

ORIGINAL ARTICLE

Living Donor Decision-Making and the Complex Interplay of Finances and Other Motivators, Barriers, and Facilitators

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Received: 10 May 2023 | **Revised:** 22 May 2024 | **Accepted:** 30 May 2024

Funding: This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of two financial assistance awards totaling \$9,700,000 and \$1,992,684 with 0 percentage financed with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government.

Keywords: donor | living donation | lost wages | organ donation

ABSTRACT

Introduction: The decision to become a living donor requires consideration of a complex, interactive array of factors that could be targeted for clinical, policy, and educational interventions. Our objective was to assess how financial barriers interact with motivators, other barriers, and facilitators during this process.

Methods: Data were obtained from a public survey assessing motivators, barriers, and facilitators of living donation. We used multivariable logistic regression and consensus k-means clustering to assess interactions between financial concerns and other considerations in the decision-making process.

Results: Among 1592 respondents, the average age was 43; 74% were female and 14% and 6% identified as Hispanic and Black, respectively. Among employed respondents (72%), 40% indicated that they would not be able to donate without lost wage reimbursement. Stronger agreement with worries about expenses and dependent care challenges was associated with not being able to donate without lost wage reimbursement (OR = 1.2, 95% CI = 1.0–1.3; OR = 1.2, 95% CI = 1.1–1.3, respectively). Four respondent clusters were identified. Cluster 1 had strong motivators and facilitators with minimal barriers. Cluster 2 had barriers related to health concerns, nervousness, and dependent care. Clusters 3 and 4 had financial barriers. Cluster 3 also had anxiety related to surgery and dependent care.

Conclusions: Financial barriers interact primarily with health and dependent care concerns when considering living organ donation. Targeted interventions to reduce financial barriers and improve provider communication regarding donation-related risks are needed.

Abbreviations: HRSA, Health Resources and Services Administration; NLDAC, National Living Donor Assistance Center.

1 | Introduction

Living organ donation is critical to bridging the gap between the number of patients with end-stage organ disease needing an organ and the number of deceased donor organs available. Numerous disincentives prevent many potential donors from coming forward, resulting in underutilization of living donor transplantation (the Organ Procurement and Transplantation Network) [1]. There is near-universal consensus to remove disincentives to living donation. Key among these are financial disincentives, which include travel and subsistence costs related to evaluation and donation, lost wages, and dependent care costs. While donors' medical costs are usually covered by recipient medical insurance, donors, potential donors, and their accompanying persons often incur substantial costs directly and indirectly related to the donation process [2–5].

Almost all donors experience travel and subsistence costs related to a donation process that requires multiple trips to the transplant center. These costs average \$543 predonation and \$1253 postdonation per donor [3, 4]. Wage income lost during the donation process has been reported by 27% of kidney donors predonation (average \$691 wages lost) and 36% of kidney donors postdonation (average \$4578 wages lost) [3, 4]. Nearly three in 10 (29%) report postdonation costs related to household needs and dependent care [4]. These financial burdens fall more heavily on low-income donors, and the prospect of them may prevent some from ever coming forward at all for evaluation [6, 7].

Financial disincentives have been partially ameliorated by the National Living Donor Assistance Center (NLDAC), which provides financial assistance to living organ donors meeting recipient income criteria [8]. Funded by the Health Resources and Services Administration (HRSA), NLDAC has provided reimbursement for travel and subsistence costs related to evaluation and donation since 2007. In Q4 2020, NLDAC began to provide lost wage reimbursement; dependent and elder care costs have been reimbursable since Q1 2021 (Figure 1). These added areas of support move further toward financial neutrality in the living donation process for nearly half of US households [9, 10]. Other programs in the US also address financial disincentives through paired exchange programs, with fees supported by participating transplant centers, and other nonprofit and state programs [11, 12].

There is sparse data on whether the availability of lost wage replacement affects the decision to initiate living donor evaluation, and how this interacts with other factors that may affect this complex decision. We conducted the HRSA-funded Lost Wages Demonstration Project (Lost Wages program) to help address this question. The project's goals were to (1) assess the effect of reimbursement of lost wages on the decision of individuals to initiate evaluation for living organ donation and (2) to inform HRSA on the most effective and efficient mechanism for providing this reimbursement. To answer the first question, we developed a public survey to evaluate various motivators, barriers, and facilitators to living organ donation to determine how financial barriers interact with other factors in the decision-making process. The objectives of this research were to: (1) assess differences in motivators, barriers, and facilitators of living organ donation between those who report being able to donate without

lost wage reimbursement and those who report being unable to do so without reimbursement, and (2) to identify groupings of potential donors based on the presence and importance of motivators, barriers, and facilitators.

2 | Materials and Methods

Data were collected as part of the HRSA-funded Lost Wages program administered by the NLDAC program team. This study is exempt from IRB under Category 5. The pilot program provided up to \$5000 of lost wage reimbursement to actual living donors donating at one of seven participating transplant centers between March 2020 and January 2021. Potential applicants were ineligible if they were able to receive lost wage reimbursement from other means such as the recipient, their employer, or other state or private programs. In order to understand the role of financial barriers in the decision-making process, a survey was developed to assess motivators, barriers, and facilitators of living donation and made available to the public on the homepage of the NLDAC website (<https://www.livingdonorassistance.org/Resources/Living-Donation-Survey>) in March of 2020 in both English and Spanish. The survey is open to potential respondents across the spectrum of the decision-making process, from those who had never seriously considered organ donation to those who had previously donated. No targeted recruitment was conducted; the sample represents a convenient sample of respondents who found the survey online and volunteered to respond. The survey remains active as a program evaluation and quality improvement tool; data in this report represent responses received through June 2023.

2.1 | Survey Development

Topics were identified based on a literature review of factors relevant to the decision-making process for living organ donation, relevant concepts from other surveys, and team expertise. Survey items were then developed, reviewed, and revised by the multidisciplinary program team consisting of experts in transplant medicine, qualitative and quantitative survey methods, and program implementation. To ensure survey clarity, two rounds of cognitive interviews were conducted. In the first round, three participants who had not donated an organ responded to a paper version of the survey and feedback was elicited via in-person interviews. The second round included five living organ donors who had previously participated in the NLDAC Travel Program, sampled for diversity across race/ethnicity, gender, and education level to ensure clarity across heterogeneous target populations. Participants in this round responded to the survey online while the interviewers simultaneously elicited their feedback on the phone. After each round, the interviewers met to discuss the feedback and revise the survey. Feedback was also requested and incorporated from a health communication firm with expertise in health literacy to improve readability for respondents with low literacy levels.

