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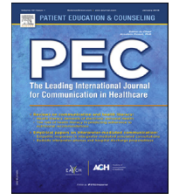
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How well do healthcare professionals know of the priorities of their older patients regarding treatment outcomes?



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ABSTRACT

Objectives: For shared decision making, it is crucial to identify patients' priorities regarding health outcomes. Our aim was to study whether healthcare professionals know these priorities.

Methods: In this cross-sectional study we included older patients who had to make a treatment decision, their general practitioners (GPs) and their medical specialists. Agreement between the patients' main health outcome as prioritised by using the Outcome Prioritization Tool (OPT) and the perception of the same outcome by their healthcare professionals.

Results: Eighty-seven patients were included. Median age was 76 years, 87.4% of patients presented with malignant disease. The majority prioritised maintaining independence (51.7%), followed by extending life (27.6%). The agreement between patients and healthcare professionals was low (GPs 41.7%, kappa 0.067, $p = 0.39$), medical specialists 40.3%, kappa 0.074, $p = 0.33$). Positively related to agreement was patient's age > 75, and a longer relation with their patients (for GPs), and the patient having no partner (for medical specialist). Having a malignant disease, dependent living and functional deficits were negatively related to agreement.

Conclusions: Healthcare professionals have poor perceptions of their patients' priorities.

Practice implications: To realise patient-centered care, it is crucial to discuss priorities explicitly with all patients.

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1. Introduction

Decision-making for older patients comprises a trade-off and weighing the risks and benefits of a specific treatment. There has been increased consensus on the importance of shared decision-making which involves tailoring treatments to the patient's situation and priorities [1]. The manner in which patients are involved in the decision-making process differs, and many patients find it difficult to participate in decision-making, leaving the final decision up to their healthcare professionals [2]. To guide patients in this process of shared decision-making, it is crucial to discuss their priorities regarding treatment outcomes, in order to align the treatment to these priorities. Previous research has shown that many older patients prioritize maintaining independence over extending life [3].

Health care professionals, however, do not always have correct knowledge of their patients' priorities [4–6]. GPs often know their patients for a longer time and therefore have better knowledge of the patients' context than medical specialists do [7,8]. They also play an important role in the management of coexisting chronic diseases. Consequentially, GP's might have better knowledge of their patients' priorities. This study aims to assess to what extent GPs and medical specialists are aware of their patients' priorities regarding health outcomes in the setting of treatment decision-making.

2. Methods

We performed a cross-sectional study among patients of the University Medical Center Groningen (UMCG) (the Netherlands) about to make a treatment decision, and their GPs and medical specialists. The treatment decisions were about starting a treatment (performing surgery, starting radiation therapy, chemotherapy or renal replacement therapy). The UMCG is a tertiary

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center providing complex patient care. The UMCG is also a head and neck center. All patients received a geriatric assessment (GA) during their visit to the outpatient clinic or were referred for a GA to the geriatrics outpatient clinic by their treating medical specialist. Patients were eligible when 1) they had to make a treatment decision and 2) the Outcome Prioritisation Tool (OPT) was used in the GA to assess patients' priorities. The decision-making process could be regarding a treatment for a malignant or benign disease or for renal replacement therapy.

The OPT (Fig. 1) is an instrument to assess patients' priorities regarding health outcomes. Patients are invited to prioritise between four universal health outcomes: extending life, maintaining independence, reducing or eliminating pain and reducing or eliminating other symptoms. During an OPT-guided conversation, patients value (0–100) and prioritise the different outcomes [9,10]. The outcome with the highest value is defined as the most important goal for this patient [9,10]. In this study the OPT guided conversations were performed by either a trained nurse or a geriatrician.

The GP and the treating medical specialist (or resident) of each patient were contacted by phone and/or e-mail to provide their assumptions of their patient's priorities, as soon as possible after the OPT guided conversation had taken place. They did so by ranking the four goals of the OPT according to their assumption of their patient's priorities by placing them in order from 1 to 4 (1 for what they thought was the patients most important health

outcome). The healthcare professionals were blinded to the OPT scores of the patients. Furthermore, the healthcare professionals answered a questionnaire regarding their demographic characteristics, work experience and the duration of their relation with the patient.

