

ORIGINAL ARTICLE Reconstructive

Attitudes May Be Hard to Change: Canadian Organ Donors Consider Face and Hand Donation

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Objective: Despite the success of composite tissue allograft (CTA) such as face and hand transplant at improving recipients' quality of life, organ donors' hesitation needs to be better understood. The aim of the study was to assess Canadian organ donors' willingness to donate their face and hands, and the efficacy of an educational intervention.

Methods: Canadians registered for organ donation were invited to complete an online survey about CTA. An interactive vignette was introduced part way through to clarify transplant-related concepts, with repeat of questions post-vignette exposure to assess attitudes pliability.

Results: A total of 942 participants completed the survey. Fifty-two percent of donors were willing to donate their face after passing, whereas 80% were willing to donate their hands. Reasons to refuse CTA donation included the risk of upsetting their family, having someone look like them, and wanting their body to remain intact. Donors' willingness to donate their face (38%, P < 0.001) and hands (79%, P < 0.001)P = 0.67) decreased following vignette exposure. Comparative analysis of our interventional vignette with a similar study where donors' donation readiness increased after an educational intervention revealed that our vignette lacked a strong enough emotional component to positively impact donors' attitude to CTA, and may have exposed participants to alternatives to transplant they were not previously aware of. Conclusions: Canadian organ donors surveyed were willing to donate their face and hands following death, a willingness reduced after watching our informative vignette. Further qualitative work is required to better understand the educational needs and areas to address to increase donors' acceptance of CTA. (Plast Reconstr Surg Glob Open 2021;9:e3958; doi: 10.1097/GOX.00000000003958; Published online 29 November 2021.)

INTRODUCTION

Despite its success at improving recipients' quality of life, composite tissue allograft (CTA) lacks unanimous approval from the medical community.^{1,2} A previous survey of North American burn and plastic surgeons strongly supported CTA, with experts' hesitancy stemming from life-long immunosuppression and the absence of longterm data on CTA survival.^{3,4} Similarly, the public remains concerned about CTA.¹ Face and hands are strongly associated with personal identity, and CTA transplant is newer and perhaps not as well understood.⁵ Feelings and

From the *Division of Plastic and Reconstructive Surgery, University of Calgary, Alberta, Canada; and †Division of Plastic and Reconstructive Surgery, McGill University, Quebec, Canada. Received for publication May 24, 2021; accepted October 1, 2021. Copyright © 2021 The Authors. Published by Wolters Kluwer Health, Inc. on behalf of The American Society of Plastic Surgeons. This is an open-access article distributed under the terms of the Creative Commons Attribution-Non Commercial-No Derivatives License 4.0 (CCBY-NC-ND), where it is permissible to download and share the work provided it is properly cited. The work cannot be changed in any way or used commercially without permission from the journal. DOI: 10.1097/GOX.00000000003958 religious beliefs are often cited by donors as reasons for refusing donation.⁶ Despite the public's skepticism about face transplant, some groups have outlined factors positively associated with CTA donation such as younger age (10–39 years old) and tertiary education.^{6,7} A group in New York City (NYC) specifically looked at public awareness of face transplant and found that willingness to donate increased after watching an educational video emphasizing the heroic nature of donors.⁸

There is demand for face and hand transplant in Canada, with some provinces' CTA transplant programs actively recruiting donors.⁹ As the CTA donor-recipient matching process requires additional matching criteria, such as age, sex, height, weight, craniofacial dimensions, skin, and hair color,¹⁰ a larger donor pool is required to make a match. However, face and hand donation awareness is lower than that of solid organs, secondary to their

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Related Digital Media are available in the full-text version of the article on www.PRSGlobalOpen.com. relatively recent introduction in mass media.⁷ Initiating discussions about CTA with organ donors is important, as their registration for face and hand donation is needed to progress in the field of CTA.⁸ The objective of this study was to assess the Canadian organ donor population's attitudes toward CTA, and whether further education around the procedure, outcomes, and alternatives could increase willingness to donate.

METHODS

Study Population

Canadians registered for organ donation through their provincial organ donation organizations were invited to complete a self-administered online survey. Participants had to be over 16 years of age, registered for organ donation in Canada, and French or English speaking.

