%, and 49% of survivors would initiate discussions of physical, daily, emotional, social, and sexual functioning, respectively. Survivors who indicated their physician "always" spent enough time with them or rated their care as "excellent" were more willing to discuss HRQOL problems ($P < .05$). Survivors reporting poorer physical health were less willing to discuss their daily functioning problems ($P < .001$). Men were more willing to discuss sexual problems than women ($P < .001$). One in three survivors cited "nothing can be done" as a reason for not discussing daily functioning problems, and at least one in four cited "this was not their doctor's job" and a preference to "talk to another clinician" as reasons for not discussing emotional, social, and sexual functioning.

Conclusion

NHL survivors' willingness to raise HRQOL problems with their physician varied by HRQOL domain. For some domains, even when survivors were experiencing problems, they may not discuss them. To deliver cancer care for the whole patient, interventions that facilitate survivor-clinician communication about survivors' HRQOL are needed.

J Clin Oncol 31:3964-3970. © 2013 by American Society of Clinical Oncology

INTRODUCTION

Non-Hodgkin lymphoma (NHL) ranks fifth in incidence among all cancers.¹ Individuals diagnosed with aggressive NHL (intermediate or high grade) receive multimodality treatments that can result in severe deficits in their health-related quality of life (HRQOL).² Survivors of aggressive NHL are at risk for experiencing adverse physical and psychosocial sequelae over a period of several years following treatment.^{3,4} Identifying and addressing HRQOL problems experienced by these survivors is an important goal of follow-up care.

Addressing HRQOL problems during follow-up visits depends on effective communication between clinicians and survivors. It is critical for clinicians to gain a detailed understanding from sur-

vivors about their HRQOL. Although there is a large body of literature on patient-physician communication in oncology,⁵⁻⁷ few studies have focused on communication about HRQOL⁸⁻¹³; those that exist predominantly focus on patients receiving curative or palliative treatment. These studies suggest that although clinicians and patients are comfortable discussing physical functioning, both parties are often reluctant to discuss psychosocial problems.^{8,12} The reasons why patients may be reluctant to discuss different HRQOL issues have rarely been assessed. Furthermore, to what extent patients' willingness to discuss HRQOL problems during treatment extends to the post-treatment survivorship phase is unclear.

By using data from a population-based study (Experience of Care and Health Outcomes of Survivors of Non-Hodgkin's Lymphoma; ECHOS-NHL

study), we conducted this analysis to better understand NHL survivors' willingness to discuss problems experienced in multiple HRQOL domains with their follow-up care physician. The following research questions were addressed: To what extent are NHL survivors willing to bring up specific HRQOL problems (physical, daily, emotional, social, and sexual functioning) with their physician? What are the reasons why some survivors may be reluctant to initiate discussion of their HRQOL problems? What sociodemographic, clinical, and follow-up care-related factors are associated with survivors' willingness to discuss HRQOL problems? and Are survivors who experience greater limitations in a particular HRQOL domain more willing to initiate discussion of problems in that domain?

PATIENTS AND METHODS

Study Design

The ECHOS-NHL study identified NHL survivors through the Los Angeles (LA) County Cancer Surveillance Program's Surveillance, Epidemiology, and End Results (SEER) registry. Data were collected between 2003 and 2005 via a cross-sectional patient survey with relevant clinical information also obtained from the registry and medical records. Details on the study design, recruitment methods, measures, and differences between responders and nonresponders are published elsewhere.¹⁴

Survivors were eligible if they were diagnosed with intermediate- or high-grade NHL between June 1, 1998, and August 31, 2001 (2 to 5 years before study enrollment; mean time since diagnosis, 3.6 years); diagnosed as adults (age ≥ 20 years); LA county residents at diagnosis; and not previously diagnosed with NHL. The study protocol was approved by the institutional review board at the University of Southern California.

