

Determinants of Consent to Organ Donation

Laura A. Siminoff, Ph.D.
Case Western Reserve University

Funded in part by the Division of Transplantation, HRSA (Grant #OTO1126) and the
Agency for Health Care Policy and Research (grant #R01-HS08209)

Overview

- n **Two basic components for obtaining consent**
 - **Need to know that there is a potential donor (timely referral)**
 - **Need to obtain consent (effective communication)**

Timely Referral

n Why is this important?

First Component: Timely Referral

- n Can't ask families to donate if no one has identified the patient as a potential donor and if the OPO not notified
- n Referrals not useful unless they are 'timely'

What is timely referral?

- n Referrals are classified as **timely** if any of the following are true:
 - n The patient is ready to or is undergoing brain death assessment
 - n A decision has been made to initiate discussion of end of life issues with the family
 - n The family is indicating that they wish to discuss end of life issues or organ donation

What is timely referral?

- n Referrals are **not** timely if any of the following are true:
 - n The patient is already dead by cardio-pulmonary or brain death criteria when the OPO is called
 - n The family has already been asked by hospital staff and a decision about donation has been made prior to referral to the OPO
 - n A decision to make the patient DNR is made prior to the request
 - n The family has left the hospital without meeting an OPO requester

Early Referral Study

Methods

- n OPO record reviews

- n Call records

- n Hospital record reviews

- n OPO requester surveys

- n Self-administered surveys completed by OPO staff after each family contact

Early Referral Study

Sample

- n 831 cases called into OPO (18 month period)
- n 461 (55.5%) appropriate for further OPO evaluation and follow-up
 - n 52.4% Male
 - n 76.0% White
 - n 30.6% trauma-related injuries
 - n Mean length of stay: 2.53 days (median, 1 day)

Early Referral Study

- n 74% of eligible cases seen by OPO for evaluation
- n 60% of referrals were timely
- n 36% of referrals made after patient made DNR, already removed from mechanical supports, or declared dead
- n Of 40 hospitals reporting deaths, time sensitive referrals ranged from 9% - 70%
- n Overall donation rate of 56%

Early Referral Study

- n Most common reasons for not obtaining consent from families for donation
 - n 54% Decision to withdraw support by families
 - n 33% Family belief that patient did not wish to donate
- n Approximately 184 donors lost due to late referrals over an 18 month period

Second Component: Effective Communication

Communication with families about the option to donate in a way that provides them with sufficient information to make an informed decision within an environment that maximizes their ability to consider the request. Requests must be persuasive but not coercive.

Second Component: Effective Communication

- n **Communication is effective if it:**
 - n **Is cognizant of families' different sociodemographic traits, personalities and the emotional climate in which the exchange takes place**
 - n **Builds rapport, reduces uncertainty, and exchanges information using active listening skills**
 - n **Engages families in a discussion of key donation-related issues**
 - n **Presents statistical and refutational information to counteract donation myths and advocates for donation**

Effective Communication

n Why is this is important?

Comprehensive study of organ donation requests*

- n Used a large sample size and a triangulated data collection strategy consisting of medical record reviews, health care provider and OPO staff interviews, family decision maker interviews to examine the organ donation request process.

- n *Siminoff, et al 1999; 2001; 2002; 2003

Study Methodology

Sites:

§ Nine trauma hospitals including two pediatric hospitals, located in Southwest Pennsylvania and Northeast Ohio

Deaths reviewed	11,560
Number of potential solid organ donors	741
Requests for organ donation	596
Consent to donation	283 (47.5%)

Study Sample

Requester interviews	1,285
Response rate	92%

Requester Type

Physician

241 (45.8)

Nurse

205 (39.0)

Social Worker/Clergy

49 (9.3)

OPO

31 (5.9)

Family interviews (cases)	420
---------------------------	-----

Family response rate	74%
----------------------	-----

List of Variables Constituting Factors Used in the Multivariate Analyses

Factor 1: Pre-Request Variables defined as characteristics of the patient, family, HCPs or health care setting that existed prior to the donation request

Family/patient sociodemographic and medical care

Patient age

Family's ethnicity

Insurance

Cause of death

Termination of mechanical supports

Family attitudes and beliefs about organ donation (OD)

