

Influence of Family Communication on Organ Donation

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Student's Name: Arielle Melino
Faculty Sponsor: Chris Morse
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ABSTRACT

Organ donors are in high demand and although many individuals have a favorable attitude toward organ donation, very few are committed to donating. This study aims to examine the impact of mother-daughter relationships and the conversation that stems from this bond on decisions to donate. Some factors that exist within family communication such as attitudes, willingness to communicate, experience, and knowledge may not just impact the perspectives of adults but also the donation decisions of their college-aged children.

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INTRODUCTION

Organ donation is a prevalent issue today. Thousands of people are currently in need of organs and many die each day waiting for a transplant. Right now, there are 76,880 active waiting list candidates and only 6,961 donors (OPTN). Donors, both living and deceased, can eliminate this need by registering to become a donor and discussing donation preferences with close support networks, such as family. Although many people have a favorable attitude toward donation and recognize that there are countless individuals in need of organs, very few are actually registered organ donors. This disparity is creating a wide gap between the number of individuals waiting to receive organs and the number of donors available to provide essential organs including, but not limited to, kidneys, hearts, livers, and lungs.

The purpose of this study is to understand differences and factors that contribute to an individual's commitment to organ donation or refusal to become a donor. One factor that plays a role in forming opinions on controversial topics such as organ donation is the influence of family. Parents can play an extremely large role in influencing health behaviors and major decisions regarding life and death. Mothers especially have a large influence on their children and the mother-daughter bond proves to be the strongest and most communicative of all family bonds. In communicating about relevant health issues within families, a number of themes appear to influence decisions, including attitudes, willingness to communicate, experience with the topic, and knowledge regarding this specific health issue. These four communication factors or themes appear to be some of the most influential factors when a serious health issue, such as organ donation, becomes the subject. This study examines all of these factors, determining how attitudes, willingness to communicate, experience, and level of knowledge of mothers and daughters affect one another and how this, in turn, impacts their decisions regarding organ donation.

Overall, this study aims improve understanding of the reasons that individuals choose whether or not to commit to organ donation. With the gap between those in need of organs and those donating growing significantly in recent years, it is important to understand what motivates people to donate. Understanding the major influences that contribute to donation decisions

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could assist in bridging the gap between those in need and those capable of donating. Once these factors and influences are understood, promotion in terms of advertising and health campaigns can be distributed to inform young adults, parents, or both about this health issue. Understanding what motivates organ donation is crucial in assisting many people around the world.

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LITERATURE REVIEW

Organ Donation

From current literature, it is easy to determine that organ donation is essential in saving lives. This is a very serious issue when one considers that “120,000 men, women and children currently need lifesaving organ transplants” and “an average of 18 people die each day from the lack of available organs for transplant” (Donate Life America). It is clear that there are many in need of transplants. Those whose needs remain unfulfilled suffer serious consequences, complications, and even death. While this issue is already severe, it continues to grow when it is considered that “every 10 minutes another name is added to the national organ transplant waiting list” increasing the number of people in need who risk death if their needs are unfulfilled (Donate Life America). Just one donor could “save up to 8 lives through organ donation and enhance many others through tissue donation” (organdonor.gov). Organ donation is a serious issue and many lives could be saved with the help of more organ donors.

Although there is a vast shortage of registered organ donors, people generally have a positive attitude toward organ donation, representing a huge discrepancy. Gallup polls from 2005 show “that the majority (95%) of Americans support [organ donation], yet only 53% have taken action to make their [organ donation] status known, such as signing an organ donor card” (Pitts et al., 2009, p. 413-414). From this, it is evident that most people have a favorable view of organ donation, but few of these people are actually organ donors. Bridging the gap in this discrepancy by determining why people who look favorably upon organ donation still choose not to be donors could increase the number of organ donors and save more lives. In determining why some individuals choose not to be organ donors, one important aspect to examine is communication about health within families regarding major health topics, such as the decision to become an organ donor.

Health Communication

Communicating about health within the family is pivotal in forming our individual health behaviors and maintaining stability during times when there is a major health crisis or decision that must be made (Pecchioni & Keely, 2011). Health is a factor that has an

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enormous impact on our daily lives and relationships, similar to how families greatly impact our lives. These two factors heavily influence us as individuals and become interrelated in this way. Because these two factors are so powerful in the shaping of our attitudes and routines, “family and health do not occur in separate spheres, they co-exist in the same way that a helix exists in the world, in a spiral coil that cannot or should be separated” (Pecchioni & Keely, 2011, p. 372). Consequently, health is a topic that is frequently discussed between family members. We have the need to make meaning of these influential, interconnected subjects, so “families and health are intertwined in meaningful ways and communication is central to these processes and outcomes” (p. 372). Connecting family and health through interpersonal communication is not just common but also beneficial. When all health and wellness topics are considered “from teen risk behaviors, to lifelong lifestyle choices, to coping with illness and bereavement, research consistently finds that ‘better’ communication leads to better health outcomes” (p. 364). Health and family are both essential parts of our being as individuals and, as a result, the communication that links the two topics is inevitable and important.

The benefits of communicating about our health within the family are irrefutable (Pecchioni & Keely, 2011). Communicating about health issues within the family is not just important when resolving a particular health issue, but also in maintaining overall well-being in a complex health situation. There is “a connection between the nature of one’s social relationships and the level of his or her well-being” (Segrin, 2006, p. 8). Communicating about health in a way where one shares “one’s experiences, thoughts, ideas and emotions is a positive adjustment behavior” and “has been identified as a key component of successful coping” (Mallinger, Griggs, & Shields, 2006, p. 355). Those who share their experiences, emotions, and concerns are better able to cope with difficult health issues that could potentially be traumatizing. In these situations and those where a specific issue is at hand, people principally look to family. For example, “in the context of a personal health crisis, such as a cancer diagnosis, individuals are most likely to seek support from their family members” (p. 355). Families are often closest to the individual during their time of conflict both physically and emotionally. Families can often understand the context of an issue

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because “health issues begin the moment people are conceived into a family, continue as family members learn and live healthy or risk daily health behaviors, are magnified by all family members’ reactions to a health crisis, and only come to an end with death (that is often taken with family members as witnesses to the end of life journey)” (Pecchioni & Keeley, 2011, p. 373). When the individual discloses information to their family and feels supported by those who care, the “patients’ feelings of being emotionally supported by the family are associated with lower levels of depression and anxiety” (Mallinger, Griggs, & Shields, 2006, p. 356). Communication about health, namely within the family, is extremely important as it contributes to better coping and well-being both in general and in specific situations.

In addition to helping us cope with conflicts in our health, family communication is an important factor in helping us to follow through with particular health decisions, especially major decisions such as deciding to become an organ donor. In regard to organ donation, open family communication is of the utmost importance as “consent from next-of-kin is the singular determining factor in organ procurement” and “knowledge of the deceased’s wishes regarding donation was the most significant factor in determining if families grant consent, as families almost always honor the wishes of the deceased” (Vincent, 2006, p. 300). Especially in medical situations where organ donation is a factor, it is important that an individual expresses their wishes mainly by communicating with family about health preferences, as organ donation cannot occur without the consent of immediate family. More often than not, families only grant consent if they are explicitly aware of an individual’s organ donation preferences. Thus, communicating about this particular health issue within the family is important, as it is a large factor in determining if donation can occur.

Families often have relatively similar views on major health topics, such as organ donation, that they discuss with one another. When it comes to organ donation, “56% reported having such a conversation with a family member” (Vincent, 2006, p. 300). In addition, “most respondents (69%) claimed that their family members did not argue with them, and a good proportion agreed with their donation wishes (59%)” (p. 300). Whether or not individuals choose to be donors, their decision is often supported by family members. It is evident that

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family largely influences health decisions and their support of these health decisions, especially in the context of organ donation, is extremely important. Finding patterns in communication surrounding organ donation within families can help to pinpoint the factors that make individuals choose whether or not to become a donor.

Mother-Daughter Communication

When examining communication about a topic as sensitive as health or health behaviors, it is important to consider the relationship between the two subjects. Closer relationships facilitate more discussion and disclosure. Additionally, conversations are more frequent between those who maintain close relationships with one another. One relationship in particular, the mother-daughter relationship, has proven through research to be one of the most dynamic and close of all relationships.

One important characteristic of the mother-daughter relationship that sparks great interest is the closeness that is frequently associated with this relationship. In multiple studies, it has been shown that “mother-daughter relationships are the closest of parent-adolescent relationships” (Willer, 2007, p. 6). Parent-child relationships are dynamic in nature and change in varying patterns over time. Although there is occasional conflict or tension, “mother-daughter relationships experience both conflict and comfort” and this relational dialectic of experiencing both trouble and happiness stems from “the fact that adolescents indicate that they spend more time with their mothers than they do with their fathers” (p. 6). Mothers and daughters spend copious amounts of time with one another in the early stages of growth and development, leading to a relational closeness that continues through positive and negative moments of early adolescence and early adulthood. This closeness is of crucial importance because “closeness is manifested via self-disclosure and communication” (p. 6). When studying communication, it is important for comfort in self-disclosure and ease of communication to exist. The mother-daughter relationship, through its closeness, facilitates conversation.

Additionally, the mother-daughter relationship is mutually influential and beneficial. Mothers and daughters frequently share information with one another and disclose personal

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information during their interactions. This particular pair spends a significant amount of time together, so their interactions occur frequently. It has been shown that one of the most important parts of this relationship is the mother's "critical role in providing her daughter with advice and support" (Mosavel, Simon, & Van Stade, 2006, p. 647). Not only does the mother provide support for the daughter throughout her entire life, but it has also been noted that there is a more "reciprocal portrait of the mother-daughter relationship" where daughters "can be instrumental in influencing and supporting their mothers in a variety of ways" (p. 647). Because mothers and daughters have a mutually beneficial reciprocal relationship, advice or knowledge can easily be passed through generations. When it comes to health information, influence of family members plays a huge role and the open communication between mothers and daughters could heighten this influence.

