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RESEARCH ARTICLE

## To what extent do quality-of-life ratings influence older adults' preferences regarding future health care and research participation?

[Dans quelle mesure l'évaluation de la qualité de vie influence-t-elle les préférences des personnes âgées en matière de soins de santé futurs et de participation à la recherche ?]

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**Abstract:** The objective of this article was to report the extent to which quality-of-life ratings made by older adults for several health states influence their preferences regarding future health care and research involvement, should they be in those states. During in-person interviews conducted by experienced nurses, 235 community-dwelling adults aged 70 years or older rated their quality of life in their current health state as well as in the context of three hypothetical states of increasing cognitive impairment: mild to moderate stroke, incurable brain cancer, and severe dementia. For each of these health states, study participants then rated their desire to receive life-sustaining treatments, their goals of care, and their willingness to engage in research studies. All ratings were made on Likert-type scales. The generalized estimating equation (GEE) approach was used to study the association between quality-of-life ratings and participants' preferences regarding future health care and research involvement, adjusting for potential confounders. Intraclass correlation coefficients were highly significant ( $p < 0.001$ ), ranging from 0.21 [95% CI: 0.13-0.29] to 0.73 [95% CI: 0.67-0.77]. In all situations investigated, quality-of-life viewed more favorably was associated with older adults' greater desire to receive life-sustaining treatment. To the opposite quality-of-life ratings were rarely associated with willingness to engage in research. Findings suggest that quality-of-life considerations influence older adults' desire to be treated, but not their willingness to engage in research, in their current health state as well as in hypothetical states involving cognitive impairment. These findings should be considered in designing future planning interventions.

**Keywords:** quantitative study, advance care planning, quality of life, health care, research participation, elderly.

**Résumé :** L'objet de cet article était de rapporter dans quelle mesure l'évaluation de la qualité de vie effectuée par des personnes âgées pour différents états de santé influence leurs préférences en matière de soins de santé futurs et de participation à la recherche, advenant qu'elles se retrouvent dans ces états. Dans le cadre d'entrevues conduites par des infirmières expérimentées, 235 personnes âgées de 70 ans ou plus vivant à domicile ont évalué leur qualité de vie dans leur état actuel puis dans le contexte de trois états hypothétiques caractérisés par une détérioration croissante des fonctions cognitives : AVC léger à modéré, cancer incurable du cerveau et démence grave. Pour chacun de ces états, les participants cotaient leur désir de recevoir des traitements de prolongation de la vie, leurs objectifs de soins et leur volonté de participer à la recherche. Toutes les cotations ont été faites avec des échelles de Likert. L'approche GEE (generalized estimating equation) a servi à étudier l'association entre l'évaluation de la qualité de vie et les préférences exprimées, ajustant pour de possibles facteurs de confusion. Les coefficients de corrélation intraclasse étaient significativement élevés ( $p < 0.001$ ), variant de 0,21 [IC à 95 %: 0,13-0,29] à 0,73 [IC à 95 %: 0,67-0,77]. Dans toutes les situations examinées, une évaluation plus favorable de la qualité de vie était associée à un plus grand désir du participant de recevoir les traitements de prolongation de la vie. L'évaluation de la qualité de vie était par contre rarement liée à la volonté de participer à la recherche. Nos résultats suggèrent que les

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considérations de qualité de vie influencent le désir des personnes âgées d'être traitées, mais non leur volonté de participer à la recherche, dans leur état actuel et dans des états hypothétiques d'atteinte cognitive. Ces constats devraient guider la conception de futures interventions de planification.

**Mots clés :** étude quantitative, planification préalable des soins, qualité de vie, soins de santé, participation à la recherche, personne âgée.