The final survey contained 30 items related to the current stage in the donation process, potential motivators, barriers, and facilitators to living donation, factors influencing the decision to become a living donor, awareness of the Lost Wages program,

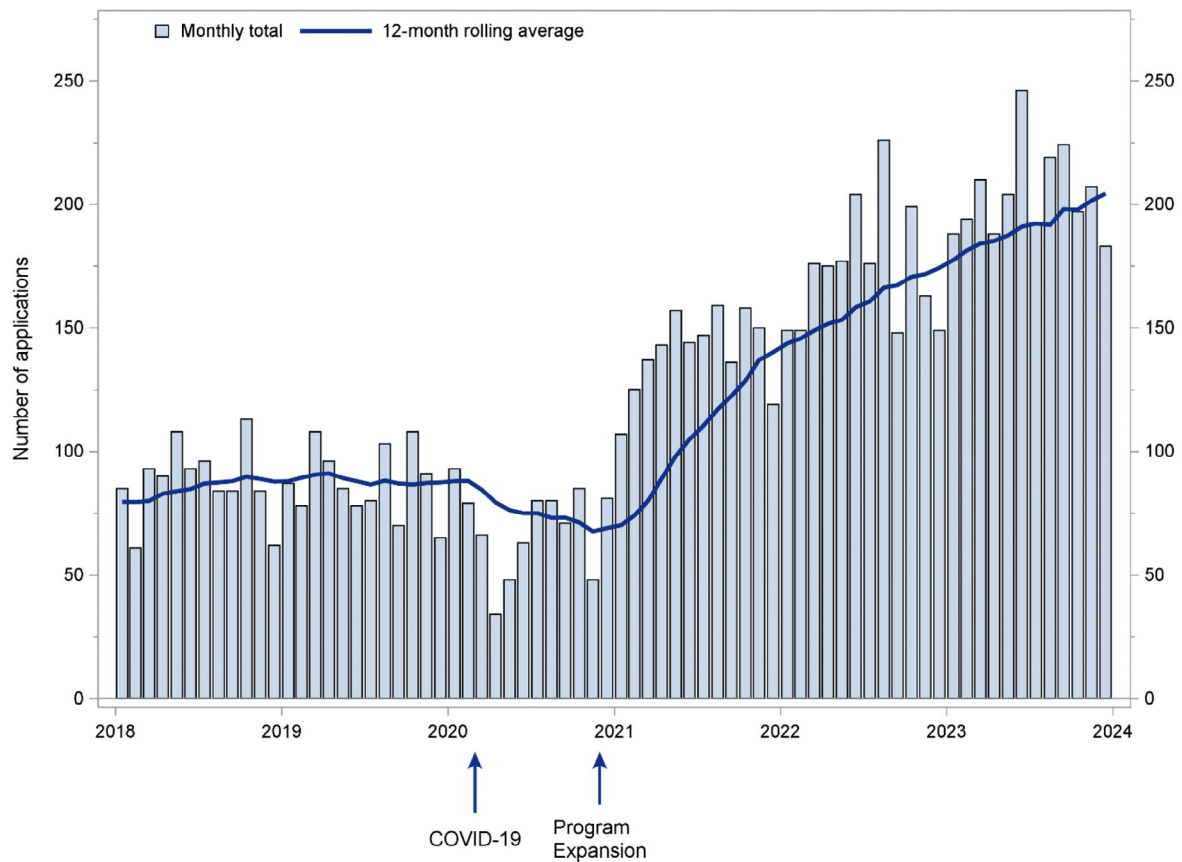


FIGURE 1 | NLDAC applications were received from January 2018 through December 2023. The bars represent the total number of monthly applications received. The line displays the 12-month rolling average number of applications received. Program expansion included increasing income eligibility from 300% to 350% FPG, inclusion of reimbursement for lost wages and dependent care.

as well as demographic and household information including employment status and income.

2.2 | Statistical Analysis

Item responses were explored descriptively using measures of central tendency, variation, frequency, and percentage. Multiple imputation was used to address missing data and implemented in IVEWare (University of Michigan, Ann Arbor, MI) using sequential regression techniques to generate 10 imputed data sets [13]. Respondents were categorized as (1) not employed, (2) employed but could donate even if lost wages were not reimbursed (Employed—Secure), and (3) employed but could not donate without lost wage reimbursement (Employed—Insecure) based on responses to items regarding the presence of paid work and the ability to donate if some or all wages were lost during the donation process and did not get reimbursed. Among the respondents who endorsed having paid work, multivariable logistic regression was used to assess the associations between motivator, barrier, and facilitator item ratings, adjusted for demographic and household characteristics, with odds of group membership. This was an exploratory analysis, therefore model selection was guided by stepwise selection with entry and exit p -values of 0.1 and 0.2, respectively. Models were fitted separately for each imputation and estimates were combined using Rubin’s rules accounting for between and within imputation variance [14]. Backward selection

was applied to the combined estimates to arrive at the final model.

In addition to the self-reported ability to donate without lost wage reimbursement, we also assessed how different motivator, barrier, and facilitator ratings grouped together. Cluster analysis is a useful way to group survey responses to multiple items based on similarity such that respondents within a cluster are more similar to each other than they are to members of a different cluster [15]. We implemented consensus clustering on the full sample using responses to motivator, barrier, and facilitator items [16]. Consensus clustering uses resampling to create robust clusters that are more stable than those identified by traditional methods. Within each imputed data set, 80% of the sample was randomly selected and k -means clustering was applied with k (number of clusters) ranging from two to twelve. This was repeated 1000 times per imputed data set. Results across imputations and repeats were summarized by assessing the probability that each pair of respondents was grouped into the same cluster, and hierarchical clustering was performed on this matrix of probabilities to identify the final clusters. The optimal number of clusters was assessed by triangulating across several measures of internal validity including contrast criterion, Calinski, Dunn, and silhouette indices, and assessment of pairwise differences in the items used for clustering, adjusted for multiple comparisons [17–20]. Radar plots were used to display cluster characteristics and the clusters were compared to the self-reported grouping

based on employment and ability to donate without lost wage reimbursement. Analyses were completed using SAS 9.4 (SAS Institute, Cary, NC) and MATLAB (MathWorks, Natick, MA).

3 | Results

Between March 2020 and June 2023, 1611 survey responses were received. The analysis sample was limited to respondents who completed at least 7 of the 14 motivator, barrier, and facilitator items on the survey, resulting in an analytical sample of 1592. Mean respondent age was 42.6 (standard deviation [SD] = 14.2) and the majority of respondents were female (74%, Table 1). The most commonly self-reported race was White (75%), followed by Hispanic (14%), Black (6%), and Asian (4%), with respondents having the opportunity to choose multiple races. About one-third of respondents reported a bachelor's (21%) or graduate (16%) degree, while 18% reported a high school degree or less and 31% had some college or technical school but no degree. One-half of respondents were married or in a civil union or domestic partnership and 72% were employed. Household income was less than \$35,000 in 24% and over \$100,000 in 25%. The mean number of household members was 3 (SD = 1.7). Among those employed, 189 (17%) were concerned about losing their job if they took time off work; 589 (52%) held jobs that provided paid time off or other benefits that would allow them to take time off to donate.

