

## ORIGINAL ARTICLE

# Hospital-based organ donation memorial ceremony: a grounded theory pilot study

Charles C Reed \*<sup>1</sup>, Elma I Fonseca<sup>1</sup>, Regina I Reed<sup>1</sup>, Stacy Foremski<sup>1</sup>, Sara L Gill<sup>2</sup>

<sup>1</sup>University Hospital San Antonio, Texas, United States

<sup>2</sup>School of Nursing, University of Texas Health Science Center at San Antonio, San Antonio, Texas, United States

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## ABSTRACT

**Objective:** Various types of organ donation memorials, to include tree planting, rose garden memorials, candle lighting, donor memorial wall events are conducted throughout the year primarily by organ procurement organizations (OPOs). Although the benefits of such events have not been explored there has been continued interest by hospital staff and administrators to host such events. The purpose of this grounded theory pilot study was to describe the process of healing that a hospital-based organ donation memorial ceremony creates at the individual level and organ donation awareness and advocacy at the community level.

**Methods:** The researchers interviewed nine organ donor family members who were invited to attend a hospital-based organ donation memorial ceremony at one Level I Trauma Center located in South Texas.

**Results:** A 4-stage social process, “makes the hole in the heart smaller”, was identified from the qualitative interview data. Participants journeyed through a four stage process to make the hole in their hearts smaller. The four stages are: choosing to attend, being able to connect, keeping the memory alive and knowing something good came from it. As participants moved between stages their meaning for attendance changed. Families shifted from personal grieving and needing support to supporting other donor families and in the process became advocates for organ donation.

**Conclusions:** The findings from this study validate the benefits of hospital-based organ donation memorial ceremonies. Families reported these ceremonies support their decision to donate, while also providing a means of continued emotional support throughout their grief process. The memorial event provides a safe venue for organ donor families to connect and share with others who have had a similar experience, while acknowledging their loved ones gift of life. Hospital-based organ donation memorial ceremonies and the permanent memorial structure increase awareness of organ donation for the community of donor families, hospital visitors and hospital staff.

**Key Words:** Organ donation, Memorial, Qualitative, Transplant, Hospital, Grounded theory

## 1. INTRODUCTION

Losing a loved one can be very painful. Keeping the memory of their loved one alive is part of the grieving process. Families fear that their loved one will not be remembered. Parents greatest fears were that their children would be forgotten.<sup>[1]</sup> Memorials serve as a focal point of remembrance

and commemorate that individuals' life. Memorials serve to remember the loved one while raising awareness. There are a number of different types of memorials such as roadside, virtual, and organ donation memorials.

Roadside memorials, whose purpose is to keep the deceased's memory alive, are seen increasingly more often and world-

\*Correspondence: Charles C Reed; Email: [Charles.reed@uhs-sa.com](mailto:Charles.reed@uhs-sa.com); Address: University Hospital, San Antonio, Texas, 78229, United States.

wide.<sup>[2]</sup> Most are small in size and easily missed by motorists, but the importance of placing the memorial at the location is important to signify the person's last place on earth. Many of these roadside memorials are maintained throughout time similar to maintaining a gravesite. The memorials serve not as an immediate way to cope with a loss, but a lasting connection to remember their loved one.<sup>[3]</sup>

There has been an increase in the number of roadside memorials. Many states have policies prohibiting the placement of memorials on roadways because of the potential safety hazard but acknowledge the need for families to express their grief by placing a memorial at the site where the loved one died.<sup>[4]</sup> Families have had difficulty articulating why they need to visit the roadside location but their actions suggest a need to remember and not let go.<sup>[2]</sup> However, some states have developed programs to provide families an opportunity to purchase a sign for placement near the site of the loss. In Texas, for example, The Memorial Sign, bearing the name(s) of the victim(s), serves to commemorate loved ones while raising awareness of this serious issue.<sup>[5]</sup>