## Introduction

Aging gradually increases the risk of losing decision-making capacity due to Alzheimer's disease or other illnesses that severely impair cognitive functioning. According to Silveira et al. [1], up to 70% of adults 60 years of age or older who require decision making about treatment in the final days of life lack the capacity to make their own decisions. Several organizations encourage individuals to make their healthcare wishes known in advance so as to maintain some control in the decision-making process in the event of incapacity and guide others in making difficult decisions for them [2-5]. Such decisions can have far-reaching consequences and include, for example, whether to administer intravenous antibiotics to treat a life-threatening infection, provide artificial nutrition and hydration, or attempt cardiopulmonary resuscitation in case of cardiac arrest. A number of influential bodies also advocate expressing wishes regarding future research participation, recognizing the need to allow promising research to go forward while protecting cognitively impaired adults whose participation is sought [6-9].

Advance care planning (ACP) is a process often led by a trained facilitator that aims at helping individuals clarify and communicate their preferences for medical care in the event of decisional incapacity [10, 11]. ACP can also address people's willingness to engage in research should they be solicited after losing capacity [12, 13]. As a means to help articulate preferences, participants are invited to consider specific activities and experiences that contribute to, or detract from, quality of life [14-16]. This focus on quality of life is founded on the belief that healthcare preferences formulated in anticipation of incapacity are likely based

not only on the potential benefit and burden of specific life-sustaining treatments, but also on quality-of-life considerations [15, 17-19]. By analogy, quality-of-life considerations combined with the potential benefit and risk of a given type of research study might also influence a person's willingness to become a research participant in the future.

To our knowledge, no study has formally tested whether quality-of-life assessments do influence wishes regarding future health care and research participation. Two qualitative studies, one reported in Caron et al. [20] and the other in McMahan et al. [21], have revealed the central role that quality-of-life assessments play in family caregivers' decisions regarding the care of a loved one. Following focus groups with patients faced with a serious medical condition, McMahan et al. [21] further identified individual definition of quality of life as central in making decisions about medical care for oneself. We know of no quantitative study that linked quality-of-life assessments to desire for specific treatments and willingness to engage in research. In a study promoting ACP within the Veterans Affairs System, Pearlman et al. [15] asked outpatients to rate their quality of life under different hypothetical health states and then their desire to be treated should they be in those states. However, the authors did not link one set of ratings to the other. To inform the design of future ACP interventions, and to help both families and healthcare providers in making decisions for an incapacitated older adult, it is important to know whether quality of life is a significant determinant of health and research related preferences expressed in anticipation of decisional incapacity.

## Objective

The purpose of the current study was to estimate the extent to which quality-of-life ratings made by older adults in the context of health states implying increasing cognitive impairment influence their desire to receive specific treatments, their goals of care, and their willingness to participate in clinical research, should they find themselves in those states.

## Methods

Data for the work presented in this paper were collected between April 2011 and June 2013 from 235 community-dwelling adults aged 70 years or older who had enrolled in a randomized trial with their self-selected proxies [22]. The proxy was defined as the person the older adult would choose to make healthcare decisions on his or her behalf should the need arise. The trial aimed to assess the efficacy of an intervention designed to (1) motivate older adults in recording their wishes regarding future health care and research participation, and (2) improve their proxies' ability to make substitute decisions on their behalf. Elders who were likely unable to discuss their wishes were screened out using a short memory test [22]. The trial was approved by the Research Ethics Board of the University Institute of Geriatrics of Sherbrooke. All participants provided written consent at entry into the trial. This paper uses data collected at baseline from the 235 trial participants.

### Data collection

The data were collected during two in-person interviews conducted one week apart at the Research Centre by specially trained research nurses. The first interview, which also included explaining the measurement process, obtaining informed consent and collecting descriptive information from trial participants, lasted approximately 3 hours. The second interview was shorter (90 minutes, on average). Quality-of-life ratings and desire to receive specific treatments were gathered during the first interview, while

