

## Perception of Curability Among Advanced Cancer Patients: An International Collaborative Study

SRIRAM YENNURAJALINGAM,<sup>a</sup> LUIS FERNANDO RODRIGUES,<sup>b</sup> OMAR SHAMIEH,<sup>c</sup> COLOMBE TRICOU,<sup>d</sup> MARILÈNE FILBET,<sup>d</sup> KYAW NAING,<sup>e</sup> AKHILESHWARAN RAMASWAMY,<sup>e</sup> PEDRO EMILIO PEREZ-CRUZ,<sup>f</sup> MARY JOCELYN S. BAUTISTA,<sup>g</sup> SOFIA BUNGE,<sup>h</sup> MARY ANN MUCKADEN,<sup>i</sup> VIKASH SEWRAM,<sup>j</sup> SARAH FAKROODEN,<sup>k</sup> ANTONIO NOGUERA-TEJEDOR,<sup>l</sup> SHOBHA S. RAO,<sup>m</sup> DIANE LIU,<sup>n</sup> MINJEONG PARK,<sup>a</sup> JANET L. WILLIAMS,<sup>a</sup> ZHANNI LU,<sup>a</sup> HILDA CANTU,<sup>a</sup> DAVID HUI,<sup>a</sup> SURESH K. REDDY,<sup>a</sup> EDUARDO BRUERA<sup>a</sup>

<sup>a</sup>Department of Palliative Care, Rehabilitation, and Integrative Medicine, The University of Texas MD Anderson Cancer Center; <sup>b</sup>Médico da Unidade de Cuidados Paliativos, Barretos Cancer Hospital, Barretos, Brazil; <sup>c</sup>Palliative Care Department, King Hussein Cancer Center, Amman, Jordan; <sup>d</sup>Centre de soins palliatifs entre Hospitalier de Lyon-Sud, Hospices Civils de Lyon, Lyon, France; <sup>e</sup>HCA Hospice Care, Singapore;

<sup>f</sup>Department of Internal Medicine, School of Medicine, Pontificia Universidad Católica de Chile, Santiago, Chile; <sup>g</sup>Pain Management and Palliative Care Unit Benavides Cancer Institute, Manila, Philippines; <sup>h</sup>Programa Argentino De Medicina, Olavaria, Argentina; <sup>i</sup>Department of Palliative Care Tata Memorial Centre, Mumbai, India; <sup>j</sup>Faculty of Medicine and Health Sciences, University of Stellenbosch, Capetown, South Africa; <sup>k</sup>Highway Hospice, Durban, South Africa; <sup>l</sup>Hospital Centro de Cuidados Laguna, Madrid, Spain; <sup>m</sup>Division of Geriatrics and Palliative Care LBJ Hospital, Houston, TX; <sup>n</sup>Department of Biostatistics, The University of Texas MD Anderson Cancer Center

Disclosures of potential conflicts of interest may be found at the end of this article.

**Key Words.** Perception of curability • Prognostic awareness • Cancer • Palliative care • Decision-making preference

### ABSTRACT

**Background.** There are limited data on illness understanding and perception of cure among advanced cancer patients around the world. The aim of the study was to determine the frequency and factors associated with inaccurate perception of curability among advanced cancer patients receiving palliative care across the globe.

**Materials and Methods.** Secondary analysis of a study to understand the core concepts in end-of-life care among advanced cancer patients receiving palliative care from 11 countries across the world. Advanced cancer patients were surveyed using a Patient Illness Understanding survey and Control Preference Scale. Descriptive statistics and multivariate logistic regression analysis were performed.

**Results.** Fifty-five percent (763/1,390) of patients receiving palliative care inaccurately reported that their cancer is curable. The median age was 58, 55% were female, 59% were married or had a partner, 48% were Catholic, and 35% were college educated. Sixty-

eight percent perceived that the goal of therapy was “to get rid of their cancer,” and 47% perceived themselves as “seriously ill.” Multivariate logistic regression analysis shows that accurate perception of curability was associated with female gender (odds ratio [OR] 0.73,  $p = .027$ ), higher education (OR 0.37,  $p < .0001$ ), unemployment status (OR 0.69,  $p = .02$ ), and being from France (OR 0.26,  $p < .0001$ ) and South Africa (OR 0.52,  $p = .034$ ); inaccurate perception of curability was associated with better Karnofsky performance status (OR 1.02 per point,  $p = .0005$ ), and being from Philippines (OR 15.49,  $p < .0001$ ), Jordan (OR 8.43,  $p < .0001$ ), Brazil (OR 2.17,  $p = .0037$ ), and India (OR 2.47,  $p = .039$ ).