Of the 744 eligible survivors, we located 563, 408 of whom completed the survey (response rate, 54.8%). Among the 408 respondents, 319 completed the full survey by mail and 89 completed a brief version by telephone. Of the 408 survivors, 374 received follow-up care in the 12 months before the study forming our analytic sample.

Measures

Discussion of HRQOL problems. We adapted items from an existing study¹² to assess NHL survivors' willingness to discuss their HRQOL problems in five domains: physical functioning (symptoms such as pain, shortness of breath), daily functioning (doing regular daily activities), emotional functioning (sadness, anxiety, depression), social functioning (relationships with partner, family members, or close friends), and sexual functioning. For each domain we asked NHL survivors if they were to experience problems, "would you talk about them during a visit with the doctor you see most often for follow-up cancer care?" The 374 survivors who received follow-up care in the past 12 months were provided with three response options: "Yes, I would bring up this issue on my own"; "Yes, but only if my doctor raises the issue"; and "No, preferably not." The latter two groups were then asked to select as many reasons as applicable for not wanting to initiate discussion about their problems. Six patient-, physician-, and system-related factors were assessed; patient factors: (1) "I don't think anything can be done about these problems" and (2) "I'm not comfortable discussing these problems with my doctor"; physician factors: (3) "I don't think my doctor is interested in discussing these problems," (4) "I don't think it is my doctor's job to address these problems," and (5) "I would prefer to talk about these problems with some other doctor or health care professional"; and the system factor: (6) "I don't think my doctor has the time to discuss these problems." For each domain, we created a dichotomous variable that distinguished survivors who were willing to initiate discussion from those who either preferred to talk only if the doctor raised the issue or preferred to not discuss the issue at all.

Sociodemographic, clinical, and follow-up care-related variables. We collected data on survivors' age, sex, race/ethnicity, marital status, education, NHL grade, number of comorbidities (based on a count of 12 medical conditions),¹⁵ current disease status (remission or not), specialty of follow-up care

physician, sex match between the survivor and physician, length of survivor-physician relationship, survivors' perception of the physician spending enough time during visits in the past 12 months (never, sometimes, usually, always),¹⁶ and survivors' rating of the quality of their follow-up care in the past 12 months (poor, fair, good, very good, excellent).¹⁶ Information on NHL grade was obtained from the registry and all other data were self-reports. Self-reported disease status was also validated against medical records.¹⁴

Current HRQOL. To evaluate whether survivors who experienced greater limitations in a given HRQOL domain were more willing to discuss problems in that domain, we identified an indicator of survivors' current HRQOL for each of the five domains. For physical, daily, emotional, and social functioning, we used measures from the Short Form-36 (SF-36v2).^{17,18} For physical and daily functioning, we used the Physical Component Summary (PCS) score; for emotional functioning, we used the Mental Component Summary (MCS) score; and for social functioning, we used the social functioning subscale of the SF-36v2. Scores on the SF-36v2 are standardized on the basis of 1999 US general population norms, with a mean of 50 (standard deviation, 10). To identify survivors experiencing greater HRQOL problems, we dichotomized the PCS, MCS, and social functioning scores at less than 40 (one standard deviation below the mean of the population norm of 50). Problems in sexual functioning were assessed with a single item that asked survivors, "In the past 4 weeks, how big a problem did you consider your sexual functioning to be?"¹⁹ Responses ranged from no problem to very small, small, moderate, and big problem and were dichotomized as "no problem" versus "any problem."

Data Analyses

We used descriptive statistics to report the percentage of survivors who were unwilling to initiate discussion of different HRQOL problems and to identify the reasons for their reluctance. Almost all survivors (94%) were willing to initiate discussion on physical functioning problems; as a result of lack of variability, we did not include discussion about physical functioning as a dependent variable in subsequent models.

We conducted bivariate analyses by using χ^2 statistics to assess the associations of each of the four outcome variables (ie, willingness to discuss daily, emotional, social, and sexual functioning) with the several sociodemographic, clinical, follow-up care, and health status variables described in the Measures section. Given that 6% of the sample was missing data on the specialty of the follow-up care physician, and of those providing data, 92% saw a cancer specialist (oncologist/hematologist), we did not include physician specialty in our models.