Patients received a GA to support treatment decision-making, during which the OPT guided-conversation was performed. During the GA, information regarding four geriatric domains was assessed: somatic, social, psychological and functional. For the somatic domain, comorbidity was rated using the Charlson Comorbidity Index [11]. For the social domain, marital status, living situation and level of education were assessed. Independent living was defined as living without professional help. Level of education was classified using the Dutch classification system, according to Verhage [12]. Lower numbers reflect a lower level of education with a range of 1–7. For the analyses, level of education was dichotomised into low versus intermediate/high. For the psychological domain, cognition was assessed by using the 6 item Cognitive Impairment Test (6CIT), Mini Mental State Examination (MMSE) or Montreal Cognitive Assessment (MOCA [13–15] 'Cognitive deficits' was defined as a 6CIT score of 10 or higher, a MMSE score of less than 24 or a MOCA score of less than 26. For the functional domain, activities of daily living (ADL) and instrumental activities of daily living (iADL) were assessed. This could be either by the Katz Activities of Daily Living, the Lawton Instrumental Activities of Daily Living or the KATZ 15; a combined test of ADL and iADL. These measures were combined to a 'functional deficits' variable, with 'deficits' defined as 1 or more points on the combined score of ADL and iADL [16]. The Groningen Frailty Index was used as a frailty screener, with a score of >4 considered as frail. [17].

Data were collected from 1 July 2019 to 1 January 2020. Consecutive patients were approached following the GA to inform them about the study and to obtain written informed consent. The prioritisation of health outcomes using the OPT was extracted from their medical record. For each patient the GP and treating medical specialist were approached. Patients were excluded if both their GP and their medical specialist refused to participate or failed to respond.

The study was conducted in accordance with the Declaration of Helsinki and Good Clinical Practice Guidelines. According to the Institutional Review Board of the UMCG, no approval was needed, as this non-invasive study was not subject to the Dutch Medical Research Involving Human Subjects Act.

Based on the disagreement proportion of 0.65 in former research [4], an alpha of 0.05 and a beta of 0.20, we calculated our required sample size to be 87 patients [18]. Characteristics of both patients and healthcare professionals were described. Agreement on the most important outcome for both GP and patient and for medical specialist and patient was calculated both absolute and using Cohen's kappa. A kappa value ≤ 0 indicates no agreement, 0.01–0.20 none to slight agreement, 0.21–0.40 fair, 0.41–0.60 moderate, 0.61–0.80 substantial and 0.81–1.00 indicates almost perfect agreement. Furthermore, we calculated healthcare professionals agreement, which we defined as the percentage of cases for which at least one of the healthcare professionals prioritised the same health outcome as the patient, and agreement between general practitioner and medical specialist. To explore the correlations between patient and healthcare professional characteristics and agreement, univariate logistic regression analysis were performed. We considered variables with an OR > 1.5 or <0.6 or a p value <0.05 as possibly related to agreement. Data analysis was performed using the software package IBM SPSS Statistics, version 23.0 for Windows (SPSS, Inc., Chicago, IL, USA).