the second elicited willingness to participate in research and goals of care (cf. Figure 1). Specifically, the first interview began by asking older adults to rate their quality of life in their current health state and then under three hypothetical states of increasing cognitive impairment: mild to moderate stroke, incurable brain cancer, and severe dementia [22]. Response options ranged from 1 (*excellent*) to 5 (*unbearable*). Next, for each of these four health states, they indicated whether they would want to receive each of four life-sustaining treatments: intravenous antibiotics, cholecystitis surgery, tube feeding, and cardiopulmonary resuscitation (CPR). Desire for treatment was measured on a Likert scale ranging from 0 (*definitely not*) to 3 (*yes, definitely*). This task was repeated at the second interview, this time asking participants whether they would be willing to enrol in each of three research studies involving a blood draw, physical exercises, and an experimental drug, respectively. Lastly, for each health state, participants were asked to select one of four goals of care (from *comfort care only* coded 0 to *life-prolonging care* coded 3) should they develop severe pneumonia, undergo a haemorrhagic shock, or sustain a brain trauma.

Research nurses were provided written material to describe hypothetical situations (health states, treatment options, research studies, and sudden health events) to study participants in lay terms. Vignettes were modeled on those used by others [22]. They were adapted to each health state, as illustrated in Bravo et al. [23]. Health states placed study participants in situations where the involvement of a proxy would be increasingly needed. Health events were chosen to capture conditions varying in severity, nature of impairment, and prognosis. Research studies covered a range of risks and benefits likely to influence a person's willingness to enroll.

### Data analysis

First, for each health state, we considered

<b>First Interview</b>		<b>Second Interview</b>																			
How would you rate your quality of life in the following health state?	In that state, would you want to receive the following life-sustaining treatment?	0				1				2				3							
		0	1	2	3	0	1	2	3	0	1	2	3	0	1	2	3				
		<i>Definitely not</i>	<i>Probably not</i>	<i>Yes probably</i>	<i>Yes definitely</i>	<i>Definitely not</i>	<i>Probably not</i>	<i>Yes probably</i>	<i>Yes definitely</i>	<i>Definitely not</i>	<i>Probably not</i>	<i>Yes probably</i>	<i>Yes definitely</i>	<i>Comfort care only</i>	<i>Comfort care first</i>	<i>Proportionate care</i>	<i>Life-prolonging care</i>				
<b>Current health state</b>	<input type="checkbox"/>	Intravenous antibiotics	<input type="checkbox"/>	Cholecystitis surgery	<input type="checkbox"/>	Tube feeding	<input type="checkbox"/>	CPR	<input type="checkbox"/>	Blood draw	<input type="checkbox"/>	Exercise program	<input type="checkbox"/>	Drug trial	<input type="checkbox"/>	Severe pneumonia	<input type="checkbox"/>	Haemorrhagic shock	<input type="checkbox"/>	Brain trauma	<input type="checkbox"/>
<b>Mild to moderate stroke</b>	<input type="checkbox"/>	Intravenous antibiotics	<input type="checkbox"/>	Cholecystitis surgery	<input type="checkbox"/>	Tube feeding	<input type="checkbox"/>	CPR	<input type="checkbox"/>	Blood draw	<input type="checkbox"/>	Exercise program	<input type="checkbox"/>	Drug trial	<input type="checkbox"/>	Severe pneumonia	<input type="checkbox"/>	Haemorrhagic shock	<input type="checkbox"/>	Brain trauma	<input type="checkbox"/>
<b>Incurable brain cancer</b>	<input type="checkbox"/>	Intravenous antibiotics	<input type="checkbox"/>	Cholecystitis surgery	<input type="checkbox"/>	Tube feeding	<input type="checkbox"/>	CPR	<input type="checkbox"/>	Blood draw	<input type="checkbox"/>	Exercise program	<input type="checkbox"/>	Drug trial	<input type="checkbox"/>	Severe pneumonia	<input type="checkbox"/>	Haemorrhagic shock	<input type="checkbox"/>	Brain trauma	<input type="checkbox"/>
<b>Severe dementia</b>	<input type="checkbox"/>	Intravenous antibiotics	<input type="checkbox"/>	Cholecystitis surgery	<input type="checkbox"/>	Tube feeding	<input type="checkbox"/>	CPR	<input type="checkbox"/>	Blood draw	<input type="checkbox"/>	Exercise program	<input type="checkbox"/>	Drug trial	<input type="checkbox"/>	Severe pneumonia	<input type="checkbox"/>	Haemorrhagic shock	<input type="checkbox"/>	Brain trauma	<input type="checkbox"/>

using the following response scale

<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
<i>Excellent</i>	<i>Good</i>	<i>Acceptable</i>	<i>Poor</i>	<i>Unbearable</i>

