Preference for death at home and associated factors among older people in the city of Belo Horizonte, Brazil

Preferência por morrer em casa e fatores associados de pessoas idosas da cidade de Belo Horizonte, Brasil

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Abstract *We examined people's preferences for place of death and identified factors associated with a home death preference. We asked a representative sample (N = 400) of older people (≥ 60 years) residents in the city of Belo Horizonte, about their preferences for place of death in a situation of serious illness with less than a year to live. Data were analyzed using binomial regression to identify associated factors. 52.2% indicate home as the preferred place of death. Five variables were associated with preference for death at home: those living with 1 child (odds ratio (OR)0.41; 95% confidence interval (CI):0.18-0.92; ref: without children); being in education for up to 4 years (OR0.42; 95% CI:0.20-0.89; ref: higher education); finding it difficult to live with the present income (OR3.18; 95% CI:1.53-6.62; ref: living comfortably); self-assessed fair overall health (OR2.07; 95% CI:1.06-4.03; ref: very good health) and selecting "choosing who makes decisions about your care" as the care priority that would matter to them the most (OR2.43; 95%CI:1.34-4.40; ref: dying in the place you want). Most respondents chose home as preferred place of death. However, most residents of Belo Horizonte die in hospitals, suggesting that preferences are not being considered.*

Key words *Aged, Palliative care, Place of death, Brazil*

Resumo *Examinamos as preferências das pessoas para o local da morte e identificamos os fatores associados com a preferência pela morte em casa. Perguntamos para uma amostra representativa (N = 400) de pessoas idosas (≥ 60 anos) residentes da cidade de Belo Horizonte, sobre suas preferências pelo local da morte numa situação de doença grave, com menos de um ano de vida. Os dados foram analisados utilizando regressão binomial para identificar os fatores associados. Indicaram a casa como o local preferido de morte, 52,2%. Cinco variáveis foram associadas à preferência por morte em casa: aqueles que vivem com 1 criança (odds ratio(OR)0,41; intervalo de confiança (CI)95%:0,18-0,92; ref: nenhuma criança); ter até 4 anos de escolaridade (OR0,42; CI95%:0,20-0,89; ref: ensino superior); ser difícil viver com o rendimento atual (OR3,18; CI95%:1,53-6,62; ref: vive confortavelmente); avaliar a sua saúde geral como razoável (OR2,07; CI95%:1,06-4,03; ref: saúde muito boa) e selecionar "escolher quem toma decisões sobre os cuidados" como a prioridade de cuidado mais importante (OR2,43; CI95%:1,34-4,40; ref: morrer no local que se quer). A maioria dos entrevistados expressaram preferência por morrer em casa. No entanto, a maioria dos residentes de Belo Horizonte morre nos hospitais, sugerindo que as preferências não estão sendo consideradas.*

Palavras-chave *Idoso, Cuidados paliativos, Local de morte, Brasil*

Introduction

Population aging is a worldwide phenomenon[1]. Brazil follows this trend; it is estimated that between 2011 and 2036 it will cease to be a "young country" (up to 7% of older people) and will become a country with an aged population (more than 14% of older people)[2]. Due to increasing life expectancy, deaths are more likely to occur among older age groups, often following end-stage of advanced chronic diseases (such as cardiovascular diseases, chronic obstructive pulmonary disease, cancer and dementia). Therefore, many people will go through a period of terminal illness before their death[3,4].

In Brazil, data from the Brazilian Institute of Geography and Statistics (IBGE) show that 58.1% of the total deaths occurring in 2015 were among individuals aged ≥ 65 years (age classified as old in many developed countries) and 66% in the age group ≥ 60 years (considered as elderly by the Brazilian Statute of the Elderly)[5]. In 2013, the main causes of death in Brazil were noncommunicable diseases (72.8%), specifically the most common were: cerebrovascular diseases, acute myocardial infarction, pneumonia, and diabetes mellitus[6,7]. Faced with this reality, the World Health Organization (WHO) has urged countries to develop specific public policies for palliative care to meet the complex needs of the elderly population[4]. One such recommendation is to encourage health care providers to talk to patients about their preference for place of care and death[4].

