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Older people's preferences for prognostic information in a situation of serious illness with less than a year to live

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Abstract *This study aimed to determine the preferences of community-dwelling older people about information disclosure regarding poor prognosis, the likely symptoms and problems, and the care options available in a situation of serious illness with less than a year to live; and to identify factors associated with a preference for information disclosure regarding poor prognosis. The Brazilian version of the Preferences and Priorities for End of Life Care (PRISMA) questionnaire was administered face-to-face to 400 older people, living in the city of Belo Horizonte, Minas Gerais, Brazil. The main results indicated that 74.0% preferred to be informed that they had limited time left, 89.3% wished to be informed about symptoms and problems, and 96.3% about available care options. The factors associated with preferences for information about poor prognosis were: gender (women: OR = 0.446, 95% CI: 0.269-0.738) and choosing the least preferred place to die (home of a relative or friend: OR = 2.423, 95% CI: 1.130-5.198. These results show that most older people want to be informed in an advanced illness situation with less than a year to live. Health care professionals need to be prepared to anticipate news about poor prognosis and the disease.*

Key words *Aged, Palliative care, Information, Prognosis, Brazil.*

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Introduction

With most people facing terminal illness before death[1,2], health professionals frequently have to deliver bad news about a diagnosis and prognosis to patients[3–5]. However, disclosing a terminal diagnosis remains a difficult task for many health professionals[3,5,6], frequently leading to partial or total emission of information on the prognosis or meaning that the family is given the information rather than the patient[7–9]. The literature shows that doctors may be reluctant to give patients prognostic information for a number of reasons, including: lack of formal preparation for communicating bad news, difficulty accepting that they are unable to offer a cure to the patient, fear of the patient's/family's reaction, and uncertainty about prognosis[3,4,10,11].

However, information is vital for those who are coping with serious illness and knowing patient preferences for information enables professionals to respond adequately to the situation[3,10,12]. Clear information can help patients and their families make treatment decisions and define realistic goals, facilitate end-of-life planning, and increase rather than decrease hope[4,13]. Moreover, when patients receive less information end-of-life care is less likely to reflect their preferences[14] and more likely to be aggressive[4,15].

Evidence also suggests that, if asked, most people from different cultures would prefer to always be informed about diagnosis, while a smaller, but still substantial, proportion would want to receive detailed information about the prognosis; although this proportion diminishes in the case of a poor prognosis[3,7,8,12,16–18]. A population-based study conducted in Europe found that 73.9% of respondents showed a preference to always know if they had limited time left in a scenario of serious illness such as cancer with less than a year to live[3]. In addition, 81.3% would always want to be informed about symptoms and problems, and 89.5% would always want to be informed of their care options (services available, places where you could be looked after, treatments and medication)[3]. Another study with patients in two hospitals for cancer in São Paulo and medical oncologists working throughout Brazil showed that 92% of patients believed that all patients should know their poor prognosis[7]. The same study also showed that some doctors and family members were reluctant to give information to patients. The data shows that 18.3% of doctors and 20.8% of family members believed that not all patients should know their poor prognosis, compared to 8% of patients[7]. These findings show that some doctors adopt a paternalistic approach to patient care and that family members may create barriers to informing patients about a poor prognosis[7].

Older people's preferences for prognostic information are particularly important, given that it is this group that have to deal with terminal illness most and face more complex decisions[19,20]. Furthermore, advanced age is a risk factor for receiving less prognostic information among cancer patients[9,21]. Previous studies have shown that older cancer patients[21–23] generally want to be fully informed within a scenario of life-threatening illness. However, other studies showed that the majority of older cancer patients preferred not to be informed about expected survival[14], did not want complete information on their disease[24], preferred to receive more information about the diagnosis than the prognosis[14,25,26], and wanted to receive less information than younger patients[14,24,27]. A population-based study carried out in Europe reported that people aged under 70 were more likely to want to know if they had limited time left[3], while a study conducted in Belgium showed that younger participants (25–34, 35–44 and 45–54 years) were more likely to want to be fully informed about their disease[12].

