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ORIGINAL ARTICLE

# Factors associated with a preference for disclosure of life expectancy information from physicians: a cross-sectional survey of cancer patients undergoing radiation therapy

**Megumi Uchida**[1,2] · **Chikao Sugie**[3] · **Michio Yoshimura**[4] · **Eiji Suzuki**[5] · **Yuta Shibamoto**[3] · **Masahiro Hiraoka**[4] · **Tatsuo Akechi**[1,2]

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## Abstract

**Purpose** This study aimed to investigate experiences and preferences for disclosure of life expectancy, agreement between them, and the factors associated with preferences for disclosure of life expectancy with physicians among cancer patients undergoing radiation therapy.

**Methods** Cancer patients aged 20 years or older were consecutively sampled when they started radiation therapy at two university hospitals. Patients completed self-administered questionnaires concerning their experiences of and preferences for disclosure of life expectancy, treatment decision-making, psychological distress, physical symptoms, sociodemographic and medical factors, physician's communication style, and provision of psychological, physical, and practical support.

**Results** Among the 226 respondents (response rate: 58%) who responded, 54% experienced disclosure of life expectancy, and 45% preferred it. The agreement is 65%. Eighty-five percent recognized their aim of radiation therapy as curative. A univariate analysis indicated that having a full/part-time job and wishing to leave treatment decisions to doctors were significantly associated with preference for disclosure of life expectancy, but psychological distress was not. A multiple regression analysis revealed that having a full-time/part-time job was significantly associated with preference of communication about life expectancy.

**Conclusions** Fifty-four percent of the patients experienced and 45% of the patients preferred disclosure of life expectancy. The agreement is moderate. Our results show that there was a significant association between employment status and patient's preference for disclosure of life expectancy with physicians. Communication of prognosis is difficult but whether a patient continues to work or not may be an indicator of preference.

**Keywords** Life expectancy · Prognosis · Radiation therapy · Doctor-patient communication · Cancer

## Introduction

With advancements in cancer treatment and improvements in cancer outcomes, patients have increasing needs for accurate information about their diagnosis and prognosis [18, 26]. However, medical staff often underestimate patients' interest in or desire for this information [36], and patients report receiving less information about prognosis than desired [19]. Communication about prognosis may help cancer patients and their families select appropriate treatments and prepare for their future [32, 35]. However, in some cases, patients would prefer not to know their prognosis, a position supported by clinical concerns that the provision of such information may diminish hope and worsen patients' psychological distress [1, 12]. There is a need to explore factors associated with patients' preferences for information about their prognosis.

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✉ Megumi Uchida
ucmegumi@na.rim.or.jp

[1] Division of Palliative Care and Psycho-Oncology, Nagoya City University Hospital, Nagoya, Japan

[2] Department of Psychiatry and Cognitive-Behavioral Medicine, Nagoya City University, Graduate School of Medical Sciences, Mizuho-cho, Mizuho-ku, Nagoya, Aichi 467-8601, Japan

[3] Department of Radiology, Nagoya City University Graduate School of Medical Sciences, Nagoya, Japan

[4] Department of Radiation Oncology and Image-Applied Therapy, Kyoto University Graduate, School of Medicine, Kyoto, Japan

[5] Department of Breast Surgery, Kyoto University Graduate School of Medicine, Kyoto, Japan

Few studies of patients with cancer have investigated patients' experiences of discussions about life expectancy, particularly those undergoing curative treatment [5, 14, 30, 31]. Patients' preferences regarding disclosure of their life expectancy are influenced by their disease stage (early/advanced or terminal) and the study region (Western or Eastern) [5, 9–11, 13, 15, 22, 30, 31]. Additionally, few studies have assessed agreement between the reported preferences and experiences of communication about life expectancy among patients with cancer [19, 25, 30]. The number of studies that have examined factors associated with preferences of communication about life expectancy is limited, and the results are unclear. Furthermore, previous studies focused not on physician-related factors but mainly on patient-related factors [10, 11, 13].

Therefore, we investigated the experiences and preferences of communication about estimated life expectancy and assessed both patient- and physician-related factors associated with patients' preferences of communication about life expectancy, covering those with good estimated prognoses. We targeted patients with cancer undergoing radiation therapy to elucidate the changes in preferences of communication about life expectancy according to the timing of both curative and palliative treatment.