Survey Design

The survey was designed by identification of the problem (organ donors' attitudes to CTA are unknown). A needs assessment was performed¹¹ by consulting key stakeholders (plastic surgeons and organ donors) and reviewing the literature. The literature search identified previous surveys and publications on CTA donation barriers, providing foundation for the survey questions. A population-specific survey was determined to be an appropriate approach to fulfill our objectives.

Information from this literature search was collated, refined, and adapted to the current study population (ie, registered organ donors). Survey burden was minimized through parsimonious choice of questions.

Topics Addressed and Survey Flow

Specifically, the survey addressed donors' awareness of face and hand donation, personal (self, family member, or acquaintance) experience with facial disfigurement and hand amputation, perception of face and hand transplant as purely aesthetic surgery procedures, willingness to donate their face and/or hands after death, and perceived barriers to donation. The survey comprised 20 pre-exposure questions, a 3-minute-long vignette and three postexposure questions, requiring 10 minutes to complete in total. Participants' answers were primarily binary (yes or no), with options to justify and elaborate. Answering each question was mandatory before moving on to the next.

Interactive Vignette Design

The short interactive vignette consisted of a virtual presentation created by the authors. (See survey, Supplemental Digital Content 1, which displays the narrative of the educational video. http://links.lww.com/ PRSGO/B853.)

Participants could not skip it to complete the survey. To produce the vignette, e-learning principles were applied, using technical figures, lectures, and multimedia editors.¹² It was designed to present in a balanced way the facts around CTA. It included a discussion of the face and hand transplant indications, reconstructive challenges for

Takeaways

Question: Is an educational intervention effective at improving Canadian organ donors' willingness to donate their face and hands after death?

Findings: Of 942 Canadian organ donors surveyed, 52% were willing to donate their face and 80% their hands. Our educational intervention was ineffective at improving willingness to donate, perhaps related to its factual nature, and missing the emotional affective aspect.

Meaning: Canadian organ donors have a high willingness to donate; further increasing this rate will take careful attention to appropriately designed educational interventions.

patients with severe facial injuries and hand amputation, and CTA alternatives and barriers. The content was created from stakeholder input and literature review.

To illustrate the underlying drive for face and hand transplant, pictures of disfigured patients following burns or gunshot wounds, and upper extremity amputation were provided. Their medical and surgical journeys, including numerous reconstructive surgeries, were described up to the point where CTA became an option. The outcomes following transplant were not described in depth.

Additional Links

Extra nonmandatory links to two biographical videos were provided at the end of the vignette (requiring an additional 18 minutes). The first video described facial injuries in World War I soldiers, describing their suboptimal outcomes as a "fate worse than death."¹³ It was produced by the Romagne 14-18 museum dedicated to the First World War in Romagne-Sous-Montfaucon, France. The second video described the first bilateral upper extremity transplant performed in a child at the Children's Hospital of Philadelphia, USA.¹⁴ It told the story of an 8-year-old boy who sustained amputation of both his arms and legs following a life-threatening infection. These biographical videos emphasized the CTA recipients' need for transplant because of poor outcomes from injury or sickness, but did not discuss CTA donors.

After watching the vignette, with or without the biographical videos, the survey repeated questions investigating participants' willingness to donate their face and/or hands. The underlying hypothesis of these post-exposure repeated questions was that increased awareness of the functional challenges following severe face and/or hand injuries, such as communication, facial expression, swallowing, and comfort being in public for the former and prehension, grip, using tools, and writing for the latter, and the success of past CTAs would increase donors' willingness to donate.

The survey was piloted on medical professionals and several self-declared organ donors, and revised with feedback. The survey was available in French and in English, and was hosted on a secure platform.

Survey Distribution

Ten provincial organ donation registries were approached to distribute the survey to their registered organ donors via email or publication of the survey link on their website.

Statistical Analysis

Data was exported into a statistical analysis software, IBM SPSS Version 24 (IBM Corp., Armonk, N.Y.). Descriptive statistics were reported. Chi-square test was used for categorical data, and the Student's t-test was used for continuous variables. Statistical significance was defined by a *P* value of less than 0.05. In addition, a multivariate regression analysis was performed to determine predictive factors for donation of face and hand. Variables included language, gender, religion, rural/urban upbringing, education, age, presence of personal experience with face disfigurement/hand amputation, and perception of CTA as an aesthetic procedure.

