

Review Article

FACTORS AFFECTING THE DECISION MAKING OF AUSTRALIAN COUPLES TO DONATE THEIR CRYOPRESERVED EMPBRYOS FOR HUMAN EMBRYONIC STEM CELL RESEARCH

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Abstracts: The purpose of this review was to describe attitudes of couples in Australia towards donating their surplus frozen embryos for human embryonic stem cell research. A systematic search was conducted including articles published in English, in peer reviewed journals and scientific discourse indexed in MEDLINE / Pub Med database. Embryo donation rate among Australian couples was found to be relatively lower than other countries. Although factors like age of couples, Family completion and financial status influence the decision to donate stored embryos in many countries, however willingness to donate embryos among Australian couples based on these factors was less pronounced. Similarly, religious conviction and moral issues play a dominant role in their decision making. On the other hand, a substantial number of Australians would seek help and counseling from their treating physicians at the time of decision to donate embryo for stem cell research. Nevertheless, potential benefits associated with stem cell research should be weighed against potential social, ethical and legal harm to the society.

Keywords: Cryopreserved embryos, Stem Cell, Research, Embryos, Donation and Australian couples.

Introduction

Human stem cells are unspecialized cells which have the ability of self-renewal for long periods through cell division and they also have potential to differentiate into specialized human cells and tissues.¹ Adult stem cells, which are found in nearly all tissues and organs in the human body, are differentiated form of embryonic stem cells. However, they retain capacity for differentiation only to similar cells within the particular organ. On the other hand, embryonic stem cells are more versatile as these can modify themselves into almost every type of human cell.²

It has been known for many decades that human adult stem cells can regenerate themselves to 'replenish cell loss due to 'disease, trauma or to normal wear and tear'.³ Advance techniques have recently been developed to isolate embryonic stem cells from human embryos at 5-6 day stage and been cultured in laboratory. This implies that it is now probable to generate human tissues in laboratory. This technological capacity has paved the way for new branch of medicine called regenerative medicine and human tissue engineering.⁴ This has also unlocked an opportunity window for scientists to organize their efforts to search cure of many debilitating health problems like Parkinson's disease, Alzheimer's disease, Diabetes mellitus, Motor neuron disease, leukemia and many others.¹ Stem cell research has incited a heated debate and

controversy among researchers, ethicists, social scientists and politicians in many countries. More objections are levied against embryonic stem cells than to adult stem cells research, since in embryonic stem cells research, cells are isolated by 'damaging' human embryos.⁵ On one hand, embryo is taken as a gift of GOD, a potential child and is considered to have moral status of a human being. Deliberate damage to embryo is considered parallel to harm inflicted to any human being. On the other end, embryo at time of stem cell isolation is viewed as 'bunch of biological cells' still to be shaped as human being; therefore it is thought that it was legitimate to conduct research on them to reduce human suffering.

Surplus Embryos stored at in-vitro fertilization clinics:

Human embryonic stem cell research activities largely depend on availability of embryos and eggs in sufficient quantities. With the advent of effective in-vitro fertilization (IVF) treatment technologies, many infertile couples are using this service for assisted reproduction worldwide. Several embryos are developed in laboratory for this assisted reproduction process in order to ensure good quality embryo. However, only one or two of these cultured embryos are implanted in women's uterus. This is done to reduce multiple gestation, minimize morbidities and to avoid embryo destruction.⁷ Rest of other embryos

are stored as frozen embryos (Cryopreserved) for future pregnancy attempts of these infertile couples. These have been reports that these Cryopreserved embryos have increased to a substantial number in these IVF clinics worldwide.

It has been estimated that an approximately 396526 such embryos are stored in United States, whereas 92500 and 52000 frozen embryos are present in various in-vitro-fertilization (IVF) clinics in United Kingdom and Australia respectively.⁸ These countries have devised a legal limit to store the Cryopreserved embryos which ranges from 2-10 years and at the end of this period, couples in these countries face a intricate decision to make about fate of their embryos.⁹ They have to decide whether they like to use their embryo for further treatment or like to donate to other couples or for medical research, or eventually, want their embryos to be discarded.¹⁰ Australia joined Denmark, Sweden, South Korea, United Kingdom and United States for stem cell research endeavors in 2002, through passing an act to use surplus embryos in IVF clinics for research;¹¹ however Australia maintained ban on somatic cell nuclear transfer (SCNT) technique, which is utilized to create embryos from eggs.¹² Later, considering international developments in stem cell research, a committee under a federal Judge John Lockhart was established to review the legal, ethical and social implication of granting license to allow SCNT technique (also called cloning).