When asked whether they had ever considered living organ donation, 91% of respondents indicated that they had. Among these, most (53%) were currently considering donation but had not yet started the evaluation process, while 20% were currently undergoing evaluation and only 3% were prior organ donors (Table 2). Most respondents indicated that they would donate a kidney (79%), while 32% indicated that they would be liver donors. Among those who were considering, undergoing, or had completed an evaluation and intended to donate, and those who had previously donated ($n = 1216$), 30% were or intended to be nondirected donors.

3.1 | Motivators, Barriers, and Facilitators

Motivators for living organ donation, including saving the life of another person and feeling like a good person, were strongly endorsed (99% and 73% somewhat agree or strongly agree), while pressure from others to donate was strongly negatively endorsed (90% somewhat disagree or strongly disagree, Figure 2). The strongest reported barriers to donation were being nervous about the process (48% somewhat agree or strongly agree) and worries about paying for living expenses during recovery (48% somewhat agree or strongly agree). Challenges related to dependent care and worries about health were the second and third most common endorsed barriers (24% and 23% somewhat agree or strongly agree, respectively). Facilitators to living donation, including understanding the risks and benefits, feeling healthy, and having support during the decision-making and recovery process were all highly endorsed (88%–96% somewhat agree or strongly agree), while only 54% somewhat agreed or strongly agreed that they would be able to pay for their living expenses while recovering from surgery.

TABLE 1 | Sample characteristics.

	Mean (SD) or N (%)
Age	42.6 (14.2)
Gender	
Female	1157 (74%)
Male	396 (25%)
Trans or non-binary	17 (1%)
Race (multiple possible)	
American Indian	45 (3%)
Asian	60 (4%)
Black	91 (6%)
Pacific Islander	13 (1%)
Hispanic	215 (14%)
White	1177 (75%)
Prefer not to say	89 (6%)
Marital status	
Single, never married	448 (28%)
Married, or in a civil union or domestic partnership	803 (51%)
Widowed/Divorced/Separated	326 (21%)
Education	
High school diploma/GED or less	292 (18%)
Some college or technical school, no degree	491 (31%)
Associate's degree	206 (13%)
Bachelor's degree	336 (21%)
Graduate degree	254 (16%)
Employed	1136 (72%)
Ability to speak English	
Very well	1427 (91%)
Well	70 (4%)
Not well	42 (3%)
Not at all	24 (2%)
Household income	
Less than \$20,000	132 (10%)
\$20,000 to \$34,999	188 (14%)
\$35,000 to \$49,999	193 (15%)
\$50,000 to \$74,999	302 (23%)
\$75,000 to \$99,999	177 (13%)
Over \$100,000	325 (25%)
Number of household members	3.0 (1.7)
Survey year, n (%)	
2020	677 (43%)
2021	510 (32%)
2022	242 (15%)
2023	163 (10%)

All variables missing 0%–3% except household income (17%).

TABLE 2 | Donation characteristics among 1442 (91%) who have considered donation.

	N (%)
Stage in the donation process	
I previously considered being a living organ donor but did not start an evaluation	182 (13%)
I am now considering being a living organ donor but have not started an evaluation yet	759 (53%)
I am now going through an evaluation for living organ donation	293 (20%)
I was already evaluated for living organ donation and will donate my organ	137 (10%)
I was already evaluated for living donation but will not donate (because I was not eligible or I decided not to donate)	26 (2%)
I already donated an organ	43 (3%)
Organ (to be) Donated (multiple possible)	
Kidney	1130 (79%)
Liver	460 (32%)
Other organ	96 (7%)
Intended/Actual Recipient (among those currently considering donation, going through or completed evaluation and will donate or prior donor)	
Family member in household	176 (14%)
Family member not in household	304 (25%)
Friend	238 (20%)
Nondirected donation	362 (30%)
Other	136 (11%)

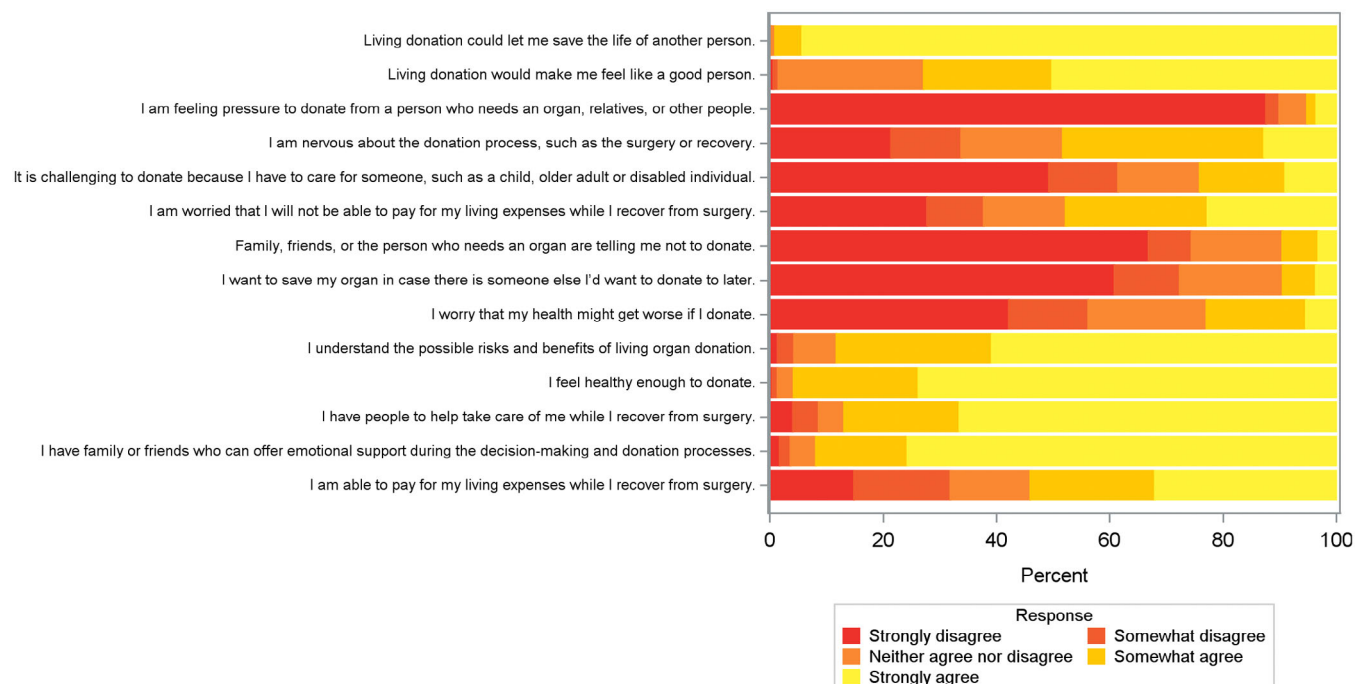


FIGURE 2 | Distribution of responses to motivator, barrier and facilitator items. Each row represents the distribution of ratings of each item listed on the left, from “strongly disagree” (red) to “strongly agree” (yellow).

