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## **Perceived Risk of Death in Older Primary Care Patients**

### **Abstract**

There is a large gap between life expectancy and healthy life years at age 65. To reduce this gap it is necessary that people with medical concerns perceived at higher risk of adverse outcomes are readily identified and treated. The same goes for the need to implement prevention plans. The main objectives of this study are: in a first step, (i) to estimate the percentage of medical concerns and (ii) to identify factors associated with this concern; in a second step, (iii) to estimate the perceived risk of death and (iv) to evaluate the ability of medical concerns to predict this risk. Results show that the existence and severity of medical concerns are crucial in the prediction of perceived risk of death. Early identification of severity of medical concerns and the availability and adequacy of informal caregiving should allow healthcare professionals to promptly initiate an appropriate assessment and treatment of older patients.

### **Keywords**

Perceived risk of death; Medical concerns; Primary care patients; Informal caregiver; Prevention.

## **Introduction**

Considering the total population in 2012 in Portugal (N=10 487 289), the number of deaths was 107 969, of which 90 235 (83.6%) were people with 65 years old or over. Main causes of death for this age group are: (1) circulatory diseases (n=30 399; 33.7% - with ischemic heart diseases and cerebrovascular diseases identified as the most prevalent); (2) Cancer (n=18 742; 20.8%); (3) respiratory diseases (n=13 283; 14.7% - pneumonia representing half of the percentage) (George, 2012; INE & DGS, 2014). These three main causes of death are also identified as the most prevalent in Europe (EUROSTAT, 2015a).

The main factors associated to the premature death (death before age 70) in Portugal were: inappropriate dietary habits (19%), hypertension (17%), high body mass index (13%) and smoking (11%). However, there is a clear improvement concerning the prevention of death before the age of 70, with consequent reduction of potential years of life lost. Some authors consider that 25% of the premature cause of death can be prevented (INE & DGS, 2014). A recent paper also concludes that extrinsic risks factors (e.g., life style) have a substantial contribution to cancer development, around 70-90% in most common cancer types (Wu, Powers, Zhu, & Hannun, 2015). These findings are relevant for the development of strategies of death prevention, namely reducing salt in the diet, reducing smoking, promoting physical activity and promoting healthy aging and at the same screening / monitoring / surveillance in the case of tumors, high blood pressure, complications associated to diabetes and overweight (INE & DGS, 2014).

Following the European trend, a recent report on the Health of the Portuguese Population demonstrated a progressive evolution of a higher life expectancy at age 65, revealed by a positive evolution of general health indicators. Additionally, an increase in the healthy life years has been observed. In the last decade, the life expectancy at age 65 increased approximately one year (18.21 years for 2006-2008 and 19.12 years for 2012-2014), and sex differences remained constant (DGS, 2015; INE & DGS, 2014). However the gap between life expectancy and healthy life expectancy is still large in Portugal and there is a lot to be done to compress morbidity (Fries, 1980). Life expectancy at 65 years for females is 21.6 years but healthy life expectancy is

only 9.3 years. For men life expectancy at 65 is 17.8 years of which only 9.6 are in good health (EUROSTAT, 2015b).

Primary Care (PC) is the keystone in any Health Care System. Considered the gatekeepers to health care, General Practitioners (GP) and Community Nurses (CN) are the pillar of health outcomes. These professionals treat and monitor patients and their families, assuming a relevant role in preventing and/or treating disease and its adverse outcomes. Financial resources for health are scarce even in developed countries and should be used carefully to guarantee equity and equality of access to people. Recent financial crises make this assumption even more pertinent and PC is ought to assume an important role in maximizing resources in order to diminish early mortality. Knowing and monitoring patients for a long period of time gives GP and CN an exclusive view about the risk condition of each patient, here onwards called the perceived risk status.

This perception is a subjective evaluation of the health status of a patient that is being followed during a considerable long period of time, and their potential risk of adverse outcomes namely the risk of death. Perception means that it is subject to a simplified mental process that retains the common features of the object, and organizes available information facilitating a general comprehension (Fleishman, 1975). This perception can be further explored, making the basis of clinical work. Before a systematic evaluation of a patient there is a clinical judgment that raises a hypothesis to be confirmed in the form of a diagnosis. Whenever regular patients are assessed, new pieces of information enter the patient file and the general perception of the patient' concerns and risk status is reconstructed in the professional' perception of the patients status. Similarly with what happens with the predictive value of mortality, the patients' self-perception of health or of the activity level (e.g. (Ferraro & Wilkinson, 2013; Lee, 2000; Mullee, Coleman, Briggs, Stevenson, & Turnbull, 2008), professionals' perception about their regular patients, may be a useful pre-screening tool for further triage and intervention.

