How Organ Transplant Recipients Cope with the Deaths of Their Donors

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There has been limited research about how people who have received organ transplants from deceased donors cope with their donors' deaths. A study was conducted with 77 anonymous recipients to determine how their coping methods may differ qualitatively or quantitatively. Results indicate that females and males use a variety of methods, with several differences noted in their levels of importance, frequency of use, and impact. Some differences, based on age, were also noted. Four overarching themes were identified in the coping process, including: resolving whether the donor "died for" the individual, the random-chance nature of receiving an organ acting as an emotional defense, thanks/faith in God being beneficial, and gratitude toward the donor and their family.

INTRODUCTION

There is a substantial body of literature regarding the mental health concerns and functioning of people during the pre- and post-organ transplantation process. The literature has focused on topics such as quality of life (QOL) (Pinson et al., 2000), depression (Dew et al., 2001), and employment (De Baere et al., 2010). Transplantation is like no other medical procedure, in that, in most cases, for someone to live someone else has to die. This has the potential for major psycho-emotional impacts in recipients. Yet, we know little about how those who have received a deceased donor organ cope with their donors' deaths. One might expect that survivor guilt is a critical developmental hurdle for recipients; however, anecdotal evidence points more toward a desire to find meaning in the donor's death. This study was completed to investigate several core questions, including: how do people cope with their donors' deaths? Do these methods vary, based on gender? Do people discuss this topic with their transplant professionals?

METHOD

A research proposal was submitted and approved by a university independent review board (IRB) prior to initiating the study. A secure, anonymous online questionnaire was created, using both numerical rating scales, as well as open-text qualitative comment boxes. A mailing list was generated of all organ transplant support groups in the United States noted on the United Network for Organ Sharing (UNOS) internet site. An email message was sent to the specified contact person for each of these groups. The message asked them to distribute the online address link for the questionnaire to their constituents. It was noted that it was only for people in the United States who were over the age of 18 who had received a solid organ transplant from a deceased donor. Instructions, along with a statement regarding the voluntary and anonymous nature of the questionnaire, were incorporated as part of the informed consent. No individually identifiable information was collected. Participants were informed that the content of the questions (i.e., death) could potentially cause emotional upset; it was recommended that they not participate if they felt this would cause them any anguish.

RESULTS

A total of 77 respondents completed the questionnaire; 50.6% (39) identified as female and 49.4% (38) as male. Respondents were 87% (67) White, 11.6% (9) Black/African American, and 1.4% (1) Asian-American. Liver transplant recipients comprised the largest group at 28.5% (22), followed by kidney (24.6% (19)), lung (22% (17)), heart (12.9% (10)), multi-organ transplants (9% (7)), and other (3% (2)). The mean current age was 60.4 (*SD* 11) and mean age at time of transplantation was 51.7 (*SD* 12).

The first group of research questions dealt with the ways that respondents coped with the phenomenon of relying on a deceased donor in order to get a transplant while they were on the waiting list. The number of coping methods did not differ based on gender (females = 2.89, males = 2.81, $t = +.17$, *df* 75, *p*.43). However, there were some differences in the types of methods used (see **Table 1**). Females were significantly more likely to engage in pleasurable pastimes ($\chi 2 = 6.78$, *df* 1, *p*.009); 31% of all female respondents did this but only 5% of males did so. Speaking with clergy was an activity completed by 13% of females and 26% of males, though it was not a statistically significant difference ($\chi 2 = 1.46$, *df* 1, *p*.22). Additionally, females more frequently responded with trying not to think about their donors' death (25% vs. 13%) though this was not significant ($\chi 2 = 1.2$, *df* 1, *p*.27). Overall, the use of

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prayer/faith/religion was the most commonly cited method of coping. It was noted by 62% of all respondents, including 64% of females and 60.5% of males. 56% of the respondents rated this as being moderate-to-extremely important as a form of coping. There was a difference based on gender, with females rating it as being more important (*t* = +1.88, *df* 75, *p*.03). There was a mild negative correlation based on age (*r* = -.26); however, female respondents were much younger at the time of their transplant age (47 (*SD* 12.9)), as compared to males (56 (*SD* 9.8)), so the influence of gender could be even greater. Talking with family/friends and speaking with others waiting for a transplant were the second and third most common forms of coping. Passive methods of coping including doing nothing, sleeping/napping, being in denial and trying not to think about it (18% of females and 15.5% of males, with no statistical difference χ2 =.14, *df* 1, *p*.70).

