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Why Do Young Adults in the United States Have Such Low Rates of Organ Donation Registration?

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Abstract: The demand for transplantable organs has outpaced the supply. Thus, 20 Americans die every day while waiting for an organ. Although most adults support organ donation, 42% are not registered. The rate is even lower among young adults who are not enrolled in/never graduated from college. The aim of this study was to use the Integrated Behavior Model (IBM) to identify factors that predicted organ donation registration among a racially diverse sample of non-student young adults. The study was observational and cross-sectional. Proportional allocation was used to identify a racially diverse sample of 550 non-student, young adults from ten states in the U.S. with the lowest registration rates. A valid and reliable survey was designed, pilot-tested, and administered. A total of 407 young adults completed the survey (74%). Only 19% were registered donors. Caucasians were more likely to be registered donors than racial minorities, $\chi^2(3, N = 407) = 15.19, p = 0.002$. Those with more positive direct attitudes toward registration were 1.5 times more likely to be registered than those who had negative direct attitudes. Among non-registrants, indirect descriptive norm and direct attitude were statistically significant predictors of behavioral intention. Moreover, those who knew someone who donated an organ and knew someone who needed a transplant were nearly three times more likely to intend to register in the next year. The IBM proved useful in elucidating factors that predicted intention to register among non-student young adults. The IBM should be used by those who desire to increase registration rates.

Keywords: organ donation; registration; young adults; Integrated Behavioral Model; Precaution Adoption Process Model

1. Background

Twenty Americans die every day while waiting for an organ transplant [1]. In 2021, approximately 107,294 men, women, and children in the U.S. await a lifesaving organ; 83% of them need a kidney [2]. The number of people who need an organ is increasing faster than the number of donors. From 1991 to 2021, the number of donors nearly tripled, but the number of waiting increased by nearly five times (from 23,198 to 107,294) [2].

The gap between demand and availability is a major public health problem. Almost all adults in the U.S. (95%) support organ donation, yet 42% have chosen not to register as donors [3]. That percentage not being registered is even higher among young adults—a range of 47% to 69% depending on the study [4–7]. Globally, the demand for organs and

organ donors continues to soar, but there are challenges such as lack of awareness, lower willingness, higher medical mistrust, dwindling altruism, societal divide, and conflicts.

Almost all past studies of young adults ages 18–24 in this topical area have involved college students, with a majority being Caucasian. Hence, little is known about non-students/noncollege graduates who are racial/ethnic minorities, their rate of organ donation registration, and their decision-making process regarding registering. The current study is the first theoretical approach to study a sample of such young adults living in the ten states in the U.S. with the lowest rates of organ donation registration.

The aim of the study was to use the Integrated Behavioral Model (IBM) and the Precaution Adoption Process Model (PAPM) to identify factors that explained and/or predicted young adults' decision-making process regarding registering as an organ donor.

2. Methods and Procedures

2.1. Design and Setting

The study was a theory-based, observational, cross-sectional design that featured survey research methods. It took place at a public research university in northern Ohio. This research was approved by the university's Institutional Review Board.

2.2. Population and Sampling

The study population consisted of a racially diverse group of young adults, ages 18 to 24, not enrolled in college, never graduated from college, from the ten states in the U.S. with the lowest organ donation registration rates. Racial minorities were oversampled to increase the racial diversity of the sample.

A sample size estimate indicated that 385 completed surveys were needed for adequate external validity (95% confidence, 5% margin of error, with a 50–50 split). A subsequent power analysis (minimum of 80% power, estimated effect size of 0.30, and a two-sided 5% level of significance) indicated that 352 completed surveys were needed to achieve the criteria for the most rigorous types of planned statistical tests. To ensure that our sample was representative of the population of young adults in the ten states with the lowest organ donation registration rates, we stratified the sample using proportional allocation (See Table 1). Inclusion criteria included young adults ages 18 to 24; not enrolled in college; never graduated from college; Caucasian (35%), African American (30%), Multiracial (20%), Asian (10%), American Indian or Alaska Native (4%), and Native Hawaiian/other Pacific Islander (1%) and Hispanic ethnicity (30%).