Family is an extremely important factor in health decisions and conversations, so the mother-daughter bond relates closely to decision making in this context. It has been seen that the "positive relationship between parents and their adolescent children has been specifically emphasized as playing an important role in young people's health outcomes" (Mosavel, Simon, & Van Stade, 2006, p. 648). Specifically, when it comes to communication about issues as topical and controversial as organ donation, "women are more likely than men to discuss [organ donation], and daughters and sons are more likely to speak on the topic to their mothers than to their fathers" (Pitts et al., 2009, p. 414). In other studies, "students more often reported speaking to their mothers (67%) compared to their fathers (26%) about [organ and tissue donation]" (Vincent, 2006, p. 299). Therefore, it could be concluded that due to the closeness and positive nature of a mother-daughter relationship, mothers and daughters will be likely to communicate and share their attitudes, influencing one another's health behaviors over time, especially in regard to organ donation.

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METHOD

Sampling

This study was comprised of 10 separate participants, 5 of which were female college students between the ages of 18 and 23. The remaining 5 participants were the women that these individuals identified as their respective mothers, combining for a total of 10 distinct interviews. Participants were obtained using a purposive sample, recruiting some individuals that identified themselves as organ donors and others that did not. All participants in this study were recruited through word of mouth regarding this study, emails to Bryant University students, and snowball sampling methods. Female college students interested in participating were instructed to contact the researcher via phone or email to ensure that they met necessary qualifications before formally becoming a participant. In order to qualify to participate, the individual had to be female, between the ages of 18 and 23, knowledgeable about their organ donor status, and willing to consent to audio recording for the interviews. The selected female college student participants were asked to help recruit their mother or female parental guardian for the remainder of the interviews.

Procedures

This study relied on semi-structured interviews guided by a loose script of open-ended questions. All interviews were conducted privately over the phone and were audio recorded. These interviews ranged from 15 to 30 minutes based on the amount of knowledge the participant had regarding the subject. Interview questions for both mothers and daughters were aimed at discovering how they have discussed organ donation in their relationship, how health topics are discussed overall, their willingness to communicate, and perceived knowledge about the topic of organ donation among other questions that appeared on a case-by-case basis. Interviews, after being conducted and recorded, were saved in a confidential folder and transcribed using basic transcription processes. Upon reading the transcripts for further clarification, analyses of these interviews were conducted using a grounded theory approach as outlined by Strauss and Corbin (1998).

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RESULTS

Among these ten women, a number of themes surrounding their discussion of organ donation emerged. One of the most significant emerging themes was the similarity of their attitudes toward the subject of organ donation. All mother-daughter pairs expressed similar feelings toward organ donation and all claimed the same organ donor status, whether they were both formally listed as donors or non-donors. In addition to listing the same status as either an organ donor or a non-donor, they cited similar reasons for this overall decision, indicating that their respective attitudes influenced one another. Many of these pairs did not have direct conversations referencing their beliefs about the topic of organ donation specifically. However, they listed the same organ donor status, using the same justification. In explaining their attitudes and the reasons for their decisions, the mother-daughter pairs used the same language or similar phrases in articulating their feelings.

For example, one mother listed as an organ donor repeatedly expressed an innate feeling that registering as an organ donor was “the right thing to do” (2B). Similarly, her daughter, when describing the reason she chose to become a donor as soon as she could, used similar language in stating that there “wasn’t really one particular reason, I just kind of felt like it was the right thing to do” (2A). These individuals indicated that they had not explicitly expressed their opinions on organ donation with one another, but felt very comfortable in sharing details of their life, values, and other health experiences. However, they had the same attitudes toward organ donation and proclaimed the same status as organ donors. From the similar language they used in describing the ultimate reason for their decision to be organ donors, it is evident that they shared a similar attitude regarding organ donation.

This phenomenon was not limited to mother-daughter pairs listed as organ donors. Conversely, mother-daughter pairs listed as non-organ donors followed this same pattern in expressing their feelings regarding organ donation, even going as far to use similar language in their description.

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One mother and daughter separately stated that they were not organ donors, citing the same health issue, diabetes, as the reason they could not be donors. This mother, before she was diagnosed with her diabetes, was an organ donor and felt good about that decision stating that “I figured I could help someone. If my parts were any good, I could help someone by doing it” (1B). She expressed her desire to be an organ donor despite her medical condition, stating “I wish I could be if my health was better” (1B). Her daughter, who was diagnosed with diabetes at a young age and therefore, never had the option of becoming an organ donor, expressed a similar desire to have the option of becoming a donor. She stated that, had she possessed the ability to become a donor, her decision would be different. Regarding claiming her status as an organ donor, she stated, “I think I would do it” (1A). When explaining why she would become an organ donor if she could, she stated that “I think it’s a good thing helping someone else” (1A). Like her mother, this daughter did not have the ability to donate her organs, but expressed a desire to have the option to, believing that it was a positive choice. This mother-daughter pair, much like the first, felt comfortable communicating with one another about health topics, but when it came to organ donation in particular, the daughter explained that “we haven’t talked about it at length” (1A). This mother-daughter dyad consists of two non-organ donors yet both expressed the desire to become organ donors, citing their similar feelings using similar language. In this case, it is once again evident that this pair shares the same attitude toward organ donation and both claim the same status as non-organ donors.

This pattern of mother-daughter cohesiveness was not limited to these two cases. All mothers claimed the same organ donor status as their daughter and vice versa. These mother-daughter pairs had relatively similar attitudes on the topic, which was seen in the similar language that they used when discussing the ultimate reason for making the decision whether or not to list themselves as an organ donor.

Mothers

In addition to the themes pervasive across all subjects, there were a number of themes that emerged among similar participants. For example, all mothers demonstrated what can be described as a “family first” attitude. All mothers expressed immense concern for family

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members, regardless of whether or not they are currently a registered organ donor. These individuals care deeply for family members, namely their daughters, and in interviews, demonstrated a strong desire to protect and care for their children in any way possible.

One mother, a registered organ donor, stated that even the reason she decided to become an organ donor centered on her family. When recollecting her decision to be a donor, she stated that it occurred “when I became a mother 22 years ago” (4B). Elaborating on the reason she became an organ donor, she stressed the importance of her family:

It was the birth of my oldest child and thinking about how grateful I was to have that child and if she ever needed anything to sustain her life that I wanted that available to her and if I wanted that benefit, that gift, then I should be willing, also, to give that gift. (4B)

This mother explicitly expressed the importance of taking care of her family. For her, being an organ donor was one way that she could accomplish her goal of putting her family first.

Another mother, who is not an organ donor, stressed the importance of protecting her family in her decision not to be listed as an organ donor. Additionally, she expressed feelings against her daughters listing themselves as organ donors on their drivers’ licenses for this same reason. However, if a situation happened to arise where organ donation was the way in which she could protect her children, she voiced that she would become an organ donor, once again, to protect her family. Also, if her children do wish to be organ donors, she would respect their wishes after all other options have been exhausted. In explaining her complex decision not to be an organ donor and requesting that her children opt out of organ donation as well, she emphasized the importance of protecting life within her own family first:

I was opposed to it in both of my girls. If it was like a sibling or someone else in my family, those are their choices, but I just wanted to make sure that my children’s chances of being saved or survivability are taken into account first so that’s how I feel about being on the list but I have told each of them that, especially my oldest daughter, who would be very into wanting to be an organ donor and I told her, I assured her, that I would donate her organs. I just don’t want it on the license. (5B)

This individual strongly believes that her family would be better protected if they are not listed as organ donors. She cares about protecting her family more than anything, and for this reason, she prefers refraining from listing herself as an organ donor along with members of

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her family. She stated that “I am very selfish about the ones that I love and I would want to do everything I can to provide for the survivability of my own family first and then when all else, I would donate” (5B). This mother truly stressed that her family came first. Much like this mother, in all mothers, regardless of their organ donor status, there was a clear emphasis in their interviews on providing for the family first.

Daughters

The group of daughters in this study expressed a different similarity amongst their group. All daughters expressed a “willingness to explore” or, in other words, a willingness to think about their decision and change it based on time or situational factors. Many individuals that represented the daughter in the mother-daughter dyad reflected on the idea that they may change their organ donor status at another point in time.

A daughter not listed as an organ donor stated that when making the decision during her license renewal, “I said no because I felt like I didn’t know enough information about it” (3A). Though she is not currently a donor, she explained that this could change eventually. Regarding becoming a donor, she stated “I’m considering it, I’ve always been considering it, I just didn’t know how much of a risk it is” and eventually concluded “I’d like to be an organ donor if I knew more information about it one day” (3A). This individual asserted that while she may not currently be an organ donor, she is open to the option of becoming one someday, demonstrating a willingness to explore all options.

Additionally, a second daughter that is not currently listed as an organ donor claimed “one day maybe I’ll decide to donate but right now I like my decision of not being an organ donor” (5A). Under certain circumstances, however, she said that she would be willing to reconsider her current choice. This individual claimed “I’d become an organ donor if someone in my family needed an organ or if I knew someone personally would use it and I was about to pass away or something I would probably change to be an organ donor” (5A). Again, this daughter expressed a willingness to be flexible in her decision based on changing circumstances.

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While these individuals are not currently organ donors, they expressed a respect for individuals that were organ donors and asserted a willingness to consider becoming one eventually. Daughters often expressed that in time or under certain conditions, they were open to the idea of becoming an organ donor.

Organ Donor Pairs

All individuals listed as organ donors shared positivity in justifying their decision to be an organ donor. These individuals frequently cited a “feel good” element or a positive attitude that they hold about their decision. Namely when these individuals explained why they decided to be an organ donor, they cited that it felt like the necessary or right thing to do. In reflecting upon their decision, they looked at it with positivity and pride. For example, one mother had absolutely no hesitations about deciding to be an organ donor and took pride in her decision. Regarding her decision, she explained that she is “completely at peace with it” (4B). At the time that she decided to be an organ donor, “it felt like the right thing to do” (4B). She always had a positive attitude toward organ donation, which continued after she decided to become a donor. Likewise, her daughter described becoming an organ donor as “a good citizen thing to do,” elaborating that “I thought if I was ever in an accident or if I ever needed an organ donated I would want someone else to do it for me” (4A). Thinking about when she made the decision, she stated:

I feel good about it. I don't think about it too often but I do, whenever I take a look at my license or I hear a story about someone who has had an organ donated I feel good about it. I feel proud that I could potentially help somebody. (4A)

This mother-daughter dyad expressed extreme positivity and pride regarding their decision to become organ donors.