Family attitude scale

Family member willing to be a donor

Religion encourages organ donation

Family's questions about organ donation

Family's' prior knowledge about patients' wishes regarding donation

Family had enough information about patient's wishes

Knew if patient had donor card or thought patient wanted to donate

List of Variables Constituting Factors Used in the Multivariate Analyses

Factor 2: Family understanding of Brain Death

Rating of Family's overall understanding of BD
Family understanding of when moment of death

Factor 3: Socioemotional and communication process variables

Family felt harassed or pressured to make decision
Family perceived at least one HCP not caring or concerned
Family surprised to be asked about donation
HCPS reported family's initial reaction to donation request to be same as family's self-report (congruence)

Factor 4: Who raised issue of donation and spoke to family

First HCP/OPO to ask about donation is the same person family identifies as most important to them in process
Family raises issue of donation themselves
Optimal request pattern

List of Variables Constituting Factors Used in the Multivariate Analyses

Factor 5: OPO request-related variables

Met with OPO staff

Amount of Time spent with OPO

Factor 6: Topics discussed with family

HCP told family required to ask

HCP told family donation helps others

Discussed costs of donation

Discussed impact of donation on funeral and disfigurement

Discussed that family had a choice as to what to donate

Answered family questions about donation

Total number of topics discussed with family

Number of issues of concern to family

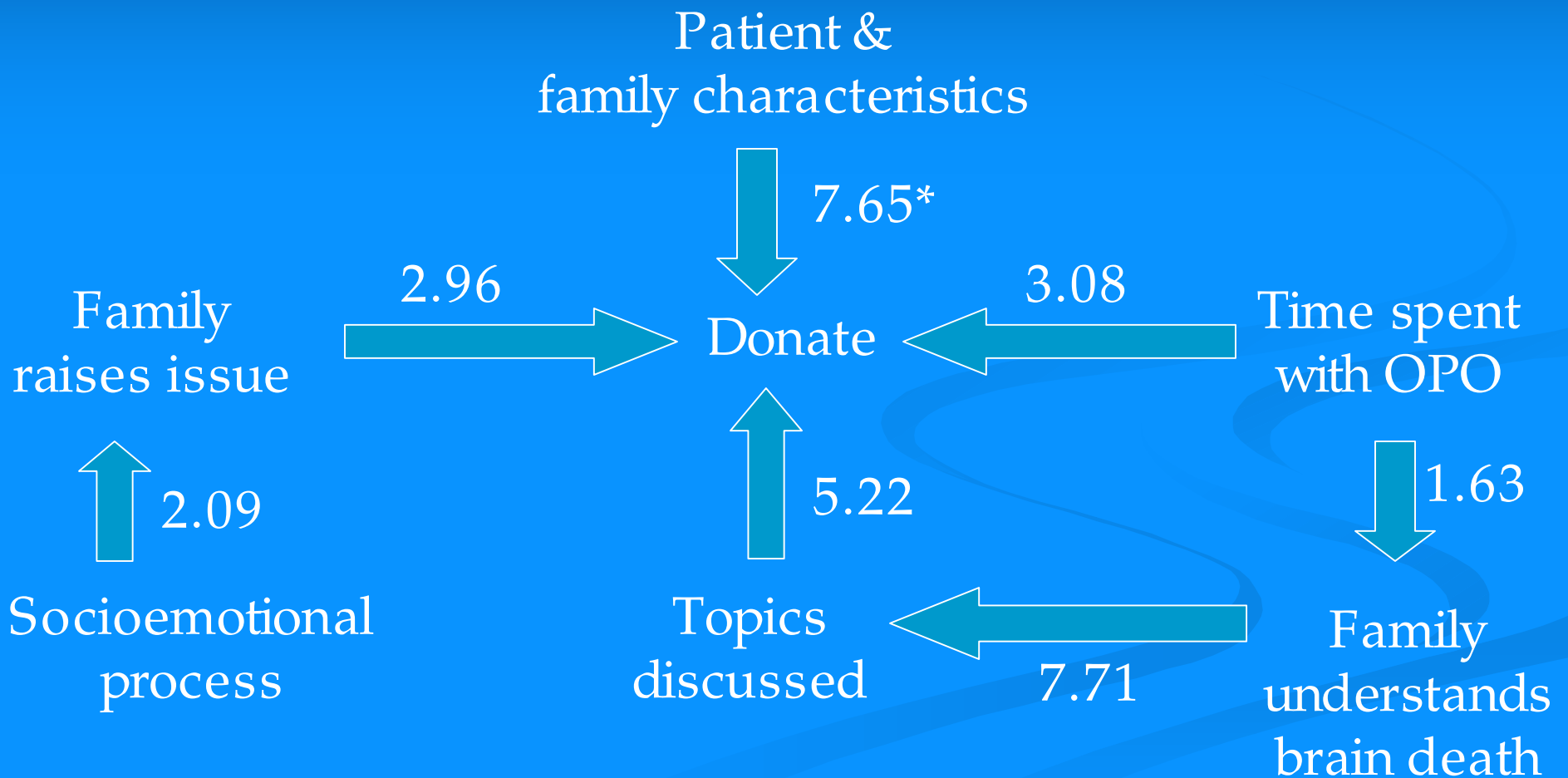
Number of discussions about organ donation