Table 1. The proportion of Young Adults Sampled versus Proportion in the Population of the ten States with the Lowest Rates of Organ Donation in the U.S. (2019).

State	Organ Donation Registration Rate	% of Adult Population Comprised of Young Adults	The Proportion of Young Adults in Each State	The Proportion of Young Adults Sampled in Each State
New York	32%	11.9%	15.5%	15.7%
Mississippi	37%	13.7%	2.6%	2.7%
New Jersey	40%	11.3%	6.5%	5.2%
West Virginia	41%	11.3%	1.3%	1.2%
Tennessee	43%	11.9%	5.1%	5.2%
Pennsylvania	47%	11.6%	9.7%	10.1%
California	47%	12.5%	31.3%	31.2%
Connecticut	48%	12.4%	2.9%	2.9%
Nevada	49%	10.8%	2.1%	2.5%
Texas	49%	13.3%	23.0%	23.3%

2.3. Theoretical Framework

We used the Integrated Behavioral Model (IBM) and the Precaution Process Adoption Model (PAPM) as the framework for our study. The IBM was designed to help explain and

predict behavioral intentions by assessing the relative impact of attitudes, perceived norms, and personal agency [8]. Similar to the Theory of Reasoned Action/Planned Behavior that preceded it, IBM proposes that attitudes drive human behavior and that behavioral intention is the primary determinant of behavior [8]. Figure 1 depicts the IBM constructs and how they apply to this study. There are also four factors outside the IBM that influence behavior directly without working through the constructs of the model: (1) Knowledge and skills to perform the behavior, (2) Saliency of the behavior, (3) Environmental constraints, and, (4) Habit [8]. Obviously, habit and environmental constraints are not relevant in the current study, but we did assess knowledge and salience. The PAPM was used to describe young adults' stage of readiness to register as organ donors. The PAPM categorizes people in one of seven possible stages of readiness to adopt or perform a positive health behavior (See Figure 2) [8].

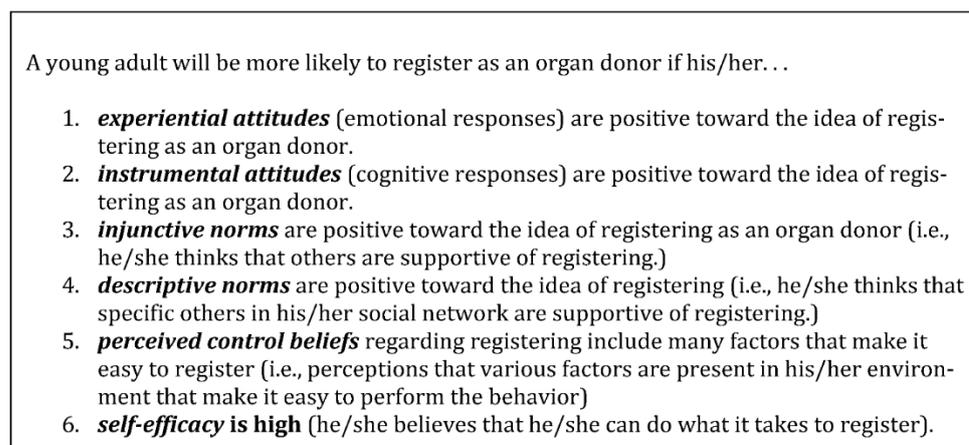


Figure 1. The Relation of IBM Constructs and Behavioral Intention to Register as an Organ Donor.