The current HRQOL items were not included on the abbreviated telephone survey; thus, we had health status data for 295 of 374 survivors. To maximize use of all available data, we conducted two sets of analyses. First, by using the full analytic sample ($N = 374$), we conducted four logistic regression analyses, one for each of the four HRQOL domains with the sociodemographic, clinical, and follow-up care factors as the independent variables. We next conducted another set of four logistic regression analyses with the subset of survivors who also provided data on current HRQOL ($n = 295$). These models evaluated the association between current HRQOL and willingness to discuss HRQOL problems, adjusting for all sociodemographic, clinical, and follow-up care factors. For each model, we included the one measure of HRQOL most pertinent to discussions regarding that domain. A P value of less than .05 was considered statistically significant; all analyses were conducted by using SAS version 9.1.3 (SAS Institute, Cary, NC).

RESULTS

Sample Characteristics

The sample (Table 1) included a broad range of ages, men and women were equally represented, and almost a fourth were Hispanics. An overwhelming majority had intermediate-grade NHL (90%) or were in remission (91%), and two thirds had at least one comorbidity. More than 75% had known their follow-up care physician for at least 2 years.

Table 1. Patient Sociodemographic, Clinical, and Follow-Up Care Characteristics (N = 374)

Characteristic	No.	%
Sociodemographics		
Age (years)		
< 50	101	27
50-64	115	31
≥ 65	158	42
Sex		
Female	181	48
Male	193	52
Race/ethnicity		
Hispanic	89	24
Non-Hispanic white	250	67
Other	35	9
Marital status		
Married/partnered	240	65
Other	129	35
Education		
High school degree or less	115	31
Some college	120	32
College degree or more	136	37
Clinical characteristics		
NHL grade		
High	38	10
Intermediate	336	90
No. of comorbidities		
≥ 3	72	19
1-2	179	48
0	121	33
Self-reported remission		
No	34	9
Yes	331	91
Follow-up care-related variables		
Physician specialty		
Oncology/hematology	325	92
Primary care/other	27	8
Patient-physician sex match		
No	168	47
Yes	187	53
Length of relationship with physician (years)		
< 2	83	23
≥ 2	278	77
Physician spends enough time during visits		
Never, sometimes, usually	103	29
Always	254	71
Quality of follow-up care rating		
Poor, fair, good	39	11
Very good	89	25
Excellent	233	65

NOTE. Percentages are based on patients with available data. Missing data were less than 2% for sociodemographic and clinical characteristics and ranged from 4% to 6% for follow-up care-related variables.
Abbreviation: NHL, non-Hodgkin lymphoma.

Willingness to Discuss HRQOL Problems

Approximately 94%, 82%, 76%, 43%, and 49% of NHL survivors expressed willingness to initiate discussion of problems with physical, daily, emotional, social, and sexual functioning, respectively (Table 2). Many survivors were not willing to discuss their social (45%) and sexual problems (39%), even if their doctor asked about them.

Reasons for Not Discussing HRQOL Problems

Reasons for survivors' reluctance to bring up HRQOL problems varied by domain (Table 3). For daily functioning, the number one reason was that nothing could be done (36%) followed by a preference to talk to another clinician (22%). The perception that this was not the follow-up care doctor's job and a preference to talk about the problem with another clinician were the top two reasons for not initiating discussion of emotional (24% and 32%, respectively) and social functioning (47% and 28%, respectively) problems. For sexual functioning, the top two reasons were that it was not the doctor's job (30%) and the survivor was not comfortable discussing sexual issues (29%).

Across all four HRQOL domains, for all six reasons, no differences were found between survivors who were willing to discuss problems only if their doctor raised them and those who did not want to discuss them at all ($P > .05$; data not shown).