**Conclusion.** Inaccurate perception of curability in advanced cancer patients is 55% and significantly differs by gender, education, performance status, employment status, and country of origin. Further studies are needed to develop strategies to reduce this misperception of curability in advanced cancer patients. *The Oncologist* 2018;23:501–506

**Implications for Practice:** The findings of this study indicate that inaccurate perception of curability among advanced cancer patients is 55%. Inaccurate perception of curability significantly differs by gender, education, performance status, employment status, and country of origin. There is great need to facilitate improved patient–physician communication so as to improve health care outcomes and patient satisfaction.

### INTRODUCTION

In recent years, with advances in cancer treatment, there is a higher frequency of cancer patients living with advanced cancer [1]. High symptom distress and poor quality of life are frequent

in advanced cancer patients [2–6]. However, various issues including patient–physician communication with regard to understanding of illness and perception of curability (UIPC)

Correspondence: Sriram Yennurajalingam M.D., Department of Palliative Care, Rehabilitation Medicine, and Integrative Medicine, Unit 1414, The University of Texas MD Anderson Cancer Center, 1515 Holcombe Blvd., Houston, Texas 77030, USA. Telephone: 713-792-3938; e-mail: syennu@mdanderson.org Received June 6, 2017; accepted for publication September 26, 2017; published Online First on November 20, 2017. <http://dx.doi.org/10.1634/theoncologist.2017-0264>

remain unresolved [4, 7]. These issues could potentially prevent early integration of palliative care [8–10]. Prior studies suggest timely UIPC discussions can potentially improve quality of life and coping, and facilitate patients to make informed decisions and set appropriate priorities with regard to diagnosis, treatment, and end-of-life care [11–14].

Prior studies also suggest that many advanced cancer patients have an inaccurate perception of curability of their cancer [4, 15–18]. However, there are limited studies to evaluate the role of patient characteristics and clinical factors on perception of curability in advanced cancer patients across the world. This is important in the context of provision of cancer care in the global health care environment because many patients are receiving cancer care in places other than their country of origin.

The primary aim of this study was to determine the frequency of perception of curability among advanced cancer patients receiving palliative care across the globe. We also examined the predictive factors associated with inaccurate perception of curability.

## MATERIALS AND METHODS

### Participants

We conducted an international study in advanced cancer patients receiving palliative care from 11 countries across the world to understand how core concepts in end-of-life care such as decisional control preferences and terminal illness understanding differ by country. This present report is a secondary analysis of this study, with a focus on patient understanding of illness and perception of curability [19].

The participating centers included the following: UT MD Anderson Cancer Center, Houston, Texas, U.S.; King Hussein Cancer Center, Amman, Jordan; Benavides Cancer Institute, Manila, Philippines; Hôpitaux Sud Centre Hospitalier Lyon-sud, Lyon, France; HCA Hospice Care, Singapore; Highway Hospice, Durban, Kwazulu-natal, South Africa; Tata Memorial Hospital, Mumbai, India; Hospital De Câncer De Barretos, Barretos, Brazil; LBJ Hospital, Houston, Texas, U.S.; Pontificia Universidad Católica De Chile, Santiago, Chile; Fundación FEMEBA, Buenos Aires, Argentina; and Hospital Centro De Cuidados Laguna, Madrid, Spain. The participating centers were a part of a research collaborative network to advance cancer research.

We received approval from the Institutional Review Board of The University of Texas MD Anderson Cancer Center and collaborating institutions to conduct this study.

Patients were enrolled into the study if they met the following eligibility criteria: (a) diagnoses of advanced cancer (defined as locally recurrent or metastatic incurable cancer); (b) 18 years of age or older; (c) having normal cognitive status as assessed by clinician as per the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition criteria; (d) willing to participate in the study and sign informed consent; and (e) all participants were seen by the palliative care consultation team for at least one visit, and have resided in the study country for at least 5 years.

