

A4 A statistical analysis of end-of-life care concerns and preferences among Brazilian older people

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Introduction

Currently, populations around the world are ageing and people can expect to live longer than ever before. The willingness to make choices about one's own death is widely regarded as a prerequisite for a 'good death'. End-of-life preferences and concerns should be encouraged to be expressed by people who wish to do it [1]. People approaching the end of their lives have shown a common and growing concern about being a burden to others [2]. For the older people, the feeling of "being a burden" can sometimes result in frustration which then leads to feelings of guilt for being responsible for the carer's difficulties [3]. The care of the older people in end-of-life care must be considered in the context of the psychological, physical and social experiences of a person's life [4].

Objective

Based on bivariate statistical methods involving both statistical tests and exploratory techniques, the existence of factors influencing the level of concern related with different symptoms and problems in end-of-life care in elderly people was investigated.

Methods

A survey on preference and priority for end-of-life care was conducted between February and July 2015 in the city of Belo Horizonte in Brazil using the Brazilian Portuguese version of a questionnaire adapted by [5] from the original English version developed by PRISMA project [6]. Socio-demographic characteristics and experiences with illness, death and general health were also included in this questionnaire. A total of 400 people over 59 years old participated in this survey. Some topics covered by this questionnaire have already been investigated in previous works [7,8,9]. In the present study, the choices given by the participants regarding a list of predefined nine symptoms and problems that they were most concerned about were examined (Table 1). The symptom 'Burden to others' ranked first and therefore it was examined in detail. Chi-Square tests were used to analyse the association between this symptom and each of the variables referring to the participants' socio-demographical characteristics (16 variables listed in Table 2). Since only one variable exhibited significant association, a heatmap of the data submatrix with the responses of the 400 participants on this variable and the symptom 'Burden to others', was constructed to visually explore this association. For evaluating the level of concordance between the groupings of the 400 participants defined by those two features, the Adjusted Rand Index (ARI) was calculated. To numerically assess the level of association, the value of the Cramer coefficient was also calculated. Finally, the Bimax algorithm of biclustering techniques [10] was applied on a binary data matrix. This matrix corresponds to the original data of the 400 participants restricted to the binary variables (a total of 30 variables). The main goal was the detection of biclusters that provide similar patterns of binary characteristics among participants who chose 'burden to others' as their first or second concern.

All statistical analyses were performed using R software (version v.4.0.2 for Windows). The following packages were used: foreign, MASS, Hmisc, gplots, vcd, mclust and biclust. Results of statistical tests were taken to be statistically significant when p-value < 0.05.

Results

For the first most concern, the top choice among the 400 participants was 'Being a burden to others' (44.3%) followed by 'Being unable to get your breath' (20.5%) and 'Being in pain' (20%) (Table 1). These three problems also corresponded to the three top choices of the second most concern, in a total of 69.1% of

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Table 1 - Survey question about most concerning symptoms and problems and frequencies of the observed responses.

A. Which of the following nine symptoms or problems do you think would concern you most?		
B. And in second place?		
Symptoms and problems	Response in A n (%)	Response in B n (%)
1. Having no energy	19 (4.8%)	46 (11.5%)
2. Being in pain	80 (20%)	89 (22.3%)
3. Changes in the way you look	4 (1%)	11 (2.8%)
4. Having no appetite at all	6 (1.5%)	6 (1.5%)
5. Being a burden to others	177 (44.3%)	84 (21%)
6. Being unable to get your breath	82 (20.5%)	103 (25.8%)
7. Being alone	23 (5.8%)	36 (9.0%)
8. Feeling as if you want to be sick	6 (1.5%)	7 (1.8%)
9. Being worried and distressed	3 (0.8%)	18 (4.5%)