**Figure 1:** Ratings made by older adults over the two baseline interviews

three separate outcomes resulting from older adults' expressed desire to receive each of the four treatments ( $Y_{11}$ ,  $Y_{12}$ ,  $Y_{13}$ ,  $Y_{14}$ ), willingness to enrol in each of the three research studies ( $Y_{21}$ ,  $Y_{22}$ ,  $Y_{23}$ ), and goals of care if faced with each of the three sudden health events ( $Y_{31}$ ,  $Y_{32}$ ,  $Y_{33}$ ). Higher scores reflect participants' greater desire to receive life-prolonging treatments or willingness to participate in clinical research. Next, to investigate whether these three dependent variables ( $Y_1$ ,  $Y_2$ ,  $Y_3$ ) were influenced by participants' quality-of-life ratings, we used the generalized estimating equation (GEE) approach introduced by Liang and Zeger [24, 25] for estimating regression coefficients when responses are correlated. GEE is a population-level approach based on a quasi-likelihood function and provides the population-averaged estimates of the parameters. Originally developed for correlated discrete and continuous outcomes, the GEE approach has been extended for modeling more complex data, including repeated responses measured on an ordinal scale [26-30]. Analyses were conducted with the IBM SPSS GENLIN command, version 24, using a cumulative logit link function for multinomial data and an independence working correlation structure of the responses [26]. Under mild regularity conditions, the parameter estimates are consistent, asymptotically normal and robust to misspecification of the initial covariance structure [30]. Adjacent rating categories were collapsed when sample sizes were too small to ensure reliable parameter estimates. Residuals from GEE regression models were checked to identify outliers that may be influential. Residual analyses were conducted with R-multgee, version 3.2.3, as SPSS does not generate residuals for clustered ordinal responses. We found 8 outliers and conducted analyses in duplicate, with and without these outliers. Lastly, we adjusted for age, sex and education to determine whether estimated parameters were confounded by participant demographic characteristics. Age and education were

both analysed as continuous variables. For analyses involving the three hypothetical health states, we additionally adjusted for older adults' rating of their current quality of life as we expected it to influence quality-of-life ratings made under the three other states. Intraclass correlation coefficients and cumulative odds ratios are reported together with their 95% confidence intervals.

## Results

As detailed elsewhere [23, 31], 2 451 older adults were solicited, 832 were ineligible and 1 384 refused to enroll in the trial. All 235 trial participants completed the two interviews. The sample consisted of 127 men (54%) and 108 women (46%). Age ranged from 71 to 91 years, with a mean of 77.6 (SD 4.6). A large majority of participants (91%) were Roman Catholic. Most were well educated, with an average of 13 years of schooling (SD 4.8, range 4-25 years). Half (55%) considered themselves in very good or excellent health. One in two (51%) personally knew someone unable to make decisions. Prior to entering the randomized trial, 32% had documented their preferences regarding health care; only 3 participants had done so regarding future research involvement. Further information on trial participants can be found in Bravo et al. [23, 31].

Figure 2 shows the distributions of quality-of-life ratings under the four health states. As expected, distributions tend to shift to the right as the state implies a greater level of cognitive impairment. Nearly 90% of older adults felt that their quality of life would be unbearable if they were severely demented. For each of the three outcome variables, intraclass correlation coefficients (ICCs) along with their 95% confidence intervals are provided in Table 1. Correlations are relatively large and all highly significant ( $p < 0.001$ ). This finding confirms the need to incorporate both within-subject correlations and between-subject variations into model fitting with an approach such as GEE. ICCs are lower for the second outcome (willingness to engage