Other mother-daughter dyads reported a similar experience. A second mother also vocalized that she felt that becoming an organ donor was “the right thing to do” (2B). Her feelings about organ donation were strong enough that she even suggested that her youngest daughter consider becoming an organ donor, stating:

I actually suggested that she do it. I said what if something did actually happen to you and you could save somebody else's life that needed an organ, I think that makes the family feel better and I think that is the right thing to do to help somebody else out that is struggling with something that needs an organ. You know, it could be a little baby,

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it could be a 12 year old, it could be a 28 year old, you know, I just feel that it is the right thing to do once you're on, you can help somebody else with this. (2B)

This mother had the intuitive sense that becoming an organ donor was the right thing to do because it would help others and encouraged the people she cared about to consider helping others as well. This mother's oldest daughter, much like herself, felt that organ donation "was the right thing to do" adding that "it is kind of extra important to me to give back" (2A). She emphasized a need to follow her own ideas of what was right and give back, especially within the medical community. Considering her decision to be a donor, she said:

I feel good about it. I really didn't have any reservations about it. It wasn't something that I really needed to sit down and think about. It was really just I was like "alright, you know what, I'm just going to do it" and there were really no regrets or anything like that when I made it. (2A)

All organ donors emphasized the positivity of organ donation and were highly satisfied with their choice of being an organ donor, as seen in their expressions of pride and lack of regret regarding their decision to become an organ donor.

Personal Connections

Many individuals narrated a story of some sort of personal connection with organ donation, such as knowing someone who has given or received an organ. This close connection made the topic of organ donation more understandable and, in a way, quite tangible for those who got to witness or learn of someone who has already experienced the organ donation process. Individuals who had this personal connection to organ donation were likely to feel favorably toward organ donation.

One daughter referenced an acquaintance who received a kidney from his mother when he was very young. This incident prompted a discussion between her and her mother that led to a positive outlook on organ donation:

I am the same age as this guy and I'm sure Mom knew before I did and we talked about it because my mom looked at that in a positive way and thought she would do that for her kids and I thought it was a great thing that his life was able to be saved from an organ donation from his parents. I thought that if I could do that for somebody, that would be a really wonderful thing to do especially if someone you know needs a kidney and it doesn't require much, like why give away something you

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don't have to give, but if it is someone you love or know, then I could see myself doing that so I feel like that is a positive story and it gave me a good outlook on it. (4A)

Knowing and understanding this experience on a more personal level through an acquaintance helped this daughter form her positive outlook on organ donation.

Another daughter similarly experienced organ donation through a friend. Her close friend's father received a heart and she learned about the entire experience. She explained how her friend felt about the situation:

I know she was really frustrated with the process because her dad had been really sick for a long time with heart failure and there is only a certain amount of time you can keep the heart beating for so it was really important that he got an organ as soon as possible so when he finally did get it, I know she had mixed feelings. She was very happy but she was angry at the same time it had taken so long but for the most part I know that she actually reached out to the family that lost a loved one who donated his/her organs so her dad could get his new heart and actually talked about it and everything like that so there is that connection there that she felt from it. (2A)

Observing a friend go through this challenging situation motivated her to make a difference by becoming an organ donor herself. These individuals with close connections received a deeper understanding of the organ donation process.

Other individuals had an experience with organ donation that made them feel more positively about the process, but did not prompt them to become organ donors. One mother who was not an organ donor knew a coworker who received an organ. This coworker was "an 80 year old man" who got "10 more years out of his life after having that liver transplant" (5B). This mother elaborated on his situation, explaining that "he was actually an extremely cranky, grumpy person beforehand with a lot of anger and when he came back, I think he made peace with everybody in his life so those 10 years were 10 very, very quality years in his life" (5B). Although she had seen organ donation affect this individual positively, she still made the decision not to list herself as an organ donor. She felt positively about organ donation after witnessing his experience, stating that "if anything happens to me, my kids are free to go ahead and donate my organs" (5B). However, she felt uncomfortable formally listing herself as an organ donor, citing a need to protect her family before donating her organs. This individual felt that becoming an organ donor diminished her ability to provide for and protect

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her family, as she stated that she believed that being an organ donor prevented an individual from receiving the best possible care in an emergency situation. She explained her hesitation, stating:

I just have this thing about if someone is in an accident and they're in an emergency room- and it might just be a prejudice- that the emergency room staff would look at their license and say "oh this person is an organ donor" and, more so for my kids, I would want them to do everything they could to save my kid's life first rather than thinking "oh there's so many organs that we can harvest and this person's quality of life may not be that great." So I don't want it necessarily on paper that they or myself are an organ donor but if something were to happen to us where at least I had the ability to know that there is no hope that the person would survive, then I'd go ahead and donate the organs. (5B)

This mother's primary concern, which was a common theme between mothers, was to protect and provide for her family first. Because she had this feeling about organ donation that led her to sense that being an organ donor would not allow her to protect her family, she chose not to formally become an organ donor. Overall, this experience gave her a positive view of organ donation, but she remains a non-organ donor.

Additionally, another mother who is not listed as an organ donor had "a cousin who had a kidney transplant" as well as a cousin that ended up "donating her entire body to Boston University" (3B). Despite having this experience with organ donation, she is not currently listed as a donor. Her close experience with her cousins led her to have a positive outlook on organ donation, causing her to state "I'd want to do it for somebody hoping that somebody would want to do it for me" (3B). Though her outlook on organ donation was entirely positive after witnessing the experiences of multiple family members, she still remains listed as a non-organ donor because, as she verbalized, she simply has not found a way to register as an organ donor. She laments the lack of information available about organ donation as well as instructions on formally becoming a donor. Regarding the lack of information available to her to assist her in making the decision, she states:

Even at the registry it's like "do you want to, or don't you want to" and there's not a lot of educational information. It doesn't give you any details of how or the pros and the cons or anything like that or some frequently asked questions. The unknown is scary to people. That's probably a big problem. It does need to be more out there and it's not. If I remember, it is just a card and there is not a lot of information with it.

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The unknown is scary, so it is just so easy to not do it because you're not comfortable with it. (3B)

Her personal connections to organ donation through family members who have given and received organs gave her a positive outlook on organ donation that made her want to be an organ donor. However, she still remains a non-organ donor because she feels as though she has not accessed the information or had the ability to formally become an organ donor.

Non-Organ Donor Pairs

One theme that was prevalent among the individuals who were not organ donors was a tendency to reference popular myths and misconceptions about the organ donation process. The most common misconception about the organ donation process is that in the event of an emergency, an individual who is not an organ donor will get preferential treatment. Conversely, an individual listed as an organ donor will not get immediate or effective treatment in an emergency situation, as practitioners will justify that they can use the patient's organs if they do not survive. One mother was concerned that this circumstance was probable. She expressed her fear of losing the best care that she could receive:

I just have this thing about if someone is in an accident and they're in an emergency room- and it might just be a prejudice- that the emergency room staff would look at their license and say "oh this person is an organ donor" and, more so for my kids, I would want them to do everything they could to save my kid's life first rather than thinking "oh there's so many organs that we can harvest and this person's quality of life may not be that great." So I don't want it necessarily on paper that they or myself are an organ donor, but if something were to happen to us where at least I had the ability to know that there is no hope that the person would survive, then I'd go ahead and donate the organs. (5B)

Her idea that non-organ donors receive preferential treatment prompted this individual to remain a non-organ donor.

In addition to concern about emergency care, a number of individuals simply did not understand the validity or legitimacy of the organ donation process, creating fear and skepticism that prevented them from donating. One daughter explained that she was tentative because she did not fully understand the organ donation process and needed to know "how much of a risk it is" (3A). She wanted to comprehend how the organs were extracted and

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transplanted, asking if there are “certain organs they can take that would make you not look right” (3A). In conversation with her mother, she attempted to grasp more of the process:

I asked her- because the way I look at organ donation is that since there are people who don't put it down and I don't see that there are many reasons not to put it down that you're an organ donor but I know that people do, so is there more information I don't know about? So, I think I just asked my mom what makes people more reserved about it and I think that she said that some people don't want to have their body cut into after for families or something like that but that is as deep as it went. (3A)

This individual, like others who felt that they did not understand the organ donation process or fell victim to common misconceptions were more hesitant about the organ donation process overall.

Also, non-organ donors cited efficacy as a reason they did not become a donor. These individuals who lacked the efficacy to become organ donors felt that they did not have enough information or the ability to become organ donors for various reasons. For one mother, her positive attitude toward organ donation was not enough to make her a registered organ donor. She remains a non-donor because she feels as though she does not have the information or ability to become a registered organ donor. When explaining her reason for not becoming an organ donor, she expressed her desire to be one, but vocalized confusion as to how to become one. When prompted for the reason she is not currently an organ donor, despite wanting to be one, she voiced her frustration with the process of declaring oneself an organ donor upon renewing a driver's license:

I mean, when does that come up, every 5 years or something? So it's just, last time I don't know why I didn't do it. I don't know if I didn't think of it. I just remember taking a card from somewhere meaning to fill it out- it must have been the registry- and I don't think I ever did. I know it states it right on your license. So, I just have to do it. I have no reason. I just think maybe it's something that should be made easier for people to do, like, just having it at the registry is probably not the best idea, you know, it just doesn't come up enough. It's not in our faces enough is what I'm trying to say. (3B)

This individual, despite wanting to be an organ donor, is currently not declared as one because she lacks the information necessary to formalize her status as an organ donor.

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DISCUSSION

Overall, there were a number of themes pervasive among the interviews and subjects. First, it was clear that mothers and daughters had similar attitudes toward organ donation since they all listed a consistent organ donor status, whether both mother and daughter were organ donors or non-organ donors. Additionally, in explaining the decision on their organ donor status, they used consistent language, either using the same phrases or similar terminology to express the reasons for their ultimate decision. Another prevalent commonality was that all mothers expressed a “family first” attitude that emphasized that they care for their families more than anything and would go to great lengths to ensure their happiness and safety. Additionally, daughters expressed a “willingness to explore,” or a willingness to think about their organ donation decision and change it based on time or situational factors. Most of them were flexible in their decisions and could see themselves changing their current opinions at another point in time. All individuals who identified themselves as current registered organ donors felt positive about their decision. Alternatively, non-organ donors frequently mentioned misconceptions and efficacy issues in becoming an organ donor. These individuals did not understand the organ donation process, and this made them express reluctance to become an organ donor. Others did not feel that they had the necessary information or ability to register to become a donor. Many of the organ donors had some sort of vicarious personal experience with donation that prompted them to consider organ donation. These individuals knew of someone who had either given or received an organ at some point in time. Conversely, a number of non-organ donors had personal experience, knowing someone that had either given or received an organ, which had provided them with a positive outlook on organ donation. However, these individuals still opted out of becoming a donor. Overall, there were many themes that emerged among similar individuals.