Most studies investigating information preferences have focused on cancer patients or the terminally ill[12]. Population-based studies have also explored end-of-life care preferences, including preferences for information, to inform policy making and public education and health promotion programs to promote awareness of these matters in the general population and health professionals[12,28]. In Brazil, despite advances in palliative care in recent years, little is known about end-of-life care preferences, including preferences for prognostic information. It is therefore vital to conduct research into people's preferences to raise awareness among health professionals of the importance of respecting patients' wishes about end-of-life care.

The objective of this study was to determine the preferences of community-dwelling older people for information on limited time left, symptoms and problems, and available care options within a scenario of serious illness with less than a year to live, and examine the influence of sociodemographic factors on preference to always be informed about limited time left.

Methods

A cross-sectional study was conducted between February and July 2015. The study sample comprised individuals of both sexes aged over 60 years living in Belo Horizonte, Brazil. The sample size was calculated based on the population of older people in Belo Horizonte reported by the 2010 Census conducted by the Brazilian Institute of Geography and Statistics (299,177 people aged ≥60). Sample size was determined using the Krejcie and Morgan table[29] adopting a 95% confidence level, a margin of error of 5%, and considering a more conservative scenario *(p = 0.5)*, it resulted in a representative sample of approximately 400 individuals. Subsamples were calculated based on the age (60-69 years; 70-79 years; ≥ 80 years) and gender distribution of older people in Belo Horizonte[30]. The number of people in each stratum was calculated using proportionate stratified random sampling to ensure that the sample was directly proportional to the sample universe.

The participants were selected from the Reference Center for Older People (CRPI, acronym in Portuguese) and 10 older people's groups from reference centers for social services (CRAS, acronym in Portuguese), managed by the city council's department of social services (SMAAS, acronym in Portuguese). The SMAAS helped select ten different groups covering all the city's regions (*Barreiro, Centro-Sul, Leste, Nordeste, Noroeste, Norte, Oeste, Pampulha, and Venda Nova*). These sites were chosen for data collection due to the non-institutionalized profile of the participants. The study was approved by the director of CRPI and secretary of the SMAAS.

The study was presented to potential participants by the first author or professionals working in the CRPI/groups over the microphone or, when the group was smaller, personally. The questionnaires were administered via an individual interview conducted by the first author, who received training from the team that trained the interviewers who administered the questionnaire in Europe. The inclusion criteria were as follows: aged ≥ 60 years, residing in Belo Horizonte, and capable of providing informed consent. People who were disoriented in time and place were excluded based on the indication of the professionals working in the CRPI/groups.

The questionnaire was developed as part of the project PRISMA (Reflecting the Positive diveRsities of European prIorities for reSearch and Measurement in end of life cAre), funded by the European Commission's Seventh Framework Programme[31]. The questionnaire analyzes end-of-life care preferences and priorities within a scenario of serious illness such as cancer with less than a year to live. It has two sections: the first consists of 10 questions on end-of-life care preferences and priorities and the second includes items on sociodemographics and experience with illness, death and dying[32].

This study used the version adapted for use in Brazil[32], which was modified based on the recommendations of Brazilian professionals with vast experience in care for older adults and palliative care[32]. In the Brazilian version we increased the range of options of serious illness (not just cancer), widening the life-threatening chronic diseases group to include heart disease, chronic obstructive pulmonary disease, kidney failure, and Alzheimer's disease. Furthermore, in Brazil the interviews were face-to-face, as opposed to Europe[3], where the questionnaire was administered by telephone, and Kenya[33], where a street survey was conducted.

The three survey questions reported in this paper were: *If you had a serious illness, and were likely to have less than one year to live, (i) Would you like to be informed that you had limited time left?; (ii) Would you like to be informed about what symptoms and problems you were likely to experience?; (iii) Would you like to be informed about the options available for care and how they might affect you? These options might be services available, places where you could be looked after, treatments and medication*. Answer options were: *Yes, always*, *Yes, but only if you ask about it*, "*No* and *You don't know*.