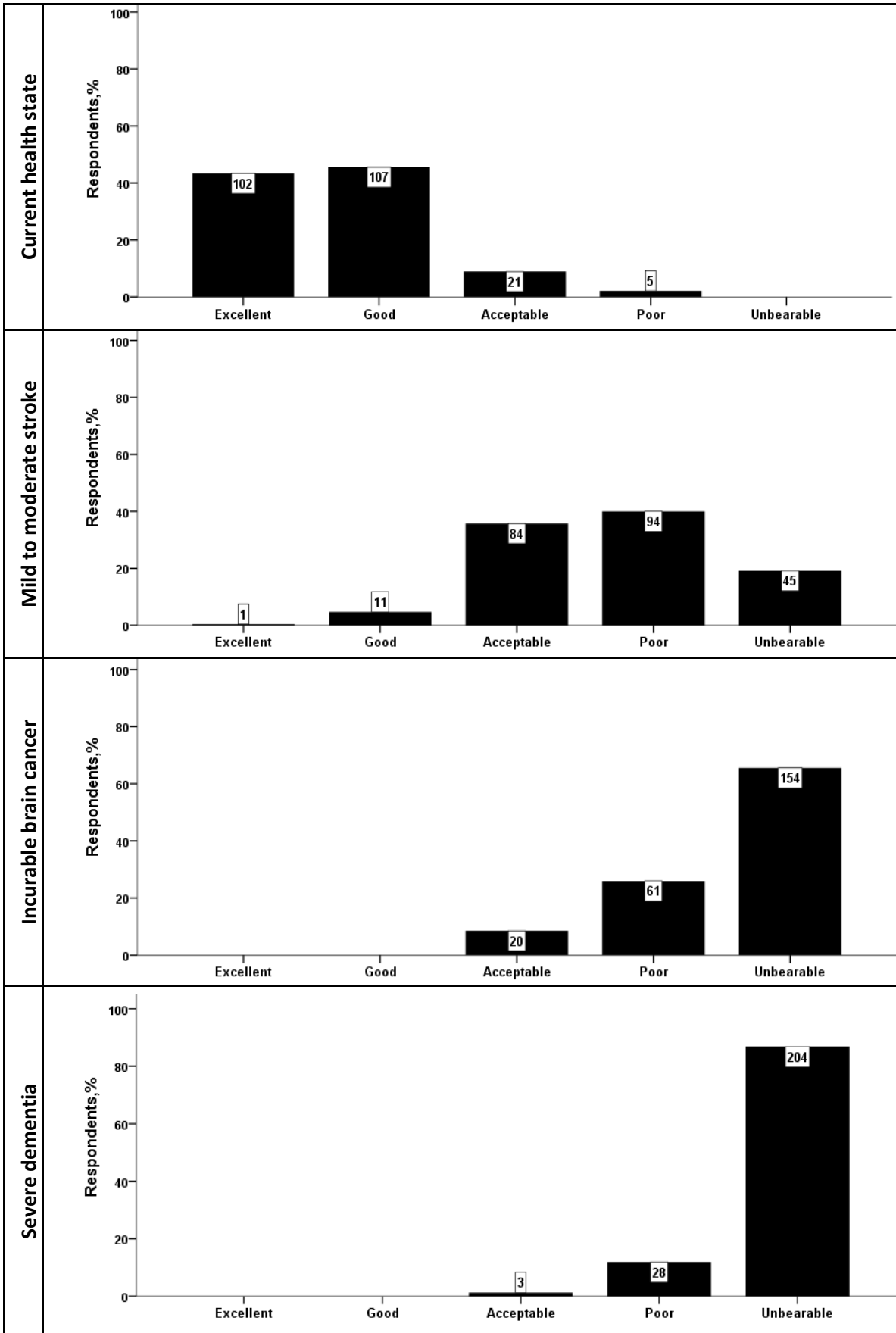


Figure 2: Quality-of-life ratings in participants' current and hypothetical health states

in research) and higher for goals of care ( $Y_3$ ). For all three outcomes, ICCs increase as cognitive functioning declines from the participant's current health state to a hypothetical state of severe dementia.