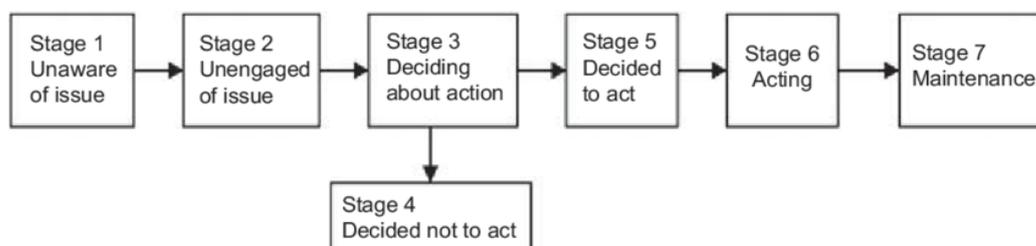


Figure 2. Stages of the Precaution Adoption Process Model.

When applied to the current study, the theoretical underpinnings of the IBM suggest that if a person's attitudes are positive toward becoming an organ donor; and he/she perceives that significant others around him/her and the general community would approve of registering as a donor, and he/she believes that he/she has the self-confidence to register, then he/she will have strong behavioral intentions to register as an organ donor in the near future. Strong behavioral intentions to register as an organ donor should then lead to a strong likelihood of officially registering to become an organ donor. A second model, the Precaution Adoption Process Model (PAPM), may also prove useful in describing young adults' decision-making to register as organ donors. The PAPM was created to describe and explain the process by which people adopt precautions or take preventive action against a new risk [8]. This model includes seven stages: Stage 1: unaware; Stage 2: aware, but not thought of adopting precautions; Stage 3: thinking but undecided; Stage 4: decided against adopting the precaution; Stage 5: decided to adopt but have not yet acted; Stage 6: acted on their decision to adopt; and Stage 7: for some behaviors, maintenance may be needed. Through this model, we intended to identify what stage participants are in regarding their decision to register as organ donors.

2.4. Data Collection and Procedure

We designed a survey instrument to assess both a past registration decision and future behavioral intention to register (for non-registrants). The survey also measured IBM and PAM variables including attitude, perceived norms, personal agency, behavioral intention, and stage of readiness to register. Face validity of the survey was established via a comprehensive review of the published literature. Content validity was established by having the survey reviewed by an external panel of four experts (based on their publication records). We incorporated the recommended revisions from this expert panel.

The reading level of the survey averaged 7.85 grade: Flesch-Kincaid (7.1 grade) and Simple Measure of Gobbledygook (SMOG) (8.6 grade) [9]. To ensure readability, reading comprehension, cultural acceptability, and user-friendliness, we pretested the online instrument with a convenience sample of ten young adults not enrolled in college. The average completion time was 10 min. Next, prior to use, we assessed the stability-reliability of the survey by analyzing 46 matched pairs of surveys obtained from undergraduate college students. Stability-reliability ranged from 0.64 to 0.96, with an average of 0.76 across all subscales. After some minor revisions, the final survey consisted of ten sections and 70 items. We then built the final survey in Qualtrics®—a 3rd party company that hosts online surveys and provides potential subjects for research. We sent the final survey hyperlink to Qualtrics® along with an email letter that invited potential subjects to participate. Based on our sampling criteria, Qualtrics randomly selected eligible young adults from their panels and invited them to participate via email. To incentivize participation, Qualtrics offered points to potential respondents that could be used to redeem gift cards.

2.5. Post Hoc Internal Reliability and Construct Validity

After data collection but prior to data analysis, we assessed the construct validity of the IBM subscales. We analyzed the factor structure of the subscales using a maximum likelihood estimation method with varimax rotation. Factors with an eigenvalue above one and factor loading values above 0.35 were retained for data analysis [10]. The Kaiser-Meyer-Olkin Measure of Sampling Adequacy was 0.913, well above the commonly recommended level of 0.60 with a significant Bartlett's Test of Sphericity. We identified 7 unique factors used for data analysis that explained 69% of the cumulative variance. Prior to data analysis, we also tested the internal reliability (Cronbach's alpha) of the theory-based scales. The Cronbach alpha coefficients for the scales ranged from 0.83 to 0.95 and averaged 0.88 across all 7 scales.

