

OLDER PEOPLE'S PREFERENCES FOR SELF-INVOLVEMENT IN DECISION-MAKING IF FACED WITH SERIOUS ILLNESS

As preferências de pessoas idosas pelo autoenvolvimento na tomada de decisão numa situação de doença grave

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ABSTRACT

OBJECTIVES: To examine older people's preferences for self-involvement in end-of-life care decision-making in scenarios of mental capacity (competency) and incapacity, and to identify associated factors. **METHODS:** A cross-sectional survey was conducted including 400 individuals aged 60+ years living in the city of Belo Horizonte, Brazil. **RESULTS:** Among 400 respondents, 95.3% preferred self-involvement when capable (due to the high percentage, associated factors were not calculated) and 64.5% preferred self-involvement when incapable through, for example, a living will. Considering that participants could choose multiple answers, the most frequent combinations in the capacity scenario were "yourself" and "other relatives" (76.8%) and "yourself" and "the doctor" (67.8%). In the incapacity scenario, the most frequent combinations were "yourself" and "other relatives" (usually their children and, less often, their grandchildren) (59.3%) and "yourself" and "the doctor" (48.5%). Three factors were associated with a preference for self-involvement in an incapacity scenario. Those who were married or had a partner (widowed; adjusted odds ratio [AOR] = 0.37; 95% confidence interval [CI] 0.19–0.68) and those who were male (female; AOR = 0.62; 95%CI 0.38–1.00) were less likely to prefer self-involvement. Those who were younger, as in age bands 60–69 years (80+; AOR = 2.35; 95%CI 1.20–4.58) and 70–79 years (80+; AOR = 2.45; 95%CI 1.21–4.94), were more likely to prefer self-involvement. **CONCLUSIONS:** Most participants preferred self-involvement in both scenarios of capacity and incapacity. Preference for self-involvement was higher in the scenario of capacity, while preference for the involvement of other relatives (usually their children) was greater in the scenario of incapacity. **KEYWORDS:** aged; palliative care; decision making; mental competency.

RESUMO

OBJETIVOS: O objetivo deste estudo foi examinar as preferências de pessoas idosas pelo autoenvolvimento na tomada de decisões nos cuidados de saúde em fim de vida em cenários de capacidade e incapacidade mental (competência), e identificar os fatores associados. **METODOLOGIA:** Foi realizado um estudo transversal, com 400 indivíduos, com idade 60 anos ou mais, residentes na cidade de Belo Horizonte, Brasil. **RESULTADOS:** Entre os 400 entrevistados, 95,3% preferiram o autoenvolvimento, quando capazes, na tomada de decisões (devido ao alt percentual, fatores associados não foram calculados); e 64,5% preferiram o autoenvolvimento, quando incapazes de tomar decisões, por meio, por exemplo, de um testamento em vida. Considerando que os participantes puderam escolher mais de uma resposta, as combinações mais frequentes para o cenário de capacidade foram: participantes e outros familiares (76,8%); e participantes e médicos (67,8%). No cenário de incapacidade, as combinações mais frequentes foram: participantes e outros familiares (geralmente filhos e netos) (59,3%); e participantes e médicos (48,5%). Três fatores foram associados à preferência pelo autoenvolvimento em um cenário de incapacidade. Aqueles que eram casados ou com companheiro (viúvo; *odds ratio* ajustada (AOR) = 0,37; intervalo de confiança (IC) 95% 0,19–0,68) e os homens (mulheres; AOR = 0,62; IC95% 0,38–1,00) foram menos propensos a preferir o autoenvolvimento. Os mais jovens: 60–69 anos (80+; AOR = 2,35; IC95% 1,20–4,58) and 70–79 anos (80+; AOR = 2,45; IC95% 1,21–4,94) foram mais prováveis de preferir o autoenvolvimento. **CONCLUSÕES:** A maioria dos participantes preferiu o autoenvolvimento em ambos os cenários de capacidade e incapacidade. A preferência pelo autoenvolvimento foi maior no cenário de capacidade, enquanto a preferência pelo envolvimento de outros familiares (geralmente filhos) foi maior no cenário de incapacidade. **PALAVRAS-CHAVE:** idoso; cuidados paliativos; tomada de decisões; competência mental.

