Comparison of preferences for end-of-life care among patients with advanced cancer and their caregivers: A discrete choice experiment

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Abstract

Background: Patients with advanced cancer often have to make difficult decisions, such as how much to spend on moderately life-extending treatments. This and other end-of-life decisions are also influenced by their informal caregivers. Understanding the relative value that patients and their caregivers place on various aspects of end-of-life care can help clinicians tailor treatments to best meet the preferences of their patients.

Aim: To quantify willingness to pay of patients with advanced cancer and their caregivers to extend the patients' life by 1 year and to compare this result to their willingness to pay for other end-of-life improvements.

Design: Cross-sectional survey using a discrete choice experiment.

Participants: A total of 211 patients with stage IV cancer and their informal caregivers.

Results: The willingness to pay of patients to extend their life by 1 year (S\$18,570; 95% confidence interval: S\$6687–S\$30,542) was not statistically different from their willingness to pay to avoid severe pain (S\$22,199; S\$11,648–S\$32,450), to die at home (S\$31,256; S\$21,249–S\$41,391), not be a burden on family and friends (S\$4051; −S\$3543 to S\$11,568), or to receive a high-quality health-care experience (S\$16,191; S\$9266–S\$23,037). Consistent with our hypothesis, caregivers had a greater willingness to pay than patients to extend life (S\$61,368; S\$37,030–S\$86,210) and for most other end-of-life improvements.

Conclusion: Results highlight the importance of pain management, supporting home deaths, and addressing other end-of-life concerns, in addition to efforts to extend life. Differences in willingness to pay of patients and caregivers suggest the need for eliciting patient preferences during treatment decision making as opposed to relying on caregiver input.

Keywords

Terminal care, palliative care, choice behavior, decision making, discrete choice experiment, willingness to pay

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What is already known about the topic?

- In addition to efforts at extending life, being free of pain and dying at home are important considerations for people at the end of life. However, the relative value, in terms of willingness to pay, that patients and caregivers place on these and other aspects of end-of-life care is not known.

What this paper adds?

- This study demonstrates that willingness to pay of patients with stage IV cancer to extend their life by 1 year (S\$18,570) was not statistically different from their willingness to pay to avoid severe pain (S\$22,199), to die at home (S\$31,256), not

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be a burden on family and friends (S$4051), or to receive a high-quality health-care experience (S$16,191). Furthermore, caregivers had a greater willingness to pay than patients to extend life (S$61,368) and for most other end-of-life improvements.

Implications for practice, theory, or policy?

- Results highlight the importance of pain management, supporting home deaths, and addressing other end-of-life concerns, in addition to efforts to extend life. Differences in willingness to pay of patients and caregivers suggest the need for eliciting patient preferences during treatment decision making as opposed to relying on caregiver input.

Introduction

Cancer mortality is projected to increase globally.[1] Treatments for advanced cancer are often expensive and, within the context of limited resources, patients are forced to make difficult choices. Cost and expected survival clearly influence treatment choices, but choices are also influenced by other factors, such as considerations about pain and quality of life, not wanting to be a burden on family and friends, and wanting to die at their place of choice, which for many is their home.[2–16] While there is some evidence that many patients consider health-related quality of life to be as important or more important than life extension,[8–16] understanding the relative value that patients place on these factors can help clinicians tailor treatments to best meet the preferences of the patients they serve.

A potential challenge to customizing treatment decisions to meet the needs of patients is that treatment decisions are not made entirely by the patient but influenced by the patient's primary informal caregivers, who are typically family members. This is especially true in Asia where caregivers often request that the doctor not provide full information to the patient and/or because patient's cede decision-making authority to a caregiver. These circumstances often occur even when patients have the full capacity to make their own decisions concerning the appropriate course of treatment. Clinicians will typically acquiesce to caregivers under the belief that they are acting in the best interest of the patient.[17,18] However, it is possible that caregivers' treatment decisions may not accurately represent patients' preferences.[19–23] Caregivers may prefer more aggressive treatment[8,24] because they are loathe to deny the patient access to an existing treatment and/or because they see the *social* value (which includes positive effects—financial or emotional—for themselves and for other family members) of treatment as greater than the *private* valuation considered by the patient.[25]

In this article, in efforts to provide a greater understanding of preferences for end-of-life (EOL) treatments, we quantify the value of life-extending treatments to advanced cancer patients by calculating their willingness to pay (WTP) for extending their life by 1 year. We then compare this WTP to that of other EOL factors, including being free of pain, being able to die at home, not being a burden on family or friends, and receiving quality health-care services.