The second group of research questions dealt with waiting for a transplant. Fifty-five percent of respondents noted that the fact they were on a deceased donor waiting list for a transplant was moderately-to-greatly on their minds. There was no statistical difference based on gender (*t* = +.71, *df* 75, *p*.23). There was a minimal negative correlation based on age (*r* = -.18). The level of distress experienced thinking about the donor's death was rated as moderate-to-severe by 39%, and there was a significant difference, based on recipient gender, with females experiencing more distress (*t* = +1.75, *df* 75, p.04). A mild negative correlation based on age was noted (*r* = -.22).

On average, the respondents in this study were nearly nine years post-transplant. The majority of them (77%) still frequently thought about their donor and a there was a difference based on gender, with females more likely to do so (*t* = +2.24, *df* 75, *p*.01). Age at time of transplantation appeared to have no correlation (*r* = -.07). After transplantation, 60% of all respondents experienced moderate-to-great sorrow/mourning for their donor's death with no gender difference noted (*t* = +1.16, *df* 75, *p*.12). Age at the time of transplant had only a minimal effect (*r* = -.18). Interest in learning about their donor's lives was experienced by 80.5% of all respondents, with no difference based on gender (*t* = +.55, *df* 75, *p*.29).

People waiting for a transplant come into contact with many medical professionals. Respondents were asked if they spoke with any of them about coping with the death of their donors. Results show that they were most likely to have spoken with mental health professionals, particularly social workers and counselors. This was noted by 25% (19), including 26% of females and 22% of males, with no noted difference between genders (χ2 =.23, *df* 1, *p*.63). There were disparities in speaking with mental health professionals, based on the type of organ received: 35% of all lung recipients had done so, as had 30% of heart recipients, 22% of liver and only 4% of kidney recipients (none of the multi-organ recipients). The second most common professionals spoken to were physicians/nurses, which was noted by 21% (16), with 15% (6) of females and 26% (10) males doing so (χ2 = 1.4, *df* 1, *p*.23).

Four overarching themes were identified in the ways that respondents coped with the deaths of their donors: (1) resolving an inner conflict as to whether or not the donor "died for" the recipient; (2) seeing death as random; (3) the role of religious faith and belief in God for both support and acceptance; and (4) a profound sense of gratitude and a desire to somehow repay the donor or their family.

DISCUSSION

The respondents to this survey used a variety of coping methods to deal with the deaths of their donors, most of which were active efforts to improve mood or to self-distract. The primary method for both genders was faith/prayer/religion. Though there was no difference in the frequency of it being cited, females rated it as being more important to them in the coping process. Prayer and faith are noted to provide various benefits for people with chronic illness. They can be sources of solace, a way to bring about a sense of control over ones' life, and a resource of strength and perseverance (Gordon et al., 2002). Being able to appeal to a "higher power" has the potential to be a mental "safety net." That is to say, that when the abilities of medical interventions (medications, surgeries, professionals, etc.) are found to have limits, there is a power that a person can turn to that transcends all of them. Research has noted that people often want their physician to inquire, or know about, their religious and spiritual beliefs especially in the face of life-threatening situations (Ehman et al., 1999; MacLean et al., 2003). A study of kidney recipients who had survived over 25 years found that many attribute their longevity to faith in God (Matteson-Kome et al., 2016). An examination of liver recipients noted that those with high levels of religious faith had longer survival rates than those who did not (Bonaguidi et al., 2010). Though the frequency of faith/prayer/religion was not significantly different between females and males in this study, females rated it qualitatively as being more important.

