

THE ROLE OF COMMUNICATION DYNAMICS IN ORGAN PROCUREMENT, ALLOCATION, AND DISTRIBUTION

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Predictors of Donor registration*

Total Sample n=1595

■ Race (White)	2.78
■ Age	.98
■ Education	1.29
■ Income	1.26
■ Attitudes (positive)	1.18
■ Trust in healthcare system	1.10

*All factors are significant in the logistic regression model

Authorization by Race and Patient Donor Designation



	Donated N (%)	Refused N (%)	Chisq, p
Black Not Designated	848 (47.3)	945 (52.7)	102.7, .0011
White Not Designated	2300 (61.7)	1427 (38.3)	
Black Designated	232 (87.6)	33 (12.4)	.0017, .96
White Designated	1354 (87.6)	191 (12.4)	

Two Studies

- Exploration of Asian American beliefs, knowledge and willingness to donate
- Outcomes of donation discussions with families of Blacks Americans asked to donate organs of a family member in hospital

Asian American National Survey

Demographics



- Representative sample of **917** Asian American participants
- Female **55.0%**
- Mean age **41 years**
- Over half of the sample has a Bachelor's degree or higher **51.3%**
- Participants had an annual household income of \$40,000 or higher **73.5%**
- Western religion **43.6%**
- About half of the sample were born in the U.S. **50.3%**

Major Findings



- Donation preferences
 - *Over half (58.8%) of participants expressed willingness to donate organs upon death*
 -
- Significant differences in organ donation willingness and knowledge between those born or raised in the U.S. vs. those not born or raised in the U.S.
- Older individuals had far lower exposure to organ donation than younger people

Major Findings

- Family role in decision making about organ donation
 - *Only 6.7% of respondents said they believed that they should make a decision to register or donate on their own.*
- Mistrust of the healthcare and donation systems
 - *Belief in black market (score: 51/10)*
- Religious and cultural beliefs
 - *Concern that their religion would not allow organ donation (score: 35/100)*
 - *Death as a taboo topic makes discussion organ donation difficult (Score: 42/100)*

Need for Directed Public Communication

- Public messaging specifically directed to the Asian American community to bring them into the national conversation about organ donation.
 - Acknowledge group decision making rather than individual decision making
 - Provide opportunities for older family members to learn about donation
 - Facilitate communication about a topic that is tied to death

Interpersonal Communication is a Key Component of Successful Organ Donation

- Every year thousands of potential donors are lost due to poor communication about the option to donate.
- Studies have demonstrated over the past 25 years the importance of effective communication with patient family decision makers when discussion of organ donation option
- Years of research has demonstrated that effective inter-personal communication between the OPO staff who discuss donation families is a significant factor in authorization

What does the data say?

- Overall predictors of consent to donate
 - *Importance of the initial discussion about donation*
 - *Development of rapport with family*
 - *Discuss donation-related issues that are of concern to families*
 - Funeral
 - Costs
 - Donation equity (will people who look like me get a chance at a transplant?)
 - Treatment of the deceased's body
 - Timeframe for the recovery of organs
 - Need in their community
 - *Amount of time spent discussing donation*
- Overall predictors of refusal to donate:
 - *Communication rated by families as uncaring*
 - *Family surprised by request for donation*
 - *Family felt harassed or pressured about donation decision*
 - *Family believes that the patient cannot donate (age, co-morbidities)*

Comparison of Communication Experiences of Black Families Who Donate and Those Who Did Not Donate (n=276)

Analyses compared the in-hospital donation experiences of Black families who donated and those who did not

- No differences in sociodemographic (age, education, gender, income, marital status)
- No differences in cause of death
- No differences in general attitudes and beliefs about organ donation

Ratings of Black Family Communication and Experiences (n=276)

	Refused M (sd)	Authorized M (sd)	<i>T-test</i> (p value)
Relational communication scale	62.3 (15.1)	75.5 (8.24)	88.3 (0.0001)
Overall communication quality with OPO DP	3.38 (1.43)	4.45 (0.82)	62.4 (0.0001)
Satisfaction with time spent discussing donation	5.32 (2.1)	6.49 (0.91)	41.3 (0.0001)
Satisfaction with request process	4.62 (2.37)	6.5 (1.1)	78.3 (0.0001)
Felt pressured or harassed at the hospital about organ donation	3.1 (2.4)	1.75 (1.7)	28.6 (0.0001)
OPO DP rated as effective communication skills	95.6 (15.4)	105.8 (9.3)	2.8 (0.0001)
Number of donation-related topics discussed	5.5 (4.1)	11.5 (3.8)	142.6 (0.0001)

Logistic Regression Examining Decision to Decline Authorization (n=276)



Variable	Odds ratio (95% CL)
Donation helps families grieve	0.89 (0.70-1.1)
Relational communication (RCS)	0.95 (0.90-.98)*
Quality of communication	1.3 (0.72-2.2)*
Satisfaction with time spent	0.93 (0.68-1.3)
Satisfaction with how requestor answered questions	0.96 (0.52-1.5)
Satisfaction with request process	0.75 (0.53-1.1)
Initial reaction to donation	0.17 (0.08-.43)**
Pressured or harassed	0.92 (0.73-1.2)
Requester communication skills	1.0 (0.96-1.1)
Topics discussed	0.76 (0.69-.83)**
FDM assessment of how caring and concerned the primary hospital (HCP was)	0.96 (0.74-1.2)
FDM spoke with hospital staff about organ donation	0.80 (0.38-1.7)

