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Patient Perspectives on Compensation for Biospecimen Donation

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Abstract

Background: The purpose of this study was to determine whether biospecimen donors believe they should receive compensation. This is the first study to report biospecimen donors' views on compensation and can potentially improve informed consent and recruitment practices.

Methods: Researchers asked patients undergoing surgical removal of tissue to donate biological materials to a biobank at their pre-surgical appointment or in the preoperative clinic of the Emory University Hospital. We interviewed 126 biospecimen donors within 30 days post-surgery regarding their perspective on compensation for biospecimen donation.

Results: In response to the question "Should you be paid for your participation in the tissue bank?," 95 (95/126, 75%) participants answered "No." 55 (55/95, 58%) of these indicated that donating biological materials should be about altruism, not gaining a monetary reward. Only 11 (11/126, 9%) participants unequivocally believed they should receive compensation while 14 (14/126, 11%) felt entitled to compensation only under specific circumstances. Eleven (11/14) "Depends" participants indicated that donors should only be compensated when researchers perform for-profit research. Responses varied by race and income level with whites more likely to not feel entitled to compensation and higher income participants more likely to respond "Depends."

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Contributors: ML, TD, KH, and TW conducted patient interviews, coded the responses into themes, edited the first draft of the manuscript, and approved the final manuscript. SCA analyzed the data, wrote the first and several subsequent drafts of the manuscript, and approved the final manuscript. MD and RP conceived of the study, provided feedback and support throughout data collection and data analysis, edited the manuscript, and approved the final manuscript.

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Conclusions: The majority of biospecimen donors stated they should not be paid for tissue bank participation. However, a minority believe they should be paid for donating tissue if the tissue is used in revenue-generating projects. These results provide some support for the current biobanking practice of not providing compensation.

Keywords

Donation/Procurement of Organs/Tissues; Patient perspective; Ethics; Research Compensation

INTRODUCTION

As biobanks become commonplace and biological materials are sometimes commercialized, the debate over whether research participants should be compensated has expanded to biospecimen use and storage (Ashburn et al. 2000; Caplan 2013; Hakimian and Korn 2004; Johnson and Wendler 2015; Kroll 2013; Moore v the Regents of the University of California et al. 1990; Truog et al. 2012). Advocates for compensating biospecimen donors garnered national attention in two court cases that ultimately established that patients are not the legal owners of excised biological materials and therefore give up any property or commercial interests at the time of donation (Moore v. the Regents of the University of California et al. 1990; Greenberg v. Miami Children's Hospital Research Institute, 2003). John Moore's spleen was surgically removed and used by researchers to create a lucrative cell line. The judge ruled that Mr. Moore did not retain property rights for his cells, though he had not been properly informed of the research use of his tissue (Truog 2012). In the Greenberg case, Mr. Greenberg and a group of parents of children with Canavan disease submitted tissue and medical information and financially supported research into the disease. When the researcher patented the gene sequence responsible for the disease and charged royalties for access to the patented information, the group sued. The judge ruled once again that the tissue was no longer property of the plaintiffs. However, since they had contributed to the research in other ways, including financially, there was "unjust enrichment" (Hakimian and Korn 2004). Johnson and Wendler argue that it is only fair that tissue donors who make project-specific contributions should receive compensation as do researchers and others (Johnson and Wendler 2015). Truog et al. argue, on the other side, that the value of the biospecimen cannot be known at donation, that a flat rate for each donor would likely be so small as to discourage the altruistic motivation for donating tissue, that those with lucrative tissue are merely lucky and should not be paid more, and that unregulated payment would be unfair (Truog et al. 2012). In support of this position, Lynch and Joffe argue that donors do not deserve compensation because they do not add any value nor effort to a research project beyond simply having a specific disease (2017).

The general public became aware of this debate after the publication of *The Immortal Life of Henrietta Lacks* (Skloot 2010), which has now been made into a movie, rekindling the debate (Joffe and Lynch 2017). Author Rebecca Skloot has reported that one of the most common questions she receives is whether the family has received financial benefit from research that has used the HeLa cell line (Kroll 2013). The common intuition driving this question is that it is only fair that the family benefit, particularly since they could not afford health insurance (Kroll 2013; Skloot 2010).