RESULTS

Demographics (Table 1)

Nine hundred forty-two registered organ donors completed the survey. Seventy-two percent of participants were aged under 45 years. The respondents were primarily women (77.3%) and francophones (57.5%). Over half (55%) of participants had completed post-secondary education.

Table 1. Sociodemographic Characteristics of Participa	nts
(n = 942)	

	Freque	Frequency*		
Sociodemographic Characteristics	n	(%)		
All	942	100		
Age - y (SD)	34.2	15.5		
≤25	419	44.5		
26-45	257	27.3		
≥46	266	28.2		
Gender				
Men	203	21.5		
Women	728	77.3		
Nonbinary	11	1.2		
First language				
English	389	41.3		
French	542	57.5		
Others	11	1.2		
Beliefs and religion				
Catholic	504	53.5		
No religion	258	27.4		
Others	46	4.9		
Protestant	44	4.7		
Muslim	44	4.7		
Don't know	34	3.6		
Hindu	12	1.3		
Upbringing				
Rural	259	27.5		
Urban	490	52.0		
Mixed	193	20.5		
Highest level of education				
High school	173	18.4		
CEGEP	201	21.3		
Diploma of vocational studies	45	4.8		
Bachelor or higher	523	55.5		
Donated organ as a live donor	33	3.5		

*Percentages may not add up to 100% due to missing data.

Pre-vignette Awareness and Attitudes toward CTA (Table 2)

Sixty percent of surveyed donors were aware of face donation, whereas 26.1% had heard of hand donation. Prior knowledge stemmed from mass media (Figs. 1, 2). Fifty-two percent of donors were willing to donate their face after passing, whereas 79.7% were willing to donate their hands.

We observed a link between female gender and willingness to donate hands (83.1%; P < 0.001). Frenchspeaking participants were also more likely to donate their face (55.2%; P < 0.001) and hands (83.6%; P < 0.001). Absence of religious beliefs was associated with willingness to donate face (64.7%; P < 0.001) and hands (91.1%; P < 0.001). Participants whose highest educational achievement was high school were more likely to donate their hands (67.6%; P < 0.001) than face (26.6%; P < 0.001).

The only variable considered positively predictive of face donation through the regression analysis was consideration of face transplant as an aesthetic procedure (P = 0.01). There was no variable predictive for hand donation.

Reasons for Not Donating (Table 3)

Barriers endorsed by participants with regard to face and hand transplant pre- and post-vignette exposure were identity concerns (48.2% pre-vignette versus 30.4% post-vignette, P < 0.001), absence of long-term data on transplant and survival (45.5% pre-vignette versus 43.6% post-vignette, P = 0.50), risks of long-term immunosuppression (37.2% pre-vignette versus 39.7% post-vignette, P = 0.27), and difficulty with future relationships (21.9% pre-vignette versus 16.1% post-vignette, P < 0.001) (Fig. 3).

Specifically looking at face donation in the prevignette exposure free text responses, some participants referred to it as unethical. Many described having never thought about it before. One participant described how the Muslim ritual bath for deceased loved ones would not be right after face donation. Following vignette exposure, a decrease was observed in the incidence of selected reasons for not donating, like "I don't want to upset my family" (17.9%) and "I don't want someone to look like me after I die (13.4%)" (Fig. 4).

Pre-vignette exposure, participants' free text responses evoked legal concerns with finger prints, crimes, and identity issues following hand transplant. Following vignette exposure, some reasons for non-donation were selected to a lesser degree: "I don't want to upset my family" (3.6%) followed by "I want my body to remain intact" (1.3%) (Fig. 5).

Post-vignette Seemingly Counterinuitive Attitude Change

Table 3 compares participants' perceptions of face and hand donation before and after the informative vignette. The frequency of personal familiarity for both face disfigurement (11.8% pre-vignette and 5.8% post-vignette; P < 0.001) and hand amputation (7.1% pre-vignette versus 4.7% post-vignette; P = 0.01) decreased after exposure. An increase in the number of participants considering hand transplant as an aesthetic procedure was noted post-vignette exposure (8.2% pre-vignette to 14.4% post-vignette; P < 0.001), as was the case for face transplant (20.2% pre-vignette to 22.7% post-vignette; P = 0.15).

