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# Factors associated with willingness to donate embryos for research among couples undergoing IVF



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**Abstract** Between 2011 and 2012, 213 heterosexual couples undergoing fertility treatments in a Portuguese public fertility centre were systematically recruited to assess factors associated with willingness to donate embryos for research. Data were collected by questionnaire. Most couples (87.3%; 95% CI 82.1 to 91.5) were willing to donate embryos for research, citing benefits for science, health and infertile patients. Almost all couples (94.3%; 95% CI 89.8 to 96.7) reached consensus about the decision. Willingness to donate was more frequent in women younger than 36 years (adjusted OR 3.06; 95% CI 1.23 to 7.61) and who considered embryo research to be very important (adjusted OR: 6.32; 95% CI 1.85 to 21.64), and in Catholic men (adjusted OR 4.16; 95% CI 1.53 to 11.30). Those unwilling to donate reported conceptualizing embryos as children or living beings and a lack of information or fears about embryo research. Men with higher levels of trait anxiety (adjusted OR 0.90; 95% CI 0.84 to 0.96) were less frequently willing to donate. Future research on embryo disposition decision-making should include the assessment of gender differences and psychosocial factors. Ethically robust policies and accurate information about the results of human embryo research are required. 

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**KEYWORDS:** cryopreserved embryos, embryo disposition, embryo research, IVF, patient-centred care

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## Introduction

Most couples enrolled in IVF and intracytoplasmic sperm injection (ICSI) cycles need to make decisions about embryo disposition (Provoost et al., 2010; Wånggren et al., 2013). It has been consistently shown that this is a complex decision-making process, involving different sequential stages that can change over time (de Lacey, 2005; Provoost et al., 2009, 2012a). Patients undergoing IVF usually reveal multifaceted views about embryo status (Haimes and Taylor, 2009; Provoost et al., 2009), disagreements between partners (Provoost et al., 2012b) and emotional distress (de Lacey, 2005; Fuscaldo et al., 2007).

Embryo donation for research is a controversial option for embryo disposition (Samorinha et al., 2014). Although unavailable in several countries, such as Argentina, Chile, Croatia, Lithuania, Slovakia and Russia (European Science Foundation [ESF], 2013; Ory et al., 2013; Kupka et al., 2014), it is offered in most European countries (ESF, 2013), and current US federal law allows research with donated embryos (Ory et al., 2013). Recent studies have revealed that over 59% of IVF patients are willing to donate their embryos for research in Switzerland (Mohler-Kuo et al., 2009), the USA (Lanzendorf et al., 2010) and Sweden (Wånggren et al., 2013). In Belgium, Provoost et al. (2012a) reported a positive trend in donating embryos for research between 1992 and 2006.

Embryo donation for research is supported by optimistic expectations concerning its potential to improve assisted reproductive techniques (Provoost et al., 2010), public health, clinical solutions for several diseases, or both (Svendson, 2007), and by feelings of reciprocity (Lyerty et al., 2006) and trust in medical-scientific institutions (Priest et al., 2003). Patients undergoing IVF, however, have also reported a perception of risks (Provoost et al., 2009), a lack of information about research projects using human embryos (Fuscaldo et al., 2007; Provoost et al., 2010) and mixed feelings about embryo status (Lyerty et al., 2006; Provoost et al., 2010). These appraisements arise within ongoing socioethical and legal debates regarding embryo status, over-expectations concerning the results from stem cell research and public funding of embryonic stem cell research (Burns, 2009; ESF, 2013).

A recent systematic review analysed 39 empirical quantitative and qualitative studies that examined the factors associated with donation and non-donation of embryos for research, from the perspective of IVF patients. The associations between sociodemographic and reproductive characteristics and willingness to donate embryos for research were inconclusive. The authors concluded that the assessment of psychosocial factors, in particular well-being and psychopathological symptoms, were absent from most of the studies (Samorinha et al., 2014) and would provide valuable insight into psychosocial care in assisted reproductive techniques. Further research on these psychosocial factors will also give a better understanding of how partner dynamics and gender differences between couples affect embryo disposition (Sydsjö et al., 2005).

As the embryo disposition decision is influenced by both circumstances of daily life and structural drivers (CSDH, 2008), research on factors influencing disposition decisions should go beyond the assessment of the elements typically addressed in studies on patient-centred care in infertility: level of satisfaction with care delivery, information provision, emo-

tional support, attitude of and relationship with staff, competence of clinic and staff, communication, autonomy and privacy, clinic's organization and accessibility (den Breejen et al., 2013; Dancet et al., 2011; Huppelschoten et al., 2013; van Empel et al., 2010). A public health approach to patient-centred care is required to produce knowledge on the determinants of the disposition decision, to disseminate ethically robust evidence that informs policies on embryo disposition and to increase awareness of public understanding of science and technology. These are necessary issues to promote the responsible regulation of embryo research and to achieve health policies respectful of, and responsive to, patient preferences, needs and values (Institute of Medicine, 2001).