This debate is part of the larger debate about compensation of research subjects in general. Grady has argued that while some may view compensation as undue inducement, coercion, or over-targeting of the poor, a monetary reward for research participants may be appropriate in certain circumstances (2005). Halpern has argued that while there are several conceptual concerns about compensation, there is no significant empirical evidence to suggest financial incentives pose additional risks to participants (2011). An empirical analysis of hypothetical clinical trial recruitment found that compensation did not significantly affect the subject's assessment of risk and that payment was no more likely to affect the judgment of poor participants compared to their wealthier counterparts (Halpern et al. 2004). However, offering compensation to a potential subject could pressure them into hiding potentially disqualifying information, thus allowing non-eligible subjects into the study (Halpern 2011).

Another empirical study found that compensation increased subjects' willingness to participate in a hypothetical study, but did not affect the subjects' views of potential risks (Bentley and Thacker 2016). Ethicists have argued that the potential for compensation to increase recruitment (Bentley and Thacker 2016; Grady 2005; Halpern 2011; Resnik 2015) and the lack of empirical evidence to support the connection between financial incentives and undue/unjust inducement (Bentley and Thacker 2016; Halpern et al. 2004; Halpern 2011) make compensation a reasonable option for many types of research projects.

Given this background, it is clear that it is important to distinguish between two possible payment schemes—a flat rate at the time of donation as a thank you, a reimbursement, a wage (Dickert and Grady 1999), or a recruitment incentive versus payment as a share of commercial profits. Most of the general discussion about research compensation has focused on an upfront flat rate compensation for participating in a research project. Support for compensation for tissue banking has sometimes, in contrast, been focused on sharing in commercial profits, e.g. the response to Henrietta Lacks and the Moore case. Although the general public's view that the Lacks family should have received a "share" of the monetary gains made by commercial entities utilizing the HeLa cell line reflects a general positive attitude toward the latter payment scheme, there are both legal and ethical considerations that hinder this model of donor compensation. Truog et al. (2012) and Lynch and Joffe (2017) pointed out this payment scheme's unfairness and the Moore and Greenberg cases undermine any legal right to sharing in profits, though Wendler and Johnson argued against these criticisms. The current study assessed the simpler notion of whether biospecimen donors believe they should receive a payment simply for participating (akin to the flat rate regardless of profits), the reasons for their viewpoints, and the specific circumstances in which they feel entitled to payment. Knowing donors' attitudes toward a flat payment model can inform biobank policies.

METHODS

This assessment of biospecimen donors' views about compensation was embedded in the Biospecimen Pre-Analytical Variables (BPV) study, a national, multisite National Cancer Institute (NCI) study of the effects of pre-analytic variables, such as the biospecimen retrieval and storage methods, on molecular analyses. BPV included an Ethical, Legal, and Social Implications (ELSI) study focusing on the acceptability of broad consent. With

permission of the BPV steering committee, our site added a question to the ELSI interview querying donors whether they thought they should be paid for tissue bank participation. The ELSI study found that with the exception of a few concerns, tissue donors support the use of broad consent (Warner et al. 2017).

At our institution, the BPV study used our standard broad consent for biobanking which asks for consent for unspecified future research and access to the patient's medical information. Tissue and information necessary for BPV was then provided to the NCI under the BPV protocol. The standard consent introduced biobanking as key to the institution's mission that includes "the study of cancer and other human diseases." The consent included the collection of excess tissue and access to the patient's medical information. It stated that no benefit would accrue to the participants, but that donation might help other people who develop cancer. Further, no compensation was offered. Each participant received the consent and no other educational materials. For BPV, this biobanking consent was offered to cancer patients who were scheduled for surgical removal of the particular tumors targeted by BPV during their pre-operative appointment. At our institution, the ELSI study was also offered to cancer patients who were presented with the biobanking consent by a nurse during a surgical oncology clinic appointment. The ELSI interviewer was alerted when the biobanking consent would be offered and came to the clinic or pre-operative suite. Immediately following the offer of the biobanking consent, patients were offered participation in the ELSI study. Those who consented were given the choice to complete the survey immediately in person or by phone prior to or up to 30 days post-surgery. Participants who chose to complete the survey at a later date were asked to fill out the Contact Information Form and were given a sealed copy of the survey.

Our site-specific question was "Should you be paid for your participation in the tissue bank?" We then followed up with participants to determine why they believed they should or should not be paid, and if they answered "Depends," what factors should result in payment. The initial code book was developed by TD, and confirmed and edited by RP. All 126 narrative answers were then independently coded by TD and ML, with discrepancies resolved by MDD. While we assigned only one code – "Yes," "No," or "Depends" – to the answer to the lead-in question "Should you be paid?", we coded all responses for the participants' explanations for their stance on payment for tissue banking. The follow up questions thus could have multiple answers.