*p<.05; **p<.001



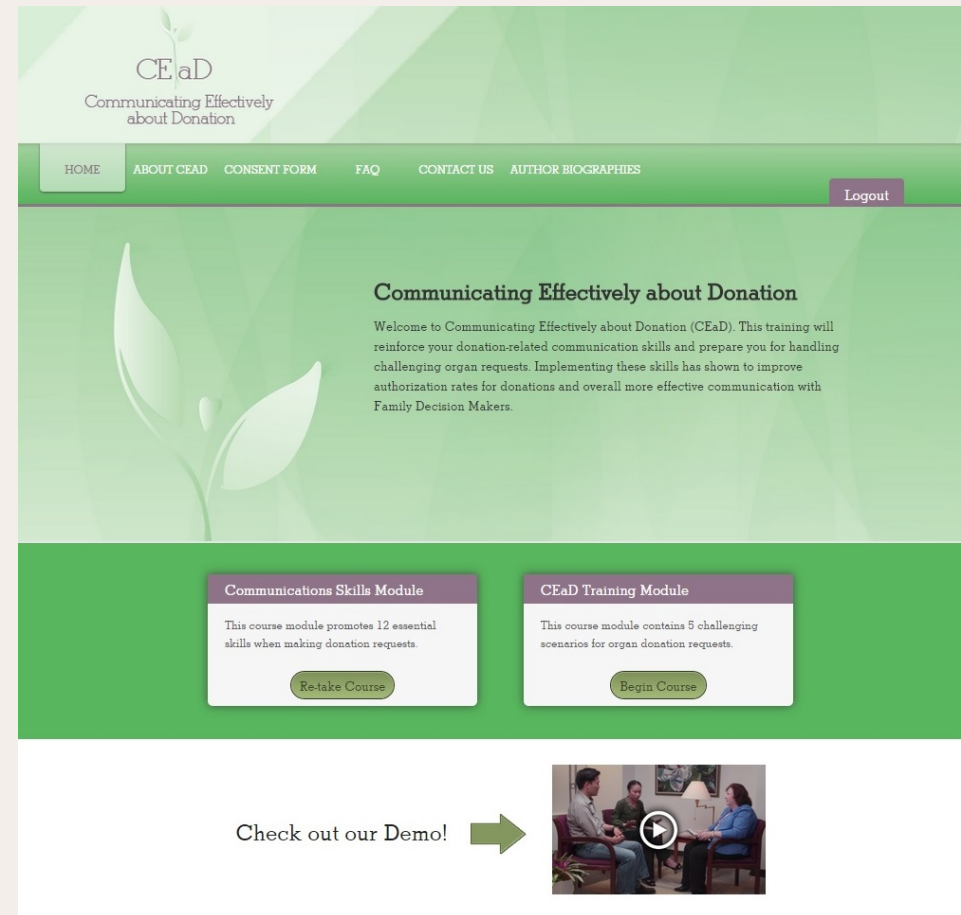
Communicating Effectively about Donation

• helping families make informed choices •

**an evidence-based program to
improve authorization request
outcomes**

CEaD Training Website

- On-line training available at the OPO DPs' schedule
- Two training modules
 - **Basic Communication Skills**, including framing donation positively, using statistics to explain donation benefits, engaging the family in a discussion of their values, probing and responding to fears or misinformation about donation, and attending to a family's emotional needs.
 - **CEaD Simulation Training**



CEaD Simulation Training Modules



- Pediatric case with divorced parent
 - *Gatekeeper healthcare provider*
 - *Re-approach*
- First-person authorization
 - *Wife is next of kin and combative with in-laws*
- Culturally opposed decision makers
 - *1st generation Asian Americans*
- Spanish speaking family
 - *Use of translator*
- Decision maker in denial
 - *OPO staff employs help of chaplain*
 - *Has to explain patient's condition*

CEaD Effectiveness



In two national studies of the CEaD training we found:

- Quality of communication improved
- Discussions about critical topics such as the timeframe for the donation decision, impact on funeral arrangements, increased.
- OPO staff reported more comfort when responding to family donation-related questions
- Post-training, families rated the OPO staff they interacted with as more....
 - *sincere*
 - *willing to listen*
 - *calm and poised*
 - *relaxed when talking to families*
 - *empathetic and supportive*

Limitations

- The two national tests of the CEaD demonstrated that it could effectively improve communication skills and authorization.
- The CEaD increased reported FDM satisfaction and assessment of the interpersonal communication skills with all families regardless of race or ethnicity
- Organ donation authorization increased only for white families but not for Black families

Conclusions

- Many minoritized communities are not included in our national conversation about organ donation
- Public/mass communication directed toward communities, such as Asian Americans, are needed to even start the conversation
- Rather than assume that minoritized communities do not want to donate, we need to consider that we have failed to engage with them in meaningful ways
- Still large gaps in performance between individual staff and OPOs
- OPO staff need quality communication training and refreshers on a regular basis: whether this happens varies greatly from OPO to OPO.
- More research is needed to understand how to tailor communication and messaging to diverse populations.
- Diversity in the OPO workforce is vital, but currently that workforce is overwhelmingly white and female
- We have lots of work to do

Disclosure Statement

I do not have an affiliation (financial or otherwise) with a commercial entity and, therefore, have no conflict of interest to disclose.