The data was processed using Microsoft Excel 2010® and SPSS Statistics 22.0®. Normality was tested using the Kolmogorov-Smirnov test (K-S test statistic). For non-normal distributions we used non-parametric tests for comparing the medians of two independent samples (Mann-Whitney, MW test statistic) and for comparing the medians of two or more independent samples (Kruskal-Wallis, KW test statistic). When the results of the Kruskal-Wallis test showed significant differences between the groups, multiple comparisons between the group pairs were performed to detect the groups that showed the differences. Non-normal continuous variables were expressed as medians (Med) and first and third quartiles ([Q_1-Q_3]).

The categorical variables were described using frequencies N (%). Logistic regression was performed to identify the factors associated with preference to always be informed about limited time left. Bivariate analysis was performed to test the association between the dependent variables (always be informed *versus* other response options) and independent variables (gender, age bands, education level, marital status, religion, ethnicity, activities in the last seven days, financial hardship, number of adults living in the respondent's home, number of children living in the respondent's home, general health, preferred place of death, least preferred place of death, and experience with illness, death and dying). Multivariate logistic regression was performed to control for confounding variables, including co-variables that showed a statistically significant association with the dependent variables (always be informed *versus* other response options) in the simple logistic regression model. A significance level of $p \leq 0.05$ was adopted for all analyses.

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 (PCEDCSS-FMUP 15/2014) and by the Research Ethics Committee of the Municipal Department of Health of Belo Horizonte (SMSA-BH). The purpose of the research was explained to participants. They were given time to ask questions and clarify any potential concerns. After answering these and clarifying any potential concerns, all the participants signed a consent form.

Results

The majority of the respondents were retired (80.5%), reported that they were coping on present income (51.7%), and Catholic (66.8%). Over half the sample (53.5%) self-reported good general health, 19% had been diagnosed with a serious illness in the last five years, and 66% had cared for close relative/friend in last months of life (Table 1).

Preferences for information on time left, likely symptoms and problems, and care options available

The data (Table 2) show that most participants (74%) would always want to be informed about limited time left within a scenario of serious illness with less than a year to live. When we combined the options ["yes, always" and "yes, but only if you ask about it"], we observed that 78.5% of the participants would always want to be informed. "No" was the second most chosen option (20.5%).

The preference to always want to be informed about time left (74%) was lower than that of to always want to be informed about symptoms and problems (89.3%) and to always want to be informed about available care options (services available, places where you could be looked after, treatments and medication) (96.3%) (Table 2). Preference to always to be informed about symptoms and problems and available care options was greater in men than in women (93% and 86.7%, respectively, and 96.8% and 95.8%, respectively).

The majority of both men and women would always want to be informed about limited time left. Preference was greater among men (83%) than in women (68%) across all age bands (Table 2). The results of the logistic regression indicate that being a woman is a significant protective factor for always wanting to be informed about limited time left (OR=0.436: 95% CI: 0.266-0.714) (Table 3). In addition, choosing the home of a close relative/friend as the least preferred place of death was a significant risk factor for always wanting to be informed about limited time left (own home; OR=2.605: 95% CI: 1.225-5.540).

Of the independent variables included in the multivariate logistic regression model, only gender and least preferred place of death maintained statistical significance (Table 4). The following factors were significantly associated with always wanting to be informed about limited time left: being a woman (OR= 0.446: 95% CI:0.269-0.738; Ref: man) and having chosen the home of a relative/friend as the least preferred place of death (OR= 2.423: 95% CI:1.130-5.198; Ref: own home).

Discussion

To the best of our knowledge, this is the first study to investigate the preferences of community-dwelling older people living in Belo Horizonte for information within a scenario of serious illness with less than a year to live. The data shows that the majority of participants would always like to be informed about limited time left (74%). However, this preference was lower than that for wanting to be informed about symptoms and problems (89.3%) and available care options (96.3%). A European population-based study showed that the majority of participants (73.9%) would want to always be informed about limited

Table 1. Participant characteristics.

