



Vascularized composite allotransplantation: Knowledge and attitudes of a national sample of organ procurement organization professionals

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Abstract

With the emergence of vascularized composite allografts (VCAs) for transplantation, donation professionals' ability to obtain authorization for these anatomical gifts has become paramount for its continued practice. Our national study examines the experience of organ procurement organization (OPO) professionals responsible for presenting the opportunity to donate VCAs to families of deceased donor-eligible patients. Semi-structured telephone interviews conducted with 157 OPO staff assessed experience with VCA discussions, VCA knowledge, and comfort, confidence, and feeling prepared with discussions about different VCA types. Standard procedures were used to code and analyze the qualitative data and summarize the quantitative data. Most respondents (70.1%) never held a VCA donation discussion, but those with experience reported overall low levels of knowledge, comfort, and confidence talking with families about VCA. Although 44.4% of the sample had VCA-related training, many felt unprepared, with most (75.0%) stating the training was insufficient. Participants without experience indicated even lower ratings of the aforementioned constructs. Findings support extant work demonstrating that no standardized procedures exist for VCA donation discussions; however, donation professionals are willing to adopt new VCA-related skills. This report concludes that sustained and content-specific training will elevate donation professionals' ability to augment the supply of VCAs available for transplantation.

KEYWORDS

family discussion, organ procurement organization (OPO), vascularized composite allograft (VCA)

1 | INTRODUCTION

The "exquisite capabilities" of vascularized composite allotransplantation (VCA) represent a significant turning point in the care of individuals with catastrophic injuries, which have not been

optimally treated with traditional reconstructive surgical procedures.¹⁻⁶ VCA allografts are recovered from human donors as single anatomical or structural units containing multiple tissue types and requiring blood flow from surgical connections of blood vessels.⁷ VCA allografts currently include the face, larynx, upper and

lower extremities, lower abdominal units, as well as the bladder, uterus, and penis.

Vascularized composite allografts transplants are still quite rare. Only one hundred and two VCAs have been transplanted nationwide to date, with the first larynx transplant occurring in 1998.⁸ Today, 28 transplant centers in the United States are home to VCA transplant programs. Whereas, as of April 2, 2020, only 28 candidates for VCA transplantation were listed on the United Network for Organ Sharing (UNOS) waitlist,⁹ the pool of potential individuals with severe and disfiguring injuries who could potentially benefit from a VCA is much greater. Each year, thousands of Americans sustain devastating injuries to the head, neck, and upper and lower extremities. In 2015 alone, over 532 000 bodily injuries (61.7% of all reported injuries) to civilians received a classification of serious to unsurvivable.¹⁰ VCAs have the potential to restore mobility and function, reduce chronic pain, and improve psychosocial status and quality of life. Most dramatic are face transplants that can transform the lives of patients who can no longer breathe, chew, swallow, see, or communicate without great difficulty.

The training and skill of OPO professionals are key to the successful recovery of VCA grafts.¹¹ Even when patients pre-designate themselves as donors, VCA allografts are not currently listed with other solid organs in first person donor pre-designations via driver's licenses, donor cards, or online registries. Therefore, donation professionals must skillfully present VCA as an additional donation opportunity and address families' associated questions and concerns. Their ability to perform this task effectively relies on masterfully explaining what VCAs are and what benefits they present, and discussing the opportunity with donor families with competence, comfort, and confidence. Decades of previous research consistently confirm the fact that donation discussions, which provide little to no essential information and do not contain the elements of effective communication, are less likely to meet success.¹²⁻¹⁷ A recent review highlights specific concerns of families considering VCA donation—including bodily integrity and funeral arrangements—and underscores the need for donation professionals to sensitively address these issues without risking the authorization of solid organs.¹⁸ To date, however, no evidence-based training program on VCA for donation professionals has been developed or tested.

The diffusion of this therapeutic modality is currently limited by several factors including the lack of a payment structure to provide VCA transplantation to a broader population and the limited availability of VCA grafts. Given its novelty, however, there is limited awareness of the need for or benefits of VCA donation among Organ Procurement Organization (OPO) professionals or the families they approach about donating the solid organs and tissues of deceased donor-eligible patients. Moreover, there are neither universal procedures nor clear guidelines for approaching families for VCA authorization by OPO professionals.¹⁸ To address this issue, we undertook a national inquiry into the experience of OPO professionals with VCA approaches. These findings have great potential to provide guidance on how to discuss VCA with families, to inform development of training programs in the area, and to ultimately enhance the informed

decision making and authorization processes for VCA donation. Family authorization in sufficient numbers is imperative to making VCA a standard therapeutic option for all Americans in need.

