

The Effects of Financial Incentives on Embryo Donor Demographics

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When bioethicists discuss the importance of informed consent, they are referring to the moral principle of autonomy. In Western philosophy, the principle of autonomy is rooted in the importance of individual freedom and choice. Autonomy is usually associated with ideas such as privacy, voluntariness, the freedom to choose, choosing one's own moral position, and accepting responsibility for one's choices. However, being autonomous is different from being respected as autonomous. A failure to respect autonomy is where many of the issues arise involving informed consent (Beauchamp and Faden 1986).

The accepted moral ideal that a person should be respected as autonomous can be defined in its own principle; the principle of respect for autonomy. This means that persons should be free to choose and act without controlling constraints imposed by others. Ruth Faden and Tom Beauchamp, two well respected ethicists, analyze what constitutes autonomous action among three basic principles: a person acts autonomously only if the person acts (1) intentionally, (2) with understanding, and (3) without controlling influences (Beauchamp and Faden 1986). In relation to embryo donors, one must question does the acquisition process ethically comply with these stipulations. Do the financial incentives act as a controlling influence?

Women who donate eggs for reproductive procedures, for example in vitro fertilization, are usually compensated between \$5,000 and \$10,000 per egg-donation cycle (Trivedi 2007). At these prices, it can be seen that some research subjects accept the inconvenient and potentially fatal health risks associated with the procedure at least partly for financial gain.

Kelly, a 24-year-old from San Diego who asked that her surname not be used, is undergoing her sixth and final cycle of egg donation for IVF purposes and says she knows the procedure entails significant risks. The most common side effect is ovarian hyperstimulation syndrome -- nausea and vomiting, fluid in the abdomen, breathing difficulties, and, in the worst cases, blood clots or kidney failure. She has endured giving herself two injections of fertility hormones every day to promote the growth of multiple eggs in her ovaries, instead of just one. Not only this, she has committed to weekly blood tests, doctor's appointments, multiple ultrasounds to check on the number and size of the eggs, psychological evaluations, and the final surgery under anesthesia to retrieve the eggs. Over two years, Kelly admits that she will have made a total of \$48,000 for her six donations (Trivedi 2007).

It would only be logical to question the ethical dilemma this presents: do high volumes of money skew research subjects' perception when giving their informed consent?

While personal theories usually overlap among multiple ethical perspectives, this case is generally argued from several distinct positions. The first general position that some bioethicists accept is based on consequences. These utilitarians believe that right or wrong is based on weighing the good and bad results from a given decision; whatever yields the greater good is right (Beauchamp and Childress 1994). Regarding the issue of financial incentives, utilitarians take into account issues such as fair payment equating to a rational decision regarding their participation. Monetary influence is acceptable in many cases, because it satisfies an individual's financial need or emotional reasoning, while also benefitting research or infertile couples. Utilitarians accept this reasoning as part of an autonomous decision.

The other basic perspective used in this case rejects many of the arguments that utilitarians would accept. From a deontological or Kantian perspective, results must not be derived from using a person as a means to an end. If a person acts from desire, fear, impulse, or habit, they are not acting from a rational will that chooses autonomously (Beauchamp and Childress 1994). Financial incentives cause reactions based on emotional reasoning, which most Kantians would deem unethical. Thus, where many utilitarians accept monetary influences as part of a rational decision and legitimate practice of informed consent, Kantians deny this legitimacy of consent on the basis of irrational reasoning or the involvement of treating people as means to an end, rather than autonomous individuals.

The use of human research subjects and donors to advance new scientific discovery has been a common practice for many years in medical biology. Many research facilities compensate those who volunteer for the various studies. To protect research subjects, the government has tried to establish guidelines that research facilities must follow. “The administrative law of research ethics insists that researchers warn subjects of the risks of experiments. The Patient Self-Determination Act compels medical institutions to remind patients about advance directives. The federal government's new privacy regulations instruct medical institutions to describe their privacy regime to patients” (Schneider 2005). All of these regulations concentrate on bioethicists’ favorite principle, informed consent. However, with the combination of compensation and risk, the subjects are faced with a virtual tug-of-war battle weighing the pros and cons. Some feel that current legislation is vague and inadequate to fully protect these research subjects (Maclean 2006). There is an ongoing debate on which laws actually apply to researchers and to what degree non-federally funded operations are responsible.