The first interesting theme that emerged was the similarity in feelings regarding organ donation and the consistent organ donor status among mother-daughter pairs. All mothers and daughters listed the same organ donor status, whether they were both organ donors or non-organ donors. In addition to this, they expressed the same attitudes toward organ donation. Even in explaining these attitudes and the ultimate reason they chose whether or

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not to become an organ donor, the mother-daughter pairs used the same language or similar phrases in articulating their feelings. From their similar attitudes vocalized in a relatively cohesive manner, it was clear that the close relationships within the mother-daughter dyads led to similar experiences throughout life and shared values regarding family and health issues. Their similar experiences and values were reflected in the nature of their explanations of the ultimate reason for the decision regarding their organ donor status and their attitudes regarding the topic itself.

This is consistent with other research on the mother-daughter bond, which maintains that this is an extremely close bond held by frequent communication. Mothers and daughters hold a close relationship as this relationship in particular “is most likely to remain important for both parties, even when major life changes occur, such as the daughter’s marriage or mother’s illness” (Bojczyk et al., 2011, p. 453). Mothers and daughters grow together, sharing in experiences throughout their lifetime, demonstrating that this bond is “lifelong, intimate, and developmentally important” (p. 453). It is not uncommon for mothers and daughters to share the same attitudes, as they share in many of the same life experiences and values.

Additionally, they hold no hesitation in sharing their feelings and opinions, especially regarding health issues like organ donation. In the specific case of organ donation, “women are more likely than men to discuss [organ donation], and daughters and sons are more likely to speak on the topic to their mothers than to their fathers” (Pitts et al., 2009, p. 414).

Mothers and daughters are more open and willing to discuss their attitudes with one another, creating mutual influence. Because of the close bond between mothers and daughters and the extent of their disclosure, it is evident that mothers’ attitudes are related to daughters’ attitudes, even when considering the subject of organ donation.

Another interesting element was that individuals who were formally registered as organ donors all looked positively on their decision and held a positive attitude toward organ donation. This is not surprising, as overall, organ donation is supported by “the majority (95%) of Americans” (Pitts et al., 2009, p. 413). Additionally, “attitudes toward OD also play a key role in determining how likely a person is to be an organ donor” where “positive

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attitudes toward organ donation are often related to OD as a form of altruism” (p. 414). People who feel positively toward organ donation exhibit a sense of altruism that leads them to donate. This altruism is “associated with increased empathy as well as feelings of involvement with OD” (p. 414). Altruistic individuals who hold a positive view of organ donation feel personally involved in this important cause, contributing to their need to be a donor. Therefore, it stands to reason that those who are already declared as organ donors hold a positive attitude toward organ donation.

Another theme that emerged was that many individuals had some sort of personal connection with organ donation. Many individuals cited a secondhand experience that they had with organ donation, knowing someone who had donated or received organs and experiencing the process and gaining knowledge vicariously through them. A number of the individuals who recalled a story of a friend or relative giving or receiving organs were organ donors themselves and knowledge of their experience prompted them to become donors. Observing a third party partake in the organ donation process prompted these mother-daughter pairs to have a conversation about the topic or simply further enhanced their positive attitudes toward organ donation, causing them to register as an organ donor. Conversely, a number of individuals who are not currently organ donors had a personal connection with organ donation. Although this connection did not prompt them to become a donor, it did contribute to positive feelings regarding organ donation. Having a close connection to organ donation also helped lead to feelings of involvement within these individuals, which are closely linked to empathy and altruism (Pitts et al., 2009).

In many cases, it is evident that personal connection to organ donation and positive attitudes regarding the subject lead to commitment to donation. All individuals that were organ donors felt positively about the decision and a number of them had a personal connection to organ donation that brought the subject into their life, making them consider the decision to donate. However, a number of cases exist where the individual feels positively about organ donation and occasionally even has a personal connection to organ donation, knowing someone who has donated or received an organ, yet the individual opted out of becoming an organ donor

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when given the option. In these circumstances, a number of mitigating factors prevented them from becoming an organ donor despite positive attitudes and personal connections. One prevalent mitigating factor was misinformation or overall lack of information while another factor was efficacy issues. These mitigating factors were not random, as they were common and prominent in other studies. It was found that “negative attitudes toward OD are linked to myths, misunderstandings, and misconceptions” (Pitts et al., 2009, p. 414). In this particular case, the individuals felt positively toward organ donation, however, the misconceptions created reluctance or hesitation in becoming an organ donor. Some common beliefs such as “that brain-dead people are not really dead, that signing an organ donor card will negatively affect the quality of hospital care, that OD incurs additional costs, that organs are bought and sold on the black market, and that OD precludes the family from having a ‘normal’ funeral service” are what “have been identified as the biggest obstacles health promoters must hurdle to increase organ donor consent” (p. 414). These common ideas were present for a number of individuals who felt reluctance in becoming an organ donor based on those factors. In other cases where mitigating factors prevented the individual from being an organ donor, they were simply ineligible based on health problems.

Overall, it is evident that a positive attitude as well as personal connection contributes to commitment to donate in cases where there are no mitigating factors. Mitigating factors including misinformation, inability to donate, and efficacy issues, which often stem from lack of knowledge, create reluctance in becoming an organ donor.

Limitations

There were a number of limitations associated with this study. One of the limitations was the sample size. In this study, the sample size allowed for extensive conversation and great depth within the interviews. Participants provided a significant amount of insightful information and were able to freely express any feelings they held. However, it would be interesting to replicate this study with a larger and more diverse sample to obtain comparative results. More participants, especially more diverse participants, could translate to more insight from these individuals regarding family communication and organ donation which would allow

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more themes to emerge. This would likely give a more inclusive explanation of the factors that influence communication within the family regarding organ donation.

Additionally, all interviews were conducted over the phone and audio recorded. This method was convenient for participants and allowed for better protection of their identity, so they were able to comment openly on their opinions regarding organ donation as well as their family relationships. It would be an interesting experiment in a similar study to visually record interviews. Interviews with a visual component could not only be analyzed for themes, but also for any nonverbal communication or behavior that occurs with the participants. Additional factors including tone, facial expressions, and other nonverbal signals could be factored into all responses.

Future Directions

The themes uncovered in this study have practical applications in the field of health communication, namely health campaigns. These themes point to the concerns that individuals have when considering a decision on becoming an organ donor. Understanding what contributes to commitment to organ donation, such as a positive attitude, as well as having a sense of what creates hesitation, such as mitigating factors like misinformation and efficacy, aids in structuring organ donation campaigns. Health campaigns could be tailored to individuals who are not donors, addressing their misinformation and efficacy concerns and touting the benefits and importance of organ donation to lead these individuals toward commitment. Additionally, campaigns aimed at individuals who are already organ donors should leverage inoculation theories to keep their attitude toward organ donation and their organ donation status consistent throughout time, despite persuasion and counterarguments. This would assist in increasing the number of organ donors, potentially saving the lives of the numerous individuals waiting for a vital organ.

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APPENDICES

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Appendix A – Interview Questions

1. Are you an organ donor?
 - a. When did you decide to become one?
 - b. Why?
2. How do you feel about being an organ donor?
3. How much do you know about organ donation?
4. How do you feel about organ donation?
5. Do you have any personal experience with a family member, friend, or acquaintance donating organs?
 - a. What was this experience?
 - b. What was it like?
6. Has anyone in your family received a donated organ?
 - a. What was this experience?
 - b. What was it like?
7. How do you feel about someone in your family being an organ donor?
8. How open is your relationship with your mother/daughter in terms of communication?
 - a. How often do you talk to one another?
 - b. What is the nature of your conversations?
 - c. Is health a topic that appears in conversation?
9. Are you comfortable communicating about health topics with your mother/daughter?
 - a. Have you ever discussed organ donation?
 - b. Give an example of a time when you discussed health.
10. Have you discussed organ donation with your mother/daughter?
 - a. How did the conversation begin?
 - b. What was the nature of the conversation?
 - c. What were the outcomes?

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Appendix B – Interview Transcripts

Transcript 1A

Are you an organ donor?

No

When did you decide that you did not want to be an organ donor?

Probably when I was like 16.

May I ask why?

I have diabetes so I don't think I am actually able to donate my organs.

Had you had the ability, do you think it would be different for you?

Yeah, I think so. I think I would do it.

How much do you know about organ donation?

Just probably general knowledge. I don't have any detailed knowledge.

If you were to be an organ donor, how would you feel about it?

I think that it's a good thing helping someone else.

Would it have been a difficult decision for you or something you would have easily decided to do?

I think I would have thought about it for a little while and maybe like talked to some of my family members but I think I have a pretty good idea of what I would do.

You said you had talked to your family members, who do you think you'd go to in this situation?

My parents.

Is there one in particular you would turn to over the other?

My mom.

Your mom. Is there a reason?

I don't know. I'm closer to my mom and she works in the health care field, so she might know a little more.

Does her experience in the health care field influence any of your decisions?

I wouldn't say it influences my decisions, like I said, she just might know more about the process and could help me decide.

Is she an organ donor herself?

I don't know, actually.

So it's not something she has ever communicated openly with you?

We might have talked about it very briefly when I was getting my license and considering the organ donation but we haven't talked about it at length and, like I said, I don't know if she is an organ donor so she's never told me that.

Are you comfortable communicating about other health topics, other than organ donation, since that hasn't come up with your mother?

Yeah.

What do you tend to talk to her about/go to her for advice for?

I'd say my diabetes, that's my most prevalent health issue and multiple people in my family have it, so, I talk to her a lot about that and my dad too since he has diabetes.

What is the nature of those conversations about those other health topics like your diabetes?

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Probably just talking about how I am feeling, like, if my blood sugar is low or something, just telling her what that feels like. Then, talking about prescriptions, picking those up, and stuff like that.

Do you feel comfortable talking about this health issue with her?

Yeah.

So would you categorize your relationship with your mom as fairly open?

