

# Transplant and organ donation education: what matters?

In 2008, an editorial team at *Progress in Transplantation* decided to designate a special issue of the journal to transplant and organ donation education. They requested manuscripts focusing on the education of transplant patients, living donors, and health care professionals. In addition, articles exploring how the general public learns about deceased organ donation were solicited. The research and patient care communities responded with interest, submitting the greatest number of articles on a special topic in the history of the journal. The original special issue became 2 issues, December 2008 and March 2009, containing a total of 18 articles on transplant and organ donation education.

So, what is most important to remember when developing and administering transplant and organ donation education? As guest editors of these special issues, we will let our fellow authors answer this question by underscoring 5 key themes that emerged across all articles.

### Early Education Through Multiple Channels

First, education of patients, donors, and the general public must occur as early as possible and through multiple communication channels. Many individuals still do not know their loved ones' organ donation wishes. Others do not know that they could be living donors or receive transplants. To reach more individuals before critical organ donation and transplant decisions have to be made, all early communication channels should be mobilized, including the media, the Internet,<sup>1</sup> dialogue in churches and other community settings, and discussion at the family dinner table. Because few patients know about the medical options of preemptive transplant,<sup>2</sup> living donation,<sup>3</sup> or paired donation,<sup>4</sup> conversations must also be occurring in health care settings other than transplant centers.<sup>2</sup> If educated early, individuals have time to ask questions, learn about all their options, and, hopefully, develop positive organ donation and transplant attitudes.<sup>5</sup>

### Unbiased and Accurate Education

Second, education materials and programs must be unbiased and medically accurate. Individuals making transplant and organ donation decisions must be provided with accurate medical information and be given the opportunity for true informed consent.<sup>6,9</sup> For kidney patients, both dialysis and transplant options

should be discussed. Information about living kidney or liver donation must be made available to both recipients and potential donors,<sup>1,4</sup> with a living donor advocate made available to ensure independent, unbiased donor care.<sup>7</sup> All treatment options and their risk factors must be demystified, including how to educate patients about the medical advantages of preemptive transplant<sup>2</sup> and the possible transplant side effect of skin cancer.<sup>10</sup> Finally, for busy health care providers, the availability of transplant education through videos, the Internet, and printed brochures can relieve some educational burden.<sup>1,3,4,6</sup>

### Tailored Education

Third, education must be tailored to reach different groups of learners. Individuals may be depressed<sup>11</sup> or have visual, auditory, or kinesthetic learning styles<sup>12</sup> that influence their ability to process information. Education materials should be written for patients at low levels of health literacy and in multiple languages.<sup>13</sup> Because ethnic and racial minorities are less likely to undergo transplantation or donate organs upon death compared with whites,<sup>14,15</sup> culturally appropriate education and media must address differences in familial values regarding living donation<sup>14</sup> or be tailored by age or race.<sup>15,16</sup>

### Education With Proven Success

Fourth, education should be motivating and use approaches shown to increase the rates of organ donation and transplantation. There is no need to reinvent the wheel. Specific educational interventions show promise in increasing positive attitudes about pursuing living donation rates<sup>3,4</sup> and increasing rates of sign-up on the organ donation registry.<sup>17,18</sup> Using effective educational strategies or materials may reduce cost and increase the probability of success. Particularly, interventions that show promise in reducing racial disparities in organ donation or transplantation should be implemented at multiple sites.<sup>3</sup>

### Well Prepared Educators

Fifth, individuals educating others about organ donation and transplant should be well prepared for these discussions. On any given day, staff in non-profit organizations and the department of motor

vehicles, organ requestors, peer educators, mental health professionals, dieticians, nurses, and physicians are answering transplant and organ donation questions. These individuals, particularly non-health care providers such as department of motor vehicles staff<sup>17</sup> and new organ procurement professionals, need to be trained and prepared to have discussions about organ donation.<sup>12</sup>

Conversations also occur within families. Because communication within the family about organ donation increases the probability that someone will become an organ donor,<sup>17</sup> accurate medical information and the opportunity to practice asking others for a kidney<sup>2</sup> may help family members have these unusual and sometimes difficult conversations.

### Summary

With more than 100 000 patients waiting for organs on the waiting list, we have our work cut out for us. Transplant education, when done well, can help patients make informed choices and may increase the number of individuals who donate organs before or after their death. The authors in the December 2008 and March 2009 issues of *Progress in Transplantation* suggest modifications to improve how transplant and organ donation education is administered; we recommend that these suggestions be used in research and educational interventions nationwide.

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