In Portugal, IVF-ICSI is only available to heterosexual couples who are married or have been living together for at least 2 years (Government of Portugal, 2006). Embryos not used in treatment can be cryopreserved under two conditions: first, they must be considered to be suitable for cryopreservation by health professionals and, second, IVF couples must jointly sign an informed consent agreeing to cryopreservation (National Council for the Assisted Reproductive Technologies, 2013). In accordance with the current informed consent form in Portugal, couples are asked for an immediate decision on embryo disposition by giving broad consent to donate or not to donate embryos to research or to other infertile couples. Patients must write "Yes" or "No" in a blank square in front of the following statements: "We consent to the use of our embryos for donation to other infertile couples"; and "We consent to the use of our embryos in scientific research projects" (National Council for the Assisted Reproductive Technologies, 2013). This consent can be revoked by either member of the couple. Embryos must be kept for a maximum period of 3 years and if, within this period, the embryos are not used by the couple or have not been given to either of the consented uses (donation to other couples or for research), the embryos are thawed and destroyed (National Council for the Assisted Reproductive Technologies, 2013). The state pays for the freezing and storage for up to three cycles per couple (Government of Portugal, 2011).

This study aimed to assess the factors associated with willingness to donate embryos for research among IVF couples, to better understand how to sustain the development of patient-centred care.

## Materials and methods

### Participants

Between 17 August 2011 and the 16 August 2012, all patients undergoing IVF or ICSI in one reproductive medicine centre in Porto, Portugal, were consecutively and systematically invited to participate in the study on the day biological samples were collected to diagnose pregnancy using the beta HCG test. The fertility centre is located in a public University Hospital that carries out IVF-ICSI homologous cycles and does not conduct research projects using human embryos.

Of the 329 eligible female patients, 226 visited the hospital with a partner and 103 women attended alone. Of the 226 couples invited, 221 agreed to participate in the study

(participation rate: 97.8%). Because we intended to assess an outcome that is shared by the members of a couple, i.e. willingness to donate embryos for research, the analysis was restricted to couples. Eight couples without information on the outcome variable were excluded from these analyses, resulting in a final sample of 213 couples.

## Study design

This is an observational cross-sectional study designed to be exploratory and hypothesis-generating, because data about the association between sociodemographic and reproductive history and the decision about embryo donation for research is inconclusive, and little is known about the role of psychosocial variables (Samorinha et al., 2014).

Patients were first approached by the nurses and given a study information sheet. One member of the research team then invited the potential participants to take part in the study, responding to all of their questions. Patients who decided to participate in the study were accompanied to a private room in the reproductive centre, where they read and signed the informed consent according to the World Association's Declaration of Helsinki.

Two trained interviewers conducted face-to-face interviews with the couples, using structured questionnaires. The questionnaire was designed to accommodate the particular social context within which the research was conducted. This was achieved by including two main dimensions to the questionnaire. First, psychosocial variables were collected (including symptoms of anxiety and depression, the partner relationship, and importance of embryo research), that went beyond the sociodemographic and reproductive/obstetric history variables that were often collected in research on this topic (gender, age, education level, country of origin, religion, household monthly income, subjective social class and length of relationship; parental status, duration of infertility, number of previous cycles and causes of infertility). Second, participants freely reported the main reasons underlying their willingness to donate embryos for research through one open-ended question, which was included to collect more detailed and complete responses (McDonald et al., 2003): "In your opinion, what are the main reasons to donate/not to donate embryos for research?". The outcome - willingness to donate embryos for research - was categorized as "yes" or "no" to donation, and the agreement between the couple to donate or not to donate embryos was also assessed. Religious belief was categorized as a yes/no response to being Catholic, given the high prevalence of the Catholic religion in Portugal (INE, 2012). The importance attributed to human embryo research was measured through the question: "How important is research with human embryos for you?". The original scale had the following categories: "very important", "important", "slightly important" and "not important". As all participants answered "very important" or "important", the variable was dichotomized into these two categories.

Data on anxiety (state and trait), depression and partner relationship were collected through self-administered questionnaires that were completed individually and consisted of scales validated in Portuguese samples. The State-Trait Anxiety Inventory (STAI) (Gunning et al., 2010) is composed