This has resulted in questionable boundaries between what are ethically acceptable methods and what breeches human rights.

In research involving human eggs, embryos, and oocytes, there is an obvious need for female donors to acquire the needed cells; the issue of compensation for these cells has become controversial topic. For example, in September of 2006, the governor of California signed a law that prohibits researchers from paying women who donate embryos for stem cell research. This same law requires donors to be informed of the risks, and researchers must acquire written and oral consent beforehand (New Scientist 2006). However, this law is not universal, and many states allow compensation. Donors make their choice by placing priority among safety, finances, and other personal reasoning. But, how does monetary compensation affect a prospective subject's clear choice? Are research facilities blinding research subjects from full informed consent? Do the demographics suggest a bias in who are volunteering for this research? These are the issues that need to be deliberated in order to form better policy that protects these individuals.

Financial incentives promote several issues from the perspective of the research subject that could possibly prevent a pure transaction of informed consent. By common definition, researchers are ethically inclined to give substantial information to promote an informed decision. However, it is possible that women may respond out of financial need, high payments could lead some subjects to conceal medical information relevant to their own health, and some might discount the physical and emotional risks to address their financial situation (The Ethics Committee of the American Society for Reproductive Medicine 2000). Some politicians, scientists, and ethicists deem that the high payments associated with egg-donation will entice poor women to donate exclusively for the money (Trivedi 2007).

Karl Marx argued that within a capitalist society, workers are inevitably exploited by capital (Anderson and Weijer 2002). Regardless of any other conditions, money itself shapes individuals' decisions. Marx believed that the product of labor was an objective means of expressing a person's creative power. Through this physical expression, the individual expands the realization of the self. By taking the product of a worker's labor for improper means, this being financial gain, the capitalist takes from the worker an element of his self. Marx was adamant in the idea that people had the right to meaningful work.

Marx is usually seen as a political or economic philosopher. However, his concepts on the exploitative properties of capitalism are highly relevant in this ethical debate. Through Marx's studies and observations, he came to the conclusion that money influences a person's decisions. In respect to the principle of autonomy, does monetary gain satisfy the principle of a decision being made without a controlling influence? Inherently, according to the Marxist philosophy, the answer to this question would have to be no. However, regarding that the current societal structure is based on capitalism, the analysis must be more lenient in its definition. Under today's social structure and ethical mentality, Marxism only gives evidence that monetary incentives possibly could be a controlling influence.

James Anderson and Charles Weijer, two professors from Dalhousie University, use Marx's philosophy and relate it toward the idea of research subjects being wage earners. The ethical importance of their argument lies within the double standards that are set between research subjects and traditional wage earners. They present the case that the monetary influences a traditional wage earning job would produce are no different than those that research subjects face. One might fear that due to the shear differences between the two, this would make for an invalid argument. However, the scholars Neil Dickert and Christine Grady have

developed a wage payment model that shows, "...from the perspective of an individual seeking income, research participation is morally indistinguishable from other lines of legitimate employment he or she might seek" (Dickert and Grady 1999). This is ethically important because it deals with the same issues previously discussed about making autonomous decisions.

They approach this argument from a utilitarian perspective. By assessing the total intrinsic value of each job, a person is able to derive what is the greatest good (Beauchamp and Childress 1994). In Dickert and Grady's publication they make the case that many of the potential subjects have other opportunities for earning similar amounts of money. Presumably, they will choose participation in research when they weigh it against their other options for earning an unskilled labor wage (Dickert and Grady 1999). From the perspective Dickert and Grady present, the ethical acceptability of a traditional wage earning job should extend to research subjects as well. Because research subjects are faced with the same issues regarding their consent, there is no substantial moral difference between research participation and any other form of unskilled labor (Anderson and Weijer 2002).