Variables	n	%
Age bands (years)		
60-69	217	54.3
70-79	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 11 years	122	30.5
Higher education	45	11.3
Marital Status		
Single	61	15.3
Married or with a partner	167	41.8
Separated or Divorced	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: Asian Brazilian; 1: Indigenous)	223	55.8
Activities in the last seven days		
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 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
Preferred place of death		
Own home/home of relative or friend*	209	52.2
Palliative care unit	71	17.8
Hospital – but not palliative care unit	86	21.5
Nursing home or residential home	34	8.5
Least preferred place of death		
Own home	60	15.0
Home of a relative or friend	88	22.0
Palliative care unit	8	2.0
Hospital – but not palliative care unit	85	21.3
Nursing home or residential home	159	39.8
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

(*)Because only 2 individuals showed preference for place of death "Home of relative or friend", in subsequent analyses, the answers "Own home" and "Home of relative or friend" were aggregated into a single group.

it continues

Table 1. Participant characteristics.

time left[3]. However, the data showed that older people in Belo Horizonte showed greater preference than those in Europe among the older age bands (60-69 years: 75.1%; ≥ 70 years: 72.7% compared to 60-69 years: 74.2%; ≥ 70 years: 67.5%)[3].

These findings suggest that health professionals should be adequately equipped with knowledge and effective patient communication skills[3,4]. Moreover, they should be prepared to deliver news about the prognosis and provide information on the disease and available treatments to terminally ill patients[3]. It is also vital

Table 2. Preferences for information on time left, likely symptoms and problems, and care options available; age bands and gender.

Would want to know about	Age bands, Male			Age bands, Female			Total
	60-69	**70-79**	**≥ 80**	**60-69**	**70-79**	**≥ 80**	
Time left							
Yes, always	79 (84.9%)	38 (80.9%)	15 (78.9%)	84 (67.7%)	55 (74.3%)	25 (58.1%)	296 (74.0%)
Yes, but only if you ask about it	2 (2.2%)	0 (-)	1 (5.3%)	10 (8.1%)	2 (2.7%)	3 (7%)	18 (4.5%)
No	12 (12.9%)	8 (17.0%)	3 (15.8%)	27 (21.8%)	17 (23.0%)	15 (34.9%)	82 (20.5%)
Don't know	0 (-)	1 (2.1%)	0(-)	3 (2.4%)	0(-)	0(-)	4 (1.0%)
Symptoms and problems							
Yes, always	86 (92.5%)	46 (97.9%)	16 (84.2%)	107 (86.3%)	70 (94.6%)	32 (74.4%)	357 (89.3%)
Yes, but only if you ask about it	1 (1.1%)	1 (2.1%)	0 (-)	7 (5.6%)	2 (2.7%)	2 (4.7%)	13 (3.3%)
No	5 (5.4%)	0(-)	3 (15.8%)	10 (8.1%)	2 (2.7%)	9 (20.9%)	29 (7.3%)
Don't know	1 (1.1%)	0(-)	0 (-)	0 (-)	0 (-)	0 (-)	1 (0.3%)
Care options							
Yes, always	90 (96.8%)	47 (100%)	17 (89.5%)	117 (94.4%)	73 (98.6%)	41 (95.3%)	385 (96.3%)
Yes, but only if you ask about it	0 (-)	0 (-)	1 (5.3%)	3 (2.4%)	1 (1.4%)	2 (4.7%)	7 (1.8%)
No	3 (3.2%)	0 (-)	1 (5.3%)	4 (3.2%)	0 (-)	0 (-)	8 (2.0%)
Don't know	0 (-)	0 (-)	0 (-)	0 (-)	0 (-)	0 (-)	0(-)

that health professionals know how to elicit and respect the preferences of patients who do not wish to be informed, which was the second most chosen option in the present study (20.5%). Support should be provided to these professionals in the form of end-of-life communication training and palliative care should be included in the medical school curriculum[4]. It is also important to promote campaigns to raise awareness among the Brazilian population regarding issues such as death and dying and palliative care and to encourage patients to talk to doctors about their wishes and end-of-life care preferences.