of two scales of 20 items each, trait (a permanent condition of anxiety) and state (anxiety in a specific situation), on a four-point Likert scale (scale range: 20 to 80). The Portuguese STAI (Silva, 2006) has shown good internal consistency ( $\alpha = 0.93$  for the State Scale and  $\alpha = 0.89$  for the Trait Scale). The Edinburgh Postnatal Depression Scale (EPDS) (Areias et al., 2006) consists of 10 items on a four-point Likert scale (scale range: 0 to 30). It is reliable for the evaluation of depression in the postnatal and prenatal periods (Tendais et al., 2014), and addresses symptoms of depression within the previous 7 days. The Portuguese EPDS presented good internal consistency ( $\alpha = 0.85$ ). The Relationship Questionnaire (Figueiredo et al., 2008) is composed of 12 items on a four-point Likert scale. The questionnaire was designed to assess two independent dimensions of the partner relationship: the positive relationship subscale, including a sense of support and care, as well as affection, closeness and joint interests and activities; and the negative relationship subscale, which included anxiety, irritability and criticism. A higher score on a relationship subscale meant that these aspects were more present in the partner relationship. The questionnaire presented good internal consistency ( $\alpha = 0.79$  for the total scale,  $\alpha = 0.90$  for the positive subscale and  $\alpha = 0.72$  for the negative subscale) and test-retest reliability ( $r = 0.74$  for the total scale).

Ethics approval was granted by the Ethics Committee for Health of the Centro Hospitalar de S. João on 11 March 2009.

## Data analysis

The association between the categorical variables and willingness to donate embryos for research was quantified through a chi-squared test. For the continuous variables (STAI, EPDS and the Relationship Questionnaire), the scores for each individual were calculated using the arithmetic mean of the scale. Separated scores were calculated for the STAI subscales (state and trait) and for the two subscales of the Relationship Questionnaire (positive and negative dimensions of the relationship). Mean differences were compared using an Independent Samples t-test or Mann-Whitney test, according to data distribution. All variables statistically significant at a  $P < 0.01$  significance level, by gender, were included in multivariate logistic regression models (Enter method) and the odds ratios (ORs) and corresponding 95% confidence intervals (95% CI) were estimated. The first two models used gender to explore which female and male variables were associated with the outcome. The final model, for analysis by couple, included all significant variables in the first two models. Trait anxiety and depression were not adjusted, owing to high intercorrelation. The IBM Statistical Package for the Social Sciences (SPSS) Statistics for Windows, version 21.0, Armonk, NY, USA, was used for all analyses.

Answers to the open-ended question about the two main reasons to be willing to donate embryos for research were synthesized into categories after emergent coding, i.e., categories were established after preliminary examination of data according to Stemler's protocol for content analysis (Stemler, 2001). The first and the last authors independently conducted emergent coding, and disagreements in classification were resolved by consensus.

## Results

The sociodemographic, reproductive and psychosocial characteristics of the participants are shown in **Table 1**. Most participants were younger than 36 years old, had less than or equal to 12 years of education, were Portuguese and Catholic. Most of the couples did not have children, had been infertile for more than 3 years and had undergone at least one previous treatment cycle.

Most of the couples were willing to donate embryos for research (87.3%; 95% CI 82.1 to 91.5). The embryo disposition decision was consensual for most of the couples (94.3%; 95% CI 89.8 to 96.7). Among those who reported a lack of

consensus within the couple ( $n = 12$  couples), the opinion of the man prevailed in eight couples (seven couples chose to donate and one opted for non-donation) and the opinion of the woman prevailed in four couples (two couples chose to donate and two chose not to donate). Catholic women and men ( $P = 0.002$  and  $P = 0.005$ , respectively), and participants who considered human embryo research to be very important ( $P < 0.001$  for women and  $P = 0.001$  for men), were more likely to be willing to donate embryos for research. Younger women ( $P = 0.002$ ), women without children ( $P = 0.008$ ) and whose country of origin was Portugal ( $P = 0.006$ ) were more likely to be willing to donate. Men with lower levels of trait anxiety ( $P < 0.001$ ) and depression