2 | MATERIALS AND METHODS

Recruitment of OPO professionals was initiated with leadership of all 58 OPOs in 2018, requesting that they encourage participation from the approximately 750 professionals who hold donation discussions with families nationwide.¹⁹ The study was introduced to Chief Executive Officers who shared the information to staff via internal listservs. Any OPO professional regularly involved in approaches for family authorization of solid organ and tissue donation was eligible to participate. In addition, passive recruitment was facilitated using a link to a secure Qualtrics form distributed via the Organ Donation and Transplantation Alliance (ODTA) and the North American Transplant Coordinators Organization (NATCO) listservs. OPO professionals interested in participating used the link to submit their contact information and availability to the Philadelphia-based research team. Interviews were conducted by telephone from November 2018 to May 2019. All participants provided informed consent, gave permission to audio-record the interview, and received a \$50 debit card for their participation. The study was approved by the Temple University Institutional Review Board (Protocol# 25254).

2.1 | Measurement and instruments

The semi-structured interviews were adapted from validated instruments used in past studies concerning organ and tissue donation knowledge, attitudes, and behaviors.^{13,16,20-22} The interviews also were designed in consultation with healthcare providers and OPO leadership knowledgeable about VCA donation and informed by the results of nine open-ended interviews of OPO professionals with experience approaching families about VCA donation. The final interview consisted of 59 open- and closed-ended questions exploring experience, knowledge, comfort, preparation, and confidence with VCA donation discussions; twelve sociodemographic questions were included to characterize the sample.

The interview began by asking respondents about previous experience with VCA donation. Individuals with experience were asked to estimate the number of VCA-specific discussions held with families and to describe the circumstances of their last VCA case, including the topics discussed. Four 10-point Likert-type questions captured respondents' self-assessed levels of preparation for, knowledge of, and comfort and confidence with VCA discussions. Scores for these measures ranged from 0 to 10.

Respondents also rated the latter three constructs across 6 different VCA allografts, such as face, hand, legs, uterus, penis, and larynx; higher ratings indicated higher levels of each construct. Predesigned qualitative probes captured reasons for self-reported ratings to further understand the underlying constructs. In addition,

OPO professionals were queried about whether they had received training about VCA (Yes/No); affirmative responses were followed by questions capturing the training's format, content, length, and source. Finally, willingness to complete training about VCA and the desired format, length, content, and frequency of such training was assessed.

2.2 | Data management and coding

The audio-recorded interviews were transcribed verbatim and reviewed for accuracy by the research team. An initial coding schema was developed using the domains from the interview guide as major coding categories; additional codes were developed inductively using the constant comparative method.²³ A codebook was created with definitions and examples to guide the coders and assure reliability. Coding was accomplished manually and entered into REDCap 9.3.5 (Research Electronic Data Capture) to enable calculation of code frequencies.^{24,25} Two qualitatively trained research staff coded the transcripts, and a cultural anthropologist (GPA) on the research team oversaw this process to avoid coding drift. Each transcript was coded independently by both coders, with interrater reliability ranging from 94.6% to 99.0% agreement; disagreements were resolved by discussion between the coders and the full research team, when needed to reach consensus.

2.3 | Data analysis

Univariate and bivariate statistics were generated using SAS 9.4.²⁶ Prior to calculating Pearson correlations and point biserial coefficients, a simple random imputation was used to replace missing and invalid values for the number of reported VCA approaches in 8 cases.

Between-group differences were assessed using two-sided Student's *t* tests; *P*-values of .05 were considered statistically significant.

3 | RESULTS

3.1 | Requester sample

Of 194 potential participants contacted, 157 professionals from 39 OPOs were enrolled (80.9% response rate). Interviews ranged from 21 to 103 minutes in duration. Data from three interviews were excluded because these participants were rarely involved in family approaches for organ or tissue donation, leaving a final sample of 154, or 20.5% of requesters in the country. Participants were predominantly non-Hispanic, White (77.3%) females (74.0%), with a mean age of 41 years (SD 9.87; Table 1). Participants' experience making donation approaches ranged from less than one year to over 30 years, with an average of 5.3 years (SD 4.8). The majority of respondents were Family Support Coordinators (53.9%) or Organ and

TABLE 1 OPO requester sociodemographic information (N = 154)