Preferences are defined by personal choices when decisions need to be made about health and treatments, based on experiences, beliefs and values, placing individual autonomy as a central value[8,9]. In this context, one of the most prominent topics is preference for place of death, especially considering the increasing hospitalization of death[10,11]. Studies suggest that people often prefer dying at home (by comparison to dying at an institution, hospital, or even at the home of family and friends), although percentages differ between countries[3,12-14]. A population-based cross-national survey in seven European countries, involving participants aged ≥ 16 years, showed that a majority of participants in all countries from 51% in Portugal to 84% in the Netherlands, would prefer to die at home[3,13]. In this study, the choice of home death became less frequent with age up to 60 years old, but this trend reversed in the older age groups 60–69 and ≥ 70 (although odds were still lower in these groups than in the reference group: 16–29)[13,15]. Although older populations have a higher

frequency of death and, consequently, more need for palliative care support, there are few quantitative studies focusing on older people´s preferences, especially in low and middle income countries, such as Brazil[3]. Results of some qualitative studies suggest that older people perceive their home as a place of familiarity and comfort, and thus, an ideal place to die. However, some factors (such as not wanting to be a burden on family members, concern about the quality of home care or not having a caregiver) may influence the preference for dying in a place other than home[3,16].

In international studies conducted mainly in Japan, Europe and the United States, people's preference for the place of death was not widely respected[3,12,13,15,17]. A recent survey in Japan with older people (≥ 65 years) indicated "home" as the preferred place of death for 68.4% of men and 52.5% of women[14]. A study published in 2013 analyzed official 45 reports of places of death of older people showed that 54% or more of all deaths occurred in hospitals. Japan is shown as the first country in the world where there are more deaths in hospitals[17]. Following Japan, Brazil was considered the second country in the world where there are more deaths in hospitals[17]. In Brazil, 71.6% of deaths occurred in hospitals in 2015, of which 68% consisted of people aged ≥ 60[5]. Some studies conducted in Brazilian municipalities have demonstrated high death rates in hospital settings[18]. In Araraquara (São Paulo State)[19], 76% of deaths happened in hospitals between 2006 and 2011. In Londrina (Paraná State)[18], more than 70% of people died in the hospital from 1996 to 2010. However, we did not find any studies that investigated preference for place of death among Brazilians.

Thus, the objective of this study is to analyze the preferences for place of death among older people (≥ 60 years) living in Belo Horizonte (Brazil) in a scenario of advanced disease with less than one year to live. We also aimed to examine the influence of social and demographic factors on a home death preference versus other locations (palliative care unit, hospital or long-term care facilities).

Methods

Study design

This study is quantitative, cross-sectional, descriptive and inferential. The study sample consisted of older people (aged ≥60), both men and

women, living in the city of Belo Horizonte. We considered the population distribution by age and gender according to the 2010 Demographic Census from IBGE when defining our study sample. According to the Census there were 299,177 older people (aged ≥ 60) living in the city of Belo Horizonte. Based on the Krejcie and Morgan[20] table, a sample size of 400 people would be needed to obtain a representative sample of the older population in Belo Horizonte (confidence level of 95% and margin of error of 5%). To define the sample, we considered distribution by age group (60-69 years; 70-79 years; ≥ 80 years) and gender.

Data collection tool

The questionnaire was developed as part of a Pan-European Commission Project funded by the 7th Framework Programme called "Reflecting the Positive diveRsities of European prIorities for reSearch and Measurement in end of life cAre (PRISMA)"[21,22]. The aim of the questionnaire is to analyze the preferences and priorities for end of life among the general population (aged 16 and older) in a situation of serious illness like cancer with less than 1 year. The survey covered England, Flanders (the Dutch speaking part of Belgium), Germany, Italy, the Netherlands, Spain, Portugal and Kenya (Nairobi)[12,13].

The Portuguese version of the PRISMA European survey questionnaire was culturally adapted to Brazilian Portuguese following the European Organisation for Research and Treatment of Cancer (EORTC)'s translation procedures[23]. A thorough description of the adaptation can be found elsewhere[24]. This study differed from the methodology of the original PRISMA study in Europe in four ways. Firstly, 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. Secondly, the scenario of hypothetical advanced illness was broadened to include other relevant conditions in addition to cancer (such as chronic kidney disease, advanced heart failure, dementia, osteoarthritis, and chronic obstructive pulmonary disease). Thirdly, similarly to the English questionnaire but differing from the other European versions, a question about the participant's ethnicity was included in the questionnaire. Finally, we focused on the older population as age and chronic/life-limiting conditions are more common among older age groups.