O'Caoimh et al. (O'Caoimh et al., 2014) developed a pre-screen test to identify the perceived level of risk of adverse health outcomes of PC patients. With this

instrument it is possible to identify patients at higher risk and intervene in order to prevent or delay an adverse outcome (O'Caoimh et al., 2014).

Considering that the main causes of death are chronic diseases and that most of them are preventable, the existing gap between life expectancy and healthy life expectancy at age 65 can be straitened by adequate interventions focusing primarily on healthy behaviors. To intervene with people that would benefit the most from the intervention implies the identification of high-risk patients in a sustainable way. This research main objectives are: in a first step, (i) to estimate the percentage of medical concerns and (ii) to identify factors associated with this concern; in a second step, it aims (iii) to estimate the perceived risk of death and (iv) to evaluate the ability of medical concerns (presence, severity and capacity of caregiver to manage) to predict this risk.

## **Methods**

### *Design*

This work is part of a large, ongoing study approved by the ethics committee of the Portuguese Regional Association of Health North (ARS North) and adhered to the tenets of Declaration of Helsinki. Twenty-four Associations of Health Centers of the ARS North have participated in the study and were involved in the data collection.

### *Participants*

The sample was composed by primary care patients with the following inclusion criteria: (1) aged 65 years or over; (2) living in the community in the area covered by the ARS North; (3) primary care patients; (4) provided informed consent. Only patients with complete information (demographic characteristics and main research measure – RISC, see next section) were considered. Patients not attending the primary care center regularly were also excluded given that no accurate data were available and they could not be scored with the RISC.

### *Measures and Procedures*

The RISC was developed in University College Cork (UCC), Ireland (O'Caoimh et al., 2014) and was adapted into Portuguese (Paúl et al., 2015). The instrument includes demographic data and records the presence (yes or no responses), magnitude

(mild, moderate, and severe) and capacity of the caregiver to manage the situation (Likert scale scored from 1 - can manage all risks to 5 - the caregiver network is a liability or is absent); it concerns three domains: mental state, activities of daily living (ADLs) and medical state. Based upon severity of concern and the caregiver networks' ability to manage them, an overall global subjective assessment of risk score is then assigned to three adverse outcomes: institutionalization, hospitalization and death at 1 year from the date of assessment (Rónán O'Caomh et al., 2015). A Likert scale scores five levels of risk from one (minimal and rare) to five (extreme and certain). In this work, perceived risk of death was settled as the main outcome, considering a dichotomous variable: minimal/low risk (levels 1 and 2) vs moderate/extreme risk (levels, 3, 4 and 5). The RISC instrument has excellent inter-rater reliability, internal consistency and takes 2–5 min to complete (R. O'Caomh, Healy, Connell, Gao, & Molloy, 2012).

Healthcare professionals (GP and CN) who agreed to participate in this study received training and certification in scoring the RISC. Once trained, general practitioners and nurses scored the RISC of their own regular patients, using their clinical knowledge of each patient's current health status (i.e. the perceived risk of adverse outcomes, namely the risk of death in the following year).

### *Statistical Analysis*

Descriptive analysis was performed to summarize sample characteristics (gender, age, presence of mental health and ADLs concerns).

Logistic regression models were considered to identify potential predictive factors of medical concerns. Odds Ratio (OR), 95% Confidence Interval (CI) and respective p-values were estimated and used to summarize results.

Three multivariable logistic regression models, using sex, age and presence of mental health and ADLs concerns as covariates, were performed considering perceived risk of death as outcome. To evaluate the diagnostic performance of different models, receiver operating characteristic (ROC) curves were constructed, considering sensitivity on the y-axis and 1–specificity on the x-axis for different cutoff levels. The area under the ROC curve (AUC) provides a measure of the overall discriminative

ability of a model. The AUC and its standard error (se) were estimated using the nonparametric approach (Pearce & Ferrier, 2000).

## **Results**

The sample comprised 4470 primary care patients with mean age 76.0 years (sd=7.2 years; min=65 years and max=103 years). Of these 2624 (58.7%) were females. One thousand, six hundred and fifty-one participants (36.9%) were scored as having mental health concerns and 2042 (45.7%) ADL concerns.

