

Dissertation Prospectus

Neglected by Assessment: Ageism and Ableism in the Competition for Scarce Kidneys

Submitted by

Lonny Douglas Meinecke

March 22, 2017

Dr. Ajay Das

Dissertation Prospectus

Introduction

End stage renal disease (ESRD) is a terminal illness that results in death unless a transplant is performed before the illness is too advanced for this form of treatment (Center for Bioethics, 2004). Unfortunately, there are not enough kidneys to go around. Those who need a kidney are placed on a waiting list and ranked by various physical and mental criteria; the waiting time on this list is a key predictor of premature death from renal disease (Center for Bioethics, 2004; Patzer, 2011). In spite of this key statistic, the waiting time for transplantation is often biased against the physically old (ageism) and the intellectually disabled (ableism) to reduce the number of candidates to match the much smaller number of organs. The unusual delays faced by the elderly with dementia and the young with special needs means that these less mentally qualified groups will not survive end stage renal disease (Curtis, 2006; Derrington et al., 2016; Grams et al., 2012; Wightman et al., 2014). A study of the relevant literature suggests that this may be more than bias or discrimination, and may be a violation of international human rights during the selection of human candidates and the allocation of sparse kidneys (Danovitch, 2014; Grams et al., 2012; Wightman et al., 2014). Although these assessment biases have been studied, a survey of the literature suggests that the relationship between physical age, mental ability, and waiting time for a transplant has not been studied. An analysis of existing data in the US Renal Data System will allow the comparison of age bias and ability bias, by analyzing mean wait times for kidney transplants for candidates on the list (Grams et al., 2012). The results of this analysis may point to violations of the Universal Declaration of Human Rights by the industries of organ allocation and candidate assessment (United Nations, 1948).

Background of the Problem

End stage renal disease (ESRD) is a serious physical condition and the outcome is always loss of life (Patzner, 2011). Although medical science can delay death from ESRD, many die while waiting for a kidney replacement. The problem is that the number of organs is much smaller than the number of candidates in need of an organ (Patzner, 2011). Inevitably, those who are refused an organ will feel they have been treated unequally by society (Fyson & Cromby, 2013; Ubel & Loewenstein, 1996).

Research has been conducted showing an assessment bias against physically aged candidates (ageism), even when their mental fitness is adequate (Curtis, 2006; Grams et al. 2012). Research has also shown assessment bias against physically young candidates (ableism and IDD prejudice), even when their physical fitness is adequate (Derrington, Goldberg, & Frader, 2016; Wightman et al., 2014). A survey of the literature suggests that what has not been studied, is a possible relationship between ageism and ableism in the selection of candidates for kidney transplant. A survey of secondary data in the US Renal Data System will allow the comparison of these two groups by analyzing mean wait times for kidney transplant for these groups (Grams et al., 2012). The results of this analysis may point to violations of the Universal Declaration of Human Rights by the organ allocation and candidate assessment industries (Danovitch, 2014; Reese, Boudville, & Garg, 2015; United Nations, 1948).

Theoretical Foundations and Review of the Literature/Themes

The model for this dissertation is based on an existing set of models of prejudice in the psychological literature which have expanded the definition gradually. Each of these has successfully described the class against class relationships that prejudice seems to pertain to. These may be summarized by three perspectives: (a) human v. human prejudice, (b) human v.

non-human prejudice, and (c) human enough v. not human enough prejudice . In the first model, the Stereotype Content Model (SCM), prejudice has been modeled as human to human, and to reach affection each human must demonstrate competence (Fisk and North, 2014). In the second model, the Interspecies Model of Prejudice (IMP), prejudice has been modeled as human to animal, and to reach affection each animal must exhibit service (Costello & Hodson, 2014). In the third model, the Value/Threat model, prejudice has been modeled as *more human* versus *less human*. In this model, to reach acceptance and survival, each human or animal must identify with a certain value while not identifying with any other value (since other values symbolize threats to that value) (Hodson, MacInnis, & Costello, 2014). For example, anthropocentrism (“humanness”) is often a revered value which results in prejudice against whatever seems less human to that group (Gilhus, 2006; Hodson et al., 2014). According to Roberts (2015), estimates of intelligence have historically been used to define more human from less.

The hallmark of each of these models is a relationship between what is held to be superior (more) versus what is held to be inferior (less). In this dissertation’s model of class prejudice, intellectual ability (mental competence) is held to be “superior to” intellectual disability (less mental competence), with the latter exploited or neglected to improve the longevity and well-being of the former. The theoretical model for this research suggests that mental bias is also a form of prejudice, and may be analyzed by exploring the process and outcome of selecting preferred candidates for kidney organ grafts, which demonstrates favoritism for the survival of mentally fit candidates.

Review of the Literature/Themes

The background of the problem is that is that there are far more persons who need an organ than available organs (Patzner, 2011). This has resulted in the need for medical

professionals to use criteria to help decide who lives and who dies. Those who are refused an organ will feel unfairly treated by society (Fyson & Cromby, 2013). The ethics of this dilemma are called distributive justice. The review of the literature will be divided into four sections—the problem, the prejudice, the past, and the premise. The problem is that there are far more persons in need of a replacement organ than there are organs. The prejudice is a bias for mental fitness over physical fitness, to solve the problem of too many people and not enough organs. The past has seen the use of psychological assessments dating back to ancient China to help decide which persons receive special treatment when there are more persons in need of a resource or social position than there are resources or social positions. The premise is that the psychosocial criteria used to screen candidates for kidney transplantation is biased against the intellectually disabled, mainly because mental assessment requires mental fitness. Issues of the violation of human rights during the decision-making process suggest that natural selection may be one of the few means of avoiding selection bias.

The gap suggests that mental fitness is preferred over physical fitness in the application of distributive justice. Among the natural sciences, such a preference is called *unnatural selection*, whereas the absence of psychosocial criteria may be a return to natural selection and offer a form of distributive justice less prone to the violation of human rights.

Problem Statement

It is not known if there is a relationship between the wait time for candidates of preferred physical age (physically fit candidates) and the wait time for candidates of preferred mental age (mentally fit candidates) on the kidney transplant waiting list. This is important because a survey of the literature suggests that physical age and intellectual disability are being discriminated against during the assessment of kidney transplant candidates (Cherkassky, 2011; Derrington et

al., 2016). The delay experienced by the elderly who may have dementia (ageism) and by young people who may have special needs (IDD and ableism) means that less mentally qualified groups will not survive end stage renal disease (Curtis, 2006; Derrington et al., 2016; Grams et al., 2012; Wightman et al., 2014).

The significance of this problem is that the current method of selecting candidates—which is based on professionally fixed criteria like physical aging and intellectual assessment—may be a violation of the Declaration of Human Rights. The primary affected population (groups such as special needs youth and the elderly) are not being granted the same chance for life as other groups (Danovitch, 2014; Reese et al., 2015). This study may add to the literature with evidence of a delay of access to vital healthcare solutions that is targeting old age and delayed intellectual development—while favoring the mentally fit. This prejudice seems related to cultural preferences such as reverence for self-care rather than social caregiving.