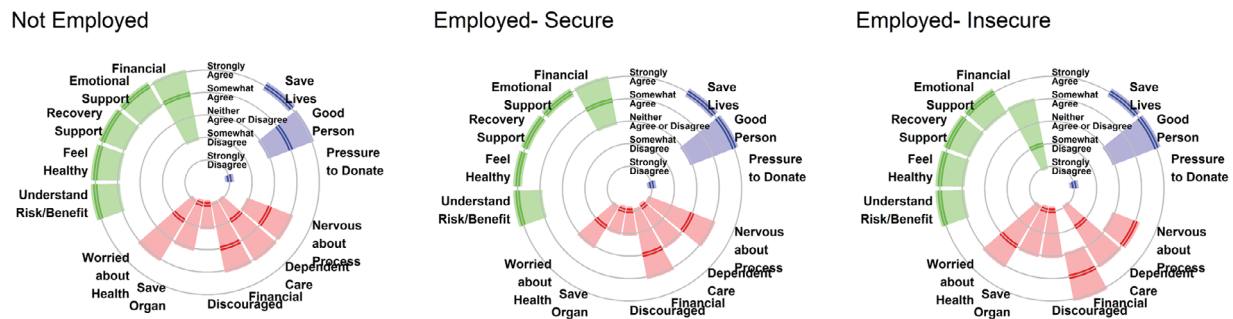


FIGURE 3 | Radar plots of responses to motivators (blue), barriers (red), and facilitators (green) by donor grouping. Each gray circle represents a rating, with the innermost circle representing “strongly disagree” and the outermost circle representing “strongly agree.” Solid colored lines represent the median rating to each item for that group and the associated colored shaded area represents interquartile range of ratings.

3.2 | Impact of Lost Wage Reimbursement Sensitivity on the Ability to Donate

Among 1569 respondents who answered items related to employment status and ability to donate with lost wages, 437 (28%) were not employed, 675 (43%) were employed and could donate even if they were not reimbursed for lost wages (Employed-Secure), and 457 (29%) were employed but would not be able to donate if they were not reimbursed for their lost wages (Employed-Insecure). The not employed group was older (mean [SD] age 46.6 [17.4] vs. 41.5 [12.4], 40.5 [12.4], $p < 0.001$), less educated (30% with bachelor's or graduate degree compared to 40%, $p < 0.001$), and had the lowest endorsement of speaking English very well (85% vs. 93%, 94%, $p < 0.001$, Table 3). The Employed-Secure group had the highest reported household income (42% over \$75,000 per year, compared to 32% of the not-employed group and 35% of the Employed-Insecure group, $p = 0.002$). More surveys were completed by the not employed and Employed-Secure groups in 2020 and 2021 (77%) compared to the Employed-Insecure group (67%, $p < 0.001$). Among those who had considered living donation ($n = 1423$), 62% of those not employed were currently considering donation, compared to 48% of Employed-Secure and 51% of Employed-Insecure groups. In the not-employed group, 14% and 4% were currently being evaluated or had completed evaluation and were planning to donate, respectively, compared to 23% and 13% in the Employed-Secure group and 22% and 10% in the Employed-Insecure group (overall p -value comparing stage in the process across all three groups < 0.001 , Table 4). Nondirected donation was least common in the Employed-Secure group (25%), compared to not employed (35%) and the Employed-Insecure (32%) groups ($p = 0.01$).

The distribution of ratings for motivators was similar for the three groups (Figure 3). The Employed-Insecure group had higher ratings (more agreement) with barriers related to being nervous about the donation process, concerns about being able to pay for living expenses during recovery and worries about health. The Employed-Secure group had lower ratings (less agreement) for the barrier related to dependent care. Facilitator ratings were similar across all three groups except for ability to pay bills during recovery, which received lower agreement on average in the Employed-Insecure group compared to the other two groups.

Among employed respondents, after accounting for between and within imputation variance, multivariable logistic regression

models showed stronger agreement with barriers related to dependent care responsibilities (odds ratio [OR] = 1.19, 95% confidence interval [CI] = 1.07–1.33) and worries about expenses (OR = 1.17, 95% CI = 1.02–1.35), and lower agreement with feeling healthy enough to donate (OR = 0.62, 95% CI = 0.47–0.82), and ability to pay bills during recovery (OR = 0.62, 95% CI = 0.54–0.72), were associated with higher odds of membership in the Employed-Insecure group (Figure 4). In addition, nondirected and having a relationship with the intended recipient other than a family member not in your household or friend were associated with higher odds of being in the Employed-Insecure group (nondirected: OR = 1.83, 95% CI = 1.08–3.10; other: OR = 2.83, 95% CI = 1.48–5.40) compared to a family member in household. Year of survey completion was not associated with odds of membership in the Employed-Insecure group in multivariable models ($p = 0.20$).

3.3 | Data-Driven Respondent Phenotyping of Donor Respondents

Consensus clustering revealed that 2, 3, and 4 clusters all had sufficiently acceptable internal consistency. Both contrast criterion and silhouette showed similar performance across 2, 3, and 4 clusters (range 0.93–0.97 for contrast, 0.94–0.98 for silhouette, both have a maximum value of one with higher values indicating higher quality clustering). When comparing across 2, 3, and 4 clusters, pairwise comparison between the 14 items included in clustering revealed 93%, 76%, and 88% significant pairwise differences after adjusting for multiple comparisons, indicating high proportions of differing responses between pairs of clusters. Due to the similarity in internal validation criteria across 2–4 clusters we explored 4 clusters in order to identify nuances in motivators, barriers, and facilitators to initiating living donor evaluation.