Age (years)	N (%)
≤34	47 (30.5)
35-44	55 (35.7)
45-54	34 (22.1)
≥55	18 (11.7)
Sex	
Female	114 (74.0)
Ethnicity	
Not Hispanic/Latino(a)	133 (86.4)
Race	
White or Caucasian	119 (77.3)
Black or African American	18 (11.7)
Asian	2 (1.3)
Other	12 (7.8)
NR/NA	3 (1.9)
Coordinator Type	
Family Support Coordinator	83 (53.9)
Organ and Tissue Procurement Coordinators	59 (38.3)
Organ and Tissue Manager	7 (4.6)
Education	
High school	2 (1.3)
Some college, trade school, Associate's degree or Licensed Practical Nursing degree (LPN)	15 (9.7)
Bachelor's degree or higher	137 (89.0)
Degree	
Health-related field	106 (68.8)

Tissue Procurement Coordinators (38.3%). Most (89.0%) had a bachelor's degree or higher, with over two-thirds holding a degree in a health-related field (68.8%).

3.2 | Knowledge and experience

Although experts in discussing solid organ and tissue donation with families, OPO professionals' knowledge and experience discussing VCA donation varied widely. For instance, when asked to estimate the number of patients waiting for a VCA transplant, responses ranged from 9 to 1000 (mean 661.9, SD 427.0). Self-assessed knowledge about VCA was generally low, ranging from a mean of 3.30 (SD 2.5) for hand donation to 1.64 (SD 1.6) for the donation of the larynx (Table 4).

The majority of participants (70.1%) reported never discussing VCA donation with families. Of the 46 requesters (29.9%) who had initiated a discussion about VCA donation, most reported having fewer than 10 approaches: 1 approach (23.9%); 2-5 approaches (45.7%); 6-10 approaches (15.2%); and more than 10 approaches (15.2%). Of the most recent discussions for VCA, 15 (32.6%) were for hands or forearms and 4 (8.7%) for face (Tables 2 and 3). While all

TABLE 2 Type of VCA OPO requester asked for in last VCA request (N = 46)

Type of VCA	N (%)
Hands/forearms	15 (32.6)
Face	4 (8.7)
Uterus	4 (8.7)
Abdominal wall	3 (6.5)
Penis	2 (4.3)
Scalp	1 (2.2)
Legs	0 (0.0)
Larynx	0 (0.0)
VCA in general	5 (10.9)
Not specified	6 (13.0)
Other	6 (13.0)

approaches for VCA donation were held after family authorization for solid organ donation, for the plurality of cases VCA was only discussed after a match was confirmed (32.6%) or during completion of the authorization form (30.4%).

3.3 | Confidence and comfort

D4 displays confidence ratings and comfort with VCA discussions. Self-rated confidence ranged from a mean of 4.69 (SD 3.0) for hand

donation to 3.2 (SD 2.7) for larynx donation. Comfort ratings were also modest, but comparatively higher than those for confidence. Participants were most comfortable approaching families about hand donation (mean 5.39, SD 3.15) and least comfortable with penis donation (mean 4.11, SD 3.06). A strong positive correlation was found between confidence and comfort (ρ 0.83; $P < .001$) (see Table 4).

3.4 | Preparation and training

Overall, 127 (80.9%) felt at least slightly prepared to discuss the VCA donation opportunity with family decision makers (mean 4.2, SD 2.6), yet 27 (17.2%) respondents reported feeling completely unprepared to make a VCA approach. A positive correlation was found between feeling prepared and the number of prior VCA discussions with families (ρ 0.28; $P < .001$). More moderate correlations were found between feeling prepared and self-assessed knowledge (ρ 0.58; $P < .001$), comfort (ρ 0.49; $P < .001$), and confidence (ρ 0.56; $P < .001$). The majority of respondents (64.9%) reported having received no VCA training, and most untrained respondents (76%) cited their lack of training as the chief reason for feeling unprepared.

Of those with training ($n = 54$, 35.1%), the majority (74.1%) received in-person training organized and provided by their OPO; others received instruction provided at industry meetings (22.2%). While the content of these sessions varied, many trainings included