These factors have been known to influence patient preferences for EOL care.[26–29] We use a discrete choice experiment (DCE) to calculate WTP estimates. We hypothesize that patients will value pain management and dying at home as much as extending life by 1 year. We further hypothesize that as compared to patients, caregivers will be more WTP for life extension and other aspects of EOL care.

DCE is a powerful method for eliciting stated preferences and has been extensively used in medical and health services literature.[30–41] The advantage of using a DCE to assess stated preferences is that it can help to quantify the relative importance of each factor influencing EOL choices. To supplement the DCE findings, we also asked patients and caregivers directly about their preferences for life-sustaining treatments (for the patient), such as artificial feeding, breathing machine, and cardio-pulmonary resuscitation (CPR). We hypothesized that caregivers will be more likely to prefer these life-sustaining treatments (for the patient) compared to patients.

We conducted our study in Singapore. Singapore presents an excellent setting for quantifying WTP for life-extending treatments because roughly three-fourths of all health expenditures are financed through direct cash payments or through patient's or family member's health savings accounts (termed Medisave).[42,43] As a result, cost is a significant consideration when choosing treatment options, and WTP estimates are reflective of the intensity of patient and caregiver preferences for EOL treatment attributes.

Methods

Samples

Between February 2012 and March 2013, 211 advanced cancer patients and their primary caregivers were interviewed in outpatient clinics at a national cancer center that receives about 70% of all cancer patients in Singapore.[44] The inclusion criteria for patients were age ⩾ 21 years, diagnosis of a stage IV cancer, and Singapore permanent resident or citizen. Patients too sick to answer the survey, cognitively impaired, and not aware of own diagnosis were excluded. As no sampling frame of advanced cancer patients was available to conduct a representative survey

and up to 23% of advanced cancer patients in Singapore are expected to be unaware of their diagnosis,[45] patients were selected either through referrals from treating physicians or approached directly at the outpatient clinic by trained interviewers after confirming the patient's diagnosis from medical records and that the patient is aware of his or her condition. Primary informal caregivers of the selected patients were also interviewed. For the purpose of this survey, primary informal caregiver was defined as the person most involved in providing care to the patient or ensuring provision of care or in making decisions regarding the patient's treatment or care. Maids or foreign domestic workers were not included. Patients and caregivers were interviewed separately to ensure confidentiality and that their responses were not biased by each other's presence and responses.

All patients and caregivers provided written informed consent. The surveys were approved by the Institutional Review Board at SingHealth (2011/860/B).

Instrument

Patients and their caregivers were administered similar questionnaires consisting of a DCE, a method to identify preferences for various features of composite nonmarket goods. Instead of goods, this method is being increasingly used to evaluate preferences for EOL scenarios that vary by levels of key features, termed attributes. Respondents are asked to choose their most-preferred scenario from a series of two or more scenarios. Their observed pattern of choices is then statistically analyzed to determine the relative importance (preference weight) of each of the attribute levels that influenced the respondent's choice of scenario, and it is common and convenient to monetize these preferences by computing the WTP estimates.

Before beginning the DCE, respondents were asked questions about their socio-economic and health status. Patients were asked to choose EOL scenarios that they would prefer for themselves. Caregivers were asked to choose EOL scenarios that they would prefer for the patient. All respondents were given definitions of included attribute levels and asked a series of questions to get them thinking about EOL decisions.

The DCE consisted of eight tasks asking respondents to choose between two scenarios with different levels of the seven attributes, determined through literature review, focus groups,[26] and pilot testing. The attributes, levels, and their description are shown in Table 1. The upper limit for cost of treatment was fixed at S$40,000 based on the maximum amount of money that one can have in a health savings account in Singapore (termed Medisave).[42] The specific levels for attributes used in the DCE were chosen to ensure tradeoffs between tasks and refined through data from pilot tests. A sample DCE task is shown in Table 2.

