Archives of Gerontology and Geriatrics 64 (2016) 103–110

Contents lists available at ScienceDirect

Archives of Gerontology and Geriatrics

journal homepage: www.elsevier.com/locate/archger

Decisions in complex clinical situations: Prevalence and factors associated in general public

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ARTICLE INFO

Article history:
Received 15 April 2015
Received in revised form 23 December 2015
Accepted 5 January 2016
Available online 22 January 2016

Keywords:
Preferences patient
Life sustaining treatment
Factors associated

ABSTRACT

Many studies have focused on advanced directives. However, the type of treatment that citizens would choose in critical health situations and whether their decision varies with their sociodemographic characteristics and their experiences of life both within and outside the family context, are unknown. This study analyzes the factors associated with choosing or refusing life support treatment in hypothetical situations of differing clinical complexity. This transversal descriptive study was carried out by questionnaires given to 1051 participants from primary care centres. The Life Support Preferences Questionnaire (LSPQ) used to assess preferences of life-sustaining treatment, describes six scenarios with different prognoses. Analysis of the sociodemographic characteristics and life experiences of the subjects led to the following findings. In situations of very severe prognosis, treatment is mostly rejected. When there is chance of recovery, treatment is mostly accepted, especially in the least aggressive cases and when deciding for another person. A greater propensity to reject treatment was observed among subjects over 55 years, those in poor health and those who had observed a terminal illness in a family member. Practising Catholics are more likely to accept treatment in all medical situations described. Preferences for life support treatment are linked to sociodemographic characteristics and life experiences of patients. Physicians should bear in mind these characteristics when confronted with critical clinical situations, involving difficult decisions.

1. Introduction

The nature of the patient-physician relationship has changed considerably over the last forty years as patient autonomy and participation in decision-making increasingly recognised (Hoving, Visser, Mullen, & van den Borne, 2010).

The most well-known form of anticipatory decision-making is an advance directive. Advance directives are documents that outline treatments that a patient considers acceptable in the event that he or she can no longer communicate or that designate a surrogate decision-maker to make treatment choices on the patient's behalf (Bravo, Dubois, & Paquet, 2003).

Advances in medicine have greatly improved possibilities to treat seriously ill patients and to prolong life. However, there is increasing recognition that the extension of life might not always be an appropriate goal of medicine and other goals have to guide medical decision-making at the end of life, such as improvements in the quality of life of patients and their families through the prevention and relief of suffering (Sepúlveda, Marlin, Yoshida, & Ullrich, 2002; Van der Heide, Deliens, Faisst, Nilstun, & Norup, 2003), so as to not practise what could be interpreted as therapeutic cruelty in the final moments of life.

Many studies show that, despite their wishes, most patients are never asked by a doctor whether or not cardiopulmonary resuscitation (CPR) or other life-sustaining treatment to should be applied (Cherniack, 2002).

Not all patients desire cardiopulmonary resuscitation (CPR) and intubation, and such measures might be medically inappropriate and might cause undue harm to the patients, families, and caregivers. Yet physicians are often unaware of their patients' resuscitation preferences (Cherniack, 2002; SUPPORT, 1995; Robinson, Kolesar, Boyko, Berkowitz, & Calam, 2012). On the other hand, patients' confidence in the capacity of their proxies to predict and respect their wishes is, in general, highly favourable, despite the fact that a surrogate's ability to predict a patient's wishes is

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http://dx.doi.org/10.1016/j.archger.2016.01.002
0167-4943/

only moderately better than chance (Covinsky et al., 2000). One study found that surrogates did not predict their patient's preferences for life-sustaining treatments accurately because the predictions reflected their own wishes for the patient instead of the patient's wishes (Marks & Arkes, 2008). The general accuracy found by a systematic review of 16 studies was 68% (Shalowitz, Garrett-Mayer, & Wendler, 2006).

This lends further credence to the assertion that patients' wishes should be explored before they become ill, and certainly before they become incompetent. It is important to encourage individuals to express their preferences to their loved ones and physicians. Healthcare providers can also help by increasing patients' awareness of the importance of a timely discussion (Klinkenberg, Willems, Onwuteaka-Philipsen, Deeg, & van der Wal, 2004).

Improved knowledge about patient preferences will assist caregivers in facilitating these life-and-death discussions, while respecting patient autonomy and decreasing the number of unwanted and unnecessary interventions (Robinson et al., 2012)

In Spain, the legal and administrative situation of advance directives is one of the most advanced in Europe (Gysels, Evans, Meñaca, Andrew, & Toscani, 2012). However, public's knowledge of their existence is very limited, and in 2014 less than 1% of the population had written advances directives (National Register of Advance Directives, 2014).