Professional subjects, meaning people whose only job is participating in human research, do exist. In fact, there is a journal based out of Philadelphia called the *Guinea Pig Zero* that is written by and for human research subjects. The contents of the journal include available research opportunities, as well as in depth reviews of facilities, reporting their working conditions and how much they pay (Anderson and Weijer 2002). By reverting to the Marxist ideal and relating it to Dickert and Grady's model, it can be assumed that the paid research subject already host an inherent conundrum. A monetary based system does alter the research participant's innate behavioral choices.

In contrast to the relationship between the Marxist perspective and Dickert and Grady's wage payment model, Grady offers alternative opinions on the properties of money affecting informed consent. Consented participation in research is unanimously defined by bioethicists as a person's voluntary decision. Assuming that a research facility has provided ample information of the study in an understandable fashion promoting the purpose, risks, benefits, alternatives, and requirements, the choice potential research subjects make revolves around their voluntarily decision of whether or not they want to participate in the study.

It is accepted, as the explanation suggests, that voluntariness is understood as being free from coercion and undue influence (Grady 2001). Coercion is typically defined as an intentional use of a credible threat of harm or force to control another or compel them to do something against their initial judgment (Beauchamp and Childress 1994). The use of coercion in research is unlikely, although not impossible, due to the current system of checks and balances. As Grady points out, money possesses no native threat or harm. In fact, the payment given to a research subject can be considered more as an offer. The individual's agreement to participate in research after deciding – based on information about the study – that it is compatible with his or her interests is informed consent (Grady 2001).

On the other hand, what happens when an offer becomes an undue influence? An undue influence is considered as too much, or excessive influence. This idea challenges the basis for an autonomous decision. To better understand this concept, a greater understanding of the nature of influence is needed. People usually act in accordance with their wants and needs, "influenced by their physical, psychological, social, economic, and cultural experiences and circumstances" (Grady 2001). All of these influences are included in the process a potential research subject

faces. Through the individual and collective impact of these influences, some are capable of serving as inducements, motivations, or stimuli for action (Grady 2001).

Referring back to Dickert and Grady's wage payment model, there is an alternate perspective to their theory. Ruth Grant and Jeremy Sugarman, professors at Duke University, state that there is a big difference between a "fair wage" and a "fair incentive." When people refer to a "fair wage," they are agreeing that the services received or the effort expended provides an equal compensation between the two parties. In other words, compensation helps sustain a balance. This means that speaking of a "fair wage" or "fair compensation" is entirely sensible. However, a "fair incentive" makes no sense. This is because incentives are not a form of compensation. An incentive is a tool to create motivation or incite some desired action (Grant and Sugarman 2004).

The inherent nature and use of an incentive is to influence someone to do what they otherwise might not. The ethical dilemma lies within incentives that are used to induce someone to do something which they are averse (Beauchamp and Faden 1986). For example, those who offer large payments for eggs as seductive offers for people with religious convictions against the use of in vitro fertilization. The potential donor would be morally obliged to reject such an offer (Grant and Sugarman 2004). This moves the motivational tool from a monetary incentive to what could be considered as a monetary bribe. Even though this might be a rare and isolated case, it shows the ability incentives possess. Inducements that are ordinarily acceptable can become undue influences if the particular subject is especially vulnerable (Grant and Sugarman 2004).

Grady proposes that inducements, many of which are nonmonetary, do not necessarily nullify voluntary choice. Many times, people welcome and respond to inducements. For

example, even if a person is attracted to a job offer with a higher salary, a number of other factors are considered before a decision is made. Human motivation is highly complex and almost always involves multiple considerations. In the same way a higher paying job may be enticing, being attracted to the financial benefits of participating as a research subject does not necessarily counteract other influential motivations. Monetary gain could be one of many inducements; this would not inherently hinder voluntariness (Grady 2001).

However, Grady's analysis could be too generalized to provide substantial evidence against individual types of research. When dealing with human research, each research study should be analyzed to determine what different influences could affect the subject's informed consent, rather than making a generalized claim. Unlike medical patients, healthy research volunteers usually have no personal stake in the illness to which the research might be applied, or the application of what their donation will provide. Many of these volunteers are responding to advertisements placed in the newspapers or on the internet (Elliott and Lemmens 2001).