Virtual memorials, like Facebook pages or funeral home memorial pages have become a popular means of remembering and honoring a loved one through social media. Social media allows for a connection to the memorial of the deceased from anywhere at any time.<sup>[6]</sup> Although the connection is not face to face, virtual contact may be preferable for persons who want to grieve privately or might not be ready for public interaction.<sup>[7]</sup>

Organ donation memorials offer an opportunity to not only remember the life lost but to also promote organ donation awareness. The Scottish Government has listed as a priority in the Donation and Transplantation Plan for Scotland 2013-2020, to ensure the public in Scotland is informed and engaged about organ donation and transplantation.<sup>[8]</sup> Recommendations for facilitating public awareness is through the establishment of a new national memorial to organ and tissue donors. In a report from the Organ Donation Taskforce 2008 the need to publically recognize the organ donor and their families was recommended. However, the taskforce felt they lacked the expertise to make specific recommendations as to the type of memorial.<sup>[9]</sup>

Each year thousands of families contemplate donating their loved one's organs. According to United Network for Organ Sharing (UNOS), 14,256 people donated organs resulting in 28,952 transplants in 2013.<sup>[10]</sup> Families who consent to donate their loved ones organs may desire a connection with others who have shared a similar experience. Memorial ceremonies provide an opportunity for donor families to initiate such connections.

There is very little known about the meaning and impact of organ donor memorial ceremonies for donor families, and even less about hospital-based memorial ceremonies. Platt (2004) explored the benefits of memorial services in the critical care unit. In this study they explored preferences of memorial events versus impact or meaning of attending the event.<sup>[11]</sup> Gibson (2002) describes an organ donation memorial as a means of recognizing the decision of those to donate and encouraging people to become organ donors.<sup>[12]</sup> Although he believes the families benefited from attending there was no evidence outside of anecdotal observation. Vale-Taylor (2009) explored the "post-funeral activities" which are most significant and important to those grieving and dealing with a loss. Using a mixed-method approach he examined the importance of various "rituals" or activities. Some rituals were a "direct link" to the deceased such as talking to a photo or visiting the gravesite or roadside memorials. Most rituals included the community such as holding family parties on the anniversary of their loved one's death. "Remembering in the community also fulfilled a need to give meaning to the deceased's life".<sup>[13]</sup> Foulstone *et al.* (1993) interviewed families about bereavement support and specifically evaluated a palliative care unit memorial service as part of a total care concept. He found that respondents were very positive about the value of the memorial service. Respondents claimed it was "helpful for the healing process".<sup>[14]</sup>

## 2. BACKGROUND

In 2005, an unfortunate and tragic event occurred in which two young men suffering non-survivable injuries were airlifted to the Surgical Trauma Intensive Care Unit at University Hospital in San Antonio, Texas. As the Level 1 trauma center of the University Health System this type of trauma event was not unusual. Both families decided to donate the organs of their loved ones. Subsequently, the hospital nursing staff decided they wanted to establish a life-affirming event within the hospital environment that would include family members and staff members who cared for the deceased donors. As a result, in 2006 an annual hospital-based organ donation "Tree of Life" memorial was created to honor such donors.

A planning committee conceptualized and organized an annual "Tree of Life" ceremony to publicly recognize those who provided a lifesaving gift through organ donation. A "Tree of Life" mural was placed in the hallway of the Transplant Unit. This annual event is held in April aligning with National Donate Life Month. Hospital invitations are distributed through the organ procurement organization (OPO) to maintain confidentiality. Invitations are sent to all donor families from the previous years. The invitations describe

the event and provide contact information for an *répondez s'il vous plait* (RSVP). In the letter, family permission is requested for placement of a brass leaf inscribed with the donor's name and year of donation on the "Tree of Life".

During the ceremony the Nursing Director of the Surgical Trauma Intensive Care Unit, physicians from the departments of Trauma and Transplant share remarks, thanking the donor families, describing the positive impact their decision to donate has made in the lives of the organ recipients. An invocation is offered by the Director of Pastoral Services. A donor family member who was previously invited agreed to speak about their loved one, then talk about their experience. Staff nurses from the intensive care units then conduct an induction service announcing the name of each donor. As the family members step forward to place the engraved leaf on the tree, they are encouraged to speak.