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INTRODUCTION

Advance directives (ADs) are written documents that give individuals the opportunity to express their own future medical care preferences as insurance against future loss of mental capacity, allowing them to accept or refuse extreme lifesaving measures.^{1,2} Countries such as the United States (US), Mexico, Argentina, the United Kingdom, Belgium, the Netherlands and, more recently, Portugal have AD legislation.^{2,3} In Brazil, there is no AD legislation yet, although discussions have advanced after the issue of Resolution no. 1995/2012.^{3,4} It recognizes the patients' right to express preferences for care and treatment by asking what they wish to receive in a situation of inability to make decisions and allows them to designate a representative for that purpose.⁴

Previous studies show significant variability among older persons regarding end-of-life (EOL) care decision-making.⁵ Some wish for self-involvement, some report the desire to include physicians and/or family members in the decision-making process, while others wish not to be personally involved (passive participation).⁵⁻⁹ A population-based cross-national survey of preferences and priorities for EOL care decision-making in seven European countries showed that 73% of participants aged 60-69 years and 62% of those aged 70+ years wished for self-involvement in a scenario of mental capacity.² However, in a scenario of mental incapacity, 60% of respondents aged 60-69 years and 65% of those aged 70+ years would rather not be self-involved through, for example, a living will.² There are reports on factors that affect preferences for decision-making showing that older persons, compared to younger persons, prefer to be less involved in health decisions.^{2,5,7,10,11} Women and those with higher levels of literacy prefer a more active role (self-involvement).^{10,11}

It is important to adapt EOL care policies to different social, economic, and cultural contexts,² as well as to people's needs, preferences, and priorities. In recent decades, there has been a growth in palliative care in Brazil and a growing debate about EOL issues.¹² However, the World Health Organization shows that palliative care in Brazil is relatively limited compared with the size of its population.¹³ As a result, many patients do not have access to EOL care or are even unaware of its existence. Furthermore, conversations about EOL care are still a taboo in Brazilian society, which makes it difficult for people to express their EOL care preferences to their family members or to physicians.¹⁴ Finally, the lack of legal regulation for EOL practices in Brazil (such as specific legislation for ADs) may lead to the risk of prosecution for providers which may compromise EOL care provision.^{12,14} Therefore, policymakers in Brazil should increase efforts to ensure that patients' EOL preferences are respected.

To our knowledge, there have been no studies in Brazil investigating preferences for self-involvement in a situation of serious illness. Based on the need for more evidence to guide national policies and clinical practices, this study aimed to examine older people's preferences for self-involvement in EOL care decision-making in scenarios of mental capacity and incapacity. Furthermore, it investigated factors associated with preference for self-involvement in a scenario of incapacity.

METHODS

Study design and setting

A cross-sectional face-to-face survey was conducted in Belo Horizonte, capital of the state of Minas Gerais, southeastern Brazil. It was informed by the PRISMA survey of preferences and priorities for EOL care.²

Sample

The study sample consisted of older people (aged 60+ years). The sample was obtained considering the Brazilian population distribution by age and gender according to the 2010 Brazilian Demographic Census. According to the Census, there were 299,177 older people (aged 60+ years) living in the city of Belo Horizonte. Based on the Krejcie and Morgan table (1970),¹⁵ for a 95% confidence level, considering a conservative scenario ($p = 0.5$), the required sample size (with a margin of error of 5%) was approximately 400 participants. Quota sampling was adopted in order to consider age distribution by age bands (60-69 years; 70-79 years; 80+ years) and gender. The number of respondents in each subsample (stratum) was proportionally calculated to ensure that the sample distribution by age bands and gender was proportional to the sample universe/frame.