Results from testing whether quality-of-life ratings influence the three response variables are summarized in Table 2. Of note, adjacent categories of the quality-of-life rating scale were collapsed differently from a health state to another, reflecting differences in the distribution of ratings across health states (cf. Figure 2). For all four health states and all three outcomes, odds ratios increase as quality of life is rated more poorly. Focusing on severe dementia, for instance, the odds ratio of 2.61 for  $Y_3$

indicates that the odds of an older adult who rated quality of life as unbearable being in lower response categories (i.e. leaning towards comfort care rather than life-prolonging care) is 2.6 times the odds of an older adult who provided a more positive quality-of-life rating being in lower response categories. In unadjusted analyses, most odds ratios related to the two healthcare outcomes ( $Y_1$  and  $Y_3$ ) are statistically significant. The effect of quality-of-life ratings on willingness to engage in research ( $Y_2$ ) is non-significant, except for the incurable brain cancer scenario (OR = 1.63, 95% CI = [1.16-2.30]). The same conclusions are reached when adjusting for potential confounders or excluding outliers.

**Table 1:** Intraclass correlation coefficients and 95% confidence intervals for each of the three outcome variables, stratified by health state ( $n = 235$ )

	$Y_1$ Desire to receive specific treatments	$Y_2$ Willingness to engage in research	$Y_3$ Goals of care
Current health state	0.24 [0.18-0.31]	0.21 [0.13-0.29]	0.45 [0.37-0.53]
Mild to moderate stroke	0.53 [0.47-0.60]	0.30 [0.22-0.39]	0.64 [0.58-0.70]
Incurable brain cancer	0.59 [0.53-0.65]	0.40 [0.32-0.48]	0.68 [0.62-0.73]
Severe dementia	0.63 [0.58-0.69]	0.43 [0.35-0.51]	0.73 [0.67-0.77]

## Discussion

To our knowledge, this is the first study to quantitatively examine the association between older adults' ratings of quality of life in several health states, on the one hand, and on the other, their desire to be treated and willingness to engage in research should they be in those states. Based on findings from earlier qualitative studies [20, 21], we expected quality-of-life ratings to influence the two healthcare outcome variables. The results confirm this influence in all four health states investigated, even after controlling for potential confounders and whether including or excluding outliers. These were older adults who, despite rating their current health state as only acceptable or even poor, expressed a strong desire to

receive treatment that would prolong their life. Their presence in the sample reminds us to use caution in extending general tendencies observed within groups to individuals. This also shows the limit of using hypothetical states to investigate the link between quality of life and desire for health care. Moreover, this study does not provide any information about the mechanisms by which appraisal of quality of life influences study outcomes. During the measurement process, study participants were not asked to describe how perceived quality of life – or change in perceived quality of life resulting from deteriorating cognitive functioning – affected their responses. Cognitive interviewing approaches would be useful in uncovering the

**Table 2:** GEE results from testing the influence of quality-of-life ratings on older adults' desire to receive specific treatments ( $Y_1$ ), willingness to engage in research ( $Y_2$ ), and goals of care ( $Y_3$ ), stratified by health state