The Brazilian version of the questionnaire examines preferences and priorities for end-of-life care in a hypothetical situation of serious illness (such as cancer, dementia, Parkinson's disease, chronic obstructive pulmonary disease, heart disease, renal failure or osteoarthritis), with less than one year to live. The questionnaire consists of two parts. The first part includes 10 questions on preferences and priorities at the end of life (approaching access to information; most concerning symptoms and problems; decision-making; dying in preferred place; most important goals). The second part includes sociodemographics questions as well as questions related to experiences with illness, death, dying and general health.

Participants responded where they preferred to die in a scenario of advanced disease by answering the question *"In a situation of serious illness with less than one year to live…Where do you think you would prefer to die if circumstances allowed you to choose?". Answer options were: "in your own home", "in the home of a relative or friend", "in a palliative care unit – places with specialized care and beds for people with advanced diseases at the end of life", "in a hospital –but not in a palliative care unit", "in Long-term care facilities" and "somewhere else".*

There were challenges when recruiting participants and some potential candidates refuse to participate after learning about the questionnaire topic. Also during questioning, it was observed that not all study participants (n = 400) recognised palliative care units as a place of death. However, an explanation about "palliative care unit" had been made available to interviewers to provide information for the respondents.

Setting

This study was conducted in the city of Belo Horizonte, Minas Gerais, Brazil, among those aged ≥ 60 years who corresponded to 8.9% of the total population in 2000, increasing to 12.7% in 2010[25]. Following national trends, the majority of people in Belo Horizonte (75.9 %) died in hospitals in 2015[5].

Participants

We have sampled our population from well-established social programmes developed by Belo Horizonte's City Council focused on assisting community-dwelling older people (providing services and activities such as physical exercises, computing, handicraft, singing lessons, etc). This strategy ensured that the potential par-

ticipants were living in households as opposed to an institution (similar to the population sampled in the PRISMA surveys).

Participants were sampled from the Reference Centre for Older People (CRPI) which is linked to the Sub-Secretariat of Older People's Rights of Citizenship (SMADC); and 10 older people's community-dwelling groups from the Reference Centre 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 (Barreiro, Centro-Sul, Leste, Nordeste, Noroeste, Norte, Oeste, Pampulha e Venda Nova) in the City of Belo Horizonte 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's principal investigator, CRPI and CRAs staff introduced the study to potential participants and discussed its objectives and methodology with those interested in taking part. After answering any queries and clarifying any potential concerns due to the nature of the topic, all who agreed to participate signed a consent form. All questionnaires were administered face to face by the first author who had been in contact with members of the PRISMA Research Team based at King's College London and received guidance about the PRISMA methodology. Data were collected between February and July 2015.

The inclusion criteria were Belo Horizonte residents living at home aged ≥ 60 years. They also had to have be able to give informed consent; with the advice from CRAS and CRPI's professionals we excluded those who were not able to orient themselves in time and space.

Statistical analysis

We used descriptive statistics to report participants' demographic, socioeconomic and clinical factors; and their preferences for place of death. Chi-square tests were carried out to investigate associations among age, gender and preference for place of death. We have tested for equality of proportions between two samples in order to compare preferences (home *versus* another location) under different classes: gender and age groups. We used binomial logistic regression (adopting the "enter" method) to examine factors significantly associated with a preference for home death (one's own or of a relative or friend). There were no missing values in the data set. Home death was considered the dependent variable. We have calculated odds ratio (OR) and 95% confidence intervals (CI). To establish the theoretical model, an initial regression model defined only by factors with significant crude OR (p<0.05) was considered. Afterwards, variables with significant more relevant crude OR (p<0.05) were sequentially entered in the model. The final model was found when the next explanatory variables entered in the model did not exhibit significant association (p>0.05) with the dependent variable. The adjusted odds ratios (AOR) and the 95% CI were calculated in the final model in order to identify associations of the categorical factors with the dependent variable. Although our analyses focused on the interpretation of the significant factors, we have assessed the goodness of fit of the model using the Hosmer-Lemershow test. All statistical analyzes were performed using IBM SPSS Statistics software, version 23.0 for Windows. Results of statistical tests were deemed statistically significant when p <0.05.

Ethical considerations

This study was approved by the Ethics Committee of the Department of Social Sciences and Health of the Faculty of Medicine of the University of Porto, Portugal and by the Research Ethics Committee of the Municipal Department of Health of Belo Horizonte (SMSA-BH).