Data collection

Data were collected between February and July 2015. The population was sampled from well-established social programs developed by Belo Horizonte's City Council that focused on assisting community-dwelling older people (by providing services and activities such as physical exercise, computing, handicraft, and singing lessons). This strategy ensured that potential participants were living in the community as opposed to an institution (similar to the population sampled in the PRISMA surveys).^{2,16}

Participants were sampled from the Reference Center for Older People (CRPI) and 10 older people's community-dwelling groups from the Reference Center of Social Services

(CRAS), managed by the City Council's Sub-Secretariat of Social Services (SMAAS). The SMAAS helped to select ten different groups which covered all nine geographical regions in the city of Belo Horizonte (Barreiro, Centro Sul [Mid-South], Leste [East], Nordeste [Northeast], Noroeste [Northwest], Norte [North], Oeste [West], Pampulha, and Venda Nova) and included older people with different levels of social deprivation. The study was approved by the CRPI's coordinator and by the SMAAS Secretary-General.

The study was introduced to potential participants in those 11 centers (by the lead author and study collaborators). The lead author had a desk in those centers and was available to answer questions from those who showed interest in participating in the study. These initial conversations were also an opportunity for the lead researcher to confirm eligibility. If potential participants were eligible and were still interested after asking questions about the study, then they received detailed study information and a consent form. All questionnaires were administered face to face by the first author, who had received methodological guidance from members of the PRISMA Research Team based at King's College London. Interviews were then conducted until 400 participants were included (which is why data collection lasted almost six months). The following inclusion criteria were used: aged 60+ years; living in the city of Belo Horizonte; and being able to give informed consent. With the collaboration of the professionals in the centers, the users considered not to be oriented in time and space were excluded.

The survey tool

The questionnaire was developed as part of PRISMA,² which covered England, Flanders (the Dutch speaking part of Belgium), Germany, Italy, the Netherlands, Spain, and Portugal.

The Portuguese version of the PRISMA questionnaire was culturally adapted to the Brazilian Portuguese language.¹⁷ This study differed from the original PRISMA methodology adopted in Europe in four ways. First, the questionnaire was administered face to face instead of over the telephone as recommended by Brazilian palliative care specialists due to the sensitive nature of the topic. Second, the hypothetical scenario of advanced illness was broadened to include other relevant conditions in addition to cancer. Third, similarly to the English questionnaire but differing from the other European versions, a question about the participant's ethnicity was included. Finally, the Brazilian survey focused on the older population as chronic/life-limiting conditions are more common among older age groups.

The Brazilian version of the questionnaire examined preferences and priorities for EOL care in a situation of serious illness (such as cancer, dementia, Parkinson's disease, chronic obstructive pulmonary disease, heart disease, renal failure, or osteoarthritis), with less than 1 year to live. The questionnaire consisted of two parts. The first part included 10 questions on preferences regarding information, care options, symptoms and problems, decision-making involvement, place of death, and priorities in treatment, care goals, information and decision-making.^{2,17} In the second part, participants were asked about their experiences with illness, death, and dying, and sociodemographic information.^{2,17} Publications on other topics covered by the questionnaire are available elsewhere.¹⁸⁻²⁰

Participants indicated preferences for self-involvement in EOL care by answering the following question: "Keeping in mind a situation of serious illness with less than 1 year to live, please consider that you were able to make decisions. Who would you like to make decisions about your care? Please choose as many as apply, you can choose more than one." Answer options were "yourself," "your spouse or partner," "other relatives," "friends," "the doctor," "others," "don't know," and "refusal/prefer not to say."

This was followed by this question: "If you had lost your ability to make decisions, who would you like to make decisions about your care? Please choose as many as apply, you can choose more than one." Answer options were "yourself, by specifying your wishes before losing ability – for example, in a living will," "your spouse or partner," "other relatives," "friends," "the doctor," "others," "don't know," and "refusal/prefer not to say."