Studies suggest that the preference for wanting to receive information depends on the type of population studied[14,34]. It has been suggested that in some traditionally Catholic countries such as Italy doctors show greater resistance to communicating complete information to seriously ill patients and are more likely to take a more paternalistic approach[3,35]. Other studies have shown that preferences for prognostic information may be influenced by ethnicity and race[34]. However, our data shows that, despite the fact that the majority of the participants were Catholic (66.8%) and that Brazilian doctors commonly take a paternalistic stance[7,36], most of our respondents would prefer to always be informed about limited time left. This may be partially explained by the profile of the participants of the present study. The study was conducted in settings where older people are offered various services, including exercise, literacy programs, computer/technology classes, and rights promotion and defense programs. The older people in these settings are therefore generally more active and independent and take care of their health. Older people with a different profile, who for example are more physically dependent, may have other preferences. However, these relations are not clear and, although evidence suggests that prognosis disclosure is vital to ensuring quality care, there is a lack of research on preferences for information among older people[34].

Gender can play a significant role in determining preferences for information and patient medical decision-making[37]. The present study shows that men were more likely to want to receive information about limited time left than women. Previous studies have also found that preference for receiving prognostic information is higher in men than women[3,38]. Other studies

Table 3. Univariate logistic regression. Dependent variable: preference to always be informed about limited time left.

Factors	OR [95% CI]	p-value
Age bands (ref: 60-69 years)		
70-79	1.100 [0.652 – 1.856]	0.720
≥80	0.602 [0.329 – 1.102]	0.100
Gender (ref: male)		
Female	0.436 [0.266 – 0.714]	**0.001***
Marital Status: (ref: single)		
Married or with a partner	1.357 [0.696 – 2.648]	0.370
Divorced or separated	0.902 [0.395 – 2.055]	0.805
Widowed	0.960 [0.485 – 1.902]	0.908
Education (ref: no formal schooling)		
Up to 4 years	0.584 [0.209 – 1.634]	0.306
Up to 8 years	0.475 [0.154 – 1.461]	0.194
Up to 11 years	0.518 [0.183 – 1.462]	0.214
Higher education	0.618 [0.191 – 2.005]	0.423
Religion (ref: Roman Catholic)		
Protestantism/Evangelical	1.393 [0.727 – 2.670]	0.318
Spiritism/Afro-Brazilian	1.194 [0.514 – 2.774]	0.681
Other	5.969 [0.775 – 45.976]	0.086
No religion	1.353 [0.482 – 3.797]	0.566
Ethnicity (ref: white)		
Black	0.790 [0.399 – 1.565]	0.499
Brown	1.030 [0.612 – 1.732]	0.912
Other	0.341 [0.021 – 5.631]	0.452
Financial hardship (ref: Very difficult on present income)		
Difficult on present income	0.976 [0.323 – 2.948]	0.966
Coping on present income	0.836 [0.316 – 2.210]	0.718
Living comfortably on present income	1.187 [0.426 – 3.307]	0.743
Health (ref: very bad)		
Fair	0.976 [0.323 – 2.948]	0.966
Good	0.836 [0.316 – 2.210]	0.718
Very good	1.187 [0.426 – 3.307]	0.743
Close relative/friend seriously ill in last 5 years (ref: yes)		
No	0.778 [0.472 – 1.285]	0.327
Death of close relative/friend in last 5 years (ref: yes)		
No	0.988 [0.614 – 1.592]	0.961
Diagnosed with serious illness in last 5 years (ref: yes)		
No	0.859 [0.479 – 1.539]	0.609
Cared for close relative/friend in last months of life (ref: yes)		
No	1.376 [0.846 – 2.238]	0.198
Preferred place of death (ref: own home/home of relative or friend)		
Palliative care unit	0.883 [0.479 – 1.631]	0.692
Hospital – but not a palliative care unit	0.745 [0.426 – 1.302]	0.745
Nursing home or residential home	1.049 [0.447 – 2.462]	0.912
Least preferred place of death (ref: own home)		
Home of a relative or friend	2.605 [1.225 – 5.540]	**0.013***
Palliative care unit	0.965 [0.210 – 4.432]	0.963
Hospital – but not a palliative care unit	1.658 [0.811 – 3.389]	0.166
Nursing home or residential home	1.666 [0.884 – 3.141]	0.114