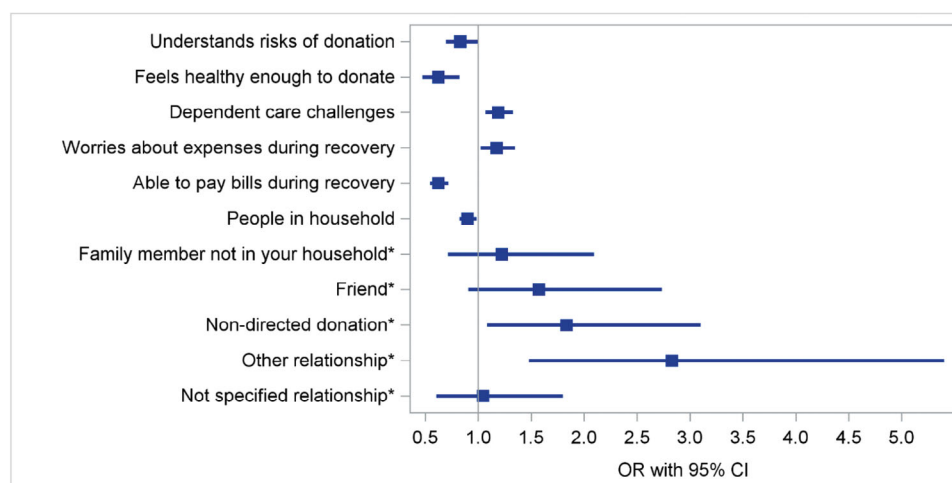
We observed that the four clusters were split across two dimensions; financial concerns and worries about health. Cluster 1 ($n = 422$, 27%) was highly motivated with strong motivators and facilitators and low barriers (Figure 5). Cluster 2 ($n = 368$, 23%) also had strong motivators and facilitators, but had slightly increased barriers, particularly being nervous about the donation process, worried about their health, and concerned about dependent care responsibilities. Clusters 3 ($n = 334$, 21%) and 4 ($n = 468$, 29%) each had strong financial barriers to donation. For Cluster 4, this was the primary barrier, while Cluster 3 also

TABLE 3 | Sample characteristics among 1569 classified into lost wage groups.

	Not employed (N = 437)	Employed-secure (N = 675)	Employed-insecure (N = 457)	p-value
Age, mean (SD)	46.6 (17.4)	41.5 (12.4)	40.5 (12.4)	<0.001
Gender, n (%)				0.11
Female	306 (72%)	484 (72%)	351 (77%)	
Male	113 (27%)	182 (27%)	99 (22%)	
Trans or non-binary	7 (2%)	4 (1%)	4 (1%)	
Race, n (%), multiple possible				
American Indian	15 (4%)	17 (3%)	11 (2%)	0.58
Asian	24 (6%)	26 (4%)	10 (2%)	0.03
Black	23 (5%)	39 (6%)	27 (6%)	0.92
Hispanic	69 (16%)	83 (12%)	60 (13%)	0.22
Pacific Islander	6 (1%)	4 (1%)	3 (1%)	0.35
White	306 (71%)	511 (76%)	346 (77%)	0.12
Prefer not to say	36 (8%)	24 (4%)	27 (6%)	0.003
Marital status, n (%)				0.13
Single, never married	117 (27%)	195 (29%)	131 (29%)	
Married, or in a civil union or domestic partnership	209 (48%)	354 (53%)	227 (50%)	
Widowed/Divorced/Separated	107 (25%)	121 (18%)	95 (21%)	
Education, n (%)				<0.001
High school/GED or less	104 (24%)	117 (17%)	67 (15%)	
Some college or technical school, no degree	151 (35%)	194 (29%)	139 (31%)	
Associate's degree	49 (11%)	88 (13%)	66 (15%)	
Bachelor's degree	81 (19%)	148 (22%)	103 (23%)	
Graduate degree	49 (11%)	123 (18%)	79 (17%)	
Ability to speak English, n (%)				<0.001
Very well	369 (85%)	617 (93%)	421 (94%)	
Well	27 (6%)	27 (4%)	15 (3%)	
Not well	22 (5%)	12 (2%)	8 (2%)	
Not at all	14 (3%)	5 (1%)	5 (1%)	
Income, n (%)				0.002
Less than \$20,000	33 (17%)	59 (9%)	39 (9%)	
\$20,000 to \$34,999	31 (16%)	93 (14%)	64 (14%)	
\$35,000 to \$49,999	29 (15%)	91 (14%)	72 (16%)	
\$50,000 to \$74,999	37 (20%)	143 (21%)	117 (26%)	
\$75,000 to \$99,999	22 (12%)	90 (13%)	64 (14%)	
Over \$100,000	37 (20%)	191 (29%)	92 (21%)	
Number of household members, mean (SD)	2.9 (1.7)	3.1 (1.7)	3.0 (1.6)	0.04
Survey year, n (%)				<0.001
2020	196 (45%)	313 (46%)	156 (34%)	
2021	142 (32%)	212 (31%)	153 (33%)	
2022	51 (12%)	96 (14%)	88 (19%)	
2023	48 (11%)	54 (8%)	60 (13%)	

TABLE 4 | Donation characteristics among 1423 (91%) who have considered donation.

	Not employed (N = 392)	Employed-secure (N = 610)	Employed-insecure (N = 421)	p-value
Stage in the donation process				<0.001
I previously considered being a living organ donor but did not start an evaluation	56 (14%)	73 (12%)	52 (12%)	
I am now considering being a living organ donor but have not started an evaluation yet	241 (62%)	292 (48%)	215 (51%)	
I am now going through an evaluation for living organ donation	55 (14%)	141 (23%)	92 (22%)	
I was already evaluated for living organ donation and will donate my organ	17 (4%)	76 (13%)	42 (10%)	
I was already evaluated for living donation but will not donate (because I was not eligible or I decided not to donate)	13 (3%)	8 (1%)	5 (1%)	
I already donated an organ	9 (2%)	20 (3%)	14 (3%)	
Organ (to be) Donated (multiple possible)				
Kidney	313 (81%)	481 (80%)	321 (77%)	0.46
Liver	140 (36%)	184 (30%)	131 (32%)	0.15
Other organ	37 (10%)	32 (5%)	26 (6%)	0.03
Intended/Actual Recipient (among those currently considering donation, going through or completed evaluation and will donate or prior donor)				<0.001
Family member in household	57 (18%)	81 (15%)	36 (10%)	
Family member not in household	61 (20%)	155 (30%)	81 (22%)	
Friend	50 (16%)	111 (21%)	74 (20%)	
Nondirected donation	108 (35%)	133 (25%)	117 (32%)	
Other	36 (12%)	44 (8%)	54 (15%)	



*Reference is family member in household

FIGURE 4 | Multivariable associations between motivators, barriers, and facilitators with inability to donate with unreimbursed lost wages. Odds ratios (squares) and 95% confidence intervals (lines) from logistic regression modeling the probability of not being able to donate without lost wage reimbursement. Odds ratios greater than 1 represent higher odds of financial barriers to living donations associated with lost wages, while odds ratios less than 1 represent lower odds of financial barriers associated with lost wages.