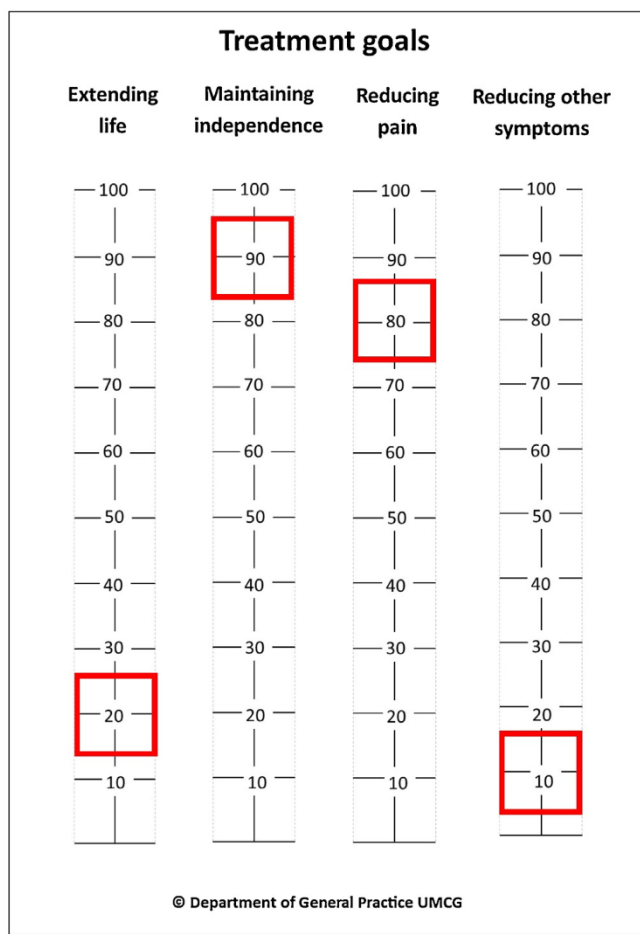


Fig. 1. Example of the Outcome Prioritisation Tool. Note that in this example of the Outcome Prioritisation Tool, the most important goal for this patient was to maintain independence.

3. Results

During the study period, 105 consecutive patients were asked to participate, of whom 2 refused and 14 were excluded because they did not have an OPT-guided conversation. For 2 patients, neither healthcare professionals participated, leaving 87 patients for analysis. For 15 of these patients the GP did not participate and for 10 patients the medical specialist did not participate. The median age of the patients was 76 years (IQR 72–80), and 87.4% of patients presented with a malignant disease, of which most had a head and neck (25.0%) or colorectal malignancy (11.8%). Of the 11 patients with a non-malignant disease, most presented with end stage renal disease (n = 7, 63.3%). Regarding comorbidities, the median CCI was 6 (IQR 5–8). Most patients (83.3%) lived independently and had a partner (67.4%). The majority (72.5%) had a low level of education. Cognitive deficits were present in 15.5%, and functional deficits in 47.4% patients. Frailty, based on the GFI was present in 14.6% (Table 1).

Sixty-eight GPs were involved; in 4 instances GPs were involved in the care of 2 different patients from the sample. The median age of the GPs was 50 years (IQR 43–59.75) and 57.4% were male (Table 2). Thirty-eight medical specialists, of whom 10 were residents, were involved; 17 were involved in the care of 2 or more patients from the sample. The median age of the medical specialists (or residents) was 39 years (IQR 33.5–48) and 71.1%

were male. GPs usually had a longer relation with their patients than did the medical specialists (GPs median 11 years (IQR 5–18.5), medical specialists median 7 days (IQR 1–28)).

The majority of the patients prioritised maintaining independence (51.7%) as their main health outcome, this was followed by extending life (27.6%), reducing or eliminating pain (13.8%), and reducing or eliminating other symptoms (6.9%). GPs rated maintaining independence the most important goal for 52.8% of the patients, medical specialists did so for 45.5%. Tables 3a and 3b show the estimation of the GP and medical specialist of the patients main prioritized health outcome, compared to the actual main health outcome of the patient. Agreement between the GP and the patient (n = 72) was 41.7%, with a kappa of 0.067 (p = 0.39). The absolute agreement between the medical specialist and the patient (n = 77) was 40.3%, with a kappa of 0.074 (p = 0.33). In 51.7% of the cases, at least one healthcare professional agreed with the patient. In 53.2% of the cases, the GP and medical specialist prioritised the same goal for the patient (Table 4).

Table 5 shows the results of the explorative analysis between patient characteristics and agreement. For agreement between GPs and their patients, patients age > 75 years (OR 3.03; 95% CI 1.10–8.31) was significantly predictive of agreement and also a longer relationship was positively related (OR 1.54; 95% CI 0.47–5.13). Having functional deficits (OR 0.34; 95% CI 0.12–0.96) was associated with a lower risk of agreement.

Table 1
Baseline characteristics and geriatric assessment (n = 87).