The only coping method found to have a significant difference in frequency, based on gender, was that females were more likely to engage in pleasurable pastimes as compared to males. This is a beneficial approach, since its influence can be global (Pressman et al., 2009).

After faith/prayer/religion and social supports, including speaking with other candidates, the most commonly cited coping method was humor. Like faith, it too provides various benefits to those who are dealing with chronic or life-threatening illnesses. It has been noted to be a source of empowerment and relaxation, and can allow for altering perceptions of negative situations (Herth, 1990). It has also been identified as a buffer in patient-physician relationships. An analysis of interactions found that humor acts in many different ways in this regard (Schöpf et al., 2017). It allows people to vent frustrations, to deal with negative emotions, and express disagreement with and criticism toward their physicians, while also increasing rapport.

Passive coping methods were used by a minority of respondents (20%). Active methods have been correlated with lessened depression, lessened anxiety and greater overall well-being for those waiting for lung transplantation (Taylor et al, 2008), whereas a study of people waiting for heart transplants identified a strong connection between the use of passive denial and depression (Burker et al., 2005). Similar negative correlations have been identified between denial and its impact on physical functioning, along with quality of life (QOL) for those awaiting a new heart (Burker et al., 2009).

There were four primary overarching themes that arose from this study. The first, one of the most common, was a developmental hurdle that not all were able to resolve, which was to distinguish between the view that ”the donor died,” versus “the donor died for me.” Those who made this distinction in a positive manner made comments such as, “I came to an understanding that I was not responsible for my donor’s death,” or as another eloquently stated, “I distinguished between the thought that my donor died to give me life, versus my donor died and gave me life.” Those who did not reach this understanding expressed “survivor guilt,” and a sense that transplantation was a zero-sum process, in that one person lived (+1) and another died (-1), thus zero lives saved. Denial seemed to be linked to guilt for a small number of respondents as in, “I couldn’t cope with it (the donor’s death). I tried to push it into the back of my mind; otherwise, it made me feel guilty.”

The second theme was that death is part of life and the common nature of it, along with the ensuing organ-matching process, provides a sense of equal chance for one to obtain a needed transplant and not the sense that some died specifically for that recipient. As with the first theme, this seems to provide a defense against the thought that someone “died for me.” As a recipient noted, “My donor would have died whether I got his liver or not” and, “I took solace in knowing that I am not in control. People die every day and I have no say in that,” along with, “It was simply that my donor’s liver was most suitable for me.”

A third theme was thanks for and faith in God for both receiving a transplant and for getting through the process. There were numerous comments such as, “I relied on God to give me strength and peace,” along with, “I prayed that God’s Will be done.” This was also frequently directed as a sentiment toward the donor family, as in, “I prayed for their family,” and, “My thoughts and prayers were with the family who was going to lose a loved one.”

Throughout the many comments made by respondents, the word “honor” was often used, and it is linked to the fourth theme of gratitude. This was frequently cited as giving meaning and purpose to one’s extended life. For example, “I focused on how to honor my gift of life, to care for it….When I received it, I wanted to show my respect to my donor by sharing my story,” and, “I am deeply grateful for this gift of life. I am inspired to live life to the fullest to honor him.” Several reported that they had gotten involved with promoting organ/tissue donation. Again, “honor” was often cited with regard to becoming active in donation awareness efforts. For example, “I strive to honor my donor by promoting organ and tissue donation,” and, “I use my donor’s death as motivation to make the most of my life now by reaching out to help others, in order to honor my donor.” Additionally, as one respondent succinctly stated, “I think of him [donor] as my hero.” This altruistic desire to somehow repay/acknowledge the donor or their family has been noted as a transformative anthropological construct in transplantation and a common desire amongst recipients (Conway et al., 2013; Evangelista et al., 2003; Sharp, 1995). A total of 76% of all respondents stated that they were involved in organ donation promotion programs, many as a means of repaying the donor or their family. Along with “gratitude,” the majority of respondents stated that their donors are still frequently in their thoughts, and most experienced a period of mourning/sorrow regarding their donors’ deaths.

