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Medical Decision Making

Predictors of consent in tissue donation: Interpersonal aspects and information provision during requests by phone

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ABSTRACT

Objective: To examine whether interpersonal behavior and provision of key information by tissue requesters (TRs) during phone requests for tissue donation with initially undecided next-of-kin (NOK) predict consent/refusal to donate.

Methods: The sample consisted of 102 TR–NOK dyads in which NOK reported that they were initially undecided about their intentions to donate their loved ones' tissue. Audiorecordings of requests, gathered from a national sample of tissue banks, were coded to assess for interpersonal behavior of each interactant. The effects of TR and NOK interpersonal behavior as well as information provision by the TR on consent/refusal were examined.

Results: Expressions of disapproval by the TR strongly predicted NOK donation decision. Predictors of consent included fewer questions asked and more supportive statements made by the TR, as well as reassurance from the TR that donation would not lead to disfigurement or affect the appearance of the body.

Conclusion: Aspects of the communication process between TR and NOK during requests for tissue donation significantly predict consent to donate among initially undecided NOK.

Practice implications: TR trainings aimed at improving interpersonal skills and provision of key information could potentially increase tissue donation consent rates.

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1. Introduction

The need for donated organs suitable for transplantation is well documented [1–3]. The majority of the population supports the idea of organ donation [2,4–6], although the level of public support for tissue donation alone in situations in which organ donation is not an option is uncertain. The lack of research on and public awareness of tissue donation is unfortunate because the number of retrieved tissues has historically fallen short of estimated needs [7–9] and more individuals are likely to be asked to consider this request.

In most states first-person consent laws assure that individuals who indicate their desire to be a donor either on their driver's license or other formal documentation do indeed become donors if eligible. However, the majority of the population has not signed such documentation (particularly documentation specifically addressing tissue donation) and therefore next-of-kin often are left to make decisions about donation. Next-of-kin who are unaware of their loved ones' wishes are particularly likely to be influenced in their decision making by the information provided and their communication with the requester during the donation request. The purpose of the present study is to evaluate how the information presented during the tissue donation request process and the nature of the interaction between the tissue requester (TR) and next-of-kin (NOK) affect the donation decision among NOK who were initially undecided about their intentions to donate.

Few prior studies have directly examined the tissue donation request process. Two studies [10,11] used the Siminoff Communication Content and Affect Program (SCCAP) [12] to code audiotaped interactions between TRs and NOK. They found that development of a meaningful personal interaction and effective information provision by requesters reduce barriers to consent. NOK who consented to donation reported that TRs were more caring and concerned and had stronger communication skills. NOK were also more likely to consent if TRs discussed key topics such as costs associated with donation and lack of impact of donation on ability to have an open casket funeral, and when TRs used more

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confirmational messages, such as providing reassurance or expressing empathy. Similarly, a study by Rodrigue et al. [13] using post-request interview data reported that individuals who consented to donation were more likely to report that requesters presented information clearly, were caring, and did not pressure NOK to consent to donation. However, these studies did not differentiate between NOK who entered into conversations with TRs with a predetermined preference about donation (and whose interactions may therefore have been partially influenced by their preexisting feelings about donation) and those who had no prior preference, or were unaware of the deceased's preferences about donation.

This study focuses on a selective subsample of TR–NOK dyads in which the NOK were clearly undecided about his or her donation decision prior to the conversation, and therefore in which the information presented and the rapport between TR and NOK likely had a greater impact on that decision. In contrast to previous research, which with only two exceptions [10,11] have involved post hoc surveys or interviews [13–17], the present study examined both TR and NOK behavior during the request process and their relationship to the NOK's decision to consent or refuse to donate. Based on past studies of organ and tissue donation using post hoc surveys and interviews [2,15,18], we hypothesized that NOK would be more likely to consent to donation when TRs expressed more positive and less negative affect, when TRs used more persuasive statements, and when TRs provided clarifying information related to common misconceptions (e.g., that donation will not affect funeral arrangements or result in significant disfigurement of the body). Further, we draw on the literature of patient-centered communication and decision making processes, which have demonstrated in examinations of doctor–patient interactions that the interpersonal behavior of one interactant influences the behavior of the other [19,20] and that provider behaviors can facilitate patient participation in the interaction and decision making process [21,22], to further hypothesize about the impact of interpersonal behavior and TR framing of the decision making process on donation decisions. More specifically, we also hypothesized that NOK would be more likely to consent to donation when both NOK and TRs asked more questions (indicating mutual interest and participation in the interaction), when TRs used more supportive statements and statements aimed at forming a partnership with NOK, and when TRs engaged in a shared decision making process with NOK.