Variable		N (%) ^a
BASELINE CHARACTERISTICS		
Age	<75	36 (41.4)
	>75	51 (58.6)
Gender	Male	45 (51.7)
	Female	42 (48.3)
Diagnosis	Malignant	76 (87.4)
	Tumor site	
	Head and Neck ^b	26 (34.2)
	Colorectal	9 (11.8)
	Upper gastrointestinal	8 (10.5)
	Sarcoma	7 (9.2)
	Breast	7 (9.2)
	Melanoma	6 (7.9)
	Other ^c	14 (17.1)
	Tumor stage	
	I-II	23 (30.3)
	III-IV	24 (31.6)
	No (full) staging available ^d	29 (38.2)
	Benign	11 (12.6)
	Type of disease	
	End stage renal disease	7 (63.3)
	Other ^e	4 (36.4)
GERIATRIC DOMAINS		
Somatic	Comorbidity	CCI ^f > 6
Social	Marital status (n = 86)	No partner
	Living situation (n = 78)	Dependent ^g
	Level of education ^h (n = 51)	Low ⁱ
Psychological	Cognitive deficits (n = 86)	Score of MMSE ^j , MOCA ^k or 6CIT ^l under norm (n = 86)
Functional	Functional deficits (n = 79) ^m	Sum ADL ⁿ + IADL ^o > 1
FRAILTY		
Frailty screening	Groningen Frailty Indicator (n = 48)	GFI > 4

a = all variables are n(%) unless otherwise specified, b = oral cavity (n = 13), squamous cell carcinoma (n = 6), salivary gland (n = 3), oropharyngeal (n = 2), laryngeal (n = 1), basal cell carcinoma (n = 1), c = gynecological, hepatobiliary, thyroid cancer, non-melanoma skin cancer, d = no (full) staging available in the patients file at the time of inclusion, e = chronic otomastoiditis, herniation, paresis of the recurrent nervus, thyroid struma, f = Charlson Comorbidity Index, g = Dependent: living at home with home care or living in a care facility, h = Verhage: level of education according to Verhage: higher number is higher level of education, range 0–7, i = low = Verhage 0–4, j = MMSE: Mini mental State Examination, k = MOCA: Montreal Cognitive Assessment, l = 6-CIT: 6-item Cognitive Assessment Test, m = Functional deficits measured by either the KATZ ADL and Lawton IADL or by the KATZ-15, a combined measure of ADL and IADL, n = ADL: Activities of Daily Living, o = IADL: Instrumental Activities of Daily Living.

Table 2
 Characteristics of health care professionals (GP or GP in training, medical specialist or nurse specialist or medical specialist in training (resident)).

Variable		GP ^a n = 68	Medical specialist n = 38
Age (median, IQR)		50 (43–59.75)	39 (33.5–48)
Gender	Female	29 (42.6)	11 (28.9)
	Male	39 (57.4)	27 (71.1)
Health care profession	Medical specialist		25 (65.8)
	Resident		10 (26.3)
	Nurse specialist		3 (7.9)
Specialism	GP	68 (100)	
	Surgery ^c		22 (57.9)
	Gynaecology ^d		3 (7.9)
	Head and Neck ^e		10 (26.3)
	Nephrology		3 (7.9)
Time (years) since completion of training	Median (IQR)	18.5 (9.25–25.5)	10 (5–17) ^b
Place of practice (GP)	Rural ^f	33 (47.1)	
	Semi urban ^g	27 (39.7)	
	Urban ^h	9 (13.2)	
Time relation (days) ⁱ	Median (IQR)	na	7 (1–28)
Time relation (years) ^j	Median (IQR)	11 (5–18.5)	na
Number of patients per specialist	1	64 (94.1)	21 (55.3)
	2	4 (5.9)	8 (21.1)
	>2	0 (0)	9 (23.7)

All variables are n(%) unless otherwise specified.

^a =GP: general practitioner.

^b =years since completion of training for medical specialists and nurse specialists, not for residents.

^c =including general surgery, abdominal surgery, hepatobiliary surgery, oncological surgery.

^d =including general gynaecology and oncological gynaecology.

^e =including general ear nose throat, oncological ear nose throat, dental surgery.

^f =<10.000 inhabitants.

^g =10.000–100.000 inhabitants.

^h =>100.000 inhabitants.

ⁱ =time relation in days between the patient and the health care professional.

^j =time relation in years (GP and patient).