2.6. Data Analysis

We completed data analyses using IBM SPSS Statistical Package, Version 25.0 (Armonk, NY, USA). Descriptive statistics, such as frequencies, percentages, means, and standard deviations were used to describe the respondents and their answers on the various subscales. Bivariate analyses including Pearson's correlation and logistic regression and were used to identify the association among key variables. Binomial logistic regression was used to determine if the IBM constructs predicted intention to register as a donor in the future.

3. Results

A total of 550 young adults met the inclusion/exclusion criteria and 407 of them completed the survey (74%). They were non-Hispanic (69.8%), female (51.4%), with a mean age of 20 years old (SD = 2.08). Less than one in four reported ever taking college classes. Respondents were White (34.6%), African American (29.5%), multi-racial (20.6%), Asian (10.8%), and American Indian or Alaska Native (3.7%). Just under a third were Hispanic. Most respondents (63%) did not have a close friend, relative, or loved one who currently needed or had needed an organ transplant in the past nor did they know anyone who had actually donated an organ (61%) (Table 2).

Table 2. Demographics and Background Characteristics of All Survey Respondents.

Characteristics	<i>n</i>	(%)
Gender		
Female	209	(51.4)
Male	195	(47.9)
Other	3	(0.7)
Race		
White	141	(34.6)
Black or African American	120	(29.5)
Multi-racial	84	(20.6)
Asian	44	(10.8)
American Indian or Alaska Native	15	(3.7)
Native Hawaiian or Other Pacific Islander	3	(0.8)
Ethnicity		
Non-Hispanic	284	(69.8)
Hispanic	123	(30.2)
Age		
18	102	(25.0)
19	74	(18.2)
20	50	(12.3)
21	52	(12.8)
22	38	(9.3)
23	45	(11.1)
24	46	(11.3)
Mean:	20.42	
SD:	2.08	
Highest Level of Education		
Less than high school	62	(15.2)
High school/GED	253	(62.2)
Some college/did not graduate	92	(22.6)
Has a close friend, relative, or loved one who currently needs or needed an organ transplant in the past		
Yes	84	(20.6)
No	257	(63.2)
Unsure	66	(16.2)
Knows someone (alive or dead) who donated an organ		
Yes	94	(23.1)
No	247	(60.7)
Unsure	66	(16.2)

n = 407.

3.1. Differences in Registration Status by Selected Socio-Demographic Variables

In terms of their current registration status, 28% were unaware of the issue; 19% were unengaged by the issue; 14% were thinking about it and deciding whether to take action; 12% had thought about it and decided not to register; 6% had decided to register in the near future, and 19% had recently registered. Thus, 62% of our respondents had either not heard about registering, never really thought about it, or were undecided.

Caucasians were almost three times more likely to be registered donors (28%) than African Americans (10%) and almost two times more likely to have registered than other races (16%), χ^2 (3, *N* = 407) = 15.19, *p* = 0.002. Older young adults (ages 21–24) were more likely to be registered (25%) than younger adults (ages 18–20), (11%), χ^2 (2, *N* = 407) = 2.10,

$p \leq 0.001$. Those who were registered were more than twice as likely to know someone who donated an organ (34%), compared to non-registrants (14%) $\chi^2 (1, N = 407) = 18.23$, $p \leq 0.001$. No statistically significant differences in registration status were noted by ethnicity, gender, having a close friend, relative, or loved one who currently needs an organ transplant or who needed one in the past, $\chi^2 (1, N = 407) = 1.65$, $p = 0.199$.