Research Questions, Hypotheses, and Variables

This research will explore whether there is a relationship between physical age bias (ageism) and mental age bias (ableism) for candidates on the waiting list for a kidney transplant. The following three questions will ask which group (physically robust candidates or mentally robust candidates) is more likely to receive scarce kidney organs sooner (Cherkassky, 2011).

Research Question 1 (Ageism Delay):

R1: Is there a relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate?

H₁₀: There is no relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate.

H1_A: There is a relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate.

Research Question 2 (Ableism Delay):

R2: Is there a relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate?

H2₀: There is no relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate.

H2_A: There is a relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate.

Research Question 3 (Mental Preference & Delay):

R3: Is there a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list?

H3₀: There is no relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list.

H3_A: There is a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list.

Research Variables:

The variables for the above research questions include two independent variables (Age Bias and Intellectual bias) and one dependent variable (Transplant Delay). See Table 2 in Appendix C for a diagram of these relationships.

Significance of the Study

Previous studies have explored prejudice but do not seem to have explored the application of favoritism for certain mentally superior groups resulting in neglect of other groups via assessment. Although previous studies have shown bias against physically aged renal candidates and mentally challenged renal candidates, the delays faced by these groups may not have been fully explored (Curtis, 2006; Derrington et al., 2016; Grams et al. 2012; Wightman et al., 2014). The average wait time for a kidney is about five years (10 in many states), but the average length of survival on dialysis is less than 5 years (Grubbs et al., 2014).

This study will advance scientific knowledge on this topic by asking whether there is a relationship between age bias and intellectual bias evident in the unusual delays these groups face while awaiting kidney transplant. If so, this may point to possibly significant violations of the Universal Declaration of Human Rights by the industries that assess human candidates and allocate scarce organs (Danovitch, 2014; Reese et al., 2015; Ubel & Loewenstein, 1996; United Nations, 1948).

This study may be significant because it may help empower less favored groups—such as the intellectually and developmentally disabled. This study may help these groups argue for their right to a kidney transplant using empirical evidence (Wightman et al., 2014). Those who are too young to be included or too old to be useful, may appeal for equality of assessment and the right to life (Grams et al., 2012).

Rationale for Methodology

A quantitative method was chosen for this research. The rationale is that the purpose of this research is to highlight a mean difference between groups (*thin description*), whereas qualitative and mixed methods seek depth (Park & Park, 2016). Quantitative methodology was

also chosen because the secondary data sets from which data will be collected are numerical totals of questionnaire data suitable for quantitative analysis. Sociologically, this research pertains to the topics of prejudice and social justice, and an argument by researchers of social justice is that, in comparison to qualitative methods, quantitative methods are used by and appreciated by the same established ingroups that outgroups seek equality from (Cokley & Awad, 2013). The focus of this design is to measure mean group differences (ageism bias and intellectual bias), and a quantitative method is more suitable. The possibility of less subjectively acquired data during the use of quantitative methods may permit exploration of these sensitive issues, and with the rigor necessary to reduce bias enough to produce sufficiently significant results (Park & Park, 2016; Pedersen & Thomas, 2013).

Nature of the Research Design for the Study

This research uses a quasi-experimental design because the data for this research is secondary data in national repositories of organ transplant data, and it has already been collected. The principal investigator cannot randomly assign the physical age and mental age conditions present in the fixed data. (Bleske-Rechek, Morrison, & Heidtke, 2015; Ejima et al., 2016). Recent studies suggest this design (quasi-experimental) is sufficient to analyze data such as the presence of mental illness or fitness in fixed data (Riemersma, van Santvoort, Janssens, Hosman, & van Doesum, 2015). This research will also be analyzing fixed data concerning mental conditions.

This research will compare wait times for kidney organ transplantation to candidates from several groups previously studied and shown to exhibit assessment and allocation bias. The population will consist of human participants awaiting their first kidney organ transplant. The target population will consist of human participants within the general population of the United

States. The sample will consist of human participants on the OPTN waiting list for kidney organ transplantation from January 1, 1999 to December 31, 2006 and will include all first-time kidney transplant applicants (whether they received a kidney or not). This range was chosen to align this proposal with previous research in which age bias was found (Grams et al., 2012). The data will be requested using the non-sensitive data request format at the USRDS and participants will not be identifiable by the data requested. All data will be drawn directly from the OPTN portion of the USRDS, which is the only official repository of data kept regarding organ candidates, donors, and outcomes.

Purpose of the Study

The purpose of this quantitative method with a quasi-experimental design is to compare groups of candidates on the waiting list for a kidney transplant in the U.S. Renal Data System (USRDS), to explore whether a delay in receiving a kidney organ transplant is more related to an age bias (ageism) or an intellectual development bias (ableism). The data source will be the Organ Procurement and Transplantation Network (OPTN) registration data publicly available from the USRDS, which is “a national data system that collects, analyzes, and distributes information about chronic kidney disease (CKD) and end-stage renal disease (ESRD) in the United States” (U.S. Renal Data System, 2016, para. 1). The groups that will be compared will be first-time kidney transplant recipients divided into three age groups (too young, too old, and just right, corresponding to under 18, over 64, and the socially productive age group between 18 and 65). The average intellectual assessment of each of these three age groups will be compared against the wait time for a replacement kidney.

Instrumentation or Sources of Data

All data will be drawn directly from the U. S. Renal Data System, which is the only official repository of data kept regarding kidney organ candidates, donors, and outcomes. The validity and reliability of this data meet compliance with federal, state, and local guidelines for the recording and documenting of conditions such as end stage renal disease (Centers for Medicare and Medicaid Services, 2008; U.S. Renal Data System, 2015). Annual reports describe the maintenance and standards of this system, and the validity of its web-based systems which are available to researchers. This use is authorized for purposes described as “to create core metrics and measures, such as the assessment and reporting of provider performance” (U.S. Renal Data System, 2015, para. 2). The type of data consists of completed that contain categorical and numerical data the group means of which can be analyzed by researchers for potential relationships.

Data Collection Procedures

Data will be obtained from a secondary data source. The OPTN portion of the USRDS database was identified as a good repository of the data needed for this study, because all organ transplants conducted in the U.S. must report candidate and recipient data to these organizations. The data are available for researchers to make requests from without special permission, so long as no patient-identifiable data is gathered. A written request with the desired data fields will be made from the USRDS. The request will specify only the data needed to identify the candidates for kidney organ recipients for the period between January 1, 1999 to December 31, 2006 and will include all first-time kidney transplant applicants (whether they received a kidney or not). This range was chosen to align this proposal with previous research in which age bias was found (Grams et al., 2012). Field data will be gathered as described in Wightman et al. (2014) and the

Researcher's Guide to the USRDS Database (U. S. Renal Data System, 2007). Database fields for inclusion have been identified as age at intake (to the waiting list), age at transplant (as appropriate), cognitive development, academic progress, and academic level. Candidates with a rating of "definitely cognitive delay/impairment" will be rated as having a definite disability. Candidates with two out of three criteria including "probable cognitive impairment," "questionable cognitive impairment," reduced academic load/nonparticipation," or "delayed grade level/special education" will be rated as having a probable intellectual disability. Since academic data under five years of age and over 18 years of age are not collected, only the "probable cognitive impairment" or "questionable cognitive impairment" ratings will be collected for candidates under five years of age (Wightman et al., 2014).