Results

Four hundred older people living in Belo Horizonte agreed to take part in the study. The median duration of the interviews was 16 minutes (range 6-39 minutes). Interviews took longer among the older age groups (60-69: 15min, 70-79: 17min, ≥ 80: 19min, p = 0.000) and women participants (Female: 17 min, Male: 15 min, p = 0.000).

Participants' median age was 69 years (interquartile range 64-76), with the oldest interviewees aged 92 (n = 2). Most participants were retired (80.8%), declared themselves as Catholics (66.8%), coping on present income (51.7%) and described their general health as "good" (53.5%). Regarding experience of illness, 19.0% of participants received a diagnosis of serious illness in last 5 years (Table 1).

Table 1. Sample characteristics.

Variables	n	%
Age group		
60-69 years	217	54.3
70-79 years	121	30.3
80+	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
Separated/ Divorced	50	12.5
Widower	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: Asian Brazilian; 1: Indigenous)	223	55.8

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Table 1. Sample characteristics.

Variables	n	%
Activities in last 7 days		
In education	26	6.5
Unemployed (actively looking for a job/ wanting a job but not actually looking for a job)	41	10.3
Permanently sick or disabled	5	1.3
In paid work	136	34.0
Retired	323	80.8
Pensioner	102	25.5
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 with: adults		
None (myself)	76	19.0
One adult	153	38.3
Two adults	98	24.5
Three adults	39	9.8
Four or more	34	8.5
Living with: children		
None	351	87.8
One Child	34	8.5
Two or more	15	3.8
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

Preferences for place of death

Regarding preferences for place of death, 52.2% preferred home, and 47.8% opted for some kind of institution (Table 2). Almost half (46.0%) of participants reported having as much information as they wanted as their most important priority, followed by "choosing who makes decisions about your care" (38.3%). The least valued aspect was "dying in the place you want" which was chosen as the most important priority by 26.8% of participants. (Table 3).

There were no statistically significant differences in preferences by gender and age, even though males chose home more often (58% versus 49% among females; p = 0.068) and those aged 70-79 chose home less often (46% compared to 52% for 60-69 and 65% for ≥ 80, p = 0.065). A large proportion of men aged 60-69 chose home

as their preferred place of death (65.4%), but results were not statistically significant (χ^2 = 25.23; p = 0.090). However, men significantly preferred home as place of death (home: 92/159 = 59%, other: 67/159 = 41%, p = 0.047), as well as people aged ≥ 80 years (home: 40/62 = 65%, other: 22/62 = 35%, p = 0.022).

Table 2. Distribution of preference for place of death by age group and gender.

First Preference for place of death	Age group						Total	
	60-69		70-79		≥ 80			
	Male	Female	Male	Female	Male	Female	n	%
Home[1]	59	54	21	35	12	28	209	52.2
Palliative care	17	21	12	13	3	5	71	17.8
Hospital	10	36	9	20	4	7	86	21.5
Long-term care facilities	7	13	5	6	0	3	34	8.5

1) To avoid bias in results, because only 2 individuals showed preference for place of death "house of relatives or friends", in subsequent analyses, the answers "Home" and "Relatives or friends´ house" were aggregated into a single group called "home".

Table 3. Information and decision-making: most important priority of three options.

Variables	n	%
Most important in the care available		
Having as much information as you want	184	46.0
Choosing who makes decisions about your care	109	27.3
Dying in the place you want	107	26.8
Second most important in the care available		
Having as much information as you want	135	33.8
Choosing who makes decisions about your care	153	38.3
Dying in the place you want	112	28.0

Three factors (age group, current income and priorities for care: "most important in the care available") showed to be independently associated with the preference for home death (p < 0.05, Table 4). Nevertheless, the influence of age group lost significance when other relevant factors were jointly incorporated in the same model. In the final model, five factors were found to be associated with choosing home as the preferred place of death: those living with one child (OR 0.41: 95%CI: 0.18-0.92; ref: without children); or being in education for up to 4 years (OR 0.42; 95%CI: 0.20-0.89; ref: higher education) were less likely to choose home. In contrast, those finding it difficult to live with the present income (OR 3.18; 95%CI: 1.53-6.62; ref: living comfortably); self-assessed fair overall health (OR 2.07; 95%CI: 1.06-4.03; ref: very good health) and selecting "choosing who makes decisions about your care" as the care factor that would matter to them the most (OR 2.43; 95%CI: 1.34-4.40; ref: dying in the preferred place) were more likely to choose home. The binomial logistic regression model showed to be well fitted to the data (p = 0.404).