Ethical approval and consent to participate

This study was approved by the Ethics Committee of the Department of Social Sciences and Health of the School of Medicine of the University of Porto/ Portugal (PCEDCSS-FMUP no. 15/2014) and by the Research Ethics Committee of the Municipal Department of Health of Belo Horizonte (SMSA-BH) (CAAE no. 40740914.3.0000.5140). After asking questions and clarifying any potential concerns due to the nature of the topic, all who agreed to participate signed a consent form.

Analysis

Raw percentages were calculated for respondents and decision-making answer options for the scenarios of capacity and incapacity, according to age bands and gender. For the incapacity scenario, answers were converted into a binary score, with a score 1 assigned to participants who chose self-involvement (independently of their choices regarding other

answer options) and a score 0 to those who did not choose self-involvement. This binary variable was the dependent variable. Bivariate analysis was used to examine the effect of independent variables in the outcome variable (19 independent variables were identified during the first three stages of survey development as relevant to EOL care priorities and preferences)¹⁶ (Figure 1). Estimated odds ratios (ORs) were reported. Independent variables found to be statistically significant (P -value < 0.10) were included in a model in the multivariate analysis. Logistic binomial regression was used, and adjusted odds ratios (AORs) were calculated (with 95% confidence intervals) in order to identify significant categorical factors associated with the outcome variable (self-involvement vs. no self-involvement). Although the analyses focused on the interpretation of significant factors, goodness of fit for the final model was assessed using the Hosmer-Lemeshow test. All statistical analyses were performed using IBM SPSS Statistics software, version 23.0 for Windows.

Similar analyses for the capacity scenario were initially planned but not carried out due to observed response distributions (see Results).

RESULTS

Four hundred older adults were interviewed. Nineteen percent reported having been seriously ill in the past five years and 66% had cared for a close relative or a friend in the last months of life (Table 1).

For the capacity scenario, 95.3% of respondents preferred self-involvement, with lower percentages found among those aged 80+ years (Table 2). This was followed by “other relatives” (usually their children and, less often, their grandchildren) (80.8%) and “the doctor” (71.3%). Across the whole sample, only 32% of respondents would prefer the involvement of a spouse or partner in their EOL care decision-making. The proportion of women wanting the participation of a spouse or partner in decision-making was lower than that of men (Table 2). Considering that participants could choose multiple answers, the most frequent combinations

were “yourself” and “other relatives” (76.8%) and “yourself” and “the doctor” (67.8%).

For the incapacity scenario, 64.5% preferred self-involvement in the event of their future incapacity, for example, through the use of a living will (Table 2). “Other relatives” was the most frequently chosen answer (92.3%; higher among women compared to men), followed by “the doctor” (76.8%; higher among women) and then “yourself” (64.5%; higher among women). Conversely, the proportion of participants choosing spouse/partner involvement was higher among men. Considering that participants could choose several answer options, the most frequent combinations were “yourself” and “other relatives” (usually their children and, less often, their grandchildren) (59.3%); and “yourself” and “the doctor” (48.5%).

Of the potential 19 independent variables (Figure 1), six potential explanatory variables were included in the multivariate analysis.

Participants who were married or had a partner were less likely to wish to be self-involved in decision-making in a scenario of incapacity when compared to those widowed (AOR = 0.37; 95%CI 0.19–0.68). Participants in the age bands 60–69 (AOR = 2.35; 95%CI 1.20–4.58) and 70–79 years (AOR = 2.45; 95%CI 1.21–4.94) preferred self-involvement more often than those aged 80+ years. Men were less likely to prefer self-involvement in comparison with women (AOR = 0.62; 95%CI 0.38–1.00) (Table 3).