Prior to the actual study, this study design will be submitted to the IRB. Standards of human participants research will be followed for the protection and well-being of participants, as well as the respect of their privacy. These standards include respect for persons, beneficence, and justice, which will be applied by assessing risk versus benefit, and ensuring the selection of participants does not take advantage of protected groups (U.S. Department of Health and Human Services, 2016). As the data is secondary and no patient-identifiable data will be requested, application for exempt review will be sought. Also in accordance with these principles, data will be kept by the principal investigator only, and secured so as not to compromise anonymity of participants. Only the data needed for the design will be gathered, in keeping with best practices. Data will be stored and encrypted after the primary analysis on a password-protected computer for a period of three years minimum—per the research standards of the American Psychological Association (Devereaux & Gottlieb, 2012). After this period, all copies of the data will be wiped (erased and scrambled) so as to be unrecoverable. The timeline for these data gathering

procedures should not extend beyond two weeks from approval by the IRB. The availability, privacy, and protection of any data collected will continue for a minimum of three years beyond which digital data will be electronically wiped and physical data shredded to protect participants, unless approved for retention.

Data Analysis Procedures

Collected data will be analyzed using a 3 X 3 between groups factorial ANOVA using IBM SPSS version 24. The assumptions for a factorial ANOVA include:

1. The two independent variables (IVs) are categorical
2. The dependent variable is continuous
3. The observations for the IVs are independent of one another (there is no relationship between the two groups)
4. The observations exhibit homogeneity of variance
5. The dependent variable is normally distributed
6. There are no significant outliers

The first, second, and third assumptions will be met by the design (IV1 and IV2 are both categorical variables and operationalized as mutually exclusive, and the DV for each is a continuous variable). The fourth assumption will be verified in SPSS using Levene's homogeneity of variance test. The fifth assumption will be checked using the Kolmogorov-Smirnov test for normality in SPSS. The sixth assumption will be checked in SPSS by visually inspecting the descriptive statistics output table and box-plots.

The data is not expected to have any missing or unusual values. However, data will be inspected using descriptive analysis in case of unusual or missing values. Any univariate outliers can be identified by running explore/frequencies with boxplots, and will be deleted unless this would affect the retained data significantly. Categorical data will be collapsed (as needed) to

binary responses and coded numerically. For example, non-binary data reported as Definite, Probable, Questionable, Delayed, and None will be coded as 2 (Definite/Probable), 1 (Questionable/Delayed), and 0 (None). Neutral results will be logically fit to the closest matching level. Data will then be analyzed using the factorial ANOVA approach in IBM SPSS version 24 (Morgan, Leech, Gloeckner, & Barrett, 2013). A Tukey post hoc will also be run to analyze the various comparisons in the 3 X 3 design.

After running the ANOVA, the Tests of Between-Subjects Effects output will be checked for the two separate IVs (main effects) and their combination/interaction (in the middle of the output table). The Levene's table will be checked to make sure there is no significance figure less than .05 (otherwise equality of variances could not be assumed). The Test of Between-Subjects Effects will be checked for a significant relationship (indicated by $p < .05$ in the Significance column). If there is a statistically significant effect for age bias or intellectual disability bias, the Tukey post hoc results will be checked in the Multiple Comparisons table to determine the relationship between them.

Ethical Considerations

The data collected for this research is from the OPTN portion of the U.S. Renal Database System, an existing repository of publicly accessible data. None of the data collected will identify specific persons (the USRDS offers a request format for general queries). The principal investigator will follow all appropriate procedures for human participants research, and under approval by the Institutional Review Board (IRB) before collecting data.

In accordance with the Belmont Principles, standards of human participants research will be followed for the protection and well-being of participants, as well as the respect of their privacy. These standards include respect for persons, beneficence, and justice, which will be

applied by requiring informed consent, assessing risk versus benefit, and ensuring the selection of participants does not take advantage of protected groups (U.S. Department of Health and Human Services, 2016). Also in accordance with these principles, only the data needed for the design will be gathered, in keeping with best practices. Data will be kept by the principal investigator only, and secured so as not to compromise anonymity of participants. As per the research standards of the American Psychological Association, data will be stored and encrypted after the primary analysis on a password-protected computer for a period of three years minimum (Devereaux & Gottlieb, 2012).

The data has already been collected in a national repository under medical standards of informed consent, therefore informed consent will not be required (U.S. Department of Health and Human Services, 2015). Site permission for the data collection portion will be officially requested prior to IRB approval. There are no known conflicts of interest, and the risk of participating in the research is minimal, because the data has already been recorded and will be retrieved as anonymous data. No incentive for participation will be offered because the data has already been collected in the secondary data source.

References

- Adams, M., Blumenfeld, W. J., Casteñada, C., Hackman, H. W., Peters, M. L., & Zúñega, X. (2013). *Readings for diversity and social justice* (3rd ed.). New York, NY: Routledge.
- Appel, J., & Vaidya, S. (2014). Ethical dilemmas in psychiatric evaluations in patients with fulminant liver failure. *Current Opinion in Organ Transplantation*, *19*(2), 175-180.
doi:10.1097/MOT.0000000000000060
- Arger, C., Sanchez, O., Simonson, J., & Mezulis, A. (2012). Section 1: Mental & physical health-pathways to depressive symptoms in young adults: Examining affective, self-regulatory, and cognitive vulnerability factors. *Psychological Reports*, *111*(2), 335.
doi:10.2466/09.02.15.PR0.111.5.335-348
- Aristotle, & Lord, C. (2013). *Aristotle's 'Politics'* (2.1273b). Chicago, IL: University of Chicago Press.
- Baker, D. L. (2017). *Disability and U.S. politics: Participation, policy, and controversy*. Santa Barbara, CA: Praeger.
- Baynton, D. C. (2013). Disability and the justification of inequality in American history. *The Disability Studies Reader*, *17*, 33-57. Retrieved from http://www.uua.org/sites/live-new.uua.org/files/documents/bayntondouglas/justification_inequality.pdf
- Biernat, M., & Danaher, K. (2013). Prejudice. In I. B. Weiner (Ed.), *Handbook of psychology* (Vol. 5, pp. 341-367). Hoboken, N.J: Wiley.
- Bleske-Rechek, A., Morrison, K., & Heidtke, L. (2015). Causal inference from descriptions of experimental and non-experimental research: Public understanding of correlation-versus-

- causation. *Journal of General Psychology*, 142(1), 48-70. Retrieved from <https://lopes.idm.oclc.org/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=edswss&AN=000346907700004&site=eds-live&scope=site>
- Brucker, R. M., & Bordenstein, S. R. (2012). Speciation by symbiosis. *Trends in Ecology & Evolution*, 27(8), 443-451. Retrieved from http://izt.ciens.ucv.ve/ecologia/Archivos/ECO_POB%202012/ECOPO4_2012/Brucker%20y%20Bordenstein%202012.pdf
- Button, K. S., Ioannidis, J. P., Mokrysz, C., Nosek, B. A., Flint, J., Robinson, E. S., & Munafò, M. R. (2013). Power failure: Why small sample size undermines the reliability of neuroscience. *Nature Reviews Neuroscience*, 14(5), 365-376. Retrieved from <http://www.nature.com/nrn/journal/v14/n5/full/nrn3475.html>
- Center for Bioethics. (2004). *Ethics of organ transplantation*. Retrieved from http://www.ahc.umn.edu/img/assets/26104/Organ_Transplantation.pdf
- Centers for Medicare and Medicaid Services. (2008). *ESRD surveyor training interpretive guidance*. Retrieved from <https://www.cms.gov/Medicare/Provider-Enrollment-and-certification/guidanceforlawsandregulations/dialysis.html>
- Chen, C. Y., Purdie-Vaughns, V., Phelan, J. C., Yu, G., & Yang, L. H. (2015). Racial and mental illness stereotypes and discrimination: An identity-based analysis of the Virginia Tech and Columbine shootings. *Cultural Diversity and Ethnic Minority Psychology*, 21(2), 279. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4381739/>