One of the most surprising findings was that, even though coping with the death of the donor appears to be a concern for many recipients, it was rarely discussed with transplant professionals. Though it cannot be assumed that all of the respondents who received kidneys had been on dialysis, it is surprising that only one recipient stated that they had discussed this topic with a social worker/counselor. Under Medicare regulations (Conditions for Coverage (CfC)), there is a social worker available in every dialysis clinic in the United States, and they are there to help people deal with a multitude of psycho-emotional concerns (Callahan, 2011; DHS, CMS, 2008). Respondents were even less likely to discuss donor death with physicians, nurses, and clergy. The question arises as to whether or not transplant candidates fail to raise this concern or if professionals don’t ask about it. It is known that discussing death-related issues differs among health professionals and that their attitudes, along with experiences, regarding death affect how they approach this topic with patients (Black, 2007). There were also differences, based on organ type, regarding whether respondents had broached the subject of donor death with their medical professionals. Heart and lung recipients more frequently had done so, as compared to liver and kidney, which is unique, since respondents had received their transplants at a variety of hospital programs across the nation. It is possible that this is due to the qualitative difference of the organs themselves. As has been noted in the literature, the heart is particularly different, in that it is constantly perceptible—there is a pulse that one can be aware of—as compared to other organs that work silently (Rauch & Kneen, 1989). That is to say, that the beating heart and the constant perception of breath might lead to someone being more aware of the life and death nature of donation and transplantation.

Most of the results from this study point to the common human need to find meaning in loss, which is particularly salient in a population who would most likely have died without transplantation. Research in related fields has noted that this need is often the most pertinent variable in post-loss adjustment (Keesee et al., 2008). It has been postulated that coping with death can lead to personal growth on various levels, such as becoming more appreciative of life and loved ones, and a general increase in resilience (Neimeyer et al., 2002).

Though this study had a relatively small number of respondents and cannot be considered generalizable, it appears that coping with the death of one's donor may be a common experience for transplant recipients. The study had the potential risk for self-selection bias within the sample population, in that respondents were from transplant support groups—which might attract people who are either coping well, or poorly, with the transplantation process. Finally, there is a multidimensional quality to coping methods that was not explored. For example, simply noting that transplant candidates used religious faith to cope does not provide in-depth understanding of how they used it or the specific benefit received.

A variety of coping methods were used, most of which were psycho-emotionally beneficial. Four primary themes were identified with regard to coping. Of particular note, the task of separating that "the donor died for the recipient" versus "the donor died and benefited the recipient" appears to be exceptionally important. Failing to successfully distinguish between the two seems to lead to feelings of guilt. Faith/prayer/religion, the random nature of death, and gratitude toward donors and their families were also commonly noted themes in the coping process. Even though coping with the death of the donor appears to be a frequent issue, it is not commonly discussed with transplant professionals. Further research into this dichotomy is recommended, especially with regard to differences noted based on the type of organ received.

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Table 1. Types of methods used to cope with pending death of organ donor

Method	Overall	Females	Males	χ2
Faith/prayer/religion	62% (48)	64% (26)	60.5% (23)	.01 ns
Talked with social supports	58% (45)	56% (22)	60.5% (23)	.02 ns
Spoke with others waiting for a transplant	35% (27)	31% (12)	39% (15)	.32 ns
Sense of humor	26% (20)	28% (11)	24% (9)	.04 ns
Spoke with clergy	19% (15)	13% (5)	26% (10)	1.46 ns
Slept/napped	19% (15)	23% (9)	16% (6)	.22 ns
Tried not to think about it	19% (15)	25% (10)	13% (5)	1.2 ns
Did pastimes that I enjoy	18% (14)	31% (12)	5% (2)	6.78*
Talked to mental health professional	15% (12)	13% (5)	18% (7)	2.14 ns
Did nothing	13% (10)	7.5% (3)	16% (6)	.56 ns

ns = not statistically significant
* = statistically significant

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