**Table 1** Sociodemographic, reproductive and psychosocial characteristics of the participants.

| Individual characteristics                                  | Women (n = 213)         | Men (n = 213)           | P         |
|---|-------------------------|-------------------------|-----------|
| Age (years), n (%)  |                         |                         |           |
| >35   | 68 (31.9)               | 99 (46.5)               | 0.003     |
| ≤35   | 145 (68.1)              | 114 (53.5)              |           |
| Education level (years), n (%)                              |                         |                         |           |
| ≤12   | 126 (59.2)              | 151 (70.9)              | NS        |
| >12   | 87 (40.8)               | 62 (29.1)               |           |
| Country of origin, n (%)                                    |                         |                         |           |
| Other   | 20 (9.4)                | 26 (12.2)               | NS        |
| Portugal  | 193 (90.6)              | 187 (87.8)              |           |
| Catholic, n (%)   |                         |                         |           |
| No  | 21 (9.9)                | 35 (16.4)               | NS        |
| Yes   | 192 (90.1)              | 178 (83.6)              |           |
| Religious practice, n (%)                                   |                         |                         |           |
| At least once a month                                       | 54 (25.5) <sup>e</sup>  | 39 (18.4) <sup>e</sup>  | NS        |
| Less than once a month                                      | 158 (74.5) <sup>e</sup> | 173 (81.6) <sup>e</sup> |           |
| Parental status, n (%)                                      |                         |                         |           |
| Children  | 21 (9.9)                | 26 (12.2)               | NS        |
| No children   | 192 (90.1)              | 187 (87.8)              |           |
| Importance of embryo research, n (%)                        |                         |                         |           |
| Important   | 48 (22.6) <sup>e</sup>  | 51 (23.9) <sup>e</sup>  | NS        |
| Very important  | 164 (77.4) <sup>e</sup> | 162 (76.1) <sup>e</sup> |           |
| State anxiety <sup>a</sup> , mean (SD)                      | 42.7 (11.9)             | 38.2 (9.7)              | <0.001    |
| Trait anxiety <sup>a</sup> , mean (SD)                      | 36.6 (7.7)              | 34.6 (6.9)              | <0.001    |
| Depression <sup>b</sup> , mean (SD)                         | 7.8 (4.8)               | 6.4 (4.5)               | <0.001    |
| Partner relationship - positive <sup>c</sup> , Md (P25-P75) | 30.0 (27.0–31.0)        | 29.0 (27.0–31.0)        | NS        |
| Partner relationship - negative <sup>d</sup> , Md (P25-P75) | 9.0 (7.0–10.0)          | 9.0 (7.0–10.0)          | NS        |
| Couple's characteristics                                    |                         |                         |           |
| Duration of infertility (years), n (%)                      |                         |                         |           |
| ≤3  | 84 (39.4)               |                         | (n = 213) |
| >3  | 129 (60.6)              |                         |           |
| Number of previous cycles, n (%)                            |                         |                         |           |
| 0   | 96 (45.1)               |                         |           |
| ≥1  | 117 (54.9)              |                         |           |
| Cause of infertility, n (%)                                 |                         |                         |           |
| Female  | 56 (26.3)               |                         |           |
| Male  | 68 (31.9)               |                         |           |
| Other   | 89 (41.8)               |                         |           |

<sup>a</sup>Lower values indicate lower anxiety symptoms (range: 20–80).

<sup>b</sup>Lower values indicate fewer depressive symptoms (range: 0–30).

<sup>c</sup>Higher scores mean that positive relationship dimensions are more present (range: 8–32).

<sup>d</sup>Higher scores mean that negative relationship dimensions are more present (range: 4–16).

<sup>e</sup>The total does not add up to 213 owing to non-responses.

Md, mean difference; NS, not statistically significant; P25, 25th percentile; P75, 75th percentile.

( $P = 0.005$ ) were more frequently willing to donate embryos (Table 2).

The main factors associated with willingness to donate embryos for research by women, men and the couple are presented in Table 3. After adjustment, women who were willing to donate embryos for research were more likely to be younger than 36 years of age (OR 3.01; 95% CI 1.12 to 8.06) and to consider embryo research to be very important (OR 6.58; 95% CI 2.42 to 17.90). Men who were willing to donate embryos for research were more likely to be Catholic (OR 4.10; 95% CI 1.60 to 10.47), to consider embryo research to be very important (OR 4.60; 95% CI 1.93 to 10.96) and to present lower levels of trait anxiety (OR 0.90; 95% CI 0.84 to 0.97) and depression (OR 0.87; 95% CI 0.79 to 0.96). In the final model, after adjustment, willingness to donate embryos for research was more frequent among women below 36 years of age (OR 3.06; 95% CI 1.23 to 7.61), Catholic men (OR 4.16; 95% CI 1.53 to 11.30) and women who considered embryo research very important (OR 6.32; 95% CI 1.85 to 21.64). Men with higher levels of trait anxiety (OR 0.90; 95% CI 0.84 to 0.96) and depression (OR 0.86; 95% CI 0.78 to 0.96) were less frequently willing to donate embryos for research.

Participants who were willing to donate embryos for research presented reasons mainly related to contributions for scientific progress (48.4% of women and 42.5% of men) and to improvements in IVF treatments (37.6% of women and 39.8% of men). Almost one-third (31.2% of women and 32.3% of men) claimed that "helping others/altruism" was a reason to donate embryos for research. Other mentioned reasons included improving human health (11.3% of women and 9.1% of men), feelings of "reciprocity" towards science and medicine (5.4% of women and 5.9% of men) and considering that donation to research was a "way to give utility to embryos", which was "better than wasting" them (6.5% of women and 3.8% of men).

The most frequently mentioned reasons among those unwilling to donate embryos for research were the conceptualization of embryos as "children", a "baby" or a "living being" (29.6% of women and 37.0% of men), a lack of information about embryo research (29.6% of women and 33.0% of men), the need to transfer the cryopreserved embryos (25.9% of women and 22.2% of men), fears about what could happen to the embryos (18.5% of women and 22.2% of men) and non-specified issues related to "personality" or "education" (22.2% of women and 18.5% of men).