Table 3a
 Patients' (rows) priority and the GP's (columns) estimation of the patients' prioritized health outcome.

Patients priority	GP's estimation of the patient's priority				Total
	Extending life	Maintaining Independence	Reducing pain	Reducing other symptoms	
Extending life	4 (22.2)	8 (44.4)	3 (16.7)	3 (16.7)	18 (25.0)
Maintaining independence	9 (22.5)	23 (57.5)	7 (17.5)	1 (2.5)	40 (55.6)
Reducing pain	0 (0)	5 (50)	3 (30)	2 (20)	10 (13.9)
Reducing other symptoms	2 (50)	2 (50)	0	0	4 (5.6)
Total	15 (20.8)	38 (52.8)	13 (18.1)	6 (8.3)	72 (100)

All values are noted as n (%). GP: general practitioner.

Table 3b
 Patients' (rows) priority and the medical specialists (columns) estimation of the patients' prioritized health outcome.

Patients priority	Medical specialists estimation of the patient's priority				Total
	Extending life	Maintaining Independence	Reducing pain	Reducing other symptoms	
Extending life	6 (26.1)	14 (60.9)	2 (8.7)	1 (4.3)	23 (29.9)
Maintaining independence	17 (42.5)	17 (42.5)	5 (12.5)	1 (2.5)	40 (51.9)
Reducing pain	1 (10)	2 (20)	6 (60)	1 (10)	10 (13.0)
Reducing other symptoms	0 (0)	2 (50)	0 (0)	2 (50)	4 (5.2)
Total	24 (31.2)	35 (45.5)	13 (16.9)	5 (6.5)	77 (100)

All values are noted as n (%).

Table 4
 Level of agreement between the patient and the healthcare provider on the most important health outcome.

AGREEMENT	Patient (n = 87)	GP ^a (n = 72)	Medical specialist (n = 77)
Agreement patient – healthcare provider	Absolute agreement (%)	30 (41.7)	31 (40.3)
	Kappa	0.067 (p = 0.39)	0.074 (p = 0.33)
Agreement patient – both HCPs ^b together	Absolute agreement (%)	45 (51.7)	
	Kappa	0.230 (p = 0.001)	
Agreement specialist and GP ^a (n = 62)	Absolute agreement (%)	33 (53.2)	
	Kappa	0.292 (p < 0.001)	

All values are noted as n (%) unless otherwise specified.

^a =GP: general practitioner.

^b =HCP: health care providers.

Table 5

Univariable analysis of predictive variables for agreement between patient and GP or patient and medical specialist on the patient's main health outcome. All analyses are given group compared to the (opposite) reference group.

		Pat-GP ^a agreement OR (95% CI)	Pat-specialist agreement OR (95% CI)
PATIENT CHARACTERISTICS			
Baseline characteristics			
Age	>75	3.03 (1.10–8.31)^b	1.67 (0.65–4.25) ^c
Gender	Male	0.75 (0.29–1.92)	1.45 (0.58–3.61)
Diagnosis	Malignant	1.22 (0.27–5.53)	0.50 (0.12–2.01)
Tumor stage	III-IV	1.05 (0.28–3.92)	0.54 (0.16–1.83)
Geriatric assessment			
SOMATIC			
Comorbidity (CCI ^d)	>6	0.73 (0.28–1.90)	0.98 (0.39–2.50)
SOCIAL			
Marital status	No partner	0.81 (0.30–2.22)	2.88 (1.06–7.81)
Living arrangements	Dependent	0.28 (0.06–1.43)	0.80 (0.21–3.03)
Education level	Low	0.89 (0.23–3.46)	0.68 (0.18–2.60)
PSYCHOLOGICAL			
Cognitive deficits ^e	yes	0.61 (0.14–2.68)	0.76 (0.20–2.87)
FUNCTIONAL			
Functional deficits ^f	yes	0.34 (0.12–0.96)	0.71 (0.27–1.88)
FRAILITY			
GFI ^g	>4	0.88 (0.34–2.24)	1.21 (0.49–3.03)
HEALTH CARE PROFESSIONAL CHARACTERISTICS			
Time relation	> 3 years	1.54 (0.47–5.13)	NA
	> 7 days	NA	0.80 (0.34–2.05)

^a =GP: General Practitioner, b = bold: statistical significant difference.