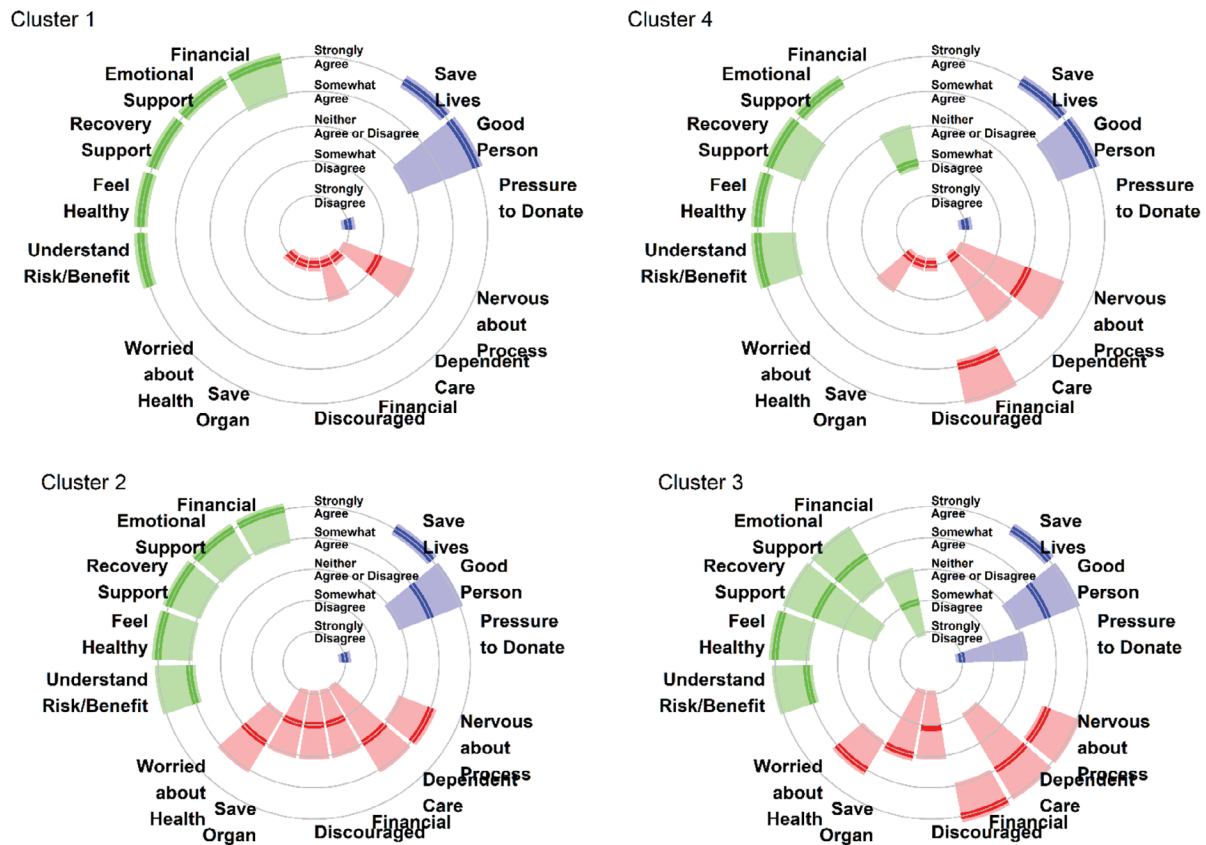


FIGURE 5 | Radar plots of responses to motivators (blue), barriers (red), and facilitators (green) by cluster. Each gray circle represents a rating, with the innermost circle representing “strongly disagree” and the outermost circle representing “strongly agree.” Solid colored lines represent the median rating to each item for that group and the associated colored shaded area represents interquartile range of ratings.

had barriers related to being nervous about the donation process, worried about their health, and concerned about dependent care responsibilities.

Cluster 1, representing those ready to initiate evaluation, was the oldest cluster (mean [SD] age 46.0 [15.0]), while Cluster 3, with the highest barriers, was the youngest (mean [SD] age 40.1 [13.3], Table 5). Clusters 3 and 4, which both had financial barriers, had the lowest percentage of White and married participants (69% and 71% White, respectively, 42% and 46% married, respectively), and 54% and 55% did not have a degree beyond high school. Cluster 3, with multiple barriers, had the lowest reported household income, with 53% making under \$50,000 per year. Cluster 4 had the highest proportion of employed participants (80%), and 46% had household incomes under \$50,000 per year. Clusters 1 and 2, which did not endorse financial barriers, had higher incomes, with 47% and 52% having household incomes over \$75,000 per year. Cluster 2, which had nonfinancial barriers, had the highest proportion of married participants (62%), and was the most highly educated (52% with a bachelor’s or graduate degree). More respondents in Clusters 1, 2, and 4 completed the survey in 2020 and 2021 (75%, 80%, and 76% respectively) compared to Cluster 3 (65%).

Among those who had ever thought about living donation ($n = 1442$), Cluster 4 had the lowest proportion of those currently considering living donation (48%) and the highest percentage of those who had been evaluated and were planning to donate

(16%, Table 6). Clusters 2 and 3 had the lowest proportion of those currently undergoing evaluation (17%). Cluster 1 had the highest proportion of respondents intending to donate a kidney (83%), while Cluster 3 had the highest proportion of respondents wanting to donate their liver (42%) as well as the highest proportion of nondirected donors (39%). Cluster 2 had the highest proportion of respondents intending to donate to a family member, not in their household.

When comparing the prespecified groups of respondents based on employment status and ability to donate without lost wage reimbursement and the clusters driven by motivators, barriers and facilitators, there was overlap among all groups (Figure 6). The not employed group was almost evenly distributed across all 4 clusters (30%, 28%, 21%, and 21% across Clusters 1-4, respectively). Among the Employed-Secure group, 61% were assigned to Clusters 1 and 2, but 30% were assigned to Cluster 4, indicating that they had some financial barriers despite indicating that they would be able to donate without having lost wages reimbursed. The Employed-Insecure group is primarily segregated into Clusters 3 (37%) and 4 (37%), with 11% in Cluster 1 and 14% in Cluster 2.

4 | Discussion

Strongly considering living organ donation entails a complex thought process that weighs multiple factors simultaneously. Many factors are considered, including worries about current

TABLE 5 | Sample characteristics by cluster group.