TABLE 3 Correlation matrix of factors in VCA approaches

Rho P N	Training (Y/N)	Approaches (#)	Feeling prepared	Knowledge	Comfort	Confidence
Training (Y/N)	1	0.1882 [*]	0.4416 ^{**}	0.40828 ^{**}	0.203 [*]	0.26765 ^{**}
		0.019	<0.001	<0.001	0.011	<0.001
	154	154	154	154	154	154
Approaches (#)	0.1882 [*]	1	0.28245 ^{**}	0.03342	0.02001	0.0304
	0.019		<0.001	0.680	0.805	0.708
	154	154	154	154	154	154
Feeling prepared	0.4416 ^{**}	0.28245 ^{**}	1	0.58176 ^{**}	0.48731 ^{**}	0.56287 ^{**}
	<0.001	<0.001		<0.001	<0.001	<0.001
	154	154	154	154	154	154
Knowledge	0.40828 ^{**}	0.03342	0.58176 ^{**}	1	0.56061 ^{**}	0.68678 ^{**}
	<0.001	0.680	<0.001		<0.001	<0.001
	154	154	154	154	154	154
Comfort	0.203 [*]	0.02001	0.48731 ^{**}	0.56061 ^{**}	1	0.83137 ^{**}
	0.011	0.805	<0.001	<0.001		<0.001
	154	154	154	154	154	154
Confidence	0.26765 ^{**}	0.0304	0.56287 ^{**}	0.68678 ^{**}	0.83137 ^{**}	1
	<0.001	0.708	<0.001	<0.001	<0.001	
	154	154	154	154	154	154

**Significance at 0.01.

*Significance at 0.05.

TABLE 4 Self-assessed ratings by VCA type (N = 154)[†]

	Mean (SD)					
	Hand	Face	Uterus	Penis	Leg	Larynx
Knowledge	3.81 (2.68)	3.30 (2.49)	2.94 (2.23)	2.58 (2.31)	2.44 (1.98)	1.64 (1.59)
Confidence	4.69 (2.99)	4.05 (2.85)	4.06 (3.01)	3.53 (2.84)	3.74 (2.73)	3.18 (2.73)
Comfort	5.39 (3.15)	4.62 (2.77)	5.14 (3.17)	4.11 (3.06)	4.63 (3.14)	4.51 (3.18)

[†]Range for all scales: 0-10.

testimonials from surgeons, experienced requesters, or VCA recipients (44.4%) and helpful language and techniques to use during family approaches (42.6%). Additionally, 16 requesters (29.6%) received training on a specific type of VCA donation, and 13 (24.1%) reported that they were trained on the general definition of VCA. Training content also included the VCA recovery process (18.5%), the timing of VCA approaches (18.5%), and the benefits of VCA to recipients (13.0%); only 9 (16.7%) included any role-playing scenarios as part of skills development. However, 44.4% of OPO professionals reporting any VCA training still felt unprepared (mean 4.5, SD 2.3), with most (75.0%) stating the training was insufficient.

Table 5 displays the self-rated preparation levels for the entire sample and by experience and training. Preparation ratings for those with both training in and experience with VCA approaches (19.5%) were significantly higher than for professionals who had never made a VCA approach nor received training in VCA (54.5%; mean 7.1, SD 2.4 vs mean 3.0, SD 2.0; $P < .001$). Additionally, those with experience discussing VCA donation (29.9%) reported higher mean preparation scores than did those with training but no experience (33.1%; mean 6.4, SD 2.5 vs mean 3.3, SD 2.1; $P < .001$). Prior training was significantly associated with the number of previous discussions with VCA (ρ 0.19; $P = .019$), comfort (ρ 0.20; $P = .011$), and confidence (ρ 0.27; $P < .001$). Training was also correlated with feeling prepared (ρ 0.44; $P < .001$) and self-assessed knowledge about VCA (ρ 0.41; $P < .001$).

3.5 | VCA training recommendations

The majority of respondents wanted comprehensive training on VCA (74.6%). Respondents suggested an average of 8.2 hours (SD 11.1) of VCA training, occurring (85.7%) throughout the year. The majority

TABLE 5 Self-reported levels of feeling prepared for VCA requests (N = 154)

Feeling prepared (1-10)	N	Mean	SD
Prior VCA requests [*]			
No	108	3.3	2.1
Yes	46	6.4	2.5
Prior VCA training received [*]			
No	103	3.4	2.2
Yes	51	5.9	2.7

^{*} $P < .0001$.

(56.1%) preferred annual training, while others (24.2%) suggested trainings occur biannually. Ninety percent of respondents indicated that they preferred training to be delivered in-person (90.3%), but many were open to participating in online trainings (44.8%). Lectures (59.1%), simulations/role-playing (57.8%), and question-and-answer sessions (47.4%) were also among the desired formats. Top priorities for content included the technical process of VCA allograft recovery and transplantation (67.5%) and recommended VCA discussion techniques (57.8%). Participants also expressed interest in hearing testimonials (42.2%) and receiving information for the differing types of VCA (40.3%). Lastly, just over half of respondents (55.6%) felt an incentive would increase their likelihood of completing any training; most would want to receive education credits (60.0%) or a monetary incentive (52.9%).

