Temple University
College of Public Health

Vascularized Composite Allotransplantation: Knowledge and Attitudes in Three Populations

National Academies of Sciences, Engineering and Medicine
Committee on Principles and Framework to Guide the Development of Protocols and Standard Operating Procedures for Face and Hand Transplants

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Population 1: Donation Professionals

- **Specific Aim 1:** Explore the knowledge, attitudes and acceptability of VCA among donation professionals and the general public
- Semi-structured interviews with 157 DPs from 39 organ procurement organizations
- 59 open- and closed-ended questions exploring experience, knowledge, comfort, confidence and preparation from VCA donation discussions

Characteristic	N (%)
Mean Age	41 y (SD 4.8y)
Sex	
Female	114 (74.0%)
Ethnicity	
Not Hispanic/Latino	133 (86.4%)
Race	
Black/African American	18 (11.7%)
White/Caucasian	119 (77.3%)
Other	17 (11.0%)
Education	
High school	2 (1.3%)
Some college	15 (9.7%)
Bachelor's degree or higher	137 (89.0%)

Siminoff LA, Alolod GP, Davis EE, Sarwer DB, Gardiner HM. Vascularized composite allotransplantation: Knowledge and attitudes of a national sample of organ procurement organization professionals. Clin Transplant. 2020;34:e14071.

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Population 1: Donation Professionals

Number of VCA Donation Approaches	%
1	23.9
2-5	45.7
6-10	15.2
10+	15.2
N = 46 (29.9%)	

Type of VCA Discussed	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)

Self Reported Preparation	Mean (SD)
Prior VCA Requests* (Range: 1-10)	
No (n=108)	3.3 (2.1)
Yes (n=46)	6.4 (2.5)
Prior VCA Training*	
No (n=103)	3.4 (2.2)
Yes (n=51)	5.9 (2.7)
*N = 154; *P<.0001*	

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Population 1: Donation Professionals

	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)
N=154; Mean (SD); Range for all scales 0-10.						

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Population 2: General Public

- **6 Focus Group Interviews**
  - 53 members of general public (of 208 expressing interest in participation)
  - 7-12 participants per group
  - Respondents completed brief self-administered survey before beginning the group discussion
  - Each focus group lasted from 78 to 110 minutes
  - Group discussions were digitally recorded, transcribed, and uploaded to MAXQDA for qualitative analysis

Characteristic	N (%)
Mean Age (years)	41
Sex	
Female	42 (79.2%)
Ethnicity	
Not Hispanic/Latino	88 (77.4%)
Race	
Black/African American	16 (11.3%)
White/Caucasian	21 (39.6%)
Other	16 (30.2%)
Education	
High school or less	11 (21.0%)
Some college	14 (26.4%)
Bachelor's degree or higher	28 (52.8%)

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Population 2: General Public

- **Analyses revealed six themes:**
  - Strong initial reactions to VCAs
  - Limited knowledge of and reservations about VCAs
  - Risk versus reward in receipt of VCA
  - Information needed to authorize VCA donation
  - Attitudes toward donation
  - Mistrust of the organ donation system

Disposition Toward Donation	N (%)
Registered Organ, Tissue and Eye Donor	
Yes	30 (56.6)
Willing to Donate Own Organs	
Yes	35 (66.0)
Willing to Donate Family Members' Organs	
Yes	22 (41.5)
If I Knew Their Wishes	27 (50.9)
Willing to Join a VCA Donor Registry	
Yes	26 (49.0)

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Population 3: Veterans

- **Specific Aim 1:** Explore the knowledge, attitudes, and interest in VCA among veterans through semi-structured interviews with 60 veterans identified as potential candidates for a VCA of the hand or face
- Sample drawn from DoD Joint Trauma Registry (ICD-9/10)
- Reviewed nearly 4,600 medical records from 2000-2019
- Identified 247 patients with injuries to hand or face
- Semi-structured interviews held with 62 veterans
  - Current health status, treatments and therapies received
  - Impact of injuries on daily life, coping and support
  - Prior knowledge, interest in and comfort with VCA

Characteristic	N (%)	
Sex		
Male	61	(98%)
Ethnicity		
Hispanic	14	(22.6%)
Race		
White	48	(77.4%)
Black	6	(9.7%)
Other	8	(12.9%)
Education		
High school or less	11	(17.7%)
Some college	19	(30.7%)
Bachelor's degree	18	(29.0%)
Graduate degree	14	(22.6%)

Population 3: Veterans

Years Since Injury	N	(%)
More than 20 years	1	(1.6%)
15-19 years	33	(53.2%)
10-14 years	24	(38.7%)
5-9 years	3	(4.8%)
0-4 years	1	(1.6%)

Potential VCA Graft Site	N	(%)
Hand/Upper Extremity	51	(82%)
Face	7	(11%)
Both Hand/UE and Face	4	(6%)

Interest in VCA	N	(%)
Not interested	40	(64.5)
Interested or would consider	20	(32.3%)
Received a VCA	1	(1.6%)
Unknown	1	(1.6%)

Population 3: Veterans

Reasons for Interest in VCA	N
Potential functional benefits	10
Becoming more independent	2
Cosmetic appearance	2
Helping to advance the science/access to the treatment	2

Reasons for Disinterest in VCA	N
Concerns about immunosuppressants	24
Satisfaction with current condition	9
Limited function or benefits of transplant	8
Transplant rejection/failure	7

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Population 3: Veterans

Prior Knowledge of VCA	N	(%)
Some prior knowledge	39	(62.9%)
No prior knowledge	21	(33.9%)
Received a VCA	1	(1.6%)
Unknown	1	(1.6%)