- Cherkassky, L. (2011). A fair trial? Assessment of liver transplant candidates with psychiatric illnesses [Online]. *Journal of Medical Ethics*, 37(19), 739-742. Retrieved from <http://hdl.handle.net/10545/305549>
- Choi, S. J., Gulati, M., & Posner, E. A. (2014). Altruism exchanges and the kidney shortage. *Law & Contemporary Problems*, 77(3), 289-322. Retrieved from <http://scholarship.law.duke.edu/cgi/viewcontent.cgi?article=4701&context=lcp>
- Cokley, K. O., & Awad, G. H. (2013). In defense of quantitative methods: Using the “master’s tools” to promote social justice. *Journal for Social Action in Counseling and Psychology*, 5(2), 26-41. Retrieved from http://www.psysr.org/jsacp/Cokley-V5N2-13_26-41.pdf
- Costarelli, S., & Gerłowska, J. (2015). I am not prejudiced towards ‘them’... I am ambivalent! The moderating roles of attitudinal basis and motivation to respond without prejudice. *Group Dynamics: Theory, Research, and Practice*, 19(1), 1. Retrieved from https://www.researchgate.net/profile/Sandro_Costarelli/publication/271723018_I_Am_Not_Prejudiced_Towards_%27Them%27_I_Am_Ambivalent_The_Moderating_Roles_of_Attitudinal_Basis_and_Motivation_to_Respond_Without_Prejudice/links/550fd0af0cf2752610a137ec.pdf
- Costello, K. (2013). *Determinants and consequences of dehumanization: An interspecies model of prejudice*. (Unpublished doctoral dissertation). Brock University, St. Catherines, Ontario, Canada.
- Costello, K., & Hodson, G. (2014). Explaining dehumanization among children: The interspecies model of prejudice. *British Journal of Social Psychology*, 53(1), 175-197. Retrieved from <http://christianebailey.com/wp-content/uploads/2013/03/The-interspecies-model-of-prejudice-Costello-Hodson-2012.pdf>

- Corballis, M. C. (2014). Left brain, right brain: Facts and fantasies. *PLoS Biology*, *12*(1), e1001767
- Crowell, S. (2016). Existentialism. In Edward N. Zalta (Ed.) *The Stanford Encyclopedia of Philosophy*. Retrieved from <https://plato.stanford.edu/archives/spr2016/entries/existentialism/>
- Curtis, J. J. (2006). Ageism and kidney transplantation. *American Journal of Transplantation: Official Journal of the American Society of Transplantation and the American Society of Transplant Surgeons*, *6*(6), 1264–6. <http://doi.org/10.1111/j.1600-6143.2006.01318.x>
- Cybulska, Eva. (2015). Nietzsche's Übermensch: A glance behind the mask of hardness. *Indo-Pacific Journal of Phenomenology*, *15*(1), 1-13. <https://dx.doi.org/10.1080/20797222.2015.1049895>
- Danovitch, G. M. (2014). The high cost of organ transplant commercialism. *Kidney International*, *85*(2), 248-250. doi: 10.1038/ki.2013.466
- Darwin, C. R. (1876). *The origin of species by means of natural selection, or the preservation of favoured races in the struggle for life* [6th ed, for Kindle]. London, England: John Murray.
- Debernardi, M., & Serrelli, E. (2013). From bacteria to Saint Francis to Gaia in the symbiotic view of evolution. *Evolution: Education and Outreach*, *6*(4), 1-13. doi:10.1186/1936-6434-6-4
- Derrington, S. F., Goldberg, A. M., & Frader, J. E. (2016). Ethical considerations in the psychosocial evaluation of pediatric organ transplant candidates, recipients and their families. In R. A. Greenberg, A. M. Goldberg, & D. Rodríguez-Arias (Eds.), *Ethical*

- Issues in Pediatric Organ Transplantation* (pp. 279–300). Cham, Switzerland: Springer International Publishing. http://doi.org/10.1007/978-3-319-29185-7_15
- Devereaux, R. L., & Gottlieb, M. C. (2012). Record keeping in the cloud: Ethical considerations. *Professional Psychology: Research and Practice*, *43*(6), 627. <http://dx.doi.org/10.1037/a0028268>
- Dhont, K., Hodson, G., Costello, K., & MacInnis, C. C. (2014). Social dominance orientation connects prejudicial human–human and human–animal relations. *Personality and Individual Differences*, *61*, 105-108. Retrieved from <https://biblio.ugent.be/publication/5041485/file/5053111>
- DiMartini, A., Crone, C., Fireman, M., & Dew, M. A. (2008). Psychiatric aspects of organ transplantation in critical care. *Critical Care Clinics*, *24*(4), 949–x. <http://doi.org/10.1016/j.ccc.2008.05.001>
- Ejima, K., Li, P., Smith, D. L., Nagy, T. R., Kadish, I., Groen, T., ... & Allison, D. B. (2016). Observational research rigour alone does not justify causal inference. *European Journal of Clinical Investigation*, *46*(12), 985–993. doi:10.1111/eci.12681
- Evans, L. D., Stock, E. M., Zeber, J. E., Morissette, S. B., MacCarthy, A. A., Sako, E. Y., ... & Copeland, L. A. (2015). Posttransplantation outcomes in veterans with serious mental illness. *Transplantation*, *99*(8), e57-e65. Retrieved from https://www.researchgate.net/profile/Sandra_Morissette2/publication/267926560_Posttransplantation_Outcomes_in_Veterans_With_Serious_Mental_Illness/links/55e5bbf008aec74dbe74c7f8.pdf
- Faul, F., Erdfelder, E., Buchner, A., & Lang, A.-G. (2009). Statistical power analyses using G*Power 3.1.9: A flexible statistical power analysis program for the social, behavioral,

and biomedical sciences. *Behavior Research Methods*, 41(4), 1149-1160.

doi:10.3758/BRM.41.4.1149

Fennell, J. G., & Baddeley, R. J. (2013). Reward is assessed in three dimensions that correspond to the semantic differential. *Plos One*, 8(2), e55588-e55588.

doi:10.1371/journal.pone.0055588

Fischer-Mamblona, H. (2000). On the evolution of attachment-disordered behaviour. *Attachment & Human Development*, 2(1), 8-21. doi:10.1080/146167300361291

Fiske, S. T. (2013). Divided by status: Upward envy and downward scorn. *Proceedings of the American Philosophical Society*, 157(3), 261–268. Retrieved from

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4479110/>

Fiske, S. T., & North, M. S. (2014). Measures of stereotyping and prejudice: Barometers of bias.