Table 2. Baseline Attitudes about Organ Donation*

Organ Donation Characteristics	All, n	All, n (%)		Willing to Donate Face,† n (%)		o Donate n (%)	Р
All	942	100	492	52.2	751	79.7	_
Age - y (SD)	34.2	15.5	35.7	15.3	34.2	15.5	0.100/0.012
Gender Female	728	77.3	379	50.8	605	83.1	0.042/0.001
Male	203	21.5	111	54.7	135	66.5	<u> </u>
Nonbinary	11	1.3	11	100.0	11	100.0	_
First language —French	542	57.5	299	55.2	453	83.6	0.001/0.001
English	389	41.3	193	49.6	298	76.6	
Others	11	1.2	0	0.0	0	0.0	
No religious beliefs	258	27.4	167	64.7	235	91.1	0.001/0.001
Catholic	504	53.5	258	51.2	392	77.8	
Upbringing—rural	259	27.5	157	60.6	169	65.3	0.001/0.001
Urban	490	52.0	256	52.2	434	88.6	<u> </u>
Mixed	193	20.5	79	40.9	148	76.7	
Education—high school	173	18.4	46	26.6	117	67.6	0.001/0.001
CEGEP	201	21.3	90	44.8	190	94.5	<u> </u>
Vocational studies	45	4.8	22	48.9	33	73.3	
Bachelor or higher	523	55.5	334	63.9	411	78.6	
Heard of face donation	561	59.5	379	66.0	516	92.0	0.001/0.001
Heard of hand donation	246	26.1	166	67.5	235	95.5	0.001/0.001
Personal history of face disfigurement	111	11.8	89	80.2	100	90.1	0.001/0.001
Personal history of hand amputation	67	7.1	34	50.7	67	100.0	0.001/0.001
Consider face transplant as aesthetic	190	20.2	77	40.5	134	70.5	0.001/0.001
Consider hand transplant as aesthetic	77	8.2	33	42.9	44	57.1	0.001/0.001
*D							

*Percentages are row percent. †Willing to donate face/hand.

The willingness of participants to donate their face decreased following exposure (52.2% pre-vignette to 38.1% post-vignette; P < 0.001), with little change in the willingness to donate their hands (79.7% pre-vignette to 78.6% post-vignette; P = 0.67).

on the pros, cons, and alternatives to CTA. Our findings were unexpected: attitudes were not altered in the way expected toward a more positive inclination to donate.

DISCUSSION

We aimed at determining how willing organ donors are to donate their face and/or hands, and whether attitudes are malleable after receiving balanced information



Mass media = Formal lecture = Scientific article = Other means
Fig. 1. Source of participants' prior knowledge about face donation.



Mass media Formal lecture Scientific article Other means
Fig. 2. Source of participants' prior knowledge about hand donation.

Table 3. Perceptions on Hand and Face Donation before and after Vignette Exposure*

Organ Donation						
Perceptions	ptions Pre-expose		ire† Post-exposure‡			
Personal history of FACE	111	11.8	55	5.8	0.001	
disfigurement						
Personal history of HAND	67	7.1	44	4.7	0.014	
amputation						
Consider FACE transplant	190	20.2	214	22.7	0.149	
as aesthetic procedure						
Consider HAND transplant	77	8.2	136	14.4	0.001	
as aesthetic procedure						
Willing to donate FACE	492	52.2	359	38.1	0.001	
Not sure	325	34.5	158	16.8	_	
1: I don't want to upset	257	27.3	169	17.9		
my family						
2: I don't want someone	214	22.7	126	13.4		
to look like me after I die						
3: I want my body to	46	4.9	57	6.1		
remain intact						
Willing to donate HANDS	751	79.7	740	78.6	0.672	
Not sure	91	9.7	67	7.1	_	
1: I don't want to	55	5.8	34	3.60		
upset my family						
2: I want my body to	23	2.4	12	1.3		
remain intact						
Major barriers to face/						
hand transplant						
Risks of long-term	350	37.2	374	39.7	0.270	
immunosuppression						
Absence of long-term	499	45.5	411	43.6	0.50	
data on transplant	140	1010		1010	0.00	
and survival						
Identity concerns	454	48.9	986	30.4	0.001	
Difficulty with future	206	91.9	152	16.1	0.001	
relationships	200	21.5	152	10.1	0.001	
Other reasons	67	71	83	88	0 197	
I don't know	156	16.6	66	5.8 7.0	0.001	
I UOII I KIIOW	150	10.0	00	7.0	0.001	