The aim of this study was to investigate the following among cancer patients undergoing curative/palliative radiation therapy: (1) the percentage of cancer patients experiences of life expectancy discussions, (2) the percentage of patients who wanted to discuss information about life expectancy with physicians, (3) agreement between patients' reported preferences and experiences of communication about life expectancy, and (4) the factors associated with a preference to discuss life expectancy.

## Materials and methods

### Design

A cross-sectional survey is done of cancer patients undergoing radiation therapy.

### Ethics approvals

The study protocol was approved by the Institutional Review Board and Ethics Committee of Nagoya City University Graduate School of Medical Sciences and Kyoto University Hospital. It was conducted in accordance with the principles of the Declaration of Helsinki. Written consent was obtained from each patient after the study was explained to them.

### Participants

The study participants were ambulatory patients with cancer who were undergoing radiation therapy at Nagoya City University Hospital or Kyoto University Hospital between August 2012 and February 2014. The patients were sampled consecutively when they started their radiation therapy. The eligibility criteria for inclusion in this study were as follows: (1) an awareness of the cancer diagnosis, (2) an age of 20 years or older, and (3) a general condition that enabled completion of the questionnaire. The exclusion criteria were the following: (1) patients whom attending physicians recognized as unable to complete the questionnaire and (2) patients who did not understand the Japanese language.

### Procedure

After obtaining informed consent, a research assistant asked patients to complete the self-administered questionnaires (described below) at home and return them within 2 weeks. When questions were answered inadequately, clarifications were sought via telephone follow-up.

### Measures

#### Experiences and preferences of communication about life expectancy

Due to the sensitive nature of the life expectancy theme, participants were given the option to skip this section of the survey [25]. Participants were asked to select a single response option when answering the following investigator derived questions. Patients' preferences for life expectancy disclosure were assessed by the question: "Would you like information from your doctor about your life expectancy (Yes; No)?"

#### Hospital Anxiety and Depression Scale (HADS)

The HADS is used to detect the state of depression and anxiety in medically ill patients, and questions about physical symptoms are excluded. This scale is composed of a self-reported questionnaire consisting of 14 items, and subjects rate how they felt during the previous week with a four-point Likert scale. The HADS consists of anxiety and depression subscales (0–21 points each), and the total score can range from 0 to 42. Higher scores indicate more severe depression and anxiety [21, 37]. The Japanese version of the HADS has been validated for cancer populations [21]. The optimal screening cut-off point for major depressive disorder is 19/20.

### MD Anderson Symptom Inventory (MDASI)

The MDASI is a self-administered questionnaire used to assess symptom intensity. It is composed of 13 symptom items and 6 interference items. Each symptom is rated at its worst level in the last 24 h on an 11-point numerical scale ranging from 0 (not at all) to 10 (as bad as you can imagine) [7]. The validity and reliability of the Japanese version of the MDASI is well established [29]. We used average score of 13 symptom items in this study. We applied a cut-off point of 3/4 for these symptoms [24].

### Quality of Patient-Centered Cancer Care measure (QPCCC)

The original QPCCC is a 48-item self-administered questionnaire that is used to assess survivors' perceptions of waiting times and overall cancer care at the hospital where most treatment was received [33]. This questionnaire was developed in English, and then translated into Japanese using the forward-backward translation method. We modified this to fit Japanese clinical situation and Japanese version is composed of 46 items. The response options are presented on a 4-point scale (strongly disagree = 1, disagree = 2, agree = 3, and strongly agree = 4). The validity of the QPCCC is well established [33]. The face validity of the Japanese version was confirmed in a pilot study. Five items from this questionnaire were used to assess the physician's communication style ("the staff showed respect for me," "the staff at the hospital talked to me in a way I could understand," "the doctors at the hospital explained all the treatments I could undergo," "the doctor at the hospital explained the consequences of not undergoing treatment," and "the doctors at the hospital explained how each treatment option may affect my length of life"), and 7 items to assess the provision of physical/psychological/practical support ("the staff at the hospital attended promptly to my pain or discomfort during my treatment," "the staff at the hospital helped me to deal with being worried, upset, or sad," "the staff at the hospital helped me to deal with my spiritual needs," "the staff at the hospital helped me to deal with changes in my personal relationship," "the staff at the hospital helped me to deal with day-to-day tasks (e.g., childcare and housework)," "the staff at the hospital helped me to get financial assistance," and "the staff at the hospital helped my family or friends to deal with being worried, upset, or sad").