Following standard practice in DCEs,[46] levels of each attribute were systematically varied in each profile to produce an experimental design with known statistical properties.[47] This design was produced using Sawtooth SSI Web. It ensures efficient statistical estimates of preferences weights for each of the attribute levels. We employed both cognitive interviews and pilot testing before fielding the final instrument to reduce potential cognitive bias. In addition, we used multiple versions of the DCE instrument (four in total) to cover more choice tasks and detect potential design effects.

Finally, patients were asked their preference for life-sustaining treatments, namely, artificial feeding, breathing machine, and CPR. Caregivers were also asked about their preference for each of these treatments for the patients. For each of these treatments, they were asked to indicate their preference on a 4-point Likert scale, the responses from which were dichotomized as "no" (definitely not or probably not) and "yes" (probably would or definitely would).

Sample size calculation

We used the Orme[30] equation to determine the minimum acceptable sample size for DCE for both groups

$$\frac{nta}{c} \geqslant 500$$

where n is the recommended minimum sample size, t is the number of tasks, a is the number of choices per task, and c is the maximum number of attribute levels in the DCE. In each of our three instruments, $t=8$, $a=2$, and $c=4$, yielding a recommended minimum sample size of 125 per group. Our actual sample size is 211 per group (patients and caregivers), suggesting that we have sufficient power to accurately estimate the effect of all attribute levels.[30]

Analysis

A random-parameters, panel logit regression model (termed a mixed logit model), considered the state-of-the art discrete choice model,[48] was used to estimate the effect of each attribute level on respondent choices. Each attribute level other than "expected cost" was included as a separate binary variable in the model. "Expected cost" was coded as a continuous variable. The models for the patients and caregivers were estimated separately using Stata 12.1.

WTP for a given change in an EOL scenario is the amount of money required to leave a respondent indifferent between the more and less preferred scenario. To estimate the WTP, we determined the difference in preference weight between the two scenarios and divided it by the preference weight of cost. Comparisons of WTP estimates between groups were done using a Robb–Krinsky bootstrap procedure.[49,50] All WTP estimates were annualized to allow for direct comparisons.

Table 1. Attributes and levels.

Attributes	Levels	Definitions or explanations provided to the respondents regarding attribute levels
Severity of pain from diagnosis until death	None, mild, moderate, severe	*Mild* pain refers to tolerable pain that does not interfere with most activities. This pain is not so strong, and it is possible to get used to it. *Moderate* pain refers to pain that interferes with many activities and that requires lifestyle changes. This pain is so strong that it is not possible to get used to it. *Severe* pain refers to intolerable pain that is so strong that the person is unable to engage in normal activities
Amount of care required from family members or friends (h/week)	10, 16, 24, 40	Please assume that the entire care is provided by family members or friends
Expected length of survival (months)	4, 6, 10, 16	
Quality of health-care experience	Very good, good, fair, poor	*Very good* refers to health-care services that are extremely well-coordinated, providers (e.g. doctors, nurses, and social workers) give you prompt attention and are caring and sympathetic. *Good* refers to health-care services that are coordinated. However, waiting and appointment times may be long, but the providers are caring and sympathetic. *Fair* refers to health-care services that are inconsistent. Waiting and appointment times are sometimes longer than expected, and providers are not always caring and sympathetic. *Poor* refers to health-care services not well-coordinated at all. Waiting and appointment times are long, and providers are neither caring nor sympathetic
Expected cost of treatment from diagnosis until death	S$4000, S$10,000, S$20,000, S$40,000	
Source of payment	Own out-of-pocket, family member's out-of-pocket, own Medisave, family member's Medisave	Please assume that the entire amount of treatment will be paid from one source only and that there is enough money available to cover the costs. We realize that at present you may be paying for your treatment from more than one source. However, for these questions, we request you to assume that it is possible to pay for the entire treatment from just one source
Place of death	Home, institution (such as hospital, hospice, or nursing home)	

Table 2. Sample conjoint task.