DV <sup>a</sup>	Quality-of-life rating	Unadjusted analyses			Adjusted analyses <sup>c</sup>			Adjusted analyses excluding outliers			
		(n = 235)			(n = 235)			(n = 227)			
		OR <sup>b</sup>	p-value	95% CI	OR <sup>b</sup>	p-value	95% CI	OR <sup>b</sup>	p-value	95% CI	
Current health state	$Y_1$	Excellent	1	-	-	1	-	-	1	-	-
		Good	1.23	0.163	0.92-1.65	1.13	0.388	0.86-1.50	1.14	0.354	0.86-1.51
		Acceptable to poor	1.49	<b>0.035</b>	1.03-2.15	1.46	0.054	0.99-2.13	1.77	<b>0.002</b>	1.23-2.53
	$Y_2$	Excellent	1	-	-	1	-	-	1	-	-
		Good	1.23	0.148	0.93-1.63	1.20	0.195	0.91-1.59	1.18	0.247	0.89-1.56
		Acceptable to poor	1.53	0.064	0.98-2.39	1.56	0.058	0.99-2.48	1.62	0.053	0.99-2.64
	$Y_3$	Excellent	1	-	-	1	-	-	1	-	-
		Good	1.37	0.061	0.99-1.90	1.31	0.103	0.95-1.81	1.30	0.104	0.95-1.81
		Acceptable to poor	1.86	<b>0.017</b>	1.12-3.11	1.84	<b>0.028</b>	1.07-3.12	2.32	<b>0.003</b>	1.33-4.04
Mild to moderate stroke	$Y_1$	Excellent to acceptable	1	-	-	1	-	-	1	-	-
		Poor	1.70	<b>0.004</b>	1.18-2.44	1.92	<b>&lt;0.001</b>	1.33-2.77	2.06	<b>&lt;0.001</b>	1.42-2.97
		Unbearable	3.27	<b>&lt;0.001</b>	1.98-5.41	4.03	<b>&lt;0.001</b>	2.38-6.82	4.36	<b>&lt;0.001</b>	2.58-7.35
	$Y_2$	Excellent to acceptable	1	-	-	1	-	-	1	-	-
		Poor	1.31	0.134	0.92-1.87	1.25	0.215	0.88-1.79	1.35	0.095	0.95-1.56
		Unbearable	1.36	0.156	0.89-2.09	1.23	0.365	0.78-1.94	1.32	0.234	0.84-2.06
	$Y_3$	Excellent to acceptable	1	-	-	1	-	-	1	-	-
		Poor	1.63	<b>0.014</b>	1.10-2.42	1.73	<b>0.010</b>	1.14-2.62	1.81	<b>0.005</b>	1.20-2.73
		Unbearable	4.29	<b>&lt;0.001</b>	2.52-7.33	4.46	<b>&lt;0.001</b>	2.58-7.71	4.92	<b>&lt;0.001</b>	2.82-8.57
Incurable brain cancer	$Y_1$	Acceptable to poor	1	-	-	1	-	-	1	-	-
		Unbearable	2.21	<b>&lt;0.001</b>	1.46-3.36	2.19	<b>&lt;0.001</b>	1.42-3.36	2.19	<b>&lt;0.001</b>	1.41-3.40
	$Y_2$	Acceptable to poor	1	-	-	1	-	-	1	-	-
		Unbearable	1.63	<b>&lt;0.001</b>	1.16-2.30	1.53	<b>0.018</b>	1.08-2.18	1.65	<b>0.006</b>	1.15-2.35
	$Y_3$	Acceptable to poor	1	-	-	1	-	-	1	-	-
		Unbearable	2.62	<b>&lt;0.001</b>	1.65-4.15	2.74	<b>&lt;0.001</b>	1.54-3.96	2.60	<b>&lt;0.001</b>	1.59-4.23
Severe dementia	$Y_1$	Acceptable to poor	1	-	-	1	-	-	1	-	-
		Unbearable	3.38	<b>&lt;0.001</b>	1.76-6.49	3.61	<b>&lt;0.001</b>	1.85-7.02	3.58	<b>&lt;0.001</b>	1.81-7.06
	$Y_2$	Acceptable to poor	1	-	-	1	-	-	1	-	-
		Unbearable	1.09	0.788	0.60-1.97	1.16	0.605	0.66-2.06	1.36	0.305	0.76-2.44
	$Y_3$	Acceptable to poor	1	-	-	1	-	-	1	-	-
		Unbearable	2.61	<b>0.007</b>	1.30-5.23	2.70	<b>0.005</b>	1.34-5.40	2.62	<b>0.007</b>	1.31-5.27

<sup>a</sup> All dependent variable (DV) levels were ordered from *definitively not* ( $Y_1$  and  $Y_2$ ) or *comfort care only* ( $Y_3$ ) to *yes definitively* ( $Y_1$  and  $Y_2$ ) or *life-prolonging care* ( $Y_3$ ).