In this study, a consecutive subsample (comprising approximately two thirds of the participants) were asked to answer this questionnaire.

### Adapted version of Control Preference Scale (CPS)

CPS asks participants the following questions: (1) how they were involved in making the decision and (2) how they prefer to be involved [8]. We developed the Japanese adapted version of CPS by the forward-backward translation method. Each item had five options: made/prefer to make the decision about which treatment I would/will receive, made/prefer to make the final decision about my treatment after seriously considering my doctor's opinion, both my doctor and I shared/share responsibility for deciding which treatment was/is best for me, my doctor made/makes the final decision about which treatment would/will be used but he/she seriously considered/consider my opinions, or I left/leave all decisions regarding my treatment to my doctor. We used item 1 as the patient's experience of treatment decision making and item 2 as the patient's preference of treatment decision-making in this study.

### Sociodemographic and medical factors

The sociodemographic data collected were age, sex, marital status, education level, and employment status, and the medical factors examined included original cancer site, period of radiotherapy, history of anticancer therapy, period from cancer diagnosis, and aim of radiation therapy. The Eastern Cooperative Oncology Group (ECOG) performance status was evaluated by researchers.

Instead of asking our participants about cancer stage directly or searching for it through medical records, we asked them the aim of their radiation therapy (curative/palliative). Some studies have shown that the understanding of cancer patients about their treatment is not always accurate [6, 34]. However, because we asked participants to answer this questionnaire just after starting radiation therapy, the patients had heard about the radiation therapy just before answering the questionnaire. Thus, we regarded their answers as almost correct.

### Statistical analysis

Participants were dichotomized based on whether or not they indicated a preference to receive information about their life expectancy from physicians. To identify potential factors that were associated with preference of communication about life expectancy with physicians, all variables were dichotomized into categorical factors (e.g., age, $< 65$ vs. $\geq 65$; they agree the staff showed respect for them vs. they disagree). Although this approach is not without limitations [2], this simple dichotomization can findings are more likely to assist the medical staff in easily evaluating patient characteristics, the symptoms, their communication style, and the provision of support.

All of the investigated variables were included in the preliminary univariate analysis to identify any associations between preference of communication about life expectancy and the investigated factors with the chi-squared test and/or Fisher's exact test as appropriate. To identify the final factors that were associated with preference of communication about life expectancy, variables with a probability ($p$) value less than 0.05 in the univariate analysis were entered into a logistic regression model as independent variables, using forced entry. A two-tailed $p$ value less than 0.05 was considered statistically significant.

Life expectancy disclosure experiences responses were dichotomized based on whether or not patients had directly experienced discussion about life expectancy. Observed percentage of agreement (estimated with 95% confidence intervals) and Cohen's kappa ($\kappa$) was used to assess agreement between patient's preferences and experiences with discussions about life expectancy. Extent of agreement was assessed according to the criteria recommended by Landis & Koch (1977): $\kappa < 0$ is none/poor; $0 \leq \kappa \leq 0.20$ is slight; $0.21 \leq \kappa \leq 0.40$ is fair; $0.41 \leq \kappa \leq 0.60$ is moderate; $0.61 \leq \kappa \leq 0.80$ is substantial; and $0.81 \leq \kappa \leq 1.0$ is almost perfect [23]. All statistical analyses were conducted with SPSS statistical software (version 22; IBM Corporation., Armonk, NY, USA).

## Results

### Patient characteristics

Of the 393 eligible patients, 282 patients (72%) agreed to participate, and 259 patients (66%) returned their questionnaire by mail. Complete data in the life expectancy section were available for 226 (58%) patients, and 33 participants (13%) completely skipped this section. We did not find significant differences with respect to disease-related (cancer site, performance status, and clinical stage) and sociodemographic (age and sex) factors between those who answered the questions about life expectancy ($n = 226$) and those who did not ($n = 33$). Characteristics of the 226 patients included in the study are listed in Table 1.