	Scenario A	Scenario B
Severity of pain from diagnosis until death	Moderate pain	No pain
Amount of care required from family members or friends	24 h/week	10 h/week
Expected length of survival	10 months	4 months
Quality of health-care experience	Poor	Very good
Expected cost of treatment from diagnosis until death	S$20,000	S$4000
Source of payment	Own Medisave account	Family member's out-of-pocket
Place of death	Home	Institution such as hospital, hospice, or nursing home
Which scenario do you prefer? (check one)	Scenario A _____	Scenario B _____

Finally, we assessed any significant difference in proportion of patients and caregivers preferring each life-sustaining treatment using McNemar test and congruence between patients' and caregivers' preference for each life-sustaining treatment using kappa statistic.[51]

Results

Patients were on average 62.7 years of age, mostly females (63.1%), Chinese (82%), and educated up to upper secondary school (89.6%). Caregivers were on average 46.5 years

of age, mostly females (62.1%), Chinese (82.9%), and educated up to upper secondary school (54%) (Table 3).

Figure 1 presents the preference weights that best explain the pattern of respondent choices. These are shown on a 0- to 10-point scale with the preference weights for each attribute centered at 5. These preference weights are based on the mixed logit regression results. Attribute levels with larger preference weights are preferred to those with smaller weights. Both patients and caregivers, for instance, preferred the "no pain" level to the "severe pain" level in the "pain" attribute.

Attributes with a greater distance between the most and least preferred level are relatively more important than the other included attributes, given the range of included levels. This figure reveals that both patients and caregivers preferred (the patient) to die at home and to extend their life by 1 year and were averse to severe pain and poor quality care. There was no significant variation in preferences across levels for amount of care received from family or friends in either patient or the caregiver sample.

We can also use the cost attribute as a way of ranking the relative value of moving across levels in the remaining attributes. This can be seen in Table 4, which shows that the WTP of patients to extend their life by 1 year was not statistically different from their WTP to avoid severe pain, to die at home, not be a burden on family and friends, or to receive a high-quality health-care experience. As hypothesized, caregivers had a significantly higher WTP for each EOL improvement (except amount of care) compared to the patients.

A higher proportion of caregivers (artificial feeding: 73.5%, breathing machine: 67.8%, and CPR: 69.2%) than the patients (artificial feeding: 55.9%, breathing machine: 58.8%, and CPR: 58.8%) wanted life-sustaining treatments ($p < 0.01$ for all treatments). Overall agreement in preference was 59.8% for artificial feeding (kappa: 0.13; 95% confidence interval (CI): 0.01–0.25), 61.3% for breathing machine (kappa: 0.17; 95% CI: 0.03–0.30), and 66.8% for CPR (kappa: 0.27; 95% CI: 0.14–0.40), indicating only slight to fair agreement in patient and caregiver preferences.[52] In 29.4% of the dyads, patients did not want artificial feeding, but caregivers wanted it; in 25.1% of the dyads, patients did not want to be put on a breathing machine, but caregivers wanted it; and in 22.7% of the dyads, patients did not want CPR, but caregivers wanted it.

Discussion

Our study quantifies the value of life extension as well as other EOL improvements for patients with advanced cancer and their primary informal caregivers. We show that extending life is not the most important consideration of patients. We also show that caregivers have a greater WTP for life extension and other EOL improvements compared to patients and are much more likely to prefer aggressive

Table 3. Sample demographics.

	Patients (N=211)		Caregivers (N=211)	
Mean age (years)	62.7		46.5	
	n	%	n	%
Age (years)				
<40	7	3.3	66	31.3
40–49	25	11.9	49	23.2
50–59	54	25.6	60	28.4
≥60	125	59.2	36	17.1
Gender				
Male	78	37.0	80	37.9
Female	133	63.0	131	62.1
Education				
Less than secondary education	189	86.7	114	54
Secondary education and more	22	12.8	97	45.9
Ethnicity				
Chinese	173	82.0	175	82.9
Malay	23	10.9	22	10.5
Indians and others	15	7.1	14	6.7

life-sustaining treatments for patients compared to the patients themselves.

The results provide guidance for where efforts can be made to improve EOL outcomes. Both patients and caregivers reported a relatively high WTP to avoid severe pain, showing that pain management is of utmost importance. Yet, a meta-analysis reported overall prevalence of pain among cancer patients to be 64%.[52] Previous reports from Singapore reveal pain to be present in 82% of patients referred to hospice care services.[53] In efforts to meet patient preferences, adequate pain management and palliative care services should be a priority.