Some families are unable to attend but give permission for hospital staff to place their loved one's engraved leaf on the memorial wall. The CEO of the OPO then speaks about benefits of organ donation. Prior to closing remarks, families are again encouraged to share stories of their loved ones. The ceremony is followed by a reception and light lunch; an opportunity for families to interact with each other and hospital staff. As families depart, they are presented with a Texas Mountain Laurel tree to plant in memory of their loved one's gift of life. This tree symbolizes hope, courage and promise of new life.

Recognizing someone's loved one for giving the gift of life might be viewed as a positive event although not all donor families attend memorial ceremonies. Asking about and then listening to donor families express their thoughts about the hospital-based organ donation memorial ceremony was an important next step undertaken by hospital nursing staff. Understanding family members' experiences allows for further refinement of the ceremony to better meet donor families' needs and further bring about organ donation awareness.

### 3. METHODS

Grounded theory, a qualitative research method, allows researchers to describe the process of "what is going on" in a particular situation. Participants share their stories about a situation with the researcher. Data sources include participant interviews and observation. Grounded theory methods were used to describe the meaning of a hospital-based organ donation memorial ceremony for donor families. The goal of this pilot study was to begin generating theory about the social process central to an organ donation memorial ceremony. Grounded theory methodology is rooted in symbolic interaction, which allows the researcher to focus on shared

meanings among participants. Qualitative data, systematically obtained and analyzed, can further understanding of the meaning of a hospital-based organ donation memorial service.<sup>[15]</sup> Generalizability is not a goal of grounded theory research.

#### 3.1 Sample

The Institutional Review Board at the University of Texas Health Science Center San Antonio approved this pilot study. The Texas Organ Sharing Alliance (TOSA) identified 450 family members who were invited to attend a hospital-based organ donation memorial ceremony. TOSA mailed invitation requests for participation in the study and information sheets regarding the study that included the interview questions. Participants were provided with the researchers contact information and asked to directly contact the researchers via phone or e-mail to arrange an interview time. A convenience sample of nine organ donor family members were interviewed. Participants included: mothers, fathers, an uncle, sister and a grandmother. All donor family members who contacted the researchers participated in the study. No attempts were made to solicit additional participants from other Organ Sharing groups.

#### 3.2 Setting

The Tree of Life ceremony is held at a Level I Trauma Center in South Texas that serves as a major transplant center. Adult and pediatric liver and kidney transplants, and adult pancreas and lung transplants are performed at this center. Forty to sixty organs are recovered from this facility annually and the transplant center performs an average of 190 transplants a year.

#### 3.3 Data collection

Participants chose whether to participate in a face-to-face interview, telephone interview, or e-mail correspondence. One participant chose face to face, six chose telephone, and two chose correspondence through e-mail. The face-to-face interview was conducted at a private, mutually agreed upon location. All interviews were conducted by the first and second authors.

Participants were asked to share what the hospital-based organ donation memorial ceremony meant to them. Interview questions included:

- Tell me what you think about organ donation ceremonies.
- How did you feel when you received the invitation to the Tree of Life event at University Hospital? (organ donation ceremony)
- Tell me about your decision to attend.

- What were your expectations of the ceremony?
- What would you want other families to know about attending?
- Tell me how participating in the ceremony has influenced your thoughts about organ donation.

Probes were used as needed for clarification of responses. Interviews were audio recorded and transcribed verbatim using a transcription service. The transcripts were compared with the audio recordings to ensure accuracy.

### 3.4 Data analysis

In keeping with grounded theory methodology, data collection and analysis occurred simultaneously using constant comparison analysis. The first two authors, using QDA Miner qualitative software, independently coded all interviews. Open coding was used to name the data. Data were coded and compared for similarities and differences. These codes were then clustered into categories congruent with axial coding. Relevant categories, along with their particular characteristics were identified. Finally a core category was identified. All authors reviewed the open and axial coding. Consensus was obtained when there was a disagreement about categories. The last author identified the core category with consensus from the other authors.