There are many studies on the degree of knowledge and attitude of the population towards advance directives (Antolín et al., 2010; Andrés-Pretel et al., 2012) but few have focused on preferences for life-sustaining treatment based on the individual's wishes at the end of life, which, is the essence of the document in question.

Few studies have investigated the treatment preferences of Spanish patients in very committed clinical situations (Rodríguez Jornet et al., 2007; Barrio-Cantalejo, Toral-López et al., 2008). Therefore, little is known about the kind of choice that citizens would perform and whether their decisions vary with the subject's sociodemographic characteristics, with their religious beliefs, and their experiences of life both within and outside the family context.

The objective of this study was to examine the factors associated with preferences of the general Spanish population for life-sustaining treatment in different clinical situations, while being helped to imagine medical situations that could occur in the future, in which the decisions to be made might be very difficult.

2. Methods

Descriptive cross-sectional study through a written questionnaire (LSPQ) completed by a sample of the general population from September 2012 to June 2013.

The sample consisted of randomly selected patients from primary care centres of 9 health areas of south-eastern Spain, inhabited by 1,472,049 people.

To recruit a representative sample of the population, we requested the cooperation of primary care physicians of these areas, explaining the purpose of the study and asking for their participation. Doctors who agreed to participate were given questionnaires and when patients attended during the study period, the doctor gave the questionnaire to those who met the criteria for inclusion and agreed to participate. Patients completed the questionnaire at home and returned it within seven days. A total of 1200 questionnaires were given out, of which 1051 were completed, a reply rate of 87.58%.

Participants are agreed to collaborate and received a document explaining the terms of anonymity and confidentiality. The study was approved by the Ethics Committee of the University of Murcia.

Demographic and clinical data were collected with the questionnaire, such as age, gender, education completed, place of residence, country of origin, marital status, religious beliefs, presence of chronic diseases, perceived health, perceived quality of live, had suffered the death of a close relative/friend in the previous year, were related to persons with terminal illness and work situation.

To obtain reasonable sized samples in the category of religion the term "other religion" included Muslims, Jehovah's witnesses and Buddhists.

The principal variable of this study was the Life Support Preferences Questionnaire (LSPQ), which assesses preferences for life-sustaining treatment (Appendix A).

The LSPQ (Beland, & Froman, 1995) is composed of six vignettes requiring choices concerning the use or not interventions to sustain life. Each vignettes covered ages ranging from childhood to old age. They include various disease conditions and different levels of impairment, acuity and distress. They are written in the first person, and respondents must choose answers that indicate how they would decide about a life-support choice for themselves or as a proxy for a dependent person, choosing between two options: "assent to treatment" and "refuse treatment".

The questionnaire was translated and validated cross-culturally for Spanish speaking population in the USA by Froman and Owen (2003), (LSPQ-s) and in 2008 was validated and translated by Barrio-Cantalejo for Spanish speakers from Spain (LSPQ-e) (Barrio-Cantalejo, Bailón Gómez, et al., 2008). The 2-week stability estimate for the original LSPQ was 0.85 and internal consistency estimates 0.94. For the Spanish version by Barrio-Cantalejo (LSPQ-e), the 2-week stability and internal consistency were 0.92 and 0.85, so the values of reliability, in terms of stability and internal consistency of the version of Barrio-Cantalejo are very similar to the original LSPQ.

Data were collected in a database created for this purpose and processed with statistical software package SPSS 19.0 for windows.

In the descriptive analysis, qualitative variables are expressed as frequencies and percentages with their corresponding 95% confidence intervals and quantitative variables as mean and standard deviation. The comparison between groups used a *t*-student test for quantitative variables and chi-square test for qualitative variables, and, in cases with expected <5 frequencies, Fisher's exact test was use

Multivariate analyses with logistic regression were carried out with all the variables that showed a significant relation with the dependent variable in the bivariate analyses. Then, by backward stepwise selection, we obtained a model with the individual variables directly related to the dependent variable (refuse treatment). A probability level of $p \leq 0.05$ was considered significant.

3. Results

In total, 1051 persons participated in the study. Their characteristics are presented in Table 1. Participants had a mean age of 39 years (range 18–87), 60.1% were women, 56.3% had graduated from high school and 55.4% had a job. 92.6% of participants were Spanish, and 54% were married or lived with a partner. 48.9% were non-practising Catholics. About 52.6% of subjects answered that they had good or excellent health, 61.7% believed that their quality of life was good or very good, 27.4% had experienced the death of a loved one in the previous year and 53.1% had a relative with a terminal illness.

3.1. General treatment preferences

The percentage of participants that accepted treatment in each of the scenarios is shown in Fig. 1. The first two, where a comatose