In Singapore, only about 30% of all cancer patients die at home.[54] This is similar to estimates from other countries (e.g. England: 25%[55–57] and Taiwan: 33%[58]). In contrast, our analyses showed higher point estimates for the WTP to die at home as compared to extending life by 1 year. Greater efforts should be made to facilitate home deaths for those who want it. Further efforts to improve capacity and outreach of home hospice services may be one strategy help to facilitate home deaths on a broad scale.

For patients and caregivers, beyond fair care, there is no statistically significant increase in WTP. While all developed health systems should strive to be responsive to patients' expectations in nonhealth domains such as having shorter waiting and appointment times, these results suggest that an overemphasis on these domains at the expense of other factors would not be a good use of resources. Similarly, reducing burden on caregivers, although important to patients, is not their top priority. However, this may be unique to Singapore where many households have access to low-cost domestic workers,
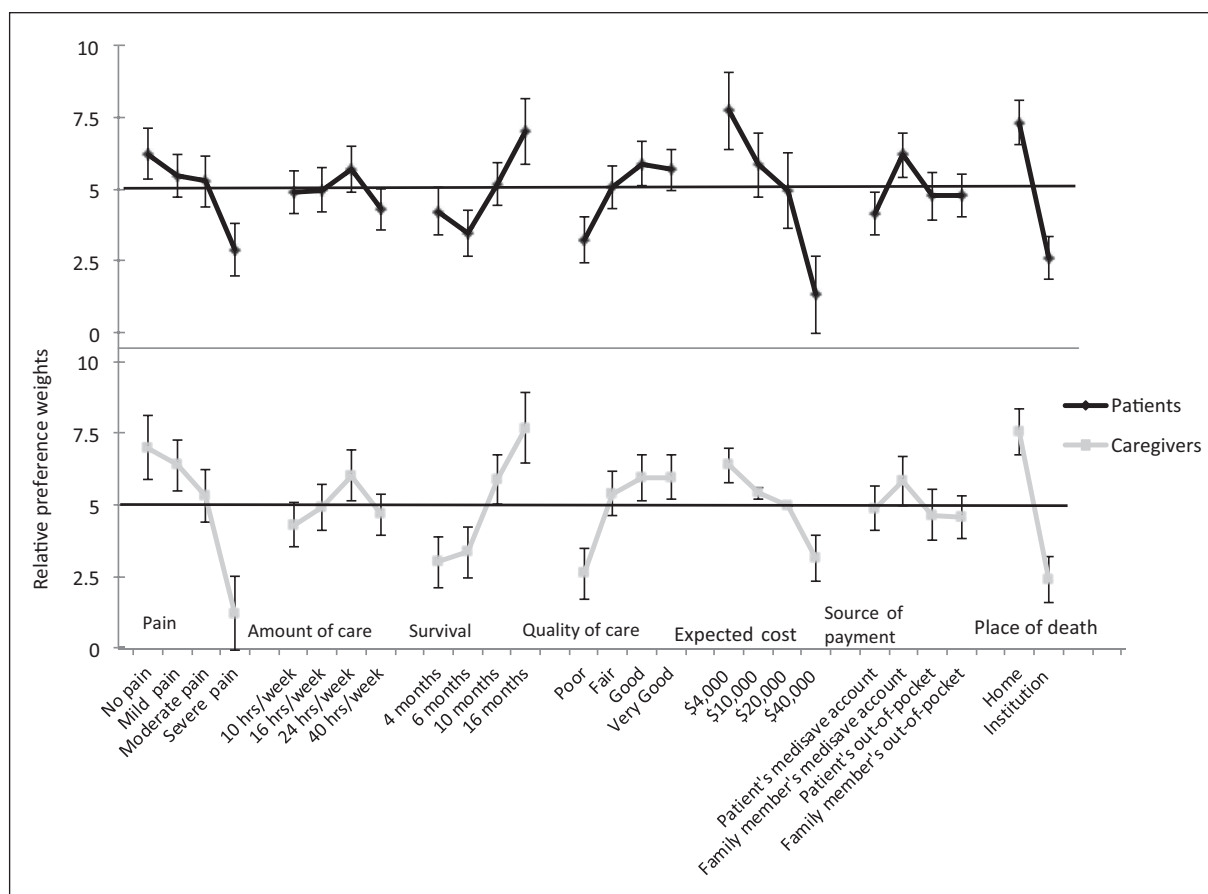
Figure 1. Preferences of patients with advanced cancer and their caregivers.