### Experiences and preferences of communication about life expectancy

Overall, 54% of patients reported that they had been involved in a discussion about life expectancy with their physician. One hundred and two patients (45%) indicated that they prefer to receive information from their physician about their life expectancy.

### The agreement between experience and preference of communication about life expectancy

Observed agreement between experience and preference of communication about life expectancy was 64.6%, with Cohen's $\kappa$ of 0.352 indicating a fair but significant extent of agreement ($p < 0.01$). Extent of agreement between experience and preference of communication about life expectancy was similar for those who reported their treatment aim was curative 58% ($\kappa = 0.382$, $p < 0.01$) and palliative 68% ($\kappa = 0.387$, $p = 0.03$).

### Factors associated with a preference to discuss life expectancy

Univariate analysis indicated that employment status (full/part time) and patient's preference of treatment decision-making (leave it to doctors or not) were associated with preference of communication about life expectancy as patient factors (Table 2), but none of the medical staffs' factors were associated with preference of communication about life expectancy (Table 3). A multiple logistic regression analysis revealed that only employment status was significantly associated with preference of communication about life expectancy (Table 4).

## Discussion

### Overall summary

To the best of our knowledge, this is the first study to investigate factors associated with preference for disclosure of life expectancy among Japanese cancer patients in relatively early disease stages. In this cross-sectional study, over 50% of the participants reported that they had discussed their life expectancy with their physicians. However, only 45% of patients reported that they preferred to discuss this. The agreement between experience and preference of communication about life expectancy was about 65%. Only employment status (full/part-time) was significantly associated with preference of communication about life expectancy.

### Experiences of discussions about life expectancy

Our study indicated that over half of the participants discussed their life expectancy. More specifically, 58% of patients undergoing curative radiotherapy and 56% of patients undergoing palliative radiotherapy experienced discussions about life expectancy. In previous studies, patients with advanced and terminal cancer tended to have more experiences with discussions about life expectancy (4–58%) [10, 14, 31] than did patients with early cancer (4–27%) [5, 30]. Although most of our participants were treated with a curative aim, the percentage of patients who heard about their life expectancy was relatively high. This may have occurred because physicians must provide patients with prognostic information to have an effective discussion of the goals of care, and thus provide high-quality treatment [3]. In addition, patients often had an oncologist besides their radiotherapist, and they may have had more of a chance to talk about their life expectancy. Even so, survival estimation has been shown to be challenging for medical staff [17].

**Table 1** Characteristics of the participants (*n* = 226)

| Characteristics | | *N* | (%) |
|---|---|---|---|
| Age, years | Mean: 63.3 (SD = 12)<br>Median: 66 (range, 27–84) | | |
| Sex | Female | 115 | 51 |
| Marital status | Married/partnered | 185 | 82 |
| Education | ≥ 12 years | 191 | 85 |
| Employment status | Full time/part time | 50 | 22 |
| Original cancer site | Breast | 89 | 39 |
| | Prostate | 63 | 28 |
| | Lung | 30 | 13 |
| | Colon | 5 | 2 |
| | Other | 39 | 17 |
| Period from cancer diagnosis (months) | Mean: 15.3 (SD = 28)<br>Median: 7 (range, 1–240) | | |
| Radiotherapy | 1st week | 96 | 43 |
| | 2nd week | 54 | 24 |
| | 3rd week | 28 | 13 |
| | 4th week | 13 | 6 |
| | 5th week | 6 | 3 |
| | Other | 24 | 11 |
| Anticancer therapy | Surgery | 132 | 61 |
| | Hormone therapy | 122 | 58 |
| | Chemotherapy | 104 | 49 |
| | Molecular target therapy | 16 | 8 |
| ECOG performance status | 0 | 134 | 60 |
| | 1 | 82 | 37 |
| | 2 | 5 | 2 |
| | 3 | 2 | 1 |

*SD* standard deviation, *ECOG* Eastern Cooperative Oncology Group

## Preferences of discussions about life expectancy

Less than half of the patients wanted to discuss their prognosis. To be more specific, 48% of the patients undergoing curative radiation therapy and 33% of the patients undergoing palliative radiotherapy preferred to know about their life expectancy.