Before discussing a case study regarding the demographics of oocyte donors, it would be irresponsible to not mention that some embryo donors donate based on altruistic reasoning. The intent of this article is not to argue against this point, but rather present a potential determinant factor that could be statistically significant in donors that some individuals might deem morally hazardous.

In 2003, an analytical article was published discussing the psychological characteristics and factors associated with anonymous oocyte donors; this was accomplished through a demographical approach. Although this sample size is relatively small, and has potential flaws due to the nature of mailed questionnaires, this demographical study still gives substantial insight into the issues that have been previously mentioned.

In the study, donors information was assessed through the use of eight types of multiple choice and open-ended questions regarding age, ethnicity, education, occupation, income, religious affiliation, marital status, and reproductive history (Klock, Stout and Davidson 2003). Out of one hundred and fifteen donors who were mailed the questionnaire, fifty-two responded. Comparisons within the data collected were conducted and supported through the use of statistical testing. Overall, the modal respondent was a 27-year-old white, single, college-educated woman who had at least one previous pregnancy (Klock, Stout and Davidson 2003).

Out of the fifty-two donors who participated in this study, all fifty-two agreed that donors should be compensated for oocyte donation. When they were asked if they would still donate without the financial compensation, only eleven percent said they would still donate (Klock, Stout and Davidson 2003). This means that the eighty-nine percent of these donors were at least partially persuaded on the grounds of compensation. Yes, it is possible that financial gain was just a part of a combination of reasons for their final decisions. However, with such a substantial margin between those who would and would not donate without the financial benefit, this figure must not be discarded without thorough deliberation.

Table 1
Income demographic distribution of donors.

Income	<i>n</i>	%
None	6	11.5
10k-30k	16	30.8
31k-50k	24	46.2
51k-70k	5	9.6
90k +	1	1.9

Klock. Anonymous oocyte donors. Fertil Steril 2003.

As seen in Table 1, over forty percent of the donors have an annual income of \$30,000 or less. According to the 2000 United States Census, the median income of women in the

metropolitan area from which these donors were recruited was a mere \$21,696. Each donor was paid between \$2,000 and \$5,000 for each donation (Klock, Stout and Davidson 2003). At this median income, the financial compensation a donor would receive would be equal to between nine and twenty-three percent of their annual income.

It is unfortunate that there isn't an in depth background on each of the subjects, because one could justly argue that these individuals are making an informed, rational decision. However, at the same time, this magnitude of extra income could most certainly have the potential of being unduly influential. As Grant and Sugarman pointed out, inducements that would be ordinarily acceptable can become undue influences if the subject is especially vulnerable. Poverty could most certainly be considered vulnerability.

Several of the donors who participated in the study reported they had donated oocytes multiple times. One of the interesting differences that can be seen in the results between first-time and repeat donors is that repeat donors rated financial compensation as a more positive aspect of donation compared to those who had only donated once ($X^2=8.0$, $P<.04$) (Klock, Stout and Davidson 2003). This statistic was seen to be consistent with open-ended questions that asked what influenced their decision to donate again. Among the 15 repeat donors who answered this question, 14 of them stated it was for the money, while only 1 stated it was to help another woman.

This result is significant because it gives substantial support to the degree of influence money has on making decisions. However, monetary incentives might not always be considered as a negative influence. If Grady's analysis is accepted from the view of research subjects as entrepreneurs, the moral issues once associated with the negative analysis still exist, however seem less influential. For example:

Robert Rodriguez, the Mexican-American filmmaker, funded his critically acclaimed feature film *El Mariachi*, a smartly directed story of a machine-gun toting minstrel, entirely through his participation in a clinical research study. He spent a month in a research hospital testing a cholesterol-lowering drug. While in the hospital he wrote the entire screenplay during his last three weeks there. After the study was over, he was paid \$7,000 for participating as a research subject, which he then put towards the production costs of his screenplay. *El Mariachi* was the lowest-budget major-studio movie ever made, grossing thousands of times its production cost (Anderson and Weijer 2001).