Measures of Personality and Social Psychological Constructs, 684. Retrieved from

<http://static1.1.sqspcdn.com/static/f/1605966>

[/24201752/1389641568813/North_Measures.pdf?token=t3Halo6NigLHdngAdSzX89pFZiE%3D](http://static1.1.sqspcdn.com/static/f/1605966/24201752/1389641568813/North_Measures.pdf?token=t3Halo6NigLHdngAdSzX89pFZiE%3D)

Foley, R. N., & Collins, A. J. (2013). The USRDS: what you need to know about what it can and can't tell us about ESRD. *Clinical Journal of the American Society of Nephrology*, 8(5),

845-851. doi:10.2215/CJN.06840712

Fowler, R. C. (2013). Validity, test. In E. Fletcher-Janzen, K. Vannest & C. Reynolds (Eds.),

Encyclopedia of Special Education: A Reference for The Education of Children,

Adolescents, and Adults with Disabilities and Other Exceptional Individuals. Hoboken,

NJ: Wiley. Retrieved from <https://lopes.idm.oclc.org>

[/login?url=http://search.credoreference.com/content/entry/wileyse/validity_test/0](https://lopes.idm.oclc.org/login?url=http://search.credoreference.com/content/entry/wileyse/validity_test/0)

- Furnham, A., Richards, S. C., & Paulhus, D. L. (2013). The Dark Triad of personality: A 10-year review. *Social and Personality Psychology Compass*, 7(3), 199-216. Retrieved from <http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.694.6559&rep=rep1&type=pdf>
- Fyson, R., & Cromby, J. (2013). Human rights and intellectual disabilities in an era of 'choice'. *Journal of Intellectual Disability Research*, 57(12), 1164-1172. doi:10.1111/j.1365-2788.2012.01641.x
- Gibbons, J. W., Scott, D. E., Ryan, T. J., Buhlmann, K. A., Tuberville, T. D., Metts, B. S., ... & Winne, C. T. (2000). The global decline of reptiles, déjà vu amphibians. *BioScience*, 50(8), 653-666. Retrieved from <http://bioscience.oxfordjournals.org/content/50/8/653.full>
- Gilbert, S. F., Sapp, J., & Tauber, A. I. (2012). A symbiotic view of life: We have never been individuals. *The Quarterly review of biology*, 87(4), 325-341. Retrieved from http://www.jstor.org/stable/pdf/10.1086/668166.pdf?_=1466731321505
- Gilhus, I. S. (2006). *Animals, gods, and humans: Changing attitudes to animals in Greek, Roman, and early Christian thought*. London, England: Routledge.
- Glaholt, H. R. (2012). Vivisection as war: The 'moral diseases' of animal experimentation and slavery in British Victorian Quaker pacifist ethics. *Society & Animals*, 20(2), 154-172. doi:10.1163/156853012X631360
- Glick, P., & Fiske, S. T. (2012). An ambivalent alliance: Hostile and benevolent sexism as complementary justifications for gender inequality. In J. Dixon & M. Levine (Eds.) *Beyond Prejudice: Extending the Social Psychology of Conflict, Inequality and Social Change* (pp. 70-88). New York, NY: Cambridge University Press.

- Grams, M. E., Plantinga, L. C., Hedgeman, E., Saran, R., Myers, G. L., Williams, D. E., ... & CDC CKD Surveillance Team. (2011). Validation of CKD and related conditions in existing data sets: A systematic review. *American Journal of Kidney Diseases*, 57(1), 44-54. Retrieved from <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2978782/>
- Grams, M. E., Kucirka, L. M., Hanrahan, C. F., Montgomery, R. A., Massie, A. B., & Segev, D. L. (2012). Candidacy for kidney transplantation of older adults. *Journal of the American Geriatrics Society*, 60(1), 1–7. <http://doi.org/10.1111/j.1532-5415.2011.03652.x>
- Grandin, T., & Johnson, C. (2005). *Animals in translation: Using the mysteries of autism to decode animal behavior*. New York, NY: Houghton Mifflin Harcourt.
- Gray, P. (2013, September 18). *The play deficit*. Retrieved from <http://aeon.co/magazine/being-human/children-today-are-suffering-a-severe-deficit-of-play/>
- Greenwood, J. D. (2015). Intelligence defined: Wundt, James, Cattell, Thorndike, Goddard, and Yerkes. In *Handbook of Intelligence* (pp. 123-135). Springer New York.
- Grubbs, V., Moss, A. H., Cohen, L. M., Fischer, M. J., Germain, M. J., Jassal, S. V., ... & Dialysis Advisory Group of the American Society of Nephrology. (2014). A palliative approach to dialysis care: a patient-centered transition to the end of life. *Clinical Journal of the American Society of Nephrology*, CJN-00650114, 1-7. Retrieved from <http://cjasn.asnjournals.org/content/early/2014/08/06/CJN.00650114.full>
- Hodson, G., Kteily, N. S., & Hoffarth, M. R. (2014). Of filthy pigs and subhuman mongrels: Dehumanization, disgust, and intergroup prejudice. *Testing Psychometrics Methodology in Applied Psychology*, 21, 267-284. Retrieved from

http://s3.amazonaws.com/academia.edu.documents/42541556/Of_filthy_pigs_and_subhuman_mongrels_De20160210-363-g2rh7n.pdf

- Hodson, G., MacInnis, C. C., & Costello, K. (2014). (Over)valuing "humanness" as an aggravator of intergroup prejudices and discrimination. In P. G. Bain, J. Vaes, and J. P. Leyens (Eds.) *Humanness and dehumanization*. New York, NY: Psychology Press.
- Holzman, L. (2014). *The overweight brain: How our obsession with knowing keeps us from getting smart enough to make a better world*. Retrieved from <http://loisholzman.org/books/latest-installment/>
- Ingsathit, A., Kamanamool, N., Thakkinstian, A., & Sumethkul, V. (2013). Survival advantage of kidney transplantation over dialysis in patients with hepatitis C a systematic review and meta-analysis. *Transplantation*, *95*(7), 943-948. doi:10.1097/TP.0b013e3182848de2
- Kervyn, N., Fiske, S. T., & Yzerbyt, V. Y. (2013). Integrating the stereotype content model (warmth and competence) and the Osgood semantic differential (evaluation, potency, and activity). *European Journal of Social Psychology*, *43*(7), 673-681. doi:10.1002/ejsp.1978
- Kervyn, N., Fiske, S. T., & Yzerbyt, Y. (2015). Forecasting the primary dimension of social cognition: Symbolic and realistic threats together predict warmth in the stereotype content model. *Social Psychology*, *46*, 36-45. Retrieved from <http://perso.uclouvain.be/vincent.yzerbyt/Kervyn%20et%20al.%20SP%202015.pdf>
- Kim, I., Noh, S., & Chun, H. (2016). Mediating and moderating effects in ageism and depression among the Korean elderly: The roles of emotional reactions and coping responses. *Osong Public Health and Research Perspectives*, *7*(1), 3-11. doi:<http://dx.doi.org/10.1016/j.phrp.2015.11.012>

