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Latent profiles of deceased organ donation registrants and non-registrants in the United States

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Latent profiles of deceased organ

donation registrants and non-registrants in the United States

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Latent profiles of deceased organ donation registrants and non-registrants in the United States

Clin. Transplant.

L.P.A.: Latent Profile Analysis

Abstract

Deceased organ donation is the greatest source of transplantable whole organs, but registration rates are a limiting factor because they remain low among certain populations. A stratified, non-probability survey was used to identify population characteristics associated with nonregistration in the United States ($N = 11,083$). Latent profile analysis (LPA) was used to identify multivariate patterns of demographic, socioeconomic, and health-related factors associated with registration. LPA yielded three distinct profiles, which all reported similar percentages of both driver's license possession (~ 80%), medical-insurance coverage (~80%), and income (median = $55,000), indicating that profiles were not significantly distinguished by these variables. Meaningful differences across the profiles included access to healthcare services, satisfaction with those services, mental health, and age; those who are both healthy and young (mean age = 25.9 years) reported the lowest percentage of organ-donation registration (35.3%). For this group, 71.48% listed either low priority or distrust in the donation process as the top reasons for non-registration. Importantly, age as a standalone variable was not uniformly associated with donation. These findings reveal previously unidentified opportunities for tailoring donor registration campaigns to populations with high potential for registration behavior change.

Keywords: Deceased organ donation, Latent profile analysis, Registration, Young adults

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Introduction

Recent estimates (March, 2024) demonstrate that 17 people die each day in the United States waiting for an organ transplant, and there are currently 103,223 on the national transplant waitlist.[1] Increasing the rate of registration for deceased organ donation is among the greatest opportunities to meet shortages in transplantable solid organs. Despite this, state policies to promote deceased organ donation have fallen short of significantly increasing registration,[2] and in fact, there appears to a be a decline in the overall percentage of United States citizens registering.[1] Sociodemographic patterns associated with registration remain unclear,[3] but age of the registrant may play an important factor.[4,5] Lower rates of registration among transition-aged youth and young adults may be related to a lack of education[6] or potentially limited reliance on the health-care system. Primary care has been identified as an important touchpoint to promote the awareness of the medical need for transplantable organs.[7]

Although these trends provide valuable insights, they are limited by their focus on mean-level characteristics, such as correlating average rates of donor registration with age. These variable-centered analyses often create an oversimplified picture of organ donation and fall short of accommodating the wide range of potential factors and high intra-individual variability that likely contribute to the decision to register. These factors include differences in demographic, socioeconomics, mental and behavioral health issues, and experiences with healthcare. Other statistical methods such as latent profile analysis (LPA) are better suited to characterizing this high multivariate heterogeneity between and within individuals. LPA is an unsupervised machine-learning approach that creates profiles (a.k.a. clusters or subgroups) based on the distinct patterns among multiple variables. A recent study by Gong et al. [12] highlighted the utility of LPA in identifying the multivariate associations between media use and willingness to donate

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and accept organs. Specifically, the authors found that those with "occluded" media use, or

media exposure that was largely limited to TV and radio, were far less likely to donate and

accept organs than those who used smartphones more frequently than any other media. The use

of LPA in that study provided a robust opportunity to explore the complex effects of both media

use frequency and type on organ donation.

This survey study utilized LPA to gain a current understanding of sociodemographic

patterns associated with deceased organ-donor registration and to elucidate the degree to which

involvement and satisfaction with the healthcare system moderates registration. The reasons for

non-registration were also assessed to provide insight on which attitudes are outstanding

obstacles toward registration.

Methods

Survey Methods

Data for this study were collected for all 50 states between October and November of

2023 as a part of an ongoing national survey called the National Behavioral Health Survey

(NBHS). Research panels from Cint™ Digital-Insights Gathering Platform were used to recruit

participants 16 years and older. This was a non-probability, purposive sampling technique in

which we used concurrent demographic quotas (e.g., % reporting per state, % gender balance,

etc.) to guide sampling. Information statements, including informed consent requirements, were

presented to participants immediately upon arrival at the survey landing page and a computer bot

check was used to screen participants. Participants were paid approximately $1-4 for survey

completion, although the exact form and amount of payment is not available to precisely

calculate from the research panels. The average completion time for this survey was

approximately 19 minutes. The Institutional Review Board at Advocates of Human Potential

(Federal Wide Assurance #6316) approved all procedures and activities of this study

(IRB#00000984).