3.2. Knowledge

Overall, respondents lacked knowledge of organ donation and registration. The proportion of correct answers on the 6-item knowledge test ranged from 18.7% to 43.2%, depending on the item. Table 3 indicates the proportion of participants who answered correctly (true) or incorrectly (false) for each question statement. Less than 1% of all respondents ($n = 3$) answered all six questions correctly. To determine if young adults' registration status differed in a statistically significant way by their knowledge level, we grouped them into four categories of knowledge based on their scores: (1) None: Zero items correct, (2) Low: 1–2 items correct, (3) Moderate: 3–4 items correct and, (4) High: 5–6 items correct. More registered donors than non-registered were in the “moderate” and “high” knowledge categories. Registered donors were statistically significantly more likely to be in the “high” knowledge category (21%) than non-registrants (3%), $\chi^2 (3, N = 407) = 44.69$, $p \leq 0.001$. Further, the median knowledge score of those who had registered (3.0) was greater than non-registrants (1.5), $U = 7716$, $p \leq 0.001$ (See Table 3).

Table 3. Knowledge of Organ Donation Registration: True and False Questions.

Characteristics	<i>n</i>	(%) Correct
To make organ donation forms legal, a person needs to hire a lawyer/attorney		
Correct	169	(41.5)
Incorrect	238	(58.5)
There are only two locations where a person can obtain the official forms to sign up as an organ donor: a doctor's office or a hospital		
Correct	124	(30.5)
Incorrect	283	(69.5)
Organ donors can have an open casket funeral if they so desire		
Correct	176	(43.2)
Incorrect	231	(56.8)
If a person donates his/her organs, removing the organs results in increased medical costs for which the donor's family must pay		
Correct	137	(33.7)
Incorrect	270	(66.3)
The family of an organ donor typically receives a one-time, financial payment of \$1000 from the hospital for the organ(s) received from the donor		
Correct	76	(18.7)
Incorrect	331	(81.3)
Most major religions in the United States support organ donation		
Correct	103	(25.3)
Incorrect	304	(74.7)

$n = 407$.

3.3. Factors outside the IBM That Explained a Past Decision to Register

We wanted to know if factors outside the IBM (e.g., age, race, salience, knowledge) predicted a past decision to register. The regression model was statistically significant, $\chi^2(9) = 99.21$, $p < 0.001$, and explained 35% (Nagelkerke R^2) of the variance in a past decision to register, and correctly classified 81% of cases. When controlling for race, Caucasians were 3.6 times more likely to be registered than African Americans (OR: 3.60, 95% CI [1.79, 7.24], $p < 0.001$). Past history of knowing someone who donated an organ (OR: 3.07, 95% CI [1.81, 5.23], $p < 0.001$), salience (OR: 2.67, 95% CI [2.04, 3.51], $p < 0.001$), increasing age (OR: 2.14, 95% CI [1.29, 3.55], $p = 0.003$), and knowledge (OR: 1.46, 95% CI [1.38, 1.93], $p < 0.001$) were also statistically significant predictors of a past decision to register.

3.4. IBM Constructs That Explained a Past Decision to Register

Our regression model using the IBM constructs was statistically significant, $\chi^2(7) = 146.91$, $p < 0.001$; explained 49% (Nagelkerke R^2) of the variance in a past decision to register; and correctly classified 88% of cases. Direct attitude (OR: 2.13, 95% CI [1.75, 2.59], $p < 0.001$), indirect descriptive norms (OR: 1.87, 95% CI [1.54, 2.28], $p < 0.001$), direct subjective norm (OR: 1.82, 95% CI [1.54, 2.16], $p < 0.001$), direct descriptive norm (OR: 1.78, 95% CI [1.51, 2.08], $p < 0.001$), indirect subjective norm (OR: 1.08, 95% CI [1.06, 1.10], $p < 0.001$), and altruistic attitudes (OR: 1.07, 95% CI [1.05, 1.09], $p < 0.001$) were statistically significant predictors of registration status. We did not assess personal agency of registrants since that construct was not applicable to them.