DISCUSSION

This study examined older people’s preferences for self-involvement in EOL care decision-making in scenarios of mental capacity and incapacity. Most respondents preferred self-involvement both in the scenarios of capacity and incapacity, and wished to involve their spouse or partner and doctor in decision-making. A preference for self-involvement was higher in the scenario of capacity, while a preference for the involvement of other relatives (usually their children) was greater in the scenario of incapacity. These findings indicate

Socio-demographic variables	Age bands, gender, education, marital status, religion, ethnicity, activities in last 7 days, financial hardship, living arrangements (i.e., living alone or with others), and health
Preferences and priorities	Preferred place of death; treatment priority of a) improving quality of life, b) extending life, or c) improving quality of life and extending life being equally important
Experiential variables	Being diagnosed with a serious illness in last 5 years; diagnosis of a close relative/friend in last 5 years; death of a close relative or friend in last 5 years; caring for a relative or friend in their last few months of life

Figure 1 Three categories involving a total of 19 independent variables were examined: socio-demographic variables, preferences and priorities, and experiential variables.

a model of shared decision-making, including the participation of patients, family members, and doctors. In Brazil, such models have yet to be promoted and implemented.^{21,22}

In the capacity scenario, respondents showed greater preferences for self-involvement when compared with PRISMA results in seven European countries.² In the incapacity

scenario, Brazilian participants reported greater preferences for self-involvement when compared with their counterparts in Belgium, Italy, the Netherlands, Portugal, and Spain (where the majority of older participants reported not wanting to be self-involved).² Findings in Brazil were more similar to those obtained in Germany and England.² A recent study carried

Table 1 Respondents' characteristics.

Variables	n	%
Age bands		
60–69 years	217	54.3
70–79 years	121	30.3
80+ years	62	15.5
Gender		
Female	241	60.3
Male	159	39.7
Education		
No formal schooling	30	7.5
Up to 4 years	149	37.3
Up to 8 years	54	13.5
Up to 12 years	122	30.5
Higher education	45	11.3
Marital status		
Single	61	15.3
Married or with a partner	167	41.8
Divorced or separated	50	12.5
Widowed	122	30.5
Religion		
Roman Catholic	267	66.8
Protestantism/Evangelical	63	15.8
Spiritism/Afro-Brazilian	37	9.3
Other	11	2.8
No religion	22	5.5
Ethnicity*		
White	114	28.5
Black	63	15.8
Brown and other (1: Yellow; 1: Indigenous)	223	55.8

Variables	n	%
Activities in last 7 days (Multiple answer options allowed)		
In education (not paid for by employer) even if on vacation	26	6.5
Unemployed	41	10.3
Permanently sick or disabled	5	1.3
In paid work	136	34.0
Retired	323	80.8
Pensioner	102	25.5
Doing housework, looking after children, or others	34	8.5
Other	38	9.5
Financial hardship		
Very difficult on present income	24	6.0
Difficult on present income	55	13.8
Coping on present income	207	51.7
Living comfortably on present income	114	28.5
Living arrangements		
Living alone	75	18.8
Health		
Fair	76	19.0
Good	214	53.5
Very good	110	27.5
Experience of illness, death, and dying		
Close relative/friend seriously ill in last 5 years	299	74.8
Death of close relative/friend in last 5 years	270	67.5
Diagnosed with serious illness in last 5 years	76	19.0
Cared for close relative/friend in last months of life	264	66.0

*Ethnicity categories were obtained from the official Brazilian Census. Participants were asked to choose among five categories (white [*branca*], brown [*parda*], black [*preta*], yellow [*amarela*], and indigenous [*indígena*]).

out in southern Brazil that examined older persons' preferences for decision-making (without mentioning a terminal condition) showed that 30.9% would like to decide on their own, while 57.4% would prefer to ask for advice ("always

seek for advice but your own opinion prevails" or "decide with spouse").²³

In this study, the high rates of preference for self-involvement in the scenario of capacity may have several explanations.

Table 2 Self-involvement preferences for capacity and incapacity scenarios according to age bands and gender.