Survey Measures

Included in the survey were standard ***demographic questions*** on income, age, and

race/ethnicity, based on *Department of Health and Human Services* designations. Participants

were asked to provide ZIP codes, which permitted a state-level analysis of how financial

incentive programs for living-organ donation might influence registration for posthumous

registration. This was used in the analysis to determine whether an awareness of state-level

insurance protections for living donors could positively impact registration for deceased

donation.

Health and wellbeing survey items included the two most reported mental health

illnesses to assess population wellbeing. The Generalized Anxiety Disorder two-item scale

(GAD-2)[8] and the Patient Health Questionnaire (PHQ-2)[9] which assesses symptoms of major

depression were used. To assess current physical health, we used a measure of chronic pain,

which was measured on a 10-point visual analog with the survey item "During the past 7 days,

what number best describes how pain interfered with your general activity, on a scale from 0 =

does not interfere, 10 = completely interferes?" This was adapted from the Pain, Enjoyment of

Life General Activity Scale (PEG-3).[10] Chronic pain tends to be a good indicator of overall

health and wellbeing.[11]

Since interactions with the healthcare system were particularly relevant to this study, we

assessed access to, and satisfaction with, healthcare. ***Healthcare satisfaction*** was measured using

a five-item Likert scale by: "Think about the most recent time you received care from a

physician or other medical professional within the past 12 months. Please indicate how satisfied

you were with the quality of the care." ***Ease of healthcare access*** was measured by: "In the past 12 months, how easy or difficult was it for you to access healthcare services when you needed them?" This was a five-item Likert scale. Obstacles to healthcare access was assessed by: "In the past 12 months, think about any and all of the health conditions you have being dealing with or have concerns about. Did you experience the following barriers when you tried to access treatment for a health condition?" This was a yes/no response to nine items which included "too costly," "lack of transportation," and "Fear of stigma or being judged by provider." ***Medical contact*** was measured by the sum of three questions, each on a five-point scale from "never" to "always," these being the frequency of going to a doctor for the treatment of illness, following a physician's treatment plan, and using a prescription as prescribed. A question about current medical insurance coverage (yes/no) was also included.

 Organ donation questions occurred at the end of the survey. Those indicating "no" to "Are you a registered organ donor?" were prompted to answer an additional multiple-choice question regarding the reasons for not donating, and they could select more than one. These included "I want my body to be whole after I die" and "my religion doesn't permit it," among others (**Table 3**). Those who answered "unsure" to the question on organ donation registration were excluded from the survey data. A single-item question on the frequency of charitable giving was used to determine whether organ-donation registration was related to a general tendency to give to others; this item appeared earlier in the survey and was therefore separated from the organ donation questions. This question was included to determine whether general prosocial tendencies were systematically related to donor registration.

Data Analysis

Latent profile analysis (LPA) was used to identify multivariate patterns of demographic, socioeconomic, and health-related factors associated with organ donor registration. To determine the optimal number of profiles, we began with a null 1-profile model and increased the number of profiles by one until stopping criteria were reached. BIC and SABIC in past simulation studies have indicated that these predict the optimal number of profiles with significantly greater accuracy compared to other fit indices including AIC, entropy, VLMRT, and BLRT. As such, BIC and SABIC were used to determine whether the k profile solution was better than the k-1 profile solution, indicated by decreases in both values. We also included as a stopping criterion a profile size of less than 5% of the sample to encourage model parsimony and maximize qualitative differences (in both item response probabilities and probabilities of latent profile membership) between profiles. Finally, we did not estimate the k+1 model if the loglikelihood was not replicated or the model did not converge, both of which are indicative of poor fit and model non-identification. After establishing the optimal profile solution, we explored differences in demographic covariates and frequency of registration using the method developed by Lanza et al.,[13] in which the distal outcome is used as a latent profile predictor in a multinomial logistic regression alongside the latent profile model. Simulation studies have established this method as one of the best approaches for estimating the associations between latent profile membership and distal outcomes.[14] Reasons for not donating were assessed using X^2 tests to compare between-profile percentages reporting "yes" for each question. All statistics were performed in SPSS (v.29.01) and Mplus (v.8.10), and GraphPad Prism (v.10) was used to create figures.