## Discussion

Data provided in this study may be helpful in the development of ethically robust patient-centred policies about decision-making on embryo donation for research, in the following ways. First, the results call for the development of guidelines for psychosocial care in the field of embryo donation decision-making that should be sensitive to women's, men's and couples' age, religion, trait anxiety, and conceptualization of cryopreserved embryos. Additionally, it highlights the responsibility of health professionals and researchers to communicate realistic expectations about the results from research on human embryos, as the patients who were willing to donate embryos for research believed it was highly important and based their decision primarily on the expected benefits for science, health and IVF patients. There is also room

to disseminate accurate information about research on human embryos, including their specific goals, objectives and procedures, to improve the robustness of the informed consent given by couples.

This study revealed one of the highest proportions of IVF patients willing to donate embryos for research among similar studies, in which willingness to donate was also assessed by a yes/no answer (Samorinha et al., 2014). A positive attitude towards the donation of embryos for research was also illustrated by the fact that none of the couples considered research on human embryos to be of slight importance. Most patients believed that human embryo research would result in scientific progress and benefits for health and for IVF couples in particular.

The high perceived value of embryo research is consistent with the changing social context in which legislation in several countries allows and regulates the use of human embryos in research (ESF, 2013). A high receptivity to scientific and technological progress and trust in medical institutions and their professionals characterizes would-be-parents' assessment of the benefits and risks of assisted reproduction techniques, which was described in previous studies as being imbued with hope, trust and altruism (Silva and Machado, 2009, 2010, 2011). The reported reasons for donating embryos in this study reflect the incorporation of this assessment and are aligned with findings from other studies: willingness to contribute to scientific progress in general (Fuscaldo et al., 2007; Lyerly et al., 2006), to the development of IVF treatments in particular (Lyerly and Faden, 2007; Provoost et al., 2010) and to the improvement of human health (Fuscaldo et al., 2007; Provoost et al., 2009). These motives may also reflect the perception that minimal risks are associated with human embryo research, as mentioned by Priest et al. (2003), which conflicts with the report of fears by patients who were unwilling to donate embryos for research. Consistent with results obtained in previous studies (Fuscaldo et al., 2007; Lyerly et al., 2006; McMahon et al., 2003; Provoost et al., 2010), participants who were willing to donate embryos for research in our study also revealed a "sense of gratitude" to science and an "altruistic desire" to help others.

These feelings might be simultaneously driven by external constraints and internal motivations, which have been previously described in the donation of biological material in Portugal (Machado and Silva, 2015; Silva and Machado, 2009). This socioethical framework redefines human embryos as a gift for the common good in the context of embryo disposition (Maus, 1954; Rose and Novas, 2005), pointing to the conceptualization of embryo donation for research as an act of individual responsibility for collective well-being (Machado and Silva, 2014). This framework is useful in understanding why the Catholic men in our study were significantly more willing to donate embryos for research. Previous studies about the role of religion in IVF patients' decision about embryo disposition reported inconsistent data; studies in Australia (McMahon et al., 2003) and in Belgium (Provoost et al., 2009, 2010) found no association between an individual's religion and the disposition decision, although other studies in Switzerland (Mohler-Kuo et al., 2009) and Australia (Burton and Sanders, 2004) suggested that having moderate or strong religious beliefs (versus not very strong beliefs) was associated with a lower likelihood of donating embryos for research. In a qualitative study in the USA (Lyerly et al., 2006), pa-

**Table 2** Willingness to donate embryos for research, according to the sociodemographic, reproductive and psychosocial characteristics of the participants.