*Percentages are row percent.

†Prior to vignette exposure.

‡Following vignette exposure.



Fig. 3. Most commonly cited barriers to hand and face donation (postexposure).



Fig. 4. Most commonly cited reasons against face donation (postexposure).



Fig. 5. Most commonly cited reasons against hand donation (postexposure).

Assessing Attitudes and Beliefs around CTA Donation

An attitude involves three things: an object, a set of beliefs, and a tendency to behave toward the object.¹⁵ In this case, the attitude object is not physical, but rather an abstraction (CTA donation). The set of beliefs around the object can be good or bad (ie, having positive or negative beliefs around CTA donation), whereas the behavior toward the object is intended psychologically to keep or rid oneself of it (ie, people with favorable attitude toward CTA are more likely to donate).¹⁵ In this survey, we sought to nudge attitudes by increasing knowledge around CTA and personalizing the abstract concept, as few are likely to ever encounter someone with this particular transplant. Although most participants are willing to donate, our intervention did not have the expected results. Herein we explore these attitudes, as well as our vignette compared with another intervention that did positively influence attitudes.⁸

Participants Are Generally Willing to Donate Their Face and Hands after Death

In this survey, most organ donors were willing to donate their face (52.2%) and hands (79.7%) following death. Willingness to donate was associated with speaking French, observing no religious beliefs or practicing the Catholic faith, and having higher educational achievements. Our survey population is similar to that of other survey studies of organ donors.^{6,16,17}

Participants Endorsed Personal Identity and Family Concerns as Deterrents to Donation

Recognizing and addressing donors' desire to preserve body integrity is key to developing an intervention to increase willingness to donate. This could be addressed in future vignettes by emphasizing the use of personalized 3D face masks, and allowing families to hold open casket funerals.¹⁸

Specifically for face donation, the literature holds conflicting views regarding donor-recipient identity concerns. Our survey and others^{6,7} demonstrated that donors were fearful of CTA recipient looking like themselves; however, another group¹ concluded that this was not a deterrent to donation. More education is needed about the hybrid appearance between the donor (soft tissues) and the recipient (bony structure) resulting from face transplant.¹⁹

Enhancing Participants' Knowledge through Education

Generally, education on organ donation increases the public's expression of willingness and registration to donate.^{20–22} Moreover, positive attitudes towards and discussions about organ donation have been shown to be predictive of consent to donate.^{23–26} Exposure to our vignette had the expected impact on participants' perception of facial and hand deformity. Following viewing of the vignette, participants were less likely to report a personal experience with facial disfigurement or hand amputation. Their definitions of these concepts were seemingly recalibrated and clarified after seeing pictures of severely disfigured patients or amputees as candidates for transplant. The vignette provided an accurate understanding of recipients' background, transplant indications and risks, and alternatives to CTA.

Attitudes Also Moved in an Unexpected Way

Following exposure, participants were more likely to describe face (20.2% versus 22.7%, P = 0.15) and hand transplant (8.2% versus 14.4%, P < 0.001) as aesthetic procedures. Perhaps we did not define this clearly for participants: our intention was to determine if participants thought CTA was for purely aesthetic reasons rather than functional, not whether the transplant improved the appearance of the individual, which, we now expect, is how participants interpreted the question.