	Age bands, Male			Age bands, Female			Total
	60–69	70–79	80+	60–69	70–79	80+	
Capacity scenario							
Self-involvement preferences							
Self-involvement	90 (96.8%)	45 (95.7%)	17 (89.5%)	119 (96.0%)	72 (97.3%)	38 (88.4%)	381 (95.3%)
No self-involvement	3 (3.2%)	2 (4.3%)	2 (10.5%)	5 (4.0%)	2 (2.7%)	5 (11.6%)	19 (4.7%)
Multiple answer options allowed							
Yourself	90 (96.8%)	45 (95.7%)	17 (89.5%)	119 (96.0%)	72 (97.3%)	38 (88.4%)	381 (95.3%)
Your spouse or partner	51 (54.8%)	25 (53.2%)	9 (47.4%)	24 (19.4%)	16 (21.6%)	3 (7.0%)	128 (32.0%)
Other relatives	73 (78.5%)	36 (76.6%)	15 (78.9%)	107 (86.3%)	55 (74.3%)	37 (86.0%)	323 (80.8%)
Friends	20 (21.5%)	9 (19.1%)	1 (5.3%)	39 (31.5%)	27 (36.5%)	6 (14.0%)	102 (25.5%)
The doctor	56 (60.2%)	38 (80.9%)	15 (78.9%)	83 (66.9%)	57 (77.0%)	36 (83.7%)	285 (71.3%)
Others	1 (1.1%)	0 (-)	1 (5.3%)	1 (0.8%)	1 (1.4%)	1 (2.3%)	5 (1.3%)
Self-involvement + Other relatives	72 (77.4%)	34 (72.3%)	14 (73.7%)	102 (82.3%)	53 (72.6%)	32 (74.4%)	307 (76.8%)
Self-involvement + The doctor	54 (58.1%)	37 (78.7%)	13 (68.4%)	80 (64.5%)	55 (74.3%)	32 (74.4%)	271 (67.8%)
Incapacity scenario							
Self-involvement preferences							
Self-involvement	53 (57.0%)	25 (53.2%)	6 (31.6%)	90 (72.6%)	58 (78.4%)	26 (60.5%)	258 (64.5%)
No self-involvement	40 (43.0%)	22 (46.8%)	13 (68.4%)	34 (27.4%)	16 (21.6%)	17 (39.5%)	142 (35.5%)
Multiple answer options allowed							
Yourself, by specifying your wishes before losing ability (e.g., in a living will)	53 (57.0%)	25 (53.2%)	6 (31.6%)	90 (72.6%)	58 (78.4%)	26 (60.5%)	258 (64.5%)
Your spouse or partner	54 (58.1%)	28 (59.6%)	10 (52.6%)	31 (25.0%)	20 (27.0%)	4 (9.3%)	147 (36.8%)
Other relatives	78 (83.9%)	43 (91.5%)	17 (89.5%)	120 (96.8%)	69 (93.2%)	42 (97.7%)	369 (92.3%)
Friends	21 (22.6%)	11 (23.4%)	3 (15.8%)	42 (33.9%)	28 (37.8%)	10 (23.3%)	115 (28.8%)
The doctor	64 (68.8%)	38 (80.9%)	15 (78.9%)	90 (72.6%)	64 (86.5%)	36 (83.7%)	307 (76.8%)
Others	0 (-)	1 (2.1%)	1 (5.3%)	1 (0.8%)	1 (1.4%)	1 (2.3%)	5 (1.3%)
Self-involvement + Other relatives	43 (46.2%)	23 (48.9%)	6 (31.6%)	86 (69.4%)	54 (73.0%)	25 (58.1%)	237 (59.3%)
Self-involvement + The doctor	33 (35.5%)	21 (44.7%)	5 (26.3%)	65 (52.4%)	50 (67.6%)	20 (46.5%)	194 (48.5%)