|   | Willingness to donate   |                  |        |
|---|-------------------------|------------------|--------|
|   | Yes (n = 186)           | No (n = 27)      | P      |
| Women (N = 213)   |                         |                  |        |
| Age (years), n (%)  |                         |                  |        |
| >35   | 52 (28.0)               | 16 (59.3)        | 0.002  |
| ≤35   | 134 (72.0)              | 11 (40.7)        |        |
| Education level (years), n (%)                              |                         |                  |        |
| ≤12   | 109 (58.6)              | 17 (63.0)        | NS     |
| >12   | 77 (41.4)               | 10 (37.0)        |        |
| Country of origin, n (%)                                    |                         |                  |        |
| Other   | 13 (7.0)                | 7 (25.9)         | 0.006  |
| Portugal  | 173 (93.0)              | 20 (74.1)        |        |
| Catholic, n (%)   |                         |                  |        |
| No  | 13 (7.0)                | 8 (29.6)         | 0.002  |
| Yes   | 173 (93.0)              | 19 (70.4)        |        |
| Religious practice, n (%)                                   |                         |                  |        |
| At least once a month                                       | 45 (24.3) <sup>e</sup>  | 9 (33.3)         | NS     |
| Less than once a month                                      | 140 (75.7) <sup>e</sup> | 18 (66.7)        |        |
| Parental status, n (%)                                      |                         |                  |        |
| Children  | 14 (7.5)                | 7 (25.9)         | 0.008  |
| No children   | 172 (92.5)              | 20 (74.1)        |        |
| Importance of embryo research, n (%)                        |                         |                  |        |
| Important   | 32 (17.3) <sup>e</sup>  | 16 (59.3)        | <0.001 |
| Very important  | 153 (82.7) <sup>e</sup> | 11 (40.7)        |        |
| State anxiety (M [SD]) <sup>a</sup>                         | 46.9 (11.8)             | 51.5 (12.9)      | NS     |
| Trait anxiety (M [SD]) <sup>a</sup>                         | 38.4 (8.1)              | 40.8 (6.6)       | NS     |
| Depression (M [SD]) <sup>b</sup>                            | 9.3 (4.6)               | 9.15 (4.91)      | NS     |
| Partner relationship - positive (Md [P25-P75]) <sup>c</sup> | 30.0 (28.0-31.0)        | 30.0 (28.0-31.0) | NS     |
| Partner relationship - negative (Md [P25-P75]) <sup>d</sup> | 8.0 (7.0-10.0)          | 9.0 (8.0-10.0)   | NS     |
| Men (N = 213)   |                         |                  |        |
| Age (years), n (%)  |                         |                  |        |
| >35   | 87 (46.8)               | 12 (44.4)        | NS     |
| ≤35   | 99 (53.2)               | 15 (55.6)        |        |
| Education level (years), n (%)                              |                         |                  |        |
| ≤12   | 133 (71.5)              | 18 (66.7)        | NS     |
| >12   | 53 (28.5)               | 9 (33.3)         |        |
| Country of origin, n (%)                                    |                         |                  |        |
| Other   | 20 (10.8)               | 6 (22.2)         | NS     |
| Portugal  | 166 (89.2)              | 21 (77.8)        |        |
| Catholic, n (%)   |                         |                  |        |
| No  | 25 (13.4)               | 10 (37.0)        | 0.005  |
| Yes   | 161 (86.6)              | 17 (63.0)        |        |
| Religious practice, n (%)                                   |                         |                  |        |
| At least once a month                                       | 34 (18.4) <sup>e</sup>  | 5 (18.5)         | NS     |
| Less than once a month                                      | 151 (81.6) <sup>e</sup> | 22 (81.5)        |        |
| Parental status, n (%)                                      |                         |                  |        |
| Children  | 20 (10.8)               | 6 (22.2)         | NS     |
| No children   | 166 (89.2)              | 21 (77.8)        |        |
| Importance of embryo research, n (%)                        |                         |                  |        |
| Important   | 37 (19.9)               | 14 (51.9)        | 0.001  |
| Very important  | 149 (80.1)              | 13 (48.1)        |        |
| State anxiety (mean [SD]) <sup>a</sup>                      | 37.5 (9.6)              | 42.1 (10.2)      | NS     |
| Trait anxiety (mean [SD]) <sup>a</sup>                      | 33.9 (6.5)              | 38.9 (8.3)       | <0.001 |
| Depression (mean [SD]) <sup>b</sup>                         | 6.0 (4.2)               | 8.6 (5.4)        | 0.005  |
| Partner relationship - positive (Md [P25-P75]) <sup>c</sup> | 29.0(27.0-31.0)         | 30.0(27.0-31.0)  | NS     |
| Partner relationship - negative (Md [P25-P75]) <sup>d</sup> | 8.0 (7.0-9.0)           | 9.5 (7.8-10.3)   | NS     |
| Couple characteristics (n = 213)                            |                         |                  |        |
| Duration of infertility (years), n (%)                      |                         |                  |        |
| ≤3  | 73 (39.2)               | 11 (40.7)        | NS     |
| >3  | 113 (60.8)              | 16 (59.3)        |        |
| Number of previous cycles, n (%)                            |                         |                  |        |
| 0   | 80 (43.0)               | 16 (59.3)        | NS     |
| ≥1  | 106 (57.0)              | 11 (40.7)        |        |
| Cause of infertility, n (%)                                 |                         |                  |        |
| Female  | 50 (26.9)               | 6 (22.2)         | NS     |
| Male  | 61 (32.8)               | 7 (25.9)         |        |
| Other   | 75 (40.3)               | 14 (51.9)        |        |

<sup>a</sup>Lower values indicate lower anxiety symptoms (range: 20-80).

<sup>b</sup>Lower values indicate fewer depressive symptoms (range: 0-30).

<sup>c</sup>Higher scores mean that positive relationship dimensions are more present (range: 8-32).

<sup>d</sup>Higher scores mean that negative relationship dimensions are more present (range: 4-16).

<sup>e</sup>The total does not add up to 186 owing to one non-response.

Md = mean difference, P25 = 25th percentile; P75 = 75th percentile.