Regarding data collection, the study principal investigator (PI) and site PIs and their research team had regular teleconferences one to two times a month. The PI also met the

coinvestigators in person to review the protocol and data to ensure data are collected in an accurate manner.

### Measures

Data collection occurred between December 15, 2013, and February 25, 2016. The research coordinator from each study site completed the assessments, after the consent process, by patient interview and review of medical records. The assessments included collection of demographic information including age, gender, race, religion, cancer type, cancer treatment, education, Karnofsky performance status, marital status, and employment status. The research coordinator then supervised the patients' completion of the patient illness understanding (PIU) survey and Control Preference Scale (CPS) questionnaire.

The PIU survey was used to evaluate the patients' level of understanding of their illness and prognosis. This survey has been used in prior studies [4, 20–22] to assess patients' perception of curability, goals of therapy, and health status in various cultures [18].

The CPS questionnaire was used to assess patients' decisional control preferences (DCP) [23, 24]. CPS was commonly used to assess DCP in research settings and has been previously used by our team [25–27]. We used the triadic form (patient-family-physician) of this scale, which assesses the patient's decisional control preferences with respect to family and the physician. The assessment is based on the following question: "In my opinion, decisions about my care should be made by...". Patients had 15 answer options and were instructed to choose 1 option, which was later categorized as a passive, active, or shared decisional control preference.

For this study, the Patient Illness Understanding survey and Control Preference Scale were linguistically validated by bilingual investigators of our team and independent back-translation by bilingual natives to determine semantic and linguistic equivalence between the English and native versions (Spanish, French, Hindi, Portuguese, Arabic, Tagalog, and Zulu).

### Statistical Analysis

Descriptive statistics were used to summarize patient demographic and clinical characteristics, PIU survey items, and CPS items. Univariate/multivariate logistic regression analysis was used to assess the effect of categorical and continuous covariates for the question "My cancer is curable" in the PIU survey. The variables included were age, gender (female vs. male), education (college or advanced degree vs. less), Karnofsky performance status, marital status (married or with partner as reference), religion including Catholicism, Christianity, Islam, Hinduism, Buddhism, others (Catholicism as reference), occupation (working as reference), countries including Argentina, Brazil, Chile, France, India, Singapore, South Africa, Spain, U.S., Philippines, Jordan (with U.S. as reference), and passive decisional control preference. All computations were carried out in SAS 9.3 (SAS Institute Inc., Cary, NC) and R-3.1.1

## RESULTS

Sixty-six percent (1,390/2,094) of advanced cancer patients approached were evaluable. Reasons for exclusion were as follows: (a) Patients declined to consent due to severe symptoms or feeling ill ( $n = 433$ ); lack of time ( $n = 49$ ); lack of interest in research ( $n = 71$ ); and/or lack of interest in the study ( $n = 51$ ).