Results

Overall sample

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A total of 13,561 were recruited for the survey, but 1,117 reported being "unsure" about whether they were registered donors and were excluded from the analyses, and 1,361 failed to complete all survey measures. The resulting $N = 11,083$, and demographics are listed in **Table 1** relative to the latest U.S. Census (2020).

Latent Profiles

The LPA indicated an optimal fit of three distinct population profiles, and each was associated with a different rate of donor registration; LPA fit indices are listed in **supplemental material**.   The profiles have been labeled below, and in the tables and figure, according to their quantitative differences pertaining to age and healthcare utilization. Demographic characteristics associated with each profile are listed in **Table 2.** Continuous variables that separated the profiles are depicted in **Figure 1** which shows that age varied significantly across the profiles, but income did not. This does not mean that income does not play roles in donor registration, because registered donors in the entire sample reported a statistically significant higher income than nondonors; independent-samples $t(11,081) = 6.23$, $p < 0.001$, $d = 0.2$.

Profile 1, or the ***younger & healthy group*** is associated with the lowest rate of registration (35.3%). They are younger (25.9 yrs) and more physically and mentally healthy when compared to the other groups (see **Fig 1**). Their income, education level, access to, and satisfaction with healthcare services is on par with the other two profiles (**Table 2**). This profile is also characterized by the highest proportion of males. Of those in this lowest-registration profile, 44.4% reported that their reasons for non-registration included "Haven't gotten around to registering." **Table 3** displays X^2 analyses results along with the percentages from other groups regarding the other reasons for not registering.

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Profile 2, or **older, optimal healthcare access group**, is associated with the highest rate

of organ-donor registration (47.5%) and is much older than the other two profiles (63.7 yrs); see

Fig 1. They are distinguished by above-average (>0.5 standard deviations) utilization of

healthcare services, as might be expected for this age group, and they are relatively satisfied with

the quality of healthcare services they receive. They reported lower levels of both anxiety and

depression symptoms, so they appear to have better mental wellbeing than those in the other two

profiles. They are slightly higher in both income and total years of education (< 0.5 standard

deviation from average) and are mostly white (>80%), and are more likely to have medical

insurance and a driver's license (**Table 2**). For those within this group who have elected not to

register, their top reason (28.9%) was "I don't think anyone would want my organs," see **Table

3**.

The *younger,* **elevated health symptoms group**, *Profile 3*, is also characterized by a

relatively high rate of donor registration (43.7%). They are less healthy than those in Profile 1

who are similar in age. They exhibit elevated symptoms of depression and anxiety and report

more chronic pain than those in either of the other profiles (**Fig 1**). They are also more

dissatisfied with the healthcare they receive and report a lack of healthcare access. Those in this

profile are not significantly lower in terms of education nor income relative to the other two

profiles. Members of this profile reported giving to charities more frequently than either of the

other groups.

Discussion

The profile associated with the lowest percentage of deceased donor registration included

the youngest survey respondents who were healthier compared to their counterparts in the other

profile groups. For this group that had the highest percentage of non-registrants, the reasons

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listed for non-donation primarily included low prioritization or apathy (i.e., "I haven't gotten around to it) and distrust of the donation system. These two reasons are distinct from others in that they present opportunities for change; the other reasons for rejecting donor registration appear less malleable to the influence of public-health messaging campaigns. Given that this profile of young and healthy individuals was associated with the lowest rate of donor registration, direct educational messaging about organ donorship could yield a substantial change in the proportion of the U.S. population who may register. This group is not considered a protected or vulnerable population, and as such, there are fewer ethical concerns about coercion; guidelines for using social media to promote organ donation are available [15], and social media may be the best resource for targeted messaging campaigns in this age group.