	Cluster 1 (n = 422)	Cluster 2 (n = 368)	Cluster 3 (n = 334)	Cluster 4 (n = 468)	p-value
Age, mean (SD)	46.0 (15.0)	44.0 (14.3)	40.1 (13.3)	40.2 (13.1)	<0.001
Gender, n (%)					0.04
Female	325 (78%)	276 (76%)	233 (72%)	323 (69%)	
Male	88 (21%)	87 (24%)	86 (27%)	135 (29%)	
Trans or non-binary	2 (0%)	2 (1%)	5 (2%)	8 (2%)	
Race, n (%), multiple possible					
American Indian	9 (2%)	7 (2%)	12 (4%)	17 (4%)	0.28
Asian	9 (2%)	14 (4%)	24 (7%)	13 (3%)	0.001
Black	20 (5%)	10 (3%)	26 (8%)	35 (8%)	0.006
Hispanic	57 (14%)	41 (11%)	43 (13%)	74 (16%)	0.27
Pacific Islander	5 (1%)	2 (1%)	3 (1%)	3 (1%)	0.74
White	327 (78%)	297 (82%)	223 (69%)	330 (71%)	<0.001
Prefer not to say	16 (4%)	20 (5%)	27 (8%)	26 (6%)	0.07
Marital status, n (%)					<0.001
Single, never married	96 (23%)	81 (22%)	108 (33%)	163 (35%)	
Married, or in a civil union or domestic partnership	225 (54%)	227 (62%)	137 (42%)	214 (46%)	
Widowed/Divorced/Separated	97 (23%)	56 (15%)	84 (26%)	89 (19%)	
Education, n (%)					<0.001
High school/GED or less	70 (17%)	50 (14%)	71 (22%)	101 (22%)	
Some college or technical school, no degree	138 (33%)	99 (27%)	104 (32%)	150 (32%)	
Associate's degree	61 (15%)	26 (7%)	40 (12%)	79 (17%)	
Bachelor's degree	83 (20%)	89 (24%)	66 (20%)	98 (21%)	
Graduate degree	66 (16%)	101 (28%)	48 (15%)	39 (8%)	
Employed	289 (69%)	242 (66%)	234 (72%)	371 (80%)	<0.001
Ability to speak English, n (%)					<0.001
Very well	387 (94%)	351 (96%)	259 (80%)	430 (93%)	
Well	14 (3%)	9 (2%)	33 (10%)	14 (3%)	
Not well	6 (1%)	4 (1%)	21 (6%)	11 (2%)	
Not at all	4 (1%)	1 (0%)	12 (4%)	7 (2%)	
Income, n (%)					<0.001
Less than \$20,000	19 (5%)	18 (6%)	45 (17%)	50 (12%)	
\$20,000 to \$34,999	42 (12%)	35 (12%)	45 (17%)	66 (16%)	
\$35,000 to \$49,999	42 (12%)	28 (9%)	51 (19%)	72 (18%)	
\$50,000 to \$74,999	81 (23%)	63 (21%)	54 (20%)	104 (26%)	
\$75,000 to \$99,999	48 (14%)	41 (14%)	32 (12%)	56 (14%)	
Over \$100,000	117 (34%)	113 (38%)	39 (15%)	56 (14%)	
Number of household members, mean (SD)	2.8 (1.5)	3.1 (1.6)	3.2 (1.9)	3.0 (1.7)	0.009
Survey year, n (%)					<0.001
2020	204 (48%)	173 (47%)	110 (33%)	190 (41%)	
2021	116 (27%)	122 (33%)	108 (32%)	164 (35%)	
2022	59 (14%)	47 (13%)	64 (19%)	72 (15%)	
2023	43 (10%)	26 (7%)	52 (16%)	42 (9%)	

TABLE 6 | Donation characteristics among 1442 (91%) who have considered donation.

	Cluster 1 (n = 389)	Cluster 2 (n = 331)	Cluster 3 (n = 288)	Cluster 4 (n = 434)	p-value
Stage in the donation process					<0.001
I previously considered being a living organ donor but did not start an evaluation	34 (9%)	39 (12%)	67 (23%)	42 (10%)	
I am now considering being a living organ donor but have not started an evaluation yet	205 (53%)	188 (57%)	156 (54%)	210 (48%)	
I am now going through an evaluation for living organ donation	89 (23%)	57 (17%)	49 (17%)	98 (23%)	
I was already evaluated for living organ donation and will donate my organ	36 (9%)	25 (8%)	7 (2%)	69 (16%)	
I was already evaluated for living donation but will not donate (because I was not eligible or I decided not to donate)	13 (3%)	5 (2%)	3 (1%)	5 (1%)	
I already donated an organ	10 (3%)	17 (5%)	6 (2%)	10 (2%)	
Organ (to be) Donated (multiple possible)					
Kidney	321 (83%)	246 (75%)	215 (76%)	348 (81%)	0.02
Liver	96 (25%)	115 (35%)	118 (42%)	131 (31%)	<0.001
Other organ	24 (6%)	21 (6%)	23 (8%)	28 (7%)	0.77
Intended/Actual Recipient (among those currently considering donation, going through or completed evaluation and will donate or prior donor)					0.01
Family member in household	61 (18%)	34 (12%)	25 (12%)	56 (15%)	
Family member not in household	81 (24%)	89 (31%)	44 (21%)	90 (24%)	
Friend	69 (21%)	56 (20%)	34 (16%)	79 (21%)	
Nondirected donation	86 (26%)	72 (25%)	83 (39%)	121 (32%)	
Other	39 (12%)	35 (12%)	26 (12%)	36 (9%)	

health status, the surgery itself, long-term health, the impact on daily life during surgical recovery, and the timeline of return to normalcy. Financial concerns related to living donation are very common and employment alone is an insufficient proxy for the ability to incur unreimbursed nonmedical costs of living organ donation. Among survey respondents who were employed, 40% (457/1132) reported that they would not be able to donate if they did not receive reimbursement for lost wages. Barriers to living donation in this self-identified group were not limited purely to financial concerns. This group was also more likely to not feel healthy enough to donate and be worried about the health effects of donation. Financial- and health concern-related barriers to donation both appeared as important dimensions in data-driven clustering of motivators, barriers, and facilitators of living donation. While some respondents had only one barrier or the other, other respondents had both to varying degrees. This suggests that donor candidate-targeted interventions intended to reduce barriers to living organ donation need to be multifaceted. Self-reported ability or willingness to donate without lost wage reimbursement and the endorsement of financial barriers to donation were not mutually exclusive, suggesting that financial barriers may not be a binary decision-making input for some who come forward for evaluation, instead representing the hardship and stress imposed by financial hardship on donors.