**Table 1.** Demographics and clinical characteristics

Characteristics	Total (n = 1,390), n (%)	Curability "Yes" (n = 681), n (%)	Curability "No" (n = 709), n (%)	p value
Age (Mean, SD)	58 (14.6)	55 (14.9)	60 (13.8)	<.001
Gender				
Female	761 (54.8)	370 (54.4)	391 (55.1)	.78
Male	628 (45.2)	310 (45.6)	318 (44.9)	
Religion				
Catholic	667 (48.2)	278 (41.0)	389 (55.1)	<.001
Christian/Protestant	250 (18.1)	115 (17.0)	135 (19.1)	
Muslim	138 (10.0)	109 (16.1)	29 (4.1)	
Others	329 (23.8)	176 (26.0)	153 (21.7)	
Marital status				
Married	805 (58.5)	406 (60.2)	399 (56.9)	.21
Single	570 (41.5)	268 (39.8)	302 (43.1)	
Education				
Less than high school	458 (36.3)	230 (37.3)	228 (35.3)	.61
High school	357 (28.3)	167 (27.1)	190 (29.5)	
College & advanced degree	447 (35.4)	220 (35.7)	227 (35.2)	
Country				
Argentina	91 (6.5)	45 (6.6)	46 (6.5)	<.001
Brazil	234 (16.8)	76 (11.2)	158 (22.3)	
Chile	97 (7.0)	39 (5.7)	58 (8.2)	
France	200 (14.4)	46 (6.8)	154 (21.7)	
India	95 (6.8)	72 (10.6)	23 (3.2)	
Jordan	174 (12.5)	146 (21.4)	28 (3.9)	
Philippines	90 (6.5)	84 (12.3)	6 (0.8)	
Singapore	89 (6.4)	46 (6.8)	43 (6.1)	
South Africa	95 (6.8)	28 (4.1)	67 (9.4)	
Spain	50 (3.6)	18 (2.6)	32 (4.5)	
U.S.	175 (12.6)	81 (11.9)	94 (13.3)	
Employment				
Employed	335 (24.1)	171 (25.1)	164 (23.1)	<.001
Unemployed	183 (13.2)	121 (17.8)	62 (8.7)	
Retired	473 (34.0)	190 (27.9)	283 (39.9)	
Other	399 (28.7)	199 (29.2)	200 (28.2)	
Cancer type				
Breast & GYN	326 (28.1)	165 (29.7)	161 (26.6)	.66
GI	280 (24.1)	133 (24.0)	147 (24.3)	
Head, neck & lung	248 (21.4)	116 (20.9)	132 (21.8)	
GU, lymphoma, myeloma & other	307 (26.4)	141 (25.4)	166 (27.4)	
Treatment				
Chemotherapy				
Yes	712 (99.7)	399 (99.8)	313 (99.7)	0.99
No	2 (0.3)	1 (0.3)	1 (0.3)	
Radiation Therapy				
Yes	628 (45.2)	275 (40.4)	353 (49.8)	<.001
No	762 (54.8)	406 (59.6)	356 (50.2)	
Immunotherapy				
Yes	64 (4.6)	27 (4.0)	37 (5.2)	.26
No	1,326 (95.4)	654 (96.0)	672 (94.8)	

(continued)

**Table 1.** (continued)

Characteristics	Total (n = 1,390), n (%)	Curability "Yes" (n = 681), n (%)	Curability "No" (n = 709), n (%)	p value
Surgery				
Yes	580 (41.7)	268 (39.4)	312 (44.0)	.079
No	810 (58.3)	413 (60.6)	397 (56.0)	
Targeted Therapy				
Yes	130 (9.4)	61 (9.0)	69 (9.7)	.62
No	1,260 (90.6)	620 (91.0)	640 (90.3)	
Karnofsky performance				
20	14 (1.0)	8 (1.2)	6 (0.8)	<.001
30	41 (2.9)	16 (2.3)	25 (3.5)	
40	149 (10.7)	60 (8.8)	89 (12.6)	
50	176 (12.7)	76 (11.2)	100 (14.1)	
60	261 (18.8)	116 (17.0)	145 (20.5)	
70	228 (16.4)	94 (13.8)	134 (18.9)	
80	259 (18.6)	139 (20.4)	120 (16.9)	
85	1 (0.1)	1 (0.1)	51 (7.2)	
90	156 (11.2)	105 (15.4)	14 (2.0)	
100	27 (1.9)	13 (1.9)	6 (0.8)	

Abbreviations: GI, gastrointestinal; GU, genitourinary; GYN, gynecologic; SD, standard deviation.

**Table 2.** Predictors of perception of curability in advanced cancer patients

Effect	OR	95% CI	p value
Karnofsky performance status	1.02	1.01–1.02	.0005
Gender	0.73	0.55–0.97	.027
Marital status	1.06	0.8–1.4	.69
Employment status	0.687	0.49–0.96	.026
Argentina <sup>a</sup>	0.87	0.48–1.58	.63
Brazil <sup>a</sup>	2.17	1.29–3.66	.0037
Chile <sup>a</sup>	0.54	0.27–1.07	.076
France <sup>a</sup>	0.26	0.15–0.44	<.0001
India <sup>a</sup>	2.474	1.05–5.84	.039
Singapore <sup>a</sup>	1.31	0.69–2.47	.41
South Africa <sup>a</sup>	0.52	0.29–0.95	.034
Spain <sup>a</sup>	0.58	0.27–1.26	.171
Philippines <sup>a</sup>	15.49	6.15–39.05	<.0001
Jordan <sup>a</sup>	8.43	4.67–15.24	<.0001
Education	0.37	0.26–0.54	<.0001

<sup>a</sup>As compared with U.S.

Abbreviations: CI, confidence interval; OR, odds ratio.