3.5. All Factors Combined That Predicted a Past Decision to Register

We then used multiple binomial logistic regression to assess which of the combined factors (both external to the IBM and within) were the strongest predictors of a past decision to register. Direct attitude (OR: 1.49, 95% CI [1.19, 1.86], $p < 0.001$), direct descriptive norm (OR: 1.40, 95% CI [1.16, 1.70], $p < 0.001$), indirect descriptive norm (OR: 1.38, 95% CI [1.06, 1.79], $p = 0.018$), knowledge (OR: 1.25, 95% CI [1.02, 1.53], $p = 0.034$), and altruism (OR: 1.03, 95% CI [1.01, 1.06], $p = 0.017$) were significant predictors of a past decision to register.

3.6. Predicting Behavioral Intentions to Register: Factors External to the IBM

We used binomial logistic regression to determine if factors external to the IBM (e.g., age, race, salience, knowledge) predicted respondents' behavioral intentions to register in the next year. The logistic regression model was statistically significant, $\chi^2(8) = 4.327$, $p < 0.001$ and explained 29% (Nagelkerke R^2) of the variance in behavioral intention. The model correctly classified 89% of cases. Having a history of knowing someone who donated an organ and knowing someone who currently needs an organ were strong predictors of intention. Young adults who knew someone who needed a transplant were almost six times more likely to intend to register compared to those who did not know such a person (OR: 5.67, 95% CI [2.86, 11.27], $p < 0.001$). Similarly, those who knew an organ donor were also six times more likely to report intention to register (OR: 6.18, 95% CI [3.09, 12.32], $p < 0.001$). Salience (OR: 2.06, 95% CI [1.47, 2.89], $p < 0.001$) and knowledge (OR: 1.43, 95% CI [1.14, 1.78], $p < 0.001$) were also statistically significant predictors of intention.

3.7. Predicting Behavioral Intentions to Register: IBM Constructs

In terms of the impact of the IBM constructs to predict behavioral intention to register, all of the IBM constructs, except altruism beliefs, were statistically significant predictors. The logistic regression model was statistically significant, $\chi^2(8) = 5.273$, $p < 0.001$ and explained 28% (Nagelkerke R^2) of the variance in behavioral intention. It correctly classified 90% of cases. Indirect descriptive norm (OR: 1.91, 95% CI [1.48, 2.46], $p < 0.001$), indirect self-efficacy (OR: 1.77, 95% CI [1.21, 2.557], $p = 0.003$), direct attitude (OR: 1.62, 95% CI [1.31, 2.02], $p < 0.001$), direct subjective norm (OR: 1.44, 95% CI [1.20, 1.72], $p < 0.001$), direct descriptive norm (OR: 1.43, 95% CI [1.20, 1.71], $p < 0.001$), direct self-efficacy (OR: 1.39, 95% CI [1.18, 1.65], $p < 0.001$), perceived behavioral control (OR: 1.23, 95% CI [1.06, 1.42], $p < 0.001$), indirect general attitude (OR: 1.07, 95% CI [1.03, 1.10], $p < 0.001$), and indirect

subjective norm (OR: 1.06, 95% CI [1.03, 1.09], $p < 0.001$) were statistically significant predictors of registration status.

3.8. Predicting Behavioral Intentions to Register: All Factors Combined

We then used binomial logistic regression to combine and analyze all statistically significant predictors (i.e., both those inside and external to the IBM) of behavioral intentions to register in the future. Young adults who knew someone who currently needed an organ transplant were almost 3 times more likely to intend to register in the next year, (OR: 2.90, 95% CI [1.31, 6.41], $p = 0.009$). Likewise, young adults who knew someone who was an organ donor were nearly 3 times more likely to intend to register in the next year, (OR: 2.75, 95% CI [1.23, 6.16], $p = 0.014$). Additionally, indirect descriptive norm, (OR: 1.67, 95% CI [1.22, 2.29], $p = 0.001$) and direct attitude, (OR: 1.54, 95% CI [1.22, 1.94], $p < 0.001$) significantly predicted whether someone had intention to register.