Demographic characteristics were collected and analyzed. The impact of age as a continuous variable on answers to the primary question was analyzed through ANOVA and categorical variables (gender, education level, race, employment status, income level) were analyzed through chi-square and Fisher's exact tests. $P < 0.05$ was considered to indicate statistical significance.

The study was approved by the Institutional Review Board at Emory University and consent was obtained from all participants.

RESULTS

Of the 140 patients approached at our site, 12 (9%) refused the survey and 2 did not agree to donate biospecimens, which left a total of 126 participants. 106 (84%) completed the survey over the phone, 6 (5%) in person, and 14 (11%) partially over the phone and partially in person. 91 (72%) participants were recruited from those consented to the biobanking consent in the pre-operative clinic and 35 (28%) from those consented during a surgical oncology clinic appointment. Of the 126 donors, 70 (56%) were male, 91 (72%) white, and the median age was 60 years old. 44 (35%) had a college degree, and the median household income bracket was \$60,000 - \$80,000. Details are provided in Table 1.

Table 2 analyzes responses by demographic characteristics. Responses varied by race and income level. White participants (n=84) responded “No” more often than non-white participants (N=33) (p<0.001). Participants who were in households that earned more than \$60,000 (n=54) responded “Depends” more frequently than participants in households that earned \$60,000 or less (n=44), (p<0.032). There was no association between race and income.

The frequency of donor preferences regarding biospecimen compensation and the corresponding themes are listed in Table 3.

Out of the 126 biospecimen donors, 95 (75%) did not think they should be paid for participating in the tissue bank. Fifty-five (55/95, 58%) cited altruism as their reason. Other reported reasons included: willingness to advance research (17/95, 18%), belief that biospecimen donation is a voluntary gift (10/95, 11%), and the hope that donation may eventually help the participant or their family (6/95, 6%).

Eleven of the 126 (9%) participants thought they should be paid. Participants who thought they should be paid cited a variety of reasons. Three out of these eleven participants believed that their ownership of their biological materials entitled them to compensation. Two thought they should be paid because they needed the money and two because they also wanted to profit from the use of their biological materials.

Fourteen of the 126 (11%) participants believed biospecimen donors should be compensated under certain circumstances. Eleven of these fourteen “depends” participants felt that biospecimen donors should be compensated if researchers utilized the biospecimen in for-profit research. Others felt that compensation should depend upon the amount of need for the biospecimen (1/14), if donation were mandatory (1/14), or if there were additional burdens placed upon donors compared to non-donors (1/14).

DISCUSSION

Most biospecimen donors (95/126, 75%) surveyed in this single institution study did not think they should be paid, but rather viewed donation as an expression of altruism (55/95, 58%). According to McGrath-Lone et al., altruism is a very common reason for cancer patients to engage in research. Altruism may be a stronger motivator for research participation in cancer patients compared to other illnesses because the chronic and genetic

nature of cancer means the disease may impact research participants themselves or their family in the future (McGrath-Lone 2016).

It is interesting to note that though altruism was the main reason that donors did not think they should be paid, a few did report views that mirrored those expressed by ethicists. A few gave reasons previously raised by ethicists against compensation, such as concerns that it would make tissue a commodity (2/95, 2%) (Grady 2005) or in other ways negatively impact research (2/95, 2%) (Halpern 2011; Lynch and Joffe 2017; Truog et al. 2012). In all, thirteen out of the twenty-five participants who believed they should be compensated under all circumstances (the “Yes” group) or certain circumstances (the “Depends” group) (13/25) echoed Johnson and Wendler’s argument for compensation—all parties who provide project-specific contributions (including researchers and some donors) to revenue generating studies should be compensated. Specifically, eleven participants in the “Depends” category believed they should only receive compensation if institutions utilize their biological materials to generate a profit while an additional two patients in the “Yes” category anticipated others would profit so they wanted to profit as well. A few of the “Yes” participants also gave reasons echoing ethicists’ arguments for compensation: payment may be an incentive that will increase recruitment (1/11) (Bentley and Thacker 2016; Grady 2005; Halpern 2011; Resnik 2015) and payment could serve as a thank you gift (1/11) (Dixon-Woods et al. 2008). Other “Yes” participants also discussed themes not emphasized by ethicists, such as believing they should receive compensation because their donated tissue is a part of them (3/11), or because they need the money (2/11), echoing the informant’s comment in the Rodriguez et al. study (2013). A “Depends” participant also noted that payment should be given when donation incurs additional burdens (1/14).