### *Medical concerns*

Approximately 78% of the sample (n=3491) was scored as having medical concerns, of which 14.4% labeled as “severe”. Of patients with medical concerns, 57.3% had a caregiver network that was perceived to be able to manage the situation. Option five (liability of care) of the caregiver networks’ ability to manage was not considered given the small number of records. In order to identify prognostic factors of medical concerns, univariable logistic regression models were performed and the results are presented in Table 1. All variables tested are statistically significant. Females, older age and presence of ADL or mental health concerns were associated to higher odds of medical concerns. Considering adjusted model, all variables remained significant with the exception of sex.

(INSERT TABLE 1)

### *Perceived risk of death*

One thousand and thirty eight participants (23.2%) were scored with perceived risk of death in the following year.

Three multivariable logistic regression models were performed for the perceived risk of death as outcome. Model 1 (M1) included the presence/absence of medical concerns, model 2 (M2) the severity of medical concerns, and model 3 (M3) the ability of the caregiver network to manage risk. Results of multivariable models (adjusted for sex, age, mental health concerns and ADLs concerns) were presented in Table 2. Patients with medical concerns had greater odds of perceived risk of death

[OR (95% CI)=5.631 (3.654-8.677)]. The odds of perceived risk of death increased with the increase of severity of medical concerns. Analyzing results of M3, the odds of perceived risk of death increased as the ability of the caregiver network to manage medical concerns decreased.

(INSERT TABLE 2)

The ROC curves of the different models are shown in Figure 1. All models presented good discriminative ability. The model M2 presented higher AUC (0.882, se=0.006), identifying the severity of medical concerns as the best predictive factor of perceived risk of death. Considering the capacity of the caregiver to manage medical concerns as predictive factor of perceived risk of death, the estimative of AUC was 0.840 (se=0.007). Finally, the model M1 that consider presence/absence of medical concerns as the predictive factor of perceived risk of death has presented an AUC of 0.821 (se=0.007).

(INSERT FIGURE 1)

## **Discussion**

Almost 80% of the participants that composed the sample presented medical concerns. After adjusting for sex and age, ADLs and mental health concerns were strong predictors of medical concerns. Approximately 23% of the primary care patients included in the study were classified by the health care professional as being at risk of death. Considering three main predictive factors related with medical concerns included in three separate models (M1: presence/absence of medical concerns; M2: severity of medical concerns, classified as without medical concerns, mild, moderate and severe; M3: capacity of the caregiver to manage medical concerns, classified as without medical concerns, can manage, carer strain, some gaps and cannot manage), all were identified as relevant to predict perceived risk of death. Analysing ROC curves and AUC for each model, all models presented good discriminative ability to predict medical concerns, with the severity identified as the best predictor and presence/absence occupying the last position. To some extent, these results were expected due to the growing vulnerability of the aging organism. Nevertheless, the classification of people according to the perceived level of risk

using the RISC is useful to initiate a comprehensive evaluation of the patients' condition and a customised intervention focusing on those perceived at higher risk. The importance of caregiving for aging results seems clear in a number of studies concerning subjective well-being, adverse outcomes as institutionalization, or the association between social support and lower rates of morbidity and mortality (e.g. (Fry & Debats, 2006; Martire & Franks, 2014; Temkin-Greener et al., 2004; Uchino, 2006)). However the specific association between caregiving ability to cope with the patients' health issues and mortality seems less consensual and less explored so far (Miller & Weissert, 2000). This study raises the hypothesis of a strong association between caregiving and mortality by showing the predictive value of caregiver's ability to manage the situation. In case of not being able to manage the patient's health condition at home, the perceived probability of death is 65 times higher than in case of the caregiver being able to manage the situation. Determining such high odds of perceived risk of death highlights the importance of PC in paying attention to the caregivers' competencies (or lack of) and in developing interventions specially targeted to informal care providers within the Health Care System.

Some limitations of this work should be addressed namely: the sample is not probabilistic given that it was dependent on the willingness of the PC teams to participate, introducing possible selection bias of professionals more sensitive to their patients' conditions. This is a cross-sectional study that does not allow us to draw conclusions on causal relations. This study presents the results of perceived risk death as scored by the RISC and further confirmation of actual outcomes should be obtained in a year and further confirmed in future studies.

## **Conclusion**

As expected the presence/absence of medical concerns and mainly its severity are the best predictive factors of perceived risk of death. The predictive value of the caregiver capacity to manage the situation for the perceived risk of death appears as the second major explanatory variable and justifies further attention. The importance of caregiving is particularly relevant for old people and may be considered a key action item for Health Care Systems' balance and sustainability, and it is necessary to know more about the mediating pathways of social networks impact in mortality.