- King, L. S., & Meehan, M. C. (1973). A history of the autopsy: A review. *The American Journal of Pathology*, 73(2), 514. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1904067/pdf/amjpathol00249-0259.pdf>
- Leyens, J. P., Cortes, B. P., Collange, J., & Renesse, E. D. (2014). Humanizing outgroups does not lead to stress but to Schadenfreude. *Testing, Psychometrics, Methodology in Applied Psychology*, 21(3), 341-348. Retrieved from <http://www.tpmap.org/wp-content/uploads/2015/11/21.3.8.pdf>
- Liu, M., & Wang, Y. (2015). Data collection mode effect on feeling thermometer questions: A comparison of face-to-face and Web surveys. *Computers in Human Behavior*, 48, 212-218. Retrieved from https://www.researchgate.net/profile/Mingnan_Liu2/publication/272753940_Data_collection_mode_effect_on_feeling_thermometer_questions_A_comparison_of_face-to-face_and_Web_surveys/links/5633d2e408aebc003ffde3fc.pdf
- Long, S. (2015). Squashed dreams and rare breeds: Ableism and the arbiters of life and death. *Disability & Society*, 30(7), 1118-1122. doi:10.1080/09687599.2015.1070544
- Maldonado, J. R., Dubois, H. C., David, E. E., Sher, Y., Lolak, S., Dyal, J., & Witten, D. (2012). The Stanford Integrated Psychosocial Assessment for Transplantation (SIPAT): A new tool for the psychosocial evaluation of pre-transplant candidates. *Psychosomatics*, 53(2), 123-132. Retrieved from https://www.researchgate.net/profile/Jose_Maldonado5/publication/271607070_The_Stanford_Integrated_Psychosocial_Assessment_for_Transplantation_SIPAT_A_New_Scale_for_the_Prediction_of_Psychosocial_and_Medical_Outcomes_in_Organ_Transplant_Candidates/links/54d7a4ae0cf2970e4e74b4cb.pdf

- Margulis, L., Asikainen, C. A., & Krumbein, W. E. (2011). *Chimeras and consciousness: Evolution of the sensory self*. Cambridge, MA: MIT Press.
- Mason, P. L. (2013). Scientific racism, history of. In *Encyclopedia of Race and Racism*. (pp. 1-16). Detroit: MI: Macmillan Reference USA.
- Mattson, R. E., Rogge, R. D., Johnson, M. D., Davidson, E. K. B., & Fincham, F. D. (2013). The positive and negative semantic dimensions of relationship satisfaction. *Personal Relationships, 20*(2), 328-355. doi:10.1111/j.1475-6811.2012.01412.x
- Meier-Kriesche, H. U., & Kaplan, B. (2002). Waiting time on dialysis as the strongest modifiable risk factor for renal transplant outcomes: A Paired Donor Kidney Analysis. *Transplantation, 74*(10), 1377-1381. Retrieved from http://www.piemonte.airt.it/pdf/marea/ProgettoPilota/Documenti/Bibliografia/Meier_Kriesche_2002.pdf
- Molony, D. A. (2016). Cognitive bias and the creation and translation of evidence into clinical practice. *Advances in Chronic Kidney Disease, 23*(6), 346-350. doi:<http://dx.doi.org/10.1053/j.ackd.2016.11.018>
- Morgan, G. A., Leech, N. L., Gloeckner, G. W., & Barrett, K. C. (2013). *IBM SPSS for introductory statistics: Use and interpretation* (5th ed.). New York, NY: Routledge.
- Moses, D., & Stone, D. (2013). *Colonialism and genocide*. Hoboken, NJ: Taylor and Francis.
- Mudge, K., Janick, J., Scofield, S., & Goldschmidt, E. E. (2009). A history of grafting. *Horticultural Reviews, 35*, 437-493. Retrieved from <https://www.hort.purdue.edu/newcrop/janick-papers/c09.pdf>
- Nascimento, R., Limeira, C. D., de Pinho, A. L. S., & Santa Rosa, J. G. (2014). Emotion, affectivity and usability in interface design. In A. Marcus (Ed.), *Design, User Experience*,

- and Usability. User Experience Design Practice: Third International Conference, DUXU 2014*, Held as Part of HCI International 2014, Heraklion, Crete, Greece, June 22-27, 2014, Proceedings, Part IV (pp. 339–346). Cham: Springer International Publishing. http://doi.org/10.1007/978-3-319-07638-6_33
- National Kidney Foundation. (2016). *Organ donation and transplantation statistics*. Retrieved from <https://www.kidney.org/news/newsroom/factsheets/Organ-Donation-and-Transplantation-Stats>
- Norton, M. I., Frost, J. H., & Ariely, D. (2013). Less is often more, but not always: Additional evidence that familiarity breeds contempt and a call for future research. *Journal of Personality and Social Psychology*, *105*(6), 921-923. doi:10.1037/a0034379
- Panksepp, J. (2010). Affective neuroscience of the emotional BrainMind: Evolutionary perspectives and implications for understanding depression. *Dialogues in Clinical Neuroscience*, *12*(4), 533–545. Retrieved from <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181986/>
- Paracer, S., & Ahmadjian, V. (2000). *Symbiosis*. Cary, GB: OUP Oxford. Retrieved from <http://www.ebrary.com.lopes.idm.oclc.org>
- Park, J., & Park, M. (2016). Qualitative versus quantitative research methods: Discovery or justification? *Journal of Marketing Thought*, *3*(1), 1. doi:10.15577/jmt.2016.03.01.1
- Patzer, R. E. (2011). *Racial disparities and poverty in access to kidney transplantation* (Doctoral thesis, Emory University). Retrieved from <https://lopes.idm.oclc.org/login?url=http://search.proquest.com.lopes.idm.oclc.org/docview/896124275?accountid=7374>

- Pedersen, A., & Thomas, E. F. (2013). "There but for the grace of God go we": Prejudice toward asylum seekers. *Peace and Conflict: Journal of Peace Psychology, 19*(3), 253. Retrieved from http://researchrepository.murdoch.edu.au/17460/1/%E2%80%9CThere_but_for_the_grace_of_God_go_we%E2%80%9D_Prejudice_toward_asylum_seekers.pdf
- Petrini, C. (2012). Kidney allocation for transplantation: Some aspects of ethics and comparative law. *Transplantation Proceedings, 44*(7), 1812-1814. <http://dx.doi.org/10.1016/j.transproceed.2012.05.059>
- Pratto, F., Çıdam, A., Stewart, A. L., Zeineddine, F. B., Aranda, M., Aiello, A., ... & Eicher, V. (2013). Social dominance in context and in individuals' contextual moderation of robust effects of social dominance orientation in 15 languages and 20 countries. *Social Psychological and Personality Science, 00*(0), 1-14. doi: 10.1177/1948550612473663
- Reese, P. P., Boudville, N., & Garg, A. X. (2015). Living kidney donation: Outcomes, ethics, and uncertainty. *The Lancet, 385*(9981), 2003-2013. [http://dx.doi.org/10.1016/S0140-6736\(14\)62484-3](http://dx.doi.org/10.1016/S0140-6736(14)62484-3)
- Riemersma, I., van Santvoort, F., Janssens, J. M., Hosman, C. M., & van Doesum, K. T. (2015). 'You are Okay': A support and educational program for children with mild intellectual disability and their parents with a mental illness: Study protocol of a quasi-experimental design. *BMC psychiatry, 15*(1), 318-326. Retrieved from <https://bmcp psychiatry.biomedcentral.com/articles/10.1186/s12888-015-0698-0>
- Roberts, D. (2015). Can research on the genetics of intelligence be 'socially neutral'? [Special issue]. In E. Parens and P. S. Appelbaum (Eds.), *The Genetics of Intelligence: Ethics and*

the Conduct of Trustworthy Research, Hastings Center Report 45(5), 50-53.

doi:10.1002/hast.499

Rogge, J., & Kittel, B. (2016). Who shall not be treated: Public attitudes on setting health care priorities by person-based criteria in 28 nations. *PloS one, 11(6)*, e0157018.