Yeah.

How often would you say you talk to her?

Well, when I am at home, every day we talk to each other. I'd say when I'm here at school, at least 2-3 times a week.

So it seems you are pretty comfortable with your family.

Yeah.

And the nature of those conversations? Positive?

Yeah.

When it comes to health, does it stay positive or does it ever get negative?

They're usually positive.

I know that your mother isn't a donor, but has anyone in your family had an experience with donating or receiving?

Not that I know of or can remember.

Is anyone else a donor?

I'm sure some of probably them are but I don't know for sure.

Do you have feelings about members of your family opting to be a donor?

I think I would be okay with it, because like I said, I think it is a good thing and I think I would support my family members if they chose to be organ donors.

Do you think they'd do the same for you if you had a choice?

Yes, I think so.

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Transcript 1B

Are you an organ donor?

I used to be but I can't be now, I don't think, because I am diabetic.

When did you decide to be one when you were?

I think when I first got my license.

Was there a particular reason you decided to be one?

Well, I figured I could help someone. If my parts were any good I could help someone by doing it.

How did you feel about being an organ donor when you were one?

It was positive, yeah.

How do you feel that you can no longer be an organ donor?

Well I wish I could be if my health was better.

How much do you know about organ donation now?

Not that much. Just the basics of it probably.

Have you ever had personal experience with someone you know donating their organs?

No.

Do you know anyone who has received an organ?

No.

How would you feel if someone in your family, say one of your daughters, was an organ donor?

That would be fine with me, because, same reason, they'd be helping somebody.

In terms of your relationships with your daughters, how open is communication with your daughters?

I'd say it is pretty good.

How often do you talk to them?

Well, (younger) every day and (older) as often as I can.

What are some topics that come up in your conversations?

Not sure, just basic day-to-day things, or, I don't know.

Is health something that comes up?

Yeah, sometimes.

What health topics usually?

Well, (older) being diabetic, her health, how she's feeling, and make sure she's doing alright with that situation.

Are you comfortable communicating health with your daughters if it came up?

Oh, it's fine. Yup, yup.

Have you discussed organ donation with them or your opinions on it?

I mean, I don't know if that has ever come up but yeah.

Have you ever expressed to them that you are an organ donor?

I don't think so.

What about the reverse? Have they told you their preference on the subject?

No, I don't think so.

If you were to have the conversation with them, would you tell them your opinion?

Yeah, I probably would, yeah.

Do you think you would encourage them?

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Oh, I would encourage them, yeah, if they were able to. Like with (older) I don't know if she can, like I'm diabetic, I don't know if you can do it but I would definitely encourage (younger) to do it. She just got her license, so I'm not sure if she put it on there, but I think she might have. I would have to check.

If (younger) were to become an organ donor, do you think she would tell you about it?

Oh, yeah, I'm sure she would.

It would be a positive conversation?

Oh yeah, I just can't remember. She got her license the past summer. She might have done it. I have to ask her.

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Transcript 2A

Are you an organ donor?

Yes, I am

When did you decided to become one?

I'm pretty sure it was my freshman year of college so I was 18 at the time.

Why did you decide to do it? Was there any particular reason?

There wasn't really one particular reason, I just kind of felt like it was the right thing to do especially since I am in the medical field. One of my friends owned this nonprofit called Take Heart for organ donation that tries to raise awareness about the importance of it and her dad ended up needing a heart transplant and waited years to get one and it's something that a lot of the time you can't come around organs very often because of different blood types and stuff, especially for children and everything, so especially since I have a very rare blood type it is kind of extra important to me to give back and stuff.

Was that the main reason you decided to?

Yeah, for the most part. It's just like I watch a lot of Grey's Anatomy and stuff, but no, I'd rather have my organs go to good use if something were to happen to me than to, you know, I'd rather save a life or multiple lives, if I can, if something were to happen to me.

Now that you've made the decision, how do you feel about the decision?

I feel good about it. I really didn't have any reservations about it. It wasn't something that I really needed to sit down and think about. It was really just I was like "alright, you know what, I'm just going to do it" and there were really no regrets or anything like that when I made it.

How much do you know about organ donation? It seems like you know a lot since your friend has that charity.

Yeah, pretty much. Not just with her, but also with just my major and being pre-med and stuff like that, it is just something we talk about a lot in our classes.

What is the conversation like in your classes?

For the most part, it is a pretty positive conversation. We are always talking about how you can't... there is no guarantee that someone on the organ donor or on the organ recipient list will be able to get the organ you need and there is such a shortage of them as well. We are always talking about the technologies they are trying to come up with to make the organs more viable for a longer amount of time because what they find is that the organs have to be within a certain radius of the hospital and if they aren't, then that organ is going to go to someone else maybe lower on the list so they're trying to create new technologies that try to allow hearts to be kept beating for 3 to 4 up to like 12 hours so that way if an organ needs to be transported across the country, they can do that.

Do you have any experience with anyone you know actually donating organs?

No, I do not.

Has anyone in your family received an organ? I know your friend's father has.

Nope.

Do you know anything about your friend's father receiving the donated organ such as the process or their feelings toward it?

I know she was really frustrated with the process because her dad had been really sick for a long time with heart failure and there is only a certain amount of time you can keep the heart beating for so it was really important that he got an organ as soon as possible so when he

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finally did get it, I know she had mixed feelings. She was very happy but she was angry at the same time it had taken so long but for the most part I know that she actually reached out to the family that lost a loved one who donated his/her organs so her dad could get his new heart and actually talked about it and everything like that so there is that connection there that she felt from it.

Is your mom an organ donor?

I have no clue.

How would you feel if she were one?

I'd be okay with it. I really wouldn't have any problems with it at all.

How open would you say your relationship is with your mother in terms of communication?

I think we are pretty open in our relationship. I mean, I don't tell her everything about my life or everything I do or something like that just because I like to keep some independence and I know my mom likes to let me do my own thing and doesn't like to be nosy or anything like that but I mean she sees on Facebook so it's not like she doesn't see what's going on or anything but I can say it is an open form of communication, like, I know that if I need to talk to her about something I could.

How often would you say you have conversations?

I'd say for the most part I talk to my mom like a couple of days a week nothing too big, normally, just like text messages or whatever but it isn't really deep or anything like that, just basic.

Is health a topic that comes up in conversations?

Not really. Not unless I need something, like I need to get my prescriptions filled or I need to come home to make an appointment to see my doctor or anything like that. That's really like the only time it comes up or if it has to do with the health insurance or something.

So it would be more specific and not just something you would bring up?

Yeah.

So, has organ donation ever been a topic that came up?

Oh no, not really, I think I pretty much, I was already an organ donor before I renewed my license when I turned 21, but when I went there I checked off the little box to put it on my license and I came back and I said "hey, mom, I put the organ thing on my card" and she said "oh, okay, cool" and that was about it.

You would say she had a positive reaction to it?

Yeah, like it wasn't like something out of the ordinary or something she wouldn't expect from me or anything like that.

So it was something she was comfortable with, with you?

Yeah, I mean, it seemed like it.

Can you give me an example of a time when you went to her for anything for your health? Prescriptions?

Yeah, pretty much. Any time I'm up at school my prescriptions are getting filled back at home, especially for my Adderall, all of that is still at home because it is easier to get it from there and I'll call her to pick it up and get it for me and sometimes she'll mail it to me or I'll plan to come home and get it, but it is just on an as-needed basis.

Do you experience any difficulty when talking to your mom? Any tense issues?

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Not really, just more or less any time any issue has come up, recently, in between health insurances and lost it in December, her and my dad were trying to find a health insurance plan and that was a bit of trouble because I had to get my prescription filled and it was going to be \$375 without insurance and that wasn't counting my sister's prescription she needed or my father's prescription but that was the only time I really thought hey, can we get this going because I really need my medication?

But you weren't worried about talking about it?

Nope.

It was just more of a money conflict?

Yeah, pretty much.

Have you ever had a conflict where you broke news in terms of your health that didn't go over well?

I'd probably say back in high school when I was having mental health issues and I couldn't figure out what was going on with me and I was a mess that was kind of tricky because no mother wants to hear that their kid isn't alright and sometimes they kind of take the blame for this because they think this is my kid and I probably did this, but it's not the case at all, so that was kind of tough but eventually we got there but it was that first thing that we really realized that we had to do this because I was on a downward slope. Just at first it was tough but after a while it got a lot easier and now it is like "oh hey, mom I just need to go to the doctor to fill my Adderall prescription" and she's just like "okay."

So now your conversations are simple and positive?

Yeah. At first it is hard to explain something new to someone because, it depends on the topic because some are more complicated than others because mental health is more complicated than, say you have a kidney infection, because mental health is an everyday thing and there is no pinpointed answer to the problem but kidney infections, you treat it and it is good to go and you know what caused it and stuff but having to explain it is the toughest part.

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Transcript 2B

Are you an organ donor?

Yes.

When did you decide to become one?

I think the first time I renewed my license after I got it so I have been an organ donor for a long time.

Is there any reason you decided to become one?

I just felt that it was the right thing to do. If something did happen to me, then I should do that.

Now that you've made the decision do you still feel the same way?

Absolutely. I think that my younger daughter is an organ donor and I don't know if my older one is. I can't remember if she did or not but I think she did.

How much do you know about organ donation?

I actually don't know much about it.

So you just feel positive about doing it because it is a good thing?

Yes.

Have you ever had any personal experience with someone donating organs?

No, I don't... nope.

Do you know anyone who has received an organ?

No.

How do you feel about your daughters being organ donors?

Well actually (younger) did ask me when she got her license and I actually suggested that she do it. I said what if something did actually happen to you and you could save somebody else's life that needed an organ, I think that makes the family feel better and I think that is the right thing to do to help somebody else out that is struggling with something that needs an organ. You know, it could be a little baby, it could be a 12 year old, it could be a 28 year old, you know, I just feel that it is the right thing to do once you're on, you can help somebody else with this.

Is that the only time the conversation about organ donation came up?

Yeah, I actually do think that is the only time it ever came up because that is when the question is really asked is when you go and get your license and you get your license renewed that is really the only opportunity when you have your license reviewed. If you don't, and you decide 5 years later that you want to, but yeah, (younger) had to answer that question, I was happy to be there with her and she asked me and I told her and I don't know whether she did it because of me or if my little speech worked but I don't know.