## 4. FINDINGS

### 4.1 Demographics

Nine donor families participated in this pilot study. Five participants including three mothers, a sister, and a grandmother attended the Tree of Life hospital-based organ donation memorial ceremony. Four participants including two fathers, a mother and an uncle chose not to attend the Tree of Life hospital-based organ donation memorial ceremony. The organ donors included daughters, sons, nephew, brother, and grandson, aged 6 years to 27 years. Organ donation occurred 2 to 19 years ago.

### 4.2 Emerging theory

A social process “makes the hole in the heart smaller”, consisting of four stages, was identified from the data (see Figure 1).

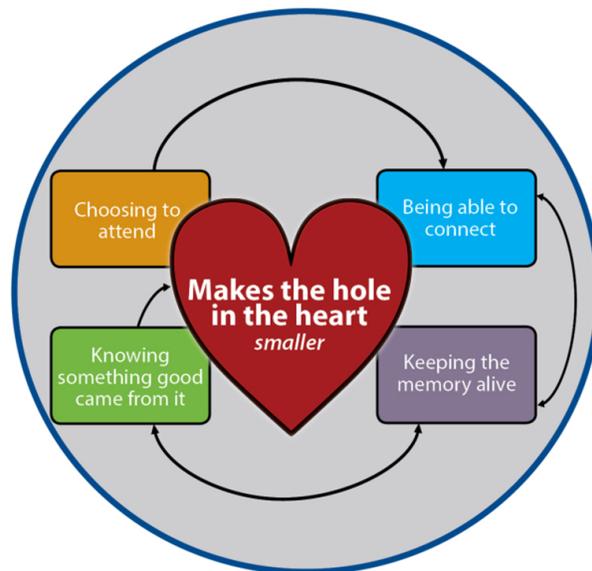
### 4.3 Core category: makes the hole in the heart smaller

Figure 1 depicts the social process generated by the grounded theory method. Participants moved through each stage of the process to make the hole in their heart smaller. This process was circular not linear and participants may move back and forth between the stages as they grieve the loss of a loved one.

Metaphorically and symbolically the heart has long been viewed as the center of emotion. It is a symbol of love, affection, joy and compassion. The heart is a place of feelings; a place where we hold our loved ones. Family members described a hole in their heart after losing their loved one.

While no physical hole existed, family members said that the loss of their loved one created a hole in their heart. The hole represented missing their loved one. Family members searched for ways to heal the hole in their hearts. The Tree of Life hospital-based organ donation memorial ceremony made the hole in these participants’ hearts smaller. One mom stated, “It makes you feel... it makes the hole in your heart not seem so big”.

Families felt that the organ donation memorial ceremonies helped to heal the hole in their hearts. Participants journeyed through a four stage process to make the hole in their hearts smaller.



**Figure 1.** Emerging theory: makes the hole in the heart smaller

### 4.4 Choosing to attend

Donor families had to make a decision whether to attend or not attend the memorial service when they received an invitation. Each donor family viewed the invitation differently depending on how they were grieving at that point in time. A donor mom said, “In my process and acceptance and, and, you know, in my whole grief process in where I am now of accepting, you know, what my circumstances are... I do look forward to things that are coming up. I mean I look forward to those events. Umm, I can’t say that I always felt that way, you know, I mean I think it just depends on where you are in your grief.”

Participants reported that receiving the invitation caused them to remember their loved one which made them sad. On the other hand, these same family members described their sadness as joyful sadness. They were joyful that the loved one was remembered by the OPO and the hospital. One donor father said, "I would recommend sending the invitation every year. There is no need to wait until a certain amount of time has passed from the date of death to send one. When we are ready we will eventually come to one."

While some participants were eager to attend the ceremony other participants did not attend for a variety of reasons. Despite a desire to attend, some donor families were unable due to other responsibilities. One donor father said, "Just because some of us don't make it, it's not because we don't want to. It's because life doesn't allow us to... Don't quit sending those letters out. Sooner or later we'll make it. Other people like me will make it."

