

# Organ Donors’ Narratives: Transformative Learning Fostered Through Organ Donation

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## Background

The approach for organ donation consent is a complicated process for family members of the deceased. While family members are provided medical information, it is not known how they process this information and if learning occurs, especially if this information conflicts with their previous beliefs about brain death and organ donation.

### Theoretical Framework

Transformative learning was used as a theoretical framework to provide insight into the learning during the organ donation consent process. Developed by Jack Mezirow, transformative learning involves learning that occurs following a disorienting event such as a loss of a family member. Transformative learning takes place when an unexpected event occurs causing someone to critically reflect on their previous understanding and/or beliefs. During the organ donation consent process, family members must comprehend the results of the brain death testing and additional information provided by the intensive care physicians and organ recovery coordinators. The following research questions were explored: 1) What do surviving family members learn though the process of organ donation, and 2) in what ways might transformative learning manifest for surviving family members during and following the organ donation process?

## Methods

### Participants

The Texas Organ Sharing Alliance (TOSA), which is the local federally designated OPO, recruits volunteers who support and advocate for organ donation throughout the community. Their volunteers share their experiences and stories at workshops, community education events, and support groups. Six TOSA volunteers (4 females and 2 males) were recruited for the study, and each participant previously made the decision to donate a family member’s organs following death.

### Data Collection

For each participant, two Zoom semi-structured interviews were conducted. Each semi-structured interview was recorded for transcription following the interview using the record feature on Zoom. Member checking was used for validation of the findings.

### Data Analysis

Each interview was transcribed paying special attention to record the accuracy of what was said. Initially a holistic-content narrative analysis was used to determine patterns and themes within each narrative interview. Main events described in each narrative interview were radically reduced to maintain focus on the core narrative of the event. Narratives were also analyzed using a holistic-form approach to determine the thematic focus/goal for the development of the plot. The progress of the plot was identified by reflecting on specific positive or negative phrases found within the narrative. Participants’ learning activities were associated with a phase of transformative learning and transformative learning outcomes were identified. A combined holistic form analysis was developed to illustrate themes among all participants’ narratives (Figure 1).

## Results

### Learning During the Organ Donation Consent Process

There was no evidence of critical reflection during or immediately following the organ donation consent process regarding prior attitudes and assumptions towards organ donation.

During the organ donation consent process, several of the participants described being in a state of shock or “in a different world”, and all could not elaborate on the specific information they were told at the time. The anxiety of the hospitalization combined with participants’ emotional state inhibited the learning and retention of the information provided to families.

Participants demonstrated a wide range of emotions, which included anger, shock, anxiety, fear, sadness, and hope. In the process of transformative learning, the organ donation consent process was part of the disorienting dilemma. This period of disorientation was found in each participant’s narrative and continued for a period of time, which ranged from weeks to years. Participants’ disorientation prevented learning and was all consuming until the emotions were not as extreme.

Participants began a period of self-reflection when they reengaged with the OPO and conducted activities such as letter writing or meeting their family members’ organ transplant recipients. Participants’ interactions with the OPO and communication with transplant recipients initiated and provided an opening for critical reflection.

### Learning Following Organ Donation Consent

Participants experienced a period of critical reflection after their invitation to volunteer with the OPO. Eventually through their volunteer work, all participants had conversations and interactions with organ transplant recipients even if it was not their family members’ organ transplant recipient. Through this interaction, participants directly learned and observed the impact organ transplantation has on the quality and longevity of life for people with end-stage organ failure. Participants meeting and interacting with transplant recipients provided a catalyst to critical reflection.

Participants demonstrated critical reflection during their volunteer work for the OPO, especially when telling their family’s organ donation story. During this time, participants made sense of the events during their family member’s hospitalization and improved the coherence of their story for themselves and their intended audiences. Transformations can be made through dialogue as a way to make meaning of the loss, and healing occurs because meaning is found.

Transformative learning outcomes were identified among five participants. These outcomes involved changes in worldview, ontology, and behavior. Participants learned how to make meaning from their loss and organ donation experience. They learned how to cope and move on from the loss of their family member.