4 | DISCUSSION

This national study comprehensively examined OPO professionals' familiarity with VCA donation, including their knowledge and professional experience with VCA donation. The results highlight that most OPO professionals have limited first-hand experience with VCA donation, underscoring the need for more training. The opportunity to discuss VCA donation with families is currently infrequent. Most respondents (70.1%) reported never offering a family an opportunity for VCA donation. Of those who had, 70% reported discussing VCA no more than 5 times.

We found wide variability in the VCA authorization process. VCA was generally presented either after a recipient match was confirmed or when guiding a family through the signing of routine authorization forms for solid organ and tissue donation. This is consistent with an earlier report noting that individual VCA transplant centers have each created and implemented their own protocols with OPOs.¹⁸ The best practice for obtaining authorization for VCA is currently unknown.

Respondents also noted an overall lack of familiarity with VCA in addition to reporting low levels of comfort and confidence in discussing VCA donation with families. Objective and self-rated assessments of knowledge about VCA were markedly low. McDiarmid noted that effective VCA discussions require OPO professionals to know and relay the benefits and outcomes of this new type of transplantation.¹⁸ Further, research of authorization of solid organs and tissues indicates that donation professionals' comfort and confidence are positively associated with family authorization.^{13,27,28} Family

authorization has also been positively correlated with providing adequate information,^{29,30} answering questions competently,³¹ and skillfully introducing and explaining multiple donation-related topics over an extended period of time.^{12,32} Therefore, professional education and training will be critical to obtaining adequate numbers of VCA donation to both advance the field and support individuals in need.

This research highlights a need for training that would better equip donation professionals to more effectively present the opportunity of VCA donation. Most study participants reported having received no VCA training or training that was rated as inadequate. Even so, previous training among respondents in our sample was associated with higher ratings of knowledge, comfort, and confidence regarding VCA discussions. The utility of training for donation professionals has been made evident by studies that report higher rates of authorization for trained staff.^{27,32} Our own past work highlights the critical importance of initial and ongoing training that provides an opportunity for skills practice.^{12,16,19} Across multiple studies, interventions focused on developing and honing donation professionals' effective communication skills when discussing donation with families led to improvements in their communication competence and comfort answering questions about donation. Training has also been associated with increased family satisfaction with the donation process, enhanced communication quality of the request, and improved authorization rates for solid organ and tissue donation.^{12,16,19}

We also explored OPO donation professional's preferences for VCA training. Uniformly there was agreement that this training is needed. Respondents expressed a strong willingness to participate in training sessions designed to appropriately prepare them for VCA discussions with families. Indeed, they were willing to dedicate significant time to this activity, including a stated preference for in-person sessions. Most wanted comprehensive training with an average duration of at least a full day that would educate participants in the technical aspects of VCA recovery and the communication techniques to employ during family discussions.

This is the first national study to explore OPO professionals' knowledge of and experience with VCA donation. It did have limitations. Although OPOs from all 58 OPOs in the United States were invited to participate, not all did. Moreover, the recruitment pool was drawn from individuals who were invited but chose to participate. Thus, participants were more likely to be drawn from individuals who had at least some interest in VCA donation. Nonetheless, a total of 154 professionals from 67.2% (n = 39) OPOs were represented in the sample, and the sample's demographics are consistent with prior research involving donation professionals.^{16,33} The interview was able to capture detailed information from respondents about their experiences with VCA donation and their assessments of their knowledge and comfort with VCA.

5 | CONCLUSION

Vascularized composite allografts transplantation holds the promise of restoring mobility and function, improving mental health

and quality of life, and reducing chronic pain for those with severe injuries. Increasing the availability of VCA to severely injured and/or functionally impaired civilians, as well as servicemen and women, will require a workforce of OPO professionals who are well prepared and skilled in the use of effective communication techniques to discuss and obtain authorization about this unfamiliar anatomical donation. These data lead us to conclude that most OPO donation professionals still lack comfort and confidence with VCA. It is true that most have yet to encounter a VCA donation opportunity, but these opportunities will increase as the field advances. Proactively training the donation professional workforce will ensure that when the time comes, donation professionals will be ready.

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DATA AVAILABILITY STATEMENT

Reasonable requests for data will be accommodated by contacting the corresponding author.

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