Table 4. Willingness to pay for specific attribute improvements (in S$).

Attribute	Level transition	Patients (95% CI) (N=211)	Caregivers (95% CI) (N=211)
Survival	4 to 16 months	18,570 (6687 to 30,542)	61,368 (37,030 to 86,210)[a]
Place of death	Institution to home	31,256 (21,249 to 41,391)	67,723 (47,660 to 88,800)[a]
Pain	Severe pain to no pain	22,199 (11,648 to 32,450)	76,047 (47,440 to 104,270)[a]
Amount of care	40 to 10 h/week	4051 (−3543 to 11,568)	−5140 (−21,230 to 10,890)
Quality of care	Poor to very good	16,191 (9266 to 23,037)	44,047 (28,750 to 59,480)[a]

CI: confidence interval.

[a]Estimates are statistically significantly different from those of patients at the 95% level.

who often serve as the primary caregivers for ailing older adults.[59]

Notably, we find that caregivers have a higher WTP to extend the patient's life, thus suggesting that they may be more willing to initiate expensive treatments in efforts to extend their life. About a quarter of patient–caregiver dyads also disagreed on their preference for life-sustaining treatments, with caregivers having a greater preference for these treatments for patients than the patients themselves. This suggests that when patients have the capacity to make decisions, clinicians should ensure that they are involved in decision making and that their preferences are elicited and respected. Efforts should also be made to elicit and

document patient preferences through advanced directives or care planning, so that even when they have lost capacity, treatment can be provided as per their wishes.

We also find that patient's WTP for treatments that extend life by 1 year was lower than the commonly accepted thresholds for cost-effectiveness used in many countries.[60,61] Even when patient's WTP to extend life by 1 year is weighted by their health-related quality of life, as measured by EQ-5D (mean score = 0.742), the WTP was S$25,027, which is also lower than the commonly accepted cost-effectiveness thresholds. This suggests that generous reimbursement by government for EOL treatments may not be appropriate, at least in Singapore. If Singapore

adopts coverage thresholds for treatments that extend life by an average of 1 year or less based on patient WTP estimates, coverage would be far more restrictive than what is recommended by NICE in the United Kingdom, which restricts coverage to treatments with cost-effectiveness ratios below £30,000 (~S$63,367) per quality adjusted life year gained[62] or that recommended by the World Health Organization, which considers interventions with cost-effectiveness ratios below three times gross domestic product per capita (~S$195,297) to be cost-effective.[63,64]

This analysis has several limitations. One common feature of all stated preference surveys is that they are hypothetical. However, several studies have examined the external validity of DCEs. Telser and Zweifel[65] compared WTP values derived from actual choices with ones derived from a DCE and found a close correspondence between the two results. Mark and Swait[66] examined the relationship between revealed and stated preference data for physicians' prescribing decisions and found that parameters from both were similar. These studies provide support for using a DCE in the context of medical decision making. Future studies should attempt to back up the results from this DCE with real choice data, although it would be challenging to observe patient preferences independently from their caregivers and physicians who may also influence their choices. Due to sample size and design considerations, we were also unable to explore interaction effects between attributes, such as pain severity and life expectancy, and consequently, are only reporting average WTPs. Another concern is that patient and caregiver preferences may not be consistent over time. Future studies should prospectively assess changes in patient's and caregiver's WTP for various aspects of EOL care to assess stability of EOL preferences. Some differences between patient's and caregiver's WTP may be attributed to their educational differences. Finally, due to the difficulty of recruiting patients and caregivers for this study, and that only patients who were accompanied by their primary informal caregiver to the clinic were included in the study, our patient sample should not be considered representative of those with late stage cancer in Singapore. Regardless, the general pattern of preferences between patients and caregivers is likely to hold across samples and setting. Quantifying the generalizability of these results in other countries should be an area of future research.

Conclusion

Our results suggest that a greater focus on pain management and supporting home deaths would be in line with the preferences of advanced cancer patients and, from that perspective, would be a more appropriate use of scarce health resources. Greater efforts should also be made to elicit and respect patient preferences in cases where caregivers are making treatment decisions presumably on behalf of the patient.

Declaration of conflicting interests

The authors declare that there is no conflict of interest.

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