^c =Italic: OR > 1.5 or <0.6.

^d =CCI: Charlson Comorbidity Index.

^e =Cognitive deficits: either a 6-CIT >10, MMSE < 24 or MOCA < 26).

^f =functional deficits: dependency in 1 or more items on a combination of ADL and IADL).

^g =GFI: Groningen Frailty Indicator. NA: not applicable.

4. Discussion and conclusion

4.1. Discussion

This study showed that there was poor agreement between patients and healthcare providers regarding health outcome priorities; both GPs and medical specialists had poor perception of the priorities of frail and/or older patients about to make a treatment decision. Because GPs often know their patients for a longer time and have better knowledge of the patients' context, we had expected a better agreement between patients and their GPs. A longer relation with the patient did have a tendency to better agreement for GPs, suggesting there might indeed be a continuity of care effect. Unfortunately, we do not have data on the frequency of contacts or the quality of the relation as perceived by patient or GP. Agreement for both GP and medical specialist was better with older patients. This might be explained by the fact that healthcare professionals can imagine maintaining independence more easily as most important healthcare outcome for a patient with advanced age. In this study the main health outcome prioritised by the patients was maintaining independence, followed by extending life. These results are in line with previous studies regarding health outcome prioritization in older patients [19,20].

As far as we know, this is the first study that explored whether both GPs and medical specialists have correct knowledge of patients priorities. There is one previous study that explored the agreement between medical specialists and patients using the OPT, but GPs were not included [4]. In this study nephrologists' perceptions about patients' priorities were correct 35% of the time, which is in the same order of magnitude as we found in our study. Healthcare professionals often assume that they know what patients find important, but studies have shown discordance of goals between patients and healthcare professionals in different settings [21–23]. This discordance could be due to several issues.

For one, older patients sometimes perceive barriers to expressing their goals and preferences and engage in the decision-making process, such as feeling rushed, or not being able to express their wishes properly. Or they believe that their healthcare professional already has knowledge regarding their values [24]. Incorrect expectations regarding treatment outcomes might influence the expression of goals and preferences as well and patients' goals might change in the face of complex treatment decision [25]. Healthcare professionals can also find it difficult to discuss goals with their patients [26].

There are several limitations to this study. Since the geriatric assessment was part of the decision-making process, it might be possible that some medical specialists learned about the patients' priorities before providing their estimation of these priorities. Another limitation is that participation in this study might have led to increased awareness among participating healthcare professionals and therefore to asking the patients about their priorities more explicitly. However, in both cases the possible bias would lead to an overestimation of agreement, which could in reality then be even poorer than we showed. Furthermore, there was a selection of older and more frail patients, due to the fact that the OPT was used as part of a GA.

Patient-centered care involves aligning treatment decisions with the patients' priorities. Especially for decisions where important trade-offs are at stake, eliciting and these priorities is highly relevant for optimal shared decision-making [27]. Since preference misdiagnoses are frequent, it is crucial to explicitly discuss priorities. This can, however, be difficult for both patients and healthcare professionals. Using a decision aid might facilitate this conversation. The OPT is a decision support that uses universal health outcomes. The tool can structure the goal-setting conversation, enabling patients to elicit their priorities and healthcare professionals to align treatment with these priorities. Future studies should investigate whether this leads to improved health outcomes from the patients point of view.

5. Conclusion

Healthcare professionals have poor knowledge of their patients priorities regarding health outcomes.

Practice implications

Structurally discussion patients' priorities, possibly by using a decision aid, might improve alignment of treatments to these priorities and improve patient centered care.

Author contribution statement

All authors meet the criteria for authorship as stated in the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, as well as their contributions to the manuscript.

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Analysis and interpretation of data: S. Festen, M.E. Stegmann, A. Prins, P. de Graeff, D. Brandenburg

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Critical revision of the manuscript for important intellectual content: S. Festen, M.E. Stegmann, A. Prins, B.C. van Munster, B.L. van Leeuwen, G.B. Halmos, P. de Graeff, D. Brandenburg

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Declaration of Competing Interest

The authors report no declarations of interest.

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