

University of Iowa Study: Emotional Aspects of Organ Donation Need Attention

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IOWA CITY, Iowa, Feb. 10 (AScribe Newswire) -- Imagine you are a nurse who has just helped provide life-saving medical treatment to a car accident victim, an otherwise healthy young woman whose devastated parents are pacing the halls wondering at their daughter's fate.

Now imagine that it is your job not only to inform the parents that their daughter is brain dead, but to ask them if they would consider donating their child's organs -- heart, kidneys, eyes -- so that someone else might live, or have a better quality of life.

Under the best of circumstances this can be a daunting task. But how well a health care provider or counselor handles such situations is quite literally a matter of life and death for people in need of organ replacement.

Raelynn Maloney, a Ph.D. student in the University of Iowa College of Education's counseling psychology program, and Elizabeth M. Altmaier, Ph.D., a professor in that program, have coauthored a study examining how well health professionals are trained, not just in protocol (e.g., getting consent forms signed) but in skills that can help them guide the grieving survivors toward making the best possible choice about organ donation.

Their paper, "Caring for Bereaved Families: Self-Efficacy in the Donation Request Process," appeared in the December issue of the *Journal of Clinical Psychology in Medical Settings*.

The topic of their research is especially salient as the number of people needing organ donations grows, as Maloney and Altmaier state in their introduction.

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"Currently a new name is added every 13 minutes to the national organ transplant waiting list that now consists of over 80,000 men, women and children," they write. "While the waiting list continues to grow, the number of organ donors has remained relatively stagnant since 1993."

All told, less than half of the patients currently waiting for a transplant will ever receive a donated organ.

One reason for the shortage is that the families of many prospective donors decline to donate their family member's organs. While providing survivors with clinically accurate information about the organ procurement procedure is important, Maloney and Altmaier suggest that knowing how to navigate the emotional waters with the grieving survivors may be even more critical to helping families make fully informed decisions about donation.

Unfortunately, they say, training for professionals involved in organ procurement tends to emphasize procedural competency rather than foster affective helping skills. As a result, professionals may be well trained to meet families' informational needs but not their emotional needs during the donation request process.

"Enhancing professionals' awareness and skills for crisis intervention, bereavement support and counseling is seldom a key aspect of training," Maloney and Altmaier write.

The pair based their findings on a study of 39 health care professionals, one man and 38 women, who attended designated organ requestor training workshops presented by a Midwestern organ procurement agency. A majority of the participants were in nursing.

To help quantify how well prepared study participants felt to use both procedural and affective skills in an organ procurement setting, the researchers developed a 31-item Donation Experience Inventory (DEI). The 31 DEI asked participants to rank their confidence in performing a range of tasks related to donation, such as referring a potential donor, explaining brain death and dispelling donation myths (procedural skills) as well as assessing the family's need for additional support and allowing expression of intense emotion by the family (affective skills).

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After the workshop, participants showed increased confidence in both their procedural and affective skills, with greater growth occurring in the procedural domain. Still, Maloney and Altmaier say the study found that the organ donation request process involves a distinct affective component that is not always adequately addressed in training materials for health care professionals. That knowledge, they say, could be used to design more affective -- and ultimately more effective -- training in the future.

"The people being trained are clearly comfortable with hospital protocols and handling forms," Maloney said. "The barrier is sometimes that they're not prepared to cope with some emotional aspects of the death and with families who are dealing with sudden, often traumatic losses."

Altmaier agreed and said the Donation Experience Inventory developed for their study should prove a useful tool for other researchers interested in follow-up studies.

Maloney, who worked with the Iowa Donor Network for five years before embarking on the counseling psychology Ph.D. program at the UI, said the study confirmed her experience as an education coordinator and then as a developer of a bereavement follow-up program for donor families. Prior to working in Donor Family Services, she said many of the health care professionals approaching families about donation had limited training in death and dying issues, and there was little support for the family of donors once the donation procedure was completed.

"We developed the Donor Family Services program to cater to Iowa families, who wanted more information, more resources and more information about the recipients," she said.

This is not Maloney's first foray into publication. In 2001, she coauthored a book with Alan D. Wolfelt, Ph.D., "Caring for Donor Families Before, during and after: How to communicate with and support families before, during and after the decision to donate organs, tissues and eyes." Wolfelt is a noted author, educator, grief counselor and director of the Center for Loss and Life Transition.

In 2003, Maloney also received the James and Coretta Stroud Fellowship, presented annually to an outstanding UI doctoral student in educational psychology or an allied field who is entering the dissertation phase of the program. She plans to continue to write and research issues related to loss and life transition.

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