The decrease in willingness to donate one's face (from 52% to 38%) following vignette exposure was even more surprising. A prior study on American citizens reported an 18% increase in willingness to donate their face after death following an educational initiative (from an initial 52%).⁸

This prompted us to re-examine our vignette in light of its lack of expected direction of attitude polarity. It might have highlighted implications and risks of CTA that participants were not previously aware of, in addition to nonsurgical options like myoelectric prostheses²⁷ or sensor gloves²⁸ and alternate surgical options like the Krukenberg procedure.²⁹ These options, which have different indications, goals, and results, may be more acceptable than transplant to participants, downgrading the role and importance of CTA. Positive outcomes following transplant were highlighted and discussed in the extra videos. As those were not mandatory, it is possible that participants missed out on substantial learning about the positive effects of CTA on recipients' function and aesthetics.

Comparative Analysis with Previous Survey of Organ Donors

A similar survey⁸ was conducted in 2018 on 300 participants approached in a public park in NYC. It gathered participants' awareness of facial transplantation. It noted an 18% increase in willingness to donate facial tissue following an educational video. Although our study was developed independently, there were many similarities in survey design and questions between the two studies. Important demographic differences included surveying the general public versus registered organ donors, citizens from a single American city versus from multiple Canadian cities, and a mixed versus purely public health care system. Our study focused on both face and hand CTA, while the NYC study explored facial donation only. Despite these differences, the main discrepancy was the video intervention.

Donors Seen as Heroes

The NYC video presented photographs of two face transplant recipients before and after surgery, and photographs of donors. Their video emphasized the positive impacts of surgery: how recipients reintegrated into society and found love, friends, and an occupation. The donors were complimented on their generosity.

A More Balanced Approach

Our vignette had a different slant, describing barriers to transplantation, complications, and nonsurgical and surgical alternatives to transplantation, which might have biased participants away from donation. Our vignette lacked an emotional component and did not glorify donors, but the nonmandatory video links did carry an emotional component. Taken as a whole, the two approaches resulted in opposing willingness to donate.

Shared Decision-making at the Heart of Donation

The ability to change attitudes is sensitive to emotions,³⁰ and educational intervention's end result appears dependent on both the information conveyed and the emotional component attached to it. Indeed, we were not able to replicate the NYC findings with our balanced pros and cons approach, which may not be a negative thing. Sound decisions around donation that will be acceptable to the donor and the family come from the combination of understanding facts, balancing transplantation's pros and cons, and understanding alternatives, without promoting one over the other. This emphasizes shared decision-making,³¹ foundational to patient-centered care by maintaining the patient as leader in their care, even in the instance of donation after death.

Reflections on Future Educational Endeavors to Improve Donors' Understanding of CTA

The regression analysis informs us about the content of future educational initiatives. For instance, if participant demographics are not relevant, then interventions should not target nor recruit participants based on age, gender, religion, etc. If participants believe that a face transplant is just an aesthetic procedure, then educational interventions should focus on demonstrating how the quality of life of recipients is improved post-transplant, specifically functional improvements (speech, swallowing, and facial expression), psychological benefits from improved social interactions, reintegration, and well-being, not only post-transplant appearance.³² Similarly, with regard to hand donation, emphasis could be placed on published, objective outcomes of hand transplant, patient satisfaction, reduced disability, reasonable proprioception, and absence of phantom pain or dysesthesia.³³ Regarding survey design, using attitude scales and statements, like a Likert scale, instead of binary yes/no questions, might better assess nuances in the intensity of participants' attitudes.34,35

Limitations and Future Directions

We failed to anticipate the lack of impact on attitudes to CTA donation resulting from the vignette, and did not flesh out reasons why. As such, we were left to form hypotheses and to retrospectively analyze how our interventional instrument differed from others. A qualitative study would help determine ways donors envision how to positively encourage CTA donation amongst their peers. The end goals would be to encourage donors to consider CTA, to correct misconceptions about CTA, and to improve donors' acceptance of face and hand donation.

CONCLUSIONS

This is the first population survey of Canadian organ donors on attitudes toward CTA. This survey demonstrated that survey participants were willing to donate their face and hands following death to help someone in need. An informative vignette enhanced participants' knowledge on the topic of CTA, but missed the mark in terms of increasing willingness to donate. Further qualitative work is required to better understand the educational needs and the areas to address to increase donors' acceptance of CTA. Claire Temple-Oberle, MD, MSc, FRCSC

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