Increased utilization of healthcare services that accompanies aging may be one factor governing age-dependent differences in organ-donation registration.[16,17] The LPA demonstrates that favorable interactions with the healthcare system are sufficiently, but not necessarily, associated with a greater percentages of donor registration. We say this because healthcare access and satisfaction failed to play a uniform role in those profiles who were most likely to donate: the *older, optimal healthcare* and *younger, elevated health symptoms* groups, which showed notable differences in healthcare satisfaction, failed to differ regarding the occurrence of registration. At least for the older group, who may interact with healthcare more regularly or incidentally, medical contact appears correlated with donor registration. For those in the younger group with elevated symptoms of chronic pain and emotional disturbances, healthcare satisfaction seems unrelated to their willingness to donate organs; this group's interest in donation could be more closely aligned with their reported charity which distinguishes them from the other two profiles. Among younger demographics, higher rates of empathy are a

significant predictor of young adults' willingness to donate organs,[18,19] so our finding involving charitable donations within this profile is consistent with previous surveys.

Overall, the percentages of registration reported in our sample are consistent with current estimates from other national samples within the past year[20] and our data on younger adults is aligned with previous findings.[17,21,22] There seems to be a discrepancy between younger adults' willingness to donate and the amount of those actually registered as donors.[23,24] Within this age group of adults under 30 years, the intention-action gap and/or psychological inertia has been cited as a central obstacle to registration.[17,25] Additionally, lack of discussion with family has also been identified as a challenge for this age demographic[23] and these important conversations tend to be delayed or dismissed because of tendencies to avoid interpersonal conflict.[26] Furthermore, our results echo previous findings in that the highest level of education achieved is positively associated with registration, and that misconceptions regarding donation remain significant barriers to registration.[23] Distrust of organ donation, especially among the younger age groups, may be related to misinformation presented via various media sources which is designed to attract attention from adolescents. Younger populations who are on the cusp of registration eligibility have reported that their media exposure is their primary source of information about organ donation,[27] and television dramas have been explicitly cited by these groups as exaggerating negative donation outcomes.[24]

The growth of organ donor need in last two decades the US parallels population growth among one particular demographic, these being Hispanic Americans; [28] yet reports have identified particularly low donor-registration rates among those in this ethnic demographic.[16,21] The profile group which involved the highest-percent registration in the current study also happened to coincide with the lowest percent of Hispanics as well as racial minorities. Both other

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profile groups contained proportions of Hispanic and Black Americans which more closely

matched to the national US census, yet they differed significantly regarding registration.

Previous reports on the willingness to donate among minority groups have shown that

willingness to donate organs is heavily influenced by the awareness of need, religion, and

pressure from family.[28] Indeed, both profile groups of younger survey respondents which

included similar proportions of ethnic and racial minorities indicated similar reasons for not

registering, which included religion, pressure from others, and a distrust in organ donation.

It would be incorrect to assert that education serves to bolster the awareness of organ

need given that the two younger profiles which corresponded with different rates of registration

were similarly educated. Furthermore, these two groups had similar low access and satisfaction

with healthcare. What may be surmised from the greater percentage of registration in the

"younger, elevated health symptoms" profile is that their higher degree of chronic pain coupled

with more symptoms of mental illness may make them more attentive to the eventual end of life.

Therefore, mortality saliency [29] may play a favorable role in the willingness to donate organs

among younger populations. To the best of our knowledge, whether mortality saliency can be

leveraged to improve rates of donation among the young and healthy remains to be tested in

messaging campaigns.

The sample for this study falls within the range of most U.S. census demographics, so we

have reason to believe that it represents a reasonable cross section of the national population

despite our sample having a lower median income. There are other limitations with our survey

design which are worth noting, such that our questions pertaining to healthcare access,

satisfaction, and medical contact are not validated measures. Furthermore, the main outcome

variable (i.e., deceased donation registration) could not be objectively verified.