**Table 3** Factors associated with willingness to donate embryos for research among couples undergoing IVF.

|                                       | <i>Willingness to donate</i> |                                   |
|---------------------------------------|------------------------------|-----------------------------------|
|                                       | <i>Crude OR (95% CI)</i>     | <i>Adjusted OR (95% CI)</i>       |
| <b>Model 1: women</b>                 |                              |                                   |
| Age                                   |                              |                                   |
| >35                                   | 1                            | 1                                 |
| ≤35                                   | 3.75 (1.63 to 8.61)          | 3.01 (1.12 to 8.06) <sup>a</sup>  |
| Country of origin                     |                              |                                   |
| Other                                 | 1                            | 1                                 |
| Portugal                              | 4.66 (1.67 to 13.03)         | 3.53 (0.84 to 14.79) <sup>a</sup> |
| Catholic                              |                              |                                   |
| No                                    | 1                            | 1                                 |
| Yes                                   | 5.60 (2.06 to 15.23)         | 3.26 (0.71 to 14.92) <sup>a</sup> |
| Parental status                       |                              |                                   |
| Children                              | 1                            | 1                                 |
| No children                           | 4.30 (1.55 to 11.91)         | 2.98 (0.77 to 11.39) <sup>a</sup> |
| Importance of embryo research         |                              |                                   |
| Important                             | 1                            | 1                                 |
| Very important                        | 6.96 (2.95 to 16.39)         | 6.58 (2.42 to 17.90) <sup>a</sup> |
| <b>Model 2: men</b>                   |                              |                                   |
| Catholic                              |                              |                                   |
| No                                    | 1                            | 1                                 |
| Yes                                   | 3.79 (1.56 to 9.20)          | 4.10 (1.60 to 10.47) <sup>b</sup> |
| Importance of embryo research         |                              |                                   |
| Important                             | 1                            | 1                                 |
| Very important                        | 4.34 (1.88 to 10.01)         | 4.60 (1.93 to 10.96) <sup>b</sup> |
| Trait anxiety                         | 0.90 (0.85 to 0.96)          | 0.90 (0.84 to 0.97) <sup>c</sup>  |
| Depression                            | 0.88 (0.81 to 0.97)          | 0.87 (0.79 to 0.96) <sup>c</sup>  |
| <b>Model 3 – Couple</b>               |                              |                                   |
| Age (women)                           |                              |                                   |
| >35                                   | 1                            | 1                                 |
| ≤35                                   | 3.75 (1.63 to 8.61)          | 3.06 (1.23 to 7.61) <sup>d</sup>  |
| Catholic (men)                        |                              |                                   |
| No                                    | 1                            | 1                                 |
| Yes                                   | 3.79 (1.56 to 9.20)          | 4.16 (1.53 to 11.30) <sup>d</sup> |
| Importance of embryo research (women) |                              |                                   |
| Important                             | 1                            | 1                                 |
| Very important                        | 6.96 (2.95 to 16.39)         | 6.32 (1.85 to 21.64) <sup>d</sup> |
| Importance of embryo research (men)   |                              |                                   |
| Important                             | 1                            | 1                                 |
| Very important                        | 4.34 (1.88 to 10.01)         | 1.09 (0.32 to 3.74) <sup>d</sup>  |
| Trait anxiety (men)                   | 0.90 (0.84 to 0.97)          | 0.90 (0.84 to 0.96) <sup>e</sup>  |
| Depression (men)                      | 0.87 (0.79 to 0.96)          | 0.89 (0.71 to 1.12) <sup>e</sup>  |

<sup>a</sup>Adjusted for each other.<sup>b</sup>Adjusted for each other.<sup>c</sup>Adjusted for being Catholic and the importance of embryo research.<sup>d</sup>Adjusted for each other.<sup>e</sup>Adjusted for age (women), being Catholic (men) and the importance of embryo research (women and men).

tients noted that religion affected their decision-making and identified themselves as Catholic (Evangelical) Christian, or Baptist, stating that they considered embryo destruction, including research, to be prohibited. These results indicate that religious faith and an understanding of scientific facts and methods are not mutually exclusive and can coexist, with religion as a “perceptual filter” that moderates the ways in which scientific knowledge affects attitudes (Allum et al., 2014).

It is worth noting that the main argument used by the Catholic Church to criticize human embryo research, that

human life begins at conception (United States Conference of Catholic Bishops, 2011), was also observed in this study in participant’s reasons to not donate embryos for research, as shown by their conceptualization of embryos as living beings or children. This perspective, however, is not always a barrier for donating embryos for research, as research may be perceived to be preferable to discarding embryos, as previously described (de Lacey et al., 2012; Lyerly et al., 2004). Furthermore, the perception that human life begins at conception may increase the value of an embryo, which could

justify their use in research, as presented by [de Lacey et al. \(2012\)](#) and [Provoost et al. \(2009\)](#). Patient's preference is not often that their remaining embryos have a chance at life, but rather that they can "be used in a way" ([Lyerly and Faden, 2007](#)). Therefore, the meanings of the moral status of embryos seem to be varied and context-dependent, not fixed entities ([de Lacey, 2005](#); [Haines et al., 2008](#)), with couples using a complex and dynamic system of embryo classification ([Haines and Taylor, 2009](#)). Patients undergoing IVF perceive embryos simultaneously as epistemic or medical objects for research and clinical practices, and ontological objects for reproduction ([Samorinha et al., 2014](#)), with an instrumental value ([Provoost et al., 2009](#)) that should not be wasted ([Luna et al., 2009](#); [Provoost et al., 2010](#)).