Discussion

To our knowledge, this is the first study to investigate preferences for place of death among older people living in Brazil. Preferences for place of death have been investigated in countries such as the United States, United Kingdom, Canada, Australia, Japan and China[3,12-14,26]. In the European Union population-based survey among seven European countries showed that 51-84% of participants preferred to die at home along with 51.1% in Kenya (Nairobi) if they were to die with advanced disease and if circumstances allowed them choose[12,13]. Our results show that home (own home or home of a relative or friend) was the preferred place of death for over half of participants (52.2%). In contrast, official mortality statistics data from 2015 show that 75.9% of older people in the municipality of Belo Horizonte died at the hospital[5]. Our results suggest a discrepancy between preferences and actual place of death.

In a scenario of serious illness, with less than one year to live our results indicate that five variables associated with a home death preference. Older people living with one child were less likely to choose home as their preferred place of death (compared with those living without children). The problem of being a burden to others is a factor found in the literature as a source of concern at the end of life[16,27-29]. Older people do not wish to be a burden on their family, especially when living with children, who also have their family to care for. However, there was no significant association between living with two or more children and a home preference. Furthermore, we found that participants who lived with more than one adult at home were not more likely to choose

Table 4. Influence of factors on preference for home death.

Variables	OR (95%-CI)	p-value OR	AOR (95%-CI)	p-value AOR
Age group (ref: 80+)				
60-69	1.67 (0.93-3.00)	0.084	NS	0.272
70-79	**2.11 (1.12-3.97)**	0.020	NS	0.072
Gender (ref. Man)				
Woman	1.46 (0.97-2.18)	0.068	NS	0.186
How many adults do you live with? (ref: none/ myself)				
1 adult	0.76 (0.44-1.32)	0.327		
2 adults	0.84 (0.46-1.53)	0.567		
3 adults	1.52 (0.69-3.33)	0.298		
4 or more	0.66 (0.29-1.51)	0.327		
How many children do you live with? (ref: none)				
1 child	0.50 (0.24-1.06)	0.072	**0.41 (0.18-0.92)**	0.031
2 or more	1.58 (0.55-4.53)	0.396	1.70 (0.55-5.22)	0.357
Marital status (ref: single)				
Married	0.77 (0.43-1.39)	0.385		
Married but separated	1.81 (0.49-6.66)	0.370		
Divorced	0.82 (0.36-1.84)	0.622		
Widower	0.74 (0.40-1.38)	0.347		
In a stable relationship	1.51 (0.33-6.89)	0.594		
Religion (ref: no religion)				
Roman Catholic	0.70 (0.29-1.68)	0.425		
Evangelical	0.98 (0.37-2.59)	0.963		
Spiritist	0.64 (0.22-1.84)	0.402		
Other	1.46 (0.33-6.46)	0.619		
Professional activity in the last 7 days				
Student (ref. No)	2.17 (0.94-5.00)	0.068	NS	0.083
Unemployed looking for a job (ref. No)	1.24 (0.47-3.29)	0.662		
Unemployed not looking for a job (ref. No)	1.57 (0.68-3.63)	0.288		
Permanently sick or disabled (ref. No)	0.73 (0.12-4.40)	0.728		
Paid work (ref. No)	0.84 (0.55-1.27)	0.405		
Retired (ref. No)	1.28 (0.77-2.11)	0.339		
Pensioner (ref. No)	1.25 (0.80-1.97)	0.324		
Housework (ref. No)	0.75 (0.37-1.53)	0.424		
Other	0.77 (0.40-1.53)	0.465		
Financial Hardship (ref: allows to live comfortably)				
Very difficult	1.75 (0.72-4.24)	0.217	1.62 (0.60-4.36)	0.342
Difficult	**2.59 (1.33-5.03)**	0.005	**3.18 (1.53-6.62)**	0.002
Coping	1.30 (0.82-2.07)	0.262	1.30 (0.78-2.16)	0.311
Health (ref: very good)				
Fair	1.68 (0.93-3.03)	0.089	**2.07 (1.06-4.03)**	0.025
Good	0.92 (0.58-1.47)	0.736	1.00 (0.61-1.64)	0.991
Experience with illness, dying and death				
Family member or friend diagnosed with serious illness (ref: No)	0.96 (0.61-1.51)	0.859	NS	0.459
Closely experienced death of a family member/ friend (ref. No)	1.00 (0.66-1.53)	0.987		
Received diagnosis of severe illness (ref. No)	0.71 (0.43-1.17)	0.178		
Involved in supporting close relative/friend in last months of life (ref. No)	0.95 (0.63-1.44)	0.823		

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Table 4. Influence of factors on preference for home death.