2. Method

2.1. Participants

Participants were 102 next-of-kin and tissue requester dyads drawn from a larger dataset of 1016 audiofiles of requests for tissue donation. In order to obtain a sample of undecided NOK, cases were included only when: (1) the deceased had not previously signed legal documentation indicating their preferences regarding donation and (2) NOK, in post-request interviews, reported initial indecision about donation. Cases were excluded if the patient was under 18 years of age because NOK were significantly less likely to consent to donation when the deceased was a minor (15.9%, compared to the overall consent rate of 70.2%). Finally, for the purposes of analyses, cases were excluded if more than one NOK or TR participated in the decision making process, if the donation decision was unclear, or if conversations lasted fewer than 2 min. After implementing these exclusion criteria, 102 cases remained. The maximum number of conversations conducted by a tissue requester in this sample was 7, although most conducted only one request (mean = 1.92, SD = 1.47). TRs were staff working at one of sixteen tissue banks sampled across the United States as part of the larger study whose duties included contacting NOK about donating tissues of recently deceased (typically within 24 h of death) individuals [10,11].

2.2. Measures

Impact Message Inventory (IMI). The IMI [23] characterizes interpersonal behavior by measuring the covert reactions people evoke from each other. A 28-item observer rating version of the IMI used previously in a simulated organ donation study [24] is used in the present study. While listening to the recorded transactions, coders are asked to complete the IMI as if they were the NOK (responding to the TR). The IMI produces four raw scores: dominance, hostility, submissiveness, and friendliness; and two axis scores: control and affiliation. The current study utilizes the summary score of affiliation (friendliness–hostility) as the focus of our IMI data analyses. Construct validity evidence for the scale is presented by Kiesler and Schmidt [25]. Inter-rater reliability in the present study for raters acting as the NOK and assessing the interpersonal behavior of the TR: Kappa = 0.677, $p < 0.001$.

The Participatory Style of Physician Scale (PSPS). The PSPS consists of 15 items that represent the essential components emphasized in models of shared decision making [26] and informed decision making [27]. It comprised three subscales and assesses the participatory style and behaviors of physicians during consultations with patients [28]. Using an observer version of this scale previously adapted for use with organ procurement coordinators and family members [24], raters assess both the requester's and next-of-kin's participatory style. The three subscales are: (1) providing medical information, such as risks and benefits of treatments, (2) gathering personal information, such as asking about next-of-kin concerns, and (3) facilitating shared decision making. The current study utilized only the latter two subscales. Inter-rater reliability obtained for the PSPS in the present study was good overall (Kappa = 0.642, $p < 0.001$), as well as for subscales (gathering NOK information, $r = 0.830$, $p < 0.001$; engaging in shared decision making, $r = 0.856$, $p < 0.001$).

Patient Participation in Medical Encounters. This method of analysis, developed by Street and Millay [21] serves as an observational coding system to examine interactions in medical settings. In the current study it is used to assess how TRs respond to and/or facilitate NOK participation in the discussion and engagement in decision-making. Raters code for two target categories of TR utterances, partnership building and supportive talk. Two coders rated TR behavior for each interaction. Coder reliabilities measured by intraclass correlations were 0.72 and 0.73, respectively.

Siminoff Communication Content and Affect Program (SCCAP). The SCAAP is a coding system based on models of relational communication theory that assesses topics discussed and interpersonal characteristics as observed in medical encounters [12]. The SCCAP measures both content themes, or the content and sequence of information exchanged, and communication types, or the relational aspects of communication. Content themes and communication types are coded to record what is said during the interaction, as well as how it is said. Coders also indicate whether or not next-of-kin consented to donation. Inter-rater reliability is high, with a previous assessment analyzing inter-reliability of donation requests ranging from 0.82 to 0.99 [12]. In the present study content themes of interest were discussion of how donation will not affect funeral arrangements, that NOK can choose which eligible tissues to donate, how tissues will be distributed, that donation will not result in body disfigurement, that donation would not affect ability to have an open casket funeral, and that donation will not result in an additional cost to the family. Communication types of interest included TR disapproval (e.g., responding to the other in an unreceptive, unfriendly, or critical