<http://dx.doi.org/10.1371/journal.pone.0157018>

Rollero, C., & Fedi, A. (2012). Ambivalent attitudes toward women and men: Recognizability of stereotypes and effects on self-perception. *Psicología Política, 44*, 69-86. Retrieved from

<http://www.uv.es/garzon/psicologia%20politica/N44-4.pdf>

Search, P. W. (1901). An ideal school, or looking forward. In W. T. Harris (Ed.), *International Education Series* (Vol. LII, pp. 1-357). New York, NY: D. Appleton and Company.

Seligman, M. E. P. (1967). *The disruptive effects of unpredictable shock*. (Unpublished doctoral dissertation). University of Pennsylvania, Pennsylvania.

Smith, S. R. (2013). Reliability in direct observation assessment. In E. Fletcher-Janzen, K.

Vannest & C. Reynolds (Eds.), *Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals*. Hoboken, NJ: Wiley. Retrieved from

https://lopes.idm.oclc.org/login?url=http://search.credoreference.com/content/entry/wiley/se/reliability_in_direct_observation_assessment/0

Spurgeon, C. H. (1889). *The salt-cellars: Being a collection of proverbs, together with homely notes thereon*. London: Passmore and Alabaster.

The United Nations. (1948). *Universal declaration of human rights*. Retrieved from

http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf

- Tong, A., Howard, K., Jan, S., Cass, A., Rose, J., Chadban, S., ... & Craig, J. C. (2010). Community preferences for the allocation of solid organs for transplantation: A systematic review. *Transplantation*, *89*(7), 796-805. doi:10.1097/TP.0b013e3181cf1ee1
- Ubel, P. A., & Loewenstein, G. (1996). Distributing scarce livers: The moral reasoning of the general public. *Social Science & Medicine*, *42*(7), 1049-1055. Retrieved from <http://www.cmu.edu/dietrich/sds/docs/loewenstein/ScarceLivers.pdf>
- United Network for Organ Sharing. (2015). *History*. Retrieved from <https://www.unos.org/transplantation/history/>
- U.S. Department of Health & Human Services. (2015). *Ethical principles in the allocation of human organs*. Retrieved from <https://optn.transplant.hrsa.gov/resources/ethics/ethical-principles-in-the-allocation-of-human-organs/>
- U.S. Department of Health and Human Services, Office for Human Research Protections. (2016). *The Belmont report*. Retrieved from <http://www.hhs.gov/ohrp/regulations-and-policy/belmont-report/index.html>
- U.S. Renal Data System. (1992). Completeness and reliability of USRDS data: Comparisons with the Michigan Kidney Registry. *American Journal of Kidney Disease*, *20*(5), 84–88. Retrieved from http://webapp1.dlib.indiana.edu/virtual_disk_library/index.cgi/4294964/FID1154/resguide/appendices/appendix_d/dvmic h.pdf
- U. S. Renal Data System. (2007). *Researcher's Guide to the USRDS Database*. Bethesda, MD: National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases.

- U.S. Renal Data System. (2015). 2015 USRDS annual data report volume 2: ESRD in the United States. Retrieved from https://www.usrds.org/2015/download/vol2_USRDS_ESRD_15.pdf
- U.S. Renal Data System. (2016). *About USRDS*. Retrieved from <https://www.usrds.org/>
- Wanderer, E. M. (2015). Biologies of betrayal: Judas goats and sacrificial mice on the margins of Mexico. *BioSocieties, 10*, 1-23. doi:10.1057/biosoc.2014.13
- Watkins, M., Fogel, A. L., & Posner, P. J. (Producers), & Posner, P. J. (Director). (1997). *Lifebreath* [Motion picture]. USA: Felder Pomus Entertainment.
- Wightman, A., Young, B., Bradford, M., Dick, A., Healey, P., McDonald, R., & Smith, J. (2014). Prevalence and outcomes of renal transplantation in children with intellectual disability. *Pediatric Transplantation, 18*(7), 714-719. Retrieved at <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4362668/>
- Wildcat, M. (2015). Fearing social and cultural death: Genocide and elimination in settler colonial Canada—an indigenous perspective. *Journal of Genocide Research, 17*(4), 391-409. doi:10.1080/14623528.2015.1096579
- Yaremko, R. M., Harari, H., Harrison, R. C., & Lynn, E. (2013a). Reliability. In *Handbook of Research and Quantitative Methods in Psychology: For Students and Professionals*. Hoboken, NJ: Taylor & Francis.
- Yaremko, R. M., Harari, H., Harrison, R. C., & Lynn, E. (2013b). Validity. In *Handbook of Research and Quantitative Methods in Psychology: For Students and Professionals*. Hoboken, NJ: Taylor & Francis.

Zuma, B. (2014). Contact theory and the concept of prejudice: Metaphysical and moral explorations and an epistemological question. *Theory & Psychology, 24*(1), 40-57.
doi:10.1177/0959354313517023

Appendix A

The *10 Strategic Points* for the Prospectus, Proposal, and Dissertation

1) Topic – Provides a broad research topic area/title.

Collect evidence of bias for mentally fit candidates over physically viable candidates for kidney organ transplantation. This evidence has been mentioned in the literature as part of assessment criteria, however an empirical study may reveal actual decisional bias, such as excessive wait time for some groups (age and intellectual ability) rather than others. Wait time is a key predictor of premature death from end stage renal disease.