The complex relationships between the conceptualizations of embryos, scientific research and individual ethical responsibilities may explain the contradictory results described in empirical studies examining the association between sociodemographic characteristics and the (un)willingness to donate embryos for research. Although our study showed that age was a significant factor in women's willingness to donate embryos for research, several studies have found no association between the age of IVF female patients and their donation decision ([Lanzendorf et al., 2010](#); [Provoost et al., 2012a](#)). Our study showed that younger women were more willing to donate embryos for research. This may be related to the perception that younger women have more opportunities to become pregnant owing to age-related decline in fertility ([American Society for Reproductive Medicine, 2014a](#)), and therefore it would not be necessary to transfer the cryopreserved embryos.

Regarding the psychosocial factors, an anxious state seemed to have had a significant influence only on men's opinion. Higher levels of trait anxiety were found among men who were unwilling to donate embryos for research, which can be associated with the fact that individuals with high anxiety levels are more likely to avoid perceived threats, especially future events ([Spielberger and Vagg, 1984](#)). Patients who were given extensive information in fertility care services have presented less psychopathological feelings ([Mourad et al., 2010](#)). In this context, donation of embryos for research can be perceived as a threat. This perception occurs when participants report a lack of information about research projects, as previously found ([Fuscaldo et al., 2007](#); [Lyerly et al., 2006](#); [Provoost et al., 2010](#)), or when they have fears about what could happen to their embryos ([Fuscaldo et al., 2007](#); [Provoost et al., 2009](#)). Additionally, those who were unwilling to donate may feel they did not accomplish the desirable action within a context mostly receptive to scientific and technological progress ([Rose and Novas, 2005](#)), which can generate higher levels of anxiety.

The present study was the first to evaluate the association between willingness to donate embryos for research and patient anxiety, depression and quality of partner relationship, while also including variables from both members of the couple. Although no association between donation decision and depression and quality of partner relationship was found in this study, further studies should be conducted to validate these results.

Furthermore, this study provides preliminary results about the development of a public health approach to patient-centred care in embryo disposition, contributing to an analysis

of open-mindedness towards and level of information about research with human embryos. It also deconstructs stereotypes about the influence of religious beliefs on embryo donation for research. It sustains stakeholders' decisions about the suitability of research projects using cryopreserved embryos, and contributes to maximize public understanding of science and technology. This study, however, does have some limitations. Participants were recruited from only one public reproductive medicine centre located in a university hospital. Although it was the largest centre in the Northern region of Portugal, the prevalence of embryo donation for research may be overestimated in this setting, as trust increases when research is conducted in universities compared with the private sector ([Critchley, 2008](#)). The recruitment of participants in private clinics, as well as couples involved in heterologous techniques, would be enriching. Nevertheless, 25% of the participants had already undergone at least one cycle in a private centre. The timing of data collection may have contributed to increased levels of state anxiety in this study. The fact that all of the individuals were exposed to the same situation, however, mitigates the possible biasing effect of a differential exposure on the main outcome of this study – the willingness to donate embryos for research. In addition, some participants were in the midst of treatments, which could affect their disposition decision-making process. The fact that couples in this centre were asked to give informed consent on embryo disposition after embryo transfer, at a time when they show increased levels of state anxiety ([ESHRE, 2015](#)), suggests that we should consider the circumstances under which the informed consent should be delivered, explained and signed. National practice in this area could be made more ethically robust by removing disposition decisions away from that point during treatment and permitting the decision to be made at a later, less stressful time. As patients' willingness to donate embryos for research may change over time, future research would benefit from a prospective analysis, with more longitudinal studies to assess causality, and with national representative samples. On the other hand, a deeper understanding of the decision-making process relating to embryo donation for research could be obtained by more studies focusing on in-depth qualitative analyses of couples, in their particular cultural context ([de Lacey, 2007](#)).

In conclusion, opportunities exist for research to assess gender differences and psychosocial factors involved in embryo disposition decisions, and these findings should be included in the guidelines for psychosocial care for infertility and assisted reproduction techniques. Ethically robust policies and practices that are sensitive to patient's information needs are required, including the provision of accurate information on the results of human embryo research that will promote a fully informed consent ([ASRM, 2014b](#)).

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