Attitudes of Australian Couples towards Embryo Donation:

There is an interesting parallel in reaching constitutional decision to back stem cell research and how couples' attitudes towards donating embryo for this research changed during these years. For instance, during a period from 1991 to 2002, among couples who received assisted reproduction in IVF clinics, the majority (89.5%) opted for discarding their stored embryos; whereas during 2003 onward, an increasing number turned their preferences towards donating either to other infertile couples or for biomedical research.¹³ Burton and Sanders (2004) reported in their mailed questionnaire based study in Western Australia that twenty-seven percent respondents expressed willingness to donate their embryos for stem cell research. This figure is consistent with an earlier finding (29%) in a study conducted in Sydney by Mc Mahon et al. 2003. Furthermore, Monash University study (based on similar study protocols) in 2006 found that 42% couples decided for donating embryo for stem cell research.¹⁴ The results of these

studies will have to be interpreted keeping in consideration of issues related to their study designs and data collection methodologies. Techniques using mailed questionnaires face concerns related to how respondents' interpret the questions, and how questions were phrased and also in which order the question were asked. Moreover, it has been demonstrated by many studies that respondents tend to obscure true values, by giving positive responses to many questions in such situations.⁹

Embryo donation rate in Australia is relatively lower than many industrial countries like Sweden, Denmark and United Kingdom. For Example, Ninety-two (92%) percent of couples in Sweden gave consent to donate their Cryopreserved embryos to develop cell lines for stem cell research, whereas fifty-seven (57%) percent couples in Denmark and fifty-four (54%) percent couples in United Kingdom responded affirmatively towards donating embryos for stem cell research respectively.^{11,12,13} These studies were conducted more or less within the same time frame as the Australian studies; however different data collection methodologies were adopted. For instance, in Sweden and United Kingdom, researchers provided a detailed information toolkit about stem cell research, its potential benefits to respondents prior to data collection phase.

Australian couples' decision for embryo donation-determinants:

Many factors have been studied over the years to find out Australian couples' attitudes and thoughts underpinning their decisions to donate embryos for stem cell research. These factors have been summarized as follows:

1. Family and personal issues:

Number of studies in United States and Denmark has suggested that personal issues like age of women and men, no desire for more children (family completed) and financial status positively affect their decisions for donating embryos;¹⁵ however, willingness to donate embryo to research was not influenced by these personal issues among Australian couples.¹²

2. Religious influences:

Religious conviction plays a dominant role in making such decisions in Australia. It has been stated that couples with moderate to strong religious beliefs were less likely to donate their embryos for stem cell research. This is in contrast to results observed in Sweden and Denmark, where religious affiliation did not influence embryo donation decisions.^{16,13} This might explain the difference in embryo donation rates

might explain the difference in embryo donation rates between Australia and these countries.

1. Moral Status and perception about embryo:

Substantial number (47%)¹⁷ of Australian couples expressed the similar view about moral status of embryo held by opponents of stem cell research. Majority of study subject (80%)¹⁸, strongly believe in the right of embryo to be born instead of being destroyed for research. In addition, significant number of couples (86%)¹⁹ in these studies responded that they deem these embryos donation 'completely different'^{20,21} to either blood donation or organ donation.

2. Lack of appropriate information and counseling:

Relevant information provision and counseling resulted in improved embryo donation rate as well as facilitation in decision making. Lack of information and insufficient support has been reported by almost all studies.⁸ Most couples find it very distressing to decide about disposing their stored embryos and many emphasized the need of appropriate counseling in this regard. Number of these couples also expressed their apprehension and fear over the type of research which might be conducted and lack of their control in these research activities.

3. Trust on Physicians and researchers:

Many respondents in Australia stated that they would seek help from their treating physicians at time of their decision to donate embryo for stem cell research. Experts have expressed concern over a possibility that couples who successfully had attained assisted reproduction find themselves obliged towards treating physicians and IVF clinics,¹⁴ therefore it is likely that these physicians and clinics could influence these couples' decisions in favor of

donation for financial gains or for stem cell research, especially if these physicians are affiliated with research and academic organizations.^{9,22}

Conclusion

Benefits associated with stem cell research and cloning are still remote and speculative. Success in this is linked to availability of generous quantities of donated eggs and embryos. Embryo donation rate in Australia is relatively lower than other countries. This may be attributed to lack of adequate information and support for their decisions on one hand and strong religious conviction regarding embryo status on the other. The existing information on factors affecting couples' decision for embryo donation to stem cell research is based on surveys which face issues concerning reliability and validity of data. More in-depth interviews of couples and focus group discussions will offer comprehensive measurements of these factors. The influence of physicians on couple's decisions to donate eggs and embryos for stem cell research is to be appraised. Finally, expected benefits of conducting such research endeavors should be weighed against potential physical, social, ethical and legal harm to the society.

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