Correlates of Willingness to Discuss HRQOL Problems

As shown in Table 4, women were less willing than men to bring up sexual problems (odds ratio [OR], 0.35; 95% CI, 0.20 to 0.63). However, the reasons for not bringing up sexual problems did not vary by sex ($P > .05$; data not shown). Survivors who felt that their physician always spent enough time during visits compared with those who did not were more willing to initiate discussion on problems with daily functioning (OR, 2.26; 95% CI, 1.08 to 4.71) and emotional functioning (OR, 2.01; 95% CI, 1.03 to 3.90). Compared with survivors who rated their care as excellent, those who rated their care as good, fair, or poor were less willing to initiate discussion of problems in daily ($P < .05$), emotional ($P < .01$), and social ($P < .01$) functioning.

Survivors with higher PCS scores were more willing to discuss problems with daily activities than survivors with lower scores (OR, 4.88; 95% CI, 2.18 to 10.94; Table 5). The association between experience of problems and willingness to discuss them was not statistically significant for emotional, social, or sexual functioning ($P \geq .05$).

DISCUSSION

This study provides insights into NHL survivors' willingness to discuss HRQOL problems during follow-up care visits. Although an overwhelming majority would discuss physical and daily functioning issues, one-in-four survivors were reluctant to bring up emotional issues and one-in-two would not initiate discussion of social and sexual problems. Similar patterns have been reported by patients undergoing treatment.⁸ This suggests that barriers to communicating important psychosocial problems may persist beyond the treatment phase.

We examined NHL survivors' perceptions of six patient-, physician-, and system-level factors that might influence their willingness to discuss HRQOL problems. With the exception of "lack of interest on the part of the doctor," all factors were endorsed by at least one in four survivors; the salience of the factors, however, varied by HRQOL domain. For example, reluctance to discuss problems in daily functioning was driven by survivors' belief that "nothing can be done." It is unclear whether this belief was a result of unsuccessful prior efforts to improve daily functioning or an underlying assumption that these problems were an expected result of cancer and its treatment that they have to "live with." Given that physicians may be able to refer survivors to appropriate physical rehabilitation services

Table 2. Willingness to Discuss HRQOL Problems With Physician

HRQOL Domain	Yes, I Would Bring Up This Issue on My Own		Yes, But Only if My Doctor Raises the Issue		No, Preferably Not		Total	
	No.	%	No.	%	No.	%	No.	% Missing
Physical functioning	339	93.9	14	3.9	8	2.2	361	3.5
Daily functioning	297	81.6	34	9.3	33	8.8	364	2.7
Emotional functioning	275	75.5	45	12.4	44	12.1	364	2.7
Social functioning	154	42.8	44	12.2	162	45.0	360	3.7
Sexual functioning	162	48.9	41	12.4	128	38.7	331	11.5

Abbreviation: HRQOL, health-related quality of life.

and interventions that are likely to improve their daily functioning,²⁰ the root cause of this belief needs to be identified. This is especially important, given our finding that survivors with lower physical functioning were less willing to discuss their daily function problems.

Physician factors were among the top two reasons for not discussing emotional and social functioning problems. Assumptions about the physician's role ("this is not my doctor's job") was commonly endorsed.²¹ Although current guidelines recommend screening for distress,²²⁻²⁴ physicians vary in their ability to elicit psychosocial information from patients.^{8,12,25,26} If survivors also consider it inappropriate to bring up these issues, important psychosocial problems may go unaddressed. Many survivors also preferred to discuss emotional and social problems with a clinician other than their follow-up care doctor. To what extent this preference is related to their belief that addressing these issues is not their follow-up care doctor's job is unclear.