Other donor families didn't attend because they "weren't ready yet". They were not ready to publically acknowledge the death and socialize with others in a similar situation. Participants stated that even though it was sad to remember the loss, receiving the invitation was a powerful mechanism to remember their loved one. The decision to attend the hospital-based organ donation memorial ceremony was a very personal one.

Some participants explained their thoughts and feelings while attending the memorial the first year of their loved one's death. One donor mom said, "You know the first ceremony because it was so close to the time of her death it was, umm, but just a little hard to process. Not a little hard, it was a lot to process and so I wasn't really absorbing what was going on around me. I was just kind of there. I don't even think I was totally engaged but, umm, but I think even then just being there, umm, it prepared me for being able to be, you know, to be present at other things."

#### 4.5 Being able to connect

The hospital-based organ donation memorial ceremony provided donor families an opportunity to connect with other donor families, with hospital staff and connect with the memory of their loved one. This public event provided donor families an opportunity to share their private loss. This public forum became a catalyst for discussion not only of personal feelings and loss but also of the heroic decisions that were made. Prior to the event, participants grieved privately, sometimes with family members and close friends. The ceremony allowed families of organ donors to share their loss, and their courageous decision to donate loved ones' organs. Donor families told their personal stories about making the choice

to donate.

The memorial ceremony brought people together who donated organs from a loved one. A donor mom said, "It's a place where I can be with other people that are in my situation and know how I'm feeling... truly know how I'm feeling...". Sharing similar experiences validated both the decisions of donation and the resultant emotional feelings. A donor father said, "You can't go through a grocery store and seeing someone and speak to them and have them understand what you go through every day."

Participants also described connecting with the hospital staff who provided care to their loved ones. Seeing the hospital staff again provided comfort and reassurance about their donation decision. One donor mom said, "The nurses... they always make it a point to come down... and some of them, I have seen, you know, in several different events. And it's just really cool to see them and to know that... that, to me, is more than just, you know, bedside courtesy. That's people who really care about their job, and care about what they... and care about the people that they do it for."

Participants who attended the hospital-based memorial ceremony more than once described reconnecting with people from previous ceremonies. Reconnecting was important because it provided comfort. "Going as many times as I have, and people recognize you, and you know, you don't see them for a year, but they still recognize you, that's an amazing thing."

Connecting helped donor families heal. New relationships were formed with others donor families. A donor mom said, "I think they're great. It's kind of a release for me to be able to talk about it to... people really don't understand our situation..." Another mom said, "I think that it was important to be present because I was so disconnected... I was literally on my own. I was numb and in shock. I was very much in shock... talking to people and being around people that had kind of shared in the experience... I wasn't alone." The need for sharing and connecting evolved over time from being about oneself to being there for others.

#### 4.6 Keeping the memory alive

Donor families did not want their loved ones to be forgotten. The Tree of Life memorial provided several means to remember the loved one. The Tree of Life memorial wall provided a visual public acknowledgment of the organ donor's decision to give the gift of life. One donor mom said, "It's a general acknowledgment to the public... it was important to me that she wasn't, you know, that she, that her name is there that she existed".

Annual hospital-based organ donation memorial ceremonies

provided a new tradition for organ donation families to gather and participate in an activity that included their missing loved one. The initial reason for participating in such ceremonies was to help cope with grief and the acceptance of the death of a loved one. A donor mom said, "Attending the first was for support and now... it feels like a tradition". Another donor mom said, "One of the things that was really important for me and my children was tradition... I can't celebrate a birthday with her but I can go there and that would be my way of... reestablishing some sort of tradition with regards to her."

At the Tree of Life memorial ceremony each donor was recognized by name. Participants reported that having their loved ones name called out and placing an inscribed leaf with their loved one's name on the memorial tree made them feel proud. A donor mom said, "It was wonderful. No, it was great to have each name called out and to, to place that plaque on there. No, it was beautiful." And she went on to say, "to see their name up on the wall was, was very touching for a lot of people, you know, kiss the plate and put it on the wall... people loved seeing their name up." The memorial served as a mechanism for keeping the memory alive and honoring their loved one's legacy.