You don't know how she feels about the decision?

I actually don't know. She did put it down. I know it is on there. I said it is up to you, this is why I did it, if you decide to do it then that is fine I think it makes it easier on the family knowing this is something you want to do because that question is always brought to a family if something did happen they always ask if they can do it and they always asked the family and it is a decision you have already made for the family.

Is your relationship with your girls open?

Yes. I try to. I think it is more open with (older) than it is with (younger). (Younger) is more private.

How often do you try to interact with your daughters?

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Oh, I don't know, I try to stay involved with their stuff at school and you know, they text me all of the time, they call me all of the time, I mean we talk about everything really, what is going on at school, we try to keep an open line of communication if anything is going on. They know that they can always call to talk to me or to vent or anything like that. (Older) comes home for no reason, just randomly comes home and pulls in the driveway deciding that she just needs a day to be home but it is pretty open and I also don't go beyond those boundaries, you know the Facebook boundary and stuff like that I kind of, they're adults, I want them to grow on their own also but I do want them to know if anything did happen to them we would be there for them.

Is health a topic that comes up?

Yeah, it does, like I said (younger) is more private. With (older), they do their physicals, they get their regular checkups once a year but there isn't anything really that happens that I've needed to have any kind of real in-depth concerns with either one of them, so I don't know whether... If they had to ask me a question about something that is going on with their health they would call me. Both of them are over 18 now and I'm not really the boss and I can't get really involved, like if they don't want to tell me things they don't have to.

So if it comes up it comes up?

Yeah, and they're pretty good about it. They're not afraid to tell me what's going on but it's not like I can call the doctor and find out.

What topics normally come up regarding health?

I would say it is usually the monthly curse, if you want to call it that, and stuff like that. We just talk about what they need to know like GYN and that kind of stuff but basically they don't have any stuff that they need, they go to those two doctors, they go to their regular doctor and the GYN so it's not anything that has really been brought up and neither has a lot of issues with that so we don't really have anything to talk about there. My (younger) was having some issues there and she called me and I set up the appointment so she is going to see the doctor but she calls me first and I have to make the phone call for her. Other than that, (older) is really on her own.

Conversations are generally positive?

Yes, always positive.

And open? Anything you can't talk to them about?

No, I wouldn't say so. I don't think there is a topic I wouldn't discuss with them. If they had a question I don't think that they would not come to me. I would hope not because I think I am pretty open. I do think I am pretty open to almost anything that would come up.

If it was questions about organ donation you'd talk to them again?

Oh yeah.

You would state your view if it came out again?

Oh yes I would definitely do that.

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Transcript 3A

Are you an organ donor?

You know, honestly, I don't think I am. I don't remember what I put.

Was that a conscious decision not to be one?

I just remember the last time I was at the RMV, the last time I went to renew my license, I think I had to answer a question on that and I think I said no because I felt like I didn't know enough information about it. So, I'm considering it, I've always been considering it, I just didn't know how much of a risk it is. So you die or something is your family going to want to, I don't know. Are there certain organs they can take that would make you not look right? Things like that.

You feel that not knowing a lot makes you hesitant?

Yes, yes.

Do you know anyone who has donated/received an organ?

I don't know anyone who has received an organ. I do have a cousin that has donated her body to science. Yeah, the one that just passed away she wanted to donate it because she was always into running studies and she didn't think they were going to take it but they did take her body. I've definitely considered it too but I want to look into it more before I actually commit to it.

How did your family feel about your cousin donating her entire body?

They were happy because they knew that's what she really wanted. She wanted that, she wanted to be cremated, she had a mass because she is a very private person so she had everything quiet.

How do you feel about the topic?

I think it is a good thing to do since there are so many people who need organs and there is a list and everything. I'd like to be an organ donor if I knew more information about it one day.

How would you feel if someone in your family were an organ donor?

Well if I knew that was what they, they wanted to help somebody, I'd be happy if their passing could help someone else.

Is your mom an organ donor?

I'm not sure if she is or not.

How open is your relationship with your mother?

It's pretty open about most things.

How often would you say you talk to her?

Daily.

What's the nature of your conversations?

Usually it is pretty casual.

Is health a topic that normally comes up?

Yeah, when it is relevant. I mean if I had any health concerns, she's the first person I'd go to.

So it only comes up when there is a concern?

Yes.

Are you comfortable talking about it when it comes up?

Yes, for the most part, there are obviously certain topics that are awkward to talk about with your mother but if I knew I had to talk to her I would.

No reservations about questions?

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Yeah, there is nothing that I would never tell her. Things like sexuality are awkward to talk about, but if I knew I had to, I could go talk to my mother.

Have you ever ended up talking about organ donation with her?

I think I remember asking her about it but we weren't opening up a big discussion about it because I wasn't really that urgent about finding information.

When did it come up?

It was after I renewed my license.

What happened?

I asked her- because the way I look at organ donation is that since there are people who don't put it down and I don't see that there are many reasons not to put it down that you're an organ donor but I know that people do, so is there more information I don't know about? So, I think I just asked my mom what makes people more reserved about it and I think that she said that some people don't want to have their body cut into after for families or something like that but that is as deep as it went.

She didn't express opinions on the matter?

No, she didn't seem to have an opinion one way or the other. I think she feels the same way I do, really.

Did that conversation seem different at all?

No, it didn't seem uncomfortable. I was comfortable going to her with it.

What do you talk about the most regarding health?

If I had more health concerns, it would probably come up more but for the most part it would be prescriptions and how can I get them.

What is the nature?

I guess it is pretty positive. It is always pretty straightforward. I mean, mostly, it is casual. How can I get what I need and do I need it?

Have you had any negative interactions about health?

I think there have been times where I have family in the hospital, and as a nursing major, I am a little more educated on how hospitals work and everything, so sometimes in those aspects when they don't understand they'll be outraged about something that isn't really a big deal.

Your mom will come to you sometimes too?

Yes, all of the time. Way more than I know she will ask me.

And she is comfortable doing that?

Yes, very very comfortable.

Does it bother you at all?

No, I like being quizzed. Although most of the time I won't know the answer and I will have to look it up but when I look things up I understand it better than she does. I don't always know the answers but I can find things. To talk about health things is pretty casual for me, because it is all I do, so I don't really feel uncomfortable about it.

If you had to bring up the topic of organ donation, would you feel okay bringing it up?

Yeah.

Is there anything you would say or ask?

If she asked me about it, I would do some research and look things up before I said anything because I don't know much about it but I think what I've asked is what are your options afterwards? Is your body attacked? Like what are the consequences? Are there any? Stuff like that.

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Any other concerns?

No, not really. I don't know if I even have a reservation about that. I just wanted to know if I was ready to commit to it. I didn't know if that was all there was to it. I really think that if you pass away and get to save someone's life, it's all better. It makes it worth it.

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Transcript 3B

Are you an organ donor?

You know what is terrible, I held out this form from the registry to sign up to do it and I really don't think I have yet. However, I intended to and I really need to.

So you're not currently, but you have the intention?

I have not officially filled out the paperwork to do it.

What made you decide to become one?

Oh, just everything. I have a cousin who had a kidney transplant and I know what it was like for him in waiting for the kidney... what they went through to get it for him. Then, just, I don't know how much (daughter) told you about my cousin that just passed away. She did the ultimate in donating her entire body to Boston University. It was just so important to her to do that and just seeing that kind of motivated me to want to do the same thing. She was a teacher her whole life and like her boyfriend said, she was a teacher to the end, you know but with her, she went through so much with her cancer and her sickness, she wanted some good to come of it all and that motivated me to want to do the same. I think it comes from... well, my brother in law, I don't believe he was officially a donor but when he passed away I was at my sister's house and the phone calls started almost immediately where someone calls you to ask if you would donate organs and it's a tough decision to make when you're on the spot like that and that's why I would like to do something ahead of time, you know, because it's hard for the family to make that decision in the heat of the moment when it happens. So, I think it's a good idea to get your ducks in order before it ever becomes an issue like that. Even with my brother in law, it was a tough call whether to have an autopsy done or not and he died of what we think was a heart attack so it was sudden, he was only 52 years old, and at the time it happens like that, it's tough to think "okay, now they're going to be slicing him open." It's hard for the family to make those kind of decisions. Now, looking back at it, we're wishing we did because you really want to know for his kids' sake what he actually died of. So, looking back, not that that has anything to do with organ donorship, but I brought that up because we had agreed to the organ donorship when it happened and my sister got a lot of nice letters, they used his skin, burn victims used his skin, also there was parts of his eyes, cornea were used, so if you can help someone to see or whatever, why wouldn't you?

This is the first time I've heard a story regarding tissue donation. It seems to be less common.

I do believe they used his liver as well, which we were chuckling at because he was a bit of a drinker- not a bad drinker- but we were chuckling. Definitely a social drinker! I'm sure that you doing this interview will light a stick of dynamite under me. I know when you go to renew your license, you can put it on there, so that's what I have to do. I took the card to fill out last time and just never followed through with it, which was stupid.

It sounds like you have a lot of personal experience. Who received the kidney?

My cousin. In fact, it's the cousin that just passed away, her brother. He has since passed away as well but he lived quite a long time, I want to say it was 10 years, with the new kidney. He did well with it. I just remember the agony of waiting for the kidney. It's just there aren't enough.

What would you say your overall feelings are after having all of this experience with it?

I just think it's a great thing and I just think if it was someone in my family, especially a kid that you know, you know how much you would want somebody to be able to donate and even

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beyond organs is like bone marrow and all of that. I've also seen that in the family where one of my cousins, my cousin Judy's son, had leukemia and he was looking for... he had 3 siblings in his family and I don't think any of them were a match but even stuff like that, it's a great thing when people would donate. When it hits home you wish. I'd want to do it for somebody hoping that somebody would want to do it for me. The science is better and better all of the time as far as the success rates they have with it.

Was there a reason you weren't an organ donor before?

No, there wasn't. It's something... I don't know why I haven't done it. I just don't even know, I have no reason. I don't know if I just... you do it when you're renewing a license right? At the registry? I mean, when does that come up, every 5 years or something? So it's just, last time I don't know why I didn't do it. I don't know if I didn't think of it. I just remember taking a card from somewhere meaning to fill it out- it must have been the registry- and I don't think I ever did. I know it states it right on your license. So, I just have to do it. I have no reason. I just think maybe it's something that should be made easier for people to do, like, just having it at the registry is probably not the best idea, you know, it just doesn't come up enough. It's not in our faces enough is what I'm trying to say.