(b) Patient was not able to complete the PIU survey ( $n = 100$ ). The mean age was 58, 55% were female, 59% were married, 48% were Catholic, and 35% were college educated (Table 1). Fifty-five percent (763/1,390) of patients inaccurately reported that their cancer is curable, 68% perceived that the goal of therapy was "to get rid of their cancer," 90% perceived that the goal of therapy was to "help them live longer," and 95% perceived that the goal of therapy was to "make them feel better." Forty-seven percent of patients perceived themselves as "seriously ill."

The frequency of shared (patient prefers to make shared decisions after consulting physician or family), active (patient prefers to make decision by him or herself), and passive DCP (patient prefers physician or family to make decision for him/her) was 33%, 44%, and 23%, respectively. Table 2 shows the results from multivariate logistic regression analysis. Accurate perception of curability was associated with female gender (OR 0.73,  $p = .027$ ), higher education (OR 0.37,  $p < .0001$ ), unemployment status (OR 0.69,  $p = .02$ ), and being from countries such as France (OR 0.26,  $p < .0001$ ) and South Africa (OR 0.52,  $p = .034$ ). Inaccurate perception of curability was associated with better Karnofsky performance status (OR 1.02 per point,  $p = .0005$ ) and being from countries such as Philippines (OR 15.49,  $p < .0001$ ), Jordan (OR 8.43,  $p < .0001$ ), Brazil (OR 2.17,  $p = .0037$ ), and India (OR 2.47,  $p = .039$ ).

Age, marital status, religion, and passive DCP were not significantly associated with perception of curability.

## DISCUSSION

The findings of this study suggest that there is a high frequency of inaccurate perception of curability among advanced cancer patients receiving palliative care (55%). Patients' gender, education, performance status, employment status, and country were significantly associated with inaccurate perception of curability.

Our study is the first to evaluate the perception of curability in a global setting in advanced cancer patients receiving palliative care. The patient population for this study were recruited from 11 countries in 5 different continents [15]. In a previous study by Weeks et al. [4], which was conducted in various cancer centers in the U.S., 69%–81% of advanced lung and colon cancer patients inaccurately reported that chemotherapy was likely to cure their cancer. Craft et al. found 30.4% of 163 advanced cancer patients inaccurately reported that the aim of

treatment was to cure their illness [17]. A study by Pronzato et al. found that 47% (41/87) of advanced cancer patients reported that the aim of cancer treatment was curative [28]. The finding that 55% of patients perceived that the goal of therapy was a cure is in line with these previous reports. This information was particularly surprising given that these results were reported in patients receiving palliative care. Compared with previous studies [18, 29, 30], patients in our study were younger, with approximately equal distribution with regard to gender, marital status, education status, employment status, cancer types, and performance status. Similar to prior studies, we found that perception of curability is more inaccurate in men [16, 21].

The findings of our study are also important because it is the first multicenter, international study to evaluate the role of country (cultural background), religion, and decision-making preferences in patient's perception of curability in advanced cancer patients [18, 29, 30]. In our study, the country of origin was strongly associated with perception of curability, whereas religion and decisional control preference showed no association. These results highlight the need to have a personalized approach to understand the patient's understanding of illness and perception of curability.

Further studies are needed to determine the association between patient information needs, patient report of information provided by their physician, and perceptions of curability. Also, further research is needed to better understand the association between perception of curability among palliative patients and outcomes such as timing of palliative consult, enrollment to hospice, and choice of more aggressive therapies. Because the availability of such services varies according to the countries, our group is unable to conduct analysis of these outcomes for this study. Future studies are needed to investigate the role of checklists, audio, or video decisional aids in improving the misperception of curability. Results from recent studies suggest that perception of curability in palliative care patients can be improved by early access to palliative care [31] and improved patient–physician communication, especially with regard to prognosis and life expectancy [20].

More research is necessary to understand why there was a significant difference among many of the countries with regard to perception of curability. The traditional difference between developed and developing countries does not seem to apply in the case of perception of curability because patients in developing countries such as Philippines, Jordan, Brazil, and India had increased expectation, whereas others such as South Africa, France, Chile, and Argentina had lower expectation (Table 2). More research is needed to understand the role of culture in misperception of curability in palliative care patients, and whether the notion of loss of hope, stigma of cancer, and discussion of nearing death in a given culture seem to factor into this misperception [32–35]. Results of our study showed that after controlling for education and performance status, country remained independently associated with perception of curability, suggesting that the other cultural factors that are not directly related to socioeconomic status may play a role in the perception of curability.