This survey represents the most recent U.S. representative sample describing donation registration and related barriers. A little under half of all U.S. citizens remain unregistered. [1] Increasing registration remains one of the most promising methods for reducing the burden of organ failure. While several organizations and programs exist to increase donor registration, the total number of registered donors has not significantly increased. It is possible that designing education and registration opportunities tailored to populations that demonstrate the greatest opportunity both in numbers and behavior modifiability could make a significant difference in registration outcomes, and thus future solid organ availability. Registration campaigns designed with attention to this survey's findings and tailored to regional needs should be implemented under a research framework to measure impact and be refined, accordingly.

Disclosures

The authors report no financial conflicts of interest. BP is a member of the scientific and ethics advisory board for Procure OnDemand.

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Figure 1. Continuous variables from the latent profile analysis for each group, relative to the grand means for all groups.
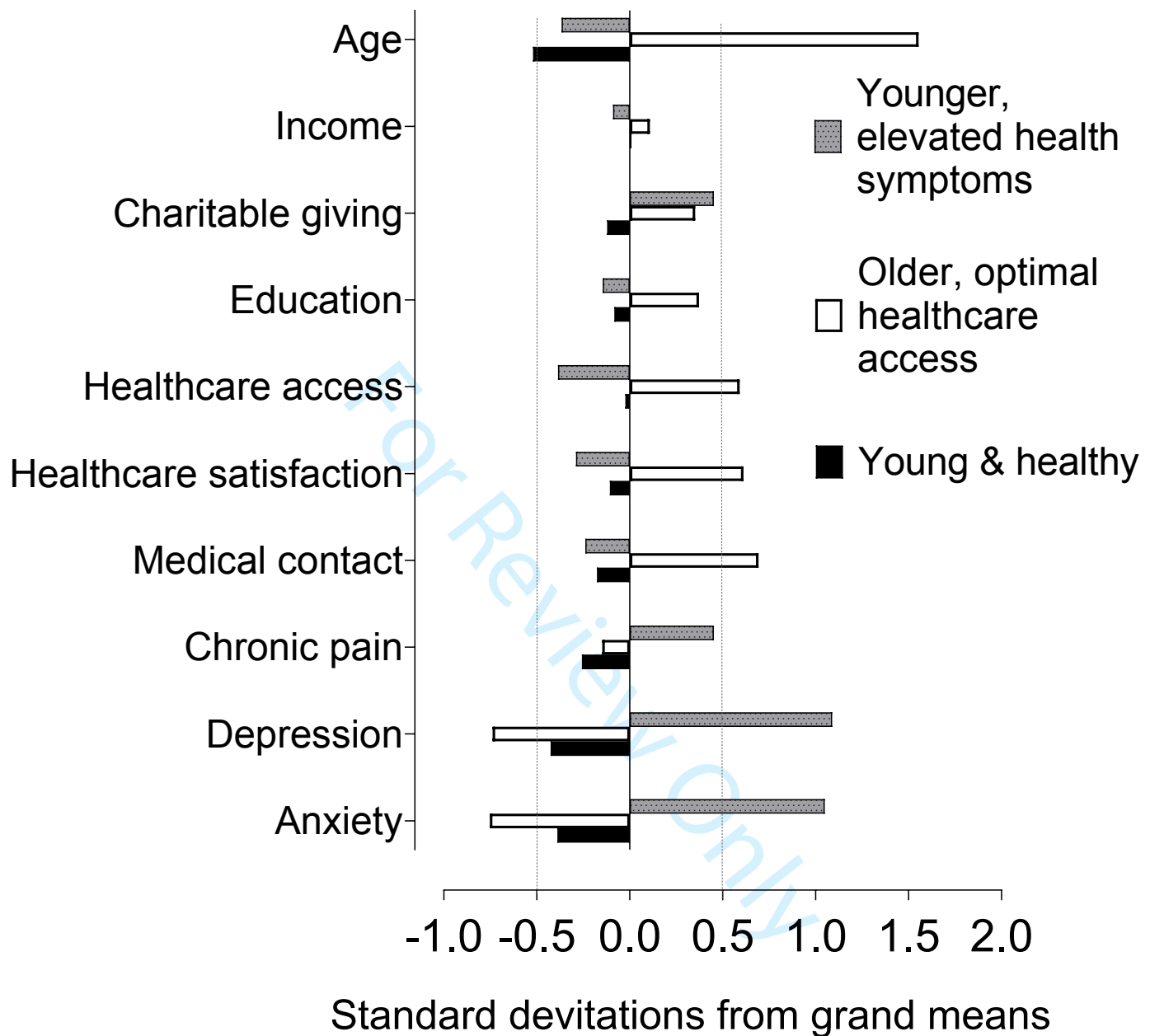
Table 1. Demographics of the survey sample relative to the most recent U.S. Census.