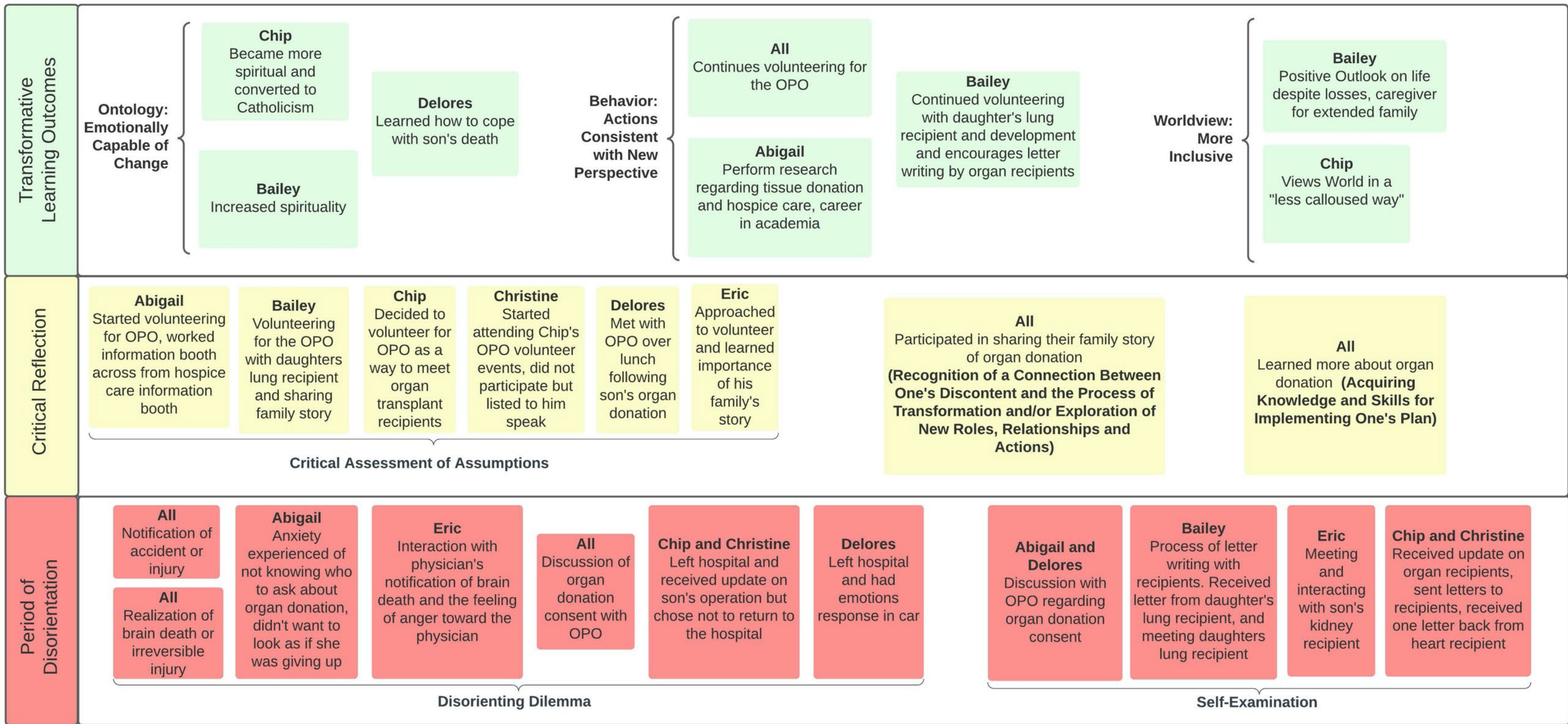


Figure 1. Combined holistic-form analysis displaying participants’ pseudonym, activity, associated phase of transformative learning, and types of transformative learning outcome.

## Conclusions

During the organ donation consent conversation, participants were not interested in hearing and were sometimes turned off about the medical information provided by the physicians or representatives from the OPO. Instead, participants were more focused on hearing about recipients and how their family members’ organ donation can help others. Due to this, OPO representatives conducting the request for organ donation should limit the amount of medical information provided to family members (unless requested by the family), and instead focus on the need for organ donations to treat people with end-stage organ failure.

This study demonstrated the benefit of contacting donor families and inviting them to volunteer for the OPO. The act of volunteering was found to have a beneficial impact on participants’ grieving. Volunteering provided support from a community of other organ donor families and recipients. Storytelling of their experiences contributed to their critical reflection and transformative learning.

Support groups offered through the OPO would be beneficial to surviving family members even if they do not choose to volunteer. Organ procurement organizations could have the ability to connect people who have had similar experiences with loss of family members and organ donation. Storytelling in organized support groups could still benefit surviving members to help make meaning from their experiences and impact their grieving process.



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