Data collection was performed at centers offering services that promote older people’s rights and strengthen their social roles. Therefore, the participants in this study were active older persons who were aware of their rights, who had cared for their health, and still had the capacity to stay involved. The preference for self-involvement in health care decisions may be influenced by experiences with diseases and medical care, the amount of information the individual has received, diagnoses, health status, and type of relationship with health professionals.^{10,24,25} Some studies have also shown that diminished health status and multiple chronic conditions are associated with a preference for less self-involvement.^{7,10,23} Furthermore, cultural aspects, in particular the relationship between patients and physicians, may influence preferences for self-involvement in decision-making.²⁶ For instance, Japanese older persons are more likely to have

a passive or submissive attitude towards physicians, allowing them to take on a paternalistic role,²⁶ while research in western countries, particularly in the US, shows higher preference for self-involvement.²⁶ In Brazil, despite increasing discussions on patient autonomy and EOL care (e.g., Resolution 1995/2012 of the Federal Council of Medicine^{3,4}), EOL care decisions are often made by physicians without the participation of patients.^{14,27} A national Brazilian survey showed that patients with advanced cancer (92.7%) and families (90.7%) were more likely to agree that do-not-resuscitate (DNR) orders should be discussed with patients when compared with physicians (70.3%).²⁷ These findings show that Brazilian physicians undertake a more paternalistic approach.^{14,27} In our study, when respondents were asked about EOL preferences, they frequently answered “I had never talked about it with anyone” and/or “I had never thought about it.” It is possible

Table 3 Self-involvement in decision-making within an incapacity scenario*.

Socio-demographic variables	Bivariate analysis		Multivariate analysis
	OR (95%CI)	p	AOR (95%CI)
Gender (ref: female)			
Male	0.43 (0.28–0.65)	< 0.001	0.62 (0.38–1.00)
Age bands (ref: 80+)			
60–69	1.81 (1.02–3.20)	0.04	2.35 (1.20–4.58)
70–79	2.05 (1.09–3.84)	0.02	2.45 (1.21–4.94)
Marital status (ref: widowed)			
Single	0.66 (0.33–1.30)	0.23	0.59 (0.27–1.29)
Married or with partner	0.34 (0.20–0.57)	< 0.001	0.37 (0.19–0.68)
Separated or divorced	0.14 (0.28–1.19)	0.13	0.61 (0.27–1.35)
Health (ref: fair)			
Good	0.48 (0.26–0.85)	0.01	0.55 (0.29–1.03)
Very good	0.71 (0.37–1.37)	0.31	0.79 (0.38–1.59)
Living with children (ref: none)			
One	2.27 (0.96–5.35)	0.06	2.11 (0.83–5.31)
Two or more	1.18 (0.39–3.51)	0.77	1.41 (0.43–4.60)
Least preferred place of death (ref: own home)			
Home of a relative or friend	0.46 (0.22–0.96)	0.03	0.50 (0.23–1.10)
Palliative care/hospital**	0.71 (0.33–1.48)	0.36	0.87 (0.39–1.91)
Care home	0.44 (0.22–0.86)	0.01	0.51 (0.24–1.91)

AOR: adjusted odds ratio; 95%CI: 95% confidence interval; OR: odds ratio; *only factors found to be significant in the bivariate analysis are shown (i.e., p [OR] < 0.10); **because only two individuals showed preference for place of death in a “palliative care unit,” in subsequent analyses the answers “hospital but not palliative care unit” and “palliative care unit” were combined into a single group.

that the high percentage of participants who preferred the participation of physicians in the decision-making process was influenced by the fact that preferences for EOL care are rarely discussed in Brazilian society. Therefore, for patients, their doctor's opinion may be crucial. However, we need more studies investigating people's opinions on medical decision-making for EOL care in Brazil.