In previous studies of mixed-stage cancer patients, 30–90% sought information about their life expectancy [5, 9, 11, 22, 28, 30]. However, 44–93% of advanced-stage cancer patients wished to hear about their life expectancy [10, 13, 15, 22]. This wide range was caused by cultural differences; fewer patients in Eastern than Western cultures prefer to discuss life expectancy [9, 13, 19, 22, 30]. In eastern cultures and religions, well-being of the family is the first priority, as opposed to western cultures where the individual is the first consideration [16, 20]. In the past nationwide survey, most Japanese felt that not being a burden to others and maintaining hope and pleasure at the end of life was important [27]. And some of the participants thought that unawareness of death was also important [27]. Culture contributes to shape patient's health-related values, beliefs, and behaviors [4]. This cultural belief might impact on our result that fewer patients undergoing palliative radiotherapy prefer to discuss about their life expectancy.

## Agreement between preference and experience of communication about life expectancy

As for the discrepancy of experience and preference of communication about life expectancy in this study, 26% of the patients who wanted to know about their life expectancy could not get the information, and 39% of the participants who did not want to know their life expectancy heard about it. When we divided these patients into those undergoing curative versus palliative radiotherapy, 10% of the patients undergoing curative therapy who hoped to know about their life expectancy were unable to obtain information about it, and 21% of the patients who did not want to know about their life expectancy were informed. In contrast, physicians did not discuss life expectancy with 4% of the patients undergoing palliative radiation therapy who wanted to know about it and discussed

**Table 2** Patient-related factors associated with preference for disclosure of life expectancy information ($n = 226$)

| | | *N* (%) | Wish to have discussion about prognosis *N* (%) | ***p* |
|---|---|---|---|---|
| Demographic characteristics | Age, years | | | 0.25 |
| | ≥ 75 | 43 (19) | 27 (12) | |
| | Sex | | | 0.61 |
| | Female | 115 (51) | 65 (29) | |
| | Education | | | 0.48 |
| | > 11 | 191 (85) | 103 (46) | |
| | Employment | | | *0.02 |
| | Full time/part time | 50 (22) | 20 (9) | |
| | Marital status | | | 0.39 |
| | Married/partnered | 185 (82) | 99 (44) | |
| Aim of radiation therapy | Cure/palliative/did not know | | | 0.08 |
| | Cure | 193 (86) | 101 (45) | |
| Patient preference of treatment decision making | Wish to leave treatment decision to doctors | 23 (10) | 18 (8) | *0.02 |
| Psychological status | HADS total > 19 | 25 (11) | 15 (7) | 0.57 |
| Physical status | MADASI 13 symptom items average score > 3 | 54 (24) | 13 (7) | 0.47 |
| Period from cancer diagnosis | ≥ 15.3 months | 46 (21) | 25 (11) | 0.95 |

*$p < 0.05$; **chi-square test

*HADS* Hospital Anxiety and Depression Scale, *MADASI* MD Anderson Symptom Inventory

life expectancy with 28% of patients who did not want to know about it. Among patients who wanted to know about their life expectancy, more patients undergoing curative than palliative radiotherapy tended to receive an inadequate amount of information. To bridge the gap between preference and experience of communication about life expectancy,

**Table 3** Medical staff-related factors associated with preference for disclosure of life expectancy information ($n = 145$)

| | Perception of actual cancer care | *N* (%) | Wish to have discussion about prognosis *N* (%) | ***p* |
|---|---|---|---|---|
| Physician's communication style | The staff showed respect for me | 126 (88) | 63 (28) | 0.08 |
| | The staff at the hospital talked to me in a way I could understand | 134 (92) | 71 (31) | 0.63 |
| | The doctors at the hospital explained all of the treatments I could have to me | 117 (81) | 61 (27) | 0.98 |
| | The doctors at the hospital explained the consequences of not having treatment | 77 (55) | 41 (18) | 0.63 |
| | The doctors at the hospital explained how each treatment option may affect my length of life | 68 (48) | 0 (13) | 0.08 |
| Provision of physical, psychological, and practical support | The staff at the hospital attended promptly to my pain or discomfort during my treatment | 96 (69) | 50 (22) | 0.92 |
| | The staff at the hospital helped me to deal with being worried, upset, or sad | 49 (35) | 26 (12) | 0.78 |
| | The staff at the hospital helped me to deal with my spiritual needs | 5 (4) | 3 (1) | 0.69 |
| | The staff at the hospital helped me to deal with changes in my personal relationship | 8 (6) | 6 (3) | 0.16 |
| | The staff at the hospital helped me to deal with day-to-day tasks (e.g., childcare and housework) | 22 (16) | 12 (5) | 0.78 |
| | The staff at the hospital helped me to get financial assistance | 3 (2) | 1 (0.4) | 0.54 |
| | The staff at the hospital helped my family or friends to deal with being worried, upset, or sad | 25 (18) | 15 (7) | 0.39 |