Comfort Receiving VCA	N	(%)
Not at all comfortable	21	(33.9%)
Somewhat uncomfortable	11	(17.7%)
Neutral	8	(12.9%)
Somewhat comfortable	8	(12.9)
Very comfortable	11	(17.7%)
No response	3	(4.8%)

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Shared Decision-Making in VCA

- **Specific Aim 2:** Develop a proposal for a shared decision-making process that is inclusive of patients, their family caregivers and health care through an expert panel of clinicians who regularly provide care for veterans with catastrophic injuries, including surgeons, primary care physicians, psychologists, nurses, and social workers
- Modified e-Delphi Study (9 clinicians)
- Focus group with veterans (3) and caregivers (2)
- One-on-one interview with one veteran who had received a VCA

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Shared Decision-Making Definition

Shared decision making in VCA begins when patients present with interest in considering candidacy for VCA and includes the decisions to undergo the selection process inclusive of the medical testing needed to ascertain eligibility and, if deemed eligible, to pursue VCA as well as to follow the recommendations and management needed to care for and maintain the VCA for as long as the patient has the VCA.

Shared decision making combines the inherent responsibility of the clinical team to provide patients with the best possible outcome and the right of patients to define what best possible outcome means AND for the clinical team to understand patients' health-related values and goals. Underpinning this process is the bidirectional transfer of information needed for patients to understand required tests and the evaluations required to determine candidacy for VCA. This encompasses expected risks, rewards, lifestyle trade-offs needed to proceed with candidacy for VCA and future changes to maintain the VCA. Patients must also agree to the expected timeline and deal with potentially lethal and non-lethal complications post-transplant.

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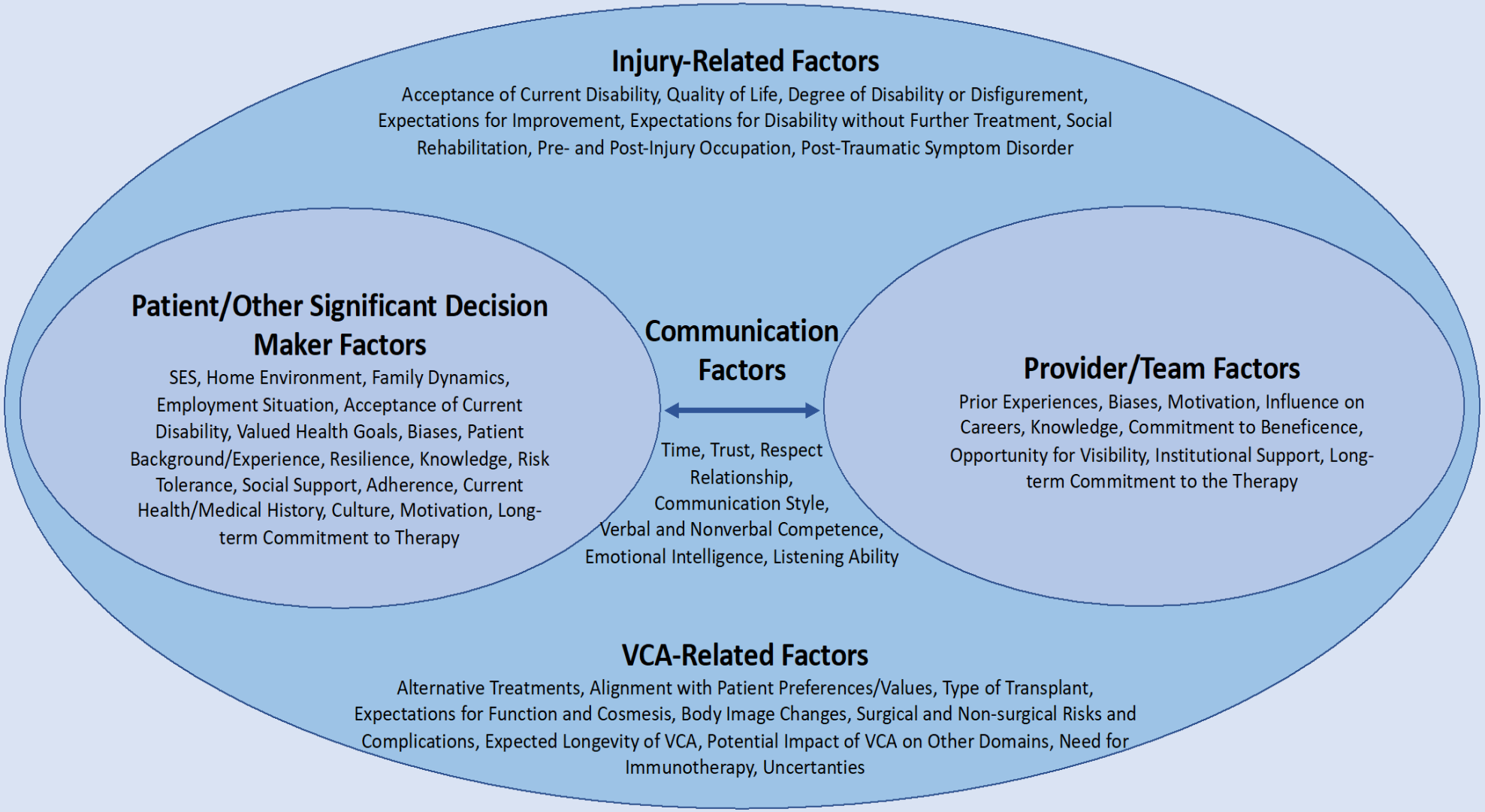
Shared Decision-Making Model



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