Due to the high percentage of respondents that demonstrated a preference for self-involvement in the capacity scenario (95.3%), associated factors were not calculated. In the incapacity scenario, three factors were significantly associated with a preference for self-involvement (with different directions): age bands, gender, and marital status. Those aged 60–69 and 70–79 years (in comparison with those aged 80+ years) were more likely to prefer self-involvement. Other studies have reported that younger people (compared to older people) and older people (compared to the oldest old) prefer self-involvement more often.^{2,7,10,11,23,28} Men were less likely to prefer self-involvement compared to women. Research has shown that women (compared to men) have a higher preference for active participation in decision-making across all ages.^{10,11,23} Those who are married or have a partner (in comparison with those widowed) were less likely to prefer to be self-involved. A study in southern Brazil reported that married older persons were more likely to seek out advice for decision-making.²³ In our study, it is possible that self-involvement was deemed to be less important for married participants because they trusted their partners to make a decision for them if/when they became incapable of doing so. However, this possibility needs to be investigated in future studies that also explore the rationale for preferences across older people.

The study findings are relevant to guide clinical practices and national policies in Brazil. Conversations between physicians and patients should start as early as possible, as having access to information is a requirement for decision-making.^{20,29} Moreover, progressively worsening conditions may make it difficult for the patient to understand information and may therefore hinder the health care professional's ability to respect patient's preferences. It is also critical to ensure that the wishes of those who do not want to be self-involved are respected. Furthermore, public health education campaigns are needed in Brazil to inform the population about self-involvement in decision-making.

It is also important to note that although older people share some attributes regarding involvement in health decisions, this group is also very heterogeneous.⁵ The approach to decision-making among this population should always be individualized according to needs, to how information

is understood, and to the willingness of the older person to participate in these decisions.⁵ The process of involving older people in decision-making is more focused on an attentive relationship (with an individual approach and receiving information) than on active participation in decision-making.⁵ Therefore, the participation of older adults in health decisions, regardless of their willingness to be involved, is related to trust, interest, support, and communication.^{5,10}

In Brazil, palliative and EOL care decision-making is still a topic that engenders little public discussion. With the rapid aging of the Brazilian population, it is urgent to bring this topic to the public arena and to have evidence which generates discussions to set policies and improve practice.

Limitations and future perspectives

This study has some limitations. As mentioned above, the participants in this study were active older persons who were aware of their rights, who had cared for their health, and still had the capacity to stay involved. Further studies are required including older people who do not attend such centers and may have different experiences, in order to assess whether their preferences are different. Furthermore, the preferences of older people who are frail and have functional dependency may be underrepresented. Similar to the original PRISMA study,^{2,16} this study did not target older people living in institutions, and it is possible that they would have different views. It is also possible that the study participants had difficulties imagining a situation of severe disease with less than 1 year to live. However, the participants' experiences with serious illness, dying, and death in the past 5 years helped them contextualize the scenario used in the questionnaire. Moreover, physicians were the only health care professionals that were considered in this study; future studies must explicitly include scenarios with other professionals (e.g., nurses, psychologists, and social workers), as health care involves multidisciplinary teamwork.² The city of Belo Horizonte is the Brazilian capital with the third highest proportion of older people.³⁰ Our results are likely to be applicable to other Brazilian metropolitan areas. Future studies should also compare patients' preferences with the perception that health care professionals have about their patients' preferences. This could shed light onto possible obstacles or strengths in the patient-professional relationship. More qualitative research is also required in order to better understand older people's preferences in decision-making. Our recruitment approach influenced our ability to calculate response rates and assess non-response bias. Due to the sensitive nature of the topic, after the study was introduced to all potentially eligible participants, it was deemed most appropriate to allow

them to approach the researcher if they were interested in participating. Only one potential participant who engaged in conversation about the study later decided not to participate (due to a fear of sharing personal information in the consent form with strangers, despite reassurances). The possibility of non-response bias was difficult to ascertain; additional studies including older people are important to allow for comparisons and better understanding of variation in preferences across different subgroups.

CONCLUSION

To our knowledge, this is the first study carried out in Brazil examining the preferences of older people for EOL care decision-making if faced with advanced illness. The majority of participants wished to be self-involved in decision-making, in both scenarios of capacity and incapacity. In Brazil, where palliative care is still underutilized, studies in this field are crucial to support the development of measures to respect people's preferences and priorities, and to inform relevant training for health care professionals.

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CONFLICT OF INTERESTS

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