Variables	OR (95%-CI)	p-value OR	AOR (95%-CI)	p-value AOR
Education (ref: higher education or more)				
No formal schooling	0.84 (0.33-2.12)	0.704	0.38 (0.13-1.10)	0.074
Up to 4 years	0.58 (0.30-1.14)	0.114	**0.42 (0.20-0.89)**	0.022
Up to 8 years	0.59 (0.26-1.30)	0.188	0.55 (0.23-1.30)	0.173
Up to 11 years	0.68 (0.34-1.36)	0.281	0.73 (0.35-1.52)	0.398
Ethnicity (ref: white)				
Black	1.83 (0.98-3.42)	0.056	NS	0.065
Brown (1 Asian Brazilian and 1 indigenous)	1.27 (0.80-2.00)	0.306	NS	0.233
Most important in the care available (ref: dying in the place you want)				
Having as much information as you want	1.28 (0.79-2.08)	0.309	1.34 (0.79-2.25)	0.277
Choosing who makes decisions about your care	**1.75 (1.02-3.00)**	0.041	**2.43 (1.34-4.40)**	0.004
Second most important (ref: dying in the place you want)				
Having as much information as you want	0.83 (0.50-1.38)	0.479		
Choosing who makes decisions about your care	1.12 (0.69-1.82)	0.656		

NS, non-significant; OR, odds ratio; CI, confidence interval; AOR, Adjusted Odds Ratio.

home as their preferred place of death. Perhaps this is because larger families often have more caregivers available.

Older people with up to 4 years of education were less likely to prefer a home death than those who had higher education. One possible explanation is that people with different levels of education engaged in planning their deaths in different ways[30,31]. Perhaps autonomy represents a greater value for those with higher education and the house is perceived as a place of greater empowerment[31]. However, there are few studies that investigates the associations between preference for home death and level of education[32]. Previous research in Ibiza[33] and China[34] showed that low educational attainment is associated with a greater preference for death at home and those with higher attainment prefer to die in institutions[32]. Our results point to a contrary association. Cultural differences between countries may explain this difference. Therefore, further studies are needed to better understand these associations.

Furthermore, older people who described their fair overall health were more likely to choose home as their preferred place of death (compared to those who evaluated their health as very good). It should be noted that no participant evaluated his/her general health as bad or very bad. There are few studies that associate self-rated health and preference of the place of death[14]. A population-Based Survey in Hong Kong found an associated poor self-rated health

with lower preference to die at home[26]. A study about preferences for the place of death among Japanese older people, found that good self-rated health was significantly associated with a home death preference[14]. Those who evaluated their self-rated health as good may have had an adequate motor function and quality of life, and this may decrease future concern about the need for a medical institution[14].

Older people finding it difficult to live on present income were more likely to prefer home, compared with those living comfortably on present income. In Brazil, delays in medical assistance, lack of doctors and hospital beds are common in public hospitals[35-37]. Participants who reported difficulties living on present income are likely to be users of these services. In this sense, older people may prefer to die at home for fear of not receiving adequate end of life care in public hospitals.

Finally, older people who stated that "choosing who makes decisions about your care" was the most important care priority were more likely to choose a home death than those who choose "dying in the place you want". It is possible that older people who stay at home feel more empowered and able to make decisions at home than at an institution.

By using the PRISMA questionnaire and adopting a similar methodology, we found that the proportion of Brazilians choosing home as their preferred place of death is similar to the one

reported in Portugal[15] but lower than in other European countries[13]. This happened even though the investigated population in Brazil is older than the one investigated in Europe, where the odds of preferring a home death actually increased for those aged ≥ 60. This may have several social, cultural and/or family reasons. It is possibly related to the limited availability of public domiciliary services and the high cost of private services, in addition to unfavorable socioeconomic circumstances among a large part of the Brazilian older population. The poor availability of such services could also help to explain the comparatively higher proportion of participants choosing hospital (over a fifth in Brazil compared to less than 7.0% in Europe) and long-term care facilities (over 8.0% compared to 2.2% in Europe) as their preferred place of death. Nonetheless, it is worth noting that participants may also have had a genuine wish to die in hospital. Other possible explanations for the lower proportion could be concerns about being a burden to family and friends if staying at home[27,28]. Nonetheless, despite the lower proportion of home preferences compared to some European countries, our results indicate that the home death preferences in Brazil are in line with international evidence reporting that most people would prefer to die at home.