While Rodriguez was most certainly influenced by the financial incentive, he was able to find mutually beneficial ends with the research system. As previously established, Grady makes her arguments predominantly from a utilitarian perspective. Assuming that all the ethically responsible precautions were met regarding consent, Mr. Rodriguez's entrepreneurial behavior is not only ethically permissible, but gives a perfect example of money being used to reimburse a research participant for their expenses and compensate them in some way for their time and effort. This payment can be considered a demonstration of respect and appreciation, rather than money being used as an undue inducement. However, this could also be interpreted as problematic due to the ability of subjects-for-hire who might "exploit" the system (Anderson and Weijer 2001).

Researchers and research firms are certainly not solely responsible for the idea and practice of informed consent. When dealing with issues regarding informed consent, there is an assumed clause that the subject involved is capable of processing the information given and able to come to a justified conclusion. If a subject is presented with accurate and substantial

information, they must be able to understand the information, believe the information, decide to use the information, and use the information intelligently (Schneider 2005). If people are unable to do this, the entire purpose of informed consent is negated.

The goal of disclosure requirements is not to fully educate a subject, because in most cases this would be impossible. For example, very few people completely understand every aspect of a medical procedure they need, and it would be ridiculous to even try to explain what took doctors years to learn. Instead, the goal is focused on improving the decisions subjects make. Success can be defined as improving their decisions “enough to justify the costs of the disclosure requirement to the government, the disclosers, and the recipients” (Schneider 2005).

The legislation encompassing the idea of informed consent is known as the “common rule.” This is a set of federal regulations that have been adopted by multiple federal agencies. They state that any federally funded research involving human subjects must be approved by an Institutional Review Board (IRB). One of the IRB’s responsibilities is to ensure that appropriate informed consent is obtained from each research subject (Korobkin 2007). However, these elements of legislation are vague, and possibly don’t apply at all to scientific research using human subjects. The direct interpretation of the common rule only applies to research that is funded with federal money, or if the researchers have given “assurances” to the federal government that they will indeed comply with the common rule. There is no attempt to protect the rights of the donors as autonomous actors to decline participation in research studies for any reason, or for no reason at all (Korobkin 2007).

The most obvious solution to this issue would be to enact legislation that prohibits compensating donors. However, this creates numerous problems for researchers in their ability to expand scientific knowledge. One example of problems being created lies within stem cell

research. Some states have already passed legislation that prevents the payment of donors for the embryos required for this research. Researchers who are trying to advance the knowledge and use of embryonic stem cells have been forced to resort to other means of acquiring embryos. One of the popular methods for deriving stem cells is recycling embryos that were initially created for reproductive purposes (Tomishima 2008). Even though this may be a loophole in the legislation, the same issues pertaining to the effects of monetary compensation are still present.

Many researchers agree that not compensating for research is illogical, regardless of the particular research medium or subject. Research participants who undergo MRIs, or those who donate blood, bone marrow, or other tissues, are compensated financially. Kathy Hudson, the director of the Genetics and Public Policy Center in Washington, adds, “To not do so for women undergoing hormonal stimulation and invasive oocyte retrieval for research is just plain unfair” (Trivedi 2007).

It is impossible to derive an ethically absolute answer pertaining to the effects of financial incentives on research subjects. However, there may be some median ground where the polarization between different ethical perspectives is reduced to some degree. For example, it could be possible to lessen the effects of financial incentives on informed consent, without removing the financial incentives. Hypothetically, this could be done through better policy and procedure.

In another article written by Dickert and Grady, with the addition of Ezekiel Emanuel, they discuss the current policies involving paying research subjects. In the conclusion of their study, they determined that with the lack of a clear statement of the purpose of payment and a standardized way to determine acceptable amounts, the likely result would be a wide variation of practice and inconsistent judgments (Dickert, Emanuel and Grady 2002). Furthermore, they

point out that most of the existing guidance discusses the need to minimize undue inducement. However, more studies and discussions need to be conducted to help understand when money is an undue influence. Not only this, but through these studies, determinations can be made about how the payment of subjects impacts subject selection and scientific integrity (Dickert, Emanuel and Grady 2002). This study is important due to the fact that ethicists and members of the science community must remember for whom they must speak.

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