Factor 7: Timing of donation request

Was OD mentioned during BD testing

Was OD mentioned before, after, or concurrent with the declaration of death

Loglinear Regression Model of Organ Donation Request Process



* Adjusted OR is the odds ratio after controlling for other factors in the model

Reasons* Cited by Families for Choosing Organ Donation (n=239)

Altruism	78%
Knew patient wanted to donate	75%
Family generally pro-donation	62%
Donation helped family cope with loss	32%
Patient dead and therefore does not need organs	22%

*All families had > 1 reason for their decision

Reasons* Cited by Families for Choosing Not to Donate Organs (n=181)

Thought patient did not want to donate	51%
Family stamina	44%
Disfigurement concerns	43%
Mistrustful of healthcare system	25 %
Family made their own (incorrect) assessment that patient ineligible to donate	19%
Family disagreement	14%
Did not want to wait for declaration of brain death	12%

*All families had > 1 reason for their decision

Why African Americans do not Donate as Frequently as the Majority Population

n Lack of knowledge about the need for organs in the African American community

- ↳ Heard about need for AA donors 33%
- ↳ Requester at hospital mentioned need 3%

§ Negative attitudes and mistrust of healthcare system

- ↳ Overall score on donation attitude scale: No significant difference between White families and AA families
- ↳ AA families more mistrustful of the healthcare system in general and the equity and fairness of the organ donation and allocation system
- ↳ AA families more likely to want donor families to receive money to help defer costs of donor patient funeral expenses

Why African Americans do not Donate as Frequently as the Majority Population

- n The experiences of African American families differ from those of white families
 - n AA families receive less information about the condition of the patient (3.5 discussion items vs 5.4 items, $p < .001$)
 - n AA families receive less information organ donation (4.5 discussion items vs 7.1 items, $p < .001$)
 - n AA families less likely to speak with OPO staff (50.8% vs 66.1%, $p = .02$)
 - n AA families who do meet with OPO staff spend, on average, less time with the OPO requester (≤ 15 minutes vs 60 minutes, $p = .02$)
 - n AA families more likely to report feeling harassed or pressured to make a decision (24.6% vs 7.6%, $p = .01$)

Why African Americans do not Donate as Frequently as the Majority Population

- n The experiences of African American families differ from those of white families
 - n African American families report being more likely to want to speak with someone of the same race or ethnicity about organ donation than white families
 - n Only 5% African American families had the opportunity to meet with an African American requester

Why African Americans do not Donate as Frequently as the Majority Population

- n The experiences of African American families differ from those of white families
 - n Hospital staff correctly identified white families as favorable toward donation more frequently than AA families (66% vs 55%, $p=.01$)
 - n Hospital staff misclassified African American families as unfavorable toward donation more frequently than white families (24% vs 8%, $p=.01$)

Conclusions

- n Early referral and a generally supportive environment in which to discuss organ donation with the family are crucial.
- n There are specific techniques that make communication with families about organ donation more effective and requesters should be trained in these techniques.

Conclusions

n The donation requester must be an advocate for organ donation. Positive messages and endorsement of organ donation, use of statistics to support the need for donation, and information that refutes the most common myths about donation must be conveyed to the family.

n Increased time with OPO staff is strongly associated with increased consent rates. Building a relationship is critical.

Conclusions

- n Families need to be actively engaged in discussions about organ donation. Requesters should discuss disfigurement, funeral arrangements and that donation will not cost the family anything. Requesters need to anticipate and actively listen to the families concerns.
- n Discuss what the patient wanted. If the family is unsure, discuss the patient's values and how organ donation can fulfill those values. Note how few people can actually donate on death and that most Americans support organ donation.
- n Approach all families as if they want to donate, no matter their religion, race or ethnicity.