Our findings also suggested a trend for survivors with lower social functioning scores to be less willing to discuss these issues with their physician ($P = .05$). Brief screening tools such as the National Comprehensive Cancer Network distress thermometer²⁷ may be effective in enabling physicians to overcome this communication barrier by identifying survivors who may need a referral to appropriate clinicians for further assessment and intervention (eg, social worker, clinical psychologist).^{28,29}

Both patient and physician factors were identified as barriers to discussing sexual problems. Similar to findings for emotional and social functioning, many survivors did not consider addressing sexual problems to be their follow-up care doctor's job. In addition, survivors themselves were not comfortable discussing these issues. Existing

studies have reported similar discomfort on the part of clinicians in bringing up this topic.³⁰⁻³³ Although several psychological, behavioral, and pharmacologic interventions exist to effectively treat sexual dysfunction,³⁴ reluctance to communicate on the part of both clinicians and survivors can result in sexual problems remaining unaddressed.

We also found that women were less willing than men to discuss sexual problems. Detmar et al¹² reported a similar reluctance by women to discuss HRQOL problems. Our finding is of concern because female cancer survivors are as likely as men to experience significant sexual dysfunction,³⁴ and they have reported levels of dissatisfaction with their sex lives similar to those of men.¹⁹ Given that more than 25% of NHL survivors preferred to talk to another clinician about their sexual problems, it is possible that female NHL survivors may be discussing sexual functioning concerns with providers other than their follow-up care physician (eg, gynecologists).

A perception that the doctor does not have the time to discuss their problems was endorsed by at least one in five survivors as a reason for not discussing daily, emotional, and social functioning problems. This is consistent with our finding that survivors who perceived that their physician always spent adequate time with them were more willing to discuss their HRQOL problems. Previous studies have shown that discussion of HRQOL issues during oncology visits is less likely to take place when visits are running behind schedule.¹³ At the same time, when oncologists do discuss HRQOL issues with patients, it does not result in longer visits.^{10,13} Whether or not patient perception of adequacy of time spent by the physician is associated with the actual length of the visit or is driven more by the physician's nonverbal behavior of being rushed due to tight schedules is not clear and needs additional study.

Table 3. Reasons for Not Initiating Discussion of HRQOL Problems With Physician

Reasons*	Daily Functioning (%) (n = 67)	Emotional Functioning (%) (n = 89)	Social Functioning (%) (n = 206)	Sexual Functioning (%) (n = 169)
Nothing can be done	36	21	11	16
Prefer to talk to other doctor or health professional	22	32	28	28
Not my doctor's job	13	24	47	30
Doctor doesn't have time	21	23	26	15
Doctor isn't interested	18	19	21	14
Not comfortable discussing	8	14	21	29

NOTE. Only 6% of the sample was unwilling to initiate discussion about physical functioning problems; hence, physical functioning is not included in this table. Abbreviation: HRQOL, health-related quality of life.

*Survivors could endorse as many reasons as applicable, so categories are not mutually exclusive.

Table 4. Factors Significantly Associated With Willingness to Discuss HRQOL Problems With Physician

Factor	Daily Functioning			Emotional Functioning			Social Functioning			Sexual Functioning		
	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
Sex			.40			.82			.31			< .001
Female	1.37	0.66 to 2.83		1.08	0.55 to 2.12		0.75	0.43 to 1.32		0.35*	0.20 to 0.63	
Male	Ref			Ref			Ref			Ref		
Enough time spent with physician			.03			.04			.26			.37
Never, sometimes, usually	Ref			Ref			Ref			Ref		
Always	2.26†	1.08 to 4.71		2.01†	1.03 to 3.90		1.43	0.77 to 2.64		1.33	0.72 to 2.44	
Quality of care			.03			.03			.003			.32
Good, fair, poor	0.32†	0.12 to 0.83		0.28*	0.11 to 0.71		0.17*	0.05 to 0.56		0.48	0.18 to 1.25	
Very good	1.15	0.52 to 2.54		0.65	0.32 to 1.31		0.49†	0.27 to 0.89		0.90	0.49 to 1.64	
Excellent	Ref			Ref			Ref			Ref		

NOTE. The logistic regression models also included the following independent variables: age, race/ethnicity, marital status, education, non-Hodgkin lymphoma grade, number of comorbidities, remission status, survivor-physician sex match, and length of the relationship with physician in years. None of these variables were significantly associated with any of the four outcomes.
Abbreviations: HRQOL, health-related quality of life; OR, odds ratio; Ref, reference.
* $P < .01$.
† $P < .05$.