The Brazilian questionnaire described a hypothetical scenario of a serious illness, without giving cancer as the only example (as in the original PRISMA survey). This allowed participants to imagine a wide range of serious conditions other than cancer (which were not possible to be recorded for the analysis). Evidence suggests that a home death preference is less frequent amongst those with a non-malignant condition; whose complex needs may not always be met at home[38].

We have focused on investigating preferences for home death and factors associated with this preference due to the international evidence showing that the majority of the population would prefer to die at home[3,12-14]. Nonetheless, it is worth noting that not everyone might wish to die at home and people's preferences should be respected. Over 20.0% of the participants chose a hospital, while almost a fifth chose a palliative care unit and 8.5% chose long-term care facilities. It is therefore urgent to expand the provision of palliative care services in these settings. Furthermore, it is crucial to implement palliative care not only at home, but also in other care settings. In Belo Horizonte, following national patterns, the majority of palliative care is offered in hospitals[39]. Hence, there is need to expand the provision of pallia-

tive care elsewhere. It is also essential to inform the population about palliative care, and enhance discussions about death and dying. The lead author noticed that speaking of death and dying was considered a taboo and potential barrier to participation. Broad at al.[17] highlighted that death is still considered a taboo in several countries, an unpleasant topic which could bring bad luck and recommends. However there is an increasing emphasis on asking older people to discuss options for end-of-life care and to plan advanced care[17].

Respecting patient autonomy is an ethical principle in health care provision, including palliative care. Furthermore, there is an increased recognition of the importance of offering information and supporting preferences from patients and their families in order to plan for appropriate care provision[14]. It is paramount to implement public policies which allow for patient preferences to be respected and for resources to be made available so they can be met whenever appropriate. International policies such as the UK`s "End of Life Strategy" have shown that it possible to reduce the proportion of hospital deaths as well as increasing the proportion of deaths at home, thereby respecting the preferences of terminal patients[40,41]. Effective strategies to allow for preferences to be met include the provision of information, discussing preferences in advance with patients and families and providing palliative care in different settings[41].

In this study, we investigated the preferences and priorities at the end of life among the elderly population of Belo Horizonte regarding the place of death. It was possible to obtain evidence to help to direct public health efforts and policies, and this has potential to avoid wasting resources on unnecessary treatments.

Limitations and research perspectives

Although the research was carried out in all regions of the city of Belo Horizonte with older people, participants were active people who cared for their health. Thus, the recruitment process excluded people with more functional dependence and fragility. Future studies should include group comparisons, considering the current health status of older people and involving participants with greater functional dependencies. The study considers a hypothetical situation of serious illness; longitudinal studies are recommended to analyze how preferences for place of death are organized when faced with a serious illness with less than one year to live.

Conclusion

Results indicate that older people's preferences for place of death in the city of Belo Horizonte are in line with the international evidence, which shows that most people prefer to die at home. In several countries, public policies in palliative care have been made based on national studies on population preferences. In Brazil, policies for older people in the final stages of life are scarce and we have not found previous studies on preferences for place of death. Therefore, we recommend the development of a national Palliative Care Program in Brazil. It is fundamental to create specialized teams, in different care settings, (instead of prioritizing hospital services), in order to respect end-of-life preferences. In this sense, this study may contribute to the development of higher quality palliative care services in Brazil.

Collaborations

All authors were involved in study design, survey development, cultural adaptation of the survey, data analysis, and took part in the interpretation of findings and manuscript preparation. R Jorge designed the study, administered the questionnaire, analyzed the results and wrote the manuscript. N Calanzani interpreted the data, revised and approved the manuscript. A Freitas analyzed and interpreted the data, prepared the article and approved the version to be published. R Nunes was involved in writing and reviewing the manuscript and approved the version to be published. L Sousa participated in the design of the study, analysis of results and writing of the manuscript.

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