4. Discussion

Our finding that only 19% of our sample participants were registered as organ donors was on the low end of past research with this age group. Surprisingly, 62% of our respondents had either not heard about registering, never really thought about it, or were undecided. This lack of awareness is likely reflective of our sample. Our sample of non-college students likely received less education regarding organ donation registration than college students. For example, in our sample, the average knowledge score was very low. In contrast, although the knowledge test was different, college students in the northeast had an average score of 80%, and 44% of them were already registered organ donors [11]. Increased education has been shown to increase awareness and organ donation registration [12,13].

Our sample of non-students included 65% racial/ethnic minorities—much higher than most other studies of college students. Caucasians in our sample were much more likely than racial/ethnic minorities to be registered donors. Our findings are corroborated by past research that has reported lower registration rates among racial/ethnic minorities [14,15]. The reticence of Black Americans to register and their negative opinions of organ donation may be due to their experiences with institutional racism and their distrust of the health care system [16–19].

Young adults who are racial/ethnic minorities may also be reticent to register as organ donors because of common perceptions that the system for allocating organs to patients is unfair; beliefs that physicians will not provide the best care if one is an organ donor; and beliefs that minorities have a lower chance of being selected to receive a donated organ [14,17,20]. Some of their perceptions may be accurate. For example, Black Americans have a greater need for organs than White Americans. Yet, in a study of almost 1400 patients in need of organs, 1/3 of Black patients were on official transplant lists compared to more than 1/2 of the White patients [21]. Furthermore, health care providers are less likely to approach people of color about organ donation registration compared to Whites [16,22]. For example, white families were more than twice as likely as black families to be approached for organ donation [22]. Such institutional racism obviously lowers rates of registration and organ donation among racial/ethnic minorities [16].

In terms of explaining the past decision to register, IBM was useful. By way of review, the constructs of attitudes and perceived norms were statistically significant predictors of past registration. Two factors outside the IBM (i.e., salience and knowledge) were also statistically significant predictors of a past decision to register. When we combined and analyzed all statistically significant predictors, young adults with more positive direct attitudes were 1.5 times more likely to be registered than those with negative direct attitudes. In future health communication campaigns, public health specialists and transplant advocates should emphasize both the cognitive and affective components of attitudes while emphasizing the benefits of registering as a donor.

The IBM was also useful in predicting future behavioral intentions to register. By way of review, the constructs of attitudes (except altruism), perceived norms, and personal

agency were statistically significant predictors of intention. Once again, factors outside the IBM, including salience, knowledge, and past history of knowing someone who needed a transplant or knowing a donor, were also predictive of behavioral intentions. When we combined and analyzed all statistically significant predictors, we found that indirect descriptive norm, direct attitude, and a history of knowing a donor and knowing someone who needed a transplant remained statistically significant. Those who knew someone who donated an organ and knew someone who needed a transplant was almost three times more likely to intend to register in the next year than those who did not know such individuals. Such results point to the need to connect young adults who are not yet registered as donors with those who need an organ and those who have served as living donors. Although past research is limited regarding the impact of knowing someone who donated or knowing someone who needs an organ, we would expect that such social influence would be positively influential. Therefore, we strongly recommend that those responsible for organ donation programs find creative ways to connect non-college students and young adults with those who need organs and those who have donated organs in the past. This could be done in person, through virtual means, or via creative health messaging campaigns.

Future studies should use IBM as a needs-assessment tool for planning interventions. Our survey could be used with a similar population of non-college students and young adults. The factors that predict and explain the greatest amount of variance in behavioral intention to register can be identified. Subsequently, interventions can be designed based on the most predictive factors. Young adults can then be randomly assigned to control and intervention groups and the theory-based intervention can be administered. Following the intervention, both the control and intervention groups can be assessed again using the same survey to determine if the intervention improved the construct(s) upon which it was based. Then program participants can be followed into the future and measured again in 6 or 12 months to determine if they actually registered. Such a study would prove beyond a doubt whether IBM was a useful framework for actually changing registration behavior. Another potential research avenue relates to social marketing campaigns targeting young adults, especially those who are minorities or who are not enrolled in post-secondary education. The impact of such campaigns could be assessed using intervention groups and matched control groups. These social marketing campaigns could be done through powerful advertisements that increase positive perceived norms and attitudes towards organ donation. Social media channels could be used to expose young adults to pro organ donation registration messages. These messages could be designed to provide cognitive and affective comfort about organ donation, show the benefits of organ donation, and provide positive normative beliefs about organ donation.