Given the potential reluctance of both physicians and survivors to raise important psychosocial problems, training focused on HRQOL communication may be warranted for both physicians and patients.^{6,35-38} Existing studies have also demonstrated an association between using standardized HRQOL assessments in clinical practice and improved patient-clinician communication about psychosocial issues.^{10,11,39} Incorporating HRQOL assessments allows for targeted discussions during patient visits, showing no increase in visit length,^{10,39} although it does increase the number of HRQOL topics discussed.³⁹⁻⁴¹ Since HRQOL assessment alone may not result in improvements in HRQOL,⁴² physicians could also be made more aware of resources and solutions available to them to ameliorate their patients' HRQOL problems.⁴³ Survivors in turn might benefit from clarification on the roles and responsibilities of their follow-up care team with respect to different HRQOL domains so they know whether or not they should bring up issues that are bothering them and with whom.

Our findings should be interpreted in light of potential limitations. First, given the cross-sectional study design, causal implications cannot be inferred. Second, although recruitment of NHL survivors from a population-based registry in LA county as opposed to a clinic-based sample improves the representativeness of our findings, these findings may not be generalizable to survivors of other common cancers or to survivors in other parts of the United States. Third, although we assessed survivors' willingness to discuss their HRQOL problems, we did not record actual interactions with physicians. Whether or not willingness to discuss problems is correlated with what actually happens during visits needs additional study. Fourth, our finding that survivors with more severe HRQOL problems may be less likely to discuss them with their physician was unexpected and needs to be replicated in future studies. Finally, given the significant awareness that has been raised about issues faced by cancer survivors since our data were collected in 2003 to 2005,⁴⁴ it is possible

Table 5. Current HRQOL and Willingness to Discuss HRQOL Problems With Physician

Variable	No. of Patients	%	Daily Functioning			Emotional Functioning			Social Functioning			Sexual Functioning		
			OR	95% CI	P	OR	95% CI	P	OR	95% CI	P	OR	95% CI	P
PCS					< .001									
< 40	96	34	Ref											
≥ 40	183	66	4.88	2.18 to 10.94										
MCS								.3						
< 40	54	19				Ref								
≥ 40	225	81				1.56	0.68 to 3.59							
Social functioning											.05			
< 40	70	24							Ref					
≥ 40	222	76							2.01	1.00 to 4.06				
Sexual functioning														.9
Any problem	131	54										Ref		
No problem	112	46										1.04	0.56 to 1.93	

NOTE. All four logistic regression models adjusted for age, sex, race/ethnicity, marital status, education, non-Hodgkin lymphoma grade, number of comorbidities, remission status, survivor-physician sex match, length of the relationship with physician in years, adequacy of time spent with physician, and ratings of quality of care.
Abbreviations: HRQOL, health-related quality of life; MCS, Mental Component Summary; OR, odds ratio; PCS, Physical Component Summary; Ref, reference.

that physicians today are more sensitive to survivors' HRQOL concerns; our findings thus need replication with a more contemporary sample of cancer survivors.

Our study examined NHL survivors' willingness to discuss important psychosocial issues that they are likely to face as they transition from active treatment to post-treatment cancer survivorship. Evaluating reasons that may inhibit survivors from bringing up important health issues during follow-up care visits helps identify barriers to optimizing patient-centered communication. Our findings suggest that unless systematic efforts are made to facilitate better patient-clinician communication, many important HRQOL problems may go unaddressed. This study lays an important foundation for future research focused on optimizing the care for and health outcomes experienced by NHL survivors.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

The author(s) indicated no potential conflicts of interest.

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