Currently, biobanks do not typically compensate donors for their contributions. Our data support this practice, which allows biobanks to avoid some of the practical difficulties that would arise in setting up a payment scheme. As Truog asked, how would one determine what to pay whom, and what metric could be used to determine fairness? Further, if a small sum were given, it would be difficult to justify the administrative expense by any modest increase in recruitment. More concerning, since the majority of these donors were motivated by altruism and viewed their donation as a gift, payment might be counterproductive as well as unwanted, since it signals that the donation is a transaction, not a gift. Further, this data provides some insights to inform recruitment practices, suggesting that appealing to altruism and donation as a gift are good approaches to attract donors.

This study has several limitations. It was conducted with a small sample size at a single academic medical center, so a larger multi-institutional follow up study including community hospitals is needed to increase generalizability. It should also be noted that participants in this study signed a biospecimen donation consent form immediately prior to the interview, which stated that donations were to be used to help others. The inclusion of this statement in the consent form may have prompted the altruistic theme identified. This biospecimen consent also stated that donors would not receive compensation; therefore, the participants in this study may have been more likely to feel they should not receive compensation. Further research is needed to determine how other populations, such as those who refuse to donate their biospecimens and non-cancer biospecimen donors, perceive

compensation, as their views may differ from the donors included in this study. Also, since this study only queried participants with regard to a flat payment at the time of donation, further research is needed to determine biospecimen donors' views regarding a payment scheme that compensates donors with the share of commercial profits obtained through the use of donated biospecimens.

However, this report does offer insight into cancer biospecimen donors' views on compensation after signing a standard broad biobanking consent and provides some support for the current biobanking practice of not providing compensation.

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REFERENCES

- Ashburn TT, Wilson SK, and Eisenstein BI 2000 Human tissue research in the genomic era of medicine: balancing individual and societal interests. *Archives of Internal Medicine* 160(22): 3377–84. [PubMed: 11112229]
- Bentley JP and Thacker PG 2004 The influence of risk and monetary payment on the research participation decision making process. *Journal of Medical Ethics* 30(3): 293–8. [PubMed: 15173366]
- Caplan A 2013 NBC News Available at: <http://www.nbcnews.com/health/nih-finally-makes-good-henrietta-lacks-family-its-about-time-6C10867941>. (accessed December 15, 2016).
- Dickert N and Grady C 1999 What's the Price of a Research Subject? Approaches to Payment for Research Participation. *New England Journal of Medicine* 341(3): 198–202. [PubMed: 10403861]
- Dixon-Woods M, Cavers D, Jackson CJ, et al. 2008 Tissue Samples as “Gifts” for Research: A Qualitative Study of Families and Professionals. *Medical Law International* 9:131–150.
- Grady C 2005 Payment of clinical research subjects. *Journal of Clinical Investigation* 115(7): 1681. [PubMed: 16007244]
- Greenberg v. Miami Children's Hospital Research Institute., 2003, *West's Federal Supplement* 264:1064–78. [PubMed: 15776537]
- Hakimian R, and Korn D. 2004 Ownership and use of tissue specimens for research. *Journal of the American Medical Association* 292(20): 2500–05. [PubMed: 15562130]
- Halpern SD 2011 Financial Incentives for Research Participation: Empirical Questions, Available Answers and the Burden of Further Proof. *The American Journal of the Medical Sciences* 342(4): 290–3. [PubMed: 21817878]
- Halpern SD, Karlawish JH, Casarett D, Berlin JA, Asch DA 2004 Empirical Assessment of Whether Moderate Payments Are Undue or Unjust Inducements for Participation in Clinical Trials. *Archives of Internal Medicine* 164(7): 801–3. [PubMed: 15078651]
- Johnson R, and Wendler D 2015 Challenging the Sanctity of Donorism: Patient Tissue Providers as Payment-Worthy Contributors. *Kennedy Institute of Ethics Journal* 25(3): 291–333. [PubMed: 26412739]
- Kroll D 2013 Forbes Available at: <http://www.forbes.com/sites/davidkroll/2013/03/24/the-henrietta-lacks-genome-consent-trust-and-common-decency/#5df97ca159b1>. (accessed December 15, 2016).
- Lynch HF, Joffe S 2017 Science Needs Your Cells. *The New York Times* 4 21.