#### 4.7 Knowing something good came from it

While no donor families questioned their decision to donate, they appreciated acknowledgement that something good came from that decision. One donor mom said, "It lets me know that we did something good for somebody that my daughter's sacrifice was not in vain". A donor mom said, "... it has been absolutely essential in our healing. I think it's a, I think it's a beautiful acknowledgment of a, you know, of a donation, umm, of the person."

The public ceremony provided public awareness about the benefits of organ donation. Donor families knew that something good did come from the donation and wanted to share that knowledge with the bigger community. These families believed that sharing their stories at public events would encourage others to become organ donors. A donor mom said "we can spread the word about organ donation with people..." Another donor mom said, "Partaking in groups in all of those things... impacts, raises awareness".

## 5. DISCUSSION

It is difficult to understand why tragedies happen. It is even more difficult to try and understand any positive outcomes/aspects of a tragedy. Donor families deal with the loss of a loved one on a daily basis. It is challenging for them to be in mourning yet feel optimistic about the events that have occurred.

Processing tragedy and grief is so painful that as humans, we would rather deny the existence or simply distance ourselves from those who mourn. The nurses in the Surgical Trauma Intensive Care Unit did neither. These nurses recognized the importance of the gift of life being made at a very tragic time in the donor families' lives and their role in supporting these grieving families. The nurses chose to focus on the celebration of these lives and their desire to help these particular families and eventually others.

The leaves on the tree recognize the donors and their individual gift that lives on in others, symbolizing hope for the future. Families and staff members support each other in their loss and simultaneously demonstrate that grieving those losses are necessary and good for the human spirit and community.

A qualitative evaluation from the participants has provided critical proof demonstrating the benefits a hospital-based organ donation memorial provides to organ donor families. The memorial ceremony helps heal the hole in donor families' hearts. The ceremony provides a safe environment for families to share their stories and remember their loved ones. Attending a hospital-based organ donation ceremony, "Tree of Life" event, provided a means of recognition, remembrance, and honor of the life lost.

Memorial ceremonies play a special role in the grieving process by honoring the memory of those who were heroic enough to save lives through organ donation. Typically, OPOs conduct memorials honoring organ donors. There is limited research about organ donor memorial services. Existing research findings speak only to attendees likes and dislikes about the service with no focus on the greater meaning to the attendee or the impact to the community. While the pilot study findings speak to the meaning of hospital based organ donor memorial for the individual, future research should also focus on family preferences for memorial services and the meanings of organ donation memorials to the greater community, specifically the awareness of the increased need for organ donation.

Participants viewed invitations as a means of support and remembrance of the family's legacy, and the importance of their loved one's life. Families reported looking forward to receiving invitations annually even if they were unable to attend. All the families reported wanting to continue to receive the invitations in the future regardless of the time since donation. One of the donor fathers' described placing the invitation on their refrigerator as a visual reminder of the significance of their loved one's gift and life.

Hospital-based organ donation ceremonies support the fam-

ilies' decision to donate through public recognition. It provides them a sense of importance. Additionally, it provides a means of continued support throughout their grieving process by facilitating communication with others who experienced similar loss. A donor mom said, "I think that, you know, connecting and re-connecting with people and being able to... there was a time that I couldn't have these conversations. There was no way; I couldn't even say her name."