Many people say they do not have enough information, would you say that's a problem for you?

Yes, because even at the registry it's like "do you want to, or don't you want to" and there's not a lot of educational information. It doesn't give you any details of how or the pros and the cons or anything like that or some frequently asked questions. The unknown is scary to people. That's probably a big problem. It does need to be more out there and it's not. If I remember, it is just a card and there is not a lot of information with it. The unknown is scary so it is just so easy to not do it because you're not comfortable with it.

How open is your relationship with your daughter?

I guess it is pretty good and the thing is my daughter, because she is in the nursing field, we have been through a lot of this together with my family members and she has been right there with me for a lot of it, visiting people and the ups and downs of it. She's been in the thick of things so we do have discussions about it all.

Are you comfortable communicating about these health topics with her?

Yes, I would say so.

Have you ever discussed organ donation specifically with her?

I don't know if we specifically have. I'm just trying to think if we have ever talked about that. Probably not but as far as my cousin that just passed away, I know that we have talked about her donating her body and we both know how important that was to her and we did have that discussion and what a great thing it was that she was doing. So, in that respect, we talked about it but typically organ donation not so much.

Would you be comfortable with it if she wanted to be an organ donor?

Yes, I would.

The other conversations that come up, are they about family?

Yes, probably and my daughter's health. She has had her ups and downs with different things and I'm on her case about health and you know vitamins and eating right and sleeping enough and all of that kind of stuff because she doesn't do any of that. We're constantly having that conversation.

If organ donation came up, would you feel comfortable talking about it?

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Sure, if I knew the answers.

Would you feel comfortable expressing your own opinions?

Yes, yes I would.

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Transcript 4A

Are you an organ donor?

I am.

When did you decide to become one?

I decided to become one I think when I got my license renewed to get an over 21 license. When I got my first license I didn't check the box.

How come you decided to be one this time around?

I thought it was kind of a good citizen thing to do and I thought if I was ever in an accident or if I ever needed an organ donated I would want someone else to do it for me. I think the first time it felt so serious right away because I was 16 and I don't know, I felt like I wanted to be a part of it and I know some people were nervous about people saying if you were an organ donor then they wouldn't, if you went to a hospital, they wouldn't try as hard to save you or something because they need organs for the list but I didn't think that was true. I understand why people would be nervous about it, but I didn't think it was true. I didn't think that was something I was concerned about.

How do you feel now that you've made the decision?

I feel good about it. I don't think about it too often but I do, whenever I take a look at my license or I hear a story about someone who has had an organ donated I feel good about it. I feel proud that I could potentially help somebody.

How much would you say you know about organ donation?

I know that there are certain organs that people need and people are put into a donor list so they know where they are in relation to getting donors. I don't know too much about the process that would happen after you die. Actually, I do. I guess there is some organ donation that happens when you're alive, like donating a kidney or something, you don't need to it live, but you can do that. But the other group, where it is their business to connect kidneys, there are people who donate their kidneys because someone wants to donate their kidney but they are not a biological match they'll make a deal with another couple that if you give this person's husband a kidney the wife will give your husband a kidney, so there are lots of ways for it to happen. I guess I don't know a lot about what happens if you die and donate your organs. I don't know if you family has to sign off still. I guess the doctors would work with the family out of consideration and see if there are organs that you wouldn't want to take away if you were having an open-casket funeral. I know that sometimes people donate their eyes, they can do surgery to do that. I think for the most part, they take whatever parts they need if you say you're an organ donor and you die.

Do you have any personal experience with anyone you know donating an organ?

I can't remember if any family members have. I do have a friend, more like an acquaintance from school, and I know his mom donated her kidney to him when he was very young. So, I think one of his kidneys failed or something, but I knew he had some health problems and his mom was able to donate to him. I don't know if there are any others.

Do you know anyone who received an organ?

No, other than that story, I don't.

Does knowledge of that process with your acquaintance change your opinions about organ donation at all?

I mean I've known about that story for a long time because I am the same age as this guy and I'm sure Mom knew before I did and we talked about it because my mom looked at that in a

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positive way and thought she would do that for her kids and I thought it was a great thing that his life was able to be saved from an organ donation from his parents. I thought that if I could do that for somebody, that would be a really wonderful thing to do especially if someone you know needs a kidney and it doesn't require much, like why give away something you don't have to give, but if it is someone you love or know, then I could see myself doing that so I feel like that is a positive story and it gave me a good outlook on it.

This prompted a conversation, so what was that conversation like?

I think that it probably got brought up just as a kind of story to share about this boy. I think it was because I mentioned he was always in my class and his mom donated a kidney to him and it was a nice story about him and his mom, their relationship. I know that I... It wasn't specifically brought up because we were talking about organ donation but I did talk to my family about that at different points. Once because I was thinking of saying that I wanted to be an organ donor on my license and we talked about it because we agreed I would read more about it before I became one. I mean, I know Mom and Dad are organ donors because they, like they said, they would want to donate organs if we could, especially to you guys if you needed them. The only real serious conversation I can remember though is there was a movie called John (inaudible). I think Denzel Washington is in it. I'm not sure if it is an organ donation or a blood transfusion that this movie centers around but it's like his son gets injured and needs something, it might be an organ or a blood transfusion, and he can't give it to his son for some reason, like he's the wrong blood type, and he can't do that, but I think the movie is him looking for someone who will give the kid an organ. I think that, in typical Hollywood fashion, he holds people hostage in a hospital at some point and you're supposed to feel bad for him because he is doing it for his son but I think we definitely talked about organ donation after that because it was a topic in the movie. I did think about that because I think the kid did end up getting an organ from someone who was in a car crash and I think that was very serendipitous for him, that person who was in a car crash, but it was a very engaging story.

What was the conversation like after seeing that film?

It was a long time ago so I don't remember exactly but I remember we were... It had been a pretty intense and moving film, so we were interested in talking about it afterward but it was probably pretty serious because we had just seen the story of a guy who was going through so much to try to save his son and it brought those human elements that organ donation is all about to life and it seemed like a very heroic thing to be able to donate your organs to someone who really needed them and I mean, also, what I think about when I think about that movie too is kind of the frustration behind knowing that you're family needs and not being able to give it to them if you happen to not be a match for them so there is that element to it too. And also, how it is asking a lot to ask someone to donate an organ if it is not of their own volition. Not that that would ever happen, that someone would ever make you donate an organ but it is a big deal to ask someone that you don't know to donate an organ like these companies that set up these exchanges between each other, like the dealers, like the person who is your person to get it or you're giving your kidney to someone you don't know. So, I think it was a serious conversation.

Would you say that film and that conversation contributed to your desire to be a donor?

Maybe it contributed to my general mood about organ donation and thinking it was important but I think it was also the time I had spent, the brief time, thank goodness, that I had spent in

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the hospital as an adolescent just for seizures and thinking that I... It wasn't an organ donation situation where I needed something like that, which was very good... but I was just thinking about being a young person who has that kind of experience where there is an emergency and you have to go to the hospital, I don't know, I just felt like I wanted to give back and be a part of helping other people in some way where I could because I felt like I had gotten good treatment and they did everything they could have for me and it just appealed to me to be able to say that I was part of this connection, that I would be able to give an organ. Also, I felt like if something terrible happen and you died, I wouldn't need my organs anymore but someone else might and why have both of us die? I mean, why not give that person my whatever? They can have it.

How do you feel about your other family members' decisions to donate? Is it something you feel good about?

Yeah, I mean, I am proud of them for being an organ donor and love them for it partially because I know that for my parents they wanted to be a part of that decision if it was for me or (younger sister) or if another family member needed something like that, they would want to be able to give an organ to us without there having to be too many... too much red tape, but also if you think about what people are worried about or the worries that most people have they would say "oh, do they not get the same quality care if they are in the emergency room if they say they are an organ donor" and they need that organ. They think people just look at them like they're some great livers or something really morbid but also part of me feels like we would take care of that if they were a relative. If they were in the emergency room, we would make sure that they, or at least to the best of our ability, they would be given all the care they could be and wouldn't have people just taking their organs. So I mean, I am glad that they are. I would be worried about them anyway if something happened to them and they were in the hospital but that would just be something else to keep an eye on. I love that they are organ donors.

How open is your relationship with your mother?

Very open. We chat a lot and I feel like we are pretty similar. I like to talk to her and she knows about stuff that... I talk a lot in general and I will share stuff if something is bothering me or I am happy about something.

Is health in general a topic that appears in your conversation a lot?

Oh yeah, I mean sure, especially with Nana and stuff that has been going on with that, with her being sick for a long time. We do talk about it especially because Mom will stress how important it is to go to the doctor and get tests and get checked for things especially because Mom knows Nana was sick from a very young age and with the history of heart problems, especially with other relatives with cancer, she wants to make sure we are always getting ourselves checked and always staying on top of that.

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Transcript 4B

Are you an organ donor?

Yes, I am.

When did you decide to become one?

When I became a mother 22 years ago.

Was there a particular reason?

Yes, there was. It was the birth of my oldest child and thinking about how grateful I was to have that child and if she ever needed anything to sustain her life that I wanted that available to her and if I wanted that benefit, that gift, then should be willing, also, to give that gift.

How did you feel when you made the decision initially?

Completely at peace with it.

Did you know anything about organ donation prior to making that decision?

No, other than hearing about successful transplants on the news and I don't think I actually knew of a friend or family member or colleague that actually had a transplant but hearing the success rate it felt like the right thing to do.

Any experience with anyone donating or receiving organs?

No, I do not. I would say this: no, no one I know received a transplant. When my dad died in 1997, at such a young age, I always wished he was a candidate for a heart transplant, but he wasn't, he was too sick. The only other close to home story that I have now is that I have a dear friend who is sick, kidney cancer, and I'm hoping that at some point she would be a candidate for a transplant because this year she already had to have one kidney removed.

Do you feel that you know more now than you did then?

Just more and more that you hear about successful transplants and also, maybe this is another question, but as soon as the girls got their driver's license they opted to be organ donors, so it is something we discussed as a family.

How do you feel about someone else being an organ donor?