To identify people at higher risk of death and be aware of the primary caregivers' coping ability to deal with the patients' medical concerns will help to design intervention plans in diverse ways: either by a global assessment of the older patient, the revision of medical treatment and adherence, the placement of the patients in nutrition and physical exercise programs to prevent or delay frailty, or by organizing interventions directed to caregivers to help them better cope with the health condition of their relative or friend.

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Table 1: Univariable and multivariable logistic regression models of medical concerns.

	Unadjusted			Adjusted		
	OR	95% CI	p	OR	95% CI	p
Sex						
Male	1	-	-	1	-	-
Female	1.136	0.984-1.310	0.082	0.931	0.793-1.092	0.378
Age	1.071	1.059-1.083	<0.001	1.011	0.998-1.024	0.105
ADL concerns						

No	1	-	-	1	-	-
Yes	25.25	18-80-33.32	<0.001	17.80	13.03-24.31	<0.001
Mental health concerns						
No	1	-	-	1	-	-
Yes	6.243	5.064-7.696	<0.001	2.050	1.620-2.593	<0.001

OR: Odds Ratio; 95% CI: 95% Confidence Interval.

Table 2: Multivariable logistic regression models of perceived risk of death.

Model	Factor	Perceived risk of death		
		Adjusted OR*	95% CI	p
M1	Medical concerns			
	No	1	-	-
	Yes	5.631	3.654-8.677	<0.001
M2	Severity of medical concerns			
	Without medical concerns	1	-	-
	Mild	1.607	0.998-2.589	0.051
	Moderate	9.738	5.257-15.16	<0.001
	Severe	48.63	29.84-79.24	<0.001
M3	Capacity of the caregiver to manage			
	Without medical concerns	1	-	-
	Can manage	4.536	2.929-7.024	<0.001
	Carer strain	7.189	4.557-11.34	<0.001
	Some gaps	15.96	9.800-25.99	<0.001
	Cannot manage	65.27	32.19-132.4	<0.001

OR: Odds Ratio; 95% CI: 95% Confidence Interval.

\*Adjusted for sex (male/female), age, mental health concerns (yes/no) and ADLs concerns (yes/no).

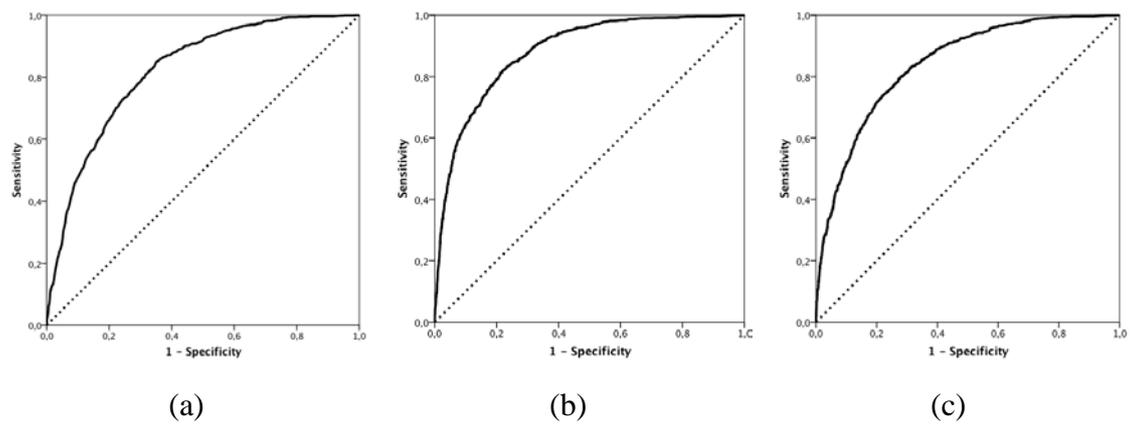


Figure 1: Receiver Operating Characteristic (ROC) curves of the three models considered to estimate perceived risk of death: (a) model M, considering as predictor the presence/absence of medical concerns [AUC=0.821(se=0.007); 95% CI 0.807-0.834]; (b) model M2, considering as predictor the severity of medical concerns [AUC=0.882(se=0.006); 95% CI 0.871-0.893]; (c) model M3, considering as predictor the capacity of the caregiver to manage medical concerns [AUC=0.840 (se=0.007); 95% CI 0.827-0.853].