The existence of financial disincentives to living donations is not a new observation [6, 21–26]. However, these data quantify how financial barriers interact with other barriers, motivators, and facilitators in the decision to initiate living donation in a way that provides opportunities for tailored interventions. It is not surprising that respondents who self-identified as Employed-Insecure (i.e., not able to donate if they lost wages that were not reimbursed) were more likely to endorse financial barriers [4, 7]. However, the nuance of dependent care challenges as a component of overall financial barriers and higher endorsement of worries about donation-related health effects and anxiety related to surgery and recovery are notable findings. The finding of a group of patients with financial barriers as well as health concern-related barriers (Cluster 3) reinforces the principle that financial barriers are only one component of a donor candidate's decision matrix. For potential donors with concerns about finances, the removal of financial barriers alone through government programs such as NLDAC may be insufficient in opening a clear path to living donation. Other strategies are needed to help donor candidates navigate their remaining concerns such as education around availability of reimbursement for dependent care expenses, nondirected, paired, and voucher donation, and other fundraising options, as well as risks and benefits of living donation (Table 7). In addition, Clusters 3 and 4 contained

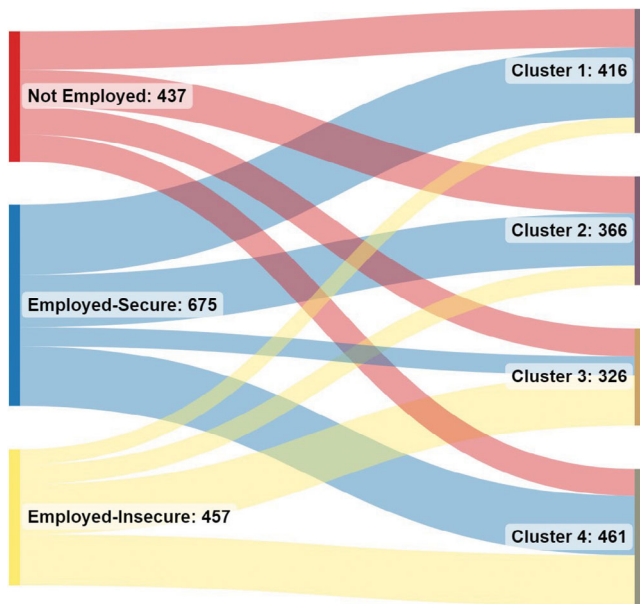


FIGURE 6 | Sankey diagram comparing self-selected donor groups and clusters. This figure compares group membership between self-identified employment and financial barriers to living donation related to lost wages (left side) and data-driven groups identified based on responses to the motivator, barrier, and facilitator items (right side). The relative width of the connecting lines indicates the proportion of the members in a given classification on the left side (self-identified) that were classified into each data-driven classification on the right side.

the highest percentage of minoritized respondents and Cluster 3 specifically was less likely to endorse speaking English very well, suggesting that additional efforts toward culturally sensitive communication around living organ donation may be beneficial to supplement efforts to reduce financial barriers for potential organ donors [27].

Of note, almost one-third of donors who self-identified as Employed-Secure, that is, they would donate even if their lost wages were not reimbursed, were nonetheless grouped into Cluster 4, which was characterized principally by financial barriers. This supports clinical observations that some donors proceed with donation despite financial hardship caused directly or indirectly by the donation itself. For these donors, programs such as NLDAC that reduce financial barriers can provide a significant source of relief from the financial impact and stress burdens of donation. However, given the current real constraints to NLDAC support around recipient household income, further expansion of the NLDAC program would be needed to help this group of employed individuals who still clearly demonstrated financial vulnerability.

Nondirected kidney donation has increased more than 10-fold in the last two decades [28], and 30% of survey respondents indicated that they would be a nondirected donor. These potential donors are not driven by the urgency of a specific loved-one’s illness, and therefore may be able to donate at a time when they are more stable financially. Interestingly, Employed-Secure donors were least likely to indicate that they would be nondirected donors, while respondents making up Cluster 3, who faced both financial and health concern-related barriers, were most likely to indicate

TABLE 7 | Cluster group characteristics and potential targeted interventions.

Cluster	Characteristics	Potential targeted intervention
1	Older, higher education and income, highly motivated, low barriers	Education on nondirected donation, paired donation, advanced donation, and voucher donation
2	Married, higher income and education, health and dependent care-related barriers	Referral to financial support programs that include dependent care costs and accompanying person benefits, additional education on donation risks and benefits, discussion of nondirected donation and paired donation, education on fundraising options (e.g., Go Fund Me)
3	Younger, more likely to be minoritized, non-English speaking, and lower income, financial and health-related barriers	Referral to financial support programs, culturally concordant education around living donation and transplantation including risks and benefits of donation, discussion of nondirected donation and paired donation
4	Younger, more likely to be minority, lower education and income, employed, with primarily financial barriers	Referral to financial support programs that include lost wages, discussion of nondirected donation and paired donation

that they would be nondirected donors. While financial assistance may be important to those considering nondirected donation, it is but one contributor to a multidimensional decision-making process.

The large sample of potential donors across the spectrum of the decision-making process and heterogenous population demographics provide strength to the study as well as generalizability. In addition, the simultaneous assessment of financial and other barriers to donation allowed for a more nuanced understanding of the interplay among motivators, barriers, and facilitators. However, this study was limited by the fact that the sample was a convenience sample of participants who accessed the survey on the NLDAC website; therefore, a true response rate cannot be known. In this context, the responses may not be representative of the full decision-making spectrum or the entirety of the population considering living donation, especially those whose barriers preclude them from considering donation at all. The survey’s location on the NLDAC website means that responses from those who have never considered donation are likely under-represented. Conversely, extremely motivated donor candidates

without any financial barriers may not ever access the NLDAC website. In addition, outcomes of donation are not known for all and therefore the impact of these factors on donation outcomes cannot be assessed. Finally, the study findings are representative of a defined cross-sectional snapshot and the results may not be time-invariant. Differences in timing of survey completion by group, which may have been driven by expansion of NLDAC to include reimbursement of lost wages and dependent care, cannot be confirmed empirically. Despite these limitations, we believe this to be one of the largest published reports on motivators, barriers, and facilitators to living donation with sufficient applied methodological rigor to illustrate the complexity of decision-making. We hope our work will motivate more targeted studies of those currently underrepresented in living donation.

5 | Conclusion

The findings in this study do have implications for targeting interventions that may help improve living donor decision-making. Table 7 describes potential interventions transplant programs could utilize to support donor candidates, based on the cluster to which these individuals may belong. The financial impact of living organ donation is a strong barrier for some potential living donors, but interventions should be tailored to specific financial needs, for example, lost wages or dependent care. For a subset, financial concerns interact with other barriers related to nervousness about surgery and long-term health. Additional targeted interventions are needed to address these barriers, including culturally-concordant education and more patient-centered tools addressing health and surgical concerns related to living donation. Multiple interventions have been proposed and implemented but have varying degrees of penetrance in living donor transplant programs [29–32]. Broader utilization of these tools by the transplant community may further reduce barriers and increase living donation in the United States, particularly given the complex matrix of factors that affect the decision to donate.

Author Contributions

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Acknowledgments

Editorial assistance was provided by Shauna Leighton, an employee at Arbor Research Collaborative for Health, on behalf of the authors and with their permission. This program is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of two financial assistance awards totaling \$9,700,000 and \$1,992,684 with 0 percentage financed

with nongovernmental sources. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA, HHS, or the U.S. Government.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

Due to the sensitive nature of the questions asked in this study, survey respondents were assured raw data would remain confidential and would not be shared.

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