2) Literature Review - Lists primary points for four sections in the Literature Review: (a) Background of the problem/gap; (b) Theoretical foundations (models and theories to be foundation for study); (c) Review of literature topics with key theme for each one; (d) Summary.

a) Background of the problem/gap:

- i) Possible avoidance of asking whether we favor mental fitness over biological fitness
- ii) Prejudice against the mentally and developmentally challenged
- iii) A relationship between ageism and ableism symbolic of reverence for cognitive superiority over biological life
- iv) Decisions reflecting the allocation of sparse resources (needed for physical survival) to those with superior mental capacities
- v) The problem with seeking an ethical way to do possibly unethical things (i.e. grafting living tissue to prolong mental life)
- vi) Possible violations of the Declaration of Human Rights in the assessment of candidates for renal transplantation

b) Theoretical Foundations (models and theories of human thought)

- i) Current models of prejudice have represented human v. human, human v. animal, and more human v. less human prejudice. As intellectual favor seems the commonality, the proposed model represents mental v. physical prejudice (when only one or the other can survive)

c) Review of literature topics with key theme for each one:

- i) History of the problem (too many candidates and not enough kidneys to go around)
- ii) An assessment prejudice that must favor some traits over others. Age and ability are two traits that exhibit assessment prejudice (a longer delay resulting in death by neglect of the less mentally fit)
- iii) The bell curve of human intelligence (the debate and the eugenics fears)
- iv) A history of grafting as a form of unnatural preference (to enhance specific traits)
- v) A brief history of bias during psychological assessment
- vi) A brief history of prejudice research
- vii) A survey of ethical paradoxes in the transplant industry
- viii) Distributive and social justice, and human rights milestones

d) Summary

- i) **Gap/problem:** The need to reduce the number of candidates in need of a kidney transplant to match the much smaller number of available kidneys requires bias during assessment, unless a random drawing were used. Bias against age and ability suggest violations of the Universal Declaration of Human Rights by the organ allocation and candidate assessment industries

- ii) **Prior studies:** prior studies have demonstrated ageism bias during the candidate assessment process. Prior studies have also demonstrated ableism and IDD bias during candidate assessment
- iii) **Quantitative study(s):** ageism delay and ableism delay will be analyzed with a quasi-experimental, between-groups, 3 X 3 factorial ANOVA followed by a Tukey's HSD as needed
- iv) **Significance:** This research will contribute by demonstrating evidence of mental bias during candidate selection, and help argue for the human rights of all classes of individuals for the right to continued survival

3) Problem Statement - Describes the phenomena to study (qualitative) or variables/groups (quantitative) to study, in one sentence.

It is not known if there is a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list

4) Sample and Location – Identifies sample, needed sample size, and location (study phenomena with small numbers and variables/groups with large numbers).

Data will be obtained from a secondary data source (the OPTN portion of the USRDS database). The request will specify only the data needed to identify the candidates for kidney organ recipients for the period between January 1, 1999 to December 31, 2006 and will include all first-time kidney transplant applicants (whether they received a kidney or not). This range was chosen to align this proposal with previous research in which age bias was found (Grams et al., 2012). Field data will be gathered as described in Wightman et al.

(2014) and the Researcher's Guide to the USRDS Database (U. S. Renal Data System, 2007). Since the sample will be analyzed using a 3 X 3 ANOVA (a between groups factorial ANOVA), nine cells will be needed, for a total of 252 (28 per cell). Since the data is official, preexisting data, no random assignment to these groups will be involved. This number per cell can easily be exceeded, since the number of transplants performed each year is much higher and the sample size spans 8 years. This will amount to approximately $N = 128,850$ or 14,316 per cell.

5) Research Questions – Provides research questions to collect data to address the problem statement.

- a) R_1 : Is there a relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate?
- b) R_2 : Is there a relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate?
- c) R_3 : Is there a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list?

6) Hypothesis/Variables or Phenomena - Provides hypotheses with variables for each research question (quantitative) or describes the phenomena to be better understood (qualitative).

- a) H_{10} : There is no relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate

- b) H1_A: There is a relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate.
- c) H2₀: There is no relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate.
- d) H2_A: There is a relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate.
- e) H3₀: There is no relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list.
- f) H3_A: There is a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list.

7) Methodology and Design - Describes the selected methodology and specific research design to address problem statement and research questions.

- a) A quantitative, quasi-experimental methodology will be used to analyze existing data in the USRDS
- b) A Tukey's HSD will be run to analyze the multiple comparisons, as needed

8) Purpose Statement – Provides one sentence statement of purpose including the problem statement, sample, methodology, and design.

The purpose of this quantitative method with a quasi-experimental design is to compare groups of candidates on the waiting list for a kidney transplant in the U.S. Renal Data System

(USRDS), to explore whether a delay in receiving a kidney organ transplant is more related to an age bias (ageism) or an intellectual development bias (ableism).

9) Data Collection – Describes primary instruments and sources of data to answer research questions.

Data will be obtained from a secondary data source—the OPTN portion of the USRDS database. All organ transplants conducted in the U.S. must report candidate and recipient data to these organizations, and this database can be queried by researchers.

10) Data Analysis – Describes the specific data analysis approaches to be used to address research questions.

- a) Data will be analyzed using a between-groups, 3 X 3 factorial ANOVA followed by a Tukey's HSD as needed. See Table 2 in Appendix C for a table visualizing the three by three design.

Appendix B

Variables/Groups, Phenomena, and Data Analysis

Table 1

Quantitative Studies

| Research Questions: State the research Questions | Hypotheses: State the hypotheses to match each Research question | List of Variables/Groups to Collect Data for: Independent and Dependent Variable(s) | Instrument(s) To collect data for each variable | Analysis Plan Data analysis approach to (1) describe data and (2) test the hypothesis |
|---|--|--|--|---|
| 1. Is there a relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate? | <p>H1₀: There is no relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate.</p> <p>H1_A: There is a relationship between the wait time for candidates on the kidney transplant list and the physical age assessment of a candidate.</p> | <p>IV1: Age Bias – a nominal/categorical variable representing the chronological age of a candidate regardless of greater overall physical/mental ability than the chronological age suggests. The levels will be Too Young, Too Old, and Just Right for the corresponding age groups at the time of implantation: under 18 years old, over 64 years old, and between 18 and 64 years old.</p> | <p>All data will be drawn directly from the OPTN portion of the U. S. Renal Data System, which is the only official repository of data kept regarding kidney organ candidates, donors, and outcomes.</p> | <p>Data will be analyzed using a between-groups, 3 X 3 factorial ANOVA followed by a Tukey's HSD. See Appendix D for a table visualizing the three by three design.</p> |
| 2. Is there a relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate? | <p>H2₀: There is no relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate.</p> <p>H2_A: There is a relationship between the wait time for candidates on the kidney transplant list and the mental age assessment of a candidate.</p> | <p>IV2: Intellectual Bias – a nominal/categorical variable representing the mentally assessed age of a candidate regardless of greater overall physical/mental ability than the mental age suggests. The levels will be Too Slow, Somewhat Slow, and Just Right for the corresponding levels of cognitive impairment: definite/probable, questionable/delayed, and none.</p> | | |

| | | | | |
|--|--|--|--|--|
| <p>3. Is there a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list?</p> | <p>H₃₀: There is no relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list.</p> <p>H_{3A}: There is a relationship between the wait time for candidates of preferred physical age (physically fit) and the wait time for candidates of preferred mental age (mentally fit) on the kidney transplant waiting list.</p> | <p><i>DV</i>: Transplant Delay – a continuous variable representing the length of time in days that a candidate with the specified criteria has waited on the waiting list to receive a kidney organ transplant. Candidates who have not yet received an organ will be indicated by a wait time equal to the sampling period (2922 days for the period from January 1, 1996 to December 31, 2006).</p> | | |
|--|--|--|--|--|

Appendix C

Table 2

Research Variables

| | | Age Bias | | |
|-------------------|---------------|------------|-----------|---------|
| | | Just Right | Too Young | Too Old |
| Intellectual Bias | Just Right | (A) | (B) | (C) |
| | Somewhat Slow | (D) | (E) | (F) |
| | Too Slow | (G) | (H) | (I) |