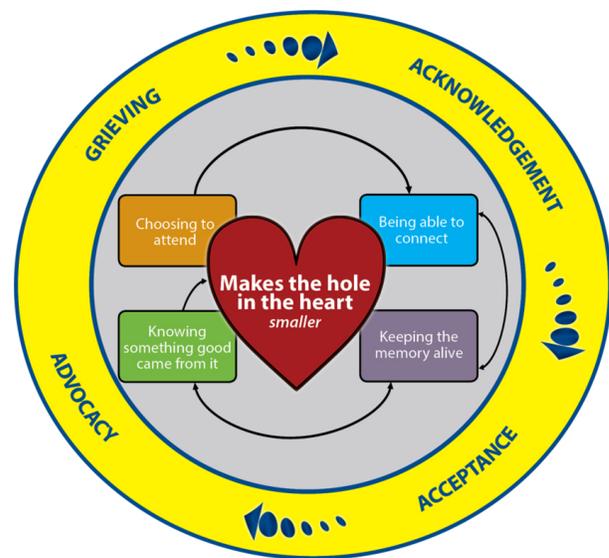
Reasons for attending the memorial ceremony changed over time. Initially donor families attended the ceremony to receive support. As these families worked through their grief they attended the ceremony to provide support to others.

Although the clinical staff who took care of the heroes who donated life initially conceived and identified the need to publically acknowledge and honor the organ donors, the Tree of Life ceremony has been highly regarded and supported throughout all levels of leadership within the University Health System. The fundamental foundation of patient-centered care is the formulation of relationships at multiple levels. Direct caregivers build relationships with not only their patients, but also with the family and close friends who are involved in the care. Healthcare leaders who recognize, appreciate, and fully support programs such as the Tree of Life, lend authenticity which furthers the concept of patient-centered care throughout as a means of aftercare for the families who are the deepest roots of the community.

Hospital administrators play a significant role in developing a culture of support for organ donor families and organ donation awareness. Serving in a central role within the communities they serve, healthcare administrators should view their hospital as not only a physical, but an emotional support system for their community. Leadership has a direct effect on families' healing through hospital leaders' active participation and support of hospital-based organ donation memorial ceremonies. Administrators are constantly looking at the ethical aspect of decisions and ensuring policies and procedures put into place are in the best interest of those they serve; this ensures patients and their families receive the best care. The Tree of Life hospital-based memorial ceremony is in the best interest of donors and donor families. It is a yearly celebration that promotes supportive healing, honors those who have given the gift of life and promotes organ donation awareness.

The Tree of Life ceremony captures the relationship that begins during patient care, and elevates it to an intimate level that connects the loved ones with the health care organization for years to come. Not only does the ceremony promote healing for the family, it helps to evolve a culture of organ donation awareness and advocacy within the community.

Our staff feel empowered to tell families about our annual ceremony to celebrate the gift their family member gave so another can live. The families can now share their experience with others and through their grieving and acceptance of support, families become advocates of memorial ceremonies and organ donation. Thus, metaphorically making the hole in the heart smaller, as well as reducing the gap between available organs and those in need through organ donation efforts and awareness. With the permanent fixture of the Tree of Life Memorial in a public area, it is a constant reminder of the gift of life that so many have given within our community. The healing that occurs transcends from an individual level to a community of awareness and promotion of organ donation (see Figure 2).



**Figure 2.** Illustrates the emerging theory "Makes the hole in the heart smaller" transcendence into the community

## 6. CONCLUSIONS

Hospital-based organ donation memorials provide a multi-faceted platform for healing, acknowledgment and public awareness of organ donation. As organ donor family reasons change over time for their attendance at a memorial, moving from grief and a need to connect to becoming advocates for organ donation, so does the importance and lasting impact of these memorials. Metaphorically speaking, just as this process makes the hole in the heart smaller it assists in closing the gap for the need of viable organs through public awareness. Hospital-based organ donation memorial ceremonies and actual memorial images provide continued emotional support for families throughout the grief process; however long their grieving may last. The memorial event provides a safe venue for organ donor families to connect and share with

others who have had a similar experience, while acknowledging their loved ones gift of life. Hospital-based organ donation memorial ceremonies and the permanent memorial structure increase awareness of organ donation.

## LIMITATIONS

While the purpose of grounded theory is to seek understanding, from persons who experience the phenomena, there are limitations to this particular study. Participants were recruited from one hospital. This was a pilot study so data

redundancy and theoretical saturation were not achieved.

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