the participants (Table 1). A new variable was created in representation of the responses to questions A and B in Table 1 according to the top concern. If the individual answered 'burden to others' in question A, this new variable received a score of 2, a score of 1 if he/she answered 'burden to others' in question B and a score of 0 if he/she did not answer 'burden to others' in either A or B. From now on, this new variable is named 'AB5'. In a bivariate context, only one factor ('Living arrangements') showed to be statistically significant associated with 'AB5' (Table 2) with a low value of the Cramer coefficient ($=0.138$). In Table 3, the observed cross frequencies related to this association are described. A person who selected 'Burden to others' as the top most concern is expected not to live alone ($135/177 > 42/177$). However, the variable 'Living arrangements' does not seem to be a 'good predictor' of the 'Burden to others' since a person who does not select 'Burden to others' is also expected to live accompanied ($114/139 > 25/139$). Similar idea is depicted in Figure 1. In the heatmap, there are clearly not distinguishable different color patterns related to the scores 0, 1, 2 for 'AB5' and the factor 'Living arrangements'. Furthermore, an ARI value of -0.017 was obtained between the clustering defined by 'AB5' (given by three groups of participants) and the factor 'Living arrangements' (given by two groups of participants). This ARI value close to zero corresponds to interpret that the participants randomly attributed for each of these two features and thus there is not agreement between them. All these facts suggest that the significant association highlighted in Table 2 can be weak. Moreover, exploring subgroups of participants with similar patterns on binary data, a bicluster with 5 variables and (only) 47 participants out of the 400 was identified. This bicluster is constituted by retired woman, between 60-70 years old, who had experienced the death of a close relative/friend in the last 5 years and who selected 'Burden to others' as their first or second concern. No larger biclusters were identified. It suggests the difficulty to capture patterns among these participants.

Table 2 - Association between 'AB5' and all other existing variables.

Categorical Variables	Chi Square Test p-value
Gender	0.1525
Age	0.4389
Education	0.6168
Religion	0.6768
Health	0.6656
Marital status	0.8481
Living arrangements	0.0221
Paid Work	0.8837
In Education	0.5604
Retired	0.3553
Financial hardship	0.0814
Ethnicity	0.5669
Close relative/friend seriously ill in last 5 years	0.8300
Death of close relative/friend in last 5 years	0.9828
Diagnosed with seriously illness in last 5 years	0.5809
Cared for close relative/friend in last months of life	0.4497

Table 3 - Frequency cross table between 'Burden to others' and 'Living arrangements'

Score – Option in response A and B	1. Living alone n (%)	2. Living with others n (%)	Total
0 - Did not selected 'burden to others'	25 (6.3%)	114 (28.5%)	139
1 - Selected 'burden to others' as the second most concern	8 (2%)	76 (19%)	84
2 - Selected 'burden to others' as the first most concern	42 (10.5%)	135 (33.8%)	177
Total	75 (18.75%)	325 (81.25%)	400

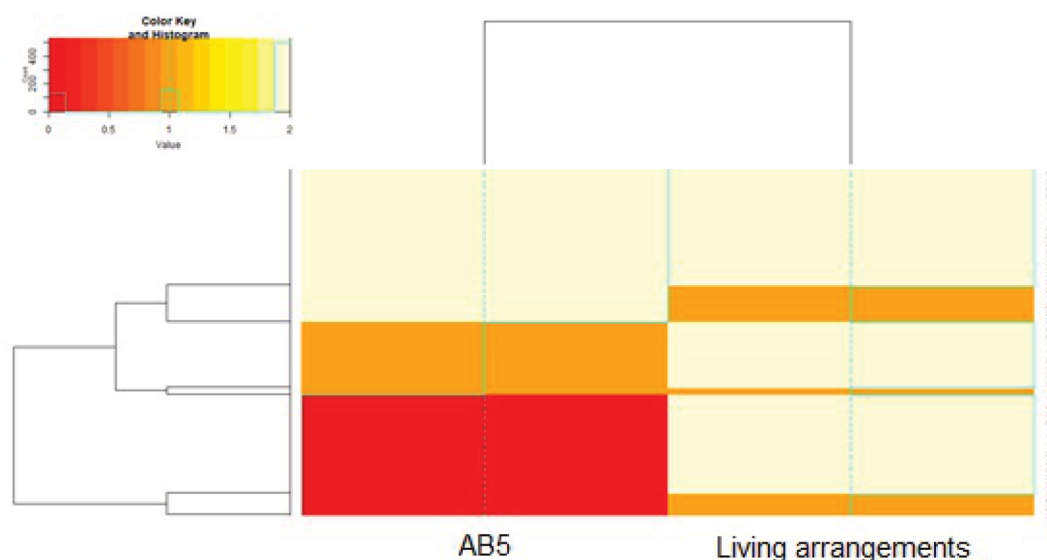


Figure 1 - Heatmap on the 400 participants (vertical axis) described by two variables 'AB5' (scores: 0,1,2) and 'Living arrangements' (scores: 1, 2) (horizontal axis). The scores are according to Table 3.

Discussion

The three main concerns among the 400 elderly surveyed were 'Burden to others', 'Being unable to get your breath' and 'Being in pain'. While 'Living arrangements' showed to be a statistically significant factor to 'AB5', applying different exploratory statistical approaches to extract more information about factors influencing the concern level in end-of-life care among 400 older people, any strong factor was not revealed which is in accordance with the low value given by the Cramer coefficient.

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