Prior studies suggest that patients' inaccurate perception of curability plays a significant role in the greater use of chemotherapy [4]. However, in our study, we were

unable to find any significant association with greater use of chemotherapy, given that these patients were unlikely to get chemotherapy if they were receiving palliative care in some of these countries. A recent study by Nipp et al. [36] in early advanced lung and colorectal cancer patients found that patients' cancer treatment goal of "to cure my cancer" was significantly associated with better quality of life and less anxiety, suggesting that their misperception could be a coping strategy, which could play a role in the greater use of chemotherapy. However, future well-designed studies should investigate how misperception affects the greater use of chemotherapy.

Our data also suggest that misperception with regard to curability is not a barrier to receiving palliative care, given that we sampled only palliative care recipients. Thus, further studies are needed to investigate how inaccurate perception of the curability of their cancer affects the patient or family member's end-of-life care planning, quality of death, and even possibly bereaved caregiver outcomes.

## CONCLUSION

There is a high frequency of inaccurate perception of curability among advanced cancer patients receiving palliative care (55%). The perception of curability significantly differs by gender, education, performance status, employment status, and country of origin. Integration of supportive/palliative care services can be more complex in these patients. Further studies are needed to develop strategies to reduce this misperception of curability among advanced cancer patients.

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## AUTHOR CONTRIBUTIONS

**Conception/design:** Sriram Yennurajalingam, Eduardo Bruera

**Administrative support:** Sriram Yennurajalingam

**Collection and/or assembly of data:** Sriram Yennurajalingam, Luis Fernando Rodrigues, Omar M. Shamieh, Colombe Tricou, Marilène Filbet, Kyaw Naing, Akhileshwaran Ramaswamy, Pedro Emilio Perez-Cruz, Mary Jocelyn S. Bautista, Sofia Bunge, Mary Ann Muckaden, Vikash Sewram, Sarah Fakrooden, Antonio Noguera-Tejedor, Shobha S. Rao, Diane Liu, Minjeong Park, Janet L. Williams, Zhanni Lu, Hilda Cantu, Eduardo Bruera

**Data analysis and interpretation:** Sriram Yennurajalingam, Diane Liu, Minjeong Park, Eduardo Bruera

**Manuscript writing:** Sriram Yennurajalingam, Luis Fernando Rodrigues, Omar M. Shamieh, Colombe Tricou, Marilène Filbet, Kyaw Naing, Akhileshwaran Ramaswamy, Pedro Emilio Perez-Cruz, Mary Jocelyn S. Bautista, Sofia Bunge, Mary Ann Muckaden, Vikash Sewram, Sarah Fakrooden, Antonio Noguera-Tejedor, Shobha S. Rao, Diane Liu, Minjeong Park, Janet L. Williams, Zhanni Lu, Hilda Cantu, David Hui, Suresh K. Reddy, Eduardo Bruera

**Final approval of manuscript:** Sriram Yennurajalingam, Luis Fernando Rodrigues, Omar M. Shamieh, Colombe Tricou, Marilène Filbet, Kyaw Naing, Akhileshwaran Ramaswamy, Pedro Emilio Perez-Cruz, Mary Jocelyn S. Bautista, Sofia Bunge, Mary Ann Muckaden, Vikash Sewram, Sarah Fakrooden, Antonio Noguera-Tejedor, Shobha S. Rao, Diane Liu, Minjeong Park, Janet L. Williams, Zhanni Lu, Hilda Cantu, David Hui, Suresh K. Reddy, Eduardo Bruera

**Critical revision of the manuscript for important intellectual content:** Sriram Yennurajalingam, Eduardo Bruera

**Obtained Funding:** Sriram Yennurajalingam

**Study Supervision:** Sriram Yennurajalingam

## DISCLOSURES

**Eduardo Bruera:** Helsinn (RF). The other authors indicated no financial relationships.

(C/A) Consulting/advisory relationship; (RF) Research funding; (E) Employment; (ET) Expert testimony; (H) Honoraria received; (OI) Ownership interests; (IP) Intellectual property rights/inventor/patent holder; (SAB) Scientific advisory board



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