- McGrath-Lone L, Ward H, Schoenborn C and Day S 2016 The effects of cancer research participation on patient experience: a mixed-methods analysis. *European Journal of Cancer Care* 25:1056–1064. [PubMed: 26094639]
- Moore v the Regents of the University of California et al, 793 P2d 479 (Cal 1990).
- Resnik DB 2015 Bioethical Issues in Providing Financial Incentives to Research Participants. *Medicolegal and Bioethics* 5:35–41. [PubMed: 26807399]
- Skloot R 2010 *The Immortal Life of Henrietta Lacks* New York, NY: Crown Publishers.
- Tavar Rahul, and Murphy TF 2001 The case for compensation of tissue donors. *Archives of internal medicine* 161(15): 1924–25. [PubMed: 11493153]
- Truog RD, Kesselheim AS, and Joffe S 2012 Paying tissue donors: The legacy of Henrietta Lacks. *Science* 337(6090): 37–8 [PubMed: 22767914]
- Warner TD, Weil CJ, Andry C, Degenholtz HB, Parker L, Carithers LJ, Feige M, Wendler D, Pentz RD Broad Consent for Research on Biospecimens: The Views of Actual Donors at Four U.S. Medical Centers, *Journal of Empirical Research on Human Research Ethics* 2018 4;13(2):115–124. doi: 10.1177/1556264617751204. Epub 2018 Feb 1. PMID: 29390947 [PubMed: 29390947]

Table 1

Demographics

Participants	N = 126	%
Female	56	44.4
Male	70	55.6
Race		
White	91	72.2
African America	28	22.2
Asian	4	3.2
Other	3	2.4
Education		
High School Diploma	39	31.0
college degree	63	50.0
college degree	23	18.2
Missing	1	.8
Employment		
Employed (full/Part)	37	29.4
Retired	47	37.3
Disabled	17	13.5
Student	2	1.5
Other	23	18.3
Household Income		
\$60,000.00	47	37.3
> \$60,000.00	56	44.4
Missing	23	18.3

Table 2.

Demographic differences in views on compensation.

Demographic Differences in Views on Compensation					
Demographics		Yes N=11	No N=95	Depends N=14	P-value*
Gender	Female (N=54)	3 (5.56)	47 (87.04)	4 (7.41)	0.158
	Male (N=66)	8 (12.12)	48 (72.73)	10 (15.15)	
Education level	Some college or less (N=59)	5 (8.47)	51 (86.44)	3 (5.08)	0.069
	College degree or higher (N=60)	6 (10)	43 (71.67)	11 (18.33)	
Race	White (N=84)	5 (5.75)	78 (89.66)	4 (4.6)	<.001
	Other (N=33)	6 (18.18)	17 (51.52)	10 (30.3)	
Employment status	Employed full- or part-time (N=34)	2 (5.88)	27 (79.41)	5 (14.71)	0.617
	Other (N=86)	9 (10.47)	68 (79.07)	9 (10.47)	
Income	\$60K or less (N=44)	6 (13.64)	36 (81.82)	2 (4.55)	0.032
	Greater than \$60K (N=54)	3 (5.56)	40 (74.07)	11 (20.37)	
Age	Number	11	95	14	0.105
	Mean	55.64	61.76	55.93	
	Median	56	64	56	

Table 3.

Donor Perspectives on Compensation.

Should you be paid for your participation in the biobank?	
No:	95 (75%)
Depends:	14 (11%)
Yes:	11 (9%)
Other:	6 (5%)
Major Themes *	
No: (n=95)	
Altruism:	55 (58%)
Will Advance Research:	17 (18%)
Is a Voluntary Gift:	10 (11%)
May help me or my family:	6 (6%)
No additional burden:	5 (5%)
It's the right thing to do:	3 (3%)
Tissue should not be a commodity:	2 (2%)
Payment could negatively affect research:	2 (2%)
Money better used for research:	2 (2%)
Other:	8 (8%)
Depends: (n=14)	
Yes, if for profit:	11 (79%)
Yes, if donation is mandatory:	1 (7%)
Yes, if donation incurs additional burdens:	1 (7%)
No, if great need for tissue:	1 (7%)
Yes: (n=11)	
The tissue is a part of me:	3 (27%)
I want to profit too:	2 (18%)
I need the money:	2 (18%)
Compensation should be an option:	1 (9%)
Compensation should be an incentive:	1 (9%)
Compensation should be a "Thank you":	1 (9%)
Other:	2 (18%)

* Participants could provide more than one reason for their choice