Organ donation tendencies have been explored from a variety of societal and individual-level perspectives. Concepts such as incentive-based versus voluntary donations, demand versus supply, altruism versus narcissism, positive versus negative attitudes, selflessness versus selfishness, and other motivations versus aversions have been employed to explore organ donation preferences [7,11,12,14,23–25]. With the global COVID-19 pandemic, rising medical mistrust, declining altruism, lower social cohesion, and increasing self-interests, organ donation and procurement may become even more challenging. While we did not measure many of these concepts, future studies should consider the inclusion of such measures in organ donation preference research. Also, policy and advocacy initiatives may help alleviate some of the aforementioned barriers. For example, a recently discussed legislation bill in the U.S. (i.e., The Living Donor Protection Act) had certain provisions that could address the aforementioned issues. Some of the key components of the legislation bill were coverage for living donors under the Family and Medical Leave Act (FMLA), prohibition of denial of life, disability, long-term care insurance coverage for donors, and increasing awareness about the benefits of organ donation [26,27].

Limitations and Strengths

Our results should be interpreted with its potential limitations and strengths in mind. First, we tested the stability–reliability of the survey with college students. This may have biased our reliability results. Second, the recruitment and sampling method used by Qualtrics did not allow us to calculate a true response rate. Thus, we do not know how many young adults were contacted, looked at the survey, and decided not to start it. Although we were able to calculate a completion rate, it is possible that our study had limitations with external validity. Third, we did not conduct an elicitation phase with the priority population prior to designing our survey items. Thus, although we established face and content validity of the items and included several text boxes in the survey to capture qualitative data, it is possible that the indirect survey items were not as valid as they could have been. Fourth, due to the cross-sectional nature of data collection, we cannot infer any causality and we lack the ability to determine whether respondents who expressed intention to register in the next year actually do so. Fifth, our study may have been hindered by recall bias. Asking respondents about their past decisions is always a potential limitation due to faulty memories. Sixth, while our sample is highly representative of the total population the extent to which the respondents differed from non-respondents could be a threat to the validity of the findings. Also, there could be other sociodemographic characteristics of respondents that could have influenced their responses and we may not have assessed these influential characteristics (e.g., the religion of the respondents, geographical location, etc.). Lastly, social desirability bias may have influenced some of the participants' answers. If that is the case, the percentage of those registered as organ donors and those stating a positive intention to register in the future may have been overstated.

Our study also features numerous strengths. We used well-accepted theoretical models as the framework of our research. Using proven theories and models in research increases the validity of such research (8). Second, ours was the first study to ever use the IBM and the PAPM to elucidate the decision-making process of a racially diverse sample of non-college students regarding organ donation registration—a population that has been grossly understudied. The majority of our respondents (65%) were racial/ethnic minorities—which is very rare in this line of investigation. Third, we designed a valid and reliable survey that can be used by researchers in the future. Our findings provide many new insights into this important yet under-researched population. Lastly, our study was also the first to assess non-college student young adults from the ten states in the U.S. with the lowest organ donation registration rates. Hence, our results will be of great importance to those who are responsible for organ donation registration and for procuring organs from both living and deceased donors.

The low rate of organ donation registration among our sample indicates that there is much work to be done, especially among racial/ethnic minorities. There is a significant need for culturally appropriate messaging and educational programs tailored to this unique population. Those who are promoting organ donation in the U.S., especially in the ten states with the lowest rates of registration, can use our results to design future health communication and education campaigns for this important population.

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