I think it is great and all four of us in the family are organ donors.

It's something you've had a conversation about every single one of them about?

Only that they knew my preference, never to encourage anyone else, everyone made that decision on their own. (Husband) made that decision on his own 22 years ago at the same time as me for the same reasons. We talked a lot about it when (older) was born and the girls made it totally uninfluenced and on their own. I never wanted to impose my own beliefs and preferences on them.

Were you comfortable communicating this topic with your daughters?

Totally.

How open is your relationship with your daughters?

Totally open. No secrets.

Is health something that comes up often in the family?

Yes, it does. With our family history, we are very open about health issues and the importance of taking care of yourself and being proactive.

What's the tone of those conversations?

Totally positive because they take place in a preventative sort of way. It's a "manage it before it manages you" sort of thing. There are some things you have no control over but we talk about things you can do that are preventative and why not do them.

Are there any specific health topics that come up frequently?

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Other than being very proactive and faithful to things like annual physicals and diagnostic tests, no. With our family history, we try to be very health-focused but I wouldn't say it is coming from a place of great concern, it's just trying to be wise about taking care of yourself.

How do you feel that your daughters are organ donors?

Totally proud and I totally think it is the right thing.

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Transcript 5A

Are you an organ donor?

No, I'm not an organ donor.

Why did you decide not to be one? Is there a particular reason?

No, I was just 15 or 16 at the time when they asked me on my license and I just said no because I have no idea why.

How do you feel about organ donation in general?

It's a good cause for some people it can help but also there is people who wait on the list who might have more severe cases than others but I feel bad for people at the bottom of the list who need it most and I do feel bad about that but I just personally choose not to be an organ donor.

How do you feel about your decision not to donate?

I mean one day maybe I'll decide to donate but right now I like my decision of not being an organ donor.

Do you have any experience with anyone actually donating organs?

No, I don't know anyone who has actually donated but I know someone who has donated blood and got like a blood transfusion but not organs.

Have you ever donated blood?

Yes, a few times.

How was that experience?

Well, I don't like needles so I closed my eyes the whole time so it wasn't that bad.

Have you ever heard stories of someone who received organs?

No, not any personal stories or anyone I can name but I have heard in school or in health class how it has been successful.

So, you said someday you might become an organ donor, what do you think would influence that decision?

I'd become an organ donor if someone in my family needed an organ or if I knew someone personally would use it and I was about to pass away or something I would probably change to be an organ donor.

So it would be a case-by-case decision?

Exactly, like a family or very close friend.

Do you know if anyone in your family is a registered organ donor?

Yes, my sister, both of my parents, and I think my aunt is too.

How do you feel about their decision to donate?

I think it is anyone's decision whether they do or not and if they're for it, I'm happy for them, if not it is their decision.

You said your mother is an organ donor?

She might be. I'm not sure.

How open is your relationship with your mother?

We're really close we talk about everything.

How often do you talk to one another?

Multiple times a day.

What's the nature of your conversations?

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She helps me if I need help with an essay or if I have a question or if I need help starting a paper she'll help me or if I got a really good grade on a test I'll call her or sometimes I'll just text her to let her know something or let her know I miss her.

Is health something you'd ever bring up in your conversations?

Yeah, we talk about different health issues and if someone else in my family had cancer and she had to get tested, then we'd talk about all that stuff or if I was sick or didn't feel good I'd go to her first.

Are there any other situations you talk about aside from specific issues? Opinions?

I know she is against abortion so we talked about that many times and different STDs and stuff that could be common.

Are you comfortable talking about these health issues with your mom?

Yeah, I can talk to her about anything.

Has she brought up her feelings to you about organ donation?

No, that's one thing we've never talked about.

Have you expressed your views on it and your decision with her at all?

No, I just decided that I'd say no at the time because I didn't know any different.

How much do you know about donation when you got your license and how much now?

I didn't know much at all then and I still don't know too much now I just know that if someone is sick and needs it, they, when you're dead, they take your organs out and give it to people who need them.

When was the last time you brought up something health related in your family?

Probably a couple of days ago, maybe.

Have you ever felt embarrassment or nervous bringing up any topics about health?

No, I never feel nervous talking to my mom.

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Transcript 5B

Are you an organ donor?

No, I am not.

Is there a particular reason you decided not to be an organ donor?

I just don't want it on my license that I am an organ donor but if anything happens to me, my kids are free to go ahead and donate my organs if that makes sense.

Can you explain why you choose to not have it on your license?

I just have this thing about if someone is in an accident and they're in an emergency room- and it might just be a prejudice- that the emergency room staff would look at their license and say "oh this person is an organ donor" and, more so for my kids, I would want them to do everything they could to save my kid's life first rather than thinking "oh there's so many organs that we can harvest and this person's quality of life may not be that great." So I don't want it necessarily on paper that they or myself are an organ donor but if something were to happen to us where at least I had the ability to know that there is no hope that the person would survive, then I'd go ahead and donate the organs.

So you are comfortable with actually donating your organs?

Yes.

How much do you know about the topic of organ donation?

I had not necessarily had really intimate personal experience with it. I had known someone personally who had a liver transplant so I am familiar with it but if there is information I'm not aware of you can tell me.

No, I'd like to hear your story if that's okay.

Okay, one of my colleagues many years ago, it was actually the year (younger) was born, he had cirrhosis of the liver and he went through the process emotionally, he was an 80 year old man, and he was able to get a liver donation and transplant and he had his surgery in maybe September and he came back to work several months later and he looked like a completely different individual. He has since passed away but he got 10 more years out of his life after having that liver transplant.

Did you know this person very well?

Yes, I worked with him for about 18 years on a daily basis.

So you really got to see what the experience was like?

Yeah, a little bit. I took the ambulance ride with him to the hospital when he collapsed at work and I did visit him a number of times in the hospital and then he came back to work and he, you know, was very, very healthy. He was actually an extremely cranky, grumpy person beforehand with a lot of anger and when he came back, I think he made peace with everybody in his life so those 10 years were 10 very, very quality years in his life and I would say for many years after I would still call his wife every year on his birthday and on the anniversary of his death just to let her know I was still thinking of him, so yes, I was close to him.

So what was it like going through this experience with him, especially the process of receiving an organ?

Interestingly enough, cirrhosis of the liver, as you know, is alcohol based, so he drank, he was an alcoholic and at the time he was talking to the doctors about his eligibility for a transplant he had a lot of anxiety around it, like people would be judging him because he was an alcoholic therefore, possibly, it may not have been worth him getting a transplant and it should have gone to somebody more worthy than him, so he had to go through a lot of

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counseling and lifestyle changes and he was thankfully approved for the transplant and I don't think he had to wait more than a couple of months for a donor liver.

So did that experience influence your opinion at all about organ donation?

Yeah, maybe a little bit, you know obviously it is sad that to get an organ donation, somebody has to pass away and there is always stuff around there and I have also heard of very young children who are born with a congenital heart defect and then have heart transplants shortly after, only being a couple of months old, and then after having a second chance at life, so there are very positive stories out there and I am for it very much so but I am very selfish about the ones that I love and I would want to do everything I can to provide for the survivability of my own family first and then when all else, I would donate.

How would you feel about someone else in your family actually being a registered organ donor?

I was opposed to it in both of my girls. If it was like a sibling or someone else in my family, those are their choices, but I just wanted to make sure that my children's chances are being saved or survivability are taken into account first so that's how I feel about being on the list but I have told each of them that, especially my oldest daughter, would be very into wanting to be an organ donor and I told her, I assured her, that I would donate her organs. I just don't want it on the license.

How open is your relationship with your daughters in terms of communication?

Very open.

How often would you say you talk to them?

I can say I talk to them every single day even though they are in college.

What's the nature of your conversations?

They'll talk about, both of them are in different courses of study, so they'll talk about their school work, they'll talk to me about activities, cheerleading and television at Bryant, she'll tell me when she's got things going on like that. My oldest is in science so she will talk to me when she's got things going on in the lab, the college biology lab at UMass Amherst so she'll tell me the status of things she's doing in lab. They'll talk to me about their intimate relationships with boyfriends and stuff like that, they fill me in on the drama with their girlfriends... They pretty much talk to me about most of it. I know they don't tell me everything but they do tell me a fair amount.

You mentioned that your other daughter is in labs, is she in biology or any other kind?

Yes, environmental science and biology.

So does that influence her desire to be an organ donor?

Yes, very much so, she's going to save the environment and I tease her saying she hugs trees and stuff but she is very, very earthy like that and I know she is very socially conscious and minded as well.

Are you comfortable, aside from relationships and things like that, discussing health with your daughters?

Yes.

Is there a health topic that comes up often?

Yes, probably the most, the one that comes up with me is breast cancer because my younger sister passed away from breast cancer 4 years ago, I don't know if my daughter mentioned that, because she gets very anxious as to whether I'm going to get sick or not so I go to the doctor every 6 months for either a mammogram or an MRI and I do let the kids know when I

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am going but there is nothing I can do. I just go and do evaluations. There is nothing wrong with me at this point but I do let them know. They're fairly open with me about anything they have going on, whether they're sick or if they have any GYN issues they will reach out and ask me.

Is it difficult to discuss with your sister passing? More difficult to talk about in the family?

No, I don't think so, I think because she was sick for a while and my dad passed away actually just 2 months beforehand and he was really sick, he had COPD and emphysema from smoking because that was normal in his generation. So our family is pretty open, clinically, medically, to talk about things, because we've had to talk a lot about things when my dad was sick and I always let the kids know what was going on with my dad when he was sick and my sister and we actually can talk fairly openly about it, more on the clinical level if that makes sense.

I think you did mention a specific conversation about organ donation, with one or both of your daughters, did that happen?

That's funny because I did have that conversation just 1 or 2 weeks ago with my daughter right before we heard from you.

What was that conversation like?

It was fine. She was renewing her driver's license and I was actually doing it over the phone with her and I said oh I just came to the box that says organ donor and I'm not checking it. When she was 16 years old and she wanted to do it the first time, I said you are a minor and you would need my permission and I am not giving you permission to check that box but I just want you to know that if something happened I will do the right thing and honor your wishes and donate your organs but I don't want this box checked and she was fine. She understood and she was perfectly comfortable with my thought process.

You still don't want to check the box but you will honor the wishes?

Yes.

Your daughter is understanding of this?

Yes.

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