*: Significant results are presented at significance level of 5%.

Table 4. Multivariate logistic regression. Dependent variable: preference to always be informed about limited time left.

Variables	OR [95% CI]	p-value
Gender (ref: male)		
Female	0.446 [0.269 – 0.738]	**0.002***
Least preferred place of death (ref: own home)		
Home of a relative or friend	2.423 [1.130 – 5.198]	**0.023***
Palliative care unit	1.059 [0.228 – 4.925]	0.942
Hospital – but not a palliative care unit	1.497 [0.724 – 3.095]	0.276
Nursing home or residential home	1.415 [0.739 – 2.706]	0.295

*: Significant results are presented at significance level of 5%.

have shown that women with advanced cancer are more likely to take a more active role in decision-making, but desire greater emotional support from their doctors[38,39]. In contrast, male patients play a more passive role in decision-making, but want to receive more information about their health[38,39]. Moreover, it is known that gender influences aging and older people's relationship with healthcare[40] , meaning that men and women may show different perceptions and behaviors when it comes to end-of-life care.

Our findings also suggest that participants who chose the option "home of relative/friend" as the least preferred place of death were more likely to choose to be always informed about limited time left than those who chose "own home". Our data show that the majority of respondents would want to participate in medical decision-making both in the scenarios capacity and incapacity to make decisions (95.3% and 64.5%, respectively)[41]. It is possible that the participants who chose the option "home of relative/friend" fear that they would have less decision-making autonomy in this setting and therefore want more information than those who chose "own home", where their preferences are more likely to be respected. However, the evidence on place of death remains unclear, particularly among the older population, and less evidence exists regarding least preferred place of death[2,42,30]. Further research is therefore needed to explore the influence of these factors on preferences.

This study has some limitations. As mentioned above, older people with greater functional dependency and frailty may have been underrepresented. Future studies should therefore include individuals with greater functional dependency. Furthermore, none of the participants self-reported bad or very bad general health, meaning that some may have difficulty imagining a scenario of serious illness with less than a year to live. However, 19% of our participants had been diagnosed with serious illness in last 5 years and ≥66% had had a close relative/friend who had been seriously ill in last 5 years, or had lost a close relative/friend in the last five years, or had cared for a close relative/friend in last months of life. Therefore, the participants' experiences with serious illness, dying and death helped them to contextualize the scenario used in the questionnaire. It is recommend that future studies should be conducted with older people with advanced disease to determine whether preferences for information change when someone is faced with a poor diagnosis.

Conclusion

The findings show that the majority of community-dwelling older people in Belo Horizonte would want to be informed about limited time left in a scenario of advanced disease. Men are more likely to want to receive prognostic information than women. These findings are a warning signal for health professionals providing care for older people with a life-limiting serious illness. It is vital to establish effective communication with patients as early as possible to ensure that their preferences are communicated and respected.

Collaborations

R Jorge participated in study conception and design, data collection, analysis, and interpretation, and in drafting this article. A Teixeira participated in data analysis and interpretation and the revision of this article. N Calanzani participated in data analysis and interpretation and the revision of this article. R Nunes participated in study conception and design and the critical revision of the version to be published. L Sousa participated in study conception and design, data analysis and interpretation, and in the critical revision of the version to be published.

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