Population Characteristics	US Census	Overall sample
n		11,083
Mean age	39	34.89
Median income	$69k	$55k
Male	50%	45.65%
Transgender male	---	0.29%
Female	50%	49.87%
Transgender female	---	1.29%
Nonbinary	---	1.79%
American Indian or Alaskan Native	1%	4.44%
Asian	6%	6.55%
Black	14%	20.26%
White	76%	66.38%
Native Hawaiian or Pacific Islander	<1%	1.22%
Hispanic	19%	17.75%

Table 2. Profile demographics by percentages.

	Younger and healthy	Older, optimal healthcare access	Younger, elevated health symptoms
n	4,953	2,516	3,614
Registered donor	35.3%	47.5%	43.7%
Demographics			
Male	51.0%	42.7%	37.2%
Transgender male	0.8%	0%	2.7%
Female	45.0%	57.2%	55.7%
Transgender female	0.2%	0%	0.4%
Nonbinary	1.3%	0%	3.4%
American Indian or Alaskan Native	2.5%	1%	2.7%
Asian	6.9%	2.3%	4%
Black	21.1%	8.2%	19.5%
White	56.8%	84.7%	66.3%
Native Hawaiian or Pacific Islander	0.8%	0%	0.6%
Hispanic	21.5%	4.1%	20.7%
Other categorical variables in LPA			
State incentive for living donation	42.8%	37.7%	40.6%
Possess driver's license	80.9%	94.2%	77.9%
Medically insured	80.9%	95.3%	77.2%

Table 3. Reasons for not donating, by profile; **bolded*** cells significantly differ ($p < 0.05$) from the others in the rows based upon $\chi^2 (1)$ tests.

	1. Younger and healthy	1 v. 2	2. Older, optimal healthcare access	2 v. 3	3. Younger, elevated health symptoms	1 v. 3
Registered organ donor	35.3%	**χ2 = 83.8***	47.5%	**χ2 = 7.4***	43.7%	**χ2 = 35.7***
Haven't gotten around to registering	44.4%	**χ2 = 81.2***	28.6%	χ2 = 0.7	24.0%	**χ2 = 67.5***
I don't trust organ donation	27.0%	**χ2 = 185.2***	9.6%	**χ2 = 114.7***	24.0%	χ2 = 3.8
My religion doesn't permit it	12.0%	**χ2 = 56.9***	4.9%	**χ2 = 29.0***	10.1%	χ2 = 2.1
I want my body to be whole after I die	26.7%	**χ2 = 15.6***	20.8%	**χ2 = 4.4***	24.0%	χ2 = 3.2
I don't think anyone would want my organs	10.5%	**χ2 = 155.6***	28.9%	**χ2 = 40.5***	18.6%	**χ2 = 46.1***
I am getting pressured from someone else in my life not to donate	3.7%	**χ2 = 10.6***	2.0%	**χ2 = 11.2***	4.1%	χ2 = 0.1

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Supplemental Material. Fit indices of the stepwise latent-profile modelling.

Profiles	AIC	BIC	Δ BIC	SABIC	Δ SABIC	% of smallest profile	Entropy
1	429692.8	429905		429813			
2	415160.8	415512	-14393.1	415359	-14453.4	24.9	0.93
3	**407468.9**	**407959**	**-7552.94**	**407746**	**-7613.32**	**22.7**	**0.851**
4	394539.8	395139	-12819.4	394879	-12867.1	21.7	0.799
5	391889.1	392620	-2519.02	392303	-2576.22	8.5	0.82

Note. Bolded row indicates fit indices of the final model; all LMRT and BLRT ps < 0.001.