<sup>b</sup> Odds of being below versus above any point on the response scale of the three dependent variables.

<sup>c</sup> All models are adjusted for age, sex, and education. Models involving the three hypothetical health states are further adjusted for older adults' quality-of-life rating in their current health state.



underlying thought processes, which may differ across persons and over time [32]. Explicitly addressing this issue, through theoretical models and empirical data, would likely enhance our understanding of the ways quality of life affects healthcare choices.

Contrary to the two healthcare outcomes, willingness to engage in research was seldom found to be influenced by participants' quality-of-life assessments. In the state of severe dementia, there is clearly no association, due to a lack of variability in quality-of-life ratings (cf. Figure 2). In the other health states, some results are borderline and might be found significant in larger samples. While requiring confirmation in future studies, our finding suggests that an older adult's assessment of his or her quality of life in a given health state is not the main driver of his or her willingness to engage in research at times of incapacity. Clearly, other considerations are at play. Altruism and aversion to unknown side effects are perhaps more influential than quality-of-life considerations [33-35].

### **Limitations**

Findings must be interpreted in the light of some study limitations. First, the data come from a sample of relatively healthy, well-educated older adults. Moreover, minorities were not well represented in the sample. Future studies could investigate the extent to which quality-of-life assessments influence the three studied outcomes among ill populations, elders with lower levels of education, younger adults, or minority ethnic groups. Second, the findings regarding willingness to engage in research may not apply to individuals who are not already involved in research as our participants were. Third, ratings and choices were made in isolation while in practice decisions about treatment and research involvement often involve significant others. Fourth, due to study constraints, quality-of-life ratings were obtained using a single item. Multi-item scales are known to be more reliable, precise, and sensitive to change in clinical status than global

measures such as the one we used for this study [36]. Still, a substantial body of research has shown that global concepts can be validly assessed with single-item scales [37, 38]. Nonetheless, because correlations are attenuated when involving less reliable measures, stronger associations might have been found between quality-of-life ratings and the three outcomes had we used a series of questions tapping different aspects of quality of life instead of a single one. Lastly, it must be borne in mind that quality-of-life ratings and choices regarding future medical care and research involvement were partly made in the context of hypothetical health states. As a result of the response shift phenomenon or disability paradox [39, 40], older adults experiencing these states may have a more positive outlook on their quality of life and express a stronger preference for life-prolonging treatment than our participants did when artificially placed in those states (cf. Figure 2). This reinforces the need to reproduce our study in sicker individuals to investigate whether change in internal conceptualization of quality of life resulting from change in health modifies the associations we found between quality-of-life assessments and desire for treatment [19].

### **Implications for practice and research**

This study has practical implications for healthcare professionals involved in advance planning with patients, and for researchers. Findings support querying about quality of life when initiating the conversation about preferences for future medical care. However, we recommend asking patients to describe the reasons underlying their choices, to better understand how quality-of-life considerations impact healthcare choices. Whenever possible, close relatives who may be called upon to make decisions on behalf of patients during periods of incapacity should take part in these discussions, so that they are better equipped to honour expressed wishes where appropriate. Moreover, means should be developed to

record reasons underlying choices in formal advance directives, to ease decision making for those who will have to interpret directive content. The same recommendations apply to discussions about future research involvement should they be included in the advance planning process. Lastly, researchers should more closely examine older adults' thought processes as they consider the kind of medical care they would like to receive, and whether to take part in research, should their ability to understand and reason be compromised in the future [41].

## Conclusion

This study has shown that quality-of-life considerations do influence desire for treatment. Quality-of-life considerations had little influence on willingness to take part in research during periods of incapacity. These findings should be taken into account in future efforts to assist older adults in communicating their preferences regarding health care and research participation for times of incapacity.

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## Conflicts of interest

The authors declare that they have no conflicts of interest.

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