**Chi-square test

**Table 4** Factors associated with preference for disclosure of life expectancy information ($n = 145$)—multiple logistic regression analysis

| | | $\beta$ | SE | Adjusted odds ratio | 95% CI | $p$ |
|---|---|---|---|---|---|---|
| Patient's factor | Employment (full time/part time) | 0.843 | 0.332 | 2.324 | 1.213–4.451 | *0.01 |
| | Do not wish to have shared decision making | − 0.067 | 0.352 | 0.935 | 0.469–1.865 | 0.85 |

*$p < 0.05$

*SE* standard error of the mean, *CI* confidence interval

clinicians need to explore what degree of information on their prognosis do patients wish to know. Thus, communication skills about disclosing bad news are essential [13].

### Factors associated with a preference to discuss life expectancy

Our study revealed that employment status (full/part time) was significantly associated with preferences of discussions about life expectancy. Because most of our participants underwent curative radiotherapy, many patients continued to work, and this may have affected the results.

Some studies have investigated the factors that are associated with overall prognostic information. However, the studies that investigated the factors associated with preference for disclosure of life expectancy were limited. For patients' factors, marital status, helplessness/hopelessness, and education were associated with preference of discussions about life expectancy among mixed cancer patients in a previous Japanese study [13]. Age, medical short prognosis, and fear of cancer were associated with wanting quantitative prognoses (how long the patient could expect to live) among cancer patients in the USA [10, 19].

Therefore, we hypothesized that age and psychological distress were associated with preference of communication about life expectancy. However, they were not associated, which suggests that oncologists discuss prognosis regardless of the patient's age. Because these results were incoherent, further study is needed.

Few studies investigated the association between preference for disclosure of life expectancy and medical staffs' factors. We tried to reveal the association but we could not find it in this study. Further study is needed as medical staffs' attitude is important in communication about life expectancy.

### Study limitations

There were several limitations associated with this study. First, the response rate was relatively row. Second, we did not collect information regarding the patients' cancer stages. Third, we sampled patients at university teaching hospitals; and thus, the results may not generalize to other settings. Fourth, 13% of the patients rejected replying to the question about life expectancy. Fifth, the answers about experiences with communication about life expectancy may include recall bias because the mean period from the cancer diagnosis was approximately 15 months. Sixth, patients might have presumed we were asking about conversations with radiation oncologists, since they were having radiotherapy. Seventh, our study examined the preferences of patients only once; therefore, the data will not reflect patient's preferences over time. Eighth, because this study only included Japanese patients, culture-related factors may have influenced the results. Finally, the univariate analysis did not show that only employment status was significantly associated with the preference of communication about life expectancy.

### Study strengths

Despite these limitations, this study had several strengths. First, we used reliable and validated assessment tools. Second, this study included patients with wide ranges of cancer stage, and the results may therefore be generalized to patients with various stages of cancer. In addition, we selected cancer patients who were undergoing radiation therapy, and these results in homogeneity about cancer treatment status.

## Conclusions

Our results indicate that clinicians need to check with patients who continue to work about whether they want prognostic information, including life expectancy. In addition, physicians' communication skills in determining the degree to which patients want to know about their prognosis are essential. Because individuality plays an important role in communication about life expectancy, further study is needed to reveal the associated factors.

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## Compliance with ethical standards

The study protocol was approved by the Institutional Review Board and Ethics Committee of Nagoya City University Graduate School of Medical Sciences and Kyoto University Hospital. It was conducted in accordance with the principles of the Declaration of Helsinki. Written consent was obtained from each patient after the study was explained to